

Iowa's Early Hearing Detection & Intervention



Families Make All the Difference

How We Hear, Hearing Tests,
Types of Hearing Loss



Hearing Aids and Other
Technologies for Children with
Hearing Loss

Communication Options for Your
Child and Your Family



Your Child's Rights and Your
Rights as a Parent

Resources in Your Community

State and National Resources

Family Resource Guide

**FOR FAMILIES OF CHILDREN
WHO ARE DEAF
OR HARD-OF-HEARING**

5th edition
December 2013



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Introduction: Our Purpose

This guide will help you understand your child's hearing loss. It will also provide you with information about resources for your child and your family. Research shows that parent involvement is crucial for a child with hearing loss to succeed in both language and educational development.

This guide will give you with the basic knowledge and resources you need to navigate Iowa's service system. Here you will find:

- information about the professionals who will work with your child
- information about family support
- your child's education and communication options
- your rights and responsibilities as the parent of child who is deaf or hard of hearing
- links to other important resources
- a glossary of new words you may encounter

Your understanding of your child's hearing loss, and of the services available to you both, will play an essential role in helping your child succeed.

Acknowledgements

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To obtain additional copies of this guide, or if you have questions or comments about the guide, please call 1-800-383-3826.



Welcome To Holland

I am often asked to describe the experience of raising a child with a disability—to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this...

When you're going to have a baby, it's like planning a fabulous vacation trip—to Italy.

You buy a bunch of guidebooks and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland." "Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy." But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine, and disease. It's just a different place. So you must go out and buy new guide books. And you must learn a whole new language.

And you will meet a whole new group of people you would never have met. It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around...and you begin to notice that Holland has windmills...and Holland has tulips. Holland even has Rembrandts.

...if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, very lovely things... about Holland.

But everyone you know is busy coming and going from Italy...and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say, "Yes, that's where I was supposed to go. That's what I had planned." And the pain of that will never, ever, ever, ever go away...because the loss of that dream is a very, very significant loss.

But...if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things...about Holland.

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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). Such involvement can also lessen the negative effects of late identification and intervention. To be most effective, you as a parent need a high level of commitment. You must place a high priority on having your child develop language. You will need to participate, support, and follow through in the daily activities that support this goal.

Other families may have valuable experiences to share—you may find that support groups are helpful in balancing the needs of your child and the needs of the rest of your family. Talk with your Early ACCESS service coordinator (see page 51, Section 6) or the Parent Training and Information Center of Iowa (see page 57, Section 6) to learn how to get connected with other families in the state.

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. Even during this time, you can encourage your baby to develop language and communication skills. Here are some tips for getting a head start on your child's language development at home before the start of intervention:

- Talk to your child, regardless of the severity of hearing loss. Speak close to her face.
- Use lots of facial expressions and gestures. Maintain eye contact.
- Sing songs, recite nursery rhymes, read books and talk to her about what you are doing, just as you would with any child.
- When you talk or sing to your baby, lay her on your chest. That way, she will feel the vibrations when you speak.
- Start a journal in which you write down what you are feeling. Record your child's responses to sounds and voices. Does she listen? 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 child's hand over your lips as you talk.



Key Terms

Early ACCESS-

provides early intervention services, which might include special instruction, speech and language therapy, assistive technology, and audiology services.

Parent Training and Information Center of Iowa-

provides services such as: family support, information about a child's disability, and skills for participating in the Individual Education Program (IEP).

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 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 with such things as attention and praise. It is important that your child learns her name.
- When you hear something, point to your ears and say, "I heard that!" This helps your child learn to pay attention to sounds. Children with hearing loss often need to be taught what sound is and that sound is important and useful 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 she is wearing her hearing aids. Reinforce your child's vocalizations.
- Write down your observations in your journal. Describe what these sounds are. Does she make certain sounds when she has certain needs?

As time goes on...

After your child has adjusted to wearing hearing aids, it is important to encourage additional communication skills.

- **When your child makes a sound, repeat that sound back to him.** This imitation reinforces your child's "talking" and should lead to him making additional sounds. Doing this will teach your child to take turns as well.
- **Encourage your child to respond to sounds without your prompting.** For example, you and your child clap hands when music comes on. Then you can wait to see if your child claps on his own when he hears music.
- **Help your child learn to recognize 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! Listen." This helps him label and identify sounds.

The success of your child's language development depends on your involvement! Always maintain high expectations for your child. Always remain confident in your ability to be a good parent to your child with hearing loss.

Your local service providers will work with you and your child. They can provide additional suggestions to facilitate your child's speech and language development.

To learn more about research into the role of parents and families in the language development of hearing loss in children, read:

Moeller, M.P. (2000). Early intervention and language outcomes in children who are deaf and hard of hearing. *Pediatrics*, 106(3), 1-9.

Robbins, A.M. (2002). Empowering parents to help their newly diagnosed child gain communication skills. *The Hearing Journal*, 55(11), 55-57.





MAPPING THE BEST CASE SCENARIO JOURNEY

Steps to take with a child who does not pass their hearing testing.

By the time your child is 1-month-old, he or she should have had a newborn hearing screen. **If your child did not pass the screen**, they should have had a newborn hearing re-screen as an outpatient.

By the time your child is 3-months-old, your child should:

- have been referred by your physician or hospital to a pediatric audiologist (a health professional who specializes in evaluating and treating hearing conditions in children).
- have been tested by a pediatric audiologist.

If hearing loss is found, your child should:

- have been referred to the Early ACCESS program for service coordination (see page 51). Early ACCESS is a free program through Medicaid Part C.
 - an individualized family service plan (IFSP, see page 48, Section 5) should be developed within 45 days of referral to Early ACCESS.
- have been referred to an otolaryngologist (ear, nose, and throat or ENT doctor) for a medical evaluation and hearing aid clearance if needed.
- have had a hearing aid evaluation and fitting by an audiologist, if appropriate.
- have been referred to genetics (doctor who specializes in genetic conditions).
- have been referred to Ophthalmology (eye doctor).

By the time your child is 6-months-old, your child should have had evaluation activities completed through Early ACCESS, been receiving needed early intervention services as outlined in the individualized family service plan (IFSP).

Your child from 6 months to 21 years of age should:

- have hearing assessed and monitored as needed.
- get Early ACCESS early intervention services until age 3, through an individualized family service plan (IFSP).
- have an individualized education program (IEP, see page 48, Section 5) by the age of 3 years if they are eligible for special education services.
- get special education services from ages 3-21 years old or until high school graduation, through an IEP, if eligible.

Key Terms

Audiologist- a specialist in the assessment of hearing ability and providing treatment services to persons with hearing loss. Audiologists who specialize with children are *pediatric audiologists*.

Ear, nose and throat (ENT) doctor- a specialist trained to diagnose and treat children with diseases and disorders of the ear, nose, or throat. also called an *otolaryngologist*.

Individualized Family Service Plan (IFSP)- Plan that outlines strategies, services, and outcomes for children with disabilities ages birth to three. This plan is put together by a team including parents and professionals specific in the child's needs.

Individualized Education Program (IEP)- Plan that outlines special education goals, changes to regular curriculum, and related support services for children with disabilities ages 3-21 years. The plan is developed by a team including parents, administrators, teachers, and special services personnel specific to the child's needs.

**Now he can hear us say, “I love you”
Brady’s Family**

Our son, Brady, was born with cytomegalovirus (CMV), which can cause severe birth defects. It can also cause a progressive hearing loss. He was born without symptoms and actually passed his newborn hearing screening. We constantly tested his hearing on our own at home by clapping, slamming doors, the dog barking, loud music, and anything else we could think of. We got such inconsistent responses that we grew concerned.

At his 2-month check-up we discussed our concern with our doctor. By the time he was 3 months he had another ABR screening, which he failed, and then the sedated ABR, which he also failed. I still remember every detail of the dreaded day when we learned our 3-month-old baby was deaf. We thought our life was over and had no idea how to care for our own baby.

How were we to go on and what were we to do?

How would we communicate with him and how would his 2-year-old brother communicate with him?

How and where would he go to school?

How would he make friends without hearing?

How could he grow up to be all we had dreamed for him if he was deaf?

After our audiologist sat down and cried with us, answered our questions, and offered much guidance, we were sent on our journey. We were given a list of people to call and things to do to get started. We called everyone and made lots of appointments to specialists.

**Because of early
identification, he can
now hear us say,
“I love you.”**

We learned so much in the next few months. Most importantly, we learned we could still hug and kiss and hold him, read and sing to him, and enjoy every moment with him. We learned that our baby was still as precious as ever and still perfect, regardless of his hearing loss.

We went through an 8-month hearing aid trial. Through this we were again testing his hearing at home constantly to see no responses. He qualified for a cochlear implant and went on to have the surgery at 13 months of age. [The implant] was activated [when he was] 14 months of age. In the past 18 months he has caught up to his hearing peers.

He receives speech therapy 5 times a week and constant auditory training and stimulation at home. The miracle of the cochlear implant has allowed him to hear, process, and produce the noises he is now hearing. It is because of early identification he can now hear us say “I love you,” and in return say “I love you, Mommy and Daddy.”

Sincerely,
Cami Wright (Baxter, IA)



EARLY INTERVENTION IS VERY, VERY IMPORTANT

Families play a key role in helping their children with hearing loss to grow, learn, and develop. Two other factors also have an enormous effect: early identification and early intervention.

Early identification is used to learn how well a baby can hear, as early as possible after the baby is born. This is why Iowa has a statewide system of newborn hearing screening.

Early intervention is used to provide, as quickly as possible, treatments that give the child ways to hear and to communicate, whether through speech, signs or both.

Even a mild hearing loss, or a hearing loss in only one ear, can make it hard for young children to hear well enough to learn.

A baby as young as 4-weeks-old, who has a hearing loss, can be fitted with hearing aids. A baby this young can also benefit from education services provided by a licensed teacher of children who are deaf or hard of hearing.



She might also benefit from the services provided by specialists such as a speech language pathologist and a rehabilitative audiologist. It is important to get connected to these services early so they can be planned and included in an individualized family service plan (IFSP).

Early identification and intervention may make it possible for the child to develop language and communication skills equal to their hearing peers. Early identification and intervention also make it possible for children who are deaf or hard of hearing to have more educational options.

Key Terms

Early Intervention- a program for children from birth to 3 years of age who have a developmental delay. Children with hearing loss typically need early intervention services.

Early interventionist- a specialist who works with infants and toddlers. She will help identify your child's needs and create an Individualized Family Service Plan (IFSP).

JOINT COMMITTEE ON INFANT HEARING POSITION STATEMENT

In its *Year 2007 Position Statement*, the Joint Committee on Infant Hearing provided the following goals for early intervention programs for infants with hearing loss:

- All families of infants with any degree of bilateral or unilateral permanent hearing loss should be considered eligible for early intervention services.
- There should be recognized central referral points of entry that ensure specialty services for infants with confirmed hearing loss.
- Early intervention services for infants with confirmed hearing loss should be provided by professionals with expertise in hearing loss, including educators of the deaf, speech language pathologists, and audiologists.
- In response to a previous emphasis on “natural environments,” the committee recommends that both home-based and center-based intervention options should be offered.

What does this mean for you and your child with hearing loss?

This means that you will be eligible for early intervention services, the professionals working with your child will be dedicated to providing you with these early intervention services, and they will provide you with a range of options for intervention including things to do in your home.

You can find the **full JCIH Position Statement**, a clarification document, and the latest supplement from 2013 at <http://jcih.org/posstatements.htm>.



Section 2

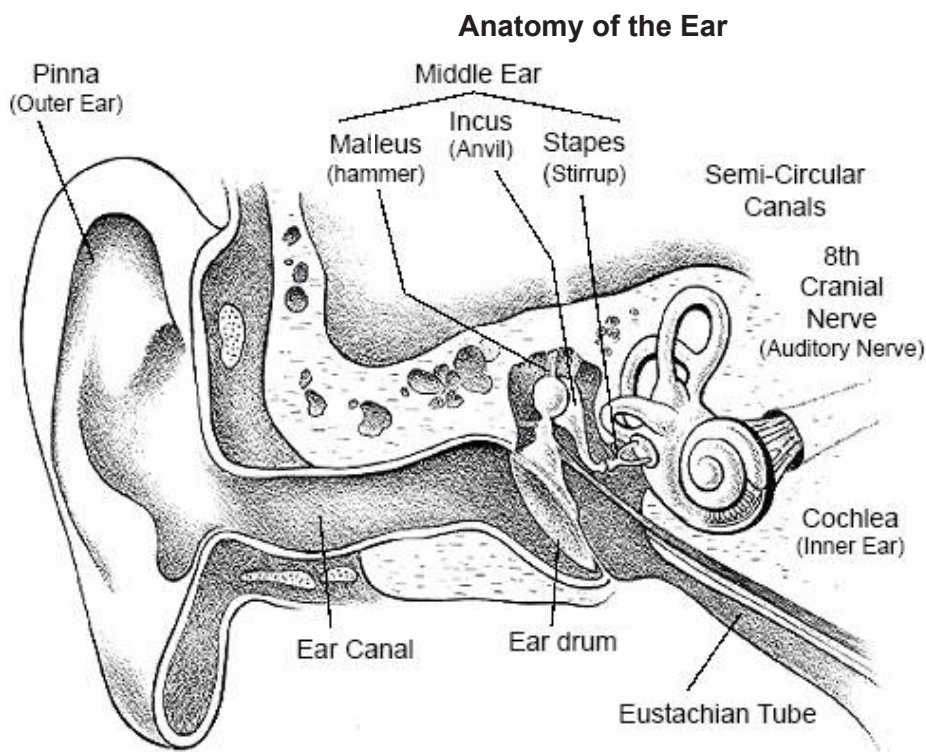
How We Hear, Hearing Tests & Types of Hearing Loss



SECTION 2: HOW WE HEAR, HEARING TESTS, TYPES OF HEARING LOSS

HOW THE EAR WORKS

The ear is a very complex sensory organ. It is designed to help us communicate with each other. When the ear works properly, we can hear a wide variety of sounds that range from very soft to very loud.



How the ear works

To understand how the ear works, it is best to divide it into three parts: Outer, middle, and inner

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 (commonly called the hammer, anvil, and stirrup)
- eustachian tube or auditory tube

The **inner ear** consists of the:

- cochlea, the part of the ear that transmits sound information to the brain
- three semicircular canals, which help control our sense of balance

| Parts of the Ear and their Functions | |
|--------------------------------------|--|
| Outer Ear | Picks up air vibrations and funnels them through the ear canal to the ear drum |
| Middle Ear | <ul style="list-style-type: none"> • Magnifies vibrations picked up by the ear drum • Maintains the proper amount of air in the middle space |
| Inner Ear | Transmits sound information to the brain |

How We Hear

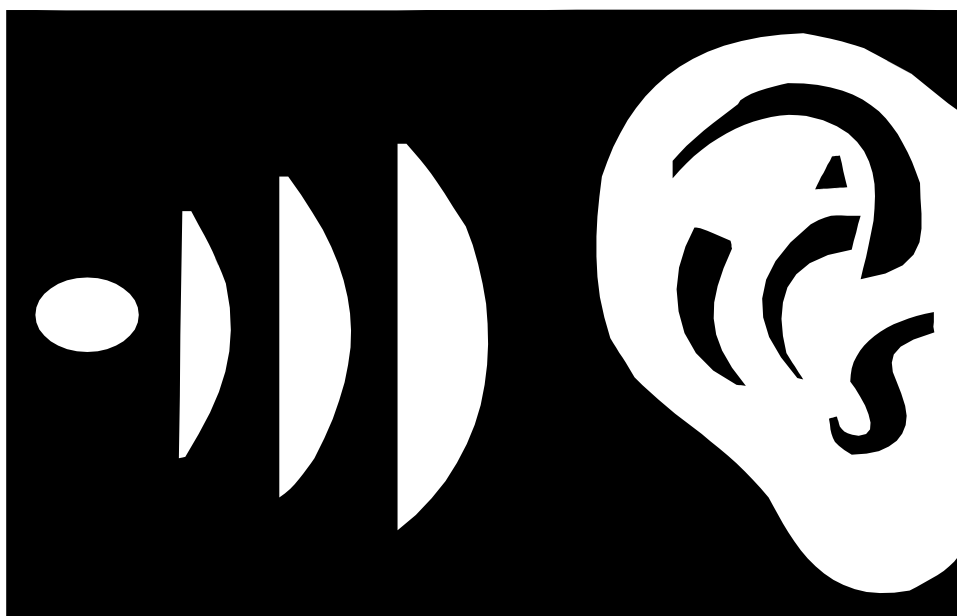
1. Sound causes air molecules to move or vibrate. These vibrations are picked up by the outer ear and travel down the ear canal to the eardrum.
2. The eardrum detects these tiny vibrations, which set the eardrum and the three bones in the middle ear into motion.
3. These movements travel through a small, 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 that the brain recognizes as sound.

Hair cells are one of the microscopic structures found along the basilar membrane. Each ear contains thousands of these hair cells. They are arranged by frequency, or pitch, just like the keyboard of a piano. Nerves are attached to the bottom of these hair cells.

4. When sound vibrations set the fluids of the inner ear into motion, each hair cell responds to a specific frequency by moving back and forth. These movements trigger the nerve endings, which send an electrical signal to the brain along the auditory (hearing) nerve.
5. The brain then 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/>



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.

**No matter the form
of communication
you choose for your
child, he or she will
speak volumes...**

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)

HEARING TESTS

Hearing can be tested in many ways, even with infants. 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 tests are called “behavioral” tests. Behavioral hearing tests are done with an audiometer, a device that produces sounds at certain frequencies and loudness levels or intensities. The child’s response to sound is observed, and the results are used to create a graph called an audiogram. The entire process is called audiometry. Other tests require no response from the child, and are called “objective” tests. Objective hearing tests are done using equipment to measure function. Usually both behavioral and objective tests are used to determine how well a child can hear.

Key Terms

Behavioral tests-

Hearing tests that require a response from the child.

Objective tests- Hearing tests that do not require a response from the child.

Threshold- The softest sound your child can hear at each pitch.

Audiometer- A device that produces sounds at certain pitches and loudness levels, used during hearing testing.

Audiometry- The testing and measurement of a person’s ability to hear.

Behavioral Tests

Visual Reinforcement Audiometry (VRA)

VRA testing takes advantage of a child’s natural desire to search for sounds they hear. Typically, children must be at a developmental age of four to seven months before they can actively listen or turn to seek the source of a sound. VRA is often performed in a sound booth, with the child on a caregiver’s lap in the middle of the room.

The audiologist uses speakers or earphones to present sounds (speech or pitches). When the child turns toward the sound, he is shown a toy. This rewards him for actively listening and turning towards the sound.

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 task might be dropping a block into a bucket or putting a peg into a hole. This test is usually done with the child wearing earphones, but it can also be done 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.

Objective Tests

Auditory Brainstem Response (ABR)

ABR measures the brain’s 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). Your child may have had an Automated ABR (AABR) for their newborn hearing screen.

During an ABR, your child wears earphones that play sounds. To evaluate the brain’s response to these sounds, sensors are placed on your child’s head. These sensors do not hurt. They are often attached with tape or a Band-Aid™. By playing sounds of different kinds, both loud and soft, the audiologist can estimate your child’s ability to hear sounds.

A child must be quiet or sleeping during an ABR. If your child is active during testing, his or her movements may cause the readings to be distorted. It is a good idea to schedule an ABR during your child’s regular naptime. Sometimes a child needs to be sedated so that an ABR can be carried out. Talk to your audiologist or physician if you have concerns regarding sedation or ABR testing.



Objective Tests (continued)

Otoacoustic emissions (OAEs)

OAE measures the function of your child's cochlea, or inner ear. Your child may have been screened this way as a newborn. For the OAE, a soft earphone will be placed in your child's ear. Sounds are played into the ear causing vibrations that move thousands of hair cells found 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 to the earphone. In the earphone, they are measured by a sensitive microphone. The presence of OAEs usually indicates 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. Additionally, OAEs cannot determine the degree of hearing loss. If your child does not pass the OAE test, more testing is needed to determine how well your child hears.

