Iowa's Early Hearing Detection & Intervention

Families Make the Difference

How We Hear

Types of Hearing Tests
and Hearing Loss

Hearing Aides and other
Technologies for Children

Communication Options

Parent Rights &
Responsibilities

Information and Resources

A Guide for Families with Children who are Deaf or Hard of Hearing

6TH EDITION,
2019

IOWA FAMILY RESOURCE GUIDE
FOR FAMILIES WITH CHILDREN WHO ARE DEAF AND HARD OF HEARING
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If you have questions or comments about this guide

Please contact Iowa EHDI

http://idph.iowa.gov/ehdi

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Introduction

This guide is designed to help you understand your child's hearing loss. It will provide information, explanations and resources for your child and family.

This guide will give you with the basic knowledge and resources you need to navigate Iowa services. Here you will find:

- descriptions of the ear and hearing process
- explanation of types of hearing tests and loss
- communication and education options for your child and family
- your rights and responsibilities as the parent of child who is deaf or hard of hearing
- the glossary includes words and definitions that may be new for families

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- *Iowa Programs Providing and Financing Children's Care and Services*, Early ACCESS, 2002.
- *Texas Connect Family Resource Guide*, 2001.

Research shows parent involvement is crucial for children with hearing loss successful language development.

Section 1

Families Make the Difference

EHDI

SECTION 1: FAMILIES MAKE ALL THE DIFFERENCE

Research clearly shows that the involvement of parents and family has a strong effect on the successful development of language by children with hearing loss (Moeller, 2000). To be most effective, families need to place high priority on a baby's language development.

Families need to **participate, encourage and follow through** in the daily activities supporting this goal.

In addition to the professionals supporting your child and family, other families have valuable experiences to share—Talk with your Audiologist, Early ACCESS coordinator or contact ASK Resource Center www.askresource.org to connect with other families with similar experiences.

What to do when you learn your child has a hearing loss

Several weeks may pass between learning that your child has a hearing loss and beginning intervention. ***Intervention*** in Iowa is called Early ACCESS. The goal is to begin interventions with professionals as soon as possible, however there are things families can do to begin a baby's introduction to language.

Below are some activities families can do to support a child's beginning language development:

- Talk to your child, regardless of the severity of hearing loss. Speak close to her face.
- Use lots of facial expressions and gestures
- Always keep eye contact with your child
- Sing songs, recite nursery rhymes, read books and talk about what you are doing
- When you talk or sing to your baby, lay her on your chest so she will feel the vibrations.
- Start a journal where you record your questions, concerns and child's responses to sounds. Does she turn toward sound? Does she ignore low pitch sounds but respond to sounds with higher pitches? You can use this journal to track your child's progress.
- Place your baby's hand up to your lips as you talk.

JOINT COMMITTEE ON INFANT HEARING POSITION STATEMENT

The Joint Committee on Infant Hearing set goals for early intervention for infants with hearing loss:

- Families of infants with any degree of hearing loss should be eligible for early intervention services
- Early intervention services for infants with hearing loss should be provided by professionals with expertise in hearing loss
- It is recommended both home-based and center-based intervention options should be offered.

*The **full JCIH Position Statement** and the latest addition from 2013* http://jcih.org/posstatemts.htm .

If your child gets hearing aids...

You can encourage your child’s language in many ways once she has her hearing aids.

- *Use your child’s name often,* speak to him/her face-to-face and close up (within 6-12 inches of the hearing aid). If you call your child’s name, have a purpose. Reinforce your child’s responses to sound, especially their name, with things as attention and praise.
- When you hear something, point to your ears and say, “I heard that!” This helps a child learn to pay attention to sounds. Children with hearing loss need to be taught what sound is and that it is important for communication.
- Make sounds for your child to listen to and draw your child’s attention to these sounds.
- Listen to the sounds your child makes when hearing aids are being worn. Reinforce vocalizations.
- Write down your observations in your journal. Describe what these sounds are. Does she make certain sounds when she has certain needs?

During the time a child gets used to wearing hearing aids it is important to keep encouraging communication**.**

- **When your child makes a sound, repeat that sound back to him**. Imitation reinforces your child’s “talking”, leads to making more sounds and taking turns.
- **Encourage your child to respond to sounds, on his own.** For example, you and your child clap when music comes on. Then, wait to see if your child claps on his own he hears music.
- **Help your child learn common sounds at home**, such as the phone ringing or a knock on the door. For example, ring the doorbell and put your hands to your ears. Say, “Do you hear the doorbell? I hear the doorbell!” This helps him label and identify sounds.

Family involvement increases a child’s successful language development!

Section 2:

How We Hear

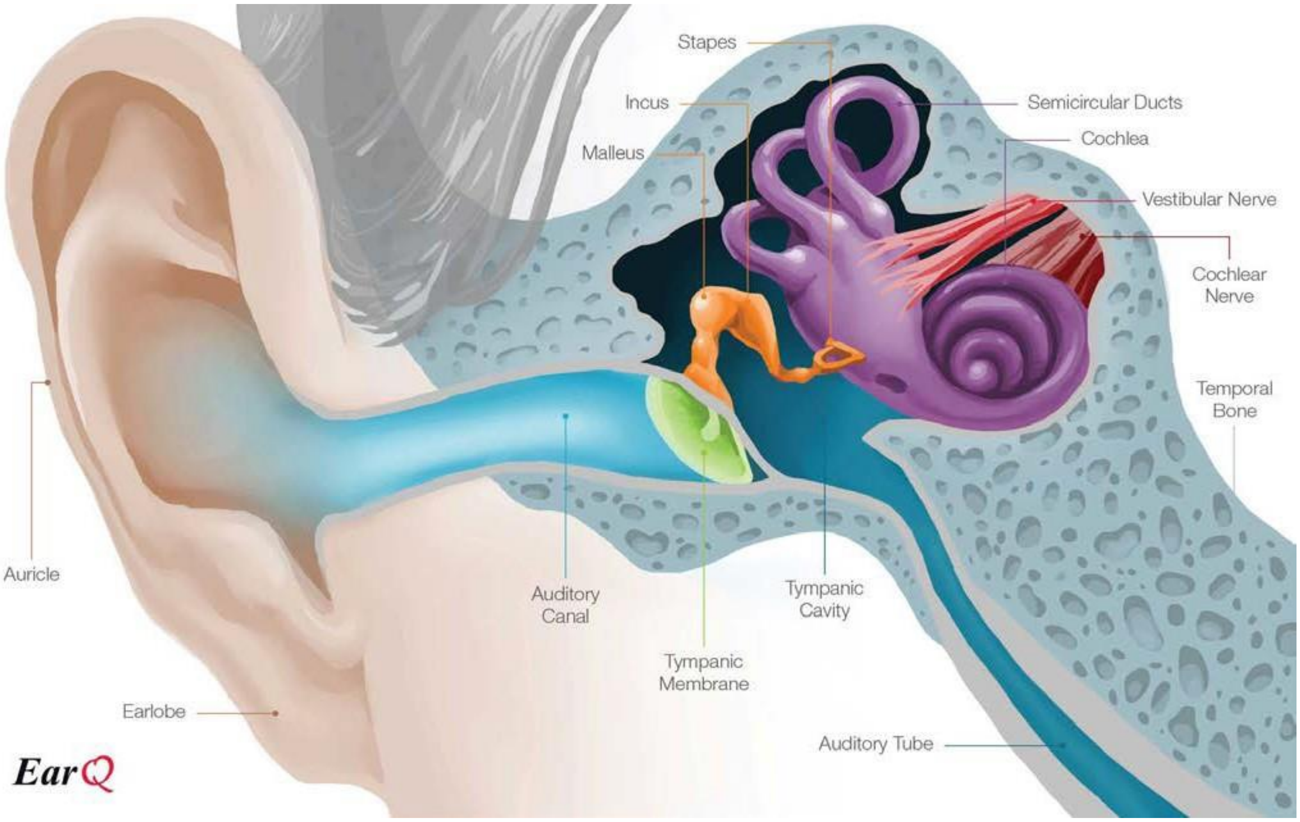
Types of Hearing Tests and Loss

SECTION 2: HOW WE HEAR

HOW THE EAR WORKS

The ear is a sensory organ with many parts. When all parts of the ear work properly, we hear a variety of sounds that range from very soft to very loud.

