

*“Mankind owes to the child
the best it has to give ...”*

— Opening words of the United Nations' Declaration of the Rights of the Child



We are pleased to have been asked to write a letter of introduction for the guide for parents of children newly diagnosed with hearing loss. We truly hope that this publication, a joint effort of interested service providers and parents of children with hearing loss, will be most helpful to you and your family.

All parents shoulder the awesome responsibility of having to make difficult, sometimes life-altering decisions for their children. As you become more familiar with your child's hearing loss and the many options available to you, you may at times feel confused, uncertain, even hesitant. Indeed, the choices you will be required to make concerning your child's education, teaching methods and, ultimately, the form(s) of communication used by your child and yourselves, may seem overwhelming. We cannot tell you that the experience will be an easy one, but it can offer blessings beyond your wildest imagination, and you and your family will not be alone on your journey.

We have found that some of the best advice comes from other parents of children with hearing loss, other family members of deaf, and of course, from deaf and hard of hearing adults and children themselves. Many well-intentioned people may offer you advice; be selective in which advice to follow and which to dismiss; above all, follow whatever feels right for you and your family. You will be determining how your child will interact with the world as well as how you will interact with your child for a lifetime.

We encourage you to meet and interact with as many other families and individuals affected by hearing loss as possible and to learn from their successes and their stories. Information will be your best tool. Once you are informed, be willing to fight for your child's needs. The payoff can be incredible. Follow your heart.

Your child's diagnosis has very likely brought sadness and grief to you and your family. These emotions are perfectly normal and healthy, and we encourage you to accept and work through your feelings at your own pace. In time, sadness and grief will subside, and you will find that you are able to tackle the challenges ahead. Yes, there are many challenges to come... and many rewards.

Children with hearing loss are limited only by imagination. All the joys of being children, of playing with other children, of wondering at butterflies and stars, of achieving their dreams...all things are possible. And this does not end with childhood. One need only look at the countless examples of independent, well-adjusted, well-educated, responsible and mature deaf and hard of hearing adults to see that this is true. Do not let others define limits on what your child can achieve. You will be your child's strongest advocate.

We wish you and your family a bright and awesome future.

Linda Erickson and Cheri Scott

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Boys Town	Stepping Stones
Texas Connect	Rhode Island Early Intervention Program
Joyful Noise	Resource Guide for Families of Children with
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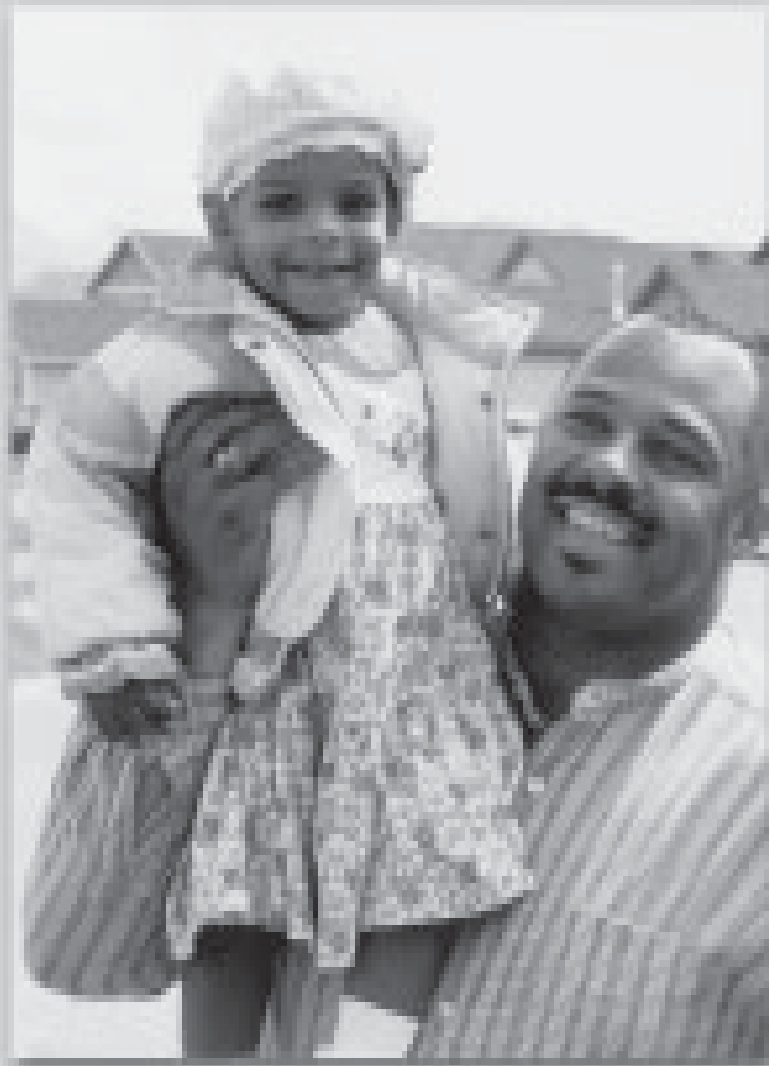
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HEARING LOSS

*“If you want to lift yourself up,
lift up someone else ...”*

— Becker T. Whittington



Introduction

More than 28 million Americans are deaf or hard of hearing, and thirty million more are exposed to dangerous levels of noise. Levels of hearing loss range from a mild but important loss, to a total loss of hearing or deafness. The most common cause of hearing loss in infants/children is otitis media, a middle ear infection that is found mostly in infants and young children. A large number of hearing impairments, or damage, is caused by factors in people's surroundings such as noise, drugs, and poisons. Many acquired sensorineural hearing losses, hearing loss caused by damage that occurs in the inner ear and/or nerve pathway to the brain, are also caused by a genetic history for hearing loss. (For more information, see the Genetic Counseling section). Important progress has been made in the last ten years towards understanding hereditary factors connected with the auditory (hearing) system.

It is important to remember when dealing with your deaf or hard of hearing infant/child, that hearing and listening are not the same. Parents often say to their infants/children "Listen to what I say" but not "Hear what I say." Hearing is a part of what the ears do. With listening, your infant/child has to focus and deal with the sound or speech that he/she hears. Then your infant/child must form a message from this. An infant/child's hearing may be normal but he/she may not know how to listen. If you have seen an audiologist (hearing loss specialist), you already know about your infant/child's hearing. The next step is to help your child find the power and fun of listening.



Fact Sheet

Hearing loss is the most common birth defect in newborns in America, and yet not all newborns are routinely tested for it.

- Approximately 1 out of 1,000 infants are born completely deaf, and another 2-3 out of 1,000 infants are born with some degree of hearing loss.
- The cost of educating a child with a hearing loss through high school today is over \$420,000.
- The combined expenses of deaf education and loss of productivity result in an average lifetime cost of over \$1 million per deaf individual.
- According to the American Academy of Pediatrics (AAP), infants/children that are found to have hearing loss, and receive early intervention (treatment) by six months of age will do much better with speech and language development/growth than infants/children found with hearing loss after six months of age.

Frequently Asked Questions

Are there many infants/children with hearing loss or am I all alone in this?

You are not alone. There are many infants/children with hearing loss and many who are deaf. Actually, approximately one child out of a thousand is born deaf. And nine out of ten of these children have parents who hear. Only about 1 out of 10 have parents who are deaf themselves.

Are there different types and degrees of hearing loss and does that make a difference?

Yes, there are several different types of hearing loss:

1. Conductive
2. Sensorineural
3. Mixed
4. Central

There are also different degrees of hearing loss:

1. Mild
2. Moderate
3. Severe
4. Profound
5. Total

Sensorineural hearing loss is permanent and is the result of something affecting the inner ear, or the nerve that deals with hearing called the auditory nerve. There are many different causes of sensorineural hearing loss, including congenital infections, medications, noise, and genetics. Congenital hearing loss is present in three to four out of every 1000 newborns and is detectable at birth through universal newborn hearing screening. Sensorineural hearing loss can also develop later in life for various reasons, one of which is excessive exposure to loud noise.

Conductive hearing loss is the result of something affecting the outer or middle ear, such as ear infections associated with fluid in the middle ear space. Middle ear infections are the second-most common reason children see doctors. Any time children have middle ear infections with fluid in their ears, they may

have an accompanying hearing loss. Other common causes of conductive hearing loss include excess wax, foreign bodies, swelling of the auditory (hearing) canal, or ear canals, eardrums, or middle ear bones that did not form correctly. In most cases, conductive hearing losses can be treated either medically or surgically, and are not permanent.

Mixed hearing losses are combinations of sensorineural and conductive hearing losses.

How common is hearing loss?

Hearing loss in young children is more common than you may think. About three to four out of every 1,000 infants born have some type of hearing loss. In fact, hearing loss is more common than all of the other illnesses (for example PKU, sickle cell anemia) for which all infants must be tested by law in the hospital.

Why did this happen to my infant/child?

In some cases, the cause of an infant/child's hearing loss may be easy to find. For example, there may be a family history of deafness, a congenital condition (present at birth), an illness, a syndrome, an accident, and/or a prescribed medication that may obviously be the cause of the hearing loss. In other cases however, there may be no obvious reason for the hearing loss, and you may never know the cause of your infant/child's hearing loss.

What does my infant/child's hearing loss mean?

Because there are many different kinds of hearing loss, it may mean different things for different infants/children. Hearing loss can be a temporary (passing) sound transfer problem caused by a blockage in the outer or middle ear (for example, middle ear fluid), or it can be permanent sensory damage (nerve damage that will not go away). A hearing loss may even be a combination of both of these things. How your infant/child's hearing loss will affect his/her language development/growth depends on many things. If the hearing loss can be fixed (for example, middle ear fluid), quick medical treatment is most impor-

tant. If the hearing loss is permanent (will not go away), the sooner the loss can be found and intervention (treatment and/or therapy) started, the better the chance for your infant/child's language development/growth. In all instances, active involvement of you as parents and other caregivers in early intervention is an important part of your infant/child's development/growth.

Will my infant/child's hearing get better?

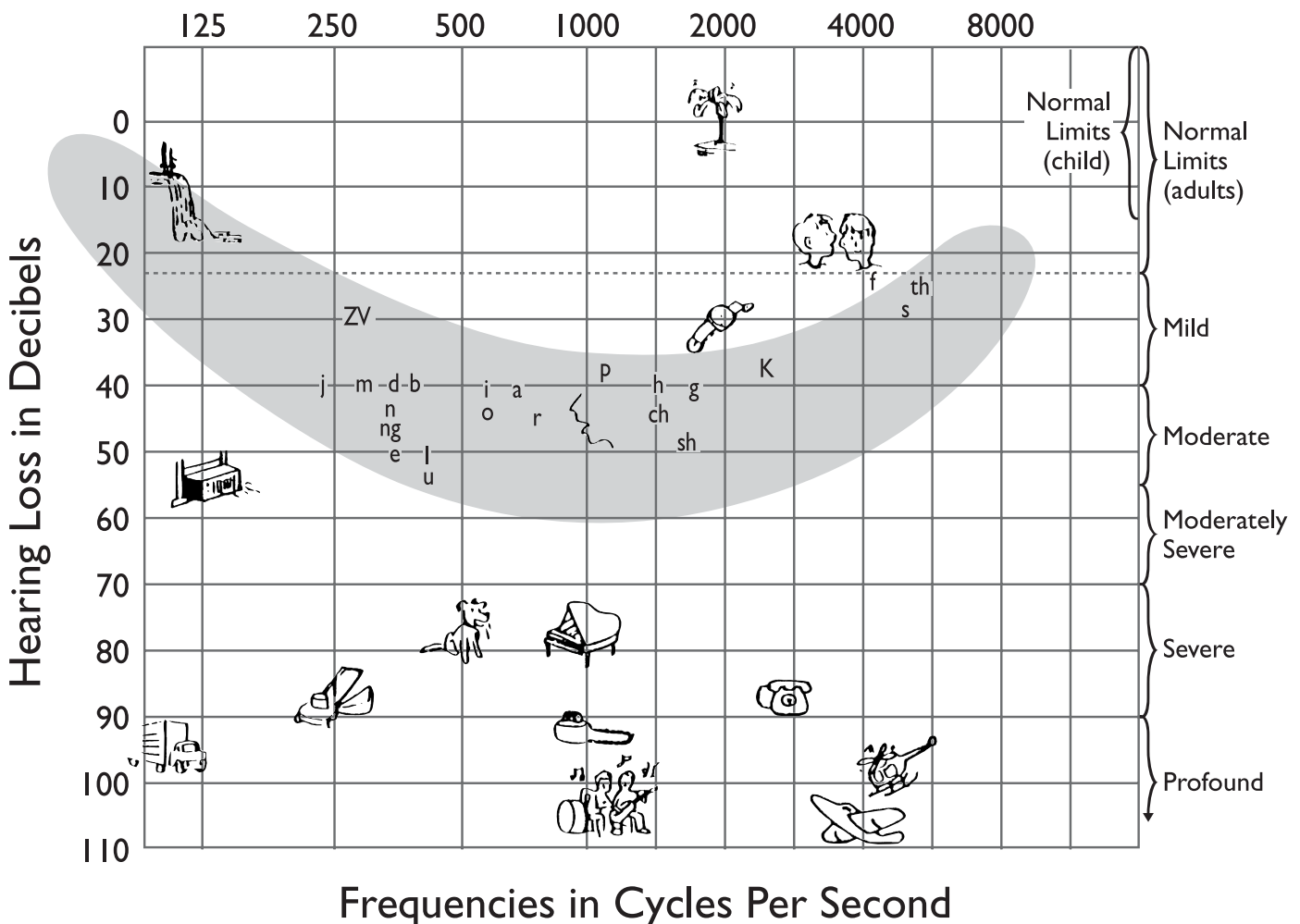
Whether or not your infant/child's hearing gets better depends on the cause of the hearing loss. If the loss is because of a medical problem, such as middle ear fluid, it may improve and may fluctuate (come

and go) with the reoccurrence (repeat) of the problem. If the loss is due to sensory or nerve damage, it will not improve.

What should I do if I think that my infant/child has a hearing problem?

Get in touch with your infant/child's doctor, let him/her know about your concern, and make plans to have your infant/child's hearing tested. This testing should be done as soon as possible and when your infant/child does not have a cold or an ear infection. Do not wait several months because finding your infant/child's hearing loss early is very important.

Comparison of the Frequency and Intensity of Various Environmental and Speech Sounds



These degrees of loss show the results of measurement of unaided hearing, or testing without a hearing aid.

DEGREE OF LOSS	DECIBELS	POTENTIAL EFFECTS
Minimal Hearing Loss	16-25dB	A minimal loss of some sounds. May have difficulty hearing quiet or distant speech especially in noisy environments.
Mild Hearing Loss	26-40DB	Can hear most speech sounds but likely to miss fragments of words, especially those that contain “s”, “f”, and “ch”. With proper amplification, likely to understand all spoken communication especially at close distances.
Moderate Hearing Loss	41-55DB	Without amplification, 50-100% of speech sounds may be missed which may effect speech development unless optimally amplified. Proper amplification should enable listener to hear and discriminate all sounds.
Moderately Severe	56-70dB	Conversation cannot be understood, unless the intensity is very loud. Age of amplification, consistency of use, and intervention will determine speech intelligibility and/or language development.
Severe Hearing Loss	71-90dB	Without amplification, may be aware of loud voices near ear. Spoken language will not develop spontaneously unless modifications and interventions are taken. Without optimal amplification, should be able to detect all the sounds of speech and identify environmental sounds.
Profound Hearing Loss	91dB or greater	Aware of vibrations more than tonal pattern. May rely on vision rather than hearing as the primary avenue for communication and learning. Speech and oral language will not develop spontaneously without amplification and intervention. Speech intelligibility often greatly reduced and atonal voice quality likely.

The audiologist, and other professionals will be able to give you more information on types and degrees of hearing loss.

What can parents do to help with speech and language development/growth in their infants/children with hearing loss?

- Make sure your infant/child wears his/her hearing aid/s as directed by the audiologist.
- Speak to your infant/child often, including talks about everyday events and routines.
- Speak at normal levels, using natural gestures, and body language.
- Speak clearly.
- Say key words several times, giving your infant/child extra chances to listen to the words.
- Praise your infant/child after using his/her voice.
- Include song and variety in your voice to highlight key words, or to add meaning to the sentence.
- Give your infant/child time to respond.
- Encourage your child to be an active reader by reading to him/her books that he/she knows rhyming words, and/or words that are said over and over.
- Form schedules for daily activities. Talk about the activity using familiar words and language.
- Read stories together. Infants/children like to hear the same story over and over. After having heard a story often enough, your infant/child can start taking part by remembering and repeating words and sounds connected with that page.
- Sing songs together. Infants/children learn from hearing, rhyming, and saying things over and over.
- Say nursery rhymes.
- Form an experience/events book. Take a regular notebook or journal, and glue pictures of the people and happenings filling your infant/child's life (for example, photos of grandparents). Sit with your infant/child and talk about the book together. Play games with your infant/child like "pattycake" and "peek-a-boo".
- Build from what your infant/child knows to what he/she does not know. For example, if your infant/child knows the word "shoe," start talking about sneakers, boots, and slippers. Slowly your infant/child will understand that sneakers, boots, and slippers are all kinds of shoes.

Why is finding hearing loss in children early (early detection) so important?

Hearing is necessary for speech and language development (growth). The sooner a hearing loss is discovered, the sooner your infant/child can be

treated and the better language and speech he/she will develop.

Do my baby's ears hurt?

If an infant/child pulls his/her ear(s) often, it may be because of uncomfortable pressure or actual pain in the ear(s). The following things may mean your infant/child has an ear infection:

1. If your infant/child cries often
2. If your infant/child does not want to eat
3. If your infant/child has a fever

If your baby is suffering from any of these things, contact your healthcare provider as soon as possible.

How is hearing loss treated?

If there is some hearing, sounds can be increased by a hearing aid(s). If the loss is severe, children may also be taught other forms of communication such as sign language or lip reading. Speech and hearing therapists can teach you how to best communicate with your infant/child. An audiologist must first figure out where the hearing problem is (outer, middle, or inner ear) before deciding on the best treatment (for example, the use of hearing aids, seeing a doctor for more treatment).

Where can I get my infant/child's hearing checked?

If your infant/child was not screened at the hospital at birth, go to a licensed pediatric audiologist (a hearing loss professional who works with infants and children). Your healthcare provider can provide you with a list.

My infant/child has a hearing loss. Is there a way for me to hear a sample of speech the way he/she hears it?

The Alaska Early Hearing Detection and Intervention (EHDI) program offers a compact disc (CD) that can show different levels and kinds of hearing loss. It will help you understand what your infant/child hears, even though it won't be exactly what he/she is hearing. Contact the Department of Health & Social Services, Division of Public Health, Section of Maternal, Child & Family Health at (907) 269-3400 for more information.

Will my grandchildren also have a hearing loss?

If your infant/child's hearing loss is due to middle ear problems, the answer is probably not. If there is a family history of hearing loss however, genetics may be a factor, and an appointment with a genetics counselor is important. Contact your health care provider or the genetics clinic for more information. (To contact the Genetics Clinic call State of Alaska, Department of Health & Social Services, Division of Public Health, Section of Maternal, Child, & Family Health at (907) 269-3400.)

Can loud noises hurt infants/children's hearing?

Yes. It is important to protect whatever hearing an infant/child has. Very loud noises can damage your infant/child's hearing, and can do so permanently (forever). Keep your infant/child away from very loud headphones, rock concerts, video arcades, and other loud noises if possible. If you cannot keep your infant/child away from the loud noises, protective earplugs should be worn every time your child is around these noises. The number of people with hearing loss caused by loud noises is growing in this country. It is more important than ever to stay away from these loud noises, or using earplugs if staying away cannot be done.

What are "risk factors"?

A risk factor is a medical condition or event that is known to be connected with hearing loss. Just because your son/daughter has a risk factor does not mean that a hearing loss will definitely happen. A risk factor means that hearing loss happened in a very high number of children with one or more of the conditions that are risk factors. The list of hearing loss risk factors includes the following:

- Family history of childhood hearing loss
- Infection during pregnancy (rubella, cytomegalovirus/CMV, syphilis, herpes, or toxoplasmosis)
- Birth defects of the head and neck (for example, malformed outer ear)
- Low birth weight (under 3.3 pounds)
- Yellowing of the skin at birth (Jaundice, Hyperbilirubinemia)
- Bacterial meningitis (illness)
- Medications for the ear (Ototoxic)
- If an infant/child is on a respirator for more than five days (Mechanical ventilation)

- Apgar scores of 0 to 4 at one minute or 0 to 6 at five minutes. (This score is given at the time of birth to figure out the newborn's condition. The score comes from evaluating the newborn's heart rate, respiratory/breathing effort, muscle tone, reflex irritability, and color. A score of 0 -2 is related on each of the five items, the highest possible score being 10.)

Finally, a hearing loss may have no known cause. Nearly half of all infants with hearing loss have no known risk factors to explain their hearing loss.

Can my infant/child's hearing loss be corrected?

Hearing loss that is caused by a disorder in the middle or outer ear (conductive) can usually be corrected with medical treatment such as antibiotics or minor surgery. Hearing loss that happens because the auditory nerve (hearing part of the inner ear) is not working correctly (sensorineural hearing loss) cannot be corrected, but can usually be improved with the use of hearing aids or a cochlear implant. With a mixed hearing loss (combination of the hearing losses above), the conductive part of it may be managed with medical treatment, but the sensorineural part will not go away. (For more information, see the Terminology section.)

How can my infant/child have a hearing loss when the newborn hearing screening was passed?

Some hearing losses are congenital, which means they happen before or during birth. Other hearing losses are acquired, which means they happen after birth. Hearing losses that take place after birth can be because of:

1. Meningitis (illness)
2. Use of ototoxic antibiotics (medicine) during the hospital stay
3. Some genetic losses that are described by progressive hearing loss (hearing loss that gets worse as an infant/child gets older), and may not be picked up until later. In some cases, the effects of certain illnesses or antibiotics may not show until months later. If your infant/child had any of the risk factors, listed above, his/her hearing should be checked regularly even if the screening at birth did not show there was a hearing loss.

What is genetic counseling and why should I have it done?

According to the Joint Committee on Infant Hearing, the families of all infants/children with hearing loss for whom there is not a clear-cut cause should be given the option of genetic evaluation or review and counseling by a medical geneticist. Many people think that the main reason for such genetic evaluation and counseling is so the family can know about their chances of having other infants/children with hearing loss. Actually, the genetic evaluation shows much more important information that can be very important on how your infant/child is treated. For example, sometimes through a genetic evaluation a certain cause of an infant/child's hearing loss can be found. If this is the case, sometimes they can tell whether an infant/child's hearing loss will become worse. Also, for a large number of infants/children, deafness is only one of many medical problems the infant/child may have, and genetic testing may tell whether the infant/child is likely to have other problems with the heart, kidneys, or eyes.

What will my son or daughter who is deaf or hard of hearing be when he/she grows up?

No one can tell how a child will progress; each is unique. Most importantly is to focus on being with your infant/child NOW. Love, share, and learn to communicate and enjoy each other. Comfort can also be found with the knowledge that deaf and hard of hearing people are everywhere and doing nearly everything.

The range of individual differences among hearing people is also among deaf and hard of hearing people. For example, some earn PhD's, while others do not complete high school, some marry deaf partners and others marry hearing partners, and some have children while others do not.

The important thing now though, is to work with others to help your infant/child to learn language as fast as possible. All children, whether deaf, hearing impaired, or hearing, improve their academic and social development (growth) as they gain good communication skills. (For more information about how to help your infant/child, see the Parents and Advocacy sections).

"Here is my advice to you parents with deaf children. It is important for you to learn how to communicate with them and how to make them happy, not feel lonely. Just make them feel as they are a part of the family. Once in awhile they may take things personally and feel they are left out but you parents have to be patient with them. Telling them the truth is all that they want to know. Be honest with them, also yourself too. If they have sisters and brothers tell them about your child's hearing loss."

— James (age 14)

Frequently Asked Questions - Otitis Media/Ear Infections

What is otitis media?

Otitis media is an ear infection. Three out of four infants/children have had otitis media by the time they are 3 years old. In fact, ear infections are the most common illnesses in infants and young children.

Are there different kinds of otitis media?

Yes. There are two main kinds. The first type is called acute otitis media (AOM). This means that parts of the ear are infected and swollen. It also means that fluid and mucus are trapped inside the ear. AOM can be painful.

The second type is called otitis media with effusion (fluid), or OME. This means fluid and mucus stay trapped in the ear after the infection is over. OME makes it harder for the ear to fight new infections. This fluid can also cause problems with your infant/child's hearing.

How does otitis media happen?

Otitis media usually happens when viruses and/or bacteria get inside the ear and cause an infection. It often happens as a result of another illness, such as a cold. If your infant/child gets sick, it might hurt his/her ears, causing otitis media.

It is harder for infants/children to fight illness than it is for adults, so children develop ear infections more often. Research shows that other environmental factors, such as being around cigarette smoke, can cause ear infections.

What's happening inside the ear when my child has an ear infection?

When the ears are infected the eustachian tubes become inflamed and swollen. The adenoids can also become infected.

The eustachian tubes are inside the ear. They keep air pressure even in the ear. These tubes also help supply the ears with fresh air.

The adenoids are found near the eustachian tubes. Adenoids are clumps of cells that fight infections.

Swollen and inflamed eustachian tubes often get clogged with fluid and mucus from a cold. If the fluids plug the openings of the eustachian tubes, air and fluid get trapped inside the ear. These tubes are smaller and straighter in infants/children than they are in adults. This makes it harder for fluid to drain out of the ear and is one reason that infants/children get more ear infections than adults. These infections are usually painful.

Adenoids are located in the throat, near the eustachian tubes. Adenoids can become infected and swollen. They can also block the openings of the eustachian tubes, trapping air and fluid. Just like the eustachian tubes, the adenoids are different in infants/children than in adults. In infants/children, the adenoids are larger, so they can more easily block the opening of the eustachian tube.


Can otitis media have an impact on my child's hearing?

Yes. An ear infection (otitis media) can cause temporary (will go away) hearing problems. Temporary speech and language problems can happen, too. If left untreated, these problems can become more serious.

An ear infection affects important parts in the ear that help us hear. Sounds around us are collected by the outer ear. Then sound travels to the middle ear, which has three tiny bones and is filled with air. After that, sound moves on to the inner ear. The inner ear is where sounds are turned into electrical signals and sent to the brain. An ear infection affects the whole ear, but especially the middle and inner ear. Hearing is changed because sound cannot get through an ear that is filled with fluid.


ANATOMY OF THE HUMAN EAR





AMERICAN SOCIETY OF AUDEOLOGISTS

 Founded in 1929


 Printed on Recycled Paper

How do I know if my child has an ear infection/otitis media?

It is not always easy to know if your infant/child has an ear infection. Sometimes you have to watch carefully. Your infant/child may get an ear infection before he/she has learned how to talk. If your infant/child is not old enough to say, “My ear hurts,” you need to look for other signals that there is a problem.

Here are a few signs your infant/child might show you if he/she has an ear infection:

- Tugging/pulling on ears
- Crying more than usual
- Fluid draining from ears
- Trouble sleeping
- Trouble keeping balance
- Trouble hearing
- Not reacting to quiet sounds

An infant/child with an ear infection may show you any of these signs. If you see any of them, call your health care provider as soon as possible.

How is and ear infection/otitis media treated?