Tympanometry

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

THE AUDIOGRAM

Audiologists use an audiometer to estimate hearing thresholds—the softest sound your child can hear at each pitch. The audiogram is a graph of your child's thresholds. The audiologist will mark your child's thresholds for each ear on the audiogram.

It is hard to get a complete audiogram for an infant during a single testing session. Often it will take several appointments. Sometimes the hearing aid can be fitted based on the limited information gained from an incomplete audiogram. The hearing aid fitting can be updated as additional tests provide more information.

For an example of an audiogram, see ***Audiogram of Familiar Sounds*** following this section. The numbers across the bottom of the audiogram represent the frequency, or pitch, of sound (numbers on the left are low pitches and the numbers on the right are high pitches). The whistle of a bird usually has a high pitch; the growling of a dog has a low pitch. Different speech sounds have different pitches, so it is important to know how well a person hears across the frequency range. The frequencies included on the audiogram are chosen because they are important for understanding speech.

The numbers along the side of the audiogram represent the intensity or loudness. The small numbers at the top are soft sounds and the large numbers at the bottom are loud sounds. With a complete audiogram, an audiologist can determine the type, degree, and configuration of hearing loss (see page 18).

The ***Audiogram of Familiar Sounds***, following this section, shows the pitch and loudness of several environmental sounds as well as typical speech sounds. The shape these speech sounds make on this audiogram is commonly called the speech banana. Mark your child's thresholds on this audiogram to see what she is able to hear. Your child should be able to hear the sounds that are as loud as or louder than her threshold at each pitch.

Key Terms

Otoacoustic emissions- sounds produced when hair cells move. These sounds are measured by a sensitive microphone and their presence usually indicates normal inner ear function.

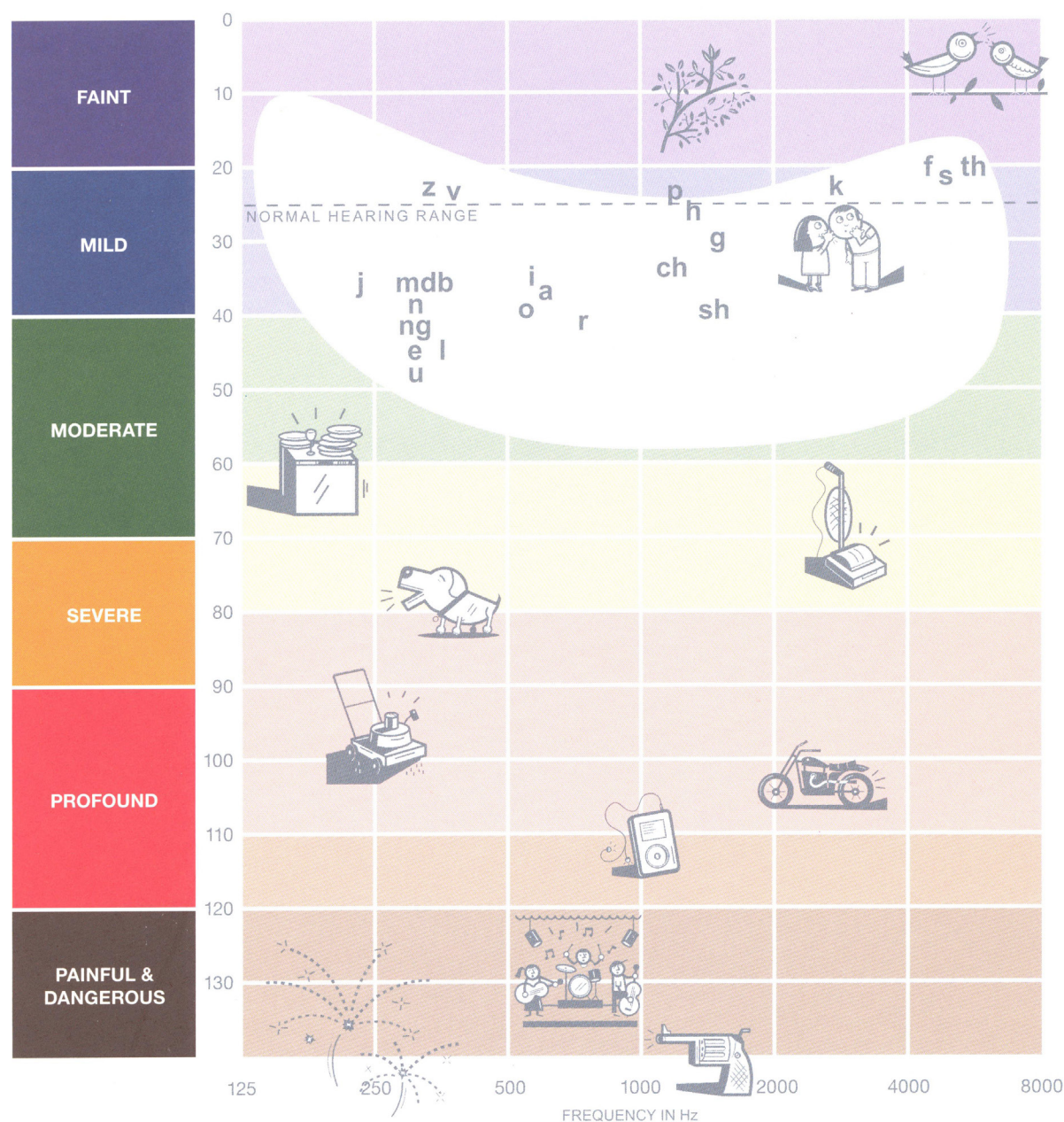
Audiogram- A graph plotting a person's ability to hear sounds of different pitches (frequencies) at different levels of loudness (intensities).

Frequency- The number of vibrations per second of a sound. Frequency, expressed in Hertz (Hz), determines the pitch of a sound. For example, a sound with a high frequency has a high pitch.

Intensity- The loudness of a sound, measured in decibels (dB). A sound with high intensity is very loud.



AUDIOGRAM OF FAMILIAR SOUNDS



American Academy of Audiology

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TYPES, DEGREES, AND CONFIGURATIONS OF HEARING LOSS

TYPES OF HEARING LOSS

Types of hearing loss are classified by where the loss occurs in the ear, including:

- Conductive Hearing Loss
- Sensorineural Hearing Loss
- Mixed Hearing Loss

Conductive Hearing Loss

A conductive hearing loss occurs when one or more of the structures of the outer or middle ear are not working properly. For example, conductive hearing loss may be caused by:

- wax build-up in the ear canal
- a hole in the eardrum
- Fluid in the middle ear
- problems with the bones of the middle ear

Having a conductive hearing loss is like wearing earplugs; you only hear loud sounds. Most types of conductive hearing loss can be medically corrected.

Sensorineural Hearing Loss

Sometimes called “nerve deafness,” this is the most common form of permanent hearing loss. It may result from problems in the cochlea, the auditory nerve, or the hearing centers of the brain.

Damage to the hair cells in the cochlea causes one kind of sensorineural hearing loss. If damaged, the hair cells can’t detect sound. When the problem lies in the auditory nerve or hearing centers in the brain, some professionals call it *auditory neuropathy*.

The causes of sensorineural hearing loss include:

inherited conditions (family genetics)

- certain infections that the mother contracts during pregnancy
- significant lack of oxygen or other complications during birth
- certain syndromes
- meningitis
- medications toxic to the ear
- sudden (as with an explosion) or prolonged (as with loud music) exposure to loud sounds
- aging

Unfortunately, most types of sensorineural hearing loss are permanent. They can’t be corrected by surgery or medication. People with sensorineural hearing loss have problems understanding conversation, especially in crowds or other noisy environments. They may also be more sensitive to loud sounds than people with normal hearing.



Mixed Hearing Loss

A hearing loss is classified as mixed when both conductive and sensorineural hearing loss are present. For example, a child with a permanent sensorineural hearing loss can get a middle ear infection that causes a conductive hearing loss. For a time, the child has a mixed hearing loss that consists of the original sensorineural loss plus the added conductive hearing loss caused by the infection. After the ear infection clears and the conductive loss disappears, the child would be said to have only a sensorineural hearing loss.

Table 1: Types of Hearing Loss

| Type of Hearing Loss | What it looks like | Possible Causes | Permanency |
|---|--|--|--|
| Conductive Hearing Loss Occurs when one or more of the structures in the outer or middle ear are not working properly. | Only can hear loud sounds. | <ul style="list-style-type: none"> • Wax build-up in the ear canal • Hole in the eardrum • Fluid in middle ear • Problems with bones of middle ear | Most types of conductive hearing loss can be medically corrected. |
| Sensorineural Hearing Loss <ul style="list-style-type: none"> • Most common form of hearing loss • Sometimes called “nerve deafness.” • Damage to hair cells in the cochlea results in one kind of sensorineural hearing loss because the hair cells cannot detect soft sounds. <p>The second kind of sensorineural hearing loss occurs in the case of auditory neuropathy This is when there are problems in the auditory nerve or hearing centers of the brain.</p> | <ul style="list-style-type: none"> • Problems understanding conversation, especially in crowds or other noisy environments. • May be more sensitive to loud sounds than people with normal hearing. | <ul style="list-style-type: none"> • Inherited conditions (family genetics) • Certain infections that the mother contracts during pregnancy • Significant lack of oxygen or other complications during birth • Certain syndromes • Meningitis • Medications toxic to the ear • Sudden (as with an explosion) or prolonged (as with loud music) exposure to loud sounds • Aging | Most types of sensorineural hearing loss are permanent. They cannot be corrected by surgery or medication. |
| Mixed Hearing Loss Both conductive and sensorineural hearing losses are present at the same time. | For example, a child with a permanent sensorineural hearing loss can get a middle ear infection that causes a conductive hearing loss. For a time, the child has a mixed hearing loss that consists of the original sensorineural loss plus the added conductive hearing loss caused by infection. After the ear infection clears and the conductive loss disappears, the child would be said to have only a sensorineural hearing loss. | | |

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 (softest sound) a person can hear |
|---------------------------------|---|
| Normal hearing | -10 to 20 decibels (dB) |
| Mild hearing loss | 21 to 40 decibels (dB) |
| Moderate hearing loss | 41 to 55 decibels (dB) |
| Moderate to severe hearing loss | 56 to 70 decibels (dB) |
| Severe hearing loss | 71 to 90 decibels (dB) |
| Profound hearing loss | 91 to 120 decibels (dB) |

Configuration of hearing loss

Configuration refers to how the results of a hearing test look on an audiogram. For example, you can have hearing loss at one frequency or pitch, and not at another. You can also have a different degree of hearing loss at each frequency or pitch. Below are some of the most common configurations of hearing loss. Please see the next page for examples.

| Configuration | The audiogram shows that hearing loss: | See Audiograms (following page) |
|---------------|---|---------------------------------|
| Flat | Is equal across all frequencies | 1 |
| Sloping | Becomes worse at high frequencies | 2 |
| Precipitous | Slopes steeply, and is typically worse at high frequencies | 3 |
| Reverse slope | Is worse at low frequencies, rising to better hearing at high frequencies | 4 |
| Cookie bite | Is worse at middle frequencies, with better hearing at high and low frequencies | 5 |
| Asymmetrical | Is greater in one ear than in the other | 6 |

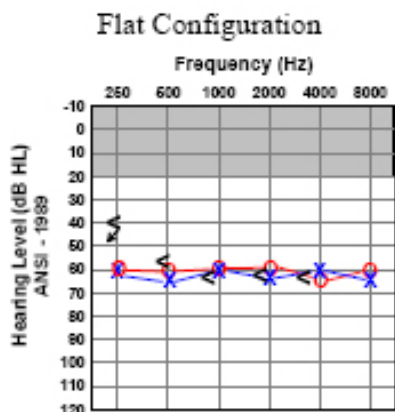
Key Terms

Decibel (dB)- The unit that describes the loudness of a sound.

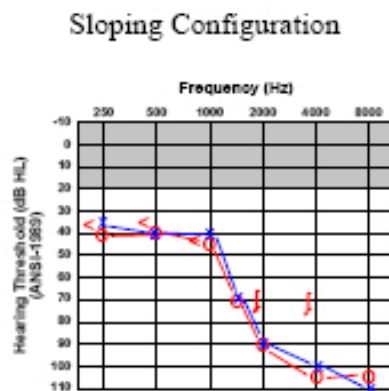
- The higher the dB level, the louder the sound.
- In describing hearing loss, the higher the dB level required for a person to hear a sound, the more severe the hearing loss.

Configuration- how the results of a hearing test look on an audiogram (graph of a person’s hearing).

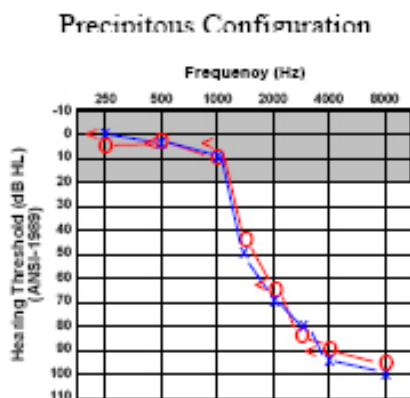
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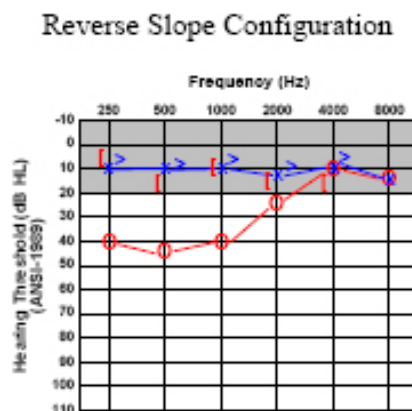
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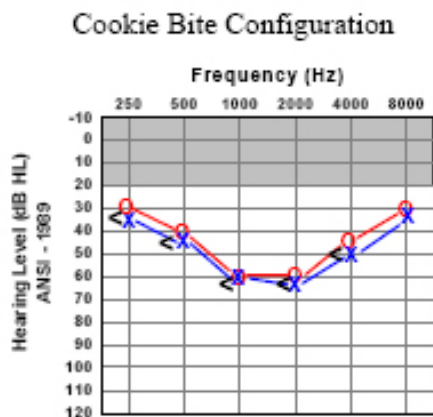
3



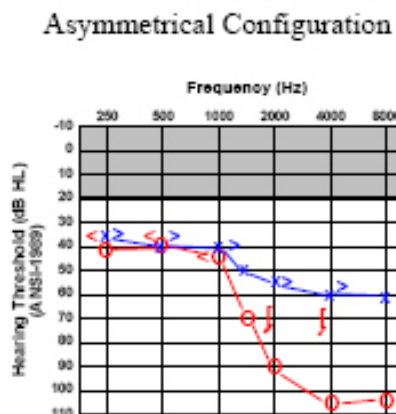
4



5



6



Right Ear

Audiologists use the symbols above on the audiogram for each ear by test.

| Legend* | | |
|--|-----------|----------|
| | Right Ear | Left Ear |
| Air Conditioned Threshold | O | X |
| Unmasked Bone Conduction Threshold | < | > |
| Masked Bone Conduction Threshold | [|] |
| *Talk with your audiologist for more information | | |

Hearing Loss

Some babies are found to have normal hearing in one ear and a significant, permanent hearing loss in the other ear. This is called *unilateral* hearing loss.

Unilateral hearing loss accounts for about 20-40% of permanent congenital hearing loss (or hearing loss present at birth). When a hearing loss is found in both ears, it is called a *bilateral* hearing loss. The effects of unilateral hearing loss (loss in one ear) on speech and language development are typically not as severe as the effects of bilateral hearing loss (loss in both ears).

There are medical reasons for following up on suspected cases of unilateral hearing loss. Permanent hearing loss can 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 a medical term. It refers to inflammation or infection in the middle ear, which is 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. This condition is one of the most common reasons for childhood visits to the doctor.

The symptoms of otitis media include:

- fever
- ear pulling
- irritability
- inattentiveness
- misunderstanding directions
- a need to have TV or radio louder than usual

Otitis media is very common in children. Sometimes it begins with a cold. In many cases, the fluid goes away without further treatment. Factors that put children at higher risk for otitis media include early enrollment in childcare, family history of otitis media, bottle feeding, and frequent exposure to tobacco smoke.

Tubes

When otitis media does not go away, or frequently comes back, treatments can include antibiotic therapy and the placement of *typanostomy tubes*. A short surgical procedure is required to insert the tubes. During the surgery, a small hole is made in the eardrum. A small plastic tube is inserted into this hole, which allows the fluid in the middle ear to drain and ear pressure to stabilize.

Key Terms

Unilateral hearing loss-

A hearing loss of any degree in only one ear.

Bilateral hearing loss-

A hearing loss of any degree that is found in both ears.

Congenital hearing loss-

Hearing loss that is present at birth, associated with the birth process, or that develops within the first few days of life.

Otitis Media- A medical term for a middle ear infection. Hearing loss in children with ear infections can be worse.

Tubes- Called 'typanostomy tubes,' surgically inserted to drain fluid from middle ear and stabilize ear pressure for children who suffer from ongoing or frequent ear infections.



Frequent otitis media is cause for concern for its effect on hearing. Mild or moderate conductive hearing loss is common when fluid is present. The degree of hearing loss may fluctuate with the child having more hearing loss when fluid is present. As the amount of fluid lessens, the child's hearing improves.

A fluctuating hearing loss means that the child doesn't hear sounds in a consistent way. When this occurs with a young child who is just developing verbal and communication abilities, it can have long-term effects on a child's ability to listen, process sounds, communicate, and socialize.

Some children who have otitis media may also have a permanent, sensorineural hearing loss. That is why it is essential to check young children's hearing following treatment of otitis media.

MEDICAL FOLLOW-UP

All children who are diagnosed with hearing loss should see an otolaryngologist (ear, nose, and throat or ENT doctor). Iowa has many otolaryngologists. Your pediatrician, family doctor, or audiologist can refer you to an otolaryngologist.

The otolaryngologist can answer your questions about:

- what caused the hearing loss
- medical or surgical treatments
- other health conditions that your child may have or be at risk of acquiring
- the possible need for genetic testing to learn whether other children in the family may be at risk for hearing loss

Components of the otolaryngology evaluation may include:

- taking a thorough medical and family history
- a physical examination of your child's head and neck
- an examination of your child's ears using an otoscope (an instrument the physician uses to see into the ear)
- referral for genetic testing and counseling
- a CT scan of the temporal bones in the skull
- tests of kidney function
- referral to an ophthalmologist (eye doctor) since many children with hearing loss also have vision disorders



FREQUENTLY ASKED QUESTION ABOUT HEARING LOSS

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.

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. It is also found with certain inherited forms of hearing loss known to get worse over time.

The use of a properly fitted hearing aid will not stop a hearing loss from progressing, nor will it cause the hearing loss to become worse.

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
- certain infections contracted by the mother while pregnant
- syndromes known to be associated with hearing loss
- abnormalities of the face or skull, such as cleft lip and palate
- newborns or infants admitted to the intensive care nursery for more than five days
- inherited conditions

Even if no one else in a family has a hearing loss, a hearing loss may have a genetic origin. You can request that your physician refer you to a genetic counselor for testing.

Is my child “deaf”?

As mentioned before, the degree of hearing loss can vary from frequency to frequency. The word deaf is typically used to describe a profound hearing loss at most or all frequencies. The word hard of hearing is typically used to describe mild to severe hearing loss.

Can surgery correct the hearing loss?

Only conductive hearing loss can be corrected by surgery. There is no cure for sensorineural hearing loss. Children with severe to profound hearing loss who aren't helped by hearing aids sometimes get a cochlear implant. Cochlear implants are discussed on page 32.

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 these children.

See page 76 in Section 7 for listings of American Sign Language online resources.