Anatomy of the Ear



How the ear works

To understand how the ear works, it is best to divide it into three parts: **Outer, Middle, and Inner Ear**

The **outer ear** consists of the:

- fleshy, visible part of the ear, also called the auricle or pinna
- ear canal or external acoustic meatus

The **middle ear** consists of the:

- Eardrum or tympanic membrane
- Three tiny bones called the malleus, incus, and stapes (common names are hammer, anvil, and stirrup)
- Auditory or Eustachian tube

The **inner ear** consists of the:

- Cochlea, the part of the ear that transmits sound information to the brain
- Three semicircular canals, help control our sense of balance

How We Hear

1. Sound causes air molecules to move or vibrate. These vibrations are picked up by the outer ear and travel down the ear canal to the eardrum.

2. The eardrum feels the tiny vibrations which then moves the small bones in the middle ear.

3. These movements travel through a small, covered opening into the cochlea or inner ear.

   The cochlea is filled with two types of fluid, separated by two membranes. Along one membrane, the basilar membrane, are microscopic structures that help to turn these sound vibrations into the electrical signals the brain recognizes as sound. Hair cells are found along the membrane. Each ear contains thousands of these hair cells. They are arranged by frequency, or pitch, just like a piano. These hair cells are attached to nerves.

4. When sound vibrations move the fluids of the inner ear, each hair cell responds to a specific frequency by moving back and forth. These movements trigger the nerves, which send an electrical signal to the brain along the auditory (hearing) nerve.

5. The brain receives and interprets these signals, and we perceive sound.

For more information about how the ear works, go to http://www.asha.org/public/hearing/How-We-Hear/

HEARING TESTS

Infant hearing can be tested in many ways. Audiologists use hearing tests to determine *threshold*—the softest sound your child can hear at each pitch. Some tests require the child to respond to sound while a pediatric audiologist observes his or her response, or behavior. These are called "behavioral" tests. Behavioral hearing tests are done with an audiometer, a device that makes sounds at certain frequencies and loudness levels. The child's response to sound is observed and recorded in a graph called an audiogram. The whole process is called audiometry.

1. Behavioral Tests

Visual Reinforcement Audiometry (VRA)

VRA testing takes advantage of a child's natural desire to search for sounds they hear. VRA is often performed in a sound booth, with the child on a caregiver's lap. The audiologist uses speakers or earphones to present sounds. When a child turns toward the sound, he is rewarded.

Conditioned Play Audiometry (CPA)

CPA is typically used with children from two to five years old. This measures hearing while the child plays a game. The audiologist teaches the child to perform a task each time she hears a sound. This test is usually done with the child wearing earphones or by using speakers in a sound booth.

Conventional Audiometry

Older children and adults typically have their hearing evaluated using conventional audiometry. The audiologist requests a response such as raising a hand when a sound is heard.

Other types of tests are called “objective” tests and do not require the child to respond. Objective hearing tests measure ear function. Behavioral and objective tests are used together to determine how well a child can hear.

2. Objective Tests

Auditory Brainstem Response (ABR)

ABR measures brain activity in response to sound. Other names for this test are brainstem auditory evoked potential (BAEP), brainstem auditory evoked response (BAER), and brainstem evoked response (BSER). Yourbaby may have an **Automated ABR (AABR)** as a hearing screening.

During an ABR, a child wears earphones that play sounds. Sensors are placed on your child’s head to measure the brain’s response. These sensors do not hurt. By playing sounds of different pitches, the audiologist can estimate a child’s ability to hear sounds. A child must be quiet or sleeping during an ABR. Sometimes a child needs to be sedated to complete an ABR.

Tympanometry

Tympanometry is not a test of hearing sensitivity, it is a measure of how the middle ear system is functioning. Tympanometry is performed by placing a small probe tip into the ear. A change of pressure is created and causes the eardrum to move. Fluid in the middle ear, a hole in the eardrum, or a blocked ear canal can cause abnormal test results.

OtoAcoustic Emissions (OAEs)

OAE measures the function of a child’s cochlea, or inner ear. For the OAE, a soft earphone will be placed in your child’s ear. Sounds are played into the ear causing vibrations that move tiny hair cells in the inner ear. When the hair cells move, they create sounds of their own that are called *otoacoustic emissions*. These sounds travel back through the ear canal where they are measured by a microphone. OAEs usually show normal inner ear function. If OAEs are not present, it may be due to blocked ear canals, ear infection, noisy testing conditions, or a permanent hearing loss.
OAEs cannot determine the degree of hearing loss.

If your child does not pass an OAE test, more testing is needed.

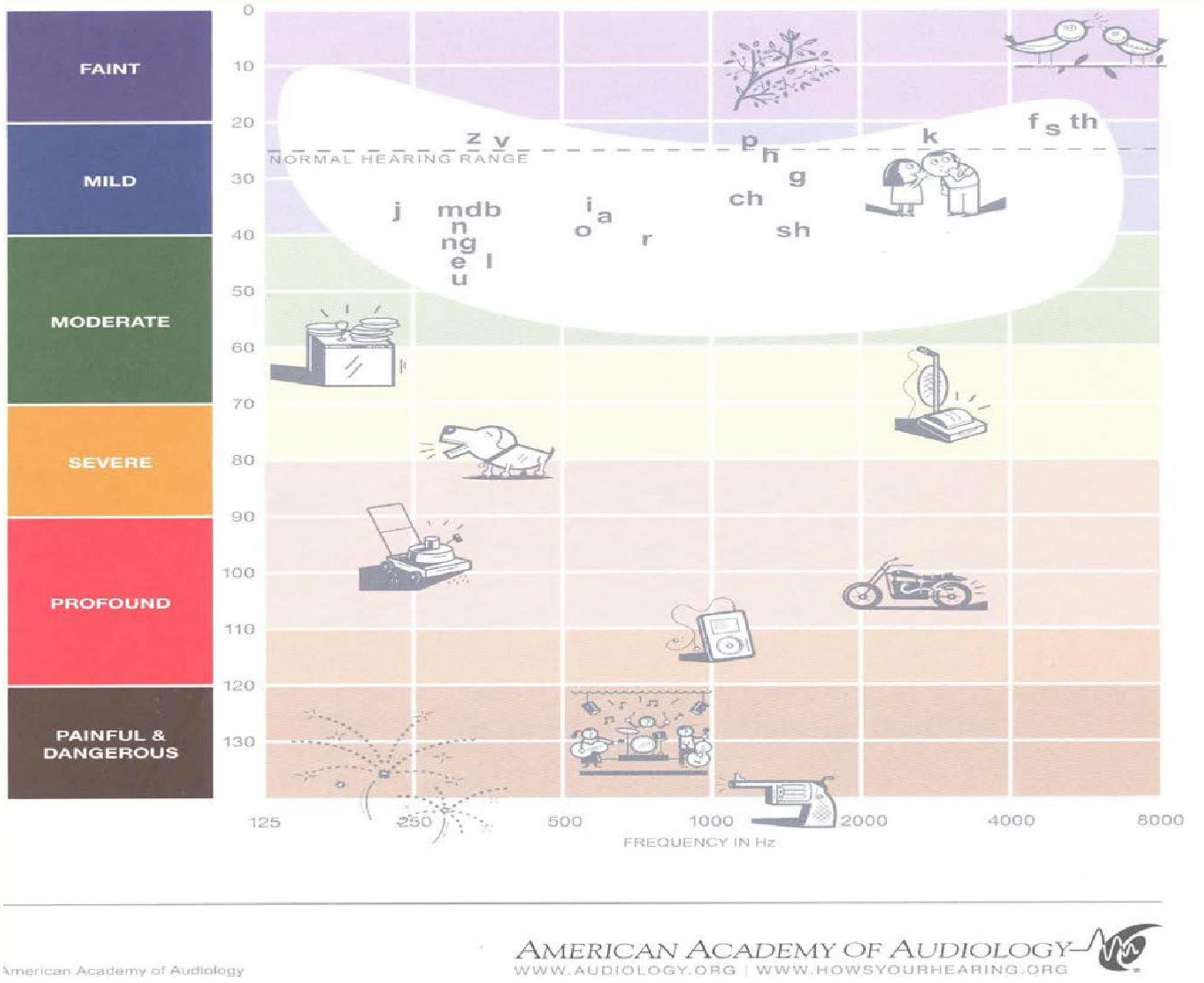
THE AUDIOGRAM

Audiologists use an audiometer to estimate and record hearing thresholds—the softest sound your child can hear at each pitch. The audiogram is a graph of your child's thresholds for each ear. See the example below ***Audiogram of Familiar Sounds***. The numbers across the bottom of the audiogram represent the frequency, or pitch, of a sound (numbers on the left are low pitches and the numbers on the right are high pitches). Different sounds, including speech, have different pitches.