Many health care providers suggest the use of an antibiotic (a drug that kills bacteria) when there is an active middle ear infection. If a child is feeling pain, the health care provider may also suggest something to lessen it, called a pain reliever. Following the health care provider’s instructions is very important. Once started, the antibiotic (medicine) should be taken until it is finished. Most health care providers will want to see your infant/child return for a follow-up examination, to see if the infection has gone away. Unfortunately, there are many bacteria that can cause ear infections, and some cannot be cured with just one antibiotic. This happens when antibiotics are given for coughs, colds, flu, or viral infections where antibiotic treatment does not work. When antibiotics stop working to kill the bacteria (bugs) in the body, those treatments do not work against infections. This means that several different antibiotics may have to be tried before an ear infection goes away. Antibiotics may also create unwanted side effects such as nausea, diarrhea, and rashes.

Once the infection goes away, fluid may remain in the middle ear for several months. Middle ear fluid that is not infected often disappears after 3 to 6 weeks. Neither antihistamines nor decongestants are sug-

gested as helpful in the treatment of ear infections at any stage in the disease process. Sometimes health care providers will treat your infant/child with an antibiotic to get rid of the fluid quickly. If the fluid lasts for more than three months and is connected with a hearing loss, many health care providers suggest putting “tubes” in the ears with the infection/s. This operation, called a myringotomy, can usually be done on an outpatient basis by a surgeon, who is usually an otolaryngologist (a doctor who specializes in the ears, nose, and throat). While the child is asleep under general anesthesia, the surgeon makes a small opening in the child’s eardrum. A small metal or plastic tube is placed into the opening in the eardrum. The tube ventilates, or airs out, the middle ear and helps keep the air pressure in the middle ear equal to the air pressure in the outside. The tube normally stays in the eardrum for six to 12 months, after which time it usually comes out on its own. If an infant/child has large or infected adenoids, the surgeon may suggest removing them at the same time the tubes are put into the ears. Removing the adenoids has been shown to limit the number of ear infections in some children, but not in those who are under four years of age. However, research has shown that removing a child’s tonsils does not cut down on the number of ear infections. Tonsillotomy and adenoidectomy may be correct for reasons other than middle ear fluid.

Hearing should be back to normal once the fluid is removed. Some children may need to have the operation again if the ear infection comes back after the tubes come out. While the tubes are in place, water should be kept out of the ears. Many health care providers suggest that a child with tubes wear special earplugs while swimming or bathing so that water does not get into the middle ear.

What will a health care provider do?

Your health care provider will check your infant/child’s ear. The health care provider can tell you for sure if your infant/child has an ear infection. He/she may also give your infant/child medicine. Medicines called antibiotics are sometimes given for ear infections. It is important to know how they work. Antibiotics only work against organisms called bacteria, which can cause illness. Antibiotics do not work against viruses, such as those connected with a cold.

In order to work, antibiotics must be taken until they are finished. A few days after the medicine starts working, your infant/child may stop pulling on his/her ear, and appear to be feeling better. This does not mean the infection is gone. The medicine must still be taken. If not, the bacteria can come back. You need to follow your health care provider's directions exactly.

Your health care provider may also give your infant/child medicine to lessen the pain, such as acetaminophen or aspirin.

How can I be sure I am giving the medicine correctly?

If your health care provider gives you a prescription for medicine for your infant/child, make sure you understand the directions completely before you leave his/her office. Here are a few suggestions about giving medicine to your child:

1. **Read.** Make sure the pharmacy has given you printed information about the medicine and clear instructions about how to give it to your infant/child. Read the information that comes with the medicine. If you have any problems understanding the information, ask the pharmacist, your health care provider, or a nurse. You should know the answers to the following questions:
 - Does the medicine need to be refrigerated?
 - How many times a day will I be giving my infant/child this medicine?
 - How many days will my infant/child take this medicine?
 - Should the medicine be given with food or without food?

2. **Plan.** Sometimes it is hard to remember when you have given your infant/child a dose of medicine. Before you give the first dose, make a written plan or chart to cover all of the days of the medication. Some infants/children may require 10 to 14 days of treatment.

Your chart might look like this if your infant/child's prescription is for 3 times a day with food:

3 TIMES A DAY WITH FOOD	BREAKFAST	LUNCH	DINNER
DAY 1			
DAY 2			
DAY 3			
DAY 4			
DAY 5			
DAY 6			
DAY 7			
DAY 8			
DAY 9			
DAY 10			

Put your chart someplace on the refrigerator so you can check off the doses at every meal. Be sure to measure carefully. Use a measuring spoon or special medicine-measuring cup if one comes with the medicine. Do not use spoons that come with tableware sets because they are not always a standard size.

3. **Follow Through.** Be sure to give all of the medicine to your infant/child. Make sure it is given at the right times. If your health care provider asks you to bring your infant/child back for a “recheck” or “follow-up”, do so on schedule. Your health care provider wants to know if the fluid in your infant/child’s ear/s is gone, and if the infection has stopped. Write down and ask the health care provider any questions you have before you leave his/her office.

Will my child need surgery?

Some infants/children with ear infections need surgery. The most common surgical treatment involves having small tubes placed inside the ear. This surgery is called a myringotomy. (For more information about the surgery, see “How is otitis media/ear infection treated?”.)

What about infants/children in daycare, pre-school, or school?

Even before your infant/child has an ear infection or needs to take medicine, ask the daycare program or school about their medication policy. Sometimes you will need a note from your health care provider for the staff at the school. The note can tell the people at your child’s school how and when to give your child medicine if it is needed during school hours. Some schools will not give children medicine. If this is the case at your child’s school, ask your health care provider how to schedule your child’s medicine.

What else can I do for my infant/child?

Here are a few specific things you can do to lower your infant/child’s chance of getting an ear infection:

- Do not put your child to sleep with a bottle
- Do not lay your child down flat with a bottle when your child is awake
- Do not smoke around your child. Tobacco smoke is bad for the delicate parts inside your infant/child’s ear.

The best thing you can do is to pay attention to your infant/child. Know the warning signs of ear infections, and be on the lookout if your infant/child gets a cold. If you think your he/she has an ear infection, call your health care provider.

What are the effects of an ear infection/otitis media?

Ear infections not only cause great pain, but may end in serious problems if they are not treated. An untreated infection can move from the middle ear to the nearby parts of the head, including the brain. Although the hearing loss caused by an ear infection does not usually last, if not treated it can lead to hearing loss that does not go away. Lasting fluid in the middle ear and constant ear infections can lessen an infant/child’s hearing at a time that is very important for speech and language development (growth). Infants/children who have early hearing loss from many ear infections are likely to have speech and language problems.

How does an infant/child’s health care provider diagnose ear infections/otitis media?

The simplest way to tell if your infant/child has an ear infection, is to look in his/her middle ear with an otoscope, a light instrument that allows the health care provider to examine the outer ear and the eardrum. Inflammation of the eardrum can mean an infection. There are several ways that a health care provider checks for middle ear fluid:

The use of a special type of otoscope called a pneumatic otoscope allows the physician to blow a puff of air onto the eardrum to test eardrum movement. (An eardrum with fluid behind it does not move as well as an eardrum with air behind it.)

A good test to see if the middle ear is working correctly is called tympanometry. With this test, a small soft plug is placed into the opening of the infant/child’s ear canal. The plug contains a speaker, a microphone, and a device that is able to change the air pressure in the ear canal, allowing for several measures of the middle ear. The infant/child feels air pressure changes in the ear or hears a few brief tones. While this test provides information about the middle ear, it does not tell how well the infant/child hears. A health care provider may suggest a hearing test for an infant/child who has many ear infections to figure out the amount of hearing loss. The hearing test is usually done by an audiologist, a person who is specially trained to measure hearing.

What research is being done on ear infections/otitis media?

Several avenues of research are being explored to improve the prevention, diagnosis, and treatment of ear infections. For example, research is better defining those infants/children who are at high risk for developing ear infections and conditions that make certain people more likely to get middle ear infections than others. Emphasis is being placed on discovering the reasons why some infants/children have more ear infections than other children. The effects of ear infections on infants/children's speech and language development/growth are important areas of study. Just

as important is research to create more exact methods help health care providers pick up middle ear infections. How the defense molecules and cells involved with immunity respond to bacteria and viruses that often lead to ear infections is also being studied. Scientists are reviewing the success of certain drugs currently being used for the treatment of ear infections and are examining new drugs that may work better, be easier to give, and be better at keeping new infections from starting. Most importantly however, research is leading to the vaccines that will keep ear infections from happening.



How Hearing Works - Sound Basics

Before you can understand hearing loss, you must first get a general understanding of how the ear functions normally. However, in order to understand how your ears hear sound, you need first to understand just what sound is.

An object gives off sound when it moves in matter. Most of the time sound is heard when it moves through the air in our atmosphere (surroundings). When something moves in the atmosphere, it moves the air particles around it. Those air particles in turn move the air particles around them, carrying the pulse of the movement through the air.

To see how this works, look at a bell. When you hit a bell, the metal moves - flexes in and out. When it flexes out on one side, it pushes on the air particles on that side. These air particles then hit the particles in front of them, which hit the particles in front of them, and so on. This is called compression. When the bell flexes away, it pulls in on the air particles around it. This forms a drop in pressure, which pulls in more air particles around it, forming another drop in pressure, which pulls in particles even farther out. This drop in pressure is called rarefaction.

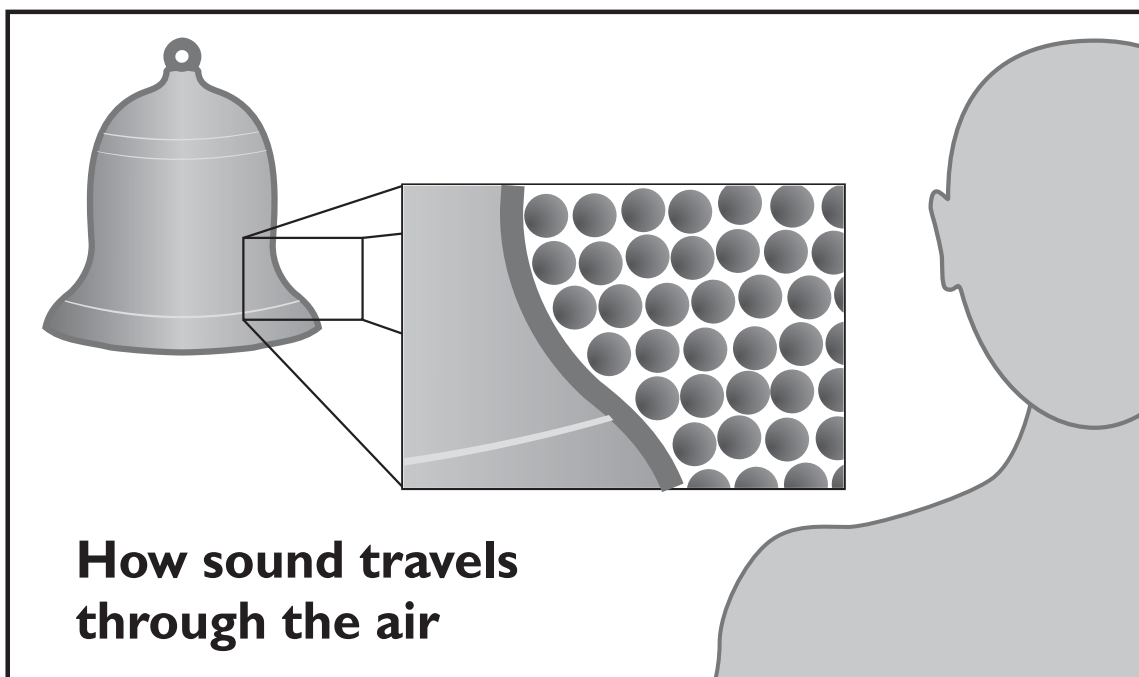
We hear different sounds from different moving objects because of differences in the sound wave frequency. A higher wave frequency simply means that the air pressure movement switches back and forth more quickly. We hear this as a higher pitch. The level of air pressure in each movement controls how loud the sound is.

How the ear works

To understand how the ear works completely, you must first learn how the ear(s) hear. The ear has three sections:

1. the outer ear
2. the middle ear
3. the inner ear

The outer ear is the part that can be seen on the outside of the head, and collects and sends sound waves down the outer ear canal to the middle ear. The middle ear includes the eardrum and three tiny bones that send the sound to the inner ear. The inner ear contains the cochlea that includes the sensory cells for hearing. These sensory cells are called hair cells.



Here is how the ear works normally:

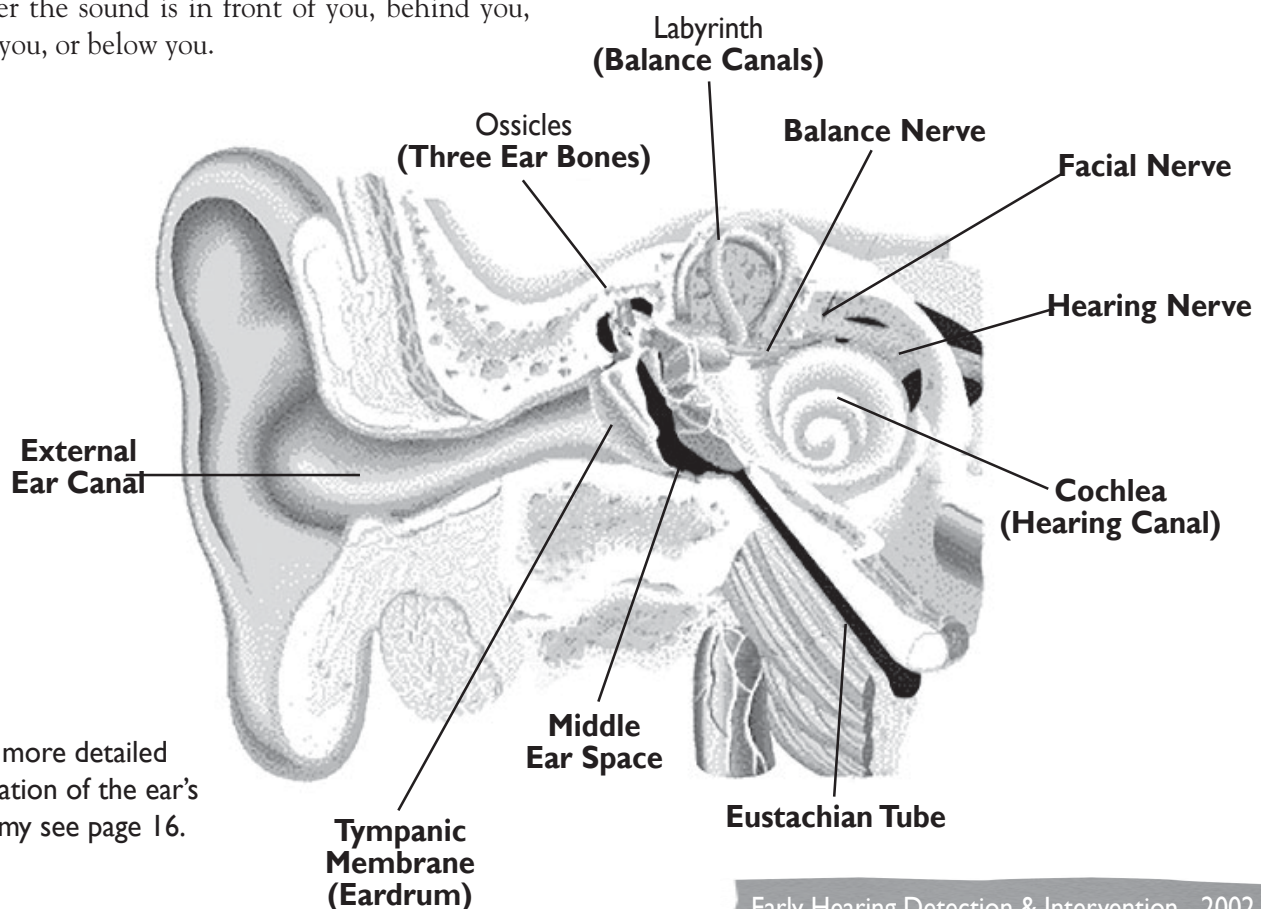
1. Sound is sent as sound waves from the environment (surroundings), gathered by the outer ear and sent down the ear canal to the eardrum.
2. The sound waves cause the eardrum to move, which sets the three tiny bones in the middle ear into motion.
3. The motion of these bones causes the fluid in the inner ear or cochlea to move.
4. The movement of the inner ear fluid causes the hair cells in the cochlea to bend. The hair cells change this movement into electrical signals.
5. These electrical signals are moved to the hearing (auditory) nerve and up to the brain where they are read as sound.

This can also be explained in a different way. The pinna, the outer part of the ear, serves to “catch” the sound waves. Your outer ear is pointed forward and it has a number of curves. This structure helps you figure out the direction of a sound. For example, if a sound comes from behind you, it will bounce off the pinna in a different way than if it is coming from in front of you or below you. This sound reflection (like a mirror image) changes the pattern of the sound wave. Your brain learns certain patterns and tells whether the sound is in front of you, behind you, above you, or below you.

Your brain can also tell the horizontal (flat) position of a sound by comparing the information coming from your two ears. If the sound is to your left, it will get to your left ear a little bit sooner than it gets to your right ear. It will also be a little bit louder in your left ear than your right ear.

Since the pinnae (outer ears) face forward, you can hear sounds in front of you better than you can hear sounds behind you. Many mammals, such as dogs have large, movable pinnae that let them focus on sounds from a certain direction. Human pinnae are not so skilled and cannot focus on such detailed sounds. They lay fairly flat against the head and do not have the necessary muscles for such movement. By cupping your ear, you can easily make your natural pinnae work like many animals.

With that information, you should be able to better understand what the ear does and how it hears sound. This should also make it easier to understand what your infant/child may, or may not, be hearing and ways to change your lifestyle to make it easier for him/her to communicate with you.



For a more detailed illustration of the ear's anatomy see page 16.

TESTS

*“Our children may learn
about heroes of the past.
Our task is to make ourselves
architects of the future.”*



Introduction

As your infant/child grows, many hearing tests will be done by a hearing loss specialist called an audiologist. Currently, the Auditory Brainstem Response (ABR) test, also called Brainstem Auditory Evoked Response (BAER), and Evoked OtoAcoustic Emissions (OAE), are available to examine hearing in newborns and infants up to six months of age. Once your infant/child reaches six months of age, there are several other tests that audiologists can do to check and measure his/her hearing loss. Some of the tests include the Behavioral Observation Audiom-

etry (BOA), Visual Reinforcement Audiometry (VRA), and Play Audiometry. (See the Terminology section.)

Each test will give the audiologist information about your infant/child's hearing loss. Most likely, many tests will need to be performed over a long period of time, to figure out the exact kind and amount of hearing loss your infant/child has.



Frequently Asked Questions

What is a decibel?

A decibel (shortened dB) is the unit used to measure the intensity of a sound, or how loud a sound is. On the decibel scale, the smallest sound a person is able to hear (near total silence) is 0 dB, and a sound 10 times more powerful is 10 dB. Any sound over 85 dB can cause hearing loss. This hearing loss (caused by too much noise, or noise-induced) is the result of both the loudness of the sound and how long a person hears the sound.

Near total silence _____	0 dB
A whisper _____	15 dB
Normal conversation _____	60 dB
Lawnmower _____	90 dB
A car horn _____	110 dB
A rock concert or a jet engine ____	120 dB
Gunshot, firecracker _____	140 dB

What is an audiologist?

An audiologist is a highly trained and licensed professional who specializes in the testing, evaluation, and management of hearing loss. The audiologist does tests to figure out the amount of hearing loss your child has, what type of hearing loss it is, and what type of help is needed.

How do I choose an audiologist?

Be sure that your audiologist is experienced in the testing and management of infants and young children. This is important because testing methods for infants and young children are different than those used for older children and adults who can talk and answer questions.

How can an infant/child's hearing be tested?

There are different ways to test an infant or young child's hearing. Some do not need any direct participation or effort from your child. Other tests rely on trained observation of your child's behavior when sound is present. Not all tests can be done on every child and every type of test gives different information. More than one type of test should always be performed to provide the most information possible.

What is an ABR?

An Auditory Brainstem Response test (may be referred to as ABR, AABR/BAER, and BSER) records the brain's response to sound through sensors that are placed on your infant/child's head. Small earphone inserts that look like earplugs, are placed into his/her ear(s) to send the sound. The test requires no direct reply or response from your infant/child. For best results, your infant/child must be asleep since movement can interfere with the test. A diagnostic ABR gives the audiologist information about the amount and type of hearing loss that your infant/child may have.

What is an OAE?

An Otoacoustic Emissions (OAE) test is a simple test to gather general information about your infant/child's hearing. A small probe is placed into your child's ear canal, after which sounds are carried inside the ear. A normal cochlea (hearing part of the ear) will send a signal back in reply/response. If no signal from the cochlea is picked up by the probe, then there may be a hearing loss. This test cannot measure how much hearing loss is present. It can only tell if the cochlea is working correctly or not.

What are BOA, VRA and Play Audiometry?

Behavioral Observation Audiometry (BOA), Visual Reinforcement Audiometry (VRA), and Play Audiometry are other methods used to review your child's hearing. These tests are all done in a soundproof booth and should include testing for both tones and speech.

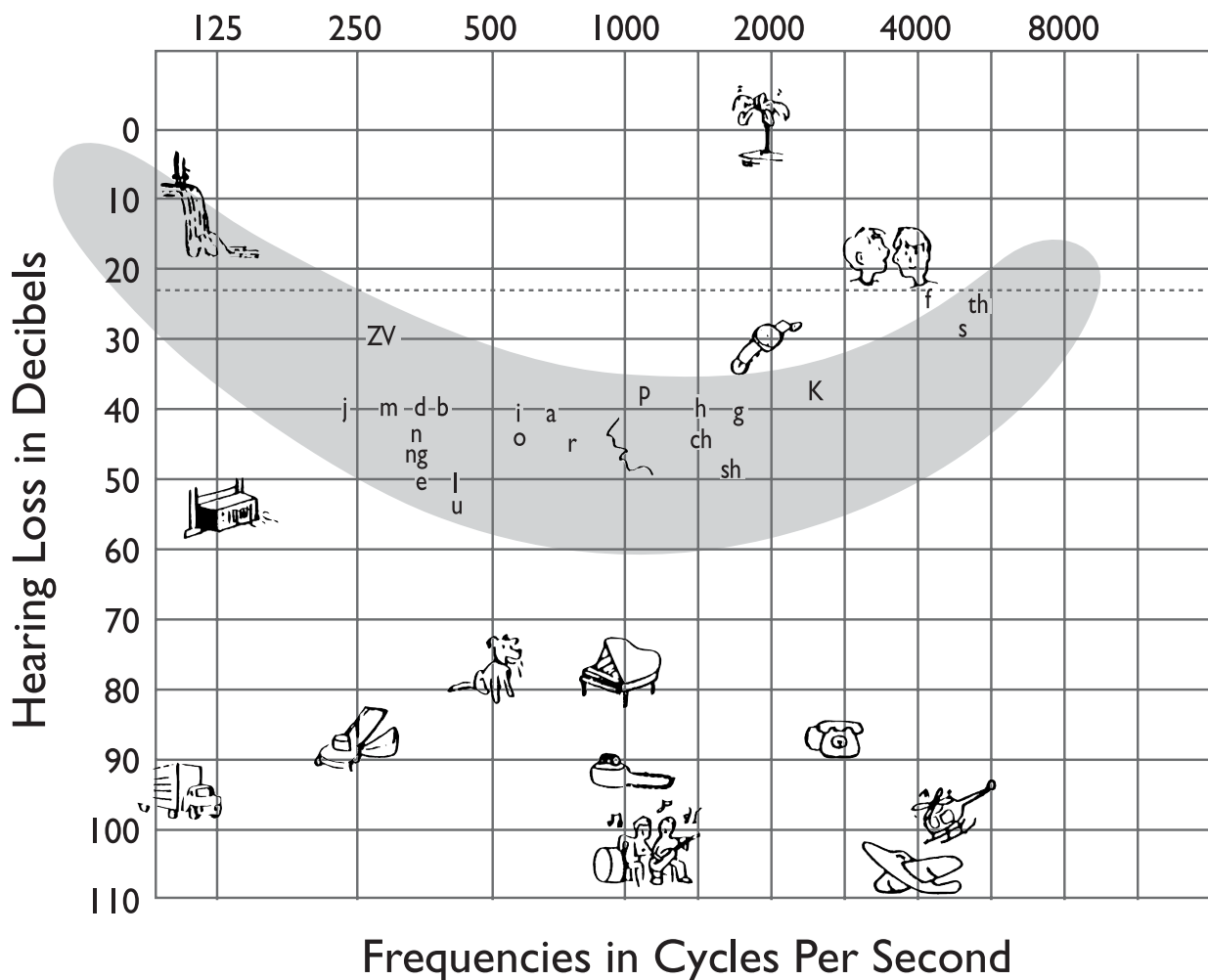
- Behavioral Observation Audiometry (BOA): This is used for infants up to approximately six to nine months of age. In this test, the audiologist closely watches your infant/child's face and body for changes in actions when he/she hears different sounds. Such actions include eye blinking and widening, changes in sucking, trying to find sound/s, and/or body tensing. Although this test gives important information, it should never be used alone to figure out whether or not your infant/child has a hearing loss.

- Visual Reinforcement Audiometry (VRA): This test is generally used for infants and young children from six months to two or three years of age. In this test, the audiologist trains your infant/child to look at a toy that lights up and/or moves whenever he/she hears the sound. Like the BOA, the VRA should not be the only test used to diagnose, or decide whether or not your infant/child has a hearing loss.
- Play Audiometry: This test is generally used for children three to six years of age. In this test, the audiologist trains your child to drop a block in a bucket (or do something like it) whenever a sound is heard. Your child may also be asked to point to simple pictures when told or shown to do so.

What is an audiogram?

An audiogram is a graph, or picture, on which the audiologist draws the findings of your infant/child's responses to different sounds, and the loudness (decibel) level at which your infant/child can hear that sound. An ABR audiogram can give a good idea of your infant/child's hearing level, usually within ten decibels of the actual hearing loss. The audiogram that you get through behavioral (your infant/child's actions) tests may give you more exact information. However, the findings depend on if, and how, your infant/child helps, or takes part in, these tests. As your infant/child gets older, you can get a more detailed audiogram done. A complete audiogram will show the loudness level at which your infant/child can hear different levels of sound in each ear with and without hearing aids.

The "Speech Banana"



What is tympanometry?

Tympanometry is not a hearing test. It measures the movement of your infant/child's eardrum (tympanic membrane) and the ability of the middle ear system to move sound to the inner ear. During the test a small probe is placed into your child's ear canal, and there is a slight change in air pressure. The feeling is very much like the feeling of air pressure change when riding in an elevator. Tympanometry can determine if there is middle ear fluid that is changing the hearing test results.

What does the ABR/BAER look at?

Just like how an electroencephalogram (EEG) looks at the way brain waves work, the ABR/BAER looks at how brain waves change when different sounds are heard by the auditory (hearing) part of the body. As the sound travels into the ear, it is changed into nerve signals by the tiny, hair-like nerve fibers of the cochlea (hearing part of the ear). These tiny nerve fibers come together at the auditory (hearing) nerve, which conducts the signals through to the brain. Research has shown that the lower parts of the brain, called the brainstem, are very important in the working of a healthy auditory (hearing) system. During the ABR/BAER test, by putting sounds at several volume (loudness) levels into the ear, we can see if the brainstem is working well. This information can give us a good idea of how well someone can hear.

How is the ABR/BAER test done?

Typically, the ABR/BAER test is done by an audiologist. Your health care provider or current audiologist will most likely refer you to a professional who can do the test, if the test cannot be done at their office.