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 probably had an undetectable blockage in the hospital that, after two weeks, has 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 than 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)



Section 3

Hearing Aids and Other Technologies 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 the degree of your child's hearing loss, hearing aids alone may or may not make sounds loud enough for your child to hear speech.

HEARING AIDS

Regardless of the degree of hearing loss your child has, hearing aids are the first technology offered if you want your child to develop spoken language. Sometimes parents choose not to have their children use hearing aids.

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

Your child's hearing should be monitored regularly, as should the fit of the earmold and hearing aids. If your child does not benefit from hearing aids and has a severe to profound hearing loss, your child may be evaluated for a cochlear implant (see page 32).

Types of Hearing Aids

Hearing aid technology has changed dramatically though the years. Most children, even those with profound hearing loss, can be helped to some degree with hearing aids. Several types of technology are available. Your audiologist will help you choose the hearing aid that is best for your child. She will show you how to place the earmold in your child's ear, adjust any controls, and how to care for the earmold and hearing aids.

Conventional Technology

Conventional hearing aids take sound in and *amplify* it, or make it louder. This is done with an amplifier, receiver, and microphone. It is called analog technology. Conventional hearing aids can be very powerful. They can often provide some benefit even for a child with profound hearing loss. These hearing aids can be adjusted to your child's hearing loss through the use of screwdriver control settings. Conventional hearing aids are less expensive, but not as flexible as other hearing aid technology.

Programmable Technology

Programmable hearing aids are adjusted with the use of a computer. They can often be readjusted to fit changes in hearing loss. These hearing aids can often be programmed to function differently in different listening situations (e.g., quiet vs. noise). Programmable hearing aids are more expensive than conventional hearing aids. Children can use them with nearly any type or degree of hearing loss.

Key Terms

Hearing aids- An electronic device that amplifies sound and directs it into the ear. consists of a microphone to make the signal louder, and a receiver or loudspeaker.

American Sign Language (ASL)- American Sign Language uses the placement, movement, and expression of the hands and body. ASL is a complete language with its own grammar and syntax just like English.

Earmold- An individually fitted plastic or vinyl piece that is worn in the outer ear and uses a small tube, or channel, to connect with a hearing aid outside the ear.

Parent Training and Information Center of Iowa- provides services such as family support information, information about a child's disability, and skills for participating in the Individual Education Program (IEP).



Digital Technology

Digital hearing aids have the same capabilities as programmable technology, but the sound is processed differently. As with a compact disc, sounds are changed into a digital code before they are amplified. Children with nearly every type and degree of hearing loss can use digital hearing aids. They are usually more expensive than other technologies.

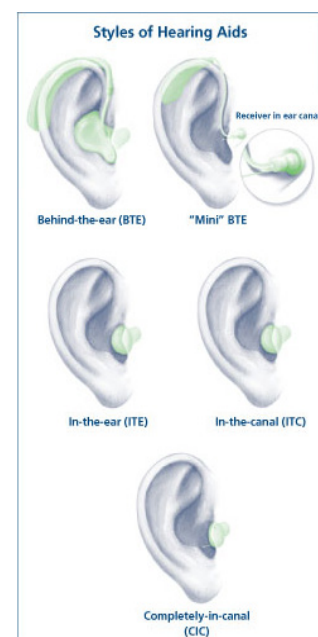
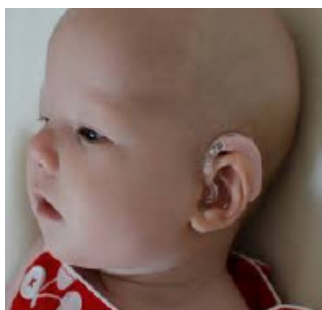
STYLE OF HEARING AIDS

Behind-the-ear (BTE) hearing aids

BTE hearing aids are placed, as the name suggests, behind the ear. They connect to the earmold with a small piece of tubing. The amplified sound from the hearing aid is routed through the tubing and earmold into the ear.

This type of hearing aid is used with children for a variety of reasons.

- Safety is one important reason for choosing behind the ear (BTE) rather than in the ear (ITE) hearing aids for children.
- The soft earmold used with BTE hearing aids can prevent injuries in physically active children if they are hit on the ear.
- Since the earmold do not contain any electronic components, they can be washed with soap and warm water.
- Wearing the hearing aid behind the ear can prevent damage from earwax or from drainage due to ear infection.
- Earmold are relatively inexpensive and easy to replace when children, and their ears, grow. New, better fitting earmold can be connected to the original hearing aids.
- Finally, BTEs usually work better with assistive listening devices, such as frequency modulation systems. See page 32 for more information about Assistive Listening Devices (ALDs).



In-the-ear (ITE), In-the-canal (ITC), and Completely-in-canal (CIC) hearing aids

This group of hearing aids does not use an earmold, and fit either in the bowl (concha) of the outer ear or in the ear canal.

- ITE hearing aids are the biggest; all the components fit in the outer ear and ear canal
- ITC hearing aids are smaller than ITE hearing aids and fill up less of the outer ear
- CIC hearing aids fit deeper in the ear canal

These hearing aids may not be appropriate for people who have profound hearing loss. They may also be more susceptible to damage from earwax and drainage. They are often not appropriate for young children whose ears are still growing.

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

A bone conduction hearing aid is another less common hearing aid.

- It is most often used with a receiver worn in a headband, or with a body style aid.
- Bone conduction hearing aids are useful for children with conductive hearing loss who can't wear an earmold because of an absent or small outer ear.
- It is also an option if a child has ongoing, severe middle ear problems.
- A surgically implanted bone conduction system is available for children older than five years of age.

Table II: Hearing Aid Styles

| Behind The Ear (BTE) hearing aids | In The Ear (ITE), In The Canal (ITC), and Completely In Canal (CIC) hearing aids | Bone Conduction hearing aid (Also known as <i>Bone Anchored Hearing Aid [BAHA]</i>) |
|--|--|--|
| <ul style="list-style-type: none"> Placed behind the ear. Connect to the earmold with a small piece of tubing. Amplified sound from the hearing aid is routed through the tubing and the earmold in the ear. | <p>This group of hearing aids does not use an earmold, and fit either in the bowl (concha) of the outer ear or in the ear canal.</p> <ul style="list-style-type: none"> In the ear (ITE) hearing aids are the biggest; all the components fit in the outer ear and ear canal In the canal (ITC) hearing aids are smaller than ITE hearing aids and fill up less of the outer ear Completely in the canal (CIC) hearing aids fit deeper in the ear canal | <ul style="list-style-type: none"> Less common hearing aid. Used with a receiver worn in a headband, or with a body style aid. |
| <p>Advantages:</p> <ul style="list-style-type: none"> Safety- soft earmold used with BTE hearing aids can prevent injuries in physically active children if they are hit on the ear. Cleaning- Earmold do not contain electronic components, so they can be washed with soap and warm water. Can prevent damage from ear-wax or from drainage due to ear infection. Earmold are relatively inexpensive and easy to replace when children's ears grow. Work better with assistive listening devices (See page 34). | <p>Considerations:</p> <ul style="list-style-type: none"> May not be appropriate for people who have profound hearing loss. May also be more susceptible to damage from earwax and drainage. Often not appropriate for young children whose ears are still growing. | <p>Advantages:</p> <ul style="list-style-type: none"> Useful for children with conductive hearing loss who can't wear an earmold because of an absent or small outer ear. An option if a child has ongoing, severe middle ear problems. A surgically implanted bone conduction system is available for children older than five years of age. |

TIPS FOR KEEPING HEARING AIDS ON LITTLE EARS

You know that hearing aids are the key to your child's development of speech and language, but how do you convince your infant or toddler to keep them in her ears?

Just as your child may prefer not to wear shoes and socks, he may prefer not to have a hearing aid inserted in his ear. You will no doubt be frustrated when, after working hard to place the hearing aid in your child's ear, his small hand reaches up and immediately pulls it out!

The key to success is to teach your child, from the very first day, that you are in control of when and where she wears her hearing aid(s). As your child gets used to having the hearing aids in her ears, being able to hear better should encourage her to leave them in. You can encourage your child's wearing of hearing aids by providing reinforcement. This can take the form of a reward that is only available when she is wearing her hearing aids, such as a special game. Or it can be a natural consequence, such as being able to hear a song, or to talk to you, or to get encouragement and smiles from you as she learns to communicate. So, how do you get started?

Retention Devices

Retention devices help keep hearing aids on a small child, and can prevent your child from losing or breaking her hearing aids. Your audiologist can help you identify such devices for your child. Some examples include Huggie Aids®, alligator clips, toupee tape, hats, and headbands.

Ease of Insertion

What your child's earmold are made of will affect how easily they slide into the ear. Also, if your child has a severe hearing loss, the part of the earmold that goes into the child's ear may be long and even curved. These factors, along with a squirming child, may make getting the earmold into the ear seem almost impossible. A lubricant and good insertion technique can make this much easier. Put a small amount of lubricant on the part of the earmold that goes into the ear canal (be careful not to block the sound opening). This makes it easier to slide the earmold into the ear.

You can find creams and oils that are made especially for use with earmolds. It is important to use a water-based lubricant, such as Otoferm® or Otoease®. These won't damage the earmold, and can prevent irritation in the ear. Vaseline® is not water based, and so is not a good lubricant. Your audiologist can help you to locate these products as well as others.

Behavior Plans

Your child should wear hearing aids during all waking hours, so that she hears sounds throughout her daily routine. That way, she will associate wearing hearing aids with hearing sounds, which will help the learning process. Be consistent in this daily routine, and reinforce or reward your child for wearing the hearing aids. Talk with your audiologist for additional suggestions if a child absolutely refuses to keep the hearing aids on, and if there isn't a good reason for him to object to wearing them (see below), you may want to confer with a behavioral psychologist.

Hearing Aid Concerns 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

Your audiologist should use *real ear measures* to determine the sound pressure level that your child's hearing aids deliver. When the level of sound delivered is too high, it is called *overamplification*. A real ear measure is taken by putting a small, soft tube into your child's ear. The audiologist then plays sounds through a loudspeaker, and measures the level of sound pressure in the ear. Using real ear measures, your audiologist can monitor the level of sound pressure in your child's ear. This can be compared to guidelines for the maximum amount of sound that can be introduced without discomfort. The guidelines are based on age norms, although individual differences may exist.



You should suspect overamplification is the problem if your child repeatedly pulls the hearing aids out of the ears or seems to be blinking his eyes more than usual when wearing the hearing aids. If you see these signs, talk with your audiologist. Remember that loud sounds should sound loud to your child when she is wearing her hearing aids, but that **even very loud sounds should not cause physical discomfort.**

Ear infection

If your child has an ear infection, she may pull off her hearing aids because her ears are hurting. Be sure to talk with your physician and audiologist if you suspect that your child has an ear infection. They may recommend that she not wear the hearing aid until the ear infection clears. If your child's ears are actively draining, remove the hearing aids until the infection clears.

Sore spots

A new earmold can cause soreness at first. Sometimes an earmold can have uneven areas that can cause redness or a sore spot in your child's ear. These areas on the earmold can often be filed smooth by your audiologist. Check your child's ears for redness often whenever she gets a new earmold. A sore spot may be the reason your child doesn't want to wear her hearing aids.

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:

- damaged hearing aid
- an earmold not completely inserted
- damaged earmold, tubing or earhook
- poorly fitting earmold
- an earmold or ear canal is blocked by wax or by discharge from an ear infection
- a hat or blanket that covers the hearing aid and its microphone (feedback stops when you remove the hat or blanket)

Don't 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, the hearing aids won't function at the correct volume for your child. (Temporarily turning down the volume is acceptable until you visit your audiologist to determine the cause of the feedback).

A damaged or poorly fitting earmold may need to be remade. The tubing or earhook may need to be changed. If earwax or discharge has blocked the earmold, the earmold will need to be cleaned. Your audiologist can troubleshoot the cause of feedback and make the changes needed to prevent it.

COCHLEAR IMPLANTS

A hearing aid trial, with well-fitted hearing aid and earmold, is required before cochlear implantation will be considered. Cochlear implants are currently approved only for children with severe to profound hearing loss.

If the hearing aid trial is not successful, and a child is unable to develop spoken language through the use of hearing aids, a cochlear implant may be an option. If parents or guardians choose this approach, cochlear implant surgery is approved for children as young as 12-months-old. Sometimes cochlear implantation is done with children younger than 12-months-old. For example, this may occur if the child had meningitis and waiting until 12 months of age may lessen the chance for a successful implant. However, cochlear implantation is not typically done until 12 months of age. As we learn more about hearing and cochlear implantation, these age guidelines may change.

Key Terms

Overamplification- When the level of sound delivered by the hearing aid is too high. You may notice excessive blinking.

Feedback- In a hearing aid, the whistling sound that can occur when an earmold does not fit well and the amplified sound goes back into the hearing aid microphone. Persistent feedback should be discussed with your audiologist.

Cochlear Implant- An electronic device that stimulates nerve endings in the inner ear (cochlea) so that a person can hear and



If you are interested in a cochlear implant, your child must be evaluated by professionals who specialize in cochlear implantation. They will determine whether your child is likely to benefit from this technology.

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, which carries them to the brain.

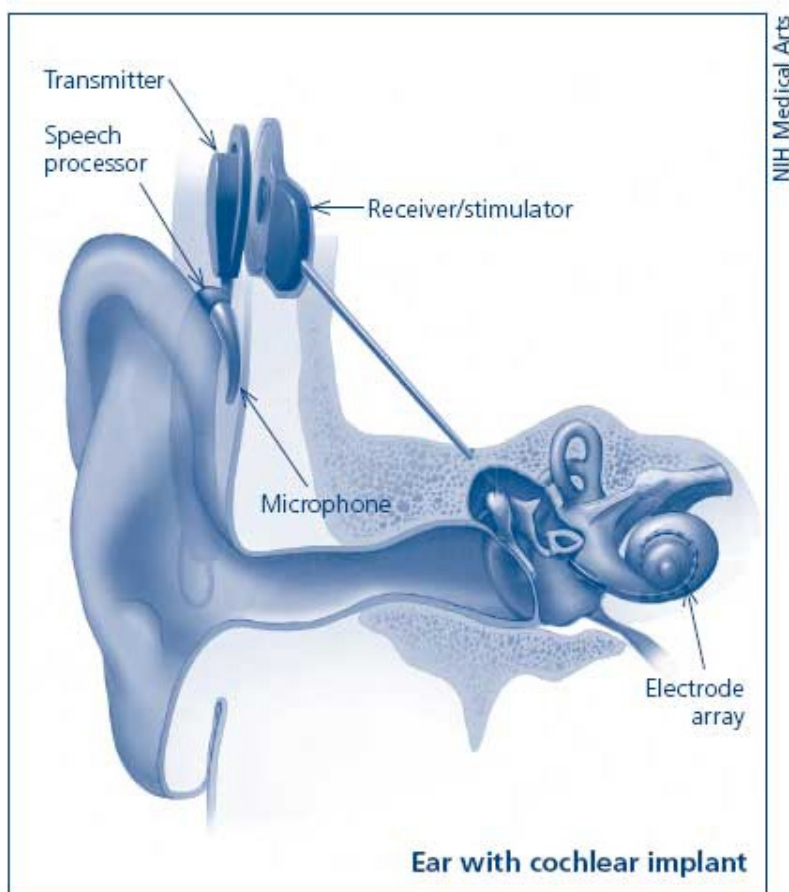
A cochlear implant does not correct hearing loss. In fact, it bypasses the normal hearing pathway, in which sounds travel through the outer, middle, and inner ear to reach the auditory nerve. A cochlear implant stimulates the auditory nerve directly. The brain then learns to take this electrical stimulation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

Research has shown that with a cochlear implant, many children with severe to profound hearing loss can develop speech and language similar to that of children with normal hearing.

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

Cochlear Implant Programs

A limited number of centers around the country specialize in pediatric cochlear implantation. Talk to your Ear, Nose, and Throat specialist for more information or for a referral to a cochlear implant specialist.



ASSISTIVE LISTENING AND ALERTING DEVICES

Assistive listening devices are used for situations like:

- communicating one on one
- therapy
- classroom education
- watching television
- listening in the car
- listening at a movie theatre
- participating in a religious service.

Many of these devices can work with your child's hearing aids or cochlear implant. Some are used to enhance listening and learning (e.g., frequency modulation systems) by improving the signal to noise ratio; that is by making speech sounds louder than background noise. Check with your audiologist for more information.

Alerting devices give notice of an event involving sound:

- a doorbell or phone ringing
- a smoke alarm going off
- an alarm clock buzzing.

They may provide 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
- text telephones (TTYs)
- voice carryover (VCO) and
- a telephone that flashes a light when ringing.

You qualify for assistance from Telecommunications Access Iowa if:

- you live in Iowa
- your child is five years old or older
- you have telephone service in your home
- telephone equipment would make using the telephone easier for your child
- you meet certain household income guidelines

If you qualify for this service you will get a voucher that will cover about 95% or more of the cost of the device. Various telephone equipment may be tried out at:

Telecommunications Access Iowa Showroom
 400 Locust Street, Capitol Square, Suite 170
 Des Moines, IA 50309
 TTY: (515) 282-5130
 Voice: (515) 282-5099
 Fax: (515) 237-3917
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) – a t-coil is a tiny coil of wire around a core. A telecoil can be an alternate or supplemental input device for a hearing aid or cochlear implant.

- The big advantage of using t-coils is that they generally cut out background noise so your child only hears the sounds from the device she is listening to.
- Because of the Americans with Disabilities Act, many public places such as movie theaters, churches, and sports stadiums provide Assistive Listening Systems (ALSs), which may include headsets or receivers that visitors can use to help them hear.
- Many of these are hearing aid compliant, so if your child has a telecoil equipped hearing aid or cochlear implant, then she can hear the magnetic signal. Many times your child can hear that a lot better than she can hear an acoustic signal.

Telephone Assistance

- Amplified telephones and cell phones, portable amplifiers, and phone captioning on the computer.
- Some cell phones are more hearing aid/cochlear implant compatible. Check with your provider to obtain a list of recommended phones.
- Bluetooth connectivity also allows for direct communication with both landline and cell phones with remote Bluetooth devices. This allows sound to transmit from phones directly to hearing aids.
- **Telephone Relay Service:** When placing a call to another party, the deaf or hard of hearing individual dials into the relay service and provides a phone number they wish to call. The relay operator dials the number and the operator will convert all of the text messages for the hearing person into voice and convert all of their verbal replies into text for the deaf or hard of hearing caller.

Special Connectivity Devices for TV

Various devices are available that can be plugged directly into a TV and the signal is transmitted wirelessly to headphones. This may be transmitted via infrared, where the signal is sent by an infrared light signal.

- Closed captioning also allows for a text display of the spoken words in television shows and movies. All televisions with screens larger than 13 inches must have built-in captioning.

DCMP

The Described and Captioned Media Program is a free loan video service with thousands of captioned educational DVD's available for streaming and viewing on a computer or for order that can be sent to home or school (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, American Sign Language apps, and many other assistive apps for deaf or hearing impaired individuals.

Text to Speech

There are several products available that use voice recognition software to convert voice to text or computerized sign language. The recognition is not always exact and the deaf or hard of hearing consumer must be able to recognize when errors occur. It may take time to train the system to recognize an individual voice.



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 is being used more and more by deaf and hard of hearing individuals, and 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. Depending on the device, the information can be saved and printed as written or can convert the hand-written materials into text. A note taker may be of assistance to someone with hearing loss in a group meeting. Some colleges train and pay note takers for students with hearing loss.

Real Time Captioning

Provides a typewritten account of all spoken information from a lecture, meeting, discussion or presentation. All of these systems require the skills of a trained captionist and specialized software or equipment such as a computer.

Video Remote Interpreter

When an interpreter is not available for an event, video interpreting another option. Using a phone or other computer device or software, an interpreter in another location can listen to a presentation and use sign language to relay the information presented through a web camera or video phone. High-speed Internet service is necessary for this type of interpreting. The deaf or hard of hearing individual can view the signed information on a computer or video telephone.

