Getting Started

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

Bureau of Early Intervention Services
Office of Child Development and Early Learning
Pennsylvania Departments of Public Welfare and Education

Acknowledgements

With the passage of the Infant Hearing Education, Assessment, Reporting and Referral (IHEARR) Act of 2001 (P.L. 849, No. 89) universal newborn hearing screening began in Pennsylvania. As a result, infants with hearing losses are being identified at younger ages than was previously possible. When an infant with deafness begins Early Intervention services at a very young age, the potentially detrimental effects of deafness and hearing loss can be minimized. *Getting Started: Resources for Parents and Families of Infants and Young Children with Hearing Loss* was designed by parents for use by parents of newly diagnosed children to assist them in understanding the impact of hearing loss on babies and families.

Getting Started was supported by the Bureau of Early Intervention Services, Office of Child Development and Early Learning, Pennsylvania Departments of Public Welfare and Education. These departments would like to acknowledge and thank MaryAnn Antal, Melisa Engel, Betsy Fallen, Lisa Haberern, and Angie Stead. These are the dedicated parents from across the Commonwealth of Pennsylvania who contributed their time, energy, wisdom, and experiences to this publication. Each of their families has chosen to use different methods of communicating with their children. Their collaboration was appreciated.

Special thanks are extended to Ginny Duncan who generously acted as a contributor and liaison to the families involved in this project. Thanks are also extended to Dr. Sue Schwartz who reviewed the document before publication. Particular acknowledgement and thanks must go to the Ski-Hi Institute for allowing the reproduction and adaptation of materials that have been included, and to Advanced Bionics for the photos of young children with cochlear implants.

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Parents' Letter

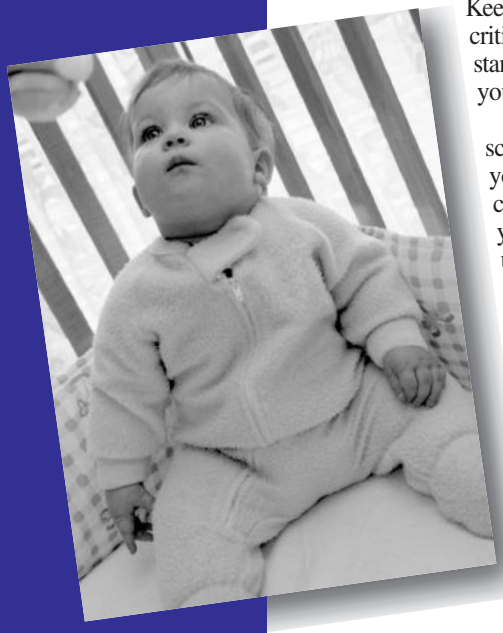
Dear Parent/Guardian,

We want to offer you a warm welcome to a new world! It's a world most of us would not typically choose for our children or ourselves, but as parents of children with hearing loss, we've worked very hard to make our way in this world for ourselves and our families. Through our contributions to this booklet, we lend our support to you so that perhaps your journey will be a bit smoother.

We each remember what the beginning was like for us. The day our child was diagnosed with a hearing loss was a day we will never forget. It was filled with many fears, emotions, regrets, questions, doubts, and so much more. It's when each of our lives took a different turn. Looking back now, we each wish we understood at that time the many things we've learned along the way. By reading and acting on the information in this booklet, you are taking some of the most important steps in building language skills in your child.

This booklet was written in part by Pennsylvania parents who, like you, have a child with hearing loss. Each one of us represents a different one of the several communication methods discussed in this booklet. Some of us use sign language with our children. Some of us speak with our children. Some of us use cued speech with our children. Some of us even use all of these! Some of us are hearing and some are Deaf parents. Some of our children wear one or more hearing aids, and some have a cochlear implant. Despite all these differences, ALL of our children are loved and have dedicated parents who have stood in the shoes that you now wear. We say to you, "Press on! Love your child with hearing loss. It's not the end of the world. Communicate in whatever way you choose, but do continue communicating with your baby. You are getting started on a journey that may be difficult at times, but is worth the effort."

We encourage you to learn as much as you can about your child's hearing loss, and the ways that you can help your child. Our descriptions of each of the communication options are intended to give you a basic understanding of each one. ***No one communication method is the only way or the right way for ALL children.*** We strongly encourage you to keep an open mind as you use the information we present, and as you use the resources available to investigate each communication method. Your choice in communication will be the first of many pivotal decisions throughout your child-rearing years. Remember that you are the parent/guardian of this child, and you need to trust your gut feeling. No matter what any professional or any other parent says, it is ultimately your choice. This choice, this freedom, is that which we each embrace and respect. Keep in mind that as time goes by, you will continue to receive more information, opinions, and even criticisms. Review each carefully and trust yourself enough to know if you need to make a change or to stand your ground. With each passing day, you will get stronger and more confident in your choices as you see the fruits of your efforts.



Many of you have received this publication due to the results of your child's newborn hearing screening. The gift of time is on your side. Many of us did not receive this news so early. Others of you have older children who have just been diagnosed with a hearing loss. No matter how old your child is, let this publication be an encouragement and a resource for you to make decisions to help your child. As Pennsylvania residents, we are fortunate to have early intervention specialists to help us. Many services for infants and young children and their families are made available through the Bureau of Early Intervention Services, Office of Child Development and Early Learning, Pennsylvania Departments of Public Welfare and Education. We thank them for recognizing the need for this publication.

Remember, you are not alone. We encourage you to contact other families who have chosen each of the various communication options. You can do so by referring to the many resources, contacts, agencies, and websites listed in the Appendices of this booklet. Learn from others' experiences. You will see firsthand the wonderful opportunities and successes that await you and your child. Your child needs you. Stay informed and never stop advocating for your child. When they are old enough, they will thank you for not throwing in the towel!

With kindest support,
Angie, Betsy, Lisa, Maryann, and Melisa
The parent contributors of this publication

Introduction

In accordance with Pennsylvania law, Act 89 of 2001, hearing is screened in all babies born in hospitals before going home. Newborn hearing screening testing is a painless procedure that is usually performed while the baby is sleeping and determines whether the baby's hearing system is functioning properly or whether more in-depth testing is needed.

A baby who does not pass the newborn hearing screening needs to have his/her hearing tested by a pediatric audiologist as soon as possible. The audiologist is able to do more complete testing of the baby's hearing to determine if there is a hearing loss or if the initial screening was not passed due to reasons other than hearing loss.

Although it requires specialized equipment and training, today an evaluation can be performed by a pediatric audiologist on even the youngest infant or toddler.

Regardless of the level of the baby's hearing loss, the most important thing families can do is to continue to love and communicate with their babies.

Bonding Through Early Communication

For many hearing families, the beginning 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!

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 the 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/her.
- Tap your baby gently on the arm. Or call/sign your baby's name as you tap/stamp on a hard surface to create a vibration.
- 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.
- If your baby is able to perceive sound, make a noise. If he/she can perceive speech, teach your baby to recognize his/her name.
- Copy facial expressions, teach him or her to blow raspberries, or play peek-a-boo.
- Keep communicating with your baby. Although your baby may or may not be able to hear your voice, he/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.
- Move your baby's legs and engage in a variety of touching behaviors such as tapping, stroking and tickling. Play, play, play anything that engages your baby.

