



A Guide for Parents and Families of Children with Hearing Loss



American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN™



Pennsylvania Chapter

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A World of Opportunity

Raising a child is one of life's most challenging yet rewarding experiences. Raising a child with a hearing loss will be more challenging but no less rewarding. Keep in mind that having a hearing loss does not define your child or his or her potential.

Most parents are shocked, frightened and confused when they are first told their child has a hearing loss. All of these feelings are perfectly normal. Most parents immediately start asking questions:

- "Can this be fixed?"
- "Why did this happen?"
- "Will it get worse?"
- "Is there anything else wrong?"
- "Was it something I did?"
- "Will my child learn to talk?"
- "Can my child go to a regular school?"
- "What will the future hold for my child?"

These questions, and others you may have, will be answered by your child's doctor and the specialists who will help you and your child.

You may feel like you are on an emotional roller coaster ride. Be patient with yourself and gather as much information as possible from doctors, audiologists (professionals who diagnose and treat hearing loss), educators and other caring professionals. Parents of children with hearing loss can also help by sharing their stories and experiences with you.

Remember, the earlier a child's hearing loss is found, the sooner the child can take the necessary steps on the road to a bright, hopeful, wonderful world of opportunity!



Your Child's Developing Brain

The first few years of your child's life are very important for learning speech and language. The good news is that by getting an early start and the right help your child can make the most of his/her abilities. Research shows that many children found to have a hearing loss and treated early can develop speech and language skills like hearing children their own age!

When a child has a hearing loss, the auditory (hearing) center of the brain does not receive the same information that a hearing child's brain receives. It is very important for children with hearing losses to receive this information so that they can develop language and communication skills.

FAST FACTS

- Hearing loss is the most common birth defect in newborns.
- The majority of children with hearing losses are born to parents who have normal hearing.
- In the United States, 33 babies are born every day with a hearing loss.
- There are many different types and degrees of hearing loss.
- Children as young as one month of age can be fitted with hearing aids.
- Most children with hearing losses have no other disability.
- When a child's hearing loss is diagnosed and treated early, he or she can develop language skills like a child without a hearing loss.



Why Does My Child Have a Hearing Loss?

You may wonder why your child has a hearing loss. There are many possible causes of hearing loss in children and your doctor will be discussing these possibilities with you.

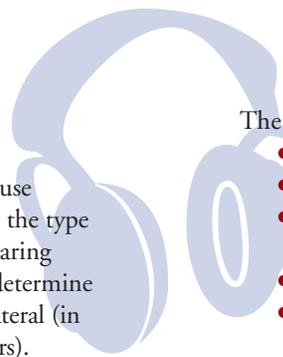
- No definite cause is found for half the children who have a hearing loss.
- Some children develop problems when they are newborns or infants that lead to hearing loss.
- Sometimes hearing loss is inherited and there are other family members with the same condition.
- A child's hearing loss may be genetic and related to changes in other parts of the body such as the heart, eyes or kidneys.
- Other children develop multiple ear infections that may lead to temporary hearing difficulty.
- Often there is no family history, no ear infections and no other physical differences to explain a child's hearing loss.

Understanding Types and Degrees of Hearing Loss

Your child's audiologist will use different tests to determine the type of hearing loss and degree of hearing loss. The audiologist will also determine whether the hearing loss is unilateral (in one ear), or bilateral (in both ears). There are four basic types of hearing loss:

- 1) **Sensorineural hearing loss** is the result of something affecting the inner ear, and it is generally a permanent type of hearing loss. Sensorineural hearing loss can be present at birth or can develop later in life.
- 2) **Conductive hearing loss** is the result of something affecting the outer or middle ear, such as an ear infection that causes fluid in the middle ear. In most cases, conductive hearing losses can be treated medically or surgically and are not permanent.
- 3) **Mixed hearing loss** is a combination of both sensorineural and conductive hearing losses.
- 4) **Central hearing loss** is the result of something affecting the part of the brain that is responsible for hearing.

Your child's audiologist will discuss the degree of your child's hearing loss by making a picture-like graph of your child's hearing, called an audiogram. The top of the audiogram represents sound frequencies that range from low-pitched to high-pitched sounds. The left side of the audiogram shows the intensity of sound measured in decibels (the greater the number of decibels, the louder the sound).