The numbers along the side of the audiogram represent loudness. The numbers at the top are soft and the large numbers at the bottom are loud sounds. With a full audiogram, an audiologist determines the type and degree of hearing loss.

The shape these speech sounds make on this audiogram is called the "speech banana". Mark your child's thresholds. Your child should hear the sounds that are the same or louder than each threshold pitch.

AUDIOGRAM OF FAMILIAR SOUNDS



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TYPES OF HEARING LOSS

Types of hearing loss are classified by where the loss occurs in the ear.

Hearing Loss Type	Description	Possible Causes	Possible Symptoms
Conductive	One or more of the structures of the outer or middle ear do not work.	- Wax build up in the ear canal - Microtia - Atresia - Hole in the eardrum - Fluid in middle ear	A conductive hearing loss is like wearing earplugs; only loud sounds are heard. Conductive hearing loss can sometimes be medically corrected.
Sensorineural	Sometimes called "nerve deafness" Most common type of hearing loss When the problem is in the auditory nerve it may be called *auditory neuropathy*	-Problems in the cochlea, the auditory nerve or hearing center of the brain -Damage to the hair cells in cochlea - Family genetics - CMV -Significant lack of oxygen at birth - Meningitis	Most types of sensorineural hearing loss cannot be corrected by medication or surgery. People with sensorineural hearing loss often have trouble understanding conversation, especially in noisy places.
Mixed	Both conductive and sensorineural hearing losses are present	For example: A child with a permanent sensorineural hearing loss can get a middle ear infection that causes a temporary conductive hearing loss. After the ear infection clears, the conductive loss disappears, the child would have only a sensorineural loss.	Can be a variety or combination of some symptoms listed above

Degrees of hearing loss

One way to describe the severity of a hearing loss is by talking about the "degree" of loss. Hearing levels are measured using a decibel scale. **Decibels (dB)** measure the intensity or loudness of a sound. In a decibel scale, the larger the number, the louder the sound. To measure hearing loss, audiologists determine the softest sound a person can hear. The softest sound a person can hear at a certain frequency or pitch is called a **threshold**.

Classification of hearing	Threshold (the softest sound) heard
Normal hearing	-10 to 20 decibels (dB)
Mild hearing loss	20 to 40 decibels (dB)
Moderate hearing loss	40 to 60 decibels (dB)
Moderate to severe hearing loss	60 to 70 decibels (dB)
Severe hearing loss	70 to 90 decibels (dB)
Profound hearing loss	90 to 120 decibels (dB)

Decibel (dB) The unit that describes the loudness of a sound. The higher the dB level, the louder the sound. In describing hearing loss, the higher the dB required for a child to hear a sound, the more severe the loss.

Some babies are found to have normal hearing in one ear and a significant hearing loss in the other ear. This is called *unilateral hearing loss*. Unilateral hearing loss accounts for about 20-40% of hearing loss present at birth. Hearing loss in both ears is called a *bilateral hearing loss*.

There are medical reasons for following up on suspected cases of unilateral hearing loss.
Permanent hearing loss sometimes signal that other significant medical conditions are present. Children with hearing loss in one ear are at high risk for developing hearing loss in the other ear. With either unilateral or bilateral hearing loss, it is very important for the baby to have both hearing and medical evaluations. In addition, your child's hearing should be checked on a regular schedule to look for changes.

Children with unilateral hearing loss often have trouble locating the sources of sounds. It can be difficult for them to understand speech in a noisy setting. They may also have more academic problems since they may not hear the teacher. Children with hearing loss in one ear may become tired during the school day because of the difficulty of listening with a hearing loss. They may be good candidates for personal hearing aids or classroom amplification systems.

OTITIS MEDIA

Otitis media is an inflammation or infection in the middle ear, the space between the eardrum and the inner ear. Fluid in the middle ear is usually, but not always, found with this condition. This fluid may be watery or like mucus, and may or may not result from infection.

The symptoms of otitis media may include, irritability, fever and/or pulling at ear(s). Otitis media is very common and many times the fluid goes away without further treatment. Some children who have otitis media may have a permanent, sensorineural hearing loss.

It is important to check baby's hearing following otitis media.

Tubes

Conductive hearing loss is common when fluid is present. When otitis media does not go away, or frequently comes back, treatment may include antibiotic therapy and the placement of *tympanostomy tubes*. A short surgical procedure is required to insert the tubes. During the surgery, a small hole is made in the eardrum and a small plastic tube is inserted which allows the fluid in the middle ear to drain and to stabilize pressure in the ear. The degree of hearing loss may change as the amount of fluid is present. As the amount of fluid lessens, the child's hearing improves.

FREQUENTLY ASKED QUESTIONS ABOUT HEARING LOSS IN CHILDREN

Q: What percentage of hearing loss does my child have?

Unfortunately, it is hard to classify hearing loss based on percentage. This is because hearing loss can vary widely from frequency to frequency. That is why hearing loss is typically classified based on the degree and configuration of loss instead. Sometimes physicians use percentage to talk about hearing loss—ask your audiologist to better understand what this means.

Q: Will the hearing loss get better? Worse?

Usually it is impossible to determine whether a hearing loss will remain stable or change. Conductive hearing losses typically get better. Sensorineural hearing losses usually do not improve. Some conditions that cause hearing loss are progressive; that is, the degree of loss increases over time. Progressive hearing loss is often found with cytomegalovirus (CMV), a viral infection caught by the mother while pregnant. Properly fitted hearing aids will not stop a hearing loss from progressing or becoming worse.

Q: What caused my child's hearing loss?

It can be hard to identify the cause of a child's hearing loss. Factors often found with hearing loss include:

- a family history of hearing loss
- CMV or syndromes associated with hearing loss
- infants in the intensive care nursery for more than five days

Q: Is my child "deaf"?

The word deaf is typically used to describe a profound hearing loss at all or most frequencies. The term "hard of hearing" is usually used to describe other degrees of hearing loss.

Q: Can surgery correct the hearing loss?

Only conductive hearing loss can be corrected by surgery. Children with severe to profound hearing loss who aren't helped by hearing aids sometimes get a cochlear implant (described in more detail later)

Q: Will my child learn to talk?

Children with mild or moderate hearing loss will likely learn to talk with the help of hearing aids and speech-language therapy. Children with more severe hearing loss may have a harder time learning how to talk, because they can't hear all of the sounds of speech even with a hearing aid. Learning some form of sign language in addition to using hearing aids and having speech-language therapy may help.

Section 3

Hearing Aids and other Technology for Children with Hearing Loss

SECTION 3: HEARING AIDS AND OTHER TECHNOLOGIES FOR CHILDREN WITH HEARING LOSS

After your child is diagnosed with a hearing loss, you will begin to make decisions about the use of hearing aids and other technologies. Children with conductive hearing loss can often benefit from medical treatment. If your child has a sensorineural hearing loss, no surgeries or medications will return your child's hearing to a normal degree.

For sensorineural hearing loss, hearing aids are the most common devices. These often make sound loud enough to allow your child to hear the sounds of speech as well as environmental sounds. Depending on your child's hearing loss, hearing aids may or may not make sounds loud enough to hear speech.

HEARING AIDS

Regardless of the degree of hearing loss your child has, hearing aids are the first technology offered. It is parents' choice whether their child will use hearing aids or not.

Hearing aids are fitted on infants with hearing loss when they are only a few months old. A pediatric audiologist will make custom earmold of the inside of your baby's outer ear. The earmold is made of soft material, and is attached by a small tube to a hearing aid that fits behind the ear. Earmolds keep the hearing aids attached to the ears and route the sound into the ear.

TIPS FOR KEEPING HEARING AIDS IN LITTLE EARS

As your child gets used to having hearing aids in his/her ears, being able to hear better should encourage them to leave them in. Your child should wear hearing aids during all waking hours, so that she hears sounds throughout her day. That way, she will associate wearing hearing aids with hearing sounds, which will help the learning process.

Be consistent and reinforce or reward your child for wearing the hearing aids.

Talk to your audiologist for suggestions if a child refuses to keep the hearing aids on.

Hearing Aid problems that need to be corrected

Although it is natural and expected that a young child will sometimes pull the hearing aids out of her ears, other correctable factors can cause this behavior.

- ***Overamplification -*** When the level of sound delivered is too high, it is called *overamplication*. A real ear measure is taken by putting a small, soft tube into your child's ear. The audiologist plays sounds through a speaker, and measures the level of sound pressure in the ear.

  Even very loud sounds should not cause discomfort.