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.
- Be aware of light sources and competing background noise. When talking to your baby, you may want to turn off the radio or television.
- Conversation is a lot like a game of volleyball - one passes the ball back and forth, taking turns. Everybody gets a chance to serve the ball, and players try to keep the ball in the air. 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. When you respond to your baby's signals, use effective communication, not simply anticipating and then giving your baby whatever he or she wants.

Develop turn taking and conversation.

• Be a good observer. Watch your baby and become aware of the ways he or she is trying to communicate.
• Look for sounds, gestures, reaching, tugging, pointing or other body movements, which can communicate meaning.
• Pay close attention to your baby's facial expressions, smiling, fussing or crying, furrowing eyebrows, and eye gaze.
• Remember that there are many ways for your baby to communicate his or her needs. It is up to you to watch, listen and respond to his/her cues.
• Tune in to situational or contextual clues to figure out what your baby is trying to communicate. Does the child go to the kitchen? Maybe he or she is hungry.
• Follow your baby's lead and comment on his/her world. 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.

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 enlarge on what your baby is communicating; for instance, if he/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.

Summary

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 Department of Health and Family Services, (2000). Babies and Hearing Loss Notebook. Wisconsin Sound Beginnings and Wisconsin CSHCN Program, pages 16-21.]

Hearing Tests

The tests that are used in newborn hearing screening are quick, painless, and completed while the baby is asleep. When a baby is referred from the newborn hearing screening program, it may not necessarily mean that the baby definitely has a hearing loss. It may mean that more in-depth testing is needed.

It is important to have your baby's hearing tested by a pediatric audiologist as soon as possible. The audiologist is able to do more complete testing to determine if there is a hearing loss or if the initial screening was not passed for reasons other than hearing loss. Although it requires equipment and training, today an evaluation can be performed by a pediatric audiologist on even the youngest infant or toddler. When you are looking for an audiologist, it is important to find one who has experience with infants and babies. The American Academy of Audiology has a directory of audiologists on their website (see Appendices for Internet sites). When first contacting the audiologist, ask what experiences he/she has had with young babies. Appendix A provides a list of questions for parents to ask when searching for a pediatric audiologist.

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 other tests to find out more specific information about it, for example, the type and degree of the hearing loss. Different hearing tests may be done depending on the age of your baby and the information the audiologist is seeking. Table 1 provides a description of different hearing tests and the ages of babies with whom they work best.

Table 1 - Types of Hearing Tests

Test and Additional Names	Who is it for?	How is it done?	What will it show?
Otoacoustic Emissions Testing (OAE) Variations include DPOAE (Distortion Product Otoacoustic Emissions) and TEOAE (Transient-Evoked Otoacoustic Emissions)	This test is used for infants up to 6 months of age, for children who cannot respond to other types of hearing tests, and for children with severe handicaps. It is also used for people of all ages. The baby should be resting, sleeping or sedated.	A small earphone is placed in the ear canal and sound is introduced. A normally functioning cochlea then produces an "echo" of that sound which is picked up by the microphone in the ear canal.	The presence of a robust otoacoustic emission indicates a normally functioning cochlea. It can rule out cochlear hearing loss of moderate to profound degree.
Auditory Brainstem Response (ABR) Other terms for the same test include BAER (Brainstem Audiometry Evoked Response), BERA (Brainstem Evoked Response Audiometry), and BSER (Brainstem Evoked Response)	This test is used for infants up to 6 months of age, for children who cannot respond to other types of hearing tests, and for children with severe handicaps. This test can only be done if the child is either asleep or sedated.	This is a more thorough test than the OAE described above because it tests both the ear and the brainstem's response to sound. Electrodes are attached to the child's head and tiny earphones are placed over or in the child's ears. Sounds are introduced through the ear piece and the electrodes measure electrical activity in the brainstem. The audiologist compares the baby's responses to information gathered on infants and children with normal hearing. This test gathers specific information about the child's hearing at different pitches and loudness levels.	This test gives an approximation of the amount of hearing. If there is a loss, the type of hearing loss can be found.
Behavioral Observation Audiometry	This test is usually done with very young babies (not newborns), especially when no other tests are available.	A person trained in observing behavioral responses (for example, startle, eye movement, head movement or turning, sucking or cessation of sucking) watches the child's reactions to sounds of different frequencies/pitches and loudness levels that are introduced. Reactions indicate the presence or absence of hearing.	The test relies heavily on parent and provider interpretation. Therefore, this test only gives an approximation of the degree of hearing loss. Earphones are not used which means that information about each ear is not available.
Visual Reinforcement Audiometry	This test is used for children of about 6 months to 2 years of age.	The child sits either in a chair or on the lap of an adult in the sound booth. A toy that is of interest to the child is near the speaker where the sound will come from. When sound is introduced, the toy lights up. Children learn to look at the toy in response to the sound. Children naturally turn to the sound source and this process uses that tendency. Earphones may or may not be used for this test.	This test gives information about how the child hears different pitches at different loudness levels. Earphones are used to collect individual ear information. If earphones are not used, the information reflects the better ear.

Test and Additional Names	Who is it for?	How is it done?	What will it show?
Play Audiometry	This test is used with children older than 17 months.	Children learn to drop a block or perform some other task when they hear a sound, such as a tone or a speech sound. The child is rewarded for a correct response. Some listening activities may include stringing beads, building block towers, putting pegs in a peg-board, putting pennies in a bank, or doing a puzzle. Earphones may or may not be used for the test.	This test gives information about how the child hears different pitches at different loudness levels. Earphones are used to collect individual ear information. If earphones are not used, the information reflects the better ear.
Traditional Pure Tone Audiometry	This test is used with children older than 30 months.	Tones of different pitch and loudness levels are introduced to the child. The child indicates if he/she hears the tone, usually by raising a hand. The tones are presented either through earphones or through a vibrator placed behind the ear.	This test gives information about how the child hears different pitches at different loudness levels. Earphones are used to collect individual ear information. If earphones are not used, the information reflects the better ear.
Tympanometry Also known as impedance testing	This test is used for any child where a middle ear problem is suspected.	A probe is placed in the child's ear and a change in pressure is introduced, making the ear drum move back and forth. Then a special machine measures the mobility of the eardrum. It only takes between 3-30 seconds per ear.	Tympanometry results in a chart of the way the eardrum is moving, which may also show how the middle ear is functioning. It shows if there is fluid in the middle ear or if the middle ear bones are working properly.

[Adapted from Wisconsin Department of Health and Family Services, (2000). Babies and Hearing Loss Notebook. Wisconsin Sound Beginnings and Wisconsin CSHCN Program, pages 7-9.]

Following the testing, the audiologist will discuss different ways to help your baby and family. The most important thing to remember is to keep communicating with your baby, even though he or she may not hear you very well.

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 structures of the ear are shown in Figure 1.

The outer ear is responsible for collecting and channeling sounds 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 tiny **middle ear bones.** These bones conduct sound across the middle ear to the inner ear. The middle ear is connected to the back of the throat by the **Eustachian tube.** The Eustachian tube allows air to pass to and from the middle ear space. The air

Figure 1.

pressure must be equal on both sides of the eardrum in order for it to vibrate most efficiently and for us to feel comfortable. The tube normally opens when we yawn or swallow.

The inner ear includes a snail-shaped structure called the **cochlea.** It is connected to the **semi-circular canals,** which control balance. The **auditory nerve** travels from the inner ear to the parts of the brain dealing with hearing and interpreting sound (**brainstem** and **auditory cortex**).