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 a phone ringing or an alarm clock. Such items include clocks, watches, door bells, fire or carbon monoxide detectors, phones or weather alerts.

- Alarm clocks can be bed shakers, they may vibrate, may be vibrating watches, or they may vibrate someone's pillow, for example.
- Door bells can connect to lamps within the home or be connected to a vibrating beeper that one might wear, or a flashing light may go off when someone knocks on the door.
- 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 anticipate the purchase of hearing aids. Families faced with the cost of hearing aids may feel overwhelmed. Private insurance companies differ in their 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.

Usually, families who are eligible for Medicaid or *hawk-i* can obtain financial support for the purchase of hearing aids or other assistive devices. *hawk-i* is an insurance program for Iowa children in families with limited income. If you have *hawk-i* insurance and want to know if hearing aids are covered, call 1-800-800-1043 with your policy number.

If you do not qualify for Medicaid or *hawk-i*, you may be eligible for hearing aid and audiological services funding through the Iowa Department of Public Health. Funds are limited, therefore claims are processed on a first come, first serve basis and considered as payer of last resort. The funding is made possible through an appropriation from the Iowa Legislature. The money could cease to exist, increase or decrease each year depending on legislative action. To find out more, visit the Iowa EHDI website, www.idph.state.ia.us/iaehdi/default.asp. Click on “parents” or “professionals” and you will see the funding announcement, application and frequently asked questions sheet. You may also call the EHDI Coordinator at (800) 383-3826 for more information.

It is very important for families to realize that the cost of hearing aids should not delay or prevent the fitting of appropriate hearing aids. Early intervention is essential if a child with a hearing loss is to develop normal communication skills. **Families should talk with their audiologist, Guide By Your Side parent guide, and their Early ACCESS service coordinator to identify funding resources.**

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

The following page provides a table with basic information about insurance and common services covered related to hearing aids and other technology.

Key Terms

hawk-i- An insurance program for Iowa children in families with limited income.

Medicaid- A federal and state program that provides health care insurance to low-income persons.



| Basic Guide to Common Insurance Policies- Is it Covered? | | | | | |
|--|--|--|---|---|---|
| | Hearing Tests | Hearing Aids | Cochlear Implants | Other Assistive Tools | Copays or Coinsurance |
| Medicaid | Yes | Yes | Yes. May also cover implantable direct bone conduction systems. | Not often. Depends on if it is thought to be needed. Preapproval may be needed. | Not often. |
| Medicare | Not often. <ul style="list-style-type: none"> It may be covered if hearing loss is due to some other health issue. It must be ordered by a doctor. | No | Yes. And covers implantable direct bone conduction system. | Not often. | There may be out of pocket costs for cochlear implants, depending on your plan; discuss with your doctor or call the number on the back of your insurance card. |
| CHIP (Hawk-i) (formerly SCHIP) | Yes, but there may be limits for which doctors and audiologists can be seen. | Yes, but there are certain cost limits for hearing aids. | No | Not often. | There may be copays involved with hearing tests or hearing aids, depending on your plan. |
| Private insurance | Some plans cover hearing tests and some do not. Check with your health plan by calling the number on the back of your card first. | Some plans cover hearing aids and some do not. Check with your health plan. Your doctor or audiologist may be able to do this for you. | 90% of private plans cover this, but many need preapproval . Be sure to talk with your doctor. | Not often. Depends on if it is thought to be needed. Preapproval may be needed. | There are often copays or deductibles involved with hearing aids or implants and similar aids; Call your health plan and talk with your doctor. |

Other Public and Private Funding Sources for Hearing Aids and Other Hearing Assistive Technology

- **Deaf Services Commission of Iowa** (www.deafservices.iowa.gov/index.html) provides a variety of support programs and services for deaf and hard-of hearing persons.
- **State assistive technology programs** may give loans of tools or buying tools and suggestions for sources. For state support, click on resources at www.resna.com.
- **Iowa Lions Foundation** (www.iowalions.org) helps give hearing aids to people less able to pay for them.
- **The United Health Care Children's Fund** (<http://www.uhccf.org>) helps to give funding to families with children with special health care needs that are not covered by their health plan.
- **Miracle Ear** (<http://www.miracle-ear.com>) supports children and adults with fixed income and gives hearing aids to people who need them.
- **The HIKE fund** (<http://www.thehikefund.org>) gives hearing tools to children under the age of 20 and their parents. The Fund may give many types of tools. Such tools are hearing aids, FM systems, closed caption converters, tactile units, alerting systems, and specialized sports equipment to aid children with hearing loss in communication.
- **First Hand Foundation** (<https://applications.cerner.com/firsthand/>) gives funding for health care needs such as medication, health care and surgeries.
- **The Starkey Foundation** (<http://www.starkeyhearingfoundation.org/>) Provides hearing aids. Program called Hear Now that helps people throughout the US who have hearing loss.
- **Audient** (<http://www.audientalliance.org/>) will help those with low incomes to access hearing tools at lower prices. Families are able to get a lower price for certain brands of hearing aids based on income.

There are many more groups that give similar supports. Sertoma's website (<http://www.sertoma.org>) has a broad list of groups with programs that help people in getting hearing tools.



Section 4

Communication Options for Your Child and Your Family



SECTION 4: COMMUNICATION OPTIONS FOR YOUR CHILD AND YOUR FAMILY

HOW HEARING LOSS AFFECTS COMMUNICATION

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

- the type of hearing loss
- the degree of hearing loss
- the configuration of hearing loss
- other factors, including:
 - family involvement
 - the age at which hearing loss occurs
 - the age at which hearing loss was identified
 - the age at which intervention was provided
 - the child's other health conditions

Key Terms

Communication methods-

The various approaches used to educate and converse with children with hearing loss. Whatever method you choose should be a comfortable “fit” for your child and family.

Hearing loss in a child is different than hearing loss in an adult. This is because a child has not yet learned speech and language. Adults with hearing loss can sometimes get by without hearing aids because they know and can apply the rules of language to daily conversations with others. For a child, even a mild hearing loss can affect his ability to develop speech and language skills. Children need to hear all of the sounds of their language in order to learn how to talk.

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 speech and language information in ways other than hearing alone.

Children with milder degrees of hearing loss may also benefit from knowing some form of visual communication. There may be times (e.g., swimming, bathing) when a child is not wearing her hearing aids, but needs to communicate.

COMMUNICATION METHODS

Below you will find the most commonly used 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.

Manually Coded English (MCE)

The Manually Coded English method uses a visual form of the English language, or sign language. English is represented (coded) by signs made with the hands. Several different systems for manually coding English exist. Each one has its own rules and variations. Most use American Sign Language (ASL) signs as a base and English word order. Manually Coded English follows English language rules.

All sign language methods require a commitment from all family members to learn and use signs for communication with the child. If the family chooses this method, it is important for parents to learn sign as quickly as possible. That way, their children can learn language from them in the same way children with hearing learn from their parents.

Systems of MCE include: Signed Exact English¹, Signed Exact English², and Rochester Method. Pidgin is a Contact Sign Language which typically uses ASL signs but in English word order.



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
- ASL is another complete language just like English is a complete language.
- It is considered by many members of 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.
- Since ASL is not a “method” of learning English but a separate language, hearing parents must work with those fluent in ASL to learn the language and to provide their child with the opportunity to learn ASL.

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. For this method to be effective, these devices must allow the child to hear speech sounds.

In addition to listening, a child is encouraged to watch the speaker to get additional information from speech reading (lip-reading), facial expressions, and gestures. Hearing through hearing aids or a cochlear implant, even in the best of circumstances, is not the same as typical hearing. Early intervention services need to include specific strategies that emphasize listening and communication.

Auditory-Verbal

The auditory-verbal method is based on a specific philosophy within the broader aural-oral category. Again, the development of language through listening and the use of residual hearing are central. The use of hearing aids or a cochlear implant will be the same as in the aural-oral method, but there is little if any emphasis on visual cues such as speech reading or gesture. 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.

- When a child is born to parents who are Deaf, the language of the home and the first language of the child is usually ASL with English as a second language.
- When a child is born to parents who are hearing, the language of the home and the first language of the child would typically be English or whatever language is spoken in the home.
- In a bilingual method, the hearing family learns and uses ASL in addition to English.
- In some programs, the family uses English and the school program uses ASL in the early years, adding English as a second language as the child gets older.



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. For example, when you speak, **p**, **b**, and **m** all look the same on the lips. As a result, the words *pat*, *bat*, and *mat* all look exactly the same to someone who is speech reading. Using different hand shapes for the **p**, **b**, and **m** allows the listener to understand which word is being said.

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 as well as sign and speech.



Total Communication

With the total communication philosophy, a child with hearing loss uses all forms of communication available to develop language skills as early as possible. These may include child-devised gestures, formal sign language, speech, speech reading, finger spelling, reading, and writing. The child may also use individual or group amplification systems to utilize residual hearing as much as possible.

FREQUENTLY ASKED QUESTIONS ABOUT COMMUNICATION METHODS

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 that all the members of your family learn to communicate with him. The different communication methods have advantages and disadvantages in terms of ease of use and ease of learning.

It is important to understand that no two families are the same, and no two 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.

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 very 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.

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. Talk with your child and treat him as you would if your child had no hearing loss. If he has a severe or profound loss, you may decide to use some type of visual communication to supplement.

DEAF CULTURE AND THE DEAF COMMUNITY

The idea that people with hearing loss have their own culture and a community is news to many hearing people. This community is called the Deaf community. The “D” in Deaf is capitalized when referring to members of this community. People who are Deaf prefer the terms *deaf* or *hard-of-hearing*, rather than *hearing impaired*. Members of the Deaf community may have a wide range of degrees of hearing loss—mild to profound.

A *community* exists among a group of people when they share:

- experiences
- interests
- language
- norms of behavior
- survival technique

Groups of people, such as individuals who are deaf or hard-of-hearing, seek each other out for social interaction and emotional support. *Deaf culture* is based on shared experiences and a shared language. Shared experiences could include attending public or private school programs for students who are deaf and hard-of-hearing. They include participation in special camps or sports activities. Most often the shared language among these adults is American Sign Language (ASL). This is true regardless of whether an adult grew up using sign language or a form of Manually Coded English (MCE). Because the syntax and structure of ASL are different than those of English, ASL is a separate language.

The Deaf community is made up of people with hearing loss. They identify with and participate in the activities of the Deaf community. This community has its own local, state, regional, and national organizations. It has its own social and athletic events, community picnics, and theatrical productions. Deaf and hard-of-hearing individuals are willing and eager to participate in these activities. All of these factors—schools, language, and organizations—have brought together people who might otherwise have been isolated in their hometowns.

The majority of deaf children are born to hearing parents. As a result, Deaf culture is passed on not through families but through contact with other Deaf people in the community. It is important for children with hearing loss to have role models similar to themselves. Your Guide By Your Side parent guide or EHDI Program Coordinator can help connect you with a Deaf Guide or mentor in your community.

To learn more about Deaf culture and the Deaf community in Iowa, contact:

Deaf Services Commission of Iowa
 Lucas State Office Building
 Des Moines, Iowa 50319
 (515) 281-3164 (voice and TTY)
www.state.ia.us/government/dhr/ds

See page 58 for more information about the Deaf Services Commission of Iowa.

Key Terms

Deaf Community- The Deaf community is comprised of individuals, both deaf and hearing, who to varying degrees embrace particular community goals that derive from Deaf cultural influences. They share the positive view of being a deaf person, and place a high value on Deaf culture.

Deaf Culture- A system of values, beliefs, and standards that is learned and shared among members of the Deaf community. Some components of Deaf culture are American Sign Language, social interaction with others who are deaf, involvement in Deaf organizations, and high value placed on its art forms.



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)

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 THAT PROTECT YOUR RIGHTS

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

The Americans with Disabilities Act (ADA)

The ADA is a comprehensive federal law that protects the civil rights of people with disabilities. It gives them equal access to employment, state and local government programs and services, public places (such as businesses, transportation, and non-profit service providers), and telecommunications. This law has had a tremendous impact on people who are deaf or hard-of-hearing. Because of it, they can now expect interpreters at events, telephone relay services, and closed-caption TV.

Section 504 of the Rehabilitation Act of 1973

Basically, Section 504 states that 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: No person with a disability can "be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal funding assistance" on the basis of their disability. If a student requires accommodations in a classroom but does not require an IEP, a 504 plan will be developed to accommodate this child.

The Individuals with Disabilities Education Act (IDEA)

IDEA provides federal funds to ensure that students with disabilities get a free, appropriate public education (FAPE). Services must be provided to children with disabilities until they graduate from high school (at the ages of 18 through 21 years). IDEA also requires that each student with a special need have an IFSP (individualized family service plan age 0-3) or an IEP (individualized education program age 3-21). Because of IDEA, your child will be educated in an environment that is appropriate and "least restrictive."

IDEA Part B (Public Law 101-476) for children 3-21 years clearly gives you the right to:

- be notified if your child's school wants to evaluate her or change her educational placement.
- request an evaluation of your child if you think that he needs additional special education or related services. The school must notify you if this request is refused.
- have your child evaluated in the language that she knows best. For example, if she uses sign language, she has the right to be tested by someone who knows sign language. If that is not possible, then the test may be interpreted by a qualified interpreter.
- obtain an independent evaluation of your child if you do not agree with the outcome of the school's evaluation.
- be asked by the school to provide *parental consent*. This means they must ensure that you understand and agree with your child's educational placement. You must give your consent in writing. Consent is voluntary, and you can withdraw it at any time.

Key Terms

Least Restrictive Environment (LRE)-

Provision of the IDEA. Means that to the maximum extent appropriate, children with disabilities are educated in a classroom with children who are not disabled.

Special classes, separate schooling, or other removal of children with disabilities from the regular educational environment occurs only if the nature or severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily.



- review, and get copies of, all of your child's records. The school has the right to charge you a reasonable fee for making copies.
- have your first language be the language the school uses to communicate with you.
- be fully informed by the school of all the rights that you and your child have under the law
- participate in the development of your child's IFSP or IEP
- have your child educated in the "least restrictive" school setting in which she can succeed
- request a due process hearing to resolve your differences with the school if these cannot be resolved informally

THE 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. The family is actively involved in the planning, carrying out, and reviewing activities and services. As the needs of the family change, the IFSP changes.

In Iowa, the family and Early ACCESS providers work together (see page 46, Section 6). They identify and address the family's concerns and priorities related to their child's overall growth and development. All early intervention services to the child are provided in the child's "natural environment." This might be the child's home and other community settings where children of the same age without disabilities are found. Early ACCESS staff can also direct the family to other community resources that address broader concerns.

THE INDIVIDUALIZED EDUCATION PROGRAM (IEP)

An *individualized education program* is a written statement for each child with a disability that describes his or her education program. The team that creates an IEP includes parents, special education teachers, regular classroom teachers, and a representative of the school district who is knowledgeable about the curriculum. Team members, including parents, may also invite other people to attend an IEP meeting, such as an audiologist or speech-language therapist. An IEP can plan for no more than a year at a time, and it must be reviewed at least once during that period.

Children with special needs who are from 3 to 21 years old have IEPs. The IEP begins by describing your child's current educational performance. It includes goals for the child, and describes special education and other services that he can use to accomplish these goals. It will also explain:

- how your child will be evaluated in statewide or district-wide assessments
- how progress will be measured and reported
- whether your child needs extended school year services
- what assistive technology your child could benefit from
- what kinds of physical education your child will participate in
- transition services (at 14 years of age) and transfer rights (at 18 years of age)



YOUR CHILD'S COMMUNICATION PLAN WITHIN THE IEP

As you and the rest of the team develop the IEP, you must look closely at how your child's communication plan is built into it. This communication plan should address your child's:

- academic level
- mode of communication (total communication, cued communication, ASL, etc.)
- communication needs
- needs other than those related to hearing and communicating
- opportunities for direct communication with peers and adults at school
- opportunities for direct instruction in your child's communication mode

Your knowledge of your child makes you a key member of your child's IEP team. It is important that you take an active role in developing the communication plan and the IEP as a whole. Whenever you (or any other member of the team) feel that changes in the plan are needed, you should call for a meeting.

YOUR RESPONSIBILITIES AS A PARENT

Just as you have rights as the parent of a child with special needs, you also have certain responsibilities or duties. You are responsible for ensuring that your child's rights are respected and protected. The following suggestions may be helpful.

- **Learn as much as you can about your rights and the rights of your child.** The more you understand about your rights under federal law, the better equipped you are to see that your school is honoring them. If you have any questions about your rights as a parent, ask your 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 member of a team whose function is to help your child get the best education possible. Your input and suggestions are an essential resource to the educators and other professionals who work with your child.
- **Understand the program laid out in your child's IFSP or IEP.** Don't be afraid to ask questions until you are sure you understand. Don't sign the IFSP or IEP until you are certain you understand all of it.
- **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.** Each year, keep a notebook in which you write down questions or comments about your child's progress or educational program. Take notes whenever you meet with staff, talk on the phone, or send notes to teachers or other staff. Jot down dates, times, what happened, and the names of the people involved. These notes can be a helpful reminder for you and for your child's educators.
- **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

Early ACCESS

The Early ACCESS system can be a valuable resource for families of children with a hearing loss. Early ACCESS provides early intervention services, which might include special instruction, speech and language therapy, assistive technology, and audiology services. An Early ACCESS service coordinator can help you learn about available resources and to get the services you need. She can also connect you to other families for support.

What is Early ACCESS?

The Individuals with Disabilities Education Act (IDEA), Part C, created Iowa's Early ACCESS system. The purpose of Early ACCESS is to identify, coordinate, and provide needed services and resources to help families assist their infants and toddlers to grow and develop.

Who is in charge of Early ACCESS?

The Department of Education is the lead agency for Early ACCESS in Iowa. It works in partnership with:

- Iowa Child Health Specialty Clinics
- Iowa Department of Human Services
- Iowa Department of Public Health

Who can use Early ACCESS?

Iowa infants or toddlers younger than three years old can use Early ACCESS if they have:

- a 25 percent delay in one or more areas of development OR
- a known condition that is likely to delay development, such as hearing loss

How is eligibility determined?

Evaluation by professionals from a variety of fields will determine whether a child meets the eligibility requirements above.

How does Early ACCESS find kids that need services?

To find children who can benefit from its services, Early ACCESS uses:

- public information and awareness activities
- child development fairs
- screening
- referral for evaluation

What can Early ACCESS do for my child and my family?

Early ACCESS provides family-centered services. This means that families actively participate in creating an individualized family service plan. Your Early ACCESS service coordinator will:

- connect your family to other families for support, if you are interested
- listen to your questions and concerns
- help you identify your family's strengths and needs
- coordinate your child's evaluations
- be a resource as you develop your own individualized family service plan (IFSP; see page 44, Section 5)
- help you find and get the services you need. Services may come from a variety of agencies
- be an advocate for your child and your family



Early ACCESS Services

Early ACCESS services may include the following (the services your child will receive are determined through a team decision):

- assistive technology
- audiology
- family training/ counseling
- health services
- medical evaluation
- nursing
- nutrition
- occupational therapy
- physical therapy
- psychological services
- service coordination
- services from a teacher of children who are deaf or hard of hearing
- social work
- special instruction
- speech language pathology
- transportation
- vision screening
- other services as needed

Where are Early ACCESS services provided?

Early ACCESS tries very hard to provide services in the child's natural environments, such as the home. Services are also provided in day care settings, usually where several children of the same age participate. Very young children usually spend most of their time with either their parents or day care providers. When Early ACCESS staff members provide services in the home or at day care, families and important caregivers learn ways to encourage the child's skills. They can make skill-building activities part of the child's daily routine.

What do Early ACCESS services cost?