- ***Ear infection -*** If your child has an ear infection, she may pull off her hearing aids because her ears are hurting. Talk with your child's doctor if you suspect that your child has an ear infection. It may be recommended that the hearing aid not be worn until the ear infection clears.
- ***Sore spots -*** Sometimes an earmold can have uneven areas that can cause redness or a sore spot in your child's ear. These spots on the mold can often be filed smooth by your audiologist. Check your child's ears for redness often when she gets a new earmold.
- ***Feedback -*** *Feedback* is a high-pitched squealing sound. It is likely to occur at some time with most hearing aids. It can have a variety of causes, such as:
    - A damaged or poorly fit hearing aid or earmold
    - An earmold or ear canal is blocked by wax or by discharge from an ear infection
    - The hearing aid and its microphone are covered (for example by a hat)

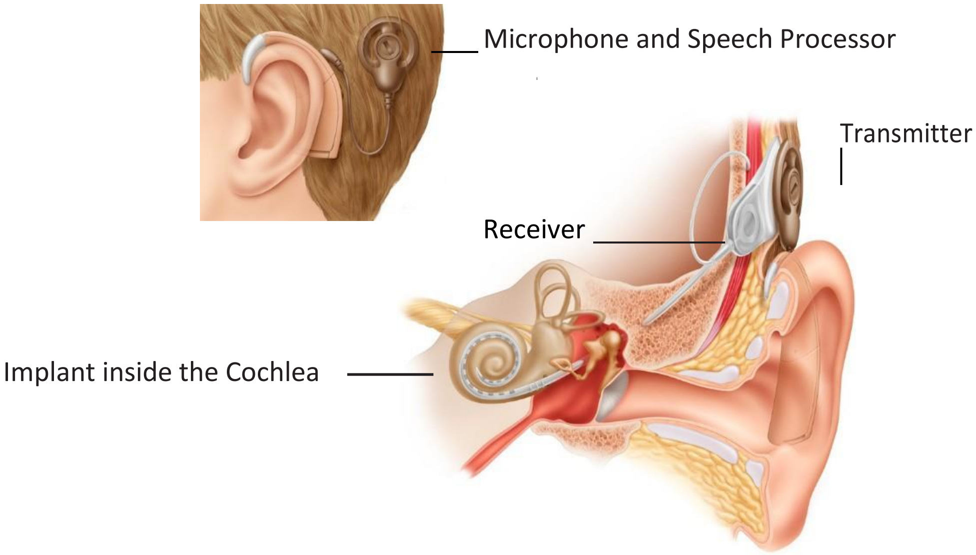
DO NOT turn down the volume of the child's hearing aid to control feedback. Hearing aids need to be worn at a certain volume. When the volume is reduced, hearing aids don't function at the correct volume. It is okay to temporarily turn down the volume until you visit your audiologist.

COCHLEAR IMPLANTS

Bone Conduction hearing aid (also known as *Bone Anchored Hearing Aid [BAHA])*

A bone-anchored hearing aid is a type of hearing aid based on bone conduction. It is primarily suited for people who have conductive hearing losses, unilateral hearing loss, and people with mixed hearing losses who cannot otherwise wear 'in the ear' or 'behind the ear' hearing aids

Ear with cochlear implant



A hearing aid trial, with well-fitted earmolds, is required before cochlear implantation will be considered. Cochlear implantation is not typically done until 12 months of age.

Cochlear implants are currently approved only for children with severe to profound hearing loss.

A cochlear implant system includes a receiver/stimulator that is permanently placed in the child's cochlea during surgery. It also includes an external sound processor, which is usually worn on the body or behind the ear. The sound processor picks up and codes speech and environmental sounds. It then "communicates" with the implanted portion of the system through the use of radio waves and a magnet. The implanted portion of the system transmits signals to the auditory nerve, carries them to the brain.

A cochlear implant does not correct hearing loss. In fact, it bypasses the normal hearing pathway, in which sounds travel through the outer, middle, and inner ear to reach the auditory nerve. A cochlear implant stimulates the auditory nerve directly. The brain learns this electrical stimulation and interprets it as speech.

Whether your child uses hearing aids or a cochlear implant, a team of speech-language pathologists, audiologists, and educators will teach you and your child how to effectively use these technologies.

ASSISTIVE LISTENING AND ALERTING DEVICES

Assistive listening *devices* are used for situations like:

- communicating one on one
- therapy
- classroom education
- watching television or listening at a movie theatre

Many of these devices can work with your child's hearing aids or cochlear implant. Some are used to enhance listening and learning by making speech sounds louder than background noise.

Alerting devices give notice of an event involving sound like a doorbell or phone ringing, a smoke detector or alarm clock buzzing. A visual signal (such as a light flashing) or a tactile signal (like a pocket receiver that vibrates). Some alerting devices are important for safety reasons and others are important for reasons of privacy and independence. You can talk with your audiologist to learn more about alerting devices.

Telecommunications Access Iowa

Telecommunications Access Iowa helps people who are hard of hearing get special telephone equipment that meets their needs. Children who are hard of hearing will likely require help to communicate on the phone. Helpful technology includes such things as:

- telephone amplifiers or lights
- text telephones (TTYs)
- voice carryover (VCO) and

You qualify for assistance from Telecommunications Access Iowa, if you live in Iowa, your child is five years or older and your family meets the household income guidelines.

If you qualify for this service, a voucher will be provided for 95% or more of the cost of the device. Equipment may be tried at Telecommunications Access Iowa 400 Locust Street, Des Moines, IA 50309; TTY: (515) 282-5130; Voice: (515) 282-5099; www.relayiowa.com/tai

Assistive Communication Devices/ Hearing Assistive Technology

Assisted Listening Devices

Personal Amplifiers amplify one-on-one or small group conversations. This may be helpful for those who need some amplification but are not able or do not wish to pursue hearing aids.

TCoils (telecoil) is a tiny coil of wire around a core that can be an alternate or supplemental input device for a hearing aid or cochlear implant.

- T-coils can cut background noise so your child only hears the sounds from the device she is listening to.
- Many public places such as movie theaters, churches, and sports stadiums provide Assistive Listening Systems (ALSs), which may include headsets or receivers
- A telecoil equipped hearing aid or cochlear implant, the magnetic signal can be heard better than acoustic signals.

Telephone Assistance

- Amplified phones, portable amplifiers, and phone captioning on the computer.
- Bluetooth connectivity allows direct communication between phones and hearing aids.
- Telephone Relay Service: Deaf or hard of hearing individual dial into the relay service and the relay operator dials the number and converts all of the text into voice for the hearing person and all verbal replies into text for the Deaf or hard of hearing caller.

Devices for TV

Various devices are available that can be plugged directly into a TV and the signal is transmitted wirelessly to headphones. Closed captioning displays the spoken words in text.

DCMP

The Described and Captioned Media Program is a free loan video service with thousands of captioned educational DVD’s available for viewing on a computer or for order sent to home or school www.dcmp.org

Smartphone and Tablet Technology (iPad) Applications

There are a variety of available apps that allow conversations to be converted from talk to text or text to talk, those for individuals to participate in video chats, with or without captions or using American Sign Language.

Text to Speech

There are several products that use voice recognition software to convert voice to text or computerized sign language. The recognition is not always exact and the consumer must be able to recognize errors.

Video Chatting

Video chatting (using Skype or Face Time or other various video chat services) is an easy-to-use and free method for communication. This technology allows for the use of sign language instead of text.

Note Taking Systems

There are products that convert hand written materials into text for note taking in school or other situations. A note taker may be of assistance to someone with hearing loss in a group meeting or large class.

Real Time Captioning

Provides a typewritten account of all spoken information from a lecture, meeting or presentation. This system requires a trained closed-caption typist and specialized software or equipment.

Video Remote Interpreter

Using a phone or other computer device or software, an interpreter can listen to a presentation and relay the information in sign language through video. High-speed Internet service is necessary.

Internet Protocol Relay (IP)

Callers can use computers to place phone calls through a relay service rather than their phone and TDD. The deaf or hard of hearing person uses their computer to connect with an IP relay service. The operator places the call and facilitates the exchange of information through converting text and voicing.

Safety and independence devices

Alerting devices typically can provide amplified and/or visual signal or vibration used to get the attention of a deaf or hard of hearing individual. They can be used for public emergency alerts, like fire alarms and tornados or for everyday situations like an alarm clock. Such items include

- Alarm clocks can be bed shakers, vibrating watches or pillows
- A smoke or carbon monoxide detector can be signaled by a strobe light.