- The degrees of hearing loss are:
- Minimal (16-25 decibel loss)
 - Mild (a 26-40 decibel loss)
 - Moderate to moderately severe (a 41-70 decibel loss)
 - Severe (a 71-90 decibel loss)
 - Profound (a greater than 90 decibel loss)

Each child is special, and regardless of the type or degree of hearing loss, it is very

Getting Started on the Right Track: Early Intervention

Early intervention is the name of the services that are provided to your family, in your home or in your community, to help your child have access to communication. There is no cost to families for these services and all children with hearing losses should be enrolled in early intervention as soon as possible.

Early intervention services are provided by a team of professionals led by an



important to begin treatment and early intervention services as soon as possible to give your child every opportunity to interact with the world around them.

early intervention service coordinator. The team may include an audiologist, a teacher of the deaf and hard of hearing, a social worker, a speech/language therapist and anyone else who might be needed. This team will help you put a plan together based on the needs of your child and the priorities of your family. The plan will be changed as your child develops and your family's needs change.

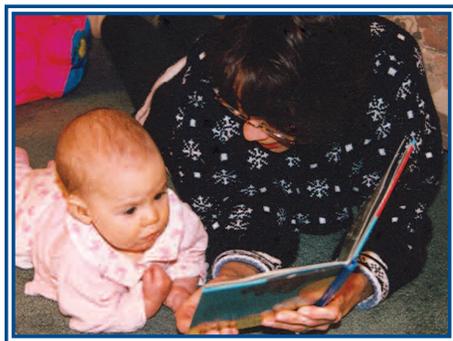
CONNECT TO EARLY INTERVENTION

The Individuals with Disabilities Education Act (IDEA) is a federal program that mandates services be provided for individuals with any type of disability, including hearing loss. The Early Intervention program, sometimes called Part C of IDEA, provides a variety of services for infants and toddlers up to age three. There is no cost to families for these services.

In Pennsylvania, the Part C Early Intervention (EI) program is funded through federal, state and county funds

with some public insurance and community resources. The Department of Public Welfare, Office of Child Development sets policy and allocates monies. The County Mental Health/ Mental Retardation Programs administer the EI programs on a local level.

For more information, contact CONNECT Information Service at 1-800-692-7288 (V/TTY) to get assistance in locating local, state and national services and associations for children ages birth to three.



COMMUNICATING WITH YOUR CHILD

Throughout the day, continually speak to your child and even name and point to objects. Your child may not be able to fully understand what is being said, but he/she may be able to hear your voice, and learn what you are trying to communicate.

- When talking, hold your child closely so that he/she can see your face and maintain eye contact.
- Use comfortable lighting so your face is clearly in view while speaking.
- Try to minimize distractions and background noise to make it easier for your child to use the hearing he/she does have.
- Keep talking! Talk during daily routines. Repeat actions, ideas and names of objects.
- Respond to your child's attempts to communicate. For example, if your child points to an object, name it, and bring it to him or her. If your child makes noises to get your attention, respond positively.

- Make the most of your child's other senses as another means of communicating. Touch, smell and look at things together as you describe them.
- Rock, snuggle, cuddle and hug your child as often as possible.
- Use facial expressions and eye contact as much as possible.



Decisions about Communication Methods

Your early intervention service coordinator and audiologist will help you determine the best way for you and your child to communicate. By getting as much information as possible about all your options, you will be able to make the best choice for your child and family.

Communication Methods

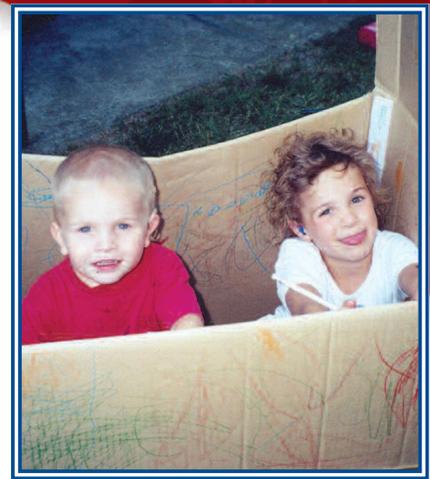
- **Auditory-Oral:** This method attempts to maximize a child's residual hearing (hearing a child does have), using hearing aids and/or cochlear implants, along with visual cues such as gestures and speech reading (sometimes referred to as lip reading). Children who use this method stress spoken language, and do not use sign language.
- **Auditory-Verbal:** This method also emphasizes the use of a child's residual hearing along with hearing aids and/or cochlear implants for developing spoken language. The child is encouraged to communicate through speaking, maintaining the focus on listening. This approach does not involve the use of speech reading or sign language. Special teachers or therapists work one-on-one with the child to enhance their listening skills.
- **Cued Speech:** This communication system focuses on information gained through sight and sound. It stresses the movements that the mouth makes when certain sounds are made, by

using hand signs near the face to give children clues as to which sounds are being spoken. Since some sounds look alike on the lips, this method helps differentiate the sounds being voiced. Cued speech can be used with any of the other communication approaches mentioned.