Some early intervention services are provided at no cost to your family; for others there may be a charge. Free Early ACCESS services include:

- comprehensive multidisciplinary evaluation
- creation of the IFSP
- ongoing service coordination

For more information about Early ACCESS, call Early ACCESS Iowa at 888-425-4371 and they will connect you to the Early ACCESS office closest to you. You can also visit the website: www.EarlyACCESSIowa.org

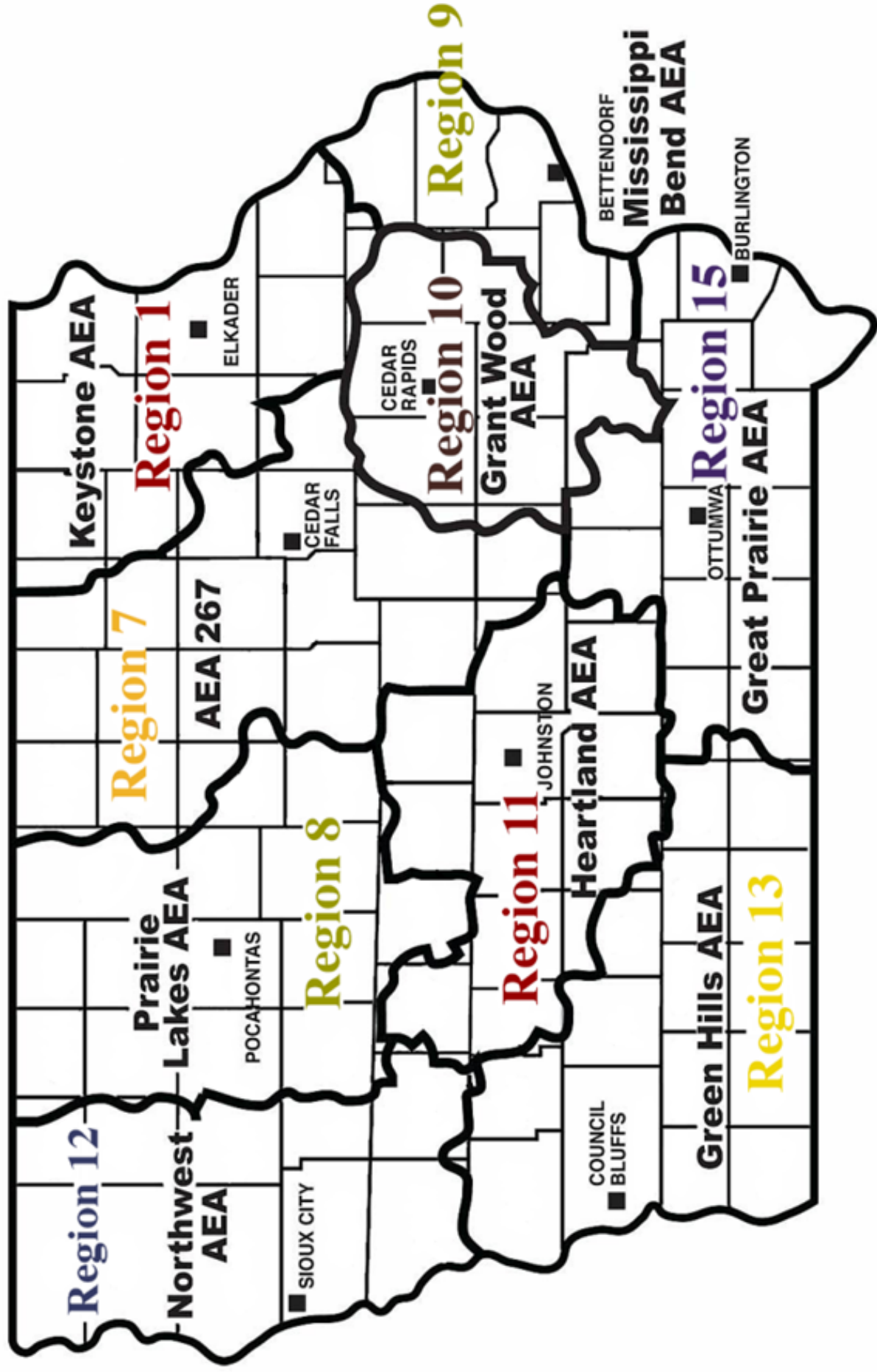


| Early ACCESS Intake Contacts | | |
|---|--|--|
| Region 1: Tiffany Kuhens or Jackie Muller Keystone AEA 1 1400 – 2nd Street NW Elkader, IA 52043 Phone: (563) 245-1480 x 404 Toll Free: (800) 632-5918 Fax: (563) 245-2920 tkuhens@aea1.k12.ia.us jamuller@aea1.k12.ia.us | Region 9: Sara Lehman Mississippi Bend AEA 9 729 21st Street Bettendorf, IA 52722 Phone: (563) 344-6271 Toll Free: (800) 947-2329 x6271 Fax: (563) 344-9951 slehman@aea9.k12.ia.us | Region 12: Lori Groth Northwest AEA 12 1520 Morningside Avenue Sioux City, IA 51106 Phone: (712) 222-6050 Toll Free: (800) 222-6050 Fax: (712) 222-6230 lgroth@nwaea.com |
| Region 7: Gina Greene Early ACCESS Liaison 3712 Cedar Heights Drive Cedar Falls, IA 50613 Phone: (319) 273-8200 Toll Free: (800) 542-8375 Fax: (319) 273-8251 ggreene@aea267.k12.ia.us | Region 10: Erlene Spicer Grant Wood AEA 10 4401 6th St SW Cedar Rapids, IA 52404 Phone: (319) 399-6746 Toll Free: (800) 332-8488 x6746 Fax: (319) 399-6486 espicer@gwaea.org | Region 13: Sheryl Fritz Green Hills AEA Halverson Center for Education 24997 Hwy 92 P.O. Box 1109 Council Bluffs, IA 51503 Phone: (712) 366-0503 x7298 Toll Free: (800) 432-5804 Fax: (712) 366 7772 sfritz@ghaea.org |
| Region 8: Gale Randall or Julie Cook Prairie Lakes AEA 8 824 Flindt Drive, Suite 105 Storm Lake, IA 50588 Phone: (712) 335-3588 x2064 Toll Free: (866) 503-4636 FAX: (712) 732-7654 grandall@aea8.k12.ia.us jcook@aea8.k12.ia.us | Region 11: Amy Hoffman Heartland AEA 11 6500 Corporate Drive Johnston, IA 50131 Phone: (515) 270-9030 Toll Free: (800) 670-4729 Fax: (641) 842-2925 ahoffman@aea11.k12.ia.us | Region 15: Linda Boshart Great Prairie AEA 15 309 East Monroe Mt. Pleasant, IA 52641 Phone: (641) 682-8591 Toll Free: (800) 382-8970 Fax: (319) 385-9006 linda.boshart@gpaea.org |

The following page contains a map of the Early ACCESS Regions in Iowa.



Iowa Area Education Agencies



IOWA AREA EDUCATION AGENCIES (AEAS)

Area Education Agencies (AEAs) provide many early intervention services for children who are deaf and hard-of-hearing. These include services to infants, toddlers, and their families, and to school-age children who require special education services. Both early intervention and special education services are at no cost to families. The Iowa Department of Education licenses service providers to assure that services are provided by highly qualified professionals.

Services

AEAs offer services for babies and children younger than 5-years-old who have an Individualized Family Service Plan (IFSP) or an Individualized Education Program (IEP). They also serve school-age children. Services for infants, toddlers, and preschoolers include:

- assistive technology
- audiology services
- family training, including sign language classes
- family counseling
- health care and related services, including services such as nursing care that enable a child to benefit from other early intervention activities
- occupational therapy
- Parent-Educator Connection/ Parent-Educator Partnership (see page 57)
- physical therapy
- psychological services
- social work services
- speech-language pathology services
- special instruction, including services provided by a teacher of children who are deaf or hard-of-hearing
- transportation and related costs
- vision services
- professional development for early childhood providers



Iowa Area Education Agencies

Keystone AEA

1400 – 2nd Street NW
Elkader, IA 52043
(563) 245-1480
(800) 632-5918
<http://www.aea1.k12.ia.us>

Heartland AEA

6500 Corporate Drive
Johnston, IA 50131
(515) 270-9030
(800) 362-2720
<http://www.aea11.k12.ia.us>

AEA 267

3712 Cedar Heights Drive
Cedar Falls, IA 50613
(319) 273-8200
(800) 542-8375
<http://www.aea267.k12.ia.us>

Northwest AEA

1520 Morningside Avenue
Sioux City, IA 51106
(712) 222-6000
(800) 352-9040
<http://www.nwaea.k12.ia.us>

Prairie Lakes AEA

500 NE 6th Street
Pocahontas, IA 50574
(712) 335-3588
(866) 540-3858
<http://www.aea8.k12.ia.us>

Green Hills AEA

24997 Hw 92
P.O Box 1109
Council Bluffs, IA 51502
(712) 366-0503
(800) 432-5804
<http://www.ghaea.k12.ia.us>

Mississippi Bend AEA

729 – 21st Street
Bettendorf, IA 52722
(563) 359-1371
(800) 947-2329
<http://www.aea9.k12.ia.us>

Great Prairie AEA

2814 North Court Street
Ottumwa, IA 52501
(641) 682-8591
(800) 622-0027
<http://www.gpaea.k12.ia.us/home.aspx>

Grant Wood AEA

4401 – 6th Street SW
Cedar Rapids, IA 52404-4499
(319) 399-6700
(800) 332-8488
<http://www.aea10.k12.ia.us>



PARENT-EDUCATOR CONNECTION (PEC)/ PARENT-EDUCATOR PARTNERSHIP (PEP)

The Parent-Educator Connection (PEC) is a program that creates partnerships between parents and educators. Each Area Education Agency (AEA) has parents and educators on staff that oversee its PEC activities (in some AEAs, PEC is called the Parent-Educator Partnership or PEP). PEC is sponsored by the Iowa Department of Education, Bureau of Children, Family and Community Services. Since their beginnings in 1984, PECs at AEAs across the state have often been able to provide better planning and programming for children with disabilities.

PEC Services

Services include family training and counseling. Depending on the AEA, other resources may include newsletters, libraries, pamphlets, videos, and audiotapes on special education, specific disabilities, parenting, and other issues. PEC staff also help parents and educators find answers to questions and locate resources.

Location of services

PEC services are provided in locations that meet the needs of families, children, educators, and others who work with children with special needs. This may be in the home, the school, the office, or elsewhere.

Eligibility

Families with children who have a disability and are younger than 21-years-old can use these services. They are also available to educators and others who work with people with disabilities.

Cost

Services are free.

For more information

Contact the parent or educator coordinator from your Area Education Agency. See the list of Area Education Agencies on page 47, or contact:

Parent-Educator Connection
Bureau of Children, Family and Community Services
Grimes State Office Building
Des Moines, Iowa 50319-0146
Phone: (515) 242-5295

PARENT TRAINING AND INFORMATION CENTER (PTI) OF IOWA

Parent Training and Information Center is a federally funded grant project of the United States Department of Education.

Specific services that are provided include:

- family support information
- information about a child's disability
- information and training on Individuals with Disabilities Education Act (IDEA) of 2004
- teaching skills to effectively participate in the Individual Education Program (IEP) process
- teaching skills to participate in school reform activities

Services are provided through parent-to-parent contact, by phone, follow-up correspondence, and e-mail. Training workshops can be organized in local community settings as well.

All children ages birth through 21 years, and their families are eligible for this service. There is no cost for information and training provided to families. Shared costs may be requested for services to professionals and others.



For more information or application contact:

Parent Training and Information Center of Iowa

321 East 6th Street
Des Moines, IA 50039
Phone: (800) 450-8667 or (515) 243-1713
Fax: (515) 243-1902
E-mail: PTIIowa@aol.com
www.askresource.org/pti.html

DEAF SERVICES COMMISSION OF IOWA (DSCI)

Deaf Services Commission of Iowa (DSCI) is located within the Iowa Department of Human Rights and was established to serve, represent and promote a greater understanding of deaf and hard-of-hearing individuals, from infancy through adulthood in the state of Iowa.

DSCI is committed to the following objectives:

- providing and coordinating interpreting services
- creating opportunities for deaf and hard-of-hearing persons to assume leadership
- offering assistance and consultation on the needs and rights of deaf and hard-of-hearing persons
- encouraging citizen awareness, participation, and involvement in the development of programs and services in public and private organizations to better serve the deaf and hard-of-hearing communities
- providing specialized programs to meet the unique needs of the deaf and hard-of-hearing communities

Services and programs offered through the DSCI include:

- sign language interpreting provided by the staff of certified interpreters
- interpreter referral services to meet requests through interpreters in private practice who are registered with the agency
- oral interpreting services for people who rely on speech reading assistance and consultation services on an individual and systems basis information and referral including a lending library, presentations and general information on the local, state, and national level
- technical assistance in compliance with accessibility laws and providing other appropriate accommodations
- Junior Commissioner Program Youth Leadership Conference to encourage the development of our future deaf and hard-of-hearing community members

For more information contact:

Deaf Services Commission of Iowa

Lucas State Office Building, 2nd Floor
Des Moines, IA 50319
(515) 281-3164 (voice and TTY)
Toll-free: (888) 221-3724 (V/TTY)
Email: dhc.dsci@iowa.gov
www.deafservices.iowa.gov/index.html



CHILD HEALTH SPECIALTY CLINICS (CHSC)

Sometimes children who are deaf or hard-of-hearing have additional medical concerns. For families where this is the case, Child Health Specialty Clinics (CHSC) may be able to help.

Our Mission

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.

CHSC Locations

CHSC has 13 regional centers located throughout the state. A list of contact information for the regional centers is included on the following page.

Eligibility

Children and youth ages birth through 21 who live in Iowa and have a chronic condition (physical, developmental, behavioral, or emotional) or who have increased risk for a chronic condition.

What do we provide?

CHSC's Birth to Five Services are of particular interest to families with infants and toddlers who have been newly identified with hearing loss.

CHSC's Birth to Five Services are provided to children birth to five years of age who are at risk for or known to have special needs. Services are provided by a nurse practitioner that has special training in assessing the growth and development of children. Birth to Five Services may include:

- Assessment, evaluation and consultation regarding your child's physical and neurological status, development and growth. These occur at regular intervals based on your child's needs and include a developmental assessment and physical examination. Assessments show how your child is progressing in gross motor, fine motor, language, and social activities.
- Recommendations for parent support, parent education, and care for your children and family. If a delay in development is detected, a referral for services to help your child will be initiated. Information on growth and development as well as ways to stimulate your child is available.
- Evaluation of your child's nutrition and feeding concerns.
- Coordination of your child's care. We can assist you in identifying community resources and coordinating special care for your child, if needed.

Your local physician/health care provider will continue to provide your child's primary health care, including well-baby checkups and immunizations. Reports about your child's assessments are sent to your physician/health care provider and assistance with identified needs is available.

What if my child is older than 5?

We provide a variety of other clinics and each regional center has information about specific clinics in their area.

Costs

When a child is seen at one of our clinics, fees may be adjusted by using a sliding scale that takes into account the family size and income. We don't charge for helping the family organize the services that a child needs or for providing family support.

For more information

Contact the CHSC regional center nearest your home. CHSC's toll-free number is 866-219-9119. TTY services are available through Relay Iowa (711). Our website is www.chsciowa.org.



Child Health Specialty Clinics (CHSC) REGIONAL CENTERS

Bettendorf

865 Lincoln Road, Suite 500
Bettendorf, IA 52722
Phone: (563) 421-3030
Toll Free: 1-866-664-3030
Fax: (563) 421-3039

Carroll

726 North Carroll, Suite 1
Carroll, IA 51401-2367
Phone: (712) 792-5530
Fax: (712) 792-4825

Clinton

1663 Lincoln Way, Suite E
Clinton, IA 52732-7018
Phone: (563) 243-0292
Toll Free: 1-877-243-0292
Fax: (563) 243-0295

Council Bluffs

Omni Center
300 West Broadway, Suite 106
Council Bluffs, IA 51503-9029
Phone: (712) 309-0041
Toll Free: 1-866-652-0041
Fax: (712) 309-0044

Creston

904 East Taylor, Suite B
Creston, IA 50801-4005
Phone: (641) 782-9500
Toll Free: 1-877-292-9500
Fax: (641) 782-9519

Decorah

308 College Drive, Suite 1
Decorah, IA 52101-1342
Phone: (563) 382-1277
Toll Free: 1-877-571-9797
Fax: (563) 382-1287

Dubuque

Nester Center, Suite 320
799 Main Street
Dubuque, IA 52001-6825
Phone: (563) 556-3700
Toll Free: 1-888-588-0903
Fax: (563) 556-3702

Fort Dodge

Physicians Office Building West
804 Kenyon Road, Suite L
Fort Dodge, IA 50501-4901
Phone: (515) 955-8326
Fax: (515) 574-5544

Mason City

22 N Georgia, Suite 310
Mason City, IA 50401-3927
Phone: (641) 424-0030
Toll Free: 1-855-522-6973
Fax: (641) 424-0080

Oelwein

212 8th Avenue SE
Oelwein, IA 50662-2448
Phone: (319) 283-4135
Toll Free: 1-866-279-5023
Fax: (319) 283-4140

Ottumwa

123 E. Third St, Suite 2
Ottumwa, IA 52501
Phone: (641) 682-8145
Fax: (641) 682-8857

Sioux City

1014 Nebraska St
Sioux City, IA 51105
Phone: (712) 224-5437
Fax: (712) 224-5444

Spencer

1200 First Avenue East
Spencer, IA 51301-4330
Phone: (712) 264-6362
Toll Free: 1-877-270-9386
Fax: (712) 262-1526

IOWA CITY STAFF

Child Health Specialty Clinics

100 Hawkins Drive, Room 247 CDD
Iowa City, Iowa 52242-1011
Voice: (319) 356-1117
TTY: (866) 236-1423
Toll Free: 1-866-219-9119
Fax: (319) 356-3715

Early ACCESS

Rae Miller
Program Coordinator
(712) 792-4500
rae-miller@uiowa.edu

EHDI Program

Tammy O'Hollearn
State EHDI Coordinator
(515) 242-5639
Toll Free: 1-800-383-3826
tammy.ohollearn@idph.iowa.gov

Executive Director

Barbara Khal
barbara-khal@uiowa.edu

HEALTH AND DISEASE MANAGEMENT

Health and Disability Waiver

Kathy Bowers, BSN, MA
Coordinator, HD Waiver
(319) 356-1035
kathleen-bowers@uiowa.edu

Regional Autism Assistance Program

Toll Free: 1-866-219-9119, ext 2
iowa-RAP@uiowa.edu

Continuity of Care Program

Janine Petitgout, MA, ARNP
(319) 384-5928

**Early and Periodic Screening,
Diagnosis and Treatment (EPSDT)**

Kathy Bowers, BSN, MA
(319) 356-1035



GUIDE BY YOUR SIDE

What is the Iowa Guide By Your Side™ (GBYS) program?

The Iowa Hands & Voices GBYS program provides emotional support and unbiased information to families of infants and toddlers with a hearing loss. Iowa Hands & Voices and the Iowa Early Hearing Detection and Intervention (EHDI) program work together to provide the GBYS program.

Who is eligible for the program?

Families of Iowa infants and toddlers (ages birth to 3) who have a hearing loss.

What can the Iowa GBYS program do for my family?

Trained GBYS Parent Guides give direct parent-to-parent support and GBYS Deaf or Hard of Hearing Guides provide the opportunity to meet adults who are deaf or hard-of-hearing.

GBYS Guides provide emotional support, unbiased information, and referrals to other services and resources as you decide what is best for your child and family.

Who are the Parent Guides?

They are fully trained parents of children who are Deaf or hard-of-hearing. They bring the experience, knowledge and compassion that come from raising a child who is deaf or hard of hearing. They have been where you are and are willing to listen and share their experience. They can provide support and guidance through the early childhood years.

Who are the Deaf/Hard of Hearing (DHH) Guides?

They are fully trained adults who are Deaf or hard-of-hearing. They can share their personal experiences with you and answer your questions about living with hearing loss. They can also connect your family to the Deaf and hard-of-hearing communities.