The audiologist uses a special computer to get and analyze, or study, the ABR/BAER. A soft, foam earplug is placed in your infant/child's ear. This earplug will send sounds at different volume (loudness) levels into the auditory (hearing) part of the body in the ear. Electrodes are placed on your infant/child's

forehead and ear lobes. These electrodes carry tiny, nerve-like signals to the computer. The computer reads these signals and creates a special wave form on paper. By looking at the shape and size of these wave forms, the audiologist can tell if your infant/child has a hearing loss or not, as well as, what type of hearing loss they may or may not have.

Why might an ABR/BAER test not be normal?

There are many reasons why an ABR/BAER test might not be normal.

1. Most importantly, if your child has a hearing loss, that will cause the ABR/BAER test not to be normal. The audiologist can tell if the hearing loss is caused by something not working in the outer or middle ear, or if it is because of a problem with the inner ear.
2. Some neurological (brain) conditions, or illnesses, can also cause ABR/BAER tests not to be normal, or abnormal. An abnormal ABR/BAER can also be caused if your infant/child moves during the test, so it is very important for him/her to stay still while the test is being done. Usually, infants/young children need to be sleeping during this procedure.

How do I know if my child needs to have an ABR/BAER test?

Your infant/child's health care provider may suggest that you see an audiologist for other, earlier tests before an ABR/BAER is done. Usually, the audiologist will try to get responses/replies to sounds through behavioral (action) testing. If the findings of these earlier tests do not give what is needed, the audiologist will likely suggest that an ABR/BAER test be done to rule out hearing loss. Currently in Alaska, two hospitals can do ABR/BAER tests for newborn infants; 1) Providence Alaska Medical Center and 2) Alaska Native Medical Center, both in Anchorage. In addition to diagnostic testing, follow-up with your infant/child's health care provider or an otolaryngologist (a ear, nose, throat doctor) may be also be suggested.

Tests

Questions for parents to begin asking about their infant/child's hearing tests?

- What does this test measure? What will this test tell me about my infant/child's hearing loss?
- How does this test work?
- Why do we do this test at this time?
- What are you looking for with this test? What do you expect to find with this test?
- How do we read the results or findings of this test?

The audiologist (hearing loss specialist) is an important part of your infant/child's team of caregivers. Make sure that he/she is willing to listen to you and take time to answer your questions. Following are some questions that you may want to ask your audiologist:

- How much experience do you have testing infants and young children? How about fitting infants and young children with hearing aids?
- How much of your time do you spend working with young children (practicing pediatric audiology)?
- Do you know what FM systems are? Do you recommend them for infant/young children?
- How soon do you suggest fitting hearing aids for a deaf or a hard-of-hearing infant/child? (The audiologist should be ready to fit your infant/child with hearing aids as soon as the loss is confirmed.)
- Will you be able to direct me to the speech and language pathologists? How about early intervention programs? (If not, the audiologist probably does not have many pediatric (infant/children) patients.)
- What do you know about cochlear implants? Where can I get more information about them?

"I've learned that it's not what happens to people that's important. It's what they do about it."

— 10 year old

EARLY INTERVENTION

*“It’s not that we’re fixing a delay,
we seem to be preventing it
from ever occurring.”*

— Dr. Christine Beckinga Horn



Introduction

One of the most amazing and important happenings that will take place during your infant/child's early years is the learning of language. Babies start to say their first words around one year of age. Around age 4, they know more than 1500 words and begin telling stories. Children learn language skills during the preschool years and these work as a wonderful base for learning in school.

Children with solid language skills often become strong readers and writers. When an infant is born with a hearing loss, this learning of language can be delayed, or not on time. Such delays can be prevented, or lessened, by finding hearing loss early (early detection) and taking action to help your infant/child learn (intervention). Family members can help with infant/children's language, listening and speech while doing natural, daily routines. The following section will give you important information about early intervention, ideas about how you and your family can help your infant/child learn language, and places to find support for your whole family.

Early intervention begins soon after your infant/child has been found to have a hearing loss. Intervention, or help, will usually be provided by Early Intervention/Infant Learning Program (EI/ILP), in or near your community.

The early intervention that you will get through working with EI/ILP can help you understand hearing loss and gain confidence as a parent of a deaf or hard of hearing child. It also will guide you in identifying your infant/child's strengths and needs, and help him/her develop important language skills necessary to become part of the larger community.

There are two main goals of early intervention:

Goal #1 is to help your infant/child who is deaf or hard of hearing, learn how to communicate, use any available hearing, and to interact with others. All children learn skills best at certain ages. During these "important periods," your infant/child's brain is ready to learn. If these learning chances are missed, it will be harder to learn the skills later in life.

Goal #2 is to help your infant/child become a fully participating member of the family. Everyone in the family is important to your infant/child's development, especially in learning language and social skills. For example, you will want your infant/child to know what your family talks about at mealtime, and what his/her big brother and sister did at school. And, like all other young children, you will want your infant/child to understand where you are going when you get into the car, when it's time to go to bed, to play, and so on.

"I've learned that when I grow up, I'm going to be an artist. It's in my blood."

— 8 year old

Frequently Asked Questions

What is early intervention?

Early intervention is the term used for many services available to children, ages birth to 3 years, who have disabilities or developmental delays. A federal law, the Individuals with Disabilities Education Act (IDEA) Part C, covers early intervention services and outlines the rules for those infants/children that qualify for these services. Early intervention services may include home visits, family training, counseling, special instruction, and therapy. These “early intervention” services are set up to help families help their infant/child be the best he/she can be.

How will I decide what services are provided?

After your infant/child’s assessment/evaluation, an Individual Family Service Plan (IFSP) will be developed. Your family works with a team (usually the same people who reviewed your infant/child) to review all of the information gathered about your infant/child. If deaf education services are being considered, a teacher of the deaf is always part of the team. You will want to ask your infant/child’s audiologist to also be involved in the development of the Individualized Family Service Plan (IFSP). The plan is based on the results that you want most for your child’s development. You and the professionals then decide on ways and services to help your infant/child reach these results.

Who provides the services?

The IFSP states who will offer each service and who is in charge of each service. A Family Service Coordinator will work with your family to support your child’s development, and to arrange for services in and outside of the Early Intervention/Infant Learning Program.

Where can I find more information about early intervention services in Alaska?

Early intervention services in Alaska are offered through the Early Intervention/Infant Learning Programs and can be found in 22 communities throughout Alaska. These programs are managed by the State of Alaska, Department of Health & Social Services, Division of Public Health, Section of Maternal, Child & Family Health, Special Needs Ser-

vices Unit. If you are unable to find your ILP Providers in the Resource section, call Alaska Info at 1-800-478-2221 or visit the AK Info website at www.ak.org.

What is the Early Intervention/Infant Learning Program?

The Early Intervention/Infant Learning Program (EI/ILP) is a family-centered program for children from birth to three years of age. They work with families whose children may have difficulties with:

- Communication/speech
- Movement
- Social/behavior
- Thinking/reasoning
- Vision/hearing
- Feeding/dressing

What can the Early Intervention/Infant Learning Program do?

- Check whether your infant/child’s learning is moving forward normally. If your infant/child is not, EI/ILP can help to figure out whether there is a developmental delay.
- Give you information about developmental milestones.
- Work with your family to form an individualized plan of services for infants/children who qualify.
- Offer services such as special instruction in occupational (work/job) therapy, physical therapy and speech therapy, and other activities and materials to improve your infant/child’s learning.
- Offer your family information and support in finding other services and assistance.

Why are Early Intervention/Infant Learning Program services important?

- The first years of your infant/child’s life are the most important ones in their growth/development.
- Every infant/child develops at their own speed/rate.
- Infants and toddlers learn by playing.
- You, as the parents or caregivers, are the most important people in moving along your infant/child’s growth/development.

Who should contact the Early Intervention/Infant Learning Program?

Any person that is worried about an infant/child's growth/development can contact EI/ILP. These people include parents, friends, healthcare providers, and social, health and education services agencies.

Who can apply for and receive services?

1. Any child who is born prematurely (early), or is in any way "at risk" of developing a delay.
2. Any child whose assessment/review points toward a setback in one or more developmental areas, such as:
 - Significant/progressive hearing loss
 - Down Syndrome
 - Complex seizure disorder
 - Cerebral palsy
 - Hydrocephaly
 - Congenital heart disease
 - Fetal Alcohol Syndrome (FAS)
 - Bronchopulmonary dysplasia (BPD)

How do I know if I can apply for the Early Intervention/Infant Learning Program for my infant/child?

Alaska law states that for an infant/child to qualify for Part C of the IDEA law, that infant/child must have a fifty percent or greater developmental delay in one or more areas of development listed above. In addition, a health care provider must state that the delay is present in the infant/child or that a diagnosed condition, illness, will most likely end up in such a delay. The state EI/ILP regulations (rules) allow infants/children with delays or risk factors that are not listed above, to be enrolled with limited services, if there is available funding.



How much will the Early Intervention/Infant Learning Program cost?

Some services including child find, evaluation and assessment (review), forming a special plan of services for your infant/child and service coordination, are offered FREE to families. There may be a fee for some Early Intervention/Infant Learning Program services, but no one will be not be given services because they are not able to pay.

Where are the services?

Early Intervention/Infant Learning Programs serve children throughout Alaska. Services can be offered in the natural surroundings for your infant/child, such as your own home, or other settings, such as a child care center.

What does the Early Intervention/Infant Learning Program system offer for children who have disabilities but do not qualify for services offered through the state Part C definition?

All families sent to the system who are not put into services are offered re-screening of their child's developmental progress on a routine basis, and receive a developmental status report and suggested home activities to improve their child's development.

Where can I get more information about the Early Intervention/Infant Learning Program?

Contact the Early Intervention/Infant Learning Program at:

Department of Health & Social Services
Maternal, Child and Family Health
3601 C Street, Suite 934
P.O. Box 240249
Anchorage, Alaska 99524-0249
Anchorage (907) 269-3400
Statewide 1-800-478-2221
www.state.ak.us/dph/mcfh/default.htm

How can I find out who the ILP provider is in my community?

See list of providers in Resources section.

Check List

- Do I think that my infant/child might have a hearing loss? Call your infant/child's health care provider now!
- Does my infant/child have a hearing loss? Call your infant/child's health care provider for the name of an audiologist (hearing loss specialist), an otolaryngologist (ear, nose, and throat doctor), and the Early Intervention/Infant Learning Program in your community (see Resource section for contact information).
- Are there other parents I can talk to? Call the audiologist or the Early Intervention/Infant Learning Program in your community for a referral (see Resource section for contact information).
- Are new people always being added to my infant/child's intervention team? Find out who they are from the service coordinators and write down their names, phone numbers, addresses, and e-mail addresses.
- What are my goals for my infant/child and for our family? Write them down and plan to share them with the infant/family specialist.
- Am I beginning to notice so many little kinds of progress that I forget them by the end of the day? Start a diary and write just a few words about each little improvement in your infant/child's growth.
- Have I found a pediatrician, an ear, nose, and throat (ENT) doctor, and an audiologist who really understand my infant/child and listen to me? Keep up the relationship.
- Have I found support for my family and myself? Remember to take care of everyone's needs. The whole family is important.

Team Members

The professionals who will play a part in the management and care of your infant/child's hearing loss are all members of your infant/child's team of experts. It is important for you, as parents, to have these experts on your team. However, don't ever forget that you are the only ones who can be the team manager or coach, and speak up for your infant/child. You know your child best! It does not matter how much professionals know, don't ever let them take your place in the management and care of your infant/child's education and development/growth.

You will probably meet the members of the team in the following order:

1. A health professional pediatrician (infant/child doctor), family doctor, or public health nurse
2. An audiologist (hearing loss specialist)
3. An otorhinolaryngologist (ear, nose, and throat doctor)
4. A child service coordinator
5. A speech and language pathologist
6. A teacher of the deaf or hard of hearing



How to Choose an Audiologist

The audiologist is a vital part of your child's team of caregivers. Make sure that he/she is willing to listen to you and take time to answer your questions. Following are some questions that you may want to ask your audiologist:

- How much experience do you have testing children? Fitting infants with hearing aids?
- How much of your practice is devoted to pediatric audiology?
- Are you familiar with FM systems? Do you recommend them for young children?
- How soon do you recommend fitting hearing aids for a deaf or a hard-of-hearing child? (The audiologist should be ready to fit your child with hearing aids as soon as the loss is confirmed.)
- Will you be able to direct me to the speech and language pathologists? To early intervention programs? (If not, the audiologist probably does not have many pediatric patients.)
- What do you know about cochlear implants? Where do I get more information?



Questions to Ask an Audiologist

The audiologist (hearing loss specialist) is an important part of your infant/child's team of caregivers. Make sure that he/she is willing to listen to you and take time to answer your questions. Following are some questions that you may want to ask your audiologist:

- How much experience do you have testing infants and young children? How about fitting infants and young children with hearing aids?
- How much of your time do you spend working with young children (practicing pediatric audiology)?
- Do you know what FM systems are? Do you recommend them for infant/young children?
- How soon do you suggest fitting hearing aids for a deaf or a hard-of-hearing infant/child? (The audiologist should be ready to fit your infant/child with hearing aids as soon as the loss is confirmed.)
- Will you be able to direct me to the speech and language pathologists? How about early intervention programs? (If not, the audiologist probably does not have many pediatric (infant/children) patients.)
- What do you know about cochlear implants? Where can I get more information about them?

Questions for parents to begin asking about their infant/child's hearing tests?

- What does this test measure? What will this test tell me about my infant/child's hearing loss?
- How does this test work?
- Why do we do this test at this time?
- What are you looking for with this test? What do you expect to find with this test?
- How do we read the results or findings of this test?

“Be gentle with yourself, learn to love yourself, to forgive yourself, for only as we have the right attitude toward ourselves can we have the right attitude toward others.”

— Willard Peterson

Infant Learning Program (ILP) - Individualized Family Service Plan (IFSP)

The Individualized Family Service Plan must contain the following:

- A statement of your infant/child's present level of development/growth.
 - A statement of your family's resources, priorities, and concerns about your infant/child.
 - A statement of the major outcomes expected.
 - A statement of specific early intervention services necessary.
- A statement of the natural surroundings (such as the home or a community setting) in which early intervention services will be done, including reason(s) if services are not provided in natural surroundings.
 - The beginning dates of services, and length of those services.
 - The service coordinator who will be in charge of putting the plan into place.
 - The steps to be taken to support your child's move to preschool or other services.



GENETIC COUNSELING

*“It takes as much courage
to have tried and failed
as it does to have tried
and succeeded.”*

— Anna Plavone Lindbergh



Check List

What indicators are related to hearing loss in newborns?

A baby is “at risk” (has a greater chance) for possible hearing loss if one or more of these signs are present:

- Family history of childhood hearing loss
- Infection during pregnancy (rubella, cytomegalovirus/CMV, syphilis, herpes, or toxoplasmosis)
- Birth defects of the head and neck (for example, deformed outer ear)
- Low birth weight (under 3.3 pounds)
- Jaundice or yellowing of the skin at birth (Hyperbilirubinemia)
- Bacterial meningitis (illness)
- Medicines for the ear (Ototoxic)
- Respirator (mechanical ventilation) for more than five days
- Apgar scores of 0 to 4 at one minute or 0 to 6 at five minutes. (This score is given at the time of birth to figure out the newborn’s condition. The score comes from evaluating the newborn’s heart rate, respiratory/breathing effort, muscle tone, reflex irritability, and color. A score of 0 –2 is related on each of the five items, the highest possible score being 10.)

Frequently Asked Questions

What is genetic counseling and why should I have it done?

According to the Joint Committee on Infant Hearing, all families who have infants/children with hearing loss that do not have a clear-cut reason for why their child has a hearing loss, should be given the choice of genetic evaluation and counseling by a medical geneticist. Many people think that the main reason for such genetic evaluation (review) and counseling is so the family can know about their chances of having more infants/children with hearing loss. Actually, the genetic evaluation tells much more important information that can have an important impact on how the infant is treated. For example, whether an infant/child's hearing loss will become worse can sometimes be predicted if the specific cause is known. Also, for many infants, deafness is only one of the medical problems the child may have, and genetic testing may tell whether the infant is likely to have other problems with the heart, kidneys, or eyes.

What is the genetics clinic?

As more is learned about how inheritance (family genes) affects health, physicians, health care providers, and patients are looking for information about genetic services. Specifically, people ask for genetic testing for specific disorders and why this is useful.

Sometimes genetic counseling is provided as part of a multidisciplinary (more than one provider) evaluation in a specialty clinic, but usually genetic services are provided through a genetics clinic in a hospital or university setting. The genetic clinic's purpose is to provide an individual or family with one or more of the following:

- Confirm or rule out the diagnosis of a genetic condition
- Find medical management issues and support services
- Figure out and discuss genetic risks/chances
- Provide or arrange for psychosocial support

Diagnostic testing is used to rule out a known or suspected genetic disorder in a symptomatic person. Genetic testing is usually by chromosome analysis

(karyotype), DNA test (molecular testing), or biochemical testing. It may give diagnostic information at a lower cost with less risk than other procedures. It may also allow for predictive (foretell) testing, carrier testing or prenatal (before birth) testing in other family members.

Who is involved in the genetic clinic?

The Alaska Genetics Clinics are funded by the State of Alaska, through a contract with Children's Hospital and Medical Center in Seattle. Health care providers travel to different hospitals and public health clinics throughout the state. The staff, or genetics practitioners, consist of:

1. Physicians who are board certified by the American Board of Medical Genetics in clinical genetics
2. Genetic counselors with graduate degrees in human genetics, and are certified by the National Society of Genetic Counselors
3. Public health nurses

In addition to the general genetic appointments, the 2003 Alaska Genetics Clinic schedule will offer clinics with a specific focus. These clinics include adult genetics, pediatric genetics, inherited eye disorders, cancer, hearing loss, and neurogenetics. Two more clinics for the diagnosis and treatment/management of metabolic genetic disorders/conditions include a nutritionist and biochemical geneticist.

Who pays for the genetic clinic appointment?

Usually third party coverage, such as private insurance, Tri-Care, Indian Health Service, Denali Kid Care, Medicaid or Medicare, will cover the cost of the clinic evaluation. The fee is generally between \$150-200. Genetic testing is billed separately by the laboratory. If a family has no coverage, a sliding fee scale is offered.

When does the genetic clinic meet?

The Alaska Genetics Clinic meets every other month in Anchorage, and less often in Bethel, Dillingham, Fairbanks, Juneau, Ketchikan, Kodiak, and Sitka. The clinic meets at The Children's Hospital at Providence Alaska Medical Center or

Alaska Native Medical Center in Anchorage, and at public health clinics in the other towns. A calendar of clinics, plus contact coordinators and medical directors is published each year. It is available from the Department of Health & Social Services, Division of Public Health, Section of Maternal Child and Family Health, (907) 269-3430 or (800) 799-7570 (in-state only).

How does a provider refer or contact the genetic clinic?

Letters of referral and supporting medical information can be faxed or mailed to the local coordinator, or to the Anchorage office (1-800-799-7570 or 907-269-3465). The address is State of Alaska, Alaska Genetics Clinic, P. O. Box 240249, Anchorage, AK 99524-0249. The clinic coordinator will contact your family by telephone or home visit to set up the appointment, answer your questions about genetic services, and gather medical and family history information. At the clinic, your family will be alone and by appointment only. Infants, children, and adults are seen at all clinics.

Physicians may contact the Alaska Genetics Clinic medical director at Children's Hospital and Regional Medical Center in Seattle for information about a referral or genetic condition. The telephone number is (206) 526-2056. The telephone number for MEDCON (University of Washington toll free consultation and referral service) is (800) 326-5300.

What role does the genetic clinic play in the evaluation of hearing impaired infants?

Genetic forms of hearing loss frequently bring to mind hearing loss connected with birth defects and conditions. More than 400 genetic syndromes/conditions with hearing loss have been described, and this is why it is important to consider it in infants. Statistically it accounts for up to thirty percent of all deafness that takes place before infants begin speaking, but its contribution to all deafness is much smaller.

For more than seventy percent of hereditary (in family genes) hearing loss, there are no symptoms or warning signs. Even though seventy percent of hereditary hearing loss is not syndromic (no obvious signs), a genetic evaluation can provide important information about:

- The etiology (the cause of the hearing loss)
- The prognosis (the future of the hearing loss and its chances for getting better or worse)
- The recurrence in future infants/children (the chance/s that other children born to the same parents will also have hearing loss)
- Carrier testing (tests to figure out which parent(s) may have hearing loss in their families)

“I’ve learned that everyone has something to teach.”

— Anonymous

ASSISTIVETECHNOLOGY

*“The new electronic independence
recreates the world in the image
of a global village.”*



Introduction

Assistive Listening Devices (ALD) are amplification systems specially made to help people hear better in many difficult listening conditions. Even hearing aids can be thought of as assistive listening devices. Most of these devices can be used with a personal hearing aid that has a telecoil (or t-switch), or by themselves to do the following:

- To help overcome background noise
- To decrease the negative impact and sound distortions of distance from the sound source

The basic function of an ALD is to improve the “signal to noise ratio” for the listener. This means that wanted sounds (signals) are amplified (increased), and not wanted sounds (noises) are made smaller.

The most common types of ALDs used with infants/children include Sound Field Systems, FM Systems, Infrared Systems, and Loop Systems. (See Terminology Section for definitions of these systems.)

The selection of the proper hearing aid is one of the first important tasks that you, as parents may or may not have to face. Therefore, it is critical that you understand what hearing aids will and will not do for your infant/child. Even though the hearing aid is essential, it is an aid and will only use your infant/child’s residual hearing, or the hearing that he/she does have. A hearing aid is not a cure. It will not allow a child to hear “normally.”

“My advice to you is to buy great hearing aids. It will pay off. Stand up for your child, it might take a little extra effort, but is well worth the time. Don’t get bothered by having to repeat some things, don’t say ‘forget it’. Hard of hearing people are normal people who have a slight disability.”

— Douglas (age 11)

Facts About Telecommunications Relay Services

The Americans with Disabilities Act (ADA) of 1990 went into effect on July 26, 1993. Title IV of the ADA requires all telephone companies across the United States to provide telecommunications relay services.

A telecommunications relay service (TRS) allows people who are deaf, hard of hearing, or speech impaired to communicate through a communications assistant (CA) with people who use a standard telephone. A CA relays the TTY (text telephone or telecommunications device for deaf and hard of hearing people) input to the telephone user and types that person's response back to the TTY user. Telecommunications relay services can be reached by dialing 711.

Just as you can dial 411 for information, you can dial 711 to access all telecommunications relay services anywhere in the United States. The 711 access eliminates the difficulties that individuals have in finding and remembering various relay numbers from state to state. The relay service is free.

CAs are trained to be as unobtrusive as possible during a call. A CA's responsibility is to relay the conversation exactly as it is received. All relay calls are confidential.

Regardless of which long-distance company or organization is providing a state's relay service, callers can continue to use the long-distance company of their choice.



Two options when using a telephone relay service are voice carry-over (VCO) and hearing carry-over (HCO). VCO allows a person with a hearing impairment to speak directly to the other party and then read the response typed by a CA. HCO allows a person with a speech impairment to hear the other party and relay the TTY response back to the telephone user through the CA. This service allows people with communication disorders to communicate with all telephone users.

For more information on telecommunications relay services, please visit the Federal Communications Commission at www.fcc.org/cib/consumerfacts/trs.html.

Hearing Aids - Frequently Asked Questions

What is a hearing aid?

A hearing aid is an electronic, battery-operated device that amplifies (increases) and changes sound to allow for better communication. Hearing aids receive sound through a microphone, which then change the sound waves to electrical signals. The amplifier increases the loudness of the signals and then sends the sound to the ear through a speaker.

How can hearing aids help?

On the basis of the hearing test results, the audiologist can figure out whether hearing aids will help. Hearing aids are very useful in improving the hearing and speech understanding for people with sensorineural hearing loss. When choosing a hearing aid, the audiologist will consider your infant/child's hearing ability, work and home activities, physical limitations, medical conditions, and what you would like regarding the way the hearing aid(s) look on him/her. For many people, cost is also an important factor. You and your audiologist must decide whether one or two hearing aids will be best for your infant/child. Wearing two hearing aids may help balance sounds, improve understanding of words in noisy situations, and make it easier to locate the source of sounds.

What are the different kinds of hearing aids?

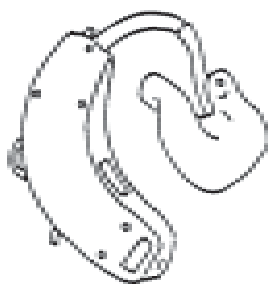
There are several types of hearing aids. Each type offers different advantages, depending on its design, levels of amplification, and size. Before purchasing any hearing aid, ask whether it has a warranty that will allow you to try it out on your infant/child. Most manufacturers allow a 30 to 60 day trial period during which aids can be returned for a refund.

There are four basic styles of hearing aids for people with sensorineural hearing loss:

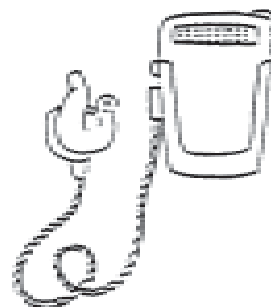
- *In-the-Ear (ITE)* hearing aids fit completely in the outer ear and are used for mild to severe hearing loss. The case, which holds the parts that make up the hearing aid, is made of hard plastic. ITE aids can accommodate added technical mechanisms such as a telecoil, a small magnetic coil contained in the hearing aid that improves sound transmission during telephone calls. ITE aids can be damaged by earwax and ear drainage, and their small size can cause adjustment problems and feedback. They are not usually worn by infants/children because the casings need to be replaced as the ear grows.
- *Behind-the-Ear (BTE)* hearing aids are worn behind the ear and are connected to a plastic ear mold that fits inside the outer ear. The parts are held in a case behind the ear. Sound travels through the ear mold into the ear. BTE aids are used by people of all ages for mild to profound hearing loss. Poorly fitting BTE ear molds may cause feedback, a whistle sound caused by the fit of the hearing aid, or by buildup of earwax or fluid.
- *Canal Aids* fit into the ear canal and are available in two sizes. The *In-the-Canal (ITC)* hearing aid is customized to fit the size and shape of the ear canal and is used for mild or moderately severe hearing loss. A *Completely-in-Canal (CIC)* hearing aid is largely concealed in the ear canal and is



In-The-Ear Aid
(ITE)



Behind-The-Ear Aid
(BTE)



Body Aid

used for mild to moderately severe hearing loss. Because of their small size, canal aids may be difficult for the user to adjust and remove, and may not be able to hold additional devices, such as a telecoil. Canal aids can also be damaged by earwax and ear drainage. They are not typically recommended for children.

- *Body Aids* are used by people with profound hearing loss. The aid is attached to a belt or a pocket, and connected to the ear by a wire. Because of its large size, it is able to incorporate many signal processing options, but it is usually used only when other types of aids cannot be used.

Do All Hearing Aids Work the Same Way?