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 about 90 dB HL. When sound reaches 100-120 dB HL, it is uncomfortable for humans.

"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. Most speech sounds fall in the range of 300-3000 Hz.

The **degree of hearing loss** is measured in terms of decibels (dB). 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.

Slight or minimal hearing loss	16 dB to 25 dB
Mild hearing loss	26 dB to 40 dB
Moderate hearing loss	41 dB to 55 dB
Moderately severe hearing loss	56 dB to 70 dB
Severe hearing loss	71 dB to 90 dB
Profound hearing loss	91 dB or greater

[Source: Flexer, C. (1999). Facilitating Hearing and Listening in Young Children. San Diego: Singular Publishing Group, Inc.]

Types of Hearing Losses

A **congenital** hearing loss is present at birth or associated with the birth process; it may occur within the first few days of life. An **acquired** hearing loss develops anytime after birth. The latter is also sometimes called an **adventitious** hearing loss.

A **bilateral** hearing impairment is a hearing loss in both ears; a **unilateral** hearing loss occurs in only one side. A **prelingual** hearing loss is one that is present prior to speech and language development. A **postlingual** hearing loss occurs after the development of speech and language.

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 loss occurs when sound cannot travel through the auditory system due to a problem in the outer or middle ear. The degree of hearing loss due to conductive involvement can range from slight to moderate.

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.

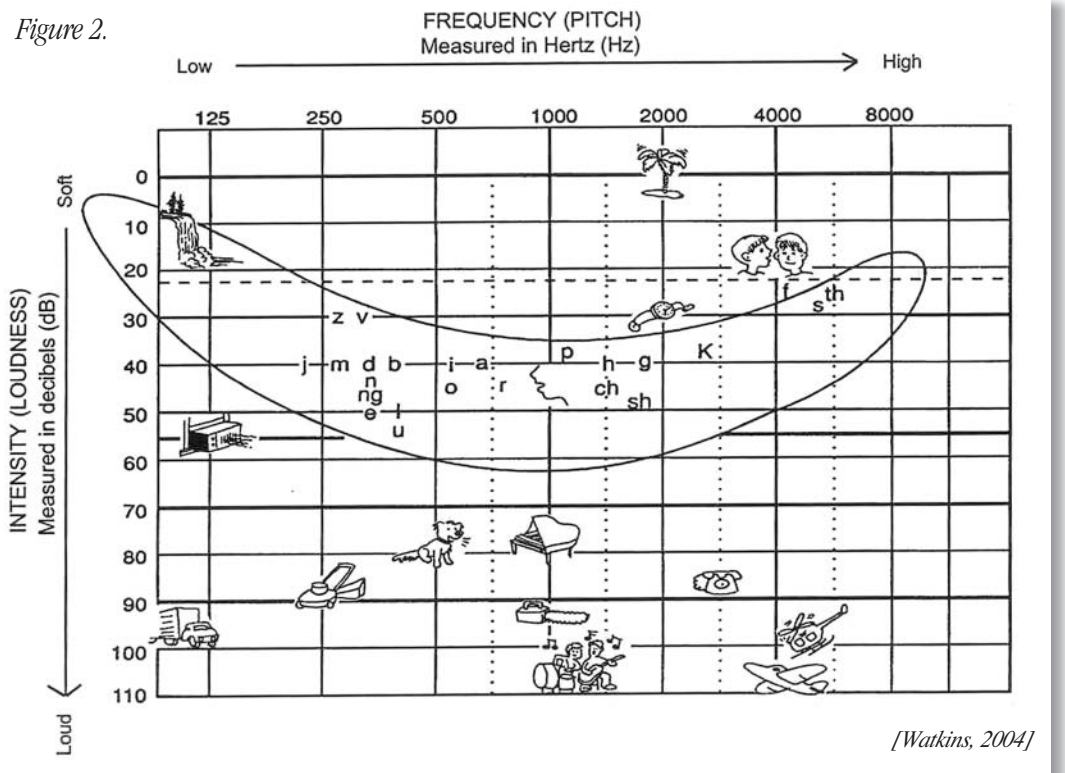
As a result of an ear infection which comes and goes, or other causes, the child may experience a **fluctuating** hearing loss; that is, the baby may appear to have better hearing one day and a greater hearing loss the next. A hearing loss that gets worse over time is said to be **progressive.** In some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

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. Across the top of the audiogram, the **frequencies** of sound (different pitches) are listed. The lower the number (125 Hz), the lower the pitch from bass to soprano type (8000 Hz) looking from left to right. Looking up and down the side of the audiogram, the **intensities** (loudness) of sound needed to hear are listed. The lower the number (0 dB HL), the quieter are sounds the person can hear. The higher the number, the greater the hearing loss.

[Adapted from Indiana State Department of Health, (2002). Indiana Family Resource Guide for Children with Hearing Loss. Indiana State Department of Health, page 6.]

Figure 2.



[Watkins, 2004]

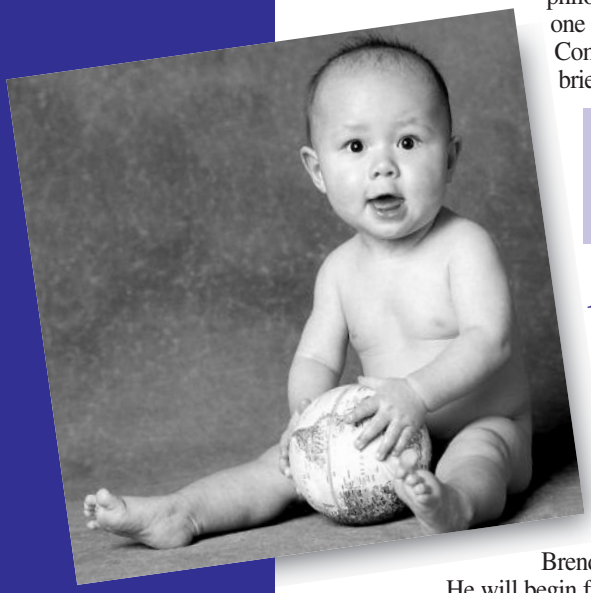
The "Speech Banana" and Common Sounds

The "**speech banana**," also known as the **speech zone,** is where the energy of the sounds of speech register on an audiogram.

Your baby's audiogram, showing hearing thresholds, can be plotted on this chart in order to help you and others determine which sounds may be problematic for the baby to hear, and perhaps also to articulate. If your baby's hearing sensitivity is below (or worse than) the volumes used in normal conversations, the hearing thresholds will fall below the "banana" and that would indicate what sounds and noises would be unheard by the baby with the hearing loss (without appropriate amplification).

Communication Options

Each parent working on this project represented a different deaf education method or philosophy, one that she and her family had chosen for their own child or children. No one communication or education method is appropriate for ALL children (see Table 2 - Communication Options, prepared by parents, on pages 10 and 11). The following are brief stories of the families and their choices.



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

Families' Stories

Angie's Story

After I met the audiologists and heard the words that my son, Brendon, was diagnosed with a profound hearing loss, I never thought the day would come that I would hear the words "Mom," or "I love you" come from his lips.