How much does the GBYS program cost?

The GBYS program is free to families.

How do I request a GBYS Guide?

Call the GBYS EHDI program at (800) 383-3826, email gbys@iowahandsandvoices.org, or complete and fax a referral form, which can be found online at www.idph.state.ia.us/iaehdi.



IOWA'S DEAFBLIND SERVICES PROJECT

Deafblindness is a combination of hearing and vision loss that affects an individual's overall development and interaction with his environment. It affects communication, development, and learning. Deafblindness may not involve a total inability to see or hear. Rather, it is a condition in which there is a combination of visual and hearing impairments. Many deafblind children have enough vision to be able to move about in their environments, recognize familiar people, see sign language at close distances, and maybe read large print. They may have sufficient hearing to recognize familiar sounds, understand some speech, and develop speech themselves. Some children with deafblindness have multiple disabilities in addition to hearing and vision loss. The range of sensory impairments included in the term "deafblindness" is great. Some people are deafblind from birth. Others may lose some or all of these senses as a result of accident or illness.

The Iowa's Deafblind Services Project is funded by federal and state dollars. It is part of the Department of Education. This project has five major goals:

- identify and track infants, toddlers, children, and youth birth to age 21 who have deafblindness, in order to maintain an Iowa Deafblind Census
- provide technical assistance to increase the knowledge and skill levels of parents, educators, administrators, and community service providers in the area of deafblindness
- provide a parent/family network to ensure that families who have children with deafblindness receive support and information, as well as opportunities to link with other families and professionals provide planning and training in the development of transition plans for children and youth with deafblindness
- provide information about the project and about effective practices to parents, programs, and agencies throughout Iowa

Services

Technical assistance, in the form of in-home, school based or community consultation services, is available to families and educational teams. The project provides assistance with observation, assessment, and evaluation in order to help families create an integrated home and school program.

Who can use these services?

Services are available to:

- individuals younger than 21 years old who are deafblind
- their parents and family members
- people providing education and support services

Cost

There is no cost for these services.

For more information contact:

Susan Brennan
Iowa Deafblind Services Project Coordinator
Iowa Braille School
1002 G Ave.
Vinton, IA 52349
sbrennan@iowa-braille.k12.ia.us
www.iadeafblind.k12.ia.us



IOWA SCHOOL FOR THE DEAF

The Iowa School for the Deaf (ISD), a residential and day program for students who are deaf or hard-of-hearing, is located in Council Bluffs. ISD was established in 1855. ISD began also serving youth from Nebraska in 1999. It provides educational programs and additional services as determined by either an individualized family service plan (IFSP) or an individualized education program (IEP).

Services

Services provided by ISD include:

- assistive technology
- audiology
- family training and counseling
- health services
- occupational therapy
- physical therapy
- psychological services
- social work services
- speech-language
- pathology
- special instruction
- vision services
- sign language development
- auditory training
- parental assistance (printed materials, videotapes, direct services)

Cost

There is no cost to families.

Eligibility

All children must be referred to ISD by an IEP staffing team including parents and representatives from the local school district, ISD, the Area Education Agency (AEA), and others.

For more information contact your local school or AEA Hearing Services (see AEA listing, page 44), or visit the web site for Iowa School for the Deaf, at www.iadeaf.k12.ia.us. You can reach ISD at:

Iowa School for the Deaf
3501 Harry Langdon Boulevard
Council Bluffs, IA 51503-7898
(712) 366-0571 (Voice and TTY)



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)

“I am learning to be an advocate for my daughter”***The Burow Family***

Getting the results that our little Katarina had profound hearing loss in one ear and moderate to severe loss in the other was devastating to me. I felt very helpless. I never had to deal with hearing loss.

I didn't know where to turn or the first steps to take.

The hardest thing for me, is dealing with the medical system.

First, we had to have Kat tested and retested and retested. Then the hearing aid option that we felt was best for her was denied through her insurance. Fortunately, I have a great support system.

I used my resources: my cousin who has a child with hearing loss, Guide by Your Side and the EarlyACCESS Program. Now we are waiting to hear from insurance again. It is taking a long time, but I feel that the hearing aid we picked is the best option for Kat. I don't want to give up just because it is difficult. My advice would be to use every resource available to get what you need for your child. We are going to start learning sign language through EarlyACCESS. When the time comes, we will have speech therapy available also. I am learning to be an advocate for my daughter. As parents of a differently-abled child, I have to be the one to speak up and ask questions. I also know what is best for her, and I cannot lose sight of that fact.

Sincerely,
Danell Burow, (Battle Creek, IA)

Section 7

State and National Resources



SECTION 7: STATE AND NATIONAL RESOURCES

IOWA RESOURCES FOR CHILDREN WITH HEARING LOSS AND THEIR CHILDREN

AUDIOLOGY CENTERS IN IOWA AND BORDERING STATES

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.

IOWA

Council Bluffs

Ear, Nose, Throat Clinic
Kathryn Beauchaine, MA, CCC-A
320 McKenzie Avenue, Suite 202
Council Bluffs, IA 51503
Phone: (712) 256-5272
Fax: (712) 256-5271

Des Moines

Iowa Ear Center
Diana Hanson, MS, CCC-A
12499 University Ave, #200
Clive, IA 50325
(515) 418-9960

Iowa Methodist Medical Center
1200 Pleasant Street
Des Moines, IA 50309-1406
Phone: (515) 241-8265
Fax: (515) 241-3407

Dubuque

Dubuque Otolaryngology
Rosemary Bauchiero, MA, CCC-A
310 North Grandview Avenue, #A
Dubuque, IA 52001-6387
Phone: (563) 588-0506
Fax: (563) 588-0451

IOWA *continued*

Iowa City

Center for Disabilities and Development
University of Iowa Children's Hospital
Lenore Holte, PhD, CCC-A
100 Hawkins Drive, Room 128
Iowa City, IA 52242-1011
Phone: (319) 356-1168
Toll Free: (877) 686-0031
Fax: (319) 356-8284

University of Iowa Health Care
Dept. of Otolaryngology
Megan Asklof, MA, CCC-A
200 Hawkins Drive, PFP
Iowa City, IA 52242-1009
Phone: (319) 356-2201
Fax: (319) 353-6739

Mason City

Hearing Associates
Tanya Harper-Rowe, MA, CCC-A
250 S. Crescent Drive
Mason City, IA 50401-2926
Phone: (641) 422-6424
Fax: (641) 421-2556

Oelwein

Child Health Specialty Clinics
Regional Center
Brenda Carradus, RN
212 8th Avenue SE
Oelwein, IA 50662
Phone: (319) 283-4135
Fax: (319) 283-4140

ABRs are available via telehealth

NEIGHBORING STATES

Minnesota
Mayo Clinic
L-5 Audiology
Joselyn Martin
200 – 1st Street SW
Rochester, MN 55905-0002
Phone: (507) 284-2577

Nebraska

Boys Town National Research Hospital
Audiology Department
Ryan McCreery
555 N. 30th Street
Omaha, NE 68131-2136
Phone: (402) 498-6511
Fax: (402) 452-5015

South Dakota

Audiology Department
Avera McKennan Hospital
Teresa Linde-Fendrich, MS, CCC-A
800 E. 21st Street
Sioux Falls, SD 57105-1016
Phone: (605) 322-5028

Wisconsin

Gunderson Clinic
Milton Schmeida, MA, CCC-A
1836 South Avenue
La Crosse, WI 54601-5429
Phone: (800) 362-9567 x 52201

Mayo Clinic Health System
Franciscan Healthcare
Otolaryngology, Audiology
700 West Ave S
La Crosse, WI 54603



EARLY HEARING DETECTION AND INTERVENTION (EHDI) PROGRAM

The Iowa Department of Public Health (IDPH), Child Health Specialty Clinics (CHSC) and other partners work together to ensure that all babies in Iowa have their hearing screened and receive any needed follow-up services. IDPH receives funding from the Centers for Disease Control and Prevention to develop and implement a statewide EHDI surveillance system. The surveillance system is an electronic reporting system used to report the results of hearing screenings, rescreens and diagnostic evaluations for children less than three years of age. The data collected allows IDPH to monitor state and local performance and to track the progress of children who need follow-up services.

CHSC receives funding from the Health Resources and Services Administration to work on reducing the number of children who fall through the cracks before getting the hearing services they need. The grant team provides technical assistance to hearing screening providers, educates families and professionals, and links families to early intervention, family-to-family support and medical homes.

If you have questions about the Iowa EHDI project or where you can find hearing-related services for your child, please contact:

Tammy O'Hollearn, LBSW

State EHDI Coordinator

Iowa Department of Public Health

(515) 242-5639

Toll Free: 1-800-383-3826

tammy.ohollearn@idph.iowa.gov



IOWA HANDS AND VOICES



Mission Statement

Iowa Hands & Voices supports all families with children who are deaf/hard-of-hearing regardless of communication choice. We embrace parent/professional collaboration to enable deaf/hard-of-hearing children to reach their potential.

Who We Are...

Hands & Voices is a non-profit, parent-driven national organization dedicated to supporting families of children who are deaf or hard-of-hearing. We are highly collaborative with professionals who are represented on our advisory board and make up approximately one third of our membership. The Iowa Hands and Voices is a program that provides non-biased information about communication methodologies and believe that families can make the best choices for their child if they have access to good information and support. (See Guide By Your Side program for additional information in Section 6.)

Why We're Here...

Most organizations for or of the deaf rally around common interests that usually include a philosophy of communication that is promoted by that group. Hands & Voices does not promote specific communication choices or methodologies. Instead we embrace the need to improve educational outcomes for our kids, and to enhance their quality of life. Our rallying points are areas of interest that are common to all people connected by the interests of the deaf or hard-of-hearing, especially parents, and include these values...

- We all want the best for our deaf or hard-of-hearing kids.
- We deserve respect and honor for our role as parents/families. We require a beneficial, successful educational experience for our kids.
- We need information from a wide variety of sources.
- We want to know about opportunities and resources.
- We need training and support to become effective advocates for our kids.
- We are stronger when united by our common interests than divided by differing communication choices.

Iowa Hands & Voices
P.O. Box 65071
West Des Moines, IA 50265

Email: info@iowahandsandvoices.org
 Websites: www.iowahandsandvoices.org (Iowa)
www.handsandvoices.org (Headquarters)

Iowa Hands & Voices is a non-profit 501(c)3 organization



OTHER IOWA RESOURCES

Child Health Specialty Clinics

100 Hawkins Drive, Room 247 CDD
Iowa City, IA 52242
Voice: (319) 356-1117
Toll Free: (866) 219-9119
Toll Free/TTY: (866) 236-1423
www.uihealthcare.com/depts/state/chsc

Iowa Department for the Blind - Des Moines

524 – 4th Street
Des Moines, IA 50309
Local: (515) 281-1333
Toll Free in Iowa: (800) 362-2587
TTY: (515) 281-1355
www.blind.state.ia.us

Iowa Department of Education Bureau of Early Childhood Services

MaLinda Hugh-Reynolds
Grimes State Office Building
Des Moines, IA 50319
Voice: (515) 281-3021
malindahugh-reynolds@iowa.gov
www.earlyaccessiowa.org

Iowa Department of Human Rights Deaf Services Commission of Iowa

Lucas State Office Building, 2nd Floor
Des Moines, IA 50319
Voice/TTY: 515-281-3164
Toll Free: (888) 221-3724
Kathryn.Baumann-Reese@iowa.gov
www.state.ia.us/government/dhr

Iowa Department of Public Health

Lucas State Office Building
321 East 12th Street
Des Moines, IA 50319
Voice: 515-242-5639
tohollea@idph.state.ia.us
www.idph.state.ia.us
Iowa Association of the Deaf
www.iowadeaf.org

Iowa's Early ACCESS System

Iowa Department of Education
Grimes State Office Building
Des Moines, IA 50319
Phone: (515) 281-3021
Voice: (800) 779-2001
Toll Free: (877) 686-0032
www.earlyaccessiowa.org

Iowa's Deafblind Services Project

Iowa Braille School
Vinton, Iowa 52349
Phone: (319) 472-5221 ext# 1002
jpease@iowa-braille.k12.ia.us
www.ladeafblind.k12.ia.us

Iowa School for the Deaf

3501 Harry Langdon Blvd
Council Bluffs, IA 51503
Voice/TTY: (712) 366-0571
www.iowaschoolforthe deaf.org

Relay Iowa

Sprint Relay
400 Locust Street
Des Moines, IA 50309
Dial 711, or call:
Voice: (800) 735-2943
TTY/ascii: (800) 735-2942 (toll free)
www.relayiowa.com

University of Iowa Hospitals and Clinics Center for Disabilities and Development

100 Hawkins Drive
Iowa City, IA 52242
Voice/local: (319) 353-6900
Voice/toll free: (877) 686-0031
TTY/toll free: (877) 686-0032
www.healthcare.uiowa.edu/cdd

Disability Resource Library

Center for Disabilities and Development
100 Hawkins Drive
Iowa City, IA 52242
Voice/local: (319) 356-1345
Voice/toll free: (800) 272-7713
TTY/toll free: (877) 686-0032
www.healthcare.uiowa.edu/cdd



NATIONAL RESOURCES

Alexander Graham Bell Association for the Deaf and Hard of Hearing

(AG Bell)
3417 Volta Place NW
Washington, DC 20007
Voice: (202) 337-5220
TTY: (202) 337-5221
www.agbell.org

A nonprofit, membership-based information center on hearing loss. Focuses specifically on children with hearing loss, providing ongoing support and advocacy for parents, professionals, and other interested parties. Information available to parents includes publications, funding sources, pamphlets, conferences, and scholarship program information. Alternatives in Education for the Hearing Impaired (AEHI)

Alternatives in Education for the Hearing Impaired (AEHI)

2020 E. Camp McDonald Road
Mount Prospect, IL 60056
Voice/TTY: (847) 297-3206
www.aehi.org

A nonprofit organization that provides information on cued speech. Provides resources and information regarding unique educational options for the hearing impaired.

American Academy of Audiology (AAA)

11730 Plaza America Drive, Suite 300
Reston, VA 20190
Voice: (703) 790-8466
TTY: (703) 790-8466
Toll Free: (800) AAA-2336 (800-222-2336)
www.audiology.org

A professional membership organization dedicated to providing high quality hearing care to the public. Provides consumer information and locates certified audiologists in a specified area. Web site contains "Ask the Audiologist," which adds to parental and public understanding of audiology.

American Academy of Pediatrics

www.aap.org

A wide variety of resources on children's health.

American Society for Deaf Children (ASDC)

3820 Hartzdale Drive
Camp Hill, PA 17011
Voice: (717) 703-0073
Voice/TTY: (866) 895-4206
Toll Free: (800) 942-ASDC (800-942-2732)
www.deafchildren.org

A nonprofit organization that educates, empowers, and supports parents and families of children who are deaf or hard-of-hearing. Helps families find meaningful communication options, particularly through the use of sign language, in their home, school, and community. A parent listserv and magazine are also available.

American Speech-Language-Hearing Association (ASHA)

10801 Rockville Pike
Rockville, MD 20852
Toll Free: (800) 638-8255
TTY: (301) 897-5700
www.asha.org

The national professional, scientific, and credentialing association for more than 93,000 audiologists, speech-language pathologists, and speech, language, and hearing scientists. Provides brochures, fact sheets, and information packets to the general public at no cost. A computerized referral database of audiology and speech-language pathology programs is available to meet individual consumer needs.



Auditory-Verbal International Inc.

1390 Chain Bridge Road, #100
McLean, VA 22101
Voice: (703) 739-1049
TTY: (703) 739-0874

A nonprofit, international organization serving children with hearing loss, their families, and the professional community. Provides information about the choice of listening and speaking strategies for children who are deaf or hard-of-hearing through education, advocacy, and family support. Also provides quarterly newsletter, membership directory, and educational scholarship opportunities for professional members.

Beginnings for Parents of Children Who are Deaf or Hard of Hearing, Inc.

(Beginnings)
PO Box 17646
Raleigh, NC 27619
Voice/TTY: (919) 850-2746
www.beginningssvcs.com

A nonprofit organization that provides unbiased support and information related to hearing loss to parents and professionals. Also provides information on communication options, placement, and educational programs; workshops for professional personnel who work with children who are deaf or hard-of-hearing, advocacy and support for young people.

Better Hearing Institute

515 King Street
Alexandria, VA 22314
Voice/TDD: (800) EAR-WELL (800-327-9355)
www.betterhearing.org

Non-profit organization. Provides information concerning hearing loss, hearing aids, and where to go for help.

Boys Town National Research Hospital

555 N. 30th Street
Omaha, NE 68131
Voice: (402) 498-6511
www.babyhearing.org
www.boystownhospital.org

A nonprofit hospital that is internationally recognized for research and treatment of childhood deafness and communication disorders. Programs include the Center for Audiology and Vestibular Services; the Center for Childhood Deafness, Language, and Learning; and the Center for Medical/ Surgical Services. Produces videotapes designed to help families learn to sign and to read more effectively with young children who are deaf.

Callier Center for Communication Disorders

University of Texas at Dallas
1966 Inwood Road
Dallas, TX 75235
Voice: (214) 905-3000
TTY: (972) 883-3605
www.callier.utdallas.edu

A nonprofit educational, clinical, and research center for individuals with communication disorders of all types. Clinical services specific to hearing loss include complete audiological testing, amplification services, aural rehabilitation classes, and cochlear implant evaluation and habilitation. Summer Listening camp offered one week each summer. Educational programs include specialized services for children with hearing loss, ages 2-5, within an early childhood preschool.



Described and Captioned Media Program (DCMP)

National Association of the Deaf

1447 E. Main Street

Spartanburg, SC 29307

Toll Free: (800) 237-6213

TTY: (800) 237-6819

info@dcmp.org

www.dcmp.org

A nonprofit program with a free-loan video collection of approximately 4,000 titles. Provides opencaptioned videos, available free of charge to any American with a hearing loss, or to any hearing person involved with hearing loss, such as parents and teachers. Funded by the U.S. Department of Education.

Central Institute for the Deaf (CID)

4560 Clayton Avenue

St. Louis, MO 63110

Voice: (314) 977-0132

TTY: (314) 977-0037

Toll Free: (877) 444-4574

www.cid.edu

CID is a private, nonprofit institute. It has research laboratories in which scientists study the normal aspects as well as disorders in hearing, language, and speech. It has a school for children who have hearing loss and professional education programs in audiology, education of persons with hearing loss, and communication sciences. CID also has speech, language, and hearing clinics.

Cochlear Implant Association, Inc. (CIAI)

5335 Wisconsin Avenue NW, Suite 440

Washington, DC 20015

Voice: (202) 895-2781

ciaiinfo@cici.org

www.cici.org

A nonprofit organization that distributes educational materials, organizes national and international meetings and conventions, promotes cochlear implant technology and deafness research, and advocates on all governmental levels for the rights and services of people who have hearing loss. Provides information and support to cochlear implant users, health professionals, and the general public.

Deafness Research Foundation

2801 M Street NW

Washington, DC 20007

Voice: (202) 719-8088

Toll Free: (866) 454-3924

TTY: (888) 435-6104

www.drf.org

A privately funded research foundation committed to finding the causes, treatment, and prevention of all types of hearing loss. Organizes a national campaign aimed at public outreach, professional education, and government relations. Provides parents with a web site detailing current research findings.

EAR Foundation (EF)

PO Box 330867

Nashville, TN 37203

Voice/TTY: (615) 627-2724

Toll Free: (800) 545-4327

A nonprofit organization aimed at integrating people with hearing loss into the mainstream of society through public awareness and medical education. Provides an educational pamphlet targeted for children from kindergarten through 3rd grade. Also administers the Meniere's Network, a national network of patient support groups.