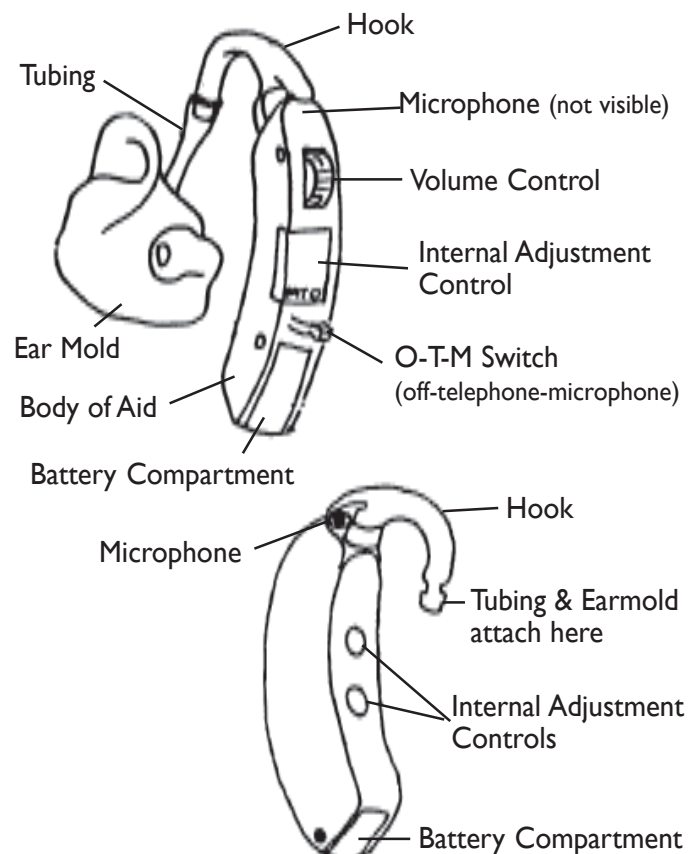
The inside mechanisms, or parts, of hearing aids vary among devices even if they are the same style. Three types of circuitry, or electronics, are used:

- *Analog/Adjustable*: The audiologist determines the volume and other specifications you need in your hearing aid, and then a laboratory builds the aid to meet those specifications. The audiologist has some flexibility to make adjustments. This type of circuitry is generally the least expensive.
- *Analog/Programmable*: The audiologist uses a computer to program your hearing aid. The circuitry of analog/programmable hearing aids will accommodate more than one program or setting. If the aid is equipped with a remote control device, the wearer can change the program to accommodate a given listening environment. Analog/programmable circuitry can be used in all types of hearing aids.
- *Digital/Programmable*: The audiologist programs the hearing aid with a computer and can adjust the sound quality and response time on an individual basis. Digital hearing aids use a microphone, receiver, battery, and computer chip. Digital circuitry provides the most flexibility for the audiologist to make adjustments for the hearing aid. Digital circuitry can be used in all types of hearing aids and is typically the most expensive.

What questions should I ask before buying hearing aids for my infant/child?

Before you buy a hearing aid, ask your audiologist these important questions:

- Are there any medical or surgical considerations or corrections for my infant/child's hearing loss?
- Which design is best for my infant/child's hearing loss?
- What is the total cost of the hearing aid?
- Is there a trial period to test the hearing aids? What fees are nonrefundable if they are returned after the trial period?
- How long is the warranty? Can it be extended?
- Does the warranty cover future maintenance and repairs?
- Can the audiologist make adjustments and provide servicing and minor repairs? Will loaner aids be provided when repairs are needed?
- What instruction does the audiologist provide?
- Can assistive devices such as a telecoil be used with the hearing aids?



What Are Some Tips for Taking Care of My Infant/Child's Hearing Aids?

The following suggestions will help you care for your infant/child's hearing aids:

- Keep hearing aids away from heat and moisture.
- Replace dead batteries immediately.
- Clean hearing aids as instructed.
- Do not use hairspray or other hair care products while wearing hearing aids.
- Turn off hearing aids when they are not in use.
- Keep replacement batteries and small aids away from pets.

How long each day does my infant/child have to wear hearing aids?

Your infant/child should wear the hearing aids all day, every day except when bathing or sleeping. Wearing both hearing aids during all possible waking hours will give your infant/child the best opportunity to listen to all the sounds around him/her.

How do I take care of the hearing aids?

- Hearing aids are tough but not unbreakable.
- Be sure to keep the hearing aids away from excessive heat (for example, glove box of car, heaters, windowsill).
- Do not put them in water.
- Keep hearing aids away from animals. A dog or cat can chew the hearing aids and ear molds.
- Have a set routine every day and night for the care of the hearing aids.
- Store the aids in a specific place when not worn.
- Dispose of hearing aid batteries safely as they are dangerous if swallowed. If your infant/child does swallow a battery, take him/her to the emergency room immediately.

What do I need to know about caring for ear molds?

It is important that ear molds fit tightly and comfortably so that the hearing aid can perform as well as possible. For infants, ear molds may have to be made frequently. As your infant/child gets older and growth slows down, ear molds will fit for a longer time period. After a few weeks, the ear mold may turn a yellowish color around the canal portion (the area that goes into the ear canal). This is a stain caused by cerumen (earwax) and is not harmful. You

can wash ear molds with warm soapy water (do not use alcohol unless your infant/child has a “draining ear”) and be sure they are completely dry before putting them back onto the hearing aid. If the tubing attached to the ear mold becomes yellow and brittle, it can affect the sound. Your audiologist can replace the tubing.

How do I make sure my infant/child's hearing aid is properly fitted?

A properly fitted hearing aid should be expected to do the following:

- Increase sounds to a level that the infant/child can hear.
- Be tailored to the infant/child's hearing loss so that frequencies that need to be louder to be heard are made louder more than the frequencies that can be heard at softer levels.
- Be designed to wear comfortably and at the same time be protected from damage.
- Be powerful enough to be useful, but avoid extreme loudness that can further damage hearing.

What tools do I need to keep the hearing aids working their best?

Your audiologist should show you the various tools needed to maintain your infant/child's hearing aids. Some useful and inexpensive tools include:

- A listening stethoscope (to check for problems with the sound quality and for volume and on/off controls that may not be working)
- A battery tester
- A dehumidifier (to store the hearing aids each night to remove excess moisture)
- An ear mold blower (to remove moisture from the ear mold tubing after it is washed)
- Cleaning tools such as a brush and a wax loop (to remove cerumen)
- Extra batteries

What kind of hearing aid will my infant/child need?

There are many different styles of hearing aids. They can be classified into two main categories: (1) in-the-ear (ITE), and (2) behind-the-ear (BTE). Your audiologist may discuss these types with you, however, infants and children generally wear BTE hearing aids. (For more information about BTE's, see earlier question about different types of hearing aids.)

What is the difference between the different hearing aid technologies?

Hearing aids have improved greatly over the years. Most infants/children, even those with profound hearing loss, can be helped to some degree with hearing aids. There are several different types of technology available and your audiologist will discuss which is best for your infant/child's specific hearing loss. Here is a summary of the various types:

- **Conventional Technology:** Conventional hearing aids take the sound in, then amplify it or simply, make it louder. This is done by the use of an amplifier receiver and microphone, and is called analog technology. This type of hearing aid can be very powerful and help even profound hearing losses with usually some benefit. The hearing aid can be adjusted to your infant/child's hearing loss through the use of screwdriver control settings. Conventional hearing aids are less costly, but not as flexible as more advanced technology. Conventional aids increase all sounds the same so background noise cannot be filtered out and may interfere with the ability to hear speech in many settings.
- **Programmable Technology:** Programmable hearing aids can be adjusted more precisely to your infant/child's hearing loss through the use of a computer and can be re-adjusted if changes are picked up in the hearing level over time. These hearing aids can also be programmed with many memories for different listening settings (for example, quiet vs. noise). Programmable hearing aids are more costly, but can make what your infant/child will hear clearer both in quiet and noisy situations. Programmable hearing aids can be fit on nearly any type or degree of hearing loss. They use both analog and digital technology to process the sound.
- **Digital Technology:** Digital hearing aids have the same abilities as programmable technology but the sound is processed in a way similar to that of a compact disc. The sound is changed into a digital code before it is increased. This makes the sound clearer. Digital technology is far more sophisticated than the other types, and is more beneficial in almost all listening settings, especially

in noisy surroundings. Digital hearing aids can also be fit on nearly every type and degree of hearing loss. Digital hearing aids are usually the most costly of all the different technologies.

Will my infant/child understand everything with hearing aids?

How much your infant/child hears with the hearing aids may be related to the type of hearing loss he/she has, the type of technology being used, and how faithfully the hearing aids are worn. Hearing aids cannot replace natural hearing, so your infant/child will always have difficulty in some places.

What are "sensory aids" for infants/children who are deaf or have a hearing loss?

Your audiologist may recommend and/or discuss with you a sensory aid or aids for your child. For example, sensory aids include the following:

- Hearing aids
- Cochlear implants
- FM systems

Sensory aids are designed to maximize available hearing primarily to help with the development and understanding of spoken language. Sensory aids are assistive technology that may be helpful, depending upon the individual child and the educational approach chosen. The assistive technology does not "cure" the hearing loss and the child who uses assistive technology will usually still need special services and programs.

My infant/child's hearing aids are always ringing or buzzing. What can I do?

Your infant/child's ear mold may be loose. As your infant/child grows, the ear increases in size, leaving gaps between it and the ear mold. Your infant/child will need new ear molds roughly every 3-6 months. Sound leakage from the hearing aid causes ringing and buzzing when it is picked up by the hearing aid's microphone, and increased a second time. However, buzzing and ringing is not always due to loose ear molds. It can also be a sign of a problem inside the hearing aid called feedback. This can be caused by an ear mold that isn't in the ear correctly, by an ear mold that is too small, by a crack in the tube that goes between the ear mold and the hearing aid, or by an actual breakdown of the hearing aid. Contact

your audiologist to have both the hearing aids and the ear molds checked.

How do I make the feedback stop?

Try pushing on, or reinserting the ear mold. If this does not take care of the problem, contact your audiologist to determine what the actual cause is and what needs to be done. Do not turn down the volume on the hearing aids lower than the recommended setting as an answer. This may stop the feedback, but your infant/child will not be able to hear.

How should I check my infant/child's hearing aid to make sure it works?

A quick test to make sure a hearing aid is actually providing a signal is to listen for a squeal as the volume control is turned up. Holding the hearing aid and ear mold in your cupped hand will alert you sooner that the hearing aid is indeed working. If you do not hear a squeal with the volume control turned all the way up, or if the squeal is much softer than usual for a given position on the volume wheel, make sure the ear mold is not blocked with earwax. Either check the hearing aid battery with a battery checker, or replace it with a new one. There are many other accessories available to keep your infant/child's hearing aid working well such as dehumidifiers and wax cleaning tools. If you have any concerns about how well a hearing aid is working, take it to your audiologist for a complete check in a special test box.

How long do hearing aid batteries last and where can I purchase them?

Hearing aid batteries last approximately one to two weeks depending on the type of hearing aid and how long your infant/child wears it each day. Batteries can be purchased at local drug stores, your audiology or hearing aid clinic, and grocery stores.

How can I keep my infant/child's hearing aids in the ears? He/she keeps taking them off.

First, make certain that the ear mold is comfortable. Are there any red spots or other signs of irritation in your infant/child's ears? Secondly, check with your audiologist to make sure the hearing aid is working well and providing enough hearing improvement for the child to notice and want to wear it. Finally, identify if your infant/child has a fever with a possible ear infection.

If your infant/child is healthy, and nothing is wrong with the hearing aid, the audiologist may suggest two-sided tape or "huggie aids" to hold the aid. Covering up the hearing aid with a hair band or hat, and finding ways to distract your infant/child with favorite toys may work. Teach your infant/child the hearing aid must be left on, just as you teach him/her not to touch breakables. As your infant/child gets older, help him/her learn that if there is a problem with the hearing aids, or they need to be taken off for any reason, he/she should come to you and let you remove or check the aids. To keep from losing the aids, the best thing is to attach the hearing aids to the child's clothing by use of a string and clip. A parent support group may also be helpful, especially with issues of behavioral modification to keep the aids in the ears.

Can hearing aids be insured?

Hearing aids are expensive. You can purchase loss and damage insurance on your infant/child's hearing aid/s. This is sometimes offered through the hearing aid manufacturer or can be purchased separately. Your audiologist can give you the names of companies that specialize in hearing aid insurance or check with your own insurance company.

How can I pay for my infant/child's hearing aid/s?

Your audiologist and Early Intervention Specialist will guide you. They will try your health insurance company first. For the future, consider getting a rider on your insurance if possible. There are also several foundations and organizations that will assist in finding financial aid for purchasing hearing aids. (For more information, see Resources section). Loaner hearing aids are also available through the State of Alaska, Department of Health & Social Services, Division of Public Health, Section of Maternal Child & Family Health, if certain eligibility criteria are met. Contact your audiologist for complete details.

Cochlear Implants - Introduction

Parents of infants/children who are deaf are sometimes offered the choice of obtaining a cochlear implant for their child. Before this choice is made, it is important for parents to gather as much information as possible regarding the technology and to understand what can realistically be expected from a cochlear implant. A cochlear implant is an electronic device with both outer and inner parts. The outer parts are made up of a microphone, sound processor, transmitter, transmitting cable, and battery. The inner parts are made up of a receiver and an electrode array. These parts are set into a infant/child's head behind the ear during surgery. The cochlear implant mechanism operates by picking up sounds through the outer parts, digitally changing them into electrical signals, and sending them into the implanted parts and to the auditory nerve, which carries them to the brain. Surgery to implant the inner device is usually done on an outpatient basis, requires general anesthesia, and takes about two to three hours. The outer parts of the implant are fitted four to six weeks after surgery when healing is complete. The speech processor unit of the implant is computer programmed or "mapped" specifically for each individual with an implant. The cochlear implant destroys all remaining hearing in the implanted ear. In comparison to traditional hearing aids, cochlear implants provide improved sound awareness to infants/children with severe to profound hearing loss. As is the cases with hearing aids, intensive, appropriate follow up therapy and ongoing observance of the device is essential to helping infants/children make sense of the many sounds in their surroundings that are picked up through the implant. While a cochlear implant may provide sound detection at close to normal listening levels, the outcomes and rate of development an infant/child may realize in relation to understanding and using spoken language, will vary due to a number of factors. A cochlear implant does not give an infant/child normal hearing and does not guarantee spoken language development similar to that of hearing infants/children.

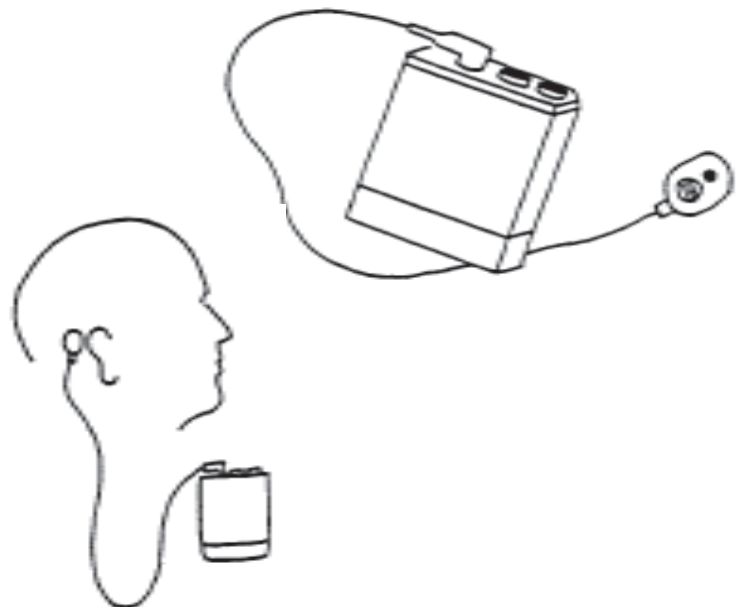
Parents who decide to have their infant/child implanted may do so because they believe it will help the infant/child in listening and speaking, and that

these skills will help their infant/child fit in better with their family and with the "hearing world" in general. They also may do so to help the infant/child develop a greater awareness of the sounds surrounding him/her.

Parents who decide against a cochlear implant for their infant/child may do so because of:

- Concern about the medical risks
- Concern that the child will not be "successful" with the implant
- Satisfaction with how the child is progressing with hearing aids
- Satisfaction with the child's progress using sign language
- Satisfaction with the child's membership in the deaf community

While in the past, a family's choosing a cochlear implant for their infant/child suggested that a family did not desire contact with the deaf community, this attitude is fading. Increasing numbers of families choose use of this technology for their infant/child and continue to use sign language and participate in the deaf community. If you are interested in cochlear implants, talk with other families and parents whose children have had the procedure done.



Cochlear Implants - Questions to Consider

You may be wondering if choosing the implant is the right decision for your infant/child and family. Here are some questions parents facing this issue have asked themselves:

Has my infant/child had a meaningful trial with hearing aids?

Proper fitting of hearing aids is an inexact science. Young children don't have the ability to describe the sounds they are hearing, or to be aware of sounds they are not hearing. Therefore, it may be difficult to tell how much benefit a young child is receiving from hearing aids. Further, high technology hearing aids may not be available to a child because many insurance plans do not pay for hearing aids.

How much time can I devote to therapy?

The ability to interpret the sounds coming through a cochlear implant does not come automatically. It requires a significant time commitment to therapy with trained specialists in the therapy room as well as work at home by family members.

What is my definition of "success" for the implant?

What will I do if my version of success is not achieved?

What is my perspective of the cochlear implant in relation to the overall needs of my infant/child?

The cochlear implant is a tool that can provide sound awareness to deaf individuals with the hope of having that infant/child achieve spoken language use with years of training.

What about the child's language development, ability to communicate, social-emotional development, and academic progress during the time while spoken language skills are developing?

How much do I know about the deaf community?

Members of the deaf community are found in all levels of education and employment, and they experience the full range of personal rewards and challenges regardless of their use of technology. Many parents



of with infants/children who have been newly identified as having a hearing loss, are not aware of the potential achievements of deaf children and adults.

Is it possible for my infant/child to use sign language and maintain his deaf identity and use the cochlear implant?

While some medical professionals discourage families from using sign language with their implanted infant/child, many families value the continued role of sign language for their children. In addition, more professionals are beginning to see the benefits of using sign language *and* participation in the deaf community for implanted infants/children.

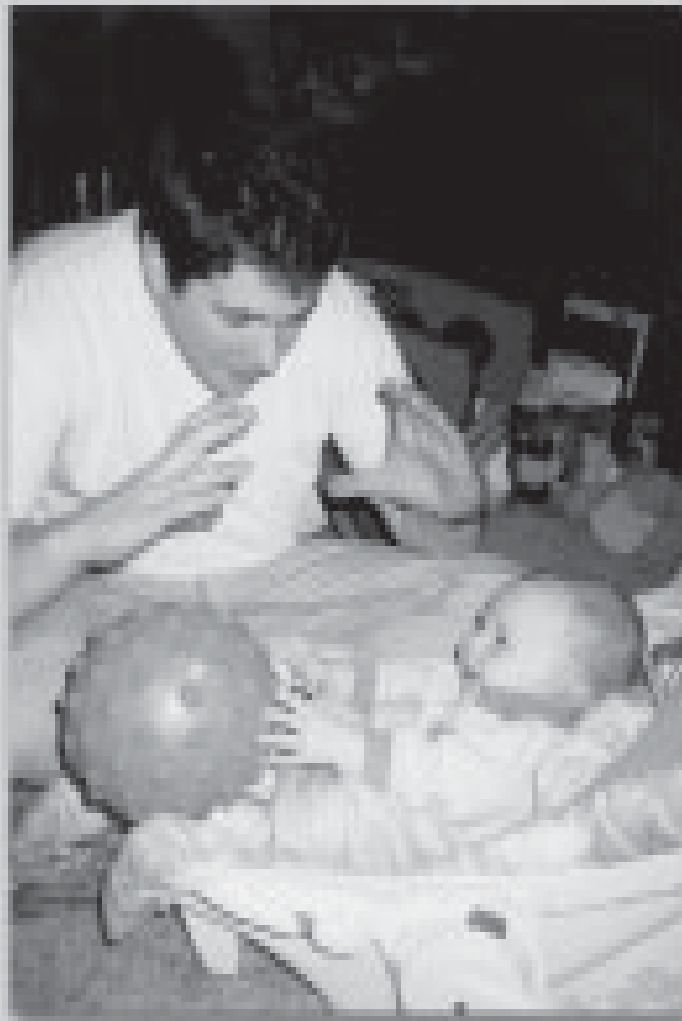
How much of an influence do portrayals of implant "miracles" and pressure from medical practitioners and others have on me?

Outcomes among children with cochlear implants vary widely, and the decision whether to implant an infant/child is a serious and individual one. It should be made only after careful consideration of the facts.

COMMUNICATION OPTIONS

*“The future has never just happened.
It was created.”*

— Will and Ariel Durant



Introduction

What Parents Should Know About Communication Approaches

Parents and professionals alike have debated for many years the best ways to provide communication skills and education for deaf and hard-of-hearing children. As a result, multiple communication methods have developed. This section will not resolve the debate, or identify the best method of communication for your child, but rather serve as a guide to assist you to better understand the communication options for your infant/child and the questions to consider. For the purposes of this resource guide ten categories of communication methodology are listed. Some have variations and subcategories so this list and the descriptions are not all inclusive.

Before beginning your journey through the different communication methods outlined in the following pages, it is important to consider some of the following questions and issues. Most importantly however, remember that you as parents and other family members, along with the infant/child who has a hearing loss, are all team members in communication. Parents and other family members, along with the infant/child, must create a communication system in order for a language system to develop and be successful.

It helps to have a general understanding of all available communication options before learning about a particular one more in depth. When you are given balanced and objective knowledge, it is much easier to make choices that are right for your infant/child and family. Parents use one or more of several modes to communicate with their deaf or hard of hearing infant/child.

As parents, you are the best people to determine the most appropriate communication option/s for your infant/child, and those that will also be in the best interests of your family as a whole. Some communication options require a large commitment in terms of time and/or financial resources. A decision to use one particular method over another must be made after careful consideration of all available options and the resulting consequences for the entire family.

Remember, there are successful children and adults using each of the many communication options. Communication between you and your infant/child, as well as other family members will be critical in helping your infant/child learn language. Two-way communication, responding to your infant/child and encouraging him/her to respond to you, is the key to your infant/child's language development. As described below, there are many different ways to communicate with your infant/child, as well as, many different philosophies about the communication methods. As you think about how your family communicates now with your infant/child and how you would like to communicate with him/her in the future, you are beginning the process of considering your infant/child's communication method/s.

A good way to decide on an approach to communication is to decide what will be best for your infant/child and family. Be open about all the methods and language choices. Ask questions. Talk to adults who are deaf and hard of hearing and other families with children who have a hearing loss. Discuss, read, and gather as much information as you can about the different methods.

Every so often, recheck your infant/child's language skills to determine if the decision is meeting his/her needs as well as your family's. If needs change, or you discover another path that better helps your infant/child, view this as a positive step toward discovering his/her best way of communicating. If a method isn't best for your infant/child, it is neither your nor his/her fault. Remember, as stated above, you may find it beneficial to combine some communication options.

Consider the following items when choosing how to communicate with your infant/child:

- Is the communication option chosen in the best interest of your infant/child and family?
- Does it allow your infant/child to have influence over his/her surroundings, discuss his/her feelings and concerns, and participate in the world of imagination and abstract thought?

- Does the communication option allow all your family to communicate with your infant/child? If not, where can you get support for teaching family members how to communicate with him/her?
- Does the communication improve your relationship with other family members? It should promote enjoyable, meaningful communication among all family members and allow your infant/child to feel part of your family and know what is going on.
- How is your infant/child going to be able to communicate with peers and the community?
- Do you and your family understand the commitment this choice will require?

"I understand how you feel about your deaf child. It is not your fault. Your deaf child is normal like other people. Just he can't hear. There is no difference about that. All you do is give the child love and take good care of him, trust him and be kind to that child. The child will know that you love him. My advice is you better learn how to sign to your child. The child will understand you. Please learn to sign for his own sake."

— Brandy (age 14)

Fact Sheet

- The earlier deafness or hearing loss is identified, the better chances a child has to acquire language, whether spoken or signed.
- Each child is unique. It is important to understand the full nature and extent of a child's hearing loss or deafness. It is also important to understand how each family member and caregiver will communicate with the child. Get to know the services that are provided in your community for infants and children through early intervention in preschool and elementary school.
- Optimizing residual (existing) hearing may be advantageous. Children may benefit from hearing aids or cochlear implants. This is a decision that you should discuss with your infant/child's health care providers.
- Exploring the options and, if possible, working with professionals in teams can be beneficial. Your infant/child may visit a pediatrician, an otolaryngologist (ear, nose and throat physician or ENT), an audiologist, and/or a speech-language pathologist. Ask each to keep the others informed about your infant/child's visits. However, only you can make sure this happens. Remember, you are your infant/child's best advocate, or voice to the world. Coordinated care can be a big help to you and your infant/child.
- It is important to interact with your deaf or hard-of-hearing infant by holding, facing, smiling, and responding to your infant from the very beginning. All of the caregivers in the infant/child's life should keep interacting with him/her. Children need love, encouragement, and care from their families.



Frequently Asked Questions

How do I communicate with my infant/child and how will he/she communicate with me and the rest of the world?

Most infants and toddlers, whether they have a hearing loss or not, use their eyes, their faces, their voices, their hands, and sometimes their whole bodies to give “communication signals”. Look for these signals from your infant/child and respond to them as a form of communication. This is your infant/child’s way of telling you that he/she is hungry, needs a diaper change, is tired of being in the same position, may want a hug, or needs some attention.

What is the difference between a language and a communication method?

A language is a shared “code” that defines the meaning of words and the rules for how words are combined to convey ideas to others. English and American Sign Language (ASL) are examples of languages. Communication methods are various ways to help a child learn one or both of these languages. Most communication methods are ways to learn or represent English. For example, ASL is a separate language and the bilingual method is a way of learning two languages.

How can I understand my infant/child’s early attempts to communicate with me?

All infants communicate through smiles, crying, and body language. By looking for these behaviors, you will begin to better understand your infant/child and recognize when he/she is hungry, in need of a diaper change, or is perhaps looking for the comfort of close body contact. As a result of better understanding your infant/child’s actions, you and your child will begin to develop non-spoken methods of communication.

How do I get my infant/child’s attention?

Try using a normal tone of voice and call your infant/child’s name, tap gently on a shoulder, and wait for a response, or move so that your infant/child can see you. Try to be close to your infant/child and at eye or ear level. Children respond to things that are rewarding or meaningful. For example, have a reason for getting your infant/child’s attention – to give a favorite toy or a bottle. Make sure to always rein-

force your child’s request for attention with a smile and a hug.

Where can I learn about communicating in sign with my infant/child?

Early Intervention will help locate the resources for instruction in sign language. There are many resources in Alaska skilled in providing information about both early language development as well as sign language development, including videotapes and books. The chance to communicate on a regular basis with people who use sign language is one of the best ways to learn.

What do people mean by “options” for communication?

One meaning of term “options” refers to the choice of a main method of learning language and communicating with others. In this use of the word option, listening and speaking as the main method is one option. Sign language, whether or not accompanied by listening and speaking, is a second option.

A second meaning of the term “option” uses American Sign Language as the first and main language of a person who is deaf as one option, and the use of English, whether the English is through a listening and speaking (oral) mode or through a signed (visual) mode as another option. There are many combinations and variations of the main communication options.

What is the spoken language approach?

A Spoken Language Approach is an approach to teaching infants/children with hearing loss that focuses on developing speech and listening skills. Any spoken language approach requires a commitment on the part of the parents and families to work with professionals to stimulate their infant/child’s spoken language development throughout their infant/child’s day. Specific communication options that develop spoken language abilities include the Auditory/Oral, Auditory-Verbal, and Cued Speech approaches. These are described in more detail earlier in this section.

How can I teach my infant/child to speak if he/she can't hear?