- **Sign Language:** The two basic types of sign language are Signed Exact English (SEE) and American Sign Language (ASL). SEE follows the grammatical structure of English and is an artificial language. ASL uses signs or hand gestures to communicate language. ASL is its own language and most children who use ASL utilize it as their primary communication form, over spoken language such as English.
- **Total Communication:** This communication method involves using a combination of spoken language, sign language and the use of residual hearing to communicate. This method also relies on the use of amplification (hearing aids or cochlear implants) to maximize the individual child's strengths in communicating.

Helping your child learn the speech and language skills necessary to communicate will take time and effort on everyone's part. You will need to receive training in the communication method chosen and work closely with your child to develop his/her language and speech skills.

For a helpful chart on communication options, see: www.beginningsvcs.com/communication_options/comm_options_chart.shtml



Understanding Types of Amplification

The most commonly used types of amplification devices are hearing aids, cochlear implants and assistive listening devices.

Hearing Aids

Babies as young as one month of age can wear hearing aids. The earlier children are fitted with hearing aids, the sooner they can start to hear and explore the world of speech, language, and environmental sounds around them.

A hearing aid is an electronic, battery operated device that can amplify (make

louder) and change incoming sound to improve your child's ability to hear sounds. A pediatric audiologist will use tests, experience and knowledge to determine the hearing aids that are best for your child. The audiologist will teach you about the operation and care of hearing aids and will closely monitor your child and the hearing aid's performance.

Cochlear Implants

A cochlear implant is a small, surgically implanted electronic device that restores partial hearing to those with severe to profound hearing loss. Unlike a hearing aid, it does not amplify sound or make

sound clearer. The cochlear implant bypasses the damaged parts of the inner ear and directly stimulates the auditory (hearing) nerve, allowing children with severe to profound hearing loss to receive sound. Through this auditory stimulation, a child can gain a perception of sound and learn to interpret speech sounds. Children with cochlear implants need to be trained how to interpret and effectively use the sounds which are heard through the implant. Although cochlear implants are very expensive, most insurance companies provide benefits that cover the cost. Contact your insurance company to discuss your coverage.

Assistive Listening Devices

Assistive listening devices (ALD) help children and adults in difficult listening conditions. The most commonly used type of assistive listening

device is an FM system that can be used along with a child's hearing aids. By using a microphone, an FM system improves the loudness of speech without significantly increasing background noise, making speech easier to understand in noisy conditions such as a classroom.

A Journey Together

Finding out that your child has a hearing loss is overwhelming and going through all the information you will receive about hearing loss is time-consuming. Remember, there are many compassionate, educated professionals as

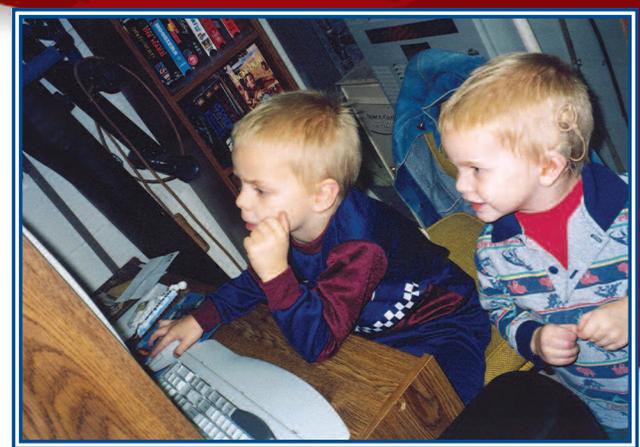
well as other parents who can help guide you through the journey. Most of all enjoy your child and focus on raising a happy, healthy child who happens to have a hearing loss.



DID YOU KNOW?

Any child with a permanent hearing loss and who lives in Pennsylvania can apply for Medical Assistance regardless of family income. Medical Assistance can help pay for hearing aids and other assistive listening devices.

Contact the Department of Public Welfare assistance office in your county to apply. (Check the phone book for contact information in your area or go to: <http://www.dpw.state.pa.us/LowInc/MedAssistance/MAEligibility/003670295.htm>)



Degrees of Hearing Loss & Effects on Speech and Listening

Slight to Mild Hearing Loss: 20-40 dB

Effects on Speech:

- Speech may be difficult to understand.
- May leave out the endings of words, or leave out certain words.