FUNDING SUPPORT AND OTHER OPTIONS FOR HEARING AIDS AND ASSISTIVE/ALERTING DEVICES

When families are preparing for the arrival of their baby, they typically do not plan for the purchase of hearing aids. Private insurance companies have different reimbursement policies for hearing aids. Call your insurance company as soon as possible to find out what your coverage is for hearing aids or other assistive devices. Families who are eligible for Medicaid or *hawk-i* can usually get financial support for the purchase of hearing aids. If you have *hawk-i* insurance you can call 1-800-257-8763 to see if hearing aids are covered.

If you do not qualify for Medicaid or *hawk-i*, you may be eligible for hearing aid funding through the Iowa Department of Public Health. These funds will NOT cover cochlear implants/BAHA devices or assistive listening devices. Requests are processed on a first come, first serve basis and considered payor of last resort. Visit the Iowa EHDI website to learn more, www.idph.state.ia.us/iaehdi/default.asp to see the funding, application and frequently asked questions.

Programs that loan hearing aids may be available in your area—TALK to your audiologist about options.

Cost should not be a reason to delay or prevent the fitting of a child with hearing aids. Early Intervention is essential for a child with a hearing loss to develop ***communication skills.***

Possible Funding Sources for Hearing Aids and Hearing Assistive Technology:

Deaf Services Commission | https://humanrights.iowa.gov/cas/dsci/events/commission-deaf-services

State Assistive Technology Programs | https://vcurrtc.org/partners/partners/RESNA/index.cfm

Iowa Lions Foundation | https://www.iowalions.org/learn/forms/

The United Health Care Children's Fund | https://www.uhccf.org/apply-for-a-grant/is-my-child-eligible/

The HIKE fund | http://www.thehikefund.org for children under the age of 20 and their parents.

First Hand Foundation | https://www.firsthandfoundation.org/

The Starkey Foundation | http://www.starkeyhearingfoundation.org

Audient | http://www.audientalliance.org/service.php helps those with low incomes access hearing tools.

Sertoma | http://www.sertoma.org has a list of programs that help people get hearing tools.

The National Hearing Aid Project | https://hearingcharities.org/programs/the-hearing-aid-project/

Easter Seals of Iowa | Equipment loan for children https://www.easterseals.com/ia/our-programs/assistive-technology-center/equipment-loan.html

Children At Home | https://www.iafamilysupportnetwork.org/children-at-home/application-process

Section 4

Communication Options for Your Child and Family

SECTION 4: COMMUNICATION OPTIONS FOR YOUR CHILD AND FAMILY

HOW HEARING LOSS AFFECTS COMMUNICATION

How a child is affected by a hearing loss depends on a number of factors:

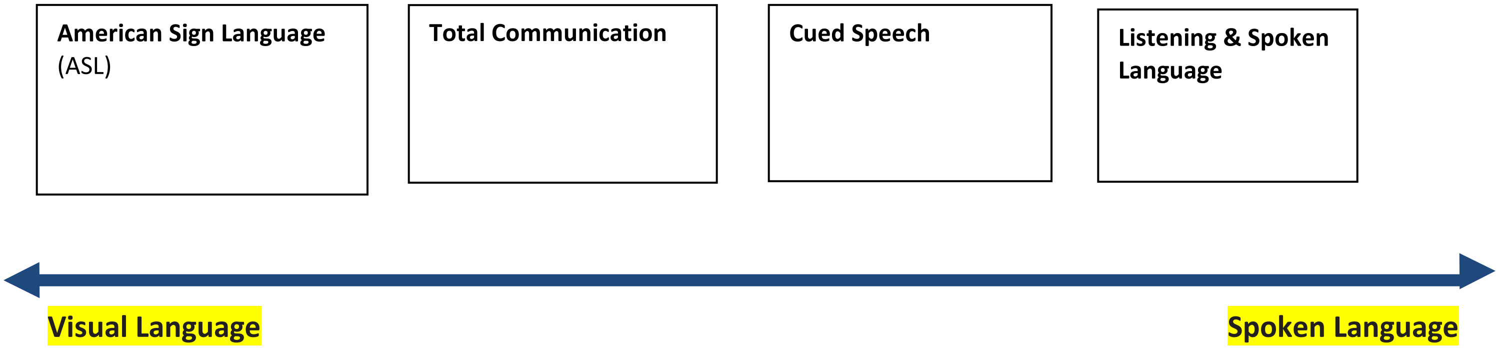
- the type and degree of hearing loss
- level of family involvement
- the age at which hearing loss occurs, is identified and intervention begins
- the child's other health conditions

Hearing loss in a child is different than hearing loss in an adult. This is because a child has not yet learned language. For a child, even a mild hearing loss can affect his ability to develop language skills.

Children with severe to profound hearing loss often need to learn some form of visual communication, such as sign language, because even with a hearing aid, they may not be able to hear all the sounds of speech. This is not to say that children with severe to profound hearing loss will never learn to talk. Rather, they may need to get language information in ways other than hearing.

COMMUNICATION METHODS

When choosing a communication method for your child and family, there are some things to consider: your family's preference, your child's development, your family support, your community services, and the expertise of the professionals working with your child. All sign language methods require a commitment from all family members to learn and use signs for communication with the child



American Sign Language (ASL)

American Sign Language uses the placement, movement, and expression of the hands, face, and body.

- ASL is a complete language with its own grammar and syntax
- It is considered by the Deaf community to be the native language of people who are deaf.
- Children born to parents who are deaf learn ASL in the same way that hearing children learn spoken language from hearing parents.
- Hearing parents must work to learn ASL along with their child.

Aural-Oral

Aural refers to hearing; *oral*, to speaking. In the aural-oral method, listening is the primary means for learning language. Speech is the primary means of expressing language. The use of whatever hearing a child has is very important. Children are encouraged to wear hearing aids or a cochlear implant during their waking hours. In addition to listening, a child is encouraged to watch the speaker to get information from lip-reading, facial expressions, and gestures.

Auditory-Verbal

The auditory-verbal method is based on a specific philosophy within the broader aural-oral category. The use of hearing aids or a cochlear implant will be the same as in the aural-oral method, but there is little use of visual cues like speech reading or gestures. Parents participate in all therapy sessions and use the techniques they learn with their child at home. Families who use an auditory-verbal approach are encouraged to place their children in regular preschool and general education classes, rather than special education or deaf education classes.

Bilingual Language Development

A person is described as bilingual when they are fluent in two languages. For a person in the United States who is deaf, these two languages are usually ASL and English. In a bilingual method, the hearing family learns and uses ASL in addition toEnglish.

Cued Speech

Cued speech uses English in a way that can be seen as well as heard. It uses a combination of speech reading, hand shapes, and hand positions near the face to communicate speech sounds.

Manually Coded English (MCE)

The Manually Coded English method uses a visual form of the English language, or sign language. English is represented by signs made with the hands and follows English language rules.

Simultaneous Communication

The simultaneous communication method combines spoken and signed communication. Parents are encouraged to both speak and sign when they communicate with their children. Some form of manually coded English is used for the sign system. Children wear hearing aids or a cochlear implant and are encouraged to use their hearing, sign and speech.

Total Communication

With Total Communication, a child with hearing loss uses all forms of communication available to develop language skills as early as possible. These may include child created gestures, formal sign language, speech, speech reading, finger spelling, reading, and writing. The child may also use individual or group amplification system.

FREQUENTLY ASKED QUESTIONS ABOUT COMMUNICATION METHODS

Q: How do we decide what's best for our child and family?

No single communication method is right for every family. The method of communication that you choose for your child should take into consideration his individual characteristics as well as the needs of your family. It is important for all the members of your family learn to communicate.

It is important to understand that no two families or hearing losses are the same. Even though two audiograms may look the same, the children with those hearing losses may function very differently. Ask the professionals working with your child for resources about communication methods and ask what is available in your community. If possible, contact families or individuals that have personal experience using the different communication methods.

Q: What if I try a communication method and later decide it isn't right?

It is very important to begin communicating with your child as soon as possible. You will be encouraged to choose a communication method soon after her hearing loss is confirmed. Her degree and type of hearing loss will play a major role in the decision you make. Professionals working with you on the speech and language development of your child can provide information on her progress. They can recommend another method you can change to if you feel this is in the best interest of your child and family.

Q: Will my child's hearing loss affect his ability to learn? How can I help my child to learn?

Many professionals will be involved with your child and family throughout his education. They can offer guidance on ways you can help your child learn. What you as a parent can do is to continue interacting with your child in a normal way. If he has a severe or profound loss, you may decide to use some type of visual communication to supplement.