There is no one answer to this question. There are too many variables in hearing loss. In addition, some people think that talking is very important and others think that being able to communicate clearly through any method is most important. In general, infants learn to talk through listening and beginning to copy what they hear, and by learning that using voice and words can be used to get their needs met. Advances in auditory (hearing) technology help many children who are deaf or hard of hearing learn to talk through the same way. For some children, learning sign language provides a first language and spoken language comes later. To encourage spoken language, put the hearing aids on your child whenever he/she is awake. Make your voice interesting, talk about things that have meaning for your child and always reinforce your child's attempts to communicate with voice or words.

Is Sign Language the Same Around the Globe?

No one form of sign language is universal. For example, British Sign Language (BSL) differs notably from ASL. Different sign languages are used in different countries or regions.

Where Did American Sign Language (ASL) Start?

The exact beginnings of ASL are not clear. Many people believe that ASL came mostly from French Sign Language (FSL). Others claim that the foundation for ASL existed before FSL was introduced in America in 1817. It was in that year that a French teacher named Laurent Clerc, brought to the United States by Thomas Gallaudet, founded the first school for the deaf in Hartford, Connecticut. Clerc began teaching FSL to Americans, though many of his students were already fluent in their own forms of local, natural sign language. Today's ASL likely contains some of this early American signing. Which language had more to do with the formation of modern ASL is difficult to prove. Modern ASL and FSL share some elements, including a substantial amount of vocabulary. However, one cannot be substituted for the other.

How Does American Sign Language (ASL) Compare With Spoken Language?

In spoken language, the different sounds created by words and tones of voice (intonation) are the most important devices used to communicate. Sign language is based on the idea that sight is the most useful tool a deaf person has to communicate and receive information. Therefore, ASL uses hand shape, position, movement, body movements, gestures, facial expressions, and other visible signals to form its words. Like any other language, fluency in ASL happens only after a long period of study and practice.

Even though ASL is used in America, it is a language completely separate from English. It contains all the basic features a language needs to function on its own. It has its own rules for grammar, punctuation, and sentence order. ASL evolves as its users do, and it also allows for regional usage and jargon. Every language expresses its features differently and ASL is no exception. Whereas English speakers often signal a question by using a particular tone of voice, ASL users do so by raising the eyebrows and widening the eyes. Sometimes, ASL users may ask a question by tilting their bodies forward while signaling with their eyes and eyebrows.

Just as with other languages, specific ways of expressing ideas in ASL vary as much as ASL users themselves do. ASL users may choose from synonyms to express common words. ASL also changes regionally, just as certain English words are spoken differently in different parts of the country. Ethnicity, age, and gender are a few more factors that affect ASL usage and contribute to its differences.

Why Does American Sign Language (ASL) Become a First Language for Many Deaf People?

Parents are often the source of a child's early acquisition of language. A deaf child who is born to deaf parents who already use ASL will begin to learn ASL as naturally as a hearing child picks up spoken language from hearing parents. However, language is learned differently by a deaf child with hearing parents who have no earlier experience with ASL. Some hearing parents choose to introduce sign language to their deaf children. Hearing parents who choose

to learn sign language often learn it along with their child. Nine out of every ten children who are born deaf are born to parents who hear. As with any language, being around other children and adults who use ASL is also very helpful in learning the language.

Why Emphasize Early Language Learning?

Parents should introduce infants/children to language as early as possible. The earlier any child is exposed to, and begins to learn language, the better that infant/child's communication skills will become. Research suggests that the first six months are the most important to an infant/child's development of language skills. All infants should be screened for deafness or hearing loss before they leave the hospital or within the first month of life. Very early discovery of an infant/child's hearing loss or deafness provides parents with an opportunity to learn about communication options. Parents can then start their infant/child's language learning process during this important stage of development.

What Does Recent Research Say About American Sign Language (ASL) and Other Sign Languages?

Some studies focus on the age of ASL is first learned. Age is an important issue for people who learn ASL, whether it is a first or second language. For anyone to fully understand any language, exposure must begin as early as possible, preferably before school age. Other studies compare the skills of native signers and non-native signers to determine differences in language processing ability. Native signers of ASL consistently display more accomplished sign language ability than non-native signers, again emphasizing the importance of early exposure and learning.

Some studies focus on different ASL processing skills. Users of ASL have shown ability to process visual mental images differently than hearing users of English. Though English speakers have the skills needed to process visual imagery, ASL users demonstrate faster processing ability suggesting that sign language enhances certain processing functions of the human brain.

Why is early communication important?

A child's first years are an important time for developing communication and language. That's why dis-

covering a hearing loss early is so important. After a hearing loss is diagnosed, then a plan to teach your infant/child language through hearing aids, cochlear implants, and/or sign language, can be developed. Specific strategies exist to encourage early communication. Some language strategies are specific to auditory (hearing) communication, and others to visual (sight) communication. However, many techniques are common to sign and speech communication.

What are some ways to encourage early communication?

- Watch closely for your infant/child's communication "signals" and respond to them. This will help your child learn that words/signs are a good way to get his/her needs met, to express feelings, and to get attention.
- When you pick up your crying child to comfort, feed or change him/her, talk/sign about what is happening.
Example: "Daddy's here." or "Are you hungry now? It's time to eat."
- Follow your child's gaze to see what is capturing his/her attention.
Example: (In response to your child looking at the family pet.) "There's Fluffy. She is our cat." or "You see Boots, our dog."
- Respond to points and gestures from your infant/child. Think about what your child is trying to convey and give him/her the words/signs for that person, object or action.
Example: (In response to your child pointing at a teddy bear.) "That's your bear." or "Do you want your bear?"
- Respond to your child's facial expressions. Let your child know that you understand and provide him/her with the appropriate words/signs.
Example: "Oh, you look sad. What's wrong?" or "You're a happy baby!"
- Use lots of facial expression when you communicate with your infant/child and be certain that your expression matches your words/signs.
Example: "Do you want more cereal?" combined with raised eyebrows and a questioning look.

- Use natural gestures in combination with words/signs.
Example: “Let’s change your diaper” while pointing to your infant/child’s diaper.
- Help your infant/child learn about reciprocal, or “back and forth” communication.
Example: “Do you want a drink?” then pause to give your infant/child a chance to respond. At first he/she may just look, point, or vocalize (speak) for his or her turn. In response, you give your infant/child a drink and model the appropriate answer by saying/signing, “Yes, you want a drink.” This helps your child learn both the words/signs and the correct way to answer a question.

What are some ways to encourage listening and speech?

- Encourage your child to wear his/her hearing aids during all waking hours.
- Point out interesting sounds and show him/her what is making the sound. The dog barking, a favorite toy’s noise, or the car horn signaling that Mommy is home are some examples.
- Get close to your infant/child when you talk. The farther away you are from the hearing aid microphone, the less your infant/child can hear. By moving closer, you will also lessen the interference from other noises in the room. If your infant/child has a cochlear implant, these same techniques will also work.
- Make your voice as interesting as possible. Use lots of intonation (up or down inflection) when you talk to your infant/child. Phrases such as “all gone” and “bye-bye” are much more interesting with a lot of voice inflection.
- Encourage your infant/child to vocalize and use his or her voice for communication. Show how happy and excited you are when your infant/child does use his/her voice. Your response encourages your infant/child to vocalize again.

What are some ways to encourage early visual communication?

- Respond to all vocalizations as if they were communication. If your infant/child babbles “ba ba” when looking at the bottle, you can say, “Yes, here’s your bottle.”
- Pay close attention to your infant/child’s hand movements and respond positively to this “manual babbling” in the same way that you might respond to early vocalizations. When your infant/child uses a handshape that resembles the word “mama,” your excited response encourages him/her to use this handshape again.
- Pay close attention to what your infant/child is looking at and provide the sign. Make the sign very close to the object your infant/child is looking at, or bring the object into his/her sight and then make the sign. For example, when it’s time to get dressed, you might hold up your infant/child’s shoes and when he/she looks, sign “shoes”.
- Make visual communication as interesting as possible by using gestures, facial expressions, and whole body movement along with signs. Using all these forms of visual communication will help to capture your infant/child’s attention.
- Wait to be certain that you have your infant/child’s attention before signing. You may need to wait patiently until your child looks up before starting to sign, or gently tap your child’s shoulder to get his or her attention.
- Make your signs easy to see by positioning yourself at your infant/child’s eye level and by making your signs slowly and clearly.

Communication Options

American Sign Language (ASL)

American Sign Language is language in which the placement, movement, and expression of the hands and body are part of the language. Research has shown that ASL is a complete language with its own grammar and language rules. ASL is considered by the Deaf community to be the native language of people who are deaf. It is often the chosen language for people who are deaf, even when they are fluent (understand) in both ASL and English. 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 who “speak” ASL to learn the language in order to give their infant/child the best opportunity to learn ASL. (For more information see Deaf Culture section).

Aural-Oral

In this method, listening is the main method for learning language. Speech is the main method of expressing language. The use of existing hearing is very important. Children are encouraged to use aided hearing (hearing aids or cochlear implants) during their waking hours. For this method to work, aided hearing must be within a range where speech can be heard. If an infant/child cannot hear speech, even with hearing aids, then a cochlear implant may be an option. In addition to listening, an infant/child is encouraged to watch the speaker to get more information from speechreading or lipreading, facial expressions, and gestures. Hearing through hearing aids or through a cochlear implant, even in the best of cases, is not the same as typical hearing. Early intervention will include certain strategies for increased emphasis on listening and communication. This approach does not include the use of sign language. The philosophy behind this method is to prepare children to work and live in a hearing society.

Auditory-Verbal

This method follows a specific philosophy within the broader aural-oral category. Development of language through listening and the use of existing hearing are very important to this method. Use of hearing aids

and/or cochlear implants will be the same as in the aural-oral method. One-on-one teaching with a specially trained auditory-verbal therapist is an important part of this method. There is little, if any, emphasis on visual clues such as speechreading or gesture during therapy sessions. Parents participate in all therapy sessions and use the same techniques 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. The goal of auditory-verbal practice is to assist children who are deaf or hard of hearing to grow up in regular learning and living environments, allowing them to become independent, participating, contributing citizens in mainstream society. The method's philosophy supports the idea that children with all degrees of hearing loss deserve a chance to develop the ability to listen and to use their voice to communicate.

Manually Coded English (MCE)

This method uses a visual (signed) form of the English language. English is visually represented (coded) through manual signs. There are a number of systems for manually coding English and each one has its own rules and variations. Most of the systems use American Sign Language signs as a base and also use English word order. Since manually coded English follows English language rules, it is easier for hearing parents to learn and use with their infants/children. All sign language methods require a commitment from all family members to learn and use signs for all communication with the infant/child. If you choose sign communication, it is important for you to learn sign as quickly as possible so that your infant/child can learn language from you in the same natural way that an infant/child with hearing learns from his/her parents.

Simultaneous Communication (Sim-com)

See Total Communication.

Total Communication (TC)

This method refers to a combination of oral communication and signed communication. In the simultaneous method, 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. Infants/children wear hearing aids and are encouraged to develop and use their existing hearing as well as sign and speech. The term total communication is a broader term and refers to speaking and signing as well as the use of speechreading and print. The belief behind TC is that your infant/child's surroundings should provide access to language by making the full range of communication choices available.

Cued Speech

This is a visual communication system combining eight hand shapes (cues) that represent different sounds of speech. These cues are used together with speaking. The hand shapes will help your infant/child differentiate sounds that look the same on the lips – such as “p” or “b”. This system is designed to clarify lip reading by using the simple hand movements around the face to indicate the exact pronunciation of any spoken word. Since many spoken words look exactly alike on the mouth (for example, pan, man), cues will allow your infant/child to see the difference between them. This is a particularly good system for an infant/child who may not be able to learn entirely through amplified (increased) hearing. For the method to work, both the speaker and the listener must know the system.

Bilingual Language Development

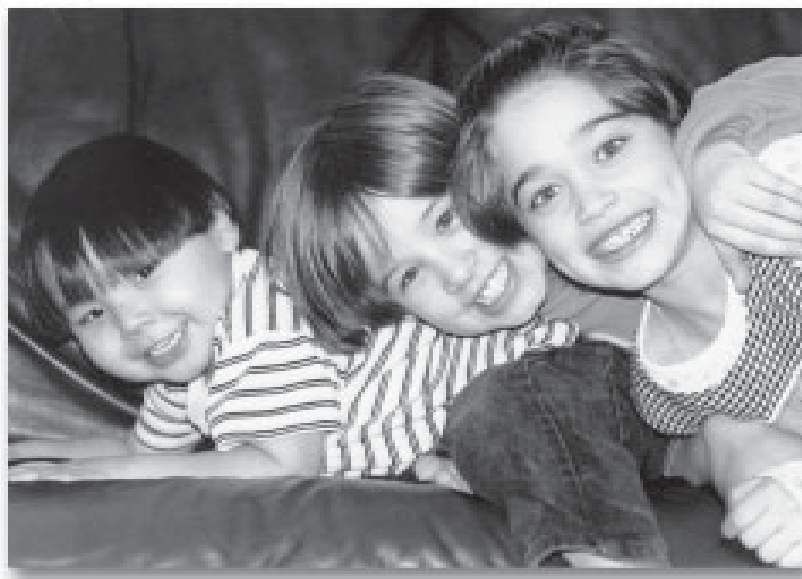
Bilingual means knowing or being fluent in two languages. For a person who is deaf, the two languages are usually American Sign Language (ASL) and English. When an infant/child is born to parents who are deaf, the language of the home and the first language of the infant/child is usually ASL with English as a second language. When an infant/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 and adds English as a second language as the child gets older.

Speechreading

The skill of understanding spoken language through movements seen on the mouth, facial expression and body language, and background clues.

Signed English

These sign systems use signs from American Sign Language along with invented signs to represent English word order and rules. The systems are not languages but are a code meant to be used to support spoken English. Some examples are Seeing Essential English (SEE I) and Signing Exact English (SEE II).



EDUCATIONAL OPTIONS

*“Leadership and learning
are indispensable to each other.”*

— John F. Kennedy



0-3 Years - Introduction

Hearing loss or deafness does not affect a person's intellectual capacity or ability to learn. However, children who are either hard of hearing or deaf generally require some form of special education services in order to receive an adequate education. Such services may include the following:

- Regular speech, language and auditory training from a specialist
- Amplification systems
- Services of an interpreter for students who use manual communication
- Favorable seating in the class to help with speechreading
- Captioned films/videos
- Assistance of a note taker so that the student can fully attend to instruction
- Instruction for the teacher and peers in alternate communication methods, such as sign language
- Counseling

Children who are hard of hearing will find it much more difficult than children who have normal hearing to learn vocabulary, grammar, word order, idiomatic expressions, and other aspects of verbal communication. For infants/children who are deaf or have severe hearing losses, early, consistent and conscious use of visible (sight) communication modes (such as Sign Language, Fingerspelling, and Cued Speech), and/or amplification (for example, hearing aids), and aural/oral training can help lessen this language delay. By age four or five, most children who are deaf are enrolled in school on a full-day basis and do special work on communication and language development. It is important for teachers, families, speech-language pathologists, and audiologists to work together to teach the child to use his/her existing hearing to the maximum extent possible, even if the preferred means of communication is manual. Since the great majority of deaf children (over 90%) are born to hearing parents, programs should provide instruction for parents on implications of deafness within the family.

Part C of IDEA, Individual with Disabilities Education Act, which was established in 1986 as Part H

and amended as Part C in 1997, covers children with disabilities from birth until the age of three. This is the law that governs the services that are provided for deaf and hard of hearing infants and toddlers. For infants/children who are deaf or hard of hearing in Alaska, the educational services should begin at the time he/she is identified with a hearing loss, preferably at birth.

Alaska Early Intervention Hearing Resource Program has teachers who travel to communities statewide to teach and provide services to deaf and hard of hearing infants, toddlers, and their families. They work with the local Early Intervention/Infant Learning Programs in order to provide these services.

All eligible children, birth to three years old, receive a multi-disciplinary evaluation/assessment before determining their eligibility for services. Following the determination of eligibility, a team of professionals, including your infant/child's family, works together to create an Individualized Family Service Plan (IFSP). This plan is based on your infant/child's developmental needs and the needs of your family in helping your infant/child learn. The plan identifies outcomes and the early intervention services and supports needed to reach those outcomes, how services will be paid for, length and locations of services, and how progress will be determined.

Transition

When your child turns three, he/she is entitled to free, public education under Part B of the Individuals Disabilities Education Act law. During this time, your child will move from an IFSP to an Individual Education Program (IEP), which is developed with goals and objectives focused on your child, rather than on the family.

This free, public education can be provided in a variety of options:

- Your child may stay in their home community and attend pre-school, Head Start, day care, or be home schooled with the needed related services support from the school district. Your school district must provide an IEP, which will define the

educational services in a school setting. Consultation services by a deaf/hard of hearing teacher may be available through the Special Education Service Agency (SESA) if needed.

- School districts vary in the type and quality of programs they offer. For example, some of the larger school districts, such as Fairbanks, Anchorage, Mat-Su Valley and Kenai Peninsula Borough offer special education pre-school classes with itinerant services provided by a teacher of the deaf/hard of hearing. Direct services from the hard of hearing itinerant teacher may also be provided at the students' home school from kindergarten through grade 12.
- Your child may attend school at the Alaska State School for Deaf and Hard of Hearing (ASSDHH) in Anchorage. This program serves children from age 3 to 22 who experience hearing losses that range from mild to profound and supports the development of both American Sign Language and English. Some families choose to move to Anchorage so that their child can attend ASSDHH. If your family does not live in Anchorage, foster care can be arranged until your child is six. At age six, he/she can move into the student living center which houses a small num-

ber of deaf/hard of hearing students and have house parents who are either deaf/hard of hearing or are fluent in sign language.

At age three, most children begin preschool or Head Start and become eligible for special education services. For children and their parents who are used to home-based services, like ILP, this transition to a school program can be challenging. The Alaska Early Intervention Committee (EIC) has identified this transition as a major concern for families statewide.

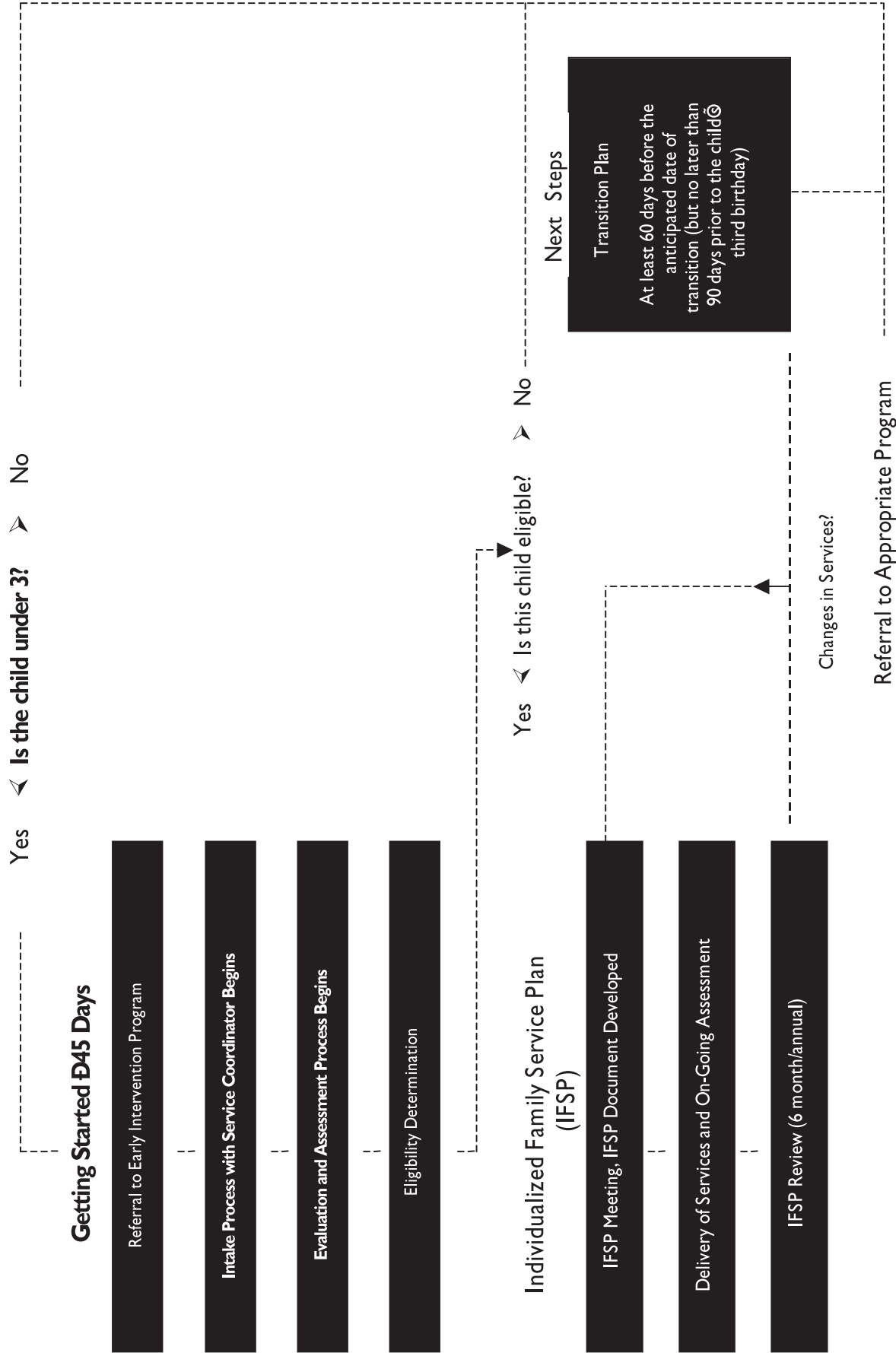
Without teamwork and effective planning among all the community agencies involved (for example, Head Start, school districts, preschools, Public Health, etc.), it is impossible to make sure that there are smooth transitions for special needs children at age three.

Alaska has been one of several states nationwide to begin exploring ways to improve this transition or move for children, families, and service providers. After gathering data on community needs, the Department of Health and Social Services in cooperation with the Department of Education developed and started the *Alaska Transition Training Initiative (ATTI)*. A skilled Alaska training team has been assembled as part of ATTI.



Steps Through the Alaska Early Intervention/Infant Learning Program

Developmental Concerns by Parent or Provider (Nurse, Doctor, Child Care Staff, etc.)



Frequently Asked Questions

What is meant by “different educational approaches to language learning”?

Young children who hear, generally develop speech and spoken language naturally, without any conscious effort. Deaf infants/children, whose parents are deaf and use American Sign Language (ASL) as the language of the home, also develop the language (ASL) naturally and without much effort. The necessary ingredient for language development, whether it is spoken language or a visual (sight) language such as ASL, is for your infant/child to be able to actually receive (take in) the language of the surroundings. Currently, there are various approaches for helping infants/children who are deaf or have a hearing loss to develop a first language. All infants/children need a first language for thinking, learning, communicating, and developing relationships with parents, family and others.

What are the educational approaches with infants/children who have a hearing loss?

- American Sign Language/English Bilingual approach
- English-Only approaches
- Auditory-Verbal approach
- Auditory-Oral approach
- Cued Speech
- Spoken English combined with a Manually Coded English Sign System known as Simultaneous Communication, sometimes referred to as TC/Total Communication

What is the “right” method for my child?

There is no “right” educational approach for your infant/child. Teachers, programs, and schools throughout the state use different approaches. Each approach can claim positive impact on the lives of many deaf and hard of hearing people. Some infants/children have moved very slowly or not at all through one approach and, with a change in approach, have learned very well. Again, there is no one, “right” approach for your infant/child.

Who makes the decision regarding the educational approach for my child?

You as a parent will need information on the differ-

ent approaches in order to make a choice for your child and family. Parents can be assisted in gathering objective information on all approaches from the audiologists, pediatricians, early interventionists, speech language therapists/pathologists, other professionals, visiting a variety of programs, talking with a variety of parents, and meeting adults who are deaf and hard of hearing.

What is IDEA?

Individuals with Disabilities Education Act (IDEA) is a law that was established in 1986 to provide services to children birth to 22 years of age with disabilities.

What is Part B of IDEA?

This portion of the IDEA law entitles children with disabilities to free public education from the ages of 3 to 22, or 3 through age 21.

What is Part C of IDEA?

Part C is a part of IDEA that was established to specifically address the early educational needs of young children with disabilities. This portion of the law governs the provision of services for children from birth until age three who have hearing loss or other disabilities.

What is special education?

Special education is instruction that is specially designed to meet the unique needs of children who have disabilities. This is done at no cost to the parents. Special education can include special instruction in the classroom, at home, in hospitals or institutions, or in other settings.

Over 5 million children ages 6 through 21 receive special education and related services each year in the United States. Each of these children receive instruction that is specially designed for the following:

- To meet the child’s unique needs (that result from having a disability), and
- To help the child learn the information and skills that other children are learning.

This definition of special education comes from the Individuals with Disabilities Education Act (IDEA), Public Law 105-17.

Who is eligible for special education?

Certain children with disabilities are eligible for special education and related services. IDEA provides a definition of a “child with a disability.” This law lists 13 different disability categories under which a child may be found eligible for special education and related services. These categories are listed in the box below.

IDEA’s Categories of Disability for children ages 3 through age 21:

- Autism
- Deafness
- Deaf-blindness
- Hearing impairment
- Mental retardation
- Multiple disabilities
- Orthopedic impairment
- Other health impairment
- Serious emotional disturbance
- Specific learning disability
- Speech or language impairment
- Traumatic brain injury
- Visual impairment, including blindness

According to the IDEA, the disability must affect the child’s educational performance. The question of eligibility, at that point, comes down to a question of whether the child has a disability that fits into one of IDEA’s 13 categories and whether that disability affects how the child does in school. That is, the disability must cause the child to need special education and related services.

How do I find out if my child is eligible for special education?

The first step is to find out if your child has a disability. To do this, ask the school to evaluate your child. Call or write the Director of Special Education, or the principal of your child’s school. Tell him/her that you think your child has a disability and needs special education help. Ask the school to evaluate your child as soon as possible.

What happens during an evaluation?

Evaluating your child appropriately will give you and the school a lot of information about your child. This information will help you and the school:

- Decide if your child has a disability
- Design an individualized instruction plan for your child

How does the school collect information for the evaluation?

The school collects information from many different people and places. The evaluation should include:

- Certain tests.
- Observations and opinions of professionals who have worked with your child.
- Your child’s medical history, when it relates to his/her performance in school.
- Your ideas about your child’s school experiences, abilities, needs, and behavior outside of school, and his/her feelings about school.

What does the school do with the information from the evaluation?

The information gathered from the evaluation will be used to make important decisions about your child’s education. All of the information will be used:

- To decide if your child is eligible for special education and related services, and
- To help you and the school decide what your child needs educationally.

What happens if my child is not eligible for services?

If your school determines that your child is not eligible for special education services, the school system must tell you this in writing and explain why your child has been found “not eligible.” Under the IDEA law, you must also be given information about what you can do if you disagree with the school’s decision.

What kinds of changes can be made in a classroom for children with hearing loss?

There are many changes that can be made in a classroom to help children with hearing loss. In conjunction with hearing aids or cochlear implants, there are changes that can be made to the classroom itself to make it a more of a sound favorable setting. Minor changes such as wall-to-wall carpeting, sound treated tiles on the ceilings and walls, well-fitted and closed windows and doors, and quiet hearing/ventilation systems are all helpful. In addition, there are assistive listening devices such as personal FM sys-

tems and sound field amplification systems, that can increase the teacher's voice over the background noise, and are quite helpful in classroom settings for children with hearing loss. In fact, strengthening the whole classroom with a sound field amplification system can help every child in the class. (For more information, see Assistive Technology section).