Effects on Listening:

- Can hear one-on-one conversations in quiet environments, at a close range, and especially if the speaker's face is visible.
- Has difficulty hearing and understanding what is being said in a noisy environment.
- School aged children may be accused of "spacing out," "not paying attention," or having "selective attention."
- Hears vowel sounds clearly.
- Misses unstressed words, such as "an", "the", "of", and voiceless consonant sounds, such as f, k, p, s, t. May miss the endings of words (work vs. worked or shoe vs. shoes).
- Tired at the end of the day due to the additional effort needed to listen.

Moderate to Moderately Severe Hearing Loss: 41-70 dB

Effects on Speech:

- Speech may be hard to understand.
- Leaves out or slurs consonant sounds.
- May have a limited vocabulary.
- Amplification and speech therapy are often needed for development of speech.

Effects on Listening:

- Misses almost all speech, unless the speaker is close by and speaking louder than a normal level.
- May rely on visual cues or lip-reading to aid in understanding speech.
- Vowels are heard easier than voiceless consonants (f, k, p, s, and t).
- Misses word endings (ing, ed, s) or prepositions (in, on, for, with).
- Listening in noise is very difficult, especially if multiple people are talking at the same time, and the speaker's face is not visible.
- Tired at the end of the day due to the additional effort needed to listen.

Severe Hearing Loss: 71-90 dB

Effects on Speech:

- If hearing loss is present at birth (congenital), spoken language will be delayed, or may not develop without intervention.
- Amplification and speech training are needed to develop spoken language.

Effects on Listening:

- Hearing is difficult in all situations.
- Does not hear speech without amplification.
- Tired at the end of the day due to the additional effort needed to listen.

Profound Hearing Loss: 90+ dB

Effects on Speech:

- If hearing loss is present at birth, spoken language will not develop spontaneously.
- Severe language delay is possible.
- Needs intensive training and amplification for spoken language to develop.

Effects on Listening:

- May not hear loud speech or loud sounds in the environment.
- May be aware of sounds due to vibrations.
- May not use hearing to communicate.

Newborn and Infant Hearing Screening Related Websites

Alexander Graham Bell Association for the Deaf and Hard of Hearing	http://www.agbell.org
American Academy of Audiology	http://www.audiology.org
American Academy of Otolaryngology – Head and Neck Surgery	http://www.entnet.org
American Academy of Pediatrics	http://www.aap.org
American Society for Deaf Children	http://www.deafchildren.org
American Speech-Language-Hearing Association	http://www.asha.org
Beginnings for Parents of Children Who Are Deaf or Hard of Hearing	http://www.ncbegin.org
Boys Town National Research Hospital (Center for Hearing Loss in Children)	http://www.boystownhospital.org
Centers for Disease Control and Prevention	http://www.cdc.gov/ncbddd/ehdi
Center on Hearing and Deafness, Inc.	http://www.chadinc.org
Deafness Research Foundation.....	http://www.drf.org
Hearing Loss Association of America	http://www.hearingloss.org
Hearing, Speech and Deafness Center	http://www.hsd.org
Listen-Up	http://www.listen-up.org
My Baby's Hearing.....	http://www.babyhearing.org
National Association of the Deaf	http://www.nad.org
National Center for Hearing Assessment and Management at Utah State University	http://www.infanthearing.org
National Cued Speech Association	http://www.cuedspeech.org
National Deaf Education Center/ Gallaudet University	http://Clercenter.gallaudet.edu/InfoToGo
National Institute on Deafness and Other Communication Disorders Information Clearinghouse.....	http://www.nidcd.nih.gov
Oral Deaf Education	http://www.oraldeafed.org

Pennsylvania Resources & Websites

Special Kids Network can give you information
about Early Intervention and Medical Assistance in your area:.....1-800-986-4550

How to establish Medicaid eligibility:

Consult information from

PA Health Law Project:<http://www.phlp.org/Loophole%20guide%20202-04.pdf>

Parent to Parent

<http://www.parenttoparent.org>

Parent Education Network.....

<http://www.parentednet.org>

Pennsylvania Academy of Audiology.....

<http://www.paaudiology.org>

Pennsylvania Chapter, American Academy of Pediatrics

<http://www.paaap.org>

Pennsylvania Department of Health.....

<http://www.health.state.pa.us>

Pennsylvania Training

& Technical Assistance Network (PaTTAN)

<http://www.pattan.net>