Q: ***What is Deaf culture AND community?***

A *community* exists among a group of people when they share experiences, language and norms of behavior. The "D" in Deaf is capitalized when referring to members of this community. The Deaf community is made up of people with hearing loss who identify with and participate in the activities of the Deaf community. To learn more about the Deaf community in Iowa, contact: Iowa Association of the Deaf www.iowadeaf.com; Iowa Office of Deaf Services humanrights.iowa.gov/cas/ds; Iowa School for the Deaf www.iowaschoolforthedeaf.org or search for a Deaf Club in your community.

Deaf culture is based on shared life experiences and a shared language. The shared language among these community members is American Sign Language (ASL).

SECTION 5

YOUR CHILD'S RIGHTS AND YOUR RIGHTS AS A PARENT

SECTION 5: YOUR CHILD'S RIGHTS AND YOUR RIGHTS AS A PARENT

FEDERAL LAWS PROTECTING YOUR CHILD AND YOU AS A PARENT

Federal laws guarantee you and your child certain rights. This section will help you understand these laws and how they apply to you and your child.

The Americans with Disabilities Act (ADA)

The ADA is a federal law that protects the civil rights of people with disabilities. It gives them equal access to employment, state and local government programs, services, public places and telecommunications.

Section 504 of the Rehabilitation Act of 1973

Section 504 states your child cannot be discriminated against in any way or refused participation in any activity that receives federal funding because he or she has a hearing loss.

The Individuals with Disabilities Education Act (IDEA)

IDEA provides federal funds to ensure that students with disabilities get a free, appropriate public education (FAPE). IDEA also requires each student with a special need have an Individualized Family Service Plan (IFSP) for ages 0-3 or an Individualized Education Program (age 3-21).

Individualized Family Service Plan (IFSP)

An *individualized family service plan* is created for children from birth to 3-years-old. It reflects the family's wishes, hopes, and dreams for their child and outlines ways to reach these goals.

PARENT RESPONSIBILITIES

- **Learn as much as you can about your rights and the rights of your child**. If you have any questions about your rights as a parent, ask your audiologist, school or educational agency to explain them to you.
- **Develop a partnership with your child's preschool, school, or education agency.** Understand that because you know your child better than anyone, you are a key memberof the team who is helping educate your child.
- **Understand your child's IFSP.** Ask questions until you understand.
- **Monitor your child's progress. If he is not progressing, talk with his teacher or providers**. Remember that you have the right to request a review of your child's educational program at any time.
- **Keep records**. Keep a notebook where you write down questions or comments about your child's progress or program. Jot down dates, times,what happened, and the names of the people involved.
- **Problem solving is most effective if you first talk with your child's school or agency** when you have concerns about assessment, placement, or educational program.

Section 6

Resources in your Community

SECTION 6: RESOURCES IN YOUR COMMUNITY

FAMILY RESOURCES

In Iowa, early intervention services are provided by a program called **Early ACCESS.** Which might include special instruction, speech and language therapy, assistive technology, and audiology services. An Early ACCESS service coordinator can help you learn about resources and to get the services you need. Early ACCESS providers work with the family identify and address the concerns and priorities related to their child's growth and development. All early intervention services to the child are provided in the child's "natural environments" such as the home or day care settings so families and important caregivers learn ways to encourage the child's skill development.

Early ACCESS provides family-centered services. This means that families actively participate in creating an Individualized Family Service Plan (IFSP). Early ACCESS service coordinators can:

- connect your family to other families for support
- help you identify your family's strengths and needs
- coordinate your child's evaluations
- help you find and get the services you need

Free Early ACCESS services include a full evaluation, creation of the IFSP and service coordination. **For more information** about Early ACCESS, call 888-425-4371 to find the office closest to you or go to https://www.iafamilysupportnetwork.org/family-support

IOWA AREA EDUCATION AGENCIES

Keystone AEA
Elkader, IA 52043
(563) 245-1480
www.keystoneaea.org

Central Rivers AEA
Cedar Falls, IA 50613
(319) 273-8200
www.centralriversaea.org

Prairie Lakes AEA
Pocahontas, IA 50574
(712) 335-3588
www.plaea.org

Mississippi Bend AEA
Bettendorf, IA 52722
(563)359-1371
www.mbaea.org

Grant Wood AEA
Cedar Rapids, IA 52404
(319) 399-6700
www.gwaea.org

Heartland AEA
Johnston, IA 50131
(515) 270-9030
www.heartlandaea.org

Northwest AEA
Sioux City, IA 51106
(712) 222-6000
www.nwaea.org

Green Hills AEA
Council Bluffs, IA 51502
(712) 366-0503
www.ghaea.org

STATE RESOURCES

ASK Resource Center | www.askresource.org ASK is a statewide non-profit organization that provides information and support to families with disabilities and/or special health care needs. We are a family-focused nonprofit organization whose mission is to empower families by providing innovative and collaborative resources, training, advocacy, and support.

Including:

- family support information – mentoring programs, including D/HH specific
- information about a child's disability, health or communication need
- information about the Individuals with Disabilities Education Act (IDEA)
- skills to effectively participate in the IFSP and for school age children, the IEP process

Early Hearing Detection and Intervention (EHDI) http://idph.iowa.gov/ehdi EHDI is a program within Iowa Department of Public Health that helps connect families with resources to help understand hearing loss, the process used to diagnose and the information needed to make decisions as a parent or provider.

Family Educator Partnership (FEP) https://educateiowa.gov/pk-12/special-education/parent-information

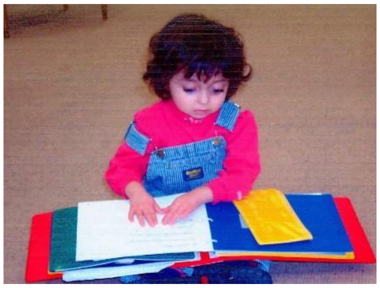
Parents and educators working to build partnerships which improve educational programs for children and young adults with special needs. Each of Iowa's Area Education Agencies (AEAs) employ parent and staff to guide the program within the AEA. See the list of Area Education Agencies or contact (515) 242-5295

DEAF SERVICES COMMISSION OF IOWA (DSCI) https://humanrights.iowa.gov/cas/ds

Deaf Services Commission of Iowa (DSCI) serves, represents and promotes a greater understanding of deaf and hard-of-hearing individuals in the state of Iowa. Services offered include sign language or oral interpreting, lending library and technical assistance.

IOWA'S DEAFBLIND SERVICES PROJECT www.deafblind.org

Deafblindness is a term describing any combination of hearing and vision loss that affects a child's overall development and require modifications and/or supports. Iowa's Deafblind Services Project is funded by federal and state dollars to provide information and resources to families and educators involved in the development of a child who is multisensory impaired.



CHILD HEALTH SPECIALTY CLINICS (CHSC) | www.chsciowa.org

CHSC is a public health program whose mission is to improve the health, development and well-being of children and youth with special health care needs. CHSC works in partnership with families, service providers, communities, and policymakers. When a child is seen at one of our clinics, fees may be adjusted using a sliding scale, considering family size and income. Contact the CHSC regional center nearest you.

Child Health Specialty Clinics

REGIONAL CENTERS

Bettendorf
Bettendorf, IA 52722
Phone: (563) 344-2250
Fax: (563) 344-2255

Carroll
Carroll, IA 51401-2367
Phone: (712) 792-5530
Fax: (712) 792-4825

Clinton
Clinton, IA 52732
Phone: (563) 243-0292
Fax: (563) 243-0295

Council Bluffs
Council Bluffs, IA 51503
Phone: (712) 309-0041
Fax: (712) 309-0044

Creston
Creston, IA 50801-4005
Phone: (641) 782-9500
Fax: (641) 782-9519

Decorah
Decorah, IA 52101-1342
Phone: (563) 382-1277
Fax: (563) 382-1287

Dubuque
Dubuque, IA 52001
Phone: (563) 583-5545

Fort Dodge
Fort Dodge, IA 50501-4901
Phone: (515) 955-8326
Fax: (515) 574-5544

Johnston
Johnston, IA 50131
Phone: (515)528-2571

Mason City
Mason City, IA 50401
Phone: (641) 424-0030
Fax: (641) 424-0080

Oelwein
Oelwein, IA 50662
Phone: (319) 283-4135
Fax: (319) 283-4140

Ottumwa
Ottumwa, IA 52501
Fax: (641) 682-8857
Phone: (641) 682-8145

Sioux City
Sioux City, IA 51105
Phone: (712) 224-543

AUDIOLOGY CENTERS IN IOWA

The centers listed below offer diagnostic services for infants and toddlers who have, or are suspected of having, hearing loss. This list is not comprehensive and is subject to change.