“There are things, such as walking, that children learn entirely on their own. There are things, such as using the toilet, that they learn with just a little bit of help from their parents. And there are things, such as reading and writing and good table manners, that children can master only with persistent and patient guidance, over many years, from their parents. For deaf children, communicating with the rest of the world falls into this third category. This makes life harder, but well within the capabilities of a competent parent — and the things in the third category seem ultimately to give the most satisfaction.”

— David (parent)

Individualized Family Service Plan (IFSP)

for the family of _____ born on ____/____/____ residing with _____

Mother	Father	Guardian or Caregiver
Name: _____	Name: _____	Name: _____
Address: _____	Address: _____	Address: _____
Phone: (____) _____ (____)	Phone: (____) _____ (____)	Phone: (____) _____ (____)

IFSP Timeline (Date due at each visit): This IFSP begins ____/____/____ and ends ____/____/____.

Behavior	Initial Evaluation	Part C Eligibility	Initial or Interim IFSP	Revised/Revised Interim	Re-Evaluation Assessment	Annual Review	Transition Plan
[REDACTED]							

Plan Development/Signature

The following individuals contribute to the development of this IFSP. The IFSP is developed in partnership with the family and the service provider. The IFSP is developed in partnership with the family and the service provider. The IFSP is developed in partnership with the family and the service provider.

Trust/Date

Parent/Coordinator

Parent/Coordinator

Family Service Coordinator

Enable

Enable/Revised/Changes

Signature: _____ Date: _____

Signature

Signature of program specialist or service coordinator or other IFSP representative



Department of Health and Human Services, State of Michigan
 1000 West Washington, Lansing, Michigan 48906
 517.335.3000

Information about _____'s development and strengths at the age of _____ judged age of _____

Evaluation assessment tools and methods used

**Parent level of development strengths and areas in need of
 Meeting special needs:**

Early levels (for parent)

Thinking/learning (expectations)

Self-learning/setting (communication)

Getting along with others (communication)

Doing things for him/herself (subject)

Birth and Medical Information - List including all medications, vitamins and other products/ingredients

Vision	Behavioral Health
Hearing	Medications(1)
Immunizations	Medicine
Other	Other

Family communication/for this the status (growth and development)

Family communication supports

Parental perceptions
Knowledgeable
Efficient

Other:

Parents concerned they cannot manage
Parental time/care

Area B

If appropriate, please copy in parent photographs of other IEP conversations

Summary of Services

Service	Provider's Name	Service Setting/Location	How Often (frequency)	Duration (hrs)	Start Date	End Date	Cost per unit of service	Pager
Service Options								
1. Service Delivery	1. Direct Service	1. Family Home	1. Weekly Service	11. 90-120 Minutes	11. 01/01/2015	11. 01/01/2015	11. \$0 per unit of service	11. Telephone
2. Multiple Service	1. Direct Service	2. Family Home	2. Weekly Service	12. 60-90 Minutes	12. 01/01/2015	12. 01/01/2015	12. \$0 per unit of service	12. Family Support
3. Family Training Program	2. Indirect Program Service	2. Community Home	2. Community Home	21. 90-120 Minutes	21. 01/01/2015	21. 01/01/2015	21. \$0 per unit of service	21. Family Support

Description of experiences developed in partnership with _____

How are you? Typical Outcome?	What We Want To Happen (Outcome/Goal)	How Do We Measure It?	Who Will Be It Accountable/Responsible	Family's Involvement Role/Strategy

*Type of Outcome: 1. Basic Medical 2. Emotional Development 3. Individual Family Support

1. Family's Involvement with program/doing

2. Service model: 1. Group meeting at h. 1. individual

Description of outcomes developed in partnership with _____'s family (see item 1).

Goal and Type of Outcome	When Will The Outcome Occur / Goals	How Will We Do Strategies / Methods / Materials	Who Will Do It Person(s) Responsible	Early's Estimated Progress Item 1 Rating
<div data-bbox="506 598 945 1528" data-label="Text"> <p style="font-size: 48px; opacity: 0.5;">SAMPLE</p> </div>				

*Type of Outcome: I. Individualized II. Educational/Developmental III. Individualized Support

**Priority: 1. Starting of Program Meeting I. Strategic model I. Beginning and I. Adjusted

The early program would work to provide opportunities for other IEP transcription

Summary of Services

Service	Provider's Name	Service Location	Plan Dates (Start/End)	Minimum visit	Visit Date	Final Date	Cost per visit of service	Notes
SAMPLE								

Service Options

- 1. Academic Instruction
- 2. Applied Behavior Analysis
- 3. Assistive Technology
- 4. Family Therapists/Paraprofessionals
- 5. Health Services
- 6. Hearing Services
- 7. Individualized Family Services
- 8. Medical Programs/Services
- 9. Occupational Therapy
- 10. Physical Therapy
- 11. Psychological Services
- 12. Speech-Language Therapy
- 13. Special Instruction
- 14. Special Services
- 15. Social Services
- 16. Therapists

Exposure to program, need only to permit photo to be taken if it is your facility

Individualized Family Service Plan (IFSP)

Your Child's Evaluation

How do I find out if my child is eligible for special education?

The first step is to find out if your child has a disability. To do this, ask the school to evaluate your child. Call or write the Director of Special Education or the principal of your child's school. Say that you think your child has a disability and needs special education help. Ask the school to evaluate your child as soon as possible.

The public school may also think your child needs special help, because he or she may have a disability. If so, then the school must evaluate your child at no cost to you.

However, the school does not have to evaluate your child just because you have asked. The school may not think your child has a disability or needs special education. In this case, the school may refuse to evaluate your child. The school must let you know this decision in writing, as well as why it has refused.

If the school refuses to evaluate your child, there are two things you can do immediately:

- Ask the school system for information about its special education policies, as well as parent rights to disagree with decisions made by the school system. These materials should describe the steps parents can take to challenge a school system's decision.
- Get in touch with your Alaska's Parent Training and Information (PTI) center. The PTI is an excellent resource for parents to learn more about special education, their rights and responsibilities, and the law. The PTI can tell you what steps to take next to find help for your infant/child. (See Resources section for PTI contact information).

What happens during an evaluation?

Evaluating your child means more than the school just giving your child a test or two. The school must evaluate your child in all the areas where your child may be affected by the possible disability. This may include looking at your child's health, vision, hear-

ing, social and emotional well-being, general intelligence, performance in school, and how well your child communicates with others and uses his or her body. The evaluation must be complete enough (full and individual) to identify all of your child's needs for special education and related services.

Evaluating your child appropriately will give you and the school a lot of information about your child, such as:

- To decide if your child has a disability
- To design instruction for your child

The evaluation process involves several steps. These are listed below:

Reviewing existing information. A group of people, including you, begins by looking at the information the school already has about your child. You may have information about your child you wish to share as well. The group will look at information such as:

- Your child's scores on tests given in the classroom or to all students in your child's grade
- The opinions and observations of your child's teachers and other school staff who know your child
- Your feelings, concerns, and ideas about how your child is doing in school

Deciding if more information is still needed. The information collected above will help the group decide the following:

- If your son or daughter has a particular type of disability
- How your child is currently doing in school
- Whether your child needs special education and related services
- What your child's educational needs are

Group members will look at the information they collected above and see if they have enough information to make these decisions. If the group needs more information to make the decisions, the school must collect it.

If more information about your child is needed, the school will give your child tests or collect the information in other ways. Your informed, written permission is required before the school may collect this information. The evaluation group will then have the information it needs to make the types of decisions listed above.

So the school needs my permission to collect this extra information?

Yes. Before the school can do more evaluations/assessments of your child to see if he/she has a disability, the school must ask for your informed written permission. It must also describe how it will conduct this evaluation. This includes describing the tests that will be used and the other ways the school will collect information about your child. After you give your informed written permission, the school may evaluate your child.

How does the school collect this information?

The school collects information about your child from many different people and in many different ways. Tests are an important part of an evaluation, but they are only a part. The evaluation should also include the following:

- The observations and opinions of professionals who have worked with your child,
- Your child's medical history, when it relates to his or her performance in school, and
- Your ideas about your child's school experiences, abilities, needs, and behavior outside of school, and his/her feelings about school.

The following people will be part of the group evaluating your child:

- You, as parents,
- At least one regular education teacher, if your child is, or may be participating in the regular education environment,
- At least one of your child's special education teachers or service providers,
- A school administrator who knows about policies for special education, about children with disabilities, about the general curriculum (the curriculum used by non-disabled students), and about available resources,
- Someone who can interpret the evaluation results and talk about what instruction may be necessary

for your child,

- Individuals (invited by you or the school) who have knowledge or special expertise about your child,
- Your child, if appropriate,
- Representatives from any other agencies that may be responsible for paying for, or providing transition services (if your child is 16 years or, if appropriate, younger and will be planning for life after high school),
- Audiologist, and
- Other qualified professionals.

These other qualified professionals may be responsible for collecting specific kinds of information about your child:

- A school psychologist,
- An occupational therapist,
- A speech and language pathologist (sometimes called a speech therapist),
- A physical therapist and/or adaptive physical education therapist or teacher,
- A medical specialist, and
- Others.

Professionals will observe your child. They may give your child written tests or personally talk with your child. They are trying to get a picture of your child as a "whole person." For example, they want to understand:

- How well your child speaks and understands language,
- How your child thinks and behaves,
- How well your child adapts to changes in his/her surroundings,
- How well your child has done academically,
- What your child's potential or aptitude (intelligence) is,
- How well your child functions in a number of areas, such as moving, thinking, learning, seeing, hearing, and
- What job-related and other post-school interests and abilities your child has.

The IDEA gives clear directions about how schools must conduct evaluations. For example, tests and interviews must be given in your child's native language (for example, Spanish) or in the way he/she typically communicates (for example, sign language). The tests must also be given in a way that

does not discriminate against your child, because he/she has a disability or is from a different racial or cultural background.

The IDEA states that schools may not place children into special education programs based on the results of only one procedure such as a test. More than one procedure is needed to see where your child may be having difficulty and to identify his/her strengths.

In some cases, schools will be able to conduct a child's entire evaluation within the school. In other cases, schools may not have the staff to do all of the evaluation needed. These schools will have to hire outside people or agencies to do some or all of the evaluation. If your child is evaluated outside of the school, the school must make the arrangements. The school will say in writing exactly what type of testing is to be done. All of these evaluation procedures are done at no cost to parents.

In some cases, once the evaluation has begun, the outside specialist may want to do more testing. If the specialist asks you if it is okay to do more testing, make sure you tell the specialist to contact the school. If the testing is going beyond what the school originally asked for, the school needs to agree to pay for the extra testing.

Your Child's Eligibility

What does the school do with these evaluation results?

The information gathered from the evaluation will be used to make important decisions about your child's education. All of the information about your child will be used for the following:

- To decide if your child is eligible for special education and related services, and
- To help you and the school decide what your child needs educationally.

How is a decision made about my child's eligibility for special education?

As was said earlier, the decision about your child's eligibility for services is based on whether your son or daughter has a disability that fits into one of the IDEA's

13 disability categories (see the list below) and whether that disability affects how your child does in school. This decision will be made when the evaluation has been completed, and the results are in.

IDEA's Categories of Disability

- Autism
- Deafness
- Deaf-blindness
- Hearing impairment
- Mental retardation
- Multiple disabilities
- Orthopedic impairment
- Other health impairment
- Serious emotional disturbance
- Specific learning disability
- Speech or language impairment
- Traumatic brain injury
- Visual impairment, including blindness

In the past, parents were not involved under IDEA in making the decision about their child's eligibility for special education and related services. Now, under the newest changes to IDEA (passed in 1997), parents are included in the group that decides a child's eligibility for special education services. This group will look at all of the information gathered during the evaluation and decide if your child meets the definition of a "child with a disability." (This definition will come from the IDEA and from the policies your state or district uses.) If so, your child will be eligible for special education and related services.

Under the IDEA, a child may not be found eligible for services if the determining reason for thinking the child is eligible is one of the following:

- The child has limited English proficiency, or
- The child has a lack of instruction in math or reading.

If your child is found eligible, you and the school will work together to design an educational program for your child. This process is described in detail in Part III of this section.

As parents, you have the right to receive a copy of the evaluation report on your child and the paperwork about your child's eligibility for special education and related services.

To find out more about these disabilities and how IDEA defines them, contact National Information Center for Children and Youth with Disabilities and ask for “General Information about Disabilities.” (See the Resources section for more information).

What happens if my child is not eligible for services?

If the evaluation team decides that your child is not eligible for special education services, the school system must tell you this in writing and explain why your child has been found “not eligible.” Under the IDEA, you must also be given information about what you can do if you disagree with this decision. Read the information the school system gives you. Make sure it includes information about how to challenge the school system’s decision. If that information is not in the materials the school gives you, ask the school for it.

Also get in touch with your state’s Parent Training and Information (PTI) Center. The PTI can tell you what steps to take next. The PTI Center in Alaska is listed below.

PARENTS, Inc.
4743 E. Northern Lights Blvd.
Anchorage, AK 99508
907-337-7678 Voice
907-337-7629 TDD
907-337-7671 FAX
1-800-478-7678 in AK
parents@parentsinc.org
www.parentsinc.org

Re-evaluation

Will my child be re-evaluated?

Yes. Under the IDEA law, your child must be re-evaluated at least every three years. The purpose of this re-evaluation is to find out the following:

- If your child continues to be a “child with a disability,” as defined within the law, and
- Your child’s educational needs.

The re-evaluation is similar to the initial evaluation. It begins by looking at the information already available about your child. More information is collected only if it is needed. If the group decides that additional assessments are needed, you must give your informed written permission before the school system may collect that information. The school system may only go ahead without your informed written permission if they have tried to get your permission and you did not respond.

Although the law requires that children with disabilities be re-evaluated at least every three years, your child may be re-evaluated more often if you or your child’s teacher/s request it.



3-22 Years - Introduction

A federal law exists which requires that an Individualized Educational Program (IEP), be developed for each child who is identified as having special needs. The IEP allows the teachers to figure out exactly what your child needs. Developing an IEP is complicated and not foolproof. It is intended that parents and professionals work together as a team to identify the special needs of your child. Sometimes you as the parent may have to fight for many of the educational services and placements for your child. You have the right to request reasonable services and placements

for your child, as well as, the right to request reasonable services and placements for your child. Fear or embarrassment should not prevent you from making such requests. New laws now cover your child from birth to age three. They require an Individual Family Service (delivery) Plan (IFSP) that has the same purpose as the IEP with additional concern for the needs of your family. Also remember, that there is an appeal process that can be used if you disagree with the professional regarding services and/or assistive listening devices.



Frequently Asked Questions

So my child has been found eligible for special education. What next?

The next step is to write what is known as an Individualized Education Program, usually called an IEP. After a child is found eligible, a meeting must be held within 30 days to develop the IEP. (For more information re: IEPs, see IEP section.)

What is an IEP?

An Individual Education Plan (IEP) is an individualized comprehensive plan that a child receives when he/she transfers from early intervention (age birth to three) to public education. This plan is developed with goals and objectives focused on your child rather than your family. The document is:

- Intended to be developed in a collaborative and cooperative effort between you and school personnel
- Describe your child's abilities and needs precisely
- Set forth in detail the placement and services specially designed to meet those unique needs

What is the purpose of the IEP meeting?

The purpose of the IEP meeting is:

- For you and the school district to jointly determine the needs of your child
- To develop an educational plan for your child that is appropriate to meet his/her needs

Who attends an IEP meeting?

The following people are to attend an IEP meeting:

- Your child's parents or guardians
- A regular education teacher (if your child is participating, or may participate in regular education)
- A special education teacher or representative
- A representative of the education department who is qualified to supervise a specially designed education program and who is knowledgeable about the general curriculum
- An individual who can interpret the instructional implications of evaluation results of your child
- A related service provider, if applicable
- Any other person/s that you, as the parent's request

What will be discussed during the IEP meeting?

Many things related to your child will be discussed

during the IEP meeting. Things to consider are:

- Your child's strengths
- Your concerns for improving the education of your child
- The results of the initial or most current evaluation of your child
- Your child's current school records
- The current IEP for your child
- Any independent educational evaluations of your child
- Information about your child's current communication mode and abilities; information about your family's communication preference; the linguistic needs of your child
- The severity of your child's hearing loss and potential for using his/her remaining hearing
- Behavioral interventions, strategies, and supports to address these problems if your child has behavioral problems that might slow down his/her learning or the learning of others
- Assistive technology devices and services
- Opportunities for direct communications with peers and professional personnel in your child's language and communication mode
- Your child's academic level
- Your child's social, emotional, and cultural needs, including opportunities for peer interaction and communication.

What type of information is included in an IEP?

According to the IDEA, your child's IEP must include specific statements about your child. These are listed below. Take a moment to read over this list. This will be the information included in your child's IEP.

Your child's IEP will contain the following statements:

- *Present levels of educational performance.* This statement describes how your child is currently doing in school. This includes how your child's disability affects his/her involvement and progress in the general curriculum.
- *Annual goals.* The IEP must state annual goals for your child, meaning what you and the school team think he/she can reasonably complete in a year.

This statement of annual goals includes individual steps that make up the goals (often called short-term objectives) or major milestones (often called benchmarks). The goals must relate to meeting the needs that result from your child's disability. They must also help your son or daughter be involved in, and progress in the general curriculum.

- *Special education and related services to be provided.* The IEP must list the special education and related services to be provided to your child. This includes supplementary aids and services (such as a communication device). It also includes changes to the program, or supports for school personnel that will be provided for your child.
- *Participation with non-disabled children.* How much of the school day will your child be educated separately from non-disabled children or not participate in extracurricular or other nonacademic activities such as lunch or clubs? The IEP must include an explanation that answers this question.
- *Participation in state and district-wide assessments.* Your state and district probably give tests of student achievement to children in certain grades or age groups. In order to participate in these tests, your child may need individual modifications or changes in how the tests are administered. The IEP team must decide what modifications your child needs and list them in the IEP. If your child will not be taking these tests, the IEP must include a statement as to why the tests are not appropriate for your child and how your child will be tested instead.
- *Dates and location.* The IEP must state:
 - (a) when services and modifications will begin,
 - (b) how often they will be provided,
 - (c) where they will be provided, and
 - (d) how long they will last.
- *Transition service needs.* If your child is age 14 (or younger, if the IEP team determines it appropriate), the IEP must include a statement of his/her transition service needs. Transition planning will help your child move through school from grade to grade.
- *Transition services.* If your child is age 16 (or younger, if determined appropriate by the IEP team), the IEP must include a statement of needed transition services and, if appropriate, a statement of the interagency responsibilities or any needed linkages.
- *Measuring progress.* The IEP must state how school

personnel will measure your child's progress toward the annual goals. It must also state how you, as parents, will be informed regularly of your child's progress and whether that progress is enough to enable your child to achieve his/her goals by the end of the year.

It is very important that children with disabilities participate in the general curriculum as much as possible. That is, they should learn the same curriculum as non-disabled children, for example, reading, math, science, social studies, and physical education, just as non-disabled children do. In some cases, this curriculum may need to be adapted for your child to learn, but it should not be deleted altogether. Participation in extracurricular activities and other nonacademic activities is also important. Your child's IEP needs to be written with this in mind.

For example, what special education services will help your child participate in the general curriculum—in other words, to study what other students are studying? What special education services or supports will help your child take part in extracurricular activities such as school clubs or sports? When your child's IEP is developed, an important part of the discussion will be how to help your child take part in regular classes and activities in the school.

Who develops my child's IEP?

Many people come together to develop your child's IEP. This group is called the IEP team and includes most of the same types of individuals who were involved in your child's evaluation. Team members will include the following:

- You, the parents
- At least one regular education teacher, if your child is (or may be) participating in the regular education environment
- At least one of your child's special education teachers or special education providers
- A representative of the public agency (school system) who,
 - (a) is qualified to provide or supervise the provision of special education,
 - (b) knows about the general curriculum, and
 - (c) knows about the resources the school system has available.

- An individual who can interpret the evaluation results and talk about what instruction may be necessary for your child
- Your child, when appropriate
- Representatives from any other agencies that may be responsible for paying for, or providing transition services (if your child is 16 years or, if appropriate, younger)
- Other individuals (invited by you or the school) who have knowledge or special expertise about your child. For example, you may wish to invite a relative who is close to the child or a childcare provider, the child's audiologist, and/or speech/language therapist.

Together, these people will work as a team to develop your child's IEP.

So I can help develop my child's IEP?

Yes, absolutely. The law is very clear that parents have the right to participate in developing their child's IEP. In fact, your input is invaluable. You know your child the best, and the school needs to know your insights and concerns.

The school staff will try to schedule the IEP meeting at a time that is convenient for all team members to attend. If the school suggests a time that is impossible for you, explain your schedule and needs. It's important that you attend this meeting and share your ideas about your child's needs and strengths. Often, another time or date can be arranged. However, if you cannot agree on a time or date, the school may hold the IEP meeting without you. In this event, the school must keep you informed, for example, by phone or mail.

What should I do before the IEP meeting?

The purpose of the IEP meeting is to develop your child's Individualized Education Program. You can prepare for this meeting by the following:

- Making a list of your child's strengths and weaknesses
- Talking to teachers and/or therapists and getting their thoughts about your child
- Visiting your child's class and perhaps other classes that may be helpful to him/her
- Talking to your child about his or her feelings toward school

It is a good idea to write down what you think your child can accomplish during the school year. It also helps to make notes about what you would like to say during the meeting.

What happens during an IEP meeting?

During the IEP meeting, the different members of the IEP team share their thoughts and suggestions. If this is the first IEP meeting after your child's evaluation, the team may go over the evaluation results, so your child's strengths and needs will be clear. These results will help the team decide what special help your child needs in school.

Remember that you are a very important part of the IEP team. You know your child better than anyone. Don't be shy about speaking up, even though there may be a lot of other people at the meeting. Share what you know about your child and what you wish others to know.

After the different team members (including you, the parent) have shared their thoughts and concerns about your child, the group will have a better idea of your child's strengths and needs. This will allow the team to discuss and decide on the following:

- The educational and other goals that are appropriate for your child
- The type of special education services your child needs

The IEP team will also talk about the related services your child may need to benefit from his/her special education. The IDEA lists many related ser-



vices that schools must provide if eligible children need them. The related services listed in IDEA are listed below. Examples of related services include the following:

Related Services, as listed in IDEA

- Transportation
- Speech-language pathology
- Audiology services
- Psychological services
- Physical therapy
- Occupational therapy
- Recreation (including therapeutic recreation)
- Early identification and assessment of disabilities in children
- Counseling services (including rehabilitation counseling)
- Orientation & mobility services
- Medical services for diagnostic or evaluation purposes
- School health services
- Social work services in schools
- Parent counseling & training
- Occupational therapy, which can help a child develop or regain movement that he or she may have lost due to injury or illness, and
- Speech therapy (called speech-language pathology), which can help children who have trouble speaking.

This list does not include every related service a child might need or that a school system may offer. To learn more about these related services and how IDEA defines them, contact National Information Center for Children and Youth with Disabilities and ask for the News Digest on Related Services. (For more information, see the Resources section.)

Depending on the needs of your child, the IEP team may also discuss the special factors listed below:

- Whether or not your child's behaviors interfere with his/her learning or the learning of others.
- The IEP team will talk about strategies and supports to address your child's behavior.
- If your child has limited understanding of the English language.
- The IEP team will talk about your child's language needs as these needs relate to his/her IEP.
- Since your child has communication needs, the IEP team must consider those needs.

- Since your child is deaf or hard of hearing, the IEP team will consider your child's language and communication needs. This includes your child's opportunities to communicate directly with classmates and school staff in his/her usual method of communication (for example, American Sign Language).

The IEP team will also talk about whether your child needs any assistive technology devices or services. Assistive technology devices can help many children do certain activities or tasks. Examples of these devices include the following:

- Devices that make the words bigger on the computer screen or that "read" the typed words aloud—which can help children who do not see well
- Electronic talking boards—which can help students who have trouble speaking
- Computers and special programs for the computer—which can help students with all kinds of disabilities learn more easily

Assistive technology services include evaluating your child to see if he/she could benefit from *using* an assistive device. These services also include providing the devices and training your child (or your family or the professionals who work with your child) to use the device. (For more information about these devices, see the Assistive Technology section.)

As you can see, there are a lot of important matters to talk about in an IEP meeting. You may feel very emotional during the meeting, as everyone talks about your child's needs. Try to keep in mind that the other team members are all there to help your child. If you hear something about your child which surprises you, or which is different from the way you see your child, bring this to the attention of the other members of the team. In order to design a good program for your child, it is important to work closely with the other team members and share your feelings about your child's educational needs. Feel free to ask questions and offer opinions and suggestions.

Based on what is discussed in the meeting above, the IEP team will then write your child's IEP. This includes the services and supports the school will provide for your child. It will also include the location where particular services will be provided. Your child's placement (where the IEP will be carried out)

will be determined every year, must be based on your child's IEP, and must be as close as possible to your child's home. The placement decision is made by a group of persons, including you the parent, and others knowledgeable about your child. The meaning of the evaluation data, and the placement options are also taken into account. In some states, the IEP team makes the placement decision. In other states, the placement decision is made by another group of people. In all cases, you as parents have the right to be members of the group that makes decisions on the educational placement of your child.

Depending on the needs of your child and the services to be provided, your child's IEP could be carried out in the following locations:

- In regular classes
- In special classes (where all the students are receiving special education services)
- In special schools
- At home
- In hospitals and institutions
- In other settings

Which of these placements is best suited for your child? Can he or she be educated in the regular classroom, with special aids and services? (The IDEA law prefers this placement.) If not, then the placement group will look at other placements for your child. Before the school system can provide your child with special education for the first time, you, as parents, must give your written consent.

Can my child's Individualized Education Plan be changed?

Yes. At least once a year a meeting must be scheduled with you to review your child's progress and develop your child's next IEP. The meeting will be similar to the IEP meeting described above. The team will talk about the following:

- Your child's progress toward the goals in the current IEP
- What new goals should be added
- Whether any changes need to be made to the special education and related services your child is currently receiving

This yearly IEP meeting allows you and the school to review your child's educational program and

change it as necessary. But you don't have to wait for this yearly review. You, or any other team member, may ask to have your child's IEP reviewed or revised at any time.

For example, you may feel that your child is not making good progress toward his/her yearly goals. Or you may want to write new goals, because your son or daughter has made such great progress! Call the principal of the school, the special education director, or your child's teacher, and express your concern. If necessary, they will call the IEP team together to talk about changing your child's IEP.

What are the Alaska Transition Training Initiative's (ATTI) goals?

- To offer statewide training to promote teamwork and support among agencies and families involved in children's transition from the Infant Learning Program to school based programs.
- To help community agencies in developing effective models for children to transition from the Infant Learning Program to school based programs.

Who is the training for?

- School district special education staff
- All teachers and aides
- Head Start and preschool staff
- Infant Learning staff
- Parents and other family members
- Medical care providers
- Day care providers

What's included in the training?

- Ways to welcome the child and family into the new program
- Family involvement in decision making
- Identification of agencies for referral
- Interagency support and agreements
- Development of transition timeline
- Support for child through curriculum planning and environmental modification (change in surroundings)
- Evaluation of transition procedures

Where can I get more information about ATTI?

State of Alaska
Department of Health & Social Services
Division of Public Health
Section of Maternal, Child & Family Health
3601 C Street, Suite 934
P.O. Box 240249
Anchorage, Alaska 99524-0249
(907) 269-3400

Is the school responsible for ensuring that my child reach the goals in his/her Individualized Education Plan?

No. The IEP sets out the individualized instruction to be provided to your child, but it is not a contract. The school is responsible for providing the instructional services listed in an IEP. School officials must make a good-faith effort to help your child meet his/her goals. However, the school is not responsible if your child does not reach the goals listed in the IEP. If you feel that your child is not making progress toward his/her goals, then you may wish to contact the school and express your concern/s. The IEP team may need to meet and revise your child's IEP.