Brendon was implanted with a cochlear implant at 27 months and now he has gained the reputation of a "chatter box." It has been about four years since he was implanted and he is growing by leaps and bounds in his language development. Brendon attends an auditory-oral program and also received speech therapy twice a week. He will begin first grade in the fall. His love for learning new words and questioning how things work fills the room with excitement. Books have a new meaning to him, more than just pictures. He is learning to read and embraces the fact that he can pull one over on you with his fast growing vocabulary!

Brendon will soon be ready for the transition into a mainstream school. He will do so without an interpreter, relying on listening through his cochlear implant and using speech reading skills.

Betsy's Story

I'm Betsy, mom to three kids, the youngest is 7-year-old Emily. When she wasn't walking or talking normally at 15 months, she was evaluated. She was diagnosed with a severe-profound hearing loss. Emily had hearing aids which helped, but not enough to get her hearing into the speech range. Later, Emily 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 (CI). We had switched programs into an Auditory-Verbal (AV) one when we decided on the CI. Emily is now entering kindergarten with a mix of inclusion and special education class time. She will still work with an AV therapist.

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!!

Lisa's Story

We're the Haberern family. When our second child was diagnosed at 8 months with a severe-profound hearing loss, we were informed of only two methods: Total Communication (TC), and the oral method. We chose TC, which meant learning sign. It was extremely frustrating to learn and teach a language at the same time and to realize that our deaf child wasn't getting all the verbal input (both silly and informative) that we had given our hearing child. After two compromising years, we learned of Cued Speech (CS). There's a way to actually teach our deaf child OUR language, and we could learn it within two days. Hallelujah! We researched CS, learned it, and began cueing. We didn't choose CS for its popularity or widespread acceptance, but to give English to our deaf child. We now have six children, four with hearing loss. CS has been "the road less traveled by, and that has made all the difference" (Robert Frost).

Mary Ann's Story

My husband's family and my own include a number of deaf people, including us. We knew our children might be deaf, and we now have three beautiful boys.

Our first language was American Sign Language (ASL), and it is the language that our boys learned first as well. When it comes to communication, our children have full access to their

environment at home. At school and in the community, this 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 have teachers who communicate proficiently in sign language and who have high expectations of deaf children.

We see our boys as handsome, intelligent and inquisitive and we do not define them solely by their deafness. We are seeing that they are given every opportunity to learn and grow. We have no doubt they will experience and enjoy all the world has to offer them.

Melisa's Story

Our twin daughters Monica and Marisa were born in 1997 and diagnosed with progressive moderate-to-severe hearing loss at eighteen months old. I remember telling my husband that I would do anything to give them a means of communicating.

After some research, we chose to use the total communication approach using speech and sign language. The girls are now 9 years old and with a lot of hard work from the girls, us as parents, and Early Intervention services, they are developmentally appropriate for speech and language skills. They attend our neighborhood school; they are fully included in the classroom with a sign language interpreter; and they keep pace with their peers.

They are very inquisitive and active young girls. They both enjoy church league basketball, girl scouts and playing with their younger brother Mikey. Marisa's activities include riding horses and singing. Monica's involvements include riding her motorcycle and soccer. After having twins, I have realized what works for one child may not work for another. Each and every child is unique.

Table 2 - Communication Options

	American Sign Language **Mary Ann's View**	Auditory-Oral **Angie's View**	Auditory-Verbal **Betsy's View**	Cued Speech **Lisa's View**	Total Communication **Melisa's View**
Definition	A manual language that is distinct from spoken English with its own grammar and syntax. Extensively used in the Deaf community.	An approach in which children learn to use whatever hearing they have, in combination with lip reading and contextual cues (speech reading) to understand and use spoken language.	The Auditory-Verbal approach encourages the child to use his/her auditory skills as much as possible. Use of other supporting information, such as gestures, speech reading and visual cues are discouraged.	A visual communication system which, in English, uses eight hand shapes in four locations combined with the natural mouth movements of speech, making all sounds of spoken language visible. However, when sounds look alike on the lips, the cues look different and vice versa.	A philosophy of using every and all means to communicate with the child. This could be in many ways: oral speech, sign language, gestures, speech reading and use of amplification. The idea is to communicate and teach your child in any manner that works.
Goals	To provide the child with a first language and allow him/her to communicate as a typically developing child would.	To maximize the child's access to sound using hearing aids and cochlear implants, in order to develop literacy and offer the child opportunity for mainstream education and an independent adult life.	The objective of this philosophy is for the children to speak and read English so they can be educated in a mainstream setting with their hearing peers.	This phonetic system makes articulation, pronunciation, dialect and even accents all visible to the person with deafness. The goal is to provide the child with an accurate mental model of the spoken language.	To provide an easy communication method between the child and the family, teachers and schoolmates. The child's simultaneous use of speech and sign language is encouraged, as is the use of all visual cues.

	American Sign Language **Mary Ann's View**	Auditory-Oral **Angie's View**	Auditory-Verbal **Betsy's View**	Cued Speech **Lisa's View**	Total Communication **Melisa's View**
Language	Language is developed through the use of ASL, which is the child's primary expressive language. Written English is added in the early years. ASL users can also develop spoken English.	The child learns to speak and understand language through immersion in an oral environment and with consistent use of amplification.	The child is expected to learn to speak and understand speech by hearing it.	The child learns to understand language which is provided to him/her using cues.	Spoken and written English and sign language are developed through exposure to speech, sign language, speech reading and the use of amplification.
Family Responsibility	Ideally, families learn ASL along with the child. Seeking and interacting with others who are fluent ASL users is important in developing ASL skills.	Parents are expected to incorporate training and practice sessions into the child's daily routine and play activities. Parents need to be highly involved with the child's teacher and/or speech and hearing therapists to carry over training activities to the home. Family is responsible for ensuring consistent use of amplification.	Auditory-Verbal Therapy (AVT) is directed as much at parents/caregivers as it is provided to the child. Outside of the therapy room, the child needs to be provided with maximum exposure to spoken language. Speaking to the child constantly, as in providing a narration of the activities of daily life, is typical. A parent of a child using AVT talks constantly. Parents are also expected to maintain all equipment in working order and ensure that spare parts are available at all times.	Family members learn Cued Speech in about eight hours; fluency takes practice and consistent use. Parents are expected to cue at all times in order to expose the deaf child to everything to which a hearing child would be actively and passively exposed.	The family is responsible for encouraging consistent use of amplification. At least one, but preferably all family members should learn the chosen sign language system in order for the child to develop age-appropriate language and communicate with family members. As the child's sign language increases, so must the parents'.

Communication Methods

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. Table 2 was prepared by parents to reflect their understanding and experiences with a variety of communication methods. The websites in Appendix E also provide information on communication options.

There are two languages that the majority of children who are deaf or hard of hearing use in the United States. They are **spoken English** and **American Sign Language (ASL).**

Spoken English

SPOKEN ENGLISH may be taught to children who are deaf or hard of hearing using some of the following methods:

- **Auditory-Oral:** Training in spoken English, listening, speech reading (lip reading) and naturally occurring gestures.
- **Auditory-Verbal:** Training in spoken English and the use of listening.
- **Cued Speech:** Training in a visual, sound based communication system, which clarifies speech reading (lip reading) and in English, uses eight hand shapes in four locations, in combination with the natural mouth movements of speech to make all the sounds of spoken language look different.