Council Bluffs
Ear, Nose, Throat Clinic
Council Bluffs, IA 51503
(712) 256-5272

Des Moines
Iowa Ear Center
Clive, IA 50325
(515) 418-9960

Iowa Methodist Medical
Des Moines, IA 50309 (515) 241-8265

Dubuque
Otolaryngology
Dubuque, IA 52001-6387
Phone: (563) 588-0506
Fax: (563) 588-0451

Iowa City
Center for Disabilities and Development University
of Iowa Children's Hospital
Iowa City, IA 52242-1011
Phone: (319) 356-1168
Fax: (319) 356-8284

University of Iowa Dept. of Otolaryngology
Iowa City, IA 52242
Phone: (319) 356-2201

Mason City
Hearing Associates
Mason City, IA 50401
(641) 422-6424

Oelwein
Child Health Specialty Clinics Oelwein, IA 50662
(319) 283-4135

Iowa Hands & Voices | www.iowahandsandvoices.org
Iowa Hands & Voices supports all families with children who are deaf/hard-of-hearing regardless of communication choice. Hands & Voices is a non-profit, parent-driven organization

Iowa Department of Education - Early Childhood Services | https://earlychildhood.iowa.gov

Early Hearing Detection and Intervention (EHDI) | http://idph.iowa.gov/ehdi

Deaf Services Commission of Iowa |https://humanrights.iowa.gov/cas/ds

Iowa Association of the Deaf | www.iowadeaf.com

Iowa School for the Deaf | www.iowaschoolforthedeaf.org

Relay Iowa | www.relayiowa.com

University of Iowa Center for Disabilities and Development | https://uichildrens.org/cdd

NATIONAL RESOURCES

Alexander Graham Bell Association for the Deaf and Hard of Hearing
Voice: (202) 337-5220
TTY: (202) 337-5221
www.agbell.org

Alternatives in Education for the Hearing Impaired (AEHI)
Voice/TTY: (847) 297-3206
www.aehi.org

American Academy of Audiology (AAA)
Voice: (703) 790-8466
TTY: (703) 790-8466
www.audiology.org

American Society for Deaf Children (ASDC)
Voice/TTY: (866) 895-4206
Toll Free: (800) 942-ASDC (800-942-2732)
www.deafchildren.org

American Speech-Language-Hearing Association
(800) 638-8255 TTY: (301) 897-5700
www.asha.org

Beginnings Parents of Children Who are D/HH
Voice/TTY: (919) 850-2746
www.beginningssvcs.com

Better Hearing Institute
Voice/TDD: (800) EAR-WELL (800-327-9355)
www.betterhearing.org

Gallaudet University Regional

Johnson County Community College
Overland Park, KS 66210
gurc.gallaudet.edu

Hear Now
The Starkey Hearing Foundation
www.sotheworldmayhear.org

Joint Committee on Infant Hearing
(800) 638-8255
www.jcih.org

National Association of the Deaf (NAD)
Voice: (301) 587-1788
TTY: (301) 587-1789
www.nad.org

Hearing Loss Association of America
Voice/TTY: (301) 657-2248
www.shhh.org

LifePrint Institute ASL University
http://www.lifeprint.com/

Section 7

Family Stories

THEY WILL ALWAYS FIND A WAY

The Dirks Family

Our daughter, Lani, was born with multiple special health care needs. She is four years old now and is still undiagnosed; the best doctors can say is that she has a genetic syndrome that has yet to be heard of. One of her biggest struggles is being profoundly deaf because communication has been very hard for her.

We found out in the NICU that she had failed her newborn hearing screen twice, she went on to have two ABRs, and by that point we were told that the only thing she may be able to hear is a sonic boom. She was fitted for hearing aids that did absolutely nothing to help her hear better. We started teaching her ASL as soon as she got home from the NICU. We wanted her to have every opportunity, so we threw all the language we could at her. Lani also has vision issues so it was important for us to give her a chance to use as many senses as possible, so we went through the process, and she had surgery for bilateral cochlear implants at 14 months of age. As soon as the surgery was over the surgeon came out to talk to us to let us know that the surgery had gone great, but that her hearing nerves were not responding to the devices, we had to wait until activation day to see if anything changed. A month later we went to activate her CIs and still had no response. The reason she was not responding to the cochlear implants is because she also has brain abnormalities and the best we could guess was that her brain did not know how to process the sound she was now receiving.

We continued to teach her sign language, and we also continued to have her wear her cochlear implants and go to speech therapy. Three and a half years later, and her brain has finally figured out how to process sound. She knows her name and recognizes many sounds, she is also babbling and says “hi” and “bye.” She may not ever have speech as a full language, and that is ok. She uses ASL as her language, but she still asks for her cochlear implants every day because she likes hearing everything that is going on in her world.

I think that no matter what the outcome for the child, they will always find a way and find out what works best for them. It’s important to realize that what works well for one child, may not work at all for another. Today Lani is thriving, and her language is expanding more and more by the day. We’re excited to see where her future will take her!

Sincerely,
Heather Dirks, (Des Moines, IA)

Life was going to be normal for Cael

The Harrisons

My husband, Mike, and I would not have expected Cael to have hearing loss. Our first child, Victoria, passed her hearing screening fine. I was in the hospital for two weeks on bed rest before having her. With the complications of my pregnancy, it wouldn't have come as a complete surprise if Victoria had some developmental problems. My second pregnancy was totally uneventful. We were shocked to learn that Cael had hearing loss.

Immediately, we began trying to explain it. How could this happen? Was there a history in the family? The tests must be wrong? How qualified are the technicians administering the tests? I just couldn't believe it was happening. The technician kept reassuring us...she said that many times when this happens it's fluid or debris in his ear. They had a test to check that.

The audiologist did the tympanogram and I thought a normal result was a good thing. I soon learned that meant there was no blockage and no fluid. That moment was when it became much more real. It was such a hard thing to believe...because I couldn't see it. I look at him and he looks fine.

We started admitting that this was an issue...what was our next step? Our audiologist was attentive to our concerns. She visited us as often as we requested. She provided us with the information that she had. As we looked through that information we kept bringing up the fact that we didn't have any of the risks that were discussed. How could this happen to us?

What do we do next? Our audiologist scheduled Cael for the BAER hearing test which she promised would give us lots more information. It was a long two weeks waiting for the day to come for that test. When we arrived for the first BAER test, even the receptionist told us this is often routine. She said most kids have an undetectable blockage in the hospital that, after two weeks, cleared up. Our hopes were high.

The first BAER test showed Cael had a moderate hearing loss in both ears. It proved that he could hear us talk. He wasn't able to hear soft, high-pitched sounds. But moderate loss... what does that mean? The chart showing the speech banana helped us understand what he might be able to hear and what he would be missing. I couldn't imagine the thought of hearing aids. Yet...I didn't want him to miss out on a thing!

We decided to wait and run the BAER a second time, around two months of age; to be sure we had the same reading before fitting him for hearing aids. I was much calmer this time. I knew what to expect. This second test showed some improvement. Our audiologist classified Cael's hearing loss as much more mild then she originally thought. We felt blessed that he was better. However, in the back of our minds I think we both knew that hearing aids would still be needed for language development. The audiologist confirmed that and said he'd be able to learn language just like any other kid that way.

When Cael got his hearing aids I really was okay. I expected some tears. They didn't come. The hearing aids weren't so bad. We were concerned about what other kids/parents would say about Cael. We heard great success stories of kids with hearing aids that played football, were Prom King, etc. Those helped a lot! Life was going to be normal for Cael.

Today we get along fine with his hearing aids. Daycare has been great with them. It has become routine. I wonder what it will be like for him as he gets older. I'm grateful for the support group that's available. I'll be looking for ways to encourage him, how to respond to those kids/parents that comment on his hearing aids, what to do if people stare, etc. We want to be his rock. We want him to know that he's okay. We want him to know what a great little guy he is... hearing aids or not.

Sincerely, Monica Harrison (Ankeny, IA)

Your Child Will Speak Volumes

The Heidenreichs

We had a very normal pregnancy and were very anxious for our first child to be born. One day I stopped feeling movement, and our daughter was then born by emergency C-section. She was in critical condition. There were many complications.

After a couple of roller coaster weeks in the NICU [Neonatal Intensive Care Unit], we asked to know just where we had come from, where we were, and what to expect next. That is when we learned that our precious daughter had a severe to profound hearing loss. We were devastated.

I had prepared myself for anything that medically could be fixed. It was as if the floor dropped out from under us. In the days, weeks, even months ahead we found ourselves in uncharted territory. I was grieving the things I thought I had lost by that diagnosis. The sound of her voice, the giggles of childhood, the whispers of secrets, the melody of songs, but especially the fear of never hearing her say, " I love you." It still stops my breath as I write this.