What if I disagree with the school about what is right for my child?

You have the right to disagree with the school's decisions concerning your child. This includes decisions about the following:

- Your child's identification as a "child with a disability"
- His/her evaluation
- His or her educational placement
- The special education and related services that the school provides to your child

In all cases where the family and school disagree, it is important for both sides to first discuss their concerns and try to compromise. The compromise can be temporary. For example, you might agree to try out a particular plan of instruction or classroom placement for a certain period of time. At the end of that period, the school can check your child's progress. You and other members of your child's IEP team can then meet again, talk about how your child is doing,

and decide what to do next. The trial period may help you and the school come to a comfortable agreement on how to help your child.

If you still cannot agree with the school, it is useful to know more about the IDEA's protections for parents and children. The law and regulations include ways for parents and schools to resolve disagreements. These include the following:

- **Mediation.** This is where you and school personnel sit down with an impartial third person (called a mediator) and talk openly about the areas where you disagree, to try to reach agreement.
- **Due process.** This is where you and the school present evidence (or information) before an impartial third person (called a hearing officer), and he/she decides how to resolve the problem.
- **Filing a complaint with the state education agency (SEA),** where you write directly to the SEA and describe what requirement of IDEA the school has violated. The SEA must either resolve your complaint itself, or it can have a system where complaints are filed with the school district and parents can have the district's decision reviewed by the SEA. In most cases, the SEA must resolve your complaint within 60 calendar days.

Your state will have specific ways for parents and schools to resolve their differences. You will need to find out what your state's policies are. Your local department of special education will probably have these guidelines. If not, contact the state department of education and ask for a copy of their special education policies. The telephone number and address of the state department of education are listed on National Information Center for Children & Youth with Disabilities, State Resource Sheet for your state. (See the Resources section for contact information).

You may also wish to call the Parent Training and Information (PTI) center in your state. The PTI has been mentioned several times in this information. They are an excellent resource for parents to learn more about special education. (For contact information, see the Resource section.)

Talking to Other Parents Helps!

You can learn a lot from talking to other parents of children who are already receiving special education services. There are many different local parent groups. (See the Resources section for more information.) Find one, and go to a meeting. If there aren't any groups in your area, contact the nearest group and ask for its newsletter. These can be full of information, too!

How do I find parent groups?

National Information Center for Children with Disabilities has a State Resource Sheet for your state. This sheet is a good source of information about parent groups or disability groups in your state. These state groups can tell you about groups in your area. If you do not already have a State Resource Sheet, call National Information Center for Children with Disabilities and ask for one. It's free and can be very useful.

How can I get more services for my child?

Suppose your child gets speech therapy two times a week, and you think he/she needs therapy three times a week. What do you do?

First, you can talk with your child's teacher or speech-language pathologist (sometimes called a speech therapist). Ask to see the evaluation of his/her progress. If you are not satisfied with your child's progress, then request an IEP meeting to review your child's progress and increase speech therapy. Discuss your child's needs with the IEP team and talk about changing the IEP. The other team members will either agree with you and change the IEP, or they will disagree with you.

If the rest of the IEP team does not agree that your child needs more services, try to work out a compromise. If you cannot, then parents can take the problem beyond the IEP team. As was mentioned above, mediation, due process, and filing a complaint are ways to resolve disagreements. But, always remember that you and the school will be making decisions together about your child's education for as long as your child goes to that school and continues to be eligible for special education services. A good working relationship with school staff is important now and in the future. Therefore,

when disagreements arise, try to work them out within the IEP team before requesting mediation, due process, or filing a complaint.

How can I support my child's learning?

Here are some suggestions that can help you support your child's learning and maintain a good working relationship with school professionals:

- Let your child's teacher/s know that you want to be involved in your child's educational program. Make time to talk with the teacher/s and, if possible, visit the classroom.
- Explain any special equipment, medication, or medical problem your child has.
- Let the teacher(s) know about any activities or big events that may influence your child's performance in school.
- Ask that samples of your child's work be sent home. If you have questions, make an appointment with the teacher/s to talk about new ways to meet your child's goals.
- Ask the teacher/s how you can build upon your child's school activities at home.
- Give your child chores at home. Encourage behavior that leads to success in school, such as accepting responsibility, behaving, being organized, and being on time.
- Volunteer to help in the classroom or school. This will let you see how things work in the school and how your child interacts with others. It will also help the school.
- Remember that you and the school want success for your child. Working together can make this happen.

What if I still have questions and need more information?

You can contact your state's Parent Training and Information (PTI) center. Your PTI will have a lot of information to share about the special education process in your state. You can also contact National Information Center for Children & Youth with Disabilities (NICHCY) again. They have information on all aspects of the IEP process. They also have information on other issues that are important to families who have a child with a disability. NICHCY staff can send you more publications, answer questions, and put you in touch with other organizations who can work with you and your family. (See the Resource section for contact information.)

Preparing for the IEP

Prior to the IEP meeting, you should do the following:

1. Carefully review your child's school records.
2. Carefully review all evaluations of your child.
3. Determine who will be attending the IEP meeting on behalf of the education department.
4. Make a list of your child's strengths, weaknesses, and needs including the surroundings he/she will require, the communication mode your child should use, and the services necessary to help him/her learn.
5. Identify realistic goals for your child to achieve during the school year and place those goals in order of importance.
6. Consider who you wish to bring with you to the meeting (such as an advocate or attorney, educational or other experts) and invite them to the meeting.
7. Prepare written notes to bring to the meeting that address your concerns, opinions, and expectations for your child, and the delivery of educational and related services to him/her.



DEAF CULTURE

*“When all else seems impossible,
I remember her first sign ...”*

— *Deaf Culture*



Introduction

Deaf children, like all children who are neurologically intact, are born with the amazing ability to learn and develop language. From the earliest moments of life, they begin to communicate their needs and to interact with those around them. Through cries, squeals, hand clapping and eye gaze, deaf and hearing children begin to engage in the process of language learning. We watch them carefully and listen to them, certain that every thing they say is meaningful. In this manner we recognize and build their skills. Through their daily efforts to make sense of the sounds of voices and/or the signs on hands, children activate the ability they are born with, to learn and develop the most sophisticated communication system of all - language.

Language, whether it is spoken or signed, whether it is English, French, or American Sign Language, is learned through interaction. Children must actively participate in figuring out meanings, rules, and structures. They cannot learn by passively observing or mimicking the language of others. Cognitive and social experiences with meaningful linguistic data must be present in large doses and in natural situations for all children. By the time hearing children enter school, they have already mastered language. They have done so without formal language instruction. In our culture, the language most often learned is English.

Deaf children have the same ability to learn language as hearing children do. However, they must interact with their world through sight instead of through hearing. Instead of listening and speaking, they watch and often gesture to make their ideas and thoughts known. Their access to interaction is through sight in a world where most people depend on hearing. It is this basic mismatch of systems which often keeps deaf children from participating in, and learning language.

It is up to you as parents, and caregivers to maximize the interactive process for your deaf child through sight. By including deaf children in social and cognitive activities, by concentrating on communicat-

ing meaning (not structure), and by providing visual (sight) access to communication whenever possible, we can take advantage of the strengths of deaf children. Sign language provides an avenue which is minimal in speech and audition. It ensures deaf children's participation in the language learning process. It helps us to expand our communication and this in itself leads to a stronger language skill.

— Margaret Finnegan, Ph.D. parent and educator

The American Society for Deaf Children (ASDC) sets out the following principles, which ASDC believes apply to all deaf infants/children, their families, and the professionals who serve them. These principles apply regardless of whether the family chooses a cochlear implant for their infant/child, hearing aids, other hearing technology, or no hearing technology at all.

ASDC believes that parents of deaf children:

- Have the right to make informed decisions on behalf of their infants/children.
- Benefit from meeting other parents of deaf infants/children from a variety of backgrounds, experiences, and philosophies.
- Benefit from meeting successful deaf infants/children and members of the deaf community from a variety of backgrounds, experiences, and philosophies.

ASDC believes that deaf infants/children have the right to:

- Be valued and respected as whole infants/children capable of high achievement, regardless of their degree of technology use.
- Meet, socialize, and be educated with other deaf children.
- Achieve fluency reading and writing English, and to the extent of their ability, speaking English.

ASDC believes that medical, hearing health, and educational professionals serving deaf infants/children and their families have a responsibility to:

- Be informed about the successes of deaf persons from all walks of life, including those who use American Sign Language as their main language and those who do and do not use cochlear implants.
- Recognize the benefits of early language – including sign language – and work to ensure that deaf infant/children’s language development – whether signed, spoken, or both – progresses at a rate equivalent to that of their hearing peers.

Refer parents to a wide range of information sources, including deaf individuals, families with deaf children, schools for the deaf, and local, state and national parent and deaf adult organizations.

“It is important to nurture and encourage the fire in the child’s belly; persistence is a characteristic trait among well-rounded deaf adults living in mainstream. Encourage the child to read books, newspapers and journals so that knowledge will become a powerful tool. Encourage the child to live on the edge and thus develop independence in the mainstream.”

— John (adult)

Frequently Asked Questions

What is the Deaf Community?

A community is a group of people who share common interests and a common heritage. The Deaf Community is made up of people, both deaf and hearing, who to different degrees have similar community goals that come from Deaf cultural influences.

Why are there so many different terms to describe deafness?

The different terms reflect differing views of deafness. The terms most often used are Deaf, Hard of Hearing, and Hearing Impaired. Some professionals use the term, “Hearing Impaired,” to identify an infant/child with a hearing loss. This is a medical or clinical term that implies a need to fix or change. Within the Deaf community, people don’t consider themselves “impaired”. Members of the Deaf community, and some hearing professionals, who share this view, prefer, and use the terms Deaf or Hard of Hearing. Individuals who are Deaf or Hard of Hearing may have individual preferences. Their choices to use one term or the other may be based on many factors, including communication and culture.

What is Deaf Culture?

A culture is generally defined as a system of values, beliefs, and standards that guide a group of people’s thoughts, feelings, and behaviors. The Deaf Culture is made up of five areas including:

- *Language: American Sign Language (ASL)* is a language in which the placement, movement, and expression of the hands and body are actually part of the language. ASL is considered by the deaf community to be the native language of people who are deaf. ASL has its own grammatical structure and linguistic principles. It is one of the most complete sign systems in the world, and it can express abstract thoughts. ASL is now accepted as a true and complete language.
- *Identity:* It is important in any culture to know your identity. It is critical for an infant/child who is deaf to have Deaf role models, so he/she will have a better idea of the future. It is equally important for that infant/child who is deaf or hard of hearing to understand both Deaf and Hearing cultures and both languages (ASL and English)

in order to succeed in a larger society. A lot of young children are exposed to more than one language and culture, and it is perfectly permissible for Deaf/Hard of Hearing children to understand more about Deaf Culture and American Sign Language.

- *Values:* Individuals who are Deaf want to have clear communication without any barriers. This is an important and shared value. It is easy to understand why people who are Deaf feel comfortable using American Sign Language. They value their eyes because they can’t depend on their hearing ability. Eye contact is often used to carry on a conversation. Deaf individuals use their hands to communicate. There is not a high value placed on the use of speech, as not all of Deaf/Hard of Hearing people are able to use their speech skills. The Deaf World is really a small world. It’s easy to become friends with many Deaf people in many cities and countries because individuals share common values.
- *Rules of Social Interaction:* It is essential to know general rules of both cultures, so your infant/child can have an opportunity to function well in any setting. Here are a few rules of interaction in the Deaf Culture.
 - Maintain eye contact, do not stare
 - Use attention getting devices such as waving, tapping the shoulder, stamping on the floor and turning the lights on and off
 - Be blunt, “tell it like it is”
 - Engage in long departures from a social event
 - Hug when greeting or leaving
 - Pointing is polite
 - Touch during conversations
 - Avoid “excuse me” when walking between two people who are signing, it is not necessary to say “excuse me”
- *Deaf Traditions:* There are many traditions that are an important part of the Deaf Culture. They include:
 - Storytelling using American Sign Language
 - Sharing folklore
 - Giving name signs that reflect something about the person

- Attending social gatherings including homecomings, tournaments, conferences and reunions
- Belonging to local or national Deaf organizations

What is it like being deaf?

Deaf people are normal. Their typical day is like yours. They can do anything, except hear! Helping people who hear to understand these things is an ongoing education process. Deafness is a handicap that you cannot see. You can't know that someone is Deaf by just looking at them. Hearing people may first realize someone is Deaf or Hard of Hearing when that person uses sign language or asks for something just said to be repeated. People who are Deaf often must fight for their rights. They want the same type of access that hearing people have. Access may mean having an interpreter when one is needed, or being able to use the telephone through a public relay service, or having a visual fire alarm system in a hotel. Advances in technology are improving access everyday. For example, hearing people have cell phones, and Deaf/Hard of Hearing people have pagers with text. Open-captioned films are available in many cities, so Deaf/Hard of Hearing people can watch a movie on a big screen. Despite all the improvements that have been made, people who hear continue to have more access to services than people who are deaf. The movement toward gaining equal access continues.

How did the deaf culture begin?

The deaf revolution began in the 1970s. The culture rebelled against attempts by some educators in the hearing world to teach deaf children to speak English. This "oral" approach discouraged the use of sign language. Unfortunately, many children, even with the powerful hearing aids, had difficulty understanding what was supposed to be their native language.

My deaf infant/child is the first deaf person I have ever met in my life. Will he/she have a normal life?

Yes! Your infant/child can have a good relationship with you and other family members, get a good education and later a good job, and lead a rich, fulfilling, contributing life. People who are deaf are found in many different professions, such as law, medicine,

drama, research, education, computer programming, accounting, and businesses. People who are deaf are found in all sorts of interesting activities, including travel, writing, sports, religious activities, social clubs and more. But your infant/child's success will not happen without your involvement and support. Some things you should do are:

- Learn to communicate with your infant/child as well as you can
- Read to your infant/child and nurturing his/her writing when the time is appropriate
- Participate in organizations that provide support and information to parents
- Gather information about child development, language learning, and infants/children with hearing loss
- Get to know other parents of deaf infants/children and deaf adults in your community

I am considering using sign language with my infant/child, but I have been told that if I do it will interfere with his/her speech development. Is this true?

There is no evidence to indicate that using sign language interferes with speech development. In fact, research shows that a higher degree of language, including sign language, is connected with better speech production. Research also shows that hearing infants/children benefit from learning sign language as well, and that they're spoken language develops appropriately.

How well will my infant/child be able to speak?

The degree to which a deaf infant/child is able to speak depends on many factors including when your child's hearing loss was identified, intervention, and what type of hearing loss. Hearing aids and other forms of assistive technology can provide a high degree of access to speech sounds. Combined with speech therapy, technology can help many infants/children who are deaf develop some level of speech, with some becoming fluent speakers. However, the ability to hear sounds, discriminate among them, and then speak about them is quite complex, and not every deaf infant/child will master these skills. The degree to which an individual infant/child will learn how to speak and understand other speakers may be difficult to predict.

Shouldn't I try to have my infant/child learn how to talk instead of sign? It's a "hearing world" isn't it?

While it is true that most people are hearing and use spoken language for face to face communication, it is important to remember the distinction between language and speech. Language is a means of communicating ideas or feelings using certain signs, sounds, gestures, or marks. Language is necessary for cognitive, academic, and psycho-social development. Speech is the communication or expression of thought in spoken words. Speech is a method of communication, or a means of expressing language, and not language itself.

Deaf infants/children with normal vision and cognitive ability who interact with people who use sign language can themselves learn sign language. Deaf infants/children's degree of success mastering spoken English will differ. In addition, factors such as background noise and distance from the speaker can impact an infant/child's ability to understand a speaker. As a result, many parents choose to provide their deaf infants/children an opportunity to learn both spoken English and sign language.

You should never be forced into choosing one mode of communication and rejecting others. Work with your infant/child's service providers (teachers, audiologists, and therapists) to ensure that your infant/child is developing language, whether signed, spoken, or both, at the same rate as your infant/child's hearing peers.



I want my infant/child to learn American Sign Language (ASL) and be part of the deaf community, but I am afraid that his/her learning ASL will prevent him/her from learning English. Will this happen?

ASL is a language of its own with a structure and grammar different from that of English. However, just like infants/children in cultures all over the world, deaf infants/children can become bilingual, using both ASL and English. Regardless of a deaf infant/child's speaking ability, he/she will need to be a fluent reader and writer of English. Research shows that characteristics that are found in good deaf readers are:

- They had their hearing loss identified early
- They had early access to language (usually sign language)
- They were exposed to English

Which is better – signed English or ASL?

When it comes to languages there is no "better" or "worse." The question is, for what purpose is the language being used? Generally, deaf adults use ASL with each other. When they are signing with a hearing person who does not know much sign language, they might sign in an order that is more like English. If they have understandable speech, they might use that either instead of, or in addition to their signs. Generally, hearing parents whose first language is English and are learning to sign, tend to sign in English word order, because that is the language with which they are most familiar.

I am afraid that if my infant/child joins the Deaf community he/she will reject the rest of our family, which is hearing. Will that happen?

As with any family, families with deaf infants/children that have the strongest bonds are those where there is love, respect, understanding, and communication. Regardless of what your infant/child's main method of communication is, you must make sure that clear and open communication exists. Deaf people value the efforts their parents made to communicate with them throughout their lives. Clear and open communication with your infant/child, and not whether their peers are deaf or hearing, will help establish healthy relationships with him/her that will last throughout your lives.

FINANCIAL ASSISTANCE

“I’ve learned that the most creative ideas come from beginners – not the experts.”

— ALBERT EINSTEIN



Health Plans

Choosing a Health Plan that Works

Most people have few choices when it comes to health plans. People are limited to the health plans offered by their employers. Even if choice is available, it is difficult to decide which health plan is best. Sometimes, we find out too late that our health plans do not cover needed medical benefits. For deaf and hard of hearing people and their families, this may mean no coverage for hearing aids, cochlear implants, and other medically necessary devices and services.

Coverage of Hearing-Related Technology & Procedures

Even under the best of circumstances, you can expect some resistance at first from your health plan if you are requesting costly devices such as cochlear implants or hearing aids. Indeed, some health plans have tried to not provide coverage for cochlear implants by lumping them into their general exclusion for hearing aids. You may need to educate your health plan about how a cochlear implant is different and why it is “medically” necessary for many deaf and hard of hearing people.

For hearing aid users, all hope is not lost. Although most health plans don’t cover hearing aids, some plans are willing to include such coverage for a small additional premium. For example, adding hearing aids as an eligible benefit under the State of Minnesota employees insurance program added only 50 cents per month to the cost of a family policy.

The first step, however, is to ask. Because approximately fifty percent of all health insurance is secured through a family member’s employer, the place to begin is with your employer’s benefits administrator. If the hearing aids are for your infant/child, emphasize that he/she needs hearing aids to learn language and to fully participate in the educational process. You should also mention that to benefit fully from hearing aids, infants/children need follow-up fittings, and rehabilitation from a qualified hearing health care provider. A successful intervention benefits the well being of the patients and their entire family. The societal impact of hearing and coverage is also worth presenting to a socially minded employer. Because infants/children who are deaf or hard of hearing need new hearing aids frequently, the expense for the individual family is considerable. “High tech,” top-of-the-line hearing aids cost thousands of dollars, and most infants/children with hearing loss have a binaural hearing loss (both ears) requiring two aids. Covering hearing aids helps spread the cost among all insured rather than overburdening the affected family.

Although some health plans will cover the full cost of hearing aids, many will cover only a percentage of the cost (for example, \$1,000 or less per hearing aid). In general, coverage is limited to once every three to five years. Nevertheless, some coverage is better than none, and you can’t lose anything by asking. If more people made the effort to get hearing aid insurance coverage, it would become easier to get this coverage for everyone.

“I’ve learned that if you want to cheer yourself up, you should try cheering someone else up.”

— Anonymous

Tax Deductions

Parents should be aware that if they itemize deductions, they are permitted to deduct as medical expenses any costs for treating or lessening the effects of hearing loss. This includes expenses for treatments by doctors and audiologists, speech therapy, special education, and transportation connected with getting these services. Special equipment such as hearing aids, batteries, cochlear implant supplies, ear molds, television captioners, and other assistive listening devices (for example, door bell ringers, TTY's, amplifiers, wake-up devices, tactile communicators, fire/burglar alarms, and baby cry signalers) may also be deductible.

In addition to deducting medical expenses, you may deduct donations made to non-profit educational or charitable groups that are dedicated to helping people with hearing loss. This includes deductions from contributions, donations of merchandise, and costs as a result of volunteering. The value of one's time however, is not deductible.

For more information about the tax law concerning parents of infants/children with disabilities, contact:

Internal Revenue Service
Correspondence Unit, Group 18
P.O. Box 538
Baltimore, MD 21203
Voice 800-829-1040
TTY 800-428-4732



PARENTS

*“There are only two lasting things
we can leave our children;
one is roots, the other is wings.”*

— Anonymous



Introduction

Discovering that your infant/child is deaf or has a hearing loss can result in many emotions. It is normal to experience a variety of feelings including relief, anger, shock, fear, denial, sadness, grief, confusion, guilt, disbelief, and surprise.

Most people have never had any experience with deafness or hearing loss of any kind, and therefore suddenly find themselves launched into very unfamiliar and uncomfortable territory. For many, this experience is not unlike the grief process. It is very individual and everyone reacts differently.

Some parents have little problem accepting the diagnosis and seem to move on without a hitch, while others find themselves struggling to come to terms with it, sometimes for an long period of time. Regardless of what your reaction is, be assured that it is normal. There is no right or wrong way to react.

You can learn a lot from talking to parents of children who have older children with a hearing loss. There are many different local parents groups. Find one, and go to a meeting. If there aren't any groups in your area, contact the nearest group and ask for its newsletter. These can be full of information too! (See Resource Section to find parent groups in your area.)

“Important advice that you should think about is having patience with your child. It will take some time to get used to some changes that you will have to sacrifice for. Remember that your child will look up to you and copy your actions. Your child will learn from you and you will learn from your child. All it takes is time and patience. Later as you get used to the changes, you will realize that learning something about your deaf child is precious. You learned that love is what brought you and your child close together. Having a deaf child might not be easy but you will be able to handle it if you have love for your child. That is most important between you both. My advice to you is to just take one day at a time and learn from your mistakes.”

— Justin (age 14)

Advocating for Your Child

An advocate is someone who takes action on behalf of someone else. As the parent of an infant/child with a hearing loss, you are an advocate when you stand up for the needs and the rights of your child. You are an advocate when you do the following:

- Let professionals know what services you want for your infant/child and your family at your IFSP/IEP meeting
- Find the best doctors, therapists, and services for your infant/child
- Talk to other families with children with hearing loss about your experiences with the services your infant/child is receiving

It can be difficult to advocate for your infant/child without knowing what your rights are as a parent. There are organizations available to help you learn more about the laws that affect your infant/child and how to advocate.

It is important to remember to take care of yourself while caring for your infant/child. Taking time for yourself will make both you and your family happier and more effective.

Five Steps to Becoming Your Infant/Child's Best Advocate

1. Begin by assuming that you are an equal partner in your infant/child's education.
2. Deal with your perceptions or feelings about yourself as a parent of an infant/child with special needs.
3. Gather information. You don't have to memorize everything, but rather be aware and ask questions.
 - Know your rights regarding IDEA (Individuals with Disabilities Education Act).
 - Other rights are protected by ADA (Americans with Disabilities Act), which ensures that all people with handicaps have access to public events, spaces, and opportunities.
 - Know that now all issues are controlled by the local school system.
 - Know how the system operates.
 - Know the people.
4. Improve your skills in:
 - Communication
 - Documentation/letter writing
 - Record keeping
5. Participation is the most important thing you can do for your infant/child.
 - Participate in Individualized Education Plans (IEPs) and share your ideas
 - Teacher conferences
 - Parent group meetings
 - School functions

Don't ever forget, that you are an equal partner and deserved to be treated like one. And remember, you and your infant/child have other rights in addition to your legal rights. You have the right to decide what is best for your infant/child.

Dealing with Professionals

The audiologist (hearing loss specialist) is an important part of your infant/child's team of caregivers. Make sure that he/she is willing to listen to you and take time to answer your questions. Following are some questions that you may want to ask your audiologist:

- How much experience do you have testing infants and young children? How about fitting infants and young children with hearing aids?
- How much of your time do you spend working with young children (practicing pediatric audiology)?
- Do you know what FM systems are? Do you recommend them for infant/young children?
- How soon do you suggest fitting hearing aids for a deaf or a hard-of-hearing infant/child? (The audiologist should be ready to fit your infant/child with hearing aids as soon as the loss is confirmed.)
- Will you be able to direct me to the speech and language pathologists? How about early intervention programs? (If not, the audiologist probably does not have many pediatric (infant/children) patients.)
- What do you know about cochlear implants? Where can I get more information about them?

Questions for parents to begin asking about their infant/child's hearing tests?

- What does this test measure? What will this test tell me about my infant/child's hearing loss?
- How does this test work?
- Why do we do this test at this time?
- What are you looking for with this test? What do you expect to find with this test?
- How do we read the results or findings of this test?



Check List

for Effective Parent-Professional Collaboration

- Do I believe that I am an equal partner with professionals, accepting my share of the responsibility for solving problems and making plans on behalf of my infant/child?
- Am I able to see the professional as a person who is working with me for the well being of my infant/child?
- Do I see as my goal for communications with professionals the mutual understanding of a problem so that we can take action as a team to reduce the problem?
- Do I clearly express my own needs and the needs of my family to professionals in an assertive manner?
- Do I state my desire to be an active participant in the decision-making process concerning services for my infant/child and do I seek agreement on how to make sure I am involved?
- Do I take an active, assertive role in planning and implementing the Individual Education Program for my child?
- Do I come to appointments having thought through the information I want to give and the questions I want answered?
- Do I accept the fact that a professional often has responsibility for service coordination and communication with many families, including my own?
- Do I treat each professional as an individual and avoid letting past negative experiences or negative attitudes get in the way of establishing a good working relationship?
- Do I communicate quickly with professionals who are serving the needs of my infant/child when there are significant changes or when notable situations occur?
- Do I communicate with other parents, thereby reducing my isolation and theirs, and sharing my expertise?
- Do I encourage the professionals involved with my infant/child to communicate with each other and to keep me informed as well?

Literacy Skills

Always remember, your deaf or hard of hearing infant/child:

- Needs to see you more than a hearing infant/child. Deaf infants/children may not know you are there without seeing you.
- Responds well to movements. For example, he/she will watch the movements and changing expressions of your eyes.
- Uses your face to understand what you say. For example, hearing infants/children learn the difference between a question and an order by listening to their parent's voices go up or down in pitch. Deaf or hard of hearing infants/children watch their parent's faces for a questioning facial expression or a firm, ordering expression.
- Keep it simple. Show pictures of simple objects and pictures to your infant/child. Infants/children become confused when there is too much to look at. For example, your infant/child will be more interested in one toy than in a chest full of toys.

- Keep a diary of your infant/child's progress. Write down the many things you and your infant/child do together such as:
 - facial expressions I used and my infant/child watched...
 - my infant/child watched with interest when I ...
 - my infant/child watched my face and signed when I said these words....
 - words I want to use with my infant/child in the future are...
 - pictures and things I want to show my infant/child in the future are...
 - facial expressions I want to show my infant/child in the future are....