American Sign Language

- **AMERICAN SIGN LANGUAGE (ASL)** is a visual-gestural language with its own sentence structure and grammar and is the native language of many Deaf people in the United States.
- **Bilingual/Bicultural** or **"BiBi"**: An educational approach where ASL is taught as a first language. English is taught as a second language through reading and writing.

Other

- **Manually Coded English Systems (MCE)** are not separate languages. They use some ASL signs and invented signs and put them into the grammatical structure and word order of spoken English. Some common forms of MCE are Signing Exact English and Seeing Essential English.
- A term that is associated with the use of MCE is **Simultaneous Communication (SimCom)**. It consists of communicating simultaneously in spoken language and an MCE system.
- **Total Communication** is a philosophy (not a method or a language) that incorporates speech, speech reading (lip reading), MCE, natural gestures and listening.

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 a personal listening device that is worn on the ear, to make sounds louder. Hearing aids vary in size, power, and cost. 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 - **binaural** hearing aids. This is especially true for babies, since the goal is to provide them with the best access to auditory stimuli in all listening situations.

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.

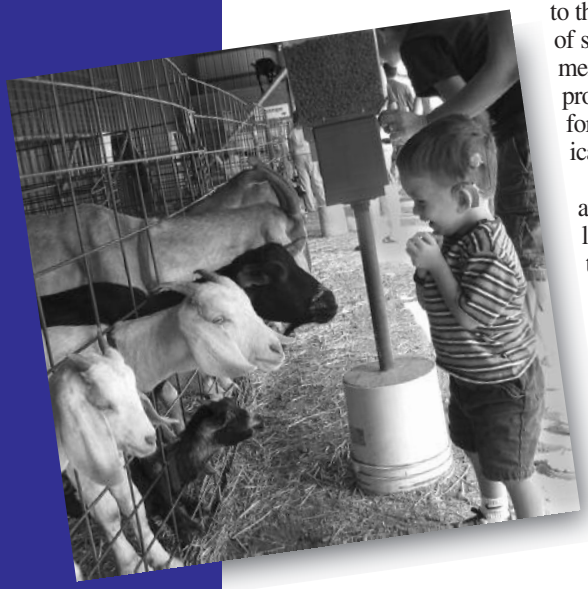
Taking care of the hearing aid requires daily checking and care. It must be kept dry, safe, and away from pets or toddlers who can quickly chew or play with a hearing aid and break it. Hearing aid batteries are small and **batteries can be harmful if swallowed**. Keep all loose batteries out of the reach 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.

A **personal FM system** is a listening device that can be used in conjunction with hearing aids. It transmits an auditory signal via an FM radio wave from the speaker's mouth, through a microphone and amplifier, to the child's hearing aid or ear. FM systems are beneficial and recommended for use in listening environments where there is significant distance between a child and the person speaking with them or when there is a lot of background noise.

Cochlear Implants

A cochlear implant is a personal listening system that has multiple pieces: a surgically implanted device and external components which include a microphone, speech processor, and transmitter. The surgically implanted internal components consist of a receiver and an electrical array. These components allow the sound stimulus to bypass the damaged inner ear and directly stimulate the auditory nerve, sending the signal to the brain. Cochlear implants do not restore hearing to the normal range, but are an option for children as young as 12 months whose hearing loss is so great that they do not receive satisfactory benefit from hearing aids. Recent research has shown that young children with cochlear implants have the potential to reach language milestones at rates similar to their hearing peers. 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.



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 Appendices C and E can provide the reader with access to 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

Parenting an infant or toddler can be especially challenging when they have deafness or hearing loss, with or without other disabilities or developmental delays. Early Intervention (EI) in Pennsylvania is a collection of services and supports designed to help families enhance their baby's development. EI is a process that promotes collaboration among parents, service providers, and others who are significantly involved with the baby.

With parents' help, early intervention supports and services can enhance the development of your baby by . . .

- Answering your family's and your own questions about your baby's development;
- Providing you with ideas about the ways you can support and help your baby;
- Assisting you to interact with your baby through daily routines and activities at home and in the community;
- Improving your baby's developmental and educational growth;
- Helping babies become more independent;
- Helping you understand different funding sources;
- Putting you in touch with resources to help your baby with a hearing loss;
- Introducing you to service providers;
- Preventing the need for more intervention in the future; and
- Helping communities become more aware of the gifts and abilities of all its babies and children.

Early intervention recognizes the care-giving family as the baby's greatest resource and supports the family in its routines in the home and in the community. Early Intervention in Pennsylvania is funded through federal, state and county funds, as well as public insurance and other community resources. Under federal and state law the **Department of Public Welfare (DPW), Bureau of Early Intervention Services** sets policy and allocates funds for the Commonwealth's Early Intervention Program for infants and toddlers who have or are at risk of having developmental delays, including babies with hearing loss. The County Mental Health/Mental Retardation Programs administer the EI programs
locally.

In accordance with federal and state law, the **Pennsylvania Department of Education (PDE)** sets the policies for programs and services for children from age three to the age of beginning school, whether that is kindergarten or first grade; this age varies in different school districts in the state. To implement federal law, the **Bureau of Special Education** contracts services through **Mutually Agreed Upon Written Arrangements (MAWAs)** with **Intermediate Units (IUs)**, school districts and other providers.

Early intervention services can include, among other things, information on how children develop, early childhood education, and interventions which can help your child move his or her body or learn to communicate, ideas for how your family can help your child at home and in the community, and plans designed to help you enhance your child's growing and learning.

Early intervention services and supports are provided in a family centered way. **Family centered** means that your child's services and/or supports are based upon the strengths, concerns, priorities, and resources as identified by you and your child's family. Services and supports are designed to respect the family's concerns, interests, values, and priorities.

In order to reach the appropriate Early Intervention office in any part of the state, parents should contact **CONNECT Information Service, at 800-692-7288 (V/TTY).** Using this telephone service, CONNECT personnel will assist parents in locating local, state and national associations for children ages birth to five, local services and information. Many additional resources for more information are located in the Appendices.

Financial Information

Many commercial health insurance companies do not cover hearing aids or other assistive listening devices in their policies. Please check with your individual carrier for any type of coverage involving hearing aids.

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 Public Welfare (DPW) 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
- Child's Social Security Number

Referrals for Audiological Services

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

1. Appropriate place of service
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 baby'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. Place of service: This varies depending upon your insurance and where you live. Please be sure your referral is made out to one provider. Your audiologist can help you determine the most convenient location.

   Examples:
   - Tru-Tone Hearing Aid Centers, Inc.
   - Associated Hearing Center
   - Charles Lindsay

2. Type of durable good:
   - Hearing Aids
   - Earmolds
   - FM System (if applicable)

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

References and Resources

Center for Childhood Communication at the Children's Hospital of Philadelphia. (n.d.) Parent Information Packet. Philadelphia, Pennsylvania.

Connecticut Birth to Three System. (1999). Service Guideline 5: Young Children who are Hard of Hearing or Deaf: Intervention Guidance for Service Providers and Families. Department of Mental Retardation, Connecticut.

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Michigan Department of Community Health. (2004). Services for Children Who Are Deaf or Hard of Hearing: A Guide to Resources for Families and Providers. Michigan Department of Community Health, Community Living, Babies and Families, Early Hearing Detection and Intervention Program: Lansing, Michigan.

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Rhode Island Department of Health Early Intervention Program. (1999). A Resource Guide for Families of Children with Hearing Loss. Rhode Island Department of Health.