Gallaudet University Regional Center

Johnson County Community College
12345 College Blvd
PO Box 10
Overland Park, KS 66210
Voice/TTY: (913) 469-3872
gurc.gallaudet.edu

Hear Now

The Starkey Hearing Foundation
6700 Washington Avenue South
Eden Prairie, MN 55344
Toll Free: (800) 769-2799
www.sotheworldmayhear.org

Holley Ear Institute

St. John Hospital and Medical Center
22151 Moross Road
Professional Building 1
Suite 223
Detroit, MI 48026
Voice: (313) 343-3165
TTY: (313) 343-8789
www.stjohnprovidence.org/holley

House Ear Institute (HEI)

2100 W. Third Street
Los Angeles, CA 90057
Voice: (213) 483-4431
TTY: (213) 484-2642
Toll Free: (800) 388-8612
webmaster@hei.org
www.hei.org

Artz Center for Developmental Health & Audiology

1675 SW Marlow Avenue, Suite 200
Portland, OR 97225
Voice/TTY: (503) 228-6479
Toll Free: (877) 702-2828
www.artzcenter.com

John Tracy Clinic

806 W. Adams Blvd
Los Angeles, CA 90007
Voice: (213) 748-5481
TTY: (213) 747-2924
Toll Free: (800) 522-4582
www.jtc.org

Affiliated with Gallaudet University, this Community College provides services to students who are deaf and hard-of-hearing, as well as to parents, educators, and educational interpreters in eleven Midwestern states including Texas. Services provided include workshops and seminars in a variety of areas related to improving the quality of education for students with hearing loss, family and parent education programs, needs assessment, technical assistance, and resource and referral.

A nonprofit domestic program of the Starkey Foundation that increases public awareness about the need for available and affordable assistive technology for people with hearing loss. Provides hearing aids to people with limited financial resources.

A nonprofit organization of volunteers, doctors, speech-language pathologists, audiologists, and other professionals. Provides services aimed at improving the quality of life and programs for deaf families, hearing families with children who are deaf, parents who are deaf with hearing children, and seniors who are deaf.

A privately funded, nonprofit research and professional education facility that investigates the causes of hearing loss and vestibular disorders. Provides outreach programs such as family camps and seminars. Web site provides educational information related to hearing health. Infant Hearing Resource, Hearing and Speech Institute

A nonprofit organization that publishes Parent-Infant Communication Curriculum materials including videotapes specifically for parents. Provides pediatric hearing assessment and hearing aid selection, fitting and monitoring. Also provides signed English classes, family support groups, and family-centered auditory language and speech habilitation for children birth through 4 years with hearing loss, including those with cochlear implants.

A private, nonprofit organization that provides free worldwide family-centered services to young children with hearing loss. Provides correspondence courses and videotapes for parents of infants and children with hearing loss. Courses are available in English and Spanish.



Joint Committee on Infant Hearing

10801 Rockville Pike
 Rockville, MD 20852
 Toll Free: (800) 638-8255
www.jcih.org

Marion Downs National Center for Infant Hearing

University of Colorado at Boulder
 Department of Speech, Language and Hearing
 Science
 Campus Box 409
 Boulder, CO 80309
www.mariondowns.com

National Association of the Deaf (NAD)

8630 Fenton Street, Suite 820
 Silver Spring, MD 20910
 Voice: (301) 587-1788
 TTY: (301) 587-1789
www.nad.org

National Cued Speech Association

23970 Hermitage Road
 Cleveland, OH 44122
 Voice/TTY: (800) 459-3529
www.cuedspeech.org

National Deaf Education Network and Clearinghouse Info to Go

Gallaudet University
 800 Florida Avenue NE
 Washington, DC 20002
 Voice: 202-651-5051
 TTY: 202-651-5052
www.gallaudet.edu/clerc-center.html

National Institute on Deafness and Other Communication Disorders (NIDCD)

Office of Health Communication and Public Liaison
 31 Center Drive, MSC 2320
 Bethesda, MD 20892
 Voice: (301) 496-7243
 Voice/Toll Free: (800) 241-1044
 TTY: (301) 402-0252
 Toll Free/TTY: (800) 241-1055
www.nidcd.nih.gov

Members of numerous professional organizations joined to create this committee. They produced a position statement in 2007 that is widely used to determine best practice in pediatric audiology.

A university affiliated center that coordinates statewide systems for screening, diagnosis, and intervention for newborns and infants with hearing loss. The center also provides information on parent participation in system building as well as a list of references that deal with early intervention on its web site.

A nonprofit consumer organization safeguarding the civil rights of persons who are deaf and hard-of-hearing in education, employment, health care, and telecommunications. Provides grassroots advocacy and empowerment, deafness-related information and publications, legal assistance, policy development, public awareness, and youth leadership development.

A nonprofit association that promotes and supports the use of cued speech for communication, language acquisition, and literacy. Provides information, referral, and support services for persons with language, hearing, speech, and learning needs. Sponsors family camps, workshops, conferences and scholarships. Distributes a catalog, newsletter, and journal on cued speech and hearing loss.

A federally funded organization that responds to inquiries about a diverse range of topics related to people age birth through 21 years who are deaf or hard-of-hearing. The clearinghouse also collaborates with authors from within the Gallaudet community and around the nation to design, produce and disseminate books, videotapes, periodicals, and other information related to deaf and hard-of-hearing children, their families, and the professionals who serve them.

A nonprofit organization affiliated with the National Institutes of Health. Conducts research and research training on normal and disordered processes of hearing, balance, smell, taste, voice, speech, and language. Provides a newsletter and other materials that educate the public and health professionals about its seven research areas in communication. Web site contains sections for parents that cover topics related to hearing loss.



Oberkotter Foundation

PO Box 50215
 Palo Alto, CA 94303
 Voice/Toll Free: (877) ORALDEAF
 TTY: (877) 672-5889
www.oberkotterfoundation.org

Hearing Loss Association of America

7910 Woodmont Avenue, Suite 1200
 Bethesda, MD 20814
 Voice/TTY: (301) 657-2248
www.shhh.org

SKI-HI Institute

Communicative Disorders and Deaf Education
 Utah State University
 6500 Old Main Hill
 Logan, UT 84322
 Voice: (435) 797-5600
 TTY: (435) 797-5584
www.skihi.org

TDI (formerly Telecommunications for the Deaf, Inc.)

8630 Fenton Street, Suite 604
 Silver Spring, MD 20910
 Voice: (301) 589-3786
 TTY: (301) 589-3006
<http://tdiforaccess.org>

ASL ONLINE RESOURCES:**Lifepoint Institute ASL University**

<http://www.lifepoint.com/>

HandSpeak.com Online Sign Language Dictionary

<http://www.handspeak.com/>

A private family foundation that advocates oral deaf education. The foundation distributes a variety of free educational materials (videos and pamphlets) for parents and professionals.

A nonprofit educational, volunteer, and international organization composed of people who are hard-of-hearing and their relatives and friends. Offers education, support, and advocacy for persons who are deaf or hard-of-hearing, their families, and friends. Within each state, local chapters provide expertise on the rights of people who are deaf or hard-of-hearing. Web site offers a listserv for parents on various aspects on deafness including support, counseling, and parental input.

A nonprofit, grant funded institute that develops programs and materials and provides workshops for professionals working with families of infants and young children who have a special need. The SKI-HI Model for Family Centered Home-Based Programming for Infants, Toddlers, and Preschool-Aged Children with Hearing Impairment is widely used by early intervention programs in both the United States and Canada.

A national advocacy organization that promotes equal access to telecommunications and media for people who are deaf, late-deafened, hard-of-hearing, or deafblind. Provides public education and promotes consumer involvement in policies which support accessibility. Publishes an annual, national directory of TTY numbers.

"This is a free series of self-paced online ASL courses. Each course covers various aspects of Deaf Culture, ASL grammar, history, terminology, and approximately 100 new signs. There are 10 courses, (plus various workshops). If you'd like to receive documentation of your progress you can register and pay tuition."

Free sign language resources for ASL students and learners, instructors and teachers, interpreters, parents and professionals who are interested in learning how to sign language online and/or beyond classes for practice or self-study. Includes searchable ASL video dictionary.



Section 8

Glossary



GLOSSARY

Acquired hearing loss: Hearing loss that is not present at birth.

American Sign Language (ASL): A visual-gestural-spatial language in which the placement, movement, and expression of the hands and body are part of the language. It has a complete grammar and syntax different from English. ASL is considered by the Deaf community to be the natural language of people who are deaf.

Americans with Disabilities Act (ADA): A federal law which bans discrimination based on disability in the areas of public accommodations, state and local government services, employment, transportation and telecommunications. All public schools must comply with the ADA.

Amplification: The use of hearing aids or other electronic devices to increase the loudness of a sound so that it may be more easily received and understood.

Area Education Agency (AEA): Provides support services to the local school districts of Iowa. AEAs also provide services to infants, toddlers, school-age children who are in need of special supports because of delays or disabilities, and their families. All services are provided to Iowa residents at no charge. Service providers are licensed by the Iowa Department of Education in order to ensure that highly qualified professionals provide services.

Assistive alerting and communication devices: Equipment or systems that help people who are deaf and hard-of-hearing to increase, maintain, or improve communication and their ability to participate at home, school, work, and in their communities. Devices include hearing aids; TTY/TDDs and telephone amplifiers; alerting systems such as vibrating alarm clocks, watches, pagers, flashing light smoke detectors.

Audiogram: A graph on which a person's ability to hear sounds of different pitches (frequencies) at various levels of loudness (intensities) are plotted. The numbers across the top from low on the left to high on the right show pitch. The numbers going from top to bottom on the left side of the audiogram show the level of loudness.

Audiological evaluation: Tests conducted by a licensed audiologist to determine whether a hearing loss is present, what frequencies/pitches are affected, how severe the hearing loss is, and what type of hearing loss it is. The evaluation also includes recommendations for the best way of dealing with the hearing loss. If a hearing aid is recommended, procedures to determine the best hearing aid may also be part of this evaluation.

Audiologist: A licensed health care professional who holds a degree in audiology and is a specialist in testing hearing and in other areas of hearing services including hearing aid evaluation and recommendations for follow-up services. A pediatric audiologist is one who specializes in the assessment of infants and children. A rehabilitative audiologist is one who specializes in therapy for those with hearing loss. There are no separate licenses for these types of specialization.



Auditory brainstem response (ABR): A hearing test that measures and records the brain's response to sound. During the test, small electrodes are placed on the baby's head and a computer is used to measure the brain's response to sound. The test does not hurt and is most often done while the baby is sleeping. The screening version may be used before the baby leaves the hospital. There is a longer version that is usually one part of a complete diagnostic hearing assessment for infants and young children. The test may also be used with adults under certain circumstances.

Auditory neuropathy: An abnormality in the auditory system caused by improper firing of auditory nerve cells. This affects the ability to understand speech signals clearly. The condition is diagnosed using sophisticated diagnostic tests (otoacoustic emissions, acoustic reflex, and auditory brain stem response). A hearing loss may be present or absent.

Auditory nerve: Referred to as the eighth cranial nerve, this nerve carries sound signals from the inner ear to the brain.

Auditory-verbal: A specific communication philosophy within the broader aural-oral category. The development of spoken language through listening and the use of residual hearing are central. One-on-one teaching, parent involvement, and inclusion in general education (rather than special or deaf education) are also emphasized.

Aural habilitation: Therapy designed to help a person who has a hearing loss make more effective use of his/her remaining or residual hearing. A licensed audiologist or speech language pathologist who specializes in this area may do this therapy. A certified teacher of the deaf may also provide aural habilitation therapy.

Aural-oral: A communication method in which listening is the primary means of understanding language and speech is the primary means of expressing language. In addition to listening, a child is encouraged to watch the speaker for additional information from speech reading, facial expression, and gesture. No sign language is used. This method is sometimes called auditory-aural.

Behind the ear (BTE) hearing aid: Behind the ear (BTE) hearing aids are placed, as the name suggests, behind the ear and are connected with a small piece of tubing to an earmold. The sound is routed from the hearing aid, through the tubing and earmold into the ear. The earmold is often made of soft material and is separated from the hearing aid. This type of hearing aid is most commonly used with children for a variety of reasons.

Bilateral hearing loss: A hearing loss of any degree that is found in both ears.

Bilingual and bicultural: Being fluent in two languages and comfortable in two cultures. For a person who is deaf, this refers to a person who is fluent in both American Sign Language and English, and comfortable in both the Deaf culture and the hearing culture.

Binaural hearing aids: Hearing aids worn on both ears.



Bone conduction: The process through which sound is transmitted to the inner ear by the vibration of the bones of the skull in response to sound. During a bone conduction hearing test, a vibrator is placed on the skull in back of the ear. Vibrations of sound are carried through the bone, bypassing the outer and middle ear, allowing for testing of the inner ear directly. This test may be one part of a complete audiologic evaluation.

Bone conduction hearing aid: A bone conduction hearing aid is another less common hearing aid. Bone conduction hearing aids are most often used with a bone conduction receiver worn in a headband, although they may be used as a body style aid as well. Bone conduction hearing aids are useful for children with conductive hearing loss who are unable to wear an earmold because of an absent or small pinna (external ear), or because of persistent, severe middle ear problems.

Child Health Specialty Clinics (CHSC): A public health program whose mission is to improve the health, development, and well-being of children and youth with special health-care needs in partnership with families, service providers, and communities. CHSC provides evaluation and treatment for children and youth with known or suspected chronic health problems, and helps families find and organize other local services that their children may need.

Closed captioning: A process in which the text version of what is being said on a TV or video is either encoded in the video or encoded in real time (for news broadcasts, etc.). Closed captioning is provided on standard TVs through an electronic chip. By law, TVs manufactured after 1993 whose screens measure 13 inches and larger must have closed captioning capability. When this option is turned on, the captions appear at the bottom of the TV screen.

Cochlea: The inner portion of the ear, which contains the hair cells responsible for transmitting sound via the auditory nerve to the brain.

Cochlear implant: An electronic device that stimulates nerve endings in the inner ear (cochlea) so that a person can hear and process sounds, including speech. The components include:

Outside the ear

- a microphone - a speech processor or miniature computer that changes sound waves into special coded signals
- a transmitter coil that sends coded signals to internal components of the implant

Surgically placed in the inner ear

- a small receiver - Changes coded signals into electrical pulses
- an electrode array - Carries decoded electrical impulses to the auditory nerve, which takes them to the brain

Communication: Sharing information through speech or other means. Communication can include gestures, facial expressions, words and signs. A baby's earliest communication with parents or other caregivers begins before they use either words or signs.



Conditioned play audiometry: A hearing test in which the audiologist measures a young child's response to sound through the use of a structured game. For example, the child may be taught to drop a block in a container when she hears a sound. A variety of sounds from high pitch to low pitch may be presented at various levels of loudness. This test may be one part of a complete hearing assessment.

Conductive hearing loss: A type of hearing loss caused by partial or complete blockage of the outer or middle portions of the ear. This blockage prevents sound from reaching the inner ear. In children, this type of hearing loss can often be treated medically. It is often found with otitis media.

Congenital hearing loss: Hearing loss that is present at birth, associated with the birth process, or that develops within the first few days of life.

Conventional audiometry: During this hearing test the audiologist requests the child to respond—for example, to raise her hand—when she hears a sound. A variety of sounds from high pitch to low pitch may be presented at various levels of loudness. This test is only one part of a complete hearing assessment.

Conventional hearing aid technology: Conventional hearing aids take sound in and make it louder. Making sound louder is accomplished by the use of an amplifier, receiver, and microphone, using what is called *analog* technology. Conventional hearing aids can be very powerful, and may provide some benefit even to people who have profound hearing loss. These hearing aids can be adjusted using screwdriver control settings. They are less expensive, but not as flexible, as more advanced technology.

Cued speech: Provides visually all the elements needed to understand spoken English. This communication system combines information that can be seen (lip movements) with information provided by hand shapes and hand positions near the face. The hand signals identify sounds that can't be clearly seen on the lips, such as *b* and *p*.

Deaf: A hearing loss so severe that a child cannot understand or process language information through hearing alone. When used, by members of the Deaf community, with a capital letter—Deaf—it refers to the cultural heritage and community of individuals who are Deaf. (See Deaf culture and Deaf community.)

Deaf community: A community is a group of people who share common interests, a common language and a common heritage. The Deaf community is comprised of individuals, both deaf and hearing, who to varying degrees embrace particular community goals that derive from Deaf cultural influences. They share the positive view of being a deaf person, and place a high value on Deaf culture.

Deaf culture: A system of values, beliefs, and standards that shape a people's thoughts, feelings, and behaviors. Culture is learned, shared, and constantly changing. Some of the central components of Deaf culture include the use of American Sign Language, social interaction with others who are deaf, and involvement in Deaf organizations. Deaf culture also places high value on its art forms, such as drama, sign mime, storytelling, sign poetry, and on stories and literature about people who are deaf.

Deafblindness: Deafblindness is a combination of hearing and vision loss that affects an individual's development and interaction with their environment. As the result of a combination of vision and hearing losses, the person may have significant communication, development, and learning needs.

Decibel (dB): The unit that describes the loudness of a sound. The higher the dB level presented, the louder the sound. In describing a hearing loss, the higher the dB level required before a person can hear a sound, the more severe the hearing loss.

Digital hearing aid technology: Digital hearing aids have the same abilities as programmable technology, but the sound is processed like that on a CD. That is, the sound is changed into a digital code before it is made louder. Digital hearing aids can be used to benefit people with nearly every type and degree of hearing loss. Digital hearing aids are usually more expensive than other technologies

Early ACCESS: Early ACCESS was created in Iowa under the mandate of the Individuals with Disabilities Education Act (IDEA), Part C. Early ACCESS identifies, coordinates, and provides services and resources that families can use to help their very young children grow and develop.

Earmold: An individually fitted plastic or vinyl piece that is worn in the outer ear and uses a small tube, or channel, to connect with a hearing aid outside the ear. Sound is passed from the hearing aid through the channel to the earmold.

ENT: A medical doctor who specializes in the treatment of the ears, nose and throat. Also called an *otolaryngologist* or *otologist*.

Etiology: The cause.

Feedback: The whistling sound made when amplified sound goes back into the microphone. In a hearing aid, feedback can occur when an earmold does not fit well and the amplified sound goes back into the hearing aid microphone. Persistent feedback should be discussed with your audiologist.

Free appropriate public education (FAPE): Special education and related services provided at no cost to the parent. These services include preschool, elementary, and secondary school education. They are guaranteed to all eligible students through the Individuals with Disabilities Education Act (IDEA). An individualized education program (IEP), developed by the family and the school, determine what services a child will receive.

Frequency modulation (FM) system: An assistive listening device often referred to as an auditory trainer. It reduces background noise interference and adjusts for the distance between the speaker and the person with the hearing loss. Increasing the loudness of speech relative to background noise is also called "improving the signal to noise ratio." One type of FM system consists of a microphone or transmitter worn by the speaker, and a receiver worn by the child. The signal is transmitted from the speaker to the child via an FM signal. These systems are often used in classrooms.



Frequency: Another name for frequency is *pitch*. It refers to the number of vibrations per second of sound, and is measured in Hertz (Hz). A lower sound, such as the growl of a dog, will have a lower Hz reading. Sounds with higher pitches, such as a referee's whistle, have a higher Hz reading.

Functional hearing: The usefulness of a person's hearing. For a person with hearing loss, this refers to residual or remaining hearing. Hearing aids can improve functional hearing, so that the person may be able to hear and understand information by listening alone.

Gain: The amount of amplification (loudness) provided by a hearing aid. For example, a child with unaided hearing may only be able to hear sounds louder than 70 dB. With hearing aids, that child may be able to hear quieter, 30 dB sounds, a gain of 40 dB.

Genetic hearing loss: Hearing loss that is caused by one of more than 100 genes known to be responsible for hereditary hearing loss and deafness. Hearing loss can be part of a syndrome (a condition that causes several problems, in addition to hearing loss) or non-syndromic (the gene causes only hearing loss).

Hard-of-hearing: Having hearing loss, whether permanent or fluctuating, affects the ability to detect or understand some sounds including speech. The term "hard-of-hearing" is preferred by the Deaf community over the term "hearing impaired" when referring to individuals with some but not profound hearing loss.