I was hoping for a medical cure, a quick fix. And that isn't possible with hearing loss. But with patience, faith, and a lot of hard work on our daughter's part and ours, we now know that we are able to imagine and dream about her future.

We were given a lot of misinformation at the time of her birth.
Of course they were only trying to prepare us for the worst.
Thank God we never allowed ourselves to completely trust
all the information that was given to us.

We will never hold her back. The sky is the limit, and so far
she has shown us that and exactly where she wants to go.
She is a daily inspiration to our family, and to the many people's lives she has touched. I would not trade her for the world; in fact, we went on to have another child. She now has a little brother who is hearing. He adores her, and she adores him.

It is incredibly scary at first, and sometimes frustrating with school and things in the future, but it is so worth the effort. In any form of communication you choose for your child, they will speak volumes, and it is worth the hard work, patience and faith.

Sincerely, Julie Heidenreich (Fort Dodge, IA)

No matter the form of communication, your child can speak VOLUMES!

Inspired and Encouraged

The Gadsons

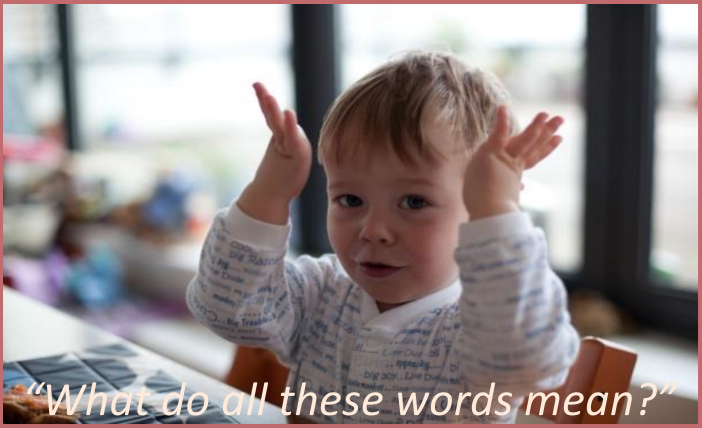
My daughter Sa'Mari was born on March 27, 2010. She was 36 weeks and a tiny 4 pounds. When she had her hearing test done she did not pass. The nurses said they couldn't get a good testing because her ear canals were very small. As time passed, we began to notice she wasn't responding to sound or noise. Upon further testing, she was diagnosed with profound hearing loss.

To find out my daughter was deaf was a lot to process, but I kept myself together for her sake. She was fitted for hearing aids. However, they did not provide any hearing for her. We were presented with information about cochlear implants. Her father and I researched them and decided that we would proceed with the procedure. At that time, she was not of age. The doctors said she had to be 1. On June 2, 2011, she had a cochlear implant surgically placed in her right ear and a month later she was activated. Sa'Mari was introduced to sound, although we knew we had a long road ahead. She began speech therapy. In January of 2012, she had surgery on her left ear and a month later she was activated. She was getting all of the help she needed. She was going to all of her appointments; was being taught sign language; and attending speech therapy several times a week, but there was something missing. Although we had great support, there was no one who had been through what her father, Sherome, and I were going through. It was in July when that all changed. My mother, Sa'Mari, and I were running late to the Farmers' Market in Waterloo. As we were walking around, we were approached by Susan Rolinger and her daughter, Madeline, who also has had cochlear implants since she was younger and is now a teenager. They were very open and we talked for nearly an hour. We went home with no vegetables or fruit but a new hope and lots of knowledge. Not only had Susan been through what we are experiencing as parents, but her daughter was able to provide even more personal insights. Susan is now my mentor through "Guide By Your Side" and Hands & Voices. She informed us of the Symposium, which my mother, Sherome, and I attended, along with Sa'Mari and her new baby sister, Kailana. It felt so good to be engulfed in the deaf culture. We learned so much and left with great material. It was very inspirational. We might have been the only non- professional hearing people in the symposium. We were certainly the youngest. Yet, we felt connected. The one take away for us was that we as parents must be involved. We know that Sa'Mari's life will be filled with an abundance of challenges beyond what most will experience. However, as I listened to Deb and Katrina Landolt, a mother and daughter team on the panel, and later spoke with them, I was inspired and encouraged that my fears of her not having an abundant and prosperous future were unfounded. None of us know what the future holds, but thanks to Guide By Your Side and Hands & Voices, Susan, and many others, we have found resources and friends who will support us and Sa'Mari as she continues to thrive as a child who is deaf.

Sincerely,
Keryth Gadson, (Waterloo, IA)

Section 8

Glossary



GLOSSARY

EXPLANATION OF HEARING RELATED TERMS AND ACRONYMS – ESPECIALLY FOR FAMILIES

“1, 3, 6” Goal – The National EHDI Goal states “All infants will receive a hearing screening before **1 month** of age. Infants not passing the screening will receive appropriate audiological and medical evaluation before **3 months** of age. All infants identified as D/HH will begin receiving early intervention services before **6 months** of age.”

ABR – Auditory Brainstem Response measures brain response to sound. It tests the hearing system from the ear to the brainstem. The test is performed by placing four to five electrodes on the infant's head, after which a variety of sounds is presented to the infant through small earphones. Testing usually takes 5-15 minutes

AEA – Area Education Agency partner with every public and accredited, nonpublic school in Iowa to serve children from birth to age 21 who require special education services.

ASK Resource Center – A statewide non-profit organization providing information, training, support, mentor and advocacy services to individuals with disabilities, special health care or communication needs, their families and professionals across Iowa.

ASL – American Sign Language

Audiologists – These are medical practitioners who work with people who have hearing loss and attempt to prevent related damage.

Bilateral Hearing Loss– A defect in the ability to perceive or understand sound, a hearing loss, to some degree in both ears.

D/HH – Deaf or Hard of Hearing.

Diagnostic hearing test – A diagnostic test session collects more information, is longer and requires more interaction with the infant. A baby needs to sleep in the office for up to 45 minutes.

Early ACCESS – The purpose of this Iowa program is for families and staff to work together in identifying, coordinating and providing needed services and resources that will help the family assist their infant or toddler to develop and learn.

ECTA – Early Childhood Technical Assistance Center guides state programs in evaluating their current systems, improving, and developing systems that support best practices.

EHDI – Early Hearing Detection and Intervention The goal is to ensure that all infants and toddlers with hearing loss are identified as early as possible and provided with timely and appropriate audiological, educational, and medical intervention.

Family Support – Assistance provided to families who are impacted by a disability, special health care or communication needs. This service is provided in different ways, including but not limited to, information sharing, resource connecting and mentor matching.

Hands & Voices – Hands & Voices is a non-profit, parent-driven national organization, with state chapters, dedicated to supporting families of children who are deaf or hard of hearing. It non-biased about communication methodologies and believe that families can make the best choices for their child if they have access to good information and support.

IDEA – Individuals with Disabilities Education Act Children with disabilities are entitled to receive a free, appropriate public education (FAPE) under the Individuals with Disabilities Education Act (IDEA). Part of IDEA is early intervention (EI), which is a program that each state administers to guarantee young children services as well *See also **Early ACCESS**

IEP – Individualized Education Plan is more than just a written legal document or “plan”. It’s a required program of special education instruction, supports and services kids need to make progress and succeed in school, for students ages 3-21.

IFSP – Individualized Family Support Program. The IFSP is a written treatment plan for children with disabilities, delays or special health care needs birth to age 3 describing what early intervention (EI) services a child will receive, how and when these services will be provided. It takes a family-based approach in setting goals, providing services and meeting needs.

JCIH – The Joint Commission on Infant Hearing is a national agency that conducts research and provides information and recommendations important to early identification, intervention and follow-up care of young children with hearing loss.

NCHAM – National Center for Hearing Assessment and Management is the national technical resource center for the state Early Hearing Detection and Intervention (EHDI) systems.

OAE – Otoacoustic Emission test (OAE) measures the response produced by the inner ear (cochlea), which bounces back out of the ear as a result of a sound stimulus. The test is done by placing a small probe with a microphone and speaker into the infant's ear as the infant rests. The test generally takes five - eight minutes.

Screening - The difference between a hearing screening and a diagnostic test is the amount of information gathered during the session. If an infant does not pass a hearing screen, it can’t state for certain there is hearing loss, how much of a loss, or whether or not the hearing loss is permanent or correctable. A diagnostic test is required to answer those questions.

Unilateral – Unilateral hearing loss (UHL) or single-sided deafness (SSD) is a type of hearing impairment where there is normal hearing in one ear and impaired hearing in the other ear.