Schwartz, S. (1996). Choices in Deafness: A Parents' Guide to Communication Options. Bethesda, MD: Woodbine House, Inc.

The Canadian Hearing Society. (1999). Starting Point: A Resource for Parents of Deaf or Hard of Hearing Children. The Canadian Hearing Society: Toronto, Ontario.

Virginia Department of Health. (n.d.). Information for Parents of Children with Hearing Loss: Virginia's Resource Guide for Parents. Virginia Department of Health, Department of Education, Department for the Deaf and Hard of Hearing, Virginia's Early Intervention System, and Department of Mental Health, Mental Retardation and Substance Abuse Services.

Watkins, S. (Ed.) (2004). Ski-Hi Curriculum. Logan, Utah: HOPE, Inc.

Wisconsin Department of Health and Family Services. (2000). Babies and Hearing Loss Notebook. Wisconsin Sound Beginnings and Wisconsin CSHCN Program.

Terms

Act 212: The Early Intervention Services System Act of 1990 that provides for early intervention services for eligible infants and toddlers and eligible young children in Pennsylvania.

Amplification: Making sounds louder; also used to mean hearing aids and other equipment.

Assistive technology (AT) device: Any and all types of electronic devices including hearing aids, FM systems, infrared systems, tactile aids, special inputs for the television or radio, amplified/visual alarm systems, and teletypewriters (TTYs) that are used by people with deafness or hearing loss to increase, maintain or improve the person's functional capabilities. Adapted smoke alarms which include flashing lights are another example of an assistive technology device. Some of these devices may also be referred to as **assistive listening devices.**

Audiological assessment / hearing test: A hearing test which may include a combination of pure tone thresholds, impedance measurements for middle ear function (immittance or tympanometry), speech recognition, and speech discrimination measurements. ABR and otoacoustic emissions testing may also be included. Together, these measurements are used to determine the type and degree of hearing loss. This can also mean a test in the aided condition to determine the benefit of amplification and might be called an aided assessment.

Audiologist: A person with a master's degree or doctoral degree in audiology who is a specialist in testing hearing and working with those who have hearing loss or deafness. The person has a certification from the American Speech-Language-Hearing Association (and in the future, perhaps from the American Academy of Audiology). The person may have CCCA (Certificate of Clinical Competence in Audiology) or FAAA (Fellow, American Academy of Audiology) after their signature. An audiologist's evaluation often results in recommendations about appropriate hearing aids and referrals to physicians and/or other professionals.

Auditory training: The process of training a person to use their residual hearing in the awareness and interpretation of sound. Sometimes also called **Aural (Re)Habilitation.**

Bone conduction: Sound received via vibration of the bones of the skull.

Cued Speech Transliterator: A trained professional who facilitates spoken communication between a hearing person and a person with a hearing loss through the use of Cued Speech.

Deaf: Hearing loss so profound that the baby is unable to process linguistic (language) information through hearing alone.

Deaf community: A group of people who share common interests and a common heritage whose primary mode of communication is American Sign Language (ASL). The Deaf community is comprised of individuals, both deaf and hearing, who respond with varying intensity to particular community goals, which derive from Deaf cultural influences. The Deaf community in the United States may have a wide range of perspectives on issues, but emphasis remains on deafness as a positive state of being.

Deaf culture: A view of life manifested by the mores, beliefs, artistic expression, understanding and language (ASL) particular to Deaf people. A capital "D" is often used in the word Deaf when it refers to community or cultural aspects of deafness.

ENT: A medical doctor who specializes in the care and treatment of the Ears, Nose, and Throat. **Otolaryngologist (ENT):** A physician who specializes in medical problems of the ear, nose and throat. This specialist provides diagnosis of medical conditions of the ear and provides medical clearance for hearing aids. May also be called an **otorhinolaryngologist** or **otologist.**

Eustachian tube: A tube that connects the middle ear with the throat and allows air to move back and forth into the middle ear. This tube can become swollen closed and cause middle ear dysfunction.

Fingerspelling: Refers to the use of finger positions and hand shapes to represent each letter of the alphabet to spell words. It is most often used to spell proper nouns and words for which there are no sign language representations.

Genetic counseling: A medical specialty which may help families understand the cause of a baby's disability, the chance of recurrence in other relatives or future babies, and whether the condition is part of a syndrome that should be watched for other medical complications.

Hard of hearing: A description of a hearing loss, either permanent or temporary, which adversely affects an individual's ability to detect and understand some sounds.

Hearing impaired: A term used to describe individuals with deafness or a hearing loss.

IDEA: The Individuals with Disabilities Education Improvement Act, Public Law 108-446; includes Part C and Part B, directly related to infants and young children. In Pennsylvania, the Department of Public Welfare (DPW) is the lead agency for the Early Intervention system for infants and toddlers from birth to age three. Thus DPW carries out the mandates of IDEA, Part C. The Department of Education supports Part B, early intervention for young children from age three to the age of beginners.

IEP: Individualized Education Program: A written plan for the provision of appropriate early intervention services to an eligible young child, including services to enable a family to enhance their child's development. The IEP identifies the child's educational levels, learning strengths and needs, annual goals, specially designed instruction, and the special education and related services necessary to support the child's learning and development.

IFSP: Individualized Family Service Plan: The written plan describing services that will be provided to the eligible infant or toddler and his or her family, as well as the expected outcomes. The IFSP is developed at least annually by a team that includes parents, a service coordinator, evaluators, and service providers.

An IFSP or IEP for a child with hearing loss should take into account such factors as 1) communication needs and the child's and family's preferred mode of communication; 2) linguistic needs; 3) severity of the hearing loss; 4) academic progress; 5) social-emotional needs, including opportunities for peer interaction and communication; 6) appropriate accommodations to facilitate learning; and 7) the care, use, and maintenance of amplification equipment and/or assistive devices.

Intermediate Unit (IU): Educational agency within a county or geographic area that can assist with specialized educational needs. Intermediate units are usually listed in your local telephone book.

Interpreter: A person who facilitates communication between a speaker and a deaf or hard of hearing person. The term usually refers to translation of a language into a visual and/or a phonemic code by an oral interpreter, an ASL translator, or cued speech interpreter.

Language: Understanding and expression in listening, speaking, reading and writing.

Middle ear: Located between the outer ear and the inner ear, it contains three tiny bones (ossicles) and is an air-filled cavity. It is connected to the throat by the Eustachian tube. The middle ear can become filled abnormally with fluid, which may cause temporary hearing loss.

Monaural amplification: The use of one hearing aid.

Otitis media / ear infection: An inflamed condition of the middle ear, which brings fluid (which can be present with or without infection) into this normally air-filled cavity. A middle-ear infection with fluid may cause temporary, fluctuating hearing loss. Without proper medical attention, chronic otitis media with fluid may impact the development of speech and language.

Output: Refers to how much amplification is being provided by a hearing aid.

Relay: A free service provided by the telephone company that allows communication between deaf, hard of hearing and speech impaired people using the telephone and TTY or TDD. In PA, call 711.

Residual hearing: The amount of measurable, usable hearing a person has that may be able to be amplified.

Speech: The physical production of the sounds in the language in order to form words, phrases, and sentences

Speech Awareness Threshold (SAT): This is the faintest level at which anyone detects speech 50 percent of the time. SAT is measured during audiological evaluation with and/or without hearing aids.