Hearing aid: An electronic device that amplifies sound and directs it into the ear. A hearing aid consists of a microphone to make the signal louder, and a receiver or loudspeaker. Sound usually enters the ear through an earmold worn in the ear. The most common style of hearing aid for children is a behind the ear hearing aid that connects via a small tube to the earmold.

Hearing screening: A hearing test that rules out a hearing loss or indicates the need for more testing to determine if a hearing loss is present.

Hearing loss: Describes a level of hearing that is less than that of the general population. The range of hearing loss is characterized as shown in the table. The ranges of numbers attached to the specific word labels may vary slightly.

| Classification of hearing | Threshold (softest sound) a person can hear |
|---------------------------------|---|
| Normal hearing | -10 to 20 decibels (dB) |
| Mild hearing loss | 21-40 decibels (dB) |
| Moderate hearing loss | 41-55 decibels (dB) |
| Moderate to severe hearing loss | 56-70 decibels (dB) |
| Severe hearing loss | 70-90 decibels (dB) |
| Profound hearing loss | 91-120 decibels (dB) |

Hearing impairment: Clinical or medical term that describes hearing that is not in the normal range. It is not the term preferred by individuals who have a hearing loss (see deaf, hard-of-hearing).

Huggies®: The brand name of a plastic-ringed device designed to “hug” the hearing aid to the ear. Huggies are popular for infants and toddlers whose ears may not hold a hearing aid snugly in place behind the ear.

In the ear (ITE), in the canal (ITC), and completely in the canal (CIC) hearing aid: This group of hearing aids does not use an earmold and does not have any portion of the hearing aid outside the ear. In the ear (ITE) hearing aids are the largest of this group and all the components fit in the outer ear. In the canal (ITC) and completely in the canal (CIC) hearing aids are fit in the ear canal to varying degrees.

Inclusion: Providing services for infants and children with disabilities in a setting that includes children who do not have special needs.

Individuals with Disabilities Education Act (IDEA): A federal law that establishes policies for comprehensive services for infants and children with disabilities, age birth through 21. Part C of IDEA outlines programs for infants and toddlers birth to three; Part B for children 3 to 21.

Individualized family service plan (IFSP): Plan that outlines the outcomes, strategies, and services for children with disabilities who are age birth to three. A team, that includes parents and the professionals who are specific to each child’s needs, develops the plan. The plan also includes location, amount of time, the person who will provide the service, and the criteria that will be used to determine if the outcomes are achieved.

Individualized education program (IEP): Education plan that outlines the special education and related services for children with disabilities age 3-21 years. The plan is developed by a team that includes parents, administrators, teachers, and special services personnel specific to each child’s needs. The plan includes educational goals and objectives, modifications to the regular curriculum, daily schedule, support services, educational setting, and other information as required by law.

Intensity: The loudness of a sound, measured in decibels (dB).

Interpreter: A person who facilitates communication between people who do not use the same language by interpreting from one language to another. For a person who is deaf or hard-of-hearing, the interpretation is from spoken language to a signed language such as ASL. The term “interpreter” is also used to describe the process of transliterating (changing) a spoken language, such as English, into a visual or visual/phonemic (sound based) code through a sign language interpreter, an oral interpreter, or a cued speech interpreter.

Language: Shared code, used by a group of people that determines what words mean and the rules for how words are combined and used to convey ideas to others. Language can be spoken, signed, or written. “Receptive language” refers to our ability to understand the information conveyed by others. “Expressive language” refers to our ability to share information with others.



Least restrictive environment (LRE): An IDEA term that states a child with disabilities shall be educated with students who are not disabled. Special classes, separate schooling, or other removal of students with disabilities from the general educational environment shall occur only when the nature of the disability would prevent effective education in regular classes, even with the use of supplementary aids and services. LRE is mandated for both public and private educational programs.

Listening age: Describes how long a child has worn a hearing aid and thus been able to “listen.” For example, after a child has worn a hearing aid for 1 year, her listening age will be 1. A child with a listening age of 1 might be just beginning to use words, even though her chronological age may be older.

Manually Coded English (MCE): A sign language system that uses visual (signed) form of English. Several different communication systems use manually coded English. Most use American Sign Language (ASL) signs as a base, with English word order. Each system for manually coding English has its own variations and rules.

Mixed hearing loss: A type of hearing loss that has both conductive and sensorineural components. (See conductive and sensorineural.)

Monaural amplification: The use of one hearing aid, rather than two.

Natural environment: An IDEA term that describes where early intervention services shall be provided. Natural environments include home or community settings that are natural and normal for same age peers who have no disabilities.

Otitis media: A medical term for a middle ear infection. Degrees of hearing loss in children with otitis media may vary. As a result, they may have speech-language delays. Fluid may be present with or without infection.

Otoacoustic emissions (OAE) test: A hearing test that measures the function of the cochlea (part of the inner ear). During the test a small probe is placed in the baby’s ear, and a computer records the ear’s response. The test is very simple and does not hurt. It is often done before a newborn leaves the hospital. It should be part of any complete hearing assessment for infants and young children.

Otoferm/Otoease®: Brand names of creams or oils for use with earmolds. A small amount is placed on the ear canal portion of the earmold to make it slide easily into the ear.

Otolaryngologist/Otologist: A physician who specializes in medical problems of the ear. (See ENT).

Programmable hearing aid technology: Programmable hearing aids have computers, so they can be adjusted more precisely to the child’s hearing loss. They can be re-adjusted if changes occur in the child’s hearing. They can also be programmed to work differently in different situations, such as quiet or noisy rooms. Children with nearly any type or degree of hearing loss can use them. Programmable hearing aids are more expensive than conventional hearing aids.

Progressive hearing loss: Hearing loss that worsens over time.



Real ear measurement: A test that measures how effectively a hearing aid amplifies sound for a child or how much sound is delivered to a child's ear. During this test a small device probe is placed in the ear canal while the hearing aid and earmold are being worn.

Relay telephone service: A service in which agents interpret telephone calls between people who can hear and people who are deaf, deaf-blind, hard-of-hearing, or have a disability that affects their speech.

Residual hearing: The remaining hearing of a person with hearing loss.

Sensorineural hearing loss: A type of hearing loss caused by damage to the inner ear (cochlea) or to the auditory nerve that carries information from the cochlea to the brain. A complete hearing assessment can usually distinguish sensory from neural impairment. Most of the time, sensory and neural hearing loss cannot be treated medically to restore hearing to normal.

Simultaneous communication: A communication system in which spoken and manually signed English are used at the same time. Children wear hearing aids, and are encouraged to develop and use their residual hearing as well as sign and speech.

Speech: The expression of language through the spoken word. "Speech sounds" are the individual consonant and vowel sounds that make up a language such as English.

Speech area or zone: The area on an audiogram within which most speech sounds are found. These sounds are displayed in decibels and frequencies. This area is called the "speech banana" because of its shape on the graph. One purpose of wearing hearing aids is to amplify sounds enough to bring them into this area. This is not possible with all types or degrees of hearing loss.

Speech-language pathologist: A licensed health care professional who specializes in the evaluation and treatment of speech, language, and voice disorders. Their patients often include children whose hearing loss has caused speech or language problems.

Telecommunications Access Iowa: Telecommunications Access Iowa is a service that assists individuals who are hard-of-hearing in selecting telephone equipment that suits their communication needs.

Threshold: The softest level at which an individual can hear a sound, usually a tone, 50% of the time that it is presented.

Total communication: Using any and all forms of communication that will enable the child to learn language. Total communication may include child-devised gestures, formal sign language, speech, speech reading, fingerspelling, reading, and writing. The child may also use individual or group amplification systems, in order to use residual hearing as much as possible.

TTY (text telephone) or TDD (telecommunications device for the deaf): Devices that look like typewriters, and attach easily to a standard phone or plug directly into a phone jack. Using a TTY, a person who is deaf is able to phone and converse with another person with a TTY. The conversation is typed and then transmitted over the phone line. When it arrives, it is displayed as print on the receiving TTY.



Tympanometry: This test measures the mobility of the eardrum. It is not a test of hearing. Rather, it measures how well the ear canal, eardrum, Eustachian tube, and middle ear bones are working. It can also assess the ability of the middle ear to conduct sound to the inner ear. An otologist uses it to learn whether a middle ear problem exists. This test is usually part of a complete hearing assessment. The test is also called *immittance audiometry*.

Unilateral hearing loss: A hearing loss of any degree in only one ear.

Visual reinforcement audiometry (VRA): This hearing test measures a child's response to sound. The audiologist pairs a light and sound, and then watches a child's response. For example, the audiologist pairs a sound that the child can hear to the action of a toy that lights up and moves. Soon the child learns to look for the toy's action when he hears the sound. Then the audiologist presents a variety of sounds that vary in both pitch and loudness. The audiologist knows that the child has heard a sound if the child then turns to see if the toy moves. This test is only part of a complete hearing assessment.

Voice Carry-Over (VCO): An alternate method of using the relay system in which one or both parties in the conversation use their voice in place of or in addition to the written message of the TTY.



Section 9

Family Care Notebook



Name of Child: _____

Date of Birth: _____

Care Providers

Pediatrician

Name: _____ Phone Number: _____
Address: _____
City: _____ State: _____ Zip: _____
Dates Started/Ended: _____

Audiologist

Name: _____ Phone Number: _____
Address: _____
City: _____ State: _____ Zip: _____
Dates Started/Ended: _____

Ear, Nose & Throat (ENT) doctor

Name: _____ Phone Number: _____
Address: _____
City: _____ State: _____ Zip: _____
Dates Started/Ended: _____

Early ACCESS

Name: _____ Phone Number: _____
Address: _____
City: _____ State: _____ Zip: _____
Dates Started/Ended: _____

Speech-Language Pathologist

Name: _____ Phone Number: _____
Address: _____
City: _____ State: _____ Zip: _____
Dates Started/Ended: _____



Care Providers (continued)

Itinerate Teacher of Hearing Impaired (ITHI) or Deaf Education teacher

Name: _____ Phone Number: _____

Address: _____

City: _____ State: _____ Zip: _____

Dates Started/Ended: _____

Other

Name: _____ Phone Number: _____

Address: _____

City: _____ State: _____ Zip: _____

Dates Started/Ended: _____

Other

Name: _____ Phone Number: _____

Address: _____

City: _____ State: _____ Zip: _____

Dates Started/Ended: _____

Other

Name: _____ Phone Number: _____

Address: _____

City: _____ State: _____ Zip: _____

Dates Started/Ended: _____



Family Support

Guide By Your Side (GBYS) Contact

Name: _____ Phone Number: _____
Address: _____
City: _____ State: _____ Zip: _____
Dates Started/Ended: _____

Family Navigator

Name: _____ Phone Number: _____
Address: _____
City: _____ State: _____ Zip: _____
Dates Started/Ended: _____

Other

Name: _____ Phone Number: _____
Address: _____
City: _____ State: _____ Zip: _____
Dates Started/Ended: _____

Other

Name: _____ Phone Number: _____
Address: _____
City: _____ State: _____ Zip: _____
Dates Started/Ended: _____

Other

Name: _____ Phone Number: _____
Address: _____
City: _____ State: _____ Zip: _____
Dates Started/Ended: _____



Insurance Information

Child's Name: _____

Insurance Company: _____

Address: _____

City: _____ State: _____ Zip: _____

Telephone number: _____

Name of contact person: _____

Insurance contact person at place of employment: _____

Telephone number: _____

Name of Employer: _____

Address of Employer: _____

City: _____ State: _____ Zip: _____

Name of Insured: _____ Policy Number: _____

Group Number: _____

Policy Effective Dates: _____

Is this policy the primary or secondary policy for payment of your child's medical bills? _____

How much is your deductible? _____

How much is covered for the following services:

Doctor's Office Visits? _____ Doctor's Hospital Visits? _____

Emergency Room Care? _____ Hospitalizations? _____

Surgeries? _____ Outpatient Hospital Care? _____

Hearing aids? _____ Cochlear Implants? _____

Assisted Listening Devices? _____ Speech Therapy? _____

Diagnostic tests? _____ Prescribed Medications? _____

These services are NOT covered: _____



Insurance Information (Secondary)

Child's Name: _____

Insurance Company: _____

Address: _____

City: _____ State: _____ Zip: _____

Telephone number: _____

Name of contact person: _____

Insurance contact person at place of employment: _____

Telephone number: _____

Name of Employer: _____

Address of Employer: _____

City: _____ State: _____ Zip: _____

Name of Insured: _____ Policy Number: _____

Group Number: _____

Policy Effective Dates: _____

Is this policy the primary or secondary policy for payment of your child's medical bills? _____

How much is your deductible? _____

How much is covered for the following services:

Doctor's Office Visits? _____ Doctor's Hospital Visits? _____

Emergency Room Care? _____ Hospitalizations? _____

Surgeries? _____ Outpatient Hospital Care? _____

Hearing aids? _____ Cochlear Implants? _____

Assisted Listening Devices? _____ Speech Therapy? _____

Diagnostic tests? _____ Prescribed Medications? _____

These services are NOT covered: _____



Family Health History

Child's Name: _____

Does anyone else in family have a similar condition to the child? _____

Do any relatives or members of your immediate family have the following condition (list relationship to child):

1. Diabetes _____

2. Heart Problems _____

3. Hearing Impairment _____

4. Vision Impairment _____

5. Allergies/Asthma _____

6. Seizure Disorder _____

7. Cerebral Palsy _____

8. Mental Retardation _____

9. Cleft Palate _____

10. Birth Defects _____

Have you, or has anyone in your family, had genetic counseling? _____

TIP: Family medical history forms may contain references to “maternal” or “paternal” relatives. “Maternal” means on the mother’s side of the family and “Paternal” means on the father’s side of the family.



Appointment Log

[illegible]

Medications

| Medication | Dosage | Time of Day | Reason prescribed | Start Date | End Date | Prescribed by |
|------------|--------|-------------|-------------------|------------|----------|---------------|
| | | | | | | |
| | | | | | | |
| | | | | | | |
| | | | | | | |
| | | | | | | |
| | | | | | | |

Information for Caregivers

Allergies

Food: _____

Drug: _____

Other: _____

Medication Instructions

Things I like:

Things I dislike:

Things I can do by myself:

Things I need help with:

Hearing aid batteries are located:

Notes: _____

Hearing aid/Cochlear implant care notes:

Other notes



Important Phone Numbers for Caregivers

Parent Name: _____ Cell Phone: _____
Work phone: _____ Email: _____

Parent Name: _____ Cell Phone: _____
Work phone: _____ Email: _____

Relatives

Name: _____ Phone: _____
Name: _____ Phone: _____

Professionals

Doctor: _____ Phone: _____
Doctor: _____ Phone: _____
Doctor: _____ Phone: _____
Pharmacy: _____ Phone: _____

Therapy: _____ Phone: _____
Therapy: _____ Phone: _____

Other: _____ Phone: _____
Other: _____ Phone: _____

School: _____ Phone: _____

In case of an emergency, call 911.

Name of Child: _____ Date of Birth: _____
Home Phone number: _____
Home Address: _____
City: _____ State: _____ Zip: _____

Fire extinguisher is located: _____
Flashlight is located: _____



**Insert a copy of your Individual Education Plan (IEP) or 504
Plan here.**



Transition Checklist

Transition Developmental Checklist

| Health Behaviors | Discussed Date | Status | Age to Discuss |
|--|----------------|--------|----------------|
| Learning self care | | | 2 |
| Has beginning knowledge of condition/special needs | | | 2 |
| Independent in self care (especially hygiene, dressing, tooth brushing, hand washing) | | | 4 |
| Is building understanding of condition/special needs and treatments | | | 5 |
| Can describe condition to others | | | 6 |
| Can determine when condition is worsening | | | 6 |
| Is active/exercises to maintain physical fitness | | | 6 |
| Knows basics of nutrition | | | 6 |
| Has someone to talk to about concerns | | | 7 |
| Working with parents/caregivers in doing self-care related to meds and treatments | | | 9 |
| Has plan for emergencies | | | 9 |
| Carries list of medications | | | 9 |
| Carries list of physicians and other health care providers | | | 9 |
| Carries summary medical information | | | 9 |
| Carries copy of insurance/medical card | | | 9 |
| Answers questions from doctor, nurse, therapists, etc. about condition | | | 9 |
| Knows how condition and treatment affects physical, mental, sexual development | | | 9 |
| Knows how smoking, drinking, chewing, drugs affect body and condition | | | 11 |
| Understands sexuality, pregnancy, and birth control | | | 11 |
| Sees doctor for some time privately | | | 13 |
| Manages own medication and treatment regime; notifies caregiver of need for med refills | | | 13 |
| Knows what equipment does and how to fix minor problems | | | 13 |
| Knows side effects of medication and interactions with food, alcohol, etc. | | | 14 |
| Family explores guardianship if needed (age 18 is age of majority when youth legally makes own decisions); assent to consent; health surrogate | | | 14 |
| Has plans for adult health care providers (primary, specialty, dental, DME, pharmacy, therapy, mental health) | | | 15 |

Transition Checklist (cont.)

| | | | |
|--|--|--|----|
| Has plans for adult health insurance | | | 16 |
| Knows how to use health insurance/medical card | | | 16 |
| Has adult health care providers | | | 17 |
| Has signed release to transfer records | | | 18 |
| Has copy of own records | | | 18 |

| Independence, School and Work Behaviors | Discussed Date | Status | Age to Discuss |
|---|----------------|--------|----------------|
| Does home chores | | | 2 |
| Goes places with family in the community | | | 2 |
| Communicates own needs and preferences | | | 2 |
| Attends preschool/Head Start | | | 2 |
| Family knows about ADA, IDEA, futures planning, wills, trusts, guardianship issues, power of attorney, health surrogate | | | 3 |
| Follows directions | | | 3 |
| Learning to make choices and experience consequences | | | 4 |
| Interacts appropriately with peers and adults | | | 4 |
| Attends school regularly and is progressing | | | 4 |
| Responds to "What will you do when you grow up?" | | | 5 |
| Has fun, recreation, hobbies | | | 6 |
| Talks about things he/she is good at | | | 6 |
| Does more advanced home chores | | | 7 |
| Uses computer | | | 7 |
| Has personal safety skills – phone, seat belts, gun safety | | | 8 |
| Discusses job and career interests | | | 10 |
| Has friends for social activities | | | 10 |
| Can manage money and has shopping skills | | | 11 |
| Knows about school to work, VR, and other community resources for work preparation | | | 12 |
| Participates in school IEP, 504, transition meetings | | | 12 |
| Has visited workplaces and/or volunteers | | | 13 |
| Can write a resume and complete a job application | | | 13 |
| Works part-time and/or volunteers | | | 13 |
| Can budget money | | | 14 |
| Can grocery shop, cook, plan meals, do laundry, and keep house | | | 14 |
| Has transportation and is planning for driver's license or ADA transportation card | | | 14 |

Transition Checklist (cont.)

| | | | |
|---|--|--|----|
| Family knows about reapplying for SSI at age 18 with adult standards, exploring supports for community living, waiver programs, respite, other community services for adults with disabilities (get on waiting lists); SSA work incentives – PASS Plan, 1619a and b, Ticket to Work | | | 14 |
| Has contacted VR to discuss services | | | 15 |
| Knows laws, policies, rights, and responsibilities for people with disabilities | | | 15 |
| Has drivers license or state ID card | | | 16 |
| Has job for pay or is actively pursuing education plan that will result in a job. | | | 16 |
| Knows how to register for college entrance exams | | | 16 |
| Knows how to apply to post-secondary institutions and for financial aid | | | 16 |
| Is completing high school | | | 17 |
| Has definite plans for work and/or vocational training /college | | | 17 |
| Has plans for independent living, housing, and personal attendant (if needed) | | | 17 |

Adopted from the Kentucky Commission for Children with Special Health Care Needs: <http://chs.ky.gov/commissionkids>
through the National Center for Medical Home Implementation- Building your Care Notebook