Speech intelligibility: An indication of how well a person's speech is understandable to the average listener.

Speech reading / lip reading: The interpretation of lip and mouth movements, facial expressions, gestures, prosodic and melodic aspects of speech, structural characteristics of language, and topical and contextual clues.

Speech-language pathologist / speech therapist / speech clinician / SLP: A master's or doctoral level trained professional who works with individuals in the areas of speech and language. Speech-language pathologists are certified by ASHA (American Speech, Hearing and Language Association) and will typically use the initials CCC-SLP (Certificate of Clinical Competence) as a credential after their signature.

Tactile aids: A type of assistive communication device that emits a vibration or signal related to the sense of touch to indicate the presence of sound.

Threshold: The softest level of sound an individual can hear 50 percent of the time. Term can be used in reference to speech or pure tones.

TTY: Devices that send and receive written messages through telephone lines. Also known as TDD, Telecommunication Devices for the Deaf.

[Adapted from Michigan Department of Community Health, (2004). Services for Children Who Are Deaf or Hard of Hearing: A Guide to Resources for Families and Providers. Michigan Department of Community Health, Community Living, Babies and Families, Early Hearing Detection and Intervention Program: Lansing, Michigan, pages 10-19].

Appendix A:

Questions to Ask in Searching for a Pediatric Audiologist

Ask a representative of the local education agency these questions:

1. Which audiologists in the local area see the children in your program?
2. When you have questions about pediatric audiology, whom do you call?

Ask an audiologist these questions:

1. How many babies do you see in a year?
2. My baby is ___ months/years of age. What kinds of tests do you recommend for my baby? Can you perform these tests? If not, can you refer me to an audiologist who can?
3. Do you dispense loaner hearing aids?
4. Are you a Pennsylvania Medical Assistance service and durable goods provider?
5. Can you refer me to a support group for families of children who are deaf and hard of hearing or a support group for the children themselves?

Appendix B

Statewide Parent Resources

CONNECT Information Service for Early Intervention
Center for Schools and Communities
275 Grandview Avenue, Suite 200
Camp Hill, PA 17011
800-692-7288
(For TTY, dial 711 for Relay Service)

Education Law Center
1315 Walnut Street, 4th Flr
Philadelphia, PA 19107-4717
215-238-6970 (Voice) 215-789-2498 (TTY)
215-772-3125 (Fax)

Education Law Center
429 Fourth Avenue
Pittsburgh, PA 15219
412-391-5225 (Voice) 412-467-8940 (TTY)
412-391-4496 (Fax)

Hispanos Unidos para Niños Excepcionales (HUNE) (Hispanics United for Exceptional Children)
202 West Cecil B. Moore Avenue
Philadelphia, PA 19122
215-425-6203 (Voice) 215-425-6204 (Fax)
www.huneinc.org

The Mentor Parent Program
P.O. Box 47
Pittsfield, PA 16340
814-563-3470 (Voice) 814-563-3445 (Fax)
888-447-1431 (Toll Free-PA only)
www.mentorparent.org
Serving: Rural Northwest Pennsylvania

Parent Education Network (PEN)
2107 Industrial Highway
York, PA 17402-2223
800-522-5827 (Voice/TTY)
www.parentednet.org

Parent Education & Advocacy Leadership (PEAL) Center
1119 Penn Avenue, Suite 400
Pittsburgh, PA 15222
412-422-1040 (Voice) 412-281-4409 (TTY)
412-281-4408 (Fax) 866-950-1040 (Toll Free)
www.pealcenter.org

Parent to Parent of Pennsylvania
Fiona Patrick, Program Director
6340 Flank Drive, Suite 600
Harrisburg, PA 17112
800-986-4550 (Voice) 717-540-4722 (TDD)
717-657-5983 (Fax)
www.parenttoparent.org

Pennsylvania Health Law Project
1414 N. Cameron Street, Suite B
Harrisburg, PA 17103
800-274-3258 (Helpline) 866-236-6310 (TTY)
www.phlp.org

Pennsylvania Office for the Deaf and Hard of Hearing
1521 N. 6th Street
Harrisburg, PA 17102800-233-3008 (Voice/TTY)
www.dli.state.pa.us/landi/cwp

Pennsylvania Training and Technical Assistance Network (PaTTAN)
www.pattan.net

PaTTAN King of Prussia
200 Anderson Road
King of Prussia, PA 19406
610-265-7321 (Voice) 610-768-9723 (TTY)
800-441-3215 (PA only)

PaTTAN Harrisburg
6340 Flank Drive, Suite 600
Harrisburg, PA 17112
717-265-7200 (Voice) 800-654-5984 (TTY)
800-360-7282 (PA only)

PaTTAN Pittsburgh
3190 William Pitt Way
Pittsburgh, PA 15238
412-826-2336 (Voice) 412-826-2338 (TTY)
800-446-5607 (PA only)

Appendix C

National Resources

A.G. Bell Association for the Deaf and Hard of Hearing
3417 Volta Place, NW
Washington, DC 20007
202-337-5220 (Voice)
202-337-5221 (TTY)
www.agbell.org

American Academy of Audiology
www.audiology.org

American Speech, Language and Hearing Association (ASHA)
www.asha.org

American Society for Deaf Children (ASDC)
3820 Hartzdale Drive
Camp Hill, PA 17011
800-942-ASDC (2732)
www.deafchildren.org.

Auditory Verbal International (AVI)
2121 Eisenhower Avenue, Suite 402
Alexandria VA 22314
703-739-1049 (Voice)
703-739-0874 (TTY)
AVI@auditory-verbal.org
www.auditory-verbal.org

Beginnings for Parents of Children who are Deaf or Hard of Hearing
3714 Benson Drive, Suite A
Raleigh, NC 27609
Mailing address: P.O. Box 17646
Raleigh, NC 27619
800-541-HEAR (V/TTY)
www.beginningssvcs.com

Boys Town National Research Hospital
555 N. 30th Street
Omaha, NE 68131
402-498-6511
www.babyhearing.org

Cochlear Implant Association, Inc.
5335 Wisconsin Ave. NW, Suite 440
Washington, D.C. 20015-2052
202-895-2781
www.cici.org

Cued Speech Discovery Bookstore
23970 Hermitage Road
Cleveland, OH 44122-4008
800-459-3529 (V/TTY)
www.cuedspeech.com
cuedspdisc@aol.com

Hands and Voices
P.O. Box 371926
Denver, CO 80237
303-300-9763
866-422-0422 (toll free)
www.handsandvoices.org

Harris Communications, Inc.
15155 Technology Drive
Eden Prairie, MN 55344
800-825-6758 (Voice)
800-825-9187 (TTY)
info@harriscomm.com
www.harriscomm.com

Hearing Loss Association of America
7910 Woodmont Avenue, Suite 1200
Bethesda, MD 20814
301-657-2248 (Voice)
301-657-2249 (TTY)
www.shhh.org

John Tracy Clinic
806 West Adams Boulevard
Los Angeles, CA 90007
800-522-4582
www.oraldeafed.org/schools/johntracy/about.html

Laurent Clerc National Deaf Education Center
Gallaudet University
800 Florida Avenue NE
Washington, DC 20002-3695
202-651-5000
http://clerccenter.gallaudet.edu/

Marion Downs National Center for Infant Hearing
University of Colorado at Boulder
Department of Speech, Language & Hearing
Campus Box 409
Boulder, CO 80309-0409
www.colorado.edu/slhs/mdnc

National Association of the Deaf
8630 Fenton Street
Silver Spring, MD 20910
301-587-1788 (Voice)
301-587-1789 (TTY)
www.nad.org

National Center for Hearing Assessment and Management (NCHAM)
Utah State University
www.infanthearing.org

National Cued Speech Association (NCSA)
23970 Hermitage Road
Cleveland, OH 44122-4008
800-459-3529 (Voice/TTY)
CuedSpDisc@aol.com
www.cuedspeech.org

National Institute on Deafness and Other Communication Disorders
National Institutes of Health
31 Center Drive, MSC 2320
Bethesda, MD 20892-2320
nidcdinfo@nidcd.nih.gov
www.nidcd.nih.gov/health/hearing/

Oberkotter Foundation
PO Box 6542
Palo Alto, CA 94303-9465
877-672-5332 (Voice)
877-672-5889 (TTY/Fax)
www.oraldeafed.org

Sign Enhancers, Inc.
10568 SE Washington Street
Portland, OR 97216-2809
800-767-4461 (Voice)
888-283-5097 (TTY)
www.iadeaf.k12.ia.us/html/sign_language1.html

The SEE* Center for the Advancement of Deaf Children
P.O. Box 1181
Los Alamitos, CA 90720
562-430-1467
www.seecenter.org

*Signing Exact English (SEE2)

Appendix D

Frequently Asked Questions / FAQs

AGE AND HEARING TESTS

1. My pediatrician told me that my child was too young to have her hearing accurately tested. She is 7 months old. Is this true?

No, that is not true. Although it is not possible for a pediatrician to accurately test the hearing of the youngest infant or toddler, a pediatric audiologist who has specific training and equipment to test babies and young children can do this.

DEAF CULTURE

2. What is Deaf culture?

Deaf culture is based on the use of American Sign Language (ASL); it includes "communication, social protocol, art, entertainment, recreation and worship."
[M. Moore & L. Levitan, (1992). *For Hearing People Only.* Rochester, NY: Deaf Life Press.]

3. Can hearing people be members of the Deaf culture?

Hearing people cannot be true members of the Deaf culture, however, they can participate in the culture by learning ASL and being involved in cultural activities and events. Most Deaf people welcome hearing people who are respectful of the culture.

HEARING AIDS

4. Can hearing aids damage my child's hearing?

The audiologist will adjust the settings of the hearing aids so they will not damage your child's hearing. If you have concerns about the loudness of the sound coming through the aids, you should speak with your audiologist.

5. We would like our child to learn to use his hearing more. We feel if he wears his hearing aids all the time he will never learn to hear without them. Should we leave his hearing aids off for a part of each day?

No, leaving the hearing aids off your child does not improve your child's hearing. This is something you should discuss with your service coordinator, your child's audiologist or early intervention specialist. They will assist you in identifying appropriate activities to help your child learn to use his hearing. You should ensure your child's hearing aids are used full-time.

Appendix E
Internet Sites

Listed below are some Internet sites that may provide helpful information or links to further resources for families of babies with hearing loss or deafness. The list has been compiled as a service to readers of this booklet and does not constitute an endorsement of any particular site. The Pennsylvania Departments of Education and Public Welfare do not assume responsibility for the content included in these World Wide Web home pages. Before making any educational or health care decision based on information obtained from the Internet, always consult your baby's own audiologist, teacher and/or physician.

Advanced Bionics
www.cochlearimplant.com

Alexander Graham Bell Association for the Deaf
www.agbell.org

American Academy of Audiology
www.audiology.org

American Academy of Family Physicians
www.aafp.org

American Academy of Pediatrics
www.aap.org

American Association of the Deaf-Blind
www.aadb.org

American Society for Deaf Children
www.deafchildren.org

American Speech-Language-Hearing Association
www.asha.org

Auditory Verbal International, Inc.
www.auditory-verbal.org

Better Hearing Institute
www.betterhearing.org

Boys Town National Research Hospital
www.boystownhospital.org

Captioned Media Program
www.cfv.org

Centers for Disease Control and Prevention
www.cdc.gov

CID Oral School and Outreach Center
cid.wustl.edu

Closed Captioning FAQ
www.robson.org/capfaq

Cochlear Inc.
www.cochlearamericas.com

Cochlear Implants: Navigating a Forest of Information… One Tree At A Time
http://clerccenter2.gallaudet.edu/KidsWorldDeafNet/e-docs/CI/

DB-LINK (deafblind)
www.tr.wou.edu/dblink

The Deaf Resource Library
www.deaflibrary.org

Deaf Zone
deafzone.com

DEAFology.com
deafology.com

DisabilityResources.org
www.disabilityresources.org/AT-DEAF.html

Dogs for the Deaf, Inc.
www.dogsforthedeaf.org

EZears.com
www.earhelp.com/

Easter Seals Disability Services
www.easterseals.com

Educational Audiology Association
www.edaud.org

For Hearing People Only
www.forhearingpeopleonly.com

Gallaudet University
www.gallaudet.edu

Hands and Voices
www.handsandvoices.org

Hearing Aids and Audiology Information Network
www.audiologyinfo.com

Hearing Exchange
www.hearingexchange.com

Hearing Loss Association of America
www.shhh.org

House Ear Institute
www.hei.org

John Tracy Clinic
www.johntracyclinic.org

The Kenneth W. Berger Hearing Aid Museum and Archives
dept.kent.edu/hearingaidmuseum/

Kid Source On Line
www.kidsource.com

Kids World Deaf Net
http://clerccenter2.gallaudet.edu/KidsWorldDeafNet

Kresge Hearing Research Institute (UM)
www.khri.med.umich.edu/

Language Matters
www.language-matters.com/

League for the Hard of Hearing
www.lhh.org

Let's Hear It for the Ear!
kidshealth.org/kid/body/ear.html

The Listen Foundation
www.listenfoundation.org

Listen Up
www.listen-up.org

Marion Downs Nat'l Center for Infant Hearing
www.colorado.edu/slhs/mdnc

National Association of the Deaf
www.nad.org

National Center on Deafness
ncod.csun.edu/

National Center for Hearing Assessment and Management
www.infanthearing.org

National Cued Speech Association
www.cuedspeech.org

National Dissemination Center for Children with Disabilities
www.nichcy.org

National Institute on Deafness and Other Communication Disorders
www.nidcd.nih.gov

National Parent Network on Disabilities
www.npnd.org

Oral Deaf Education
www.oraldeafed.org

Paws With A Cause
www.pawswithacause.org

Pennsylvania Academy of Audiology
www.paaudiology.org

Pennsylvania Initiative on Assistive Technology
http://disabilities.temple.edu/programs/assistive/piat/index.htm

Raising Deaf Kids
raisingdeafkids.org

Registry of Interpreters for the Deaf
www.rid.org

Say It With Sign!
www.deafresources.com

Voice for Hearing Impaired Children
www.voicefordeafkids.com

Where do we go from Hear?
www.gohear.org

If you have any questions about this publication, or for additional copies, contact:

Pennsylvania Training and Technical Assistance Network (PaTTAN)
200 Anderson Road
King of Prussia, PA 19406
Voice Telephone: (610) 265-7321
TTY: (610) 768-9723

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