As your infant/child starts new activities and responds to you, expand his/her language by adding new words and new ideas such as:

- A good way to stimulate your infant/child's thinking is to offer choices
- Many pre-reading activities do not require books
- Many toys and activities encourage reading, writing, and speaking
- Before you start any activity, get rid of distractions



Tips

for Reading to your Deaf or Hard of Hearing Child

- Choose books both you and your infant/child like.
- Make sure your infant/child can see your face, your signs, and the print at the same time.
- Don't be limited by the words. Expand on the book's ideas.
- Talk about the story with your infant/child as you read. Ask your infant/child questions. Connect ideas in the story with your experiences. Have your infant/child guess what will happen next.
- Be dramatic. Play with the signs and exaggerate your facial expressions and movements to show different characters.
- Vary where you make the signs. Sometimes sign on the page; sometimes sign on your child; sometimes sign in the usual place.
- If you don't know some signs, don't panic. Use gestures, point to pictures, and act out that part of the story. Later you can ask your infant/child's teacher for the sign.
- Keep attention by tapping lightly on your infant/child's shoulder, or giving him/her a gentle nudge.
- Let your infant/child guide you through the story. For very young children, this may mean letting him/her turn the pages as you briefly describe the pictures. When your child is older, you can actually read the story.
- Act out the story after you have read it.
- Read the story over and over if your infant/child asks. This is an important part of his/her language development (learning).
- Have fun! Make your time together a positive experience!

Record Keeping

Creating a Home File – How Do I Keep Track of All of This?

Getting Started

Decide what type of storage you will use.

Examples include:

- Binders
- An accordion file
- A tote bag
- A computer
- A filing cabinet
- A box
- A drawer

Organizing Your File

Use folders or dividers to separate different sections, and subsections. Examples of the sections include:

- **“Get to Know Me”**
 - Pictures
 - Likes/Dislikes (food, activities, toys, friends, pets, etc.)
 - Strengths/Weaknesses
 - Daily routine
- **Important Documents** (originals in a safe place and copies in the file)
 - Birth certificate
 - Immunization record
 - Social Security Number
 - Insurance card
 - Legal documents (guardianship, consents for emergencies, etc.)
- **Directory of Names/Phone Numbers**
 - District administration (School Board, superintendent, special education director)
 - School administration
 - Teacher
 - Related services (therapists, psychologists, etc.)
 - Case manager
 - Respite/day care providers
 - Doctors
 - Pharmacy/medical supply company
 - Hospital
 - Support groups/counselor
 - Transportation
- **Communication**
 - Keep a log of incoming and outgoing calls. Include date, name, title agency, what was discussed, highlight items on which action is expected and date on which action is expected. It may be a good idea to follow-up your call with a letter.
- **Calendar of Appointments and Meetings**
- **Current and Past Individualized Education Plans/Individualized Family Service Plans**
 - Report card
 - Samples of work
 - Evaluations and assessments
 - Correspondence from the school
 - Record of parent observations and participation
- **Medical Records/Reports**
 - Diagnostic reports/lab results
 - Primary care and consultants
 - Medical records
 - Medical care/medication schedule
 - Family medical history
 - Log of treatments and reactions
 - Log of hospitalizations
- **Developmental Records/Reports**
 - Evaluations by doctors, therapists, psychologists
 - Log of services and responses (what works and what doesn't)
- **Adaptive & Medical Equipment**
 - Instruction and service manuals
 - Catalogs
- **Resources**
 - Education rights and responsibilities
 - Local, regional & national organizations
 - Articles, fact sheets, brochures, etc.
 - Copies of laws and regulations
 - Glossary and acronyms

Your Rights

It is very important to remember that legal rights are not the only right that you and your infant/child are entitled to receive. You have the right to voice your concerns and be taken seriously. It is your right to decide what is best for your infant/child. There are many professionals and educators who are experts in the field of hearing loss available to assist you in the decision making process. You may not agree with the expert's suggestions regarding how to care for your infant/child.

Remember, you do not have to accept what the professionals advise. If you and your family feel you know of better alternatives for your infant/child, you have the right to choose those. However, if you want something else, you may have to make calls, write letters, get audiologists or physicians involved, and/or go to meetings to get what you want. Advocacy is an ongoing and very challenging process. Always pursue what you feel is in your infant/child's best interests.

There are a number of procedural safeguards in place to ensure that infants/children and their families receive appropriate services. These include:

- A means to resolve complaints by parents, including through legal means
- The right to confidentiality
- The right to accept or decline services
- The right to examine records
- Written prior notice (in the parent's native language) regarding the infant/child's identification, evaluation, and placement
- The right to use mediation (legal support) to resolve disputes

There are also important federal laws that protect the rights of the deaf and hard of hearing. These include:

IDEA

Individuals with Disabilities Education Act of 1997 (IDEA '97: PL 105-107), is the federal law that requires that all children be given a free, appropriate public education, with meaningful access to the general curriculum, and high expectations and standards.

Part C of IDEA refers to the services all states are required to provide to infants/children and their families, ages birth to three.

Part B of IDEA refers to the services all states are required to provide to children aged three through age 21, including access to public education.

ADA

Americans with Disabilities Act (PL 101-336), ensures that all people with handicaps have access to public events, spaces, and opportunities.



Hearing Check List

Here are some things a child with normal hearing should be able to do. Use the hearing milestone chart to check your child's hearing at home.

0-3 months

- Jumps at a sudden, loud noise
- Calms down when you speak

3-6 months

- Turns head or moves eyes to find your voice
- Plays at making noises and sounds

6-10 months

- Reacts to hearing his/her name
- Begins to understand easy words like "no" and "bye-bye"

10-15 months

- Repeats simple words and sounds you make
- Uses two to three words other than "ma-ma" and "da-da"

18 months

- Follows simple spoken directions
- Uses seven or more true words

24 months

- Understands when you call from another room
- Points to body parts when asked

Parent Stories

From Lisa Coleman's testimony

On behalf of The National Campaign for Hearing Health

Before the House Committee on Appropriations
Subcommittee on Labor, Health and Human Services and
Education

April 23, 2002

“Now, I would like to share with you my experience with my daughters Corrine, age 9, who was diagnosed late at age 2 and Emily, age 7, who was diagnosed at birth.

If there were ever parents that should have self-diagnosed a hearing loss on their own, it should have been my husband Lance and I. Lance is an Ear Nose and Throat physician and when Corinne was born I had just completed my Master's Degree in Child and Family Development. When Corinne was born she looked and responded very normally, but as months progressed, she didn't seem to be talking. We counseled with our pediatrician who encouraged us to watch and wait 3 months, 6 months, and then 12 months. We watched and waited, but Corrine showed no improvement. Finally, without the approval of pediatrician, we scheduled a hearing test when she was 22 months. Corinne failed the hearing test and at age 2, the average age of diagnosis without a newborn screen, Corinne was fitted with hearing aids.

Developmentally, just think about what two-year-olds are notorious for. Corinne tried to do all of those things with her hearing aids. She sucked them, threw them, and tried to hide them. We had a solution - hearing aids to assist her hearing, — but no means to keep them on. Finally a few months later by a stroke of luck, we found a hat that we cinched on and she couldn't get her hearing aids off. So Corrine wore that hat from sun up to sun down.

Soon after diagnosis, we tried to enroll Corinne in an early intervention program, but because of the school calendar, it was late spring and no one could take us on their case until early fall because of summer break. She

was eventually admitted to early intervention at age 2-1/2, but was soon forced to exit the program because early intervention stops at age three.

Corinne started preschool at age 3 with essentially no expressive and very little receptive speech. To improve her communication skills we started speech therapy, which resulted in hundreds of hours and thousands of dollars over the course of four years. With such significant language delays, our family has learned to use a communication tool, which also has taken hundreds of hours of practice and study.

Our Emily was born when Corinne was age 2-1/2. She was tested at birth with the appropriate equipment and had a hearing aid at 5 months. Emily did not reject her aids. She left them in and just soaked up the sound. Emily was enrolled in an Early Intervention Program at 6 months where her speech was monitored regularly. She developed speech normally right along with her hearing peers. Emily has never had to have regular speech therapy. Her vocabulary has been very expressive, confident and dramatic from a young age.

The contrast in our experiences dealing with every aspect of essentially the same hearing loss in both girls has been dramatic. From testing, to aiding, to early intervention, speech therapy, language development, socialization and ongoing voicing and speaking confidence issues— our younger daughter Emily has had a tremendous advantage because of her earlier identification.”

Emily: “I'm Emily and I'm so glad I got tested when I was born, I haven't had to work as hard as Corinne. Thank you.”

Corinne: “I am Corinne and because there was no newborn hearing screening when I was born I had lots and lots of speech therapy. My little sister Emily didn't have to do all that work. I wish that all kids with a hearing loss could be identified early like she was. I really hope you will put the money for hearing testing back in the budgets to help other kids. Thank you.”

Taylor's Story

I feel very strongly that a standardized test for hearing should be a requirement before a newborn leaves the hospital. I have a 7-year old son that did not have a hearing test as a newborn. It was not until he was 3 three years old that we discovered he had a hearing problem. He is currently completely deaf in his right ear.

One might ask why it took so long to discover a problem such as this. He is our second son and when I would ask the pediatrician why he wasn't speaking clearly and using words more, the response was "He has the older brother doing the talking for him." He also had very few ear infections as a baby, probably less than four. It was not until we were battling fluid in his inner ears (still not an infection) that we insisted on seeing a specialist. In fact, we discovered that he not only did not have hearing in his right ear, but his hearing in his left was approximately only 50 percent. I will never forget that feeling of terror and helplessness that I experienced that day for my son and our family. Since that day we have not stopped getting help and educating ourselves on our son's condition and how best to teach and help him. Finding out a fact such as hearing loss in your child changes the way you think about everything in his environment as it well should if he is to grow up as normally as possible.

We also discovered over a couple of months that our son has a fluctuating hearing loss in his 50 percent ear. In fact, it has fluctuated twice and is at 100 percent hearing now. Through this process he has



been in speech two to four times a week, has had ear tube surgery a few times, many hearing tests, and has worn a hearing aid. We have had incredible support but again if we had known when he was born we could have started the process of helping him much earlier in his life. As new parents, I would want to know as much as I could about my new baby so I could take care of and nurture my baby. As in the case of hearing loss, the more parents know, the better equipped they can become to help their child grow and learn in the best possible environment.

Lindsey's Story

On November 9, 1994, my husband and I received a call in mid-afternoon from a doctor in Washington stating that the birth-mother was going into labor, and that we had better make reservations to get there as soon as possible.

Well, we were having a blizzard, and on top of it, we lived in the bush of Alaska. Everybody from Alaska knows that no planes fly in blizzards.

The doctor called back at about 6:00 p.m. our time congratulating us for being the new parents of a beautiful little six lbs. ten oz. baby girl, and, that we had better make it there within the next twenty-four hours or else the birth mother was going to give the baby away to another family. I was devastated! I prayed and asked God that if this was his perfect will, to open the doors and help get us there soon.

We called Alaska Airlines and they had two seats available that same night as a cancellation just occurred. So, we drove to the airport, in a blizzard, and of course, praying all the way. The plane was circling the airport. One more round, and if they could not get through the storm, they were heading back to Anchorage.

Somehow, a hole opened up in the thick clouds, the plane got through, unloaded their passengers, loaded the new passengers and all the luggage, and took off, through the same and only opening in the sky, and then, the hole closed up immediately as we flew through it. We knew then that that little baby girl was ours!

We had many more trials and tribulations to work through within those next forty-eight hours, and many more miracles occurred. God meant business.

After we arrived back home with our little angel, we noticed that her hearing was not right! We tried the loud noises behind her, calling her by her name, thinking she was not watching us, but little did we know then that babies with no hearing, all of their other senses became stronger. Her eye vision was very quick and fast, as if she had eyes behind her head. This offset our suspicions for some time and



the doctors also. Finally, when she was eleven months old, we visited the audiologist at our hospital here in Dillingham. From that appointment, we learned that our little angel was profoundly deaf. We were devastated! Our dreams changed from then on, we learned how to become her advocates.

The audiologist called the Infant Learning Program. Within the first week, a knock came to our door, and with welcoming arms, we invited them into our lives. They came with a bag of toys and books, and wonderful information on how we could start to communicate and teach our daughter a new language. From there, the Anchorage School for the Deaf had a team of educators that did traveling throughout the state to work with families that have children who are deaf and hard of hearing. We received monthly visits from them along with the ILP (Infant Learning Program) who visited with us on more recent home visits. They were an answer to prayer. I called both of the programs our Angels sent from God. They were compassionate, full of wonderful information, and they loved and adored our little girl

as she did them. These people were dedicated and committed to their jobs and to the families they worked with. They were what we needed back then.

After we learned of our little girl's special hearing loss, the Infant Learning Program helped us set up some appointments in Anchorage for some tests to be done to see what the hearing loss was caused from and the depth of her hearing loss. Lindsey had an ABR done at Alaska Regional Hospital. Then from there, we visited with another audiologist, Joyce Sexton to receive more information about Lindsey's hearing loss. These professionals were great advocates and support to us.

It was such a vulnerable time in our life. But we knew that this child was given to us for many special reasons, so we never looked back, except to the wonderful miraculous miracles that were shown to us. This is what my hopes are for your family when you are now going through these special times.

I urge you to become your child's advocate, because she/he will need you for a very long time, and they will need the best of care to help those tiny little neurons and synapses to grow in their tiny little brains. With no hearing, or very little hearing, your child will need all the love and support they can get from you. You're the one that was chosen to be your child's parents. I encourage you to walk each day as a new beginning and thinking of this as a new adventure, for it really is. Always remember though, that your infant/toddler is a child first that needs all your love and support, and the special needs are secondary. Never forget this.

Hugs to you and God Bless.

Warmly,

Brad, Linda, Lindsey Erickson of Dillingham, Alaska

Jordyn's Story

Jordyn's story starts on January 8th 2000, when she was delivered emergency c-section due to complications in my pregnancy. She was born at 29 weeks gestation and was only 3lbs 3oz. Looking back the month and a half she was in neonatal intensive care unit was a blur. Wanting to be there with her every minute of the day, but having to pull myself away at some point to rest. Day after day I would go sitting next to the isolette where she was hooked up to cords and tubes, each day she would get a little stronger. I remember going into the NICU and seeing her hooked up to different wires and having strange electrodes on her head. When I asked what they were for I was told he had just finished a hearing test and they had done another earlier but she had failed them both. That is the moment we questioned Jordyn's hearing. We were told by the nurses not to worry that some babies failed and it did not necessarily mean they had a hearing loss. We were told to get a more in depth hearing test for Jordyn in the coming months.

The months that followed were filled with endless doctors appointments, procedures and test for various ailments. Finally, it was the day of the BAER test that we were awaiting for months. I remember it taking a long time, several hours and how the technician looked concerned when she was finished testing. "Well your daughter is deaf," she said. Those words changed my family dramatically. From there, only minutes after being told that Jordyn was deaf we went downstairs in the hospital, to a room with a sound booth. While the technician did a few small tests she told us about AEIHR and told us to find an audiologist. The technician told us that we were actually really lucky that we caught the hearing loss so early. Jordyn was 7 months old when she was diagnosed with a profound hearing loss. That day when my husband and I returned home we were still in shock. We decided right then and there that we would not dwell on the fact that our daughter was deaf, instead we would embrace



her deafness and try our best as hearing parents to teach our daughter sign language and ourselves. Our second step was calling AEIHR which has helped our family tremendously with everything from borrowing materials to coming to our first audiologist appointment to help us understand more about our daughters hearing loss. Within a month of the BAER test Jordyn was fitted with hearing aids. It has been a struggle keeping the hearing aids on her, we actually just recently found that even with hearing aids we have not found any hearing.

Now Jordyn is almost 3 and is currently in transition into preschool. She is very bright and cute and people seem to be drawn to her, not only because they see her wild expressions and her use of sign language but also they can tell that she will not let being deaf slow her down in any way.

Jack's Story

We learned of our son Jack's deafness when he was about 6 months old. It was a very traumatic and emotional discovery for our family. Having had no prior contact with deaf or hard-of-hearing people we really did not know what to expect. We certainly had no immediate idea of what to do. But we knew time was critical and got into action fast.

Jack was born several months before implementation of the state's newborn hearing screening program and was not tested at birth for hearing loss. We had suspicions about Jack's hearing within a month after his birth – unlike his twin sister, he had no startle reaction to loud sound. These suspicions were raised with Jack's pediatrician who felt that there was no immediate cause for concern. At age 6 months, it was clear Jack's response to sound continued to be abnormal. We had his hearing tested and received the first hard evidence that Jack had hearing problems. The first test was an Otoacoustic Emissions (OAE). Neither of Jack's ears produced the expected response. This test was followed by a Brainwave Audio Evoked Response (BAER) test. The results of this test were irregular but suggested a hearing loss in the severe to profound range in both ears. Jack's deafness was now fully confirmed.

We felt it important to determine the physical reason for Jack's deafness and requested a CAT scan in the hopes that it might provide some answers. Nothing helpful came from the CAT scan at this time, however these images later proved pivotal in explaining Jack's hearing loss and determining our choice of treatment.

In addition to doing the diagnostic work, one of the first things we did after seeing the results of the OAE was contact the state early intervention program who put us in touch with the Alaska Early Intervention Hearing Resource (AEIHR) and FOCUS, our local infant learning program. Both agencies became immediately involved. They helped us move through and past our initial anxiety and introduced us to the many issues we would face. We were directed to appropriate medical, audiological, and therapeutic services, and were able to learn much from their resources. We were also introduced to



sign language and provided courses and material suitable to our family.

Jack was fitted with his first pair of hearing aids by 7 months. He readily accepted these and wore them without complaint. The aids were an immediate and clear benefit. He became very interested and focused on this new sensory input. He loved toys that produced music or other interesting sounds. Jack also enjoyed exploring and expanding upon his range of skills. He rapidly became a skilled lip reader. We committed to an oral approach to Jack's language development because of his fascination with sound and his early ability to interpret and express spoken language.

Around his first birthday, it became apparent that Jack wasn't hearing as well. The hearing loss was sudden and dramatically apparent by the loss of his ability to locate sound. Despite no indication of ear infection, fluid, or inflammation, Jack's ENT prescribed ear tubes. These were placed in both ears at age 14 months. There was no improvement to hear-

ing. At age 21 months, Jack experienced sudden loss of hearing (over the course of 1 day) in his right ear. These sudden losses were very real and supported by audiograms – Jack has always been great in the sound booth. The ENT recommended another set of ear tubes. We became very frustrated at this - we knew another set of tubes would not help. We simply could not engage the interest or creativity of this ENT to pursue a more diagnostic approach to Jack's case. We e-mailed a doctor at the House Ear Institute (HEI) immediately after our disappointing visit with the ENT. This doctor asked that we overnight Jack's CAT scan images to him in Los Angeles. Within 24 hours of the initial contact, the HEI doctor phoned with a definitive diagnosis. Jack had a bilateral Mondini deformity. His cochleas had not formed properly. The explanation to Jack's progressive hearing loss had been sitting in a file for well over a year. The images taken at 7 months had been misread by the radiologist and ignored by Jack's ENT!

The sudden losses Jack had experienced over the preceding months were characteristic of Mondini. Things moved rapidly over the next several months. Now that we had a diagnosis we were able to make some critical decisions about Jack's future. Within two weeks we had our first visit to the House Ear Institute, and a little over two months after that initial visit, just prior to his second birthday, Jack re-

ceived a cochlear implant. Jack was switched on a month later in early May, and the following month we attended a three-week summer school at the John Tracy Clinic. It has been exciting to watch Jack's language skills improve in leaps and bounds. Through his implant and weekly therapies and services provided by AEIHR and his speech therapist, Jack is steadily becoming a proficient user of spoken language. Today at almost 3, Jack is in his first year of pre-school in an oral enriched environment.

Jack loves sound! He likes his speech processor to be switched on soon after he wakes in the morning and won't let you take it off until asleep at night. He can change the batteries, is able to tell us when it is not working properly, and tells us when things are too loud. He loves music and has a great sense of rhythm. He works hard at both listening and speaking. As he is going about his busy day, he will stop, put his hand to his ear and say, "what's that?" He can hear planes flying overhead, dogs barking, sirens, and the wind blowing. Spoken English is our family's first language and that of our families and friends. Our decision to raise Jack in an oral environment is right for us and has been a great success. Jack is able to speak with his family and friends and even strangers, and he can use the telephone to talk with grandparents who live far away. He is a young guy wired for sound.

ADVOCACY

“The test of our progress is not whether we add more to the abundance of those who have much; it is whether we provide enough for those who have too little.”

— Franklin D. Roosevelt



Americans with Disabilities Act of 1990 (ADA)

Type/purpose?

A civil rights law to prevent discrimination solely on the basis of disability in employment, public services, and accommodations.

Who is protected?

Any person with a disability who:

1. has a physical or mental disability that greatly limits one or more life activities,
2. has a record of such a disability, or
3. is regarded as having such a disability.

Further, the person must be qualified for the program, service, or job.

Is there a responsibility to provide a Free Appropriate Public Education (FAPE)?

Not directly. However, ADA protections apply to nonsectarian private schools, but not to organizations or entities controlled by religious organizations. ADA provides additional protection in combination with actions brought under Section 504 and the Individuals with Disabilities Education Act (IDEA). Reasonable accommodations are required for eligible students with a disability to perform essential functions of the job. This applies to any part of the special education program that may be community-based and involve job training/placement.

Is there funding to implement these requirements?

No, but limited tax credits may be available for removing architectural or transportation barriers. Also, many federal agencies provide grant funds to support training and to provide technical assistance to public and private institutions.

Are there procedural safeguards?

The ADA does not specify procedural safeguards related to special education. It does, however, detail the administrative requirements, complaint procedures, and the consequences for noncompliance, related to both services and employment.

Are there evaluation/placement procedures?

The ADA does not specify evaluation and placement procedures. It does, however, specify provision of reasonable accommodations for eligible students across educational activities and settings. Reasonable accommodations may include, but are not limited to, redesigning equipment, assigning aides, providing written communication in alternative formats, modifying tests, redesigning services to accessible locations, altering existing facilities, and building new facilities.

What is due process?

The ADA does not define specific due process procedures. People with disabilities have the same remedies that are available under Title VII of the Civil Rights Act of 1964, as amended in 1991. Thus, people who are discriminated against may file a complaint with the relevant federal agency or sue in federal court. Enforcement agencies encourage informal mediation and voluntary compliance.

Individuals with Disabilities Education Act (IDEA)

Type/purpose?

An education act to provide federal, financial assistance to State and local education agencies to guarantee special education and related services to eligible children with disabilities.

Who is protected?

Children ages 3-21 who are determined by a multidisciplinary team to be eligible within one or more of 13 specific categories of disability and who need special education and related services. Categories include:

- Autism
- Deafness
- Deaf-blindness
- Hearing impairments
- Mental retardation
- Multiple disabilities
- Orthopedic impairments
- Other health impairments
- Serious emotional disturbance
- Specific learning disabilities
- Speech or language impairments
- Traumatic brain injury, and
- Visual impairment.

Is there a responsibility to provide a Free Appropriate Public Education (FAPE)?

Yes. A FAPE is defined to mean special education and related services. Special education means “specially designed instruction, at no cost to the parents, to meet the unique needs of the child with a disability...” Related services are provided if students require them in order to benefit from specially designed instruction. States are required to ensure the provision of “full educational opportunity” to all children with disabilities. The Individual with Disabilities Education Act (IDEA) requires the development of an Individualized Education Program (IEP) document with specific content and a required number of specific participants at an IEP meeting. (See Educational Options section for information regarding IEP.)

Is there funding to implement these requirements?

Yes. IDEA provides federal funds under Parts B and C to assist State and local education agencies in meeting IDEA requirements to serve infants, toddlers, children, and youth with disabilities.

Are there procedural safeguards?

IDEA requires written notice to parents regarding identification, evaluation, and/or placement. Further, written notice must be made prior to any change in placement. The Act delineates the required components of the written notices.

Are there evaluation/placement procedures?

A comprehensive evaluation is required. A multidisciplinary team evaluates the child, and parental consent is required before an initial evaluation. IDEA requires that the IEP team is to determine if reevaluations are to be conducted every 3 years. A reevaluation is not required before a significant change in placement. For evaluation and placement decisions, IDEA requires:

1. That more than one single procedure or information source be used,
2. That information from all sources be documented and carefully considered,
3. That the eligibility decision be made by a group of persons who know about the student, the evaluation data, and placement options, and
4. That the placement decision serves the student in the least restrictive environment.

An IEP review meeting is required before any change in placement.

What is due process?

IDEA defines specific requirements for local education agencies to provide neutral hearings for parents who disagree with the identification, evaluation, or placement of a child. For more information of the IDEA as it relates to children who are deaf or hard of hearing, there is the following question and answer book.

1997 Reauthorization of IDEA - Impact on Deaf and Hard of Hearing Students

The IDEA (Individuals with Disabilities Education Act) has had some changes that have recently taken effect. You may hear it referred to as the 1997 Reauthorization. A couple of things that effect deaf and hard of hearing children are as follows:

“language and communication needs, opportunities for direct communications with peers and professional personnel in the child’s language and communication mode, academic level, and full range of needs, including opportunities for direct instruction in the child’s language and communication mode.”

The 1997 Amendments also require the Individualized Education Plan (IEP) team to consider whether the child requires assistive technology devices and services. Children enrolled in private schools no longer automatically get services from the public schools. The school district must agree that they cannot provide services for the child and that the private school is the better setting. This doesn’t mean that a school district won’t provide services but they don’t have to if they weren’t involved in the decision to place the child in the private school. Please visit the U.S. Department of Education website to obtain more information about the 1997 Reauthorization of the IDEA.

“Everybody’s special in their own way. Yes, it’s true, being deaf has disadvantages ... we are also lucky. I have friends of the deaf and hearing. I’m really happy with that! I’ve had the chance to be successful, and I believe I am! I’ve participated in the yearbook staff, drama club, FHA, basketball team and volunteering at Chippenham Hospital and Lucy Coor Nursing Home. Now, if I’m deaf and able to do these activities, anybody can! We can do things for ourselves, being deaf isn’t a handicap, it’s a part of who you are.”

— Amy (age 14)

Section 504 of the Rehabilitation Act of 1973

Type/purpose?

A civil rights law to prohibit discrimination on the basis of disability in programs and activities, public and private, that receive federal financial assistance.

Who is protected?

Any person who:

1. has a physical or mental impairment that substantially limits one or more major life activities,
2. has a record of such an impairment, or
3. is regarded as having such an impairment.

Major life activities include walking, seeing, hearing, speaking, breathing, learning, working, caring for oneself, and performing manual tasks.

Is there a responsibility to provide a Free Appropriate Public Education (FAPE)?

Yes. An “appropriate” education means an education comparable to that provided to students without disabilities. This may be defined as regular or special education services. Students can receive related services under Section 504 even if they are not provided any special education. Section 504 does require development of a plan, although this written document is not mandated. The Individualized Education Program (IEP) of the Individuals with Disabilities Education Act (IDEA) may be used for the Section 504 written plan. Many experts recommend that a group of persons knowledgeable about the student convene and specify the agreed-upon services.

Is there funding to implement these requirements?

No. State and local jurisdictions have responsibility. IDEA funds may not be used to serve children found eligible only under Section 504.

Are there procedural safeguards?

Section 504 requires notice to parents regarding identification, evaluation, and/or placement. Written notice is recommended. Notice must be made only before a “significant change” in placement. Following IDEA procedural safeguards is one way to meet Section 504 mandates.

Are there evaluation/placement procedures?

Unlike IDEA, Section 504 requires only notice, not consent, for evaluation. It is recommended that districts obtain parental consent. Like IDEA, evaluation and placement procedures under Section 504 require that information be obtained from a variety of sources in the area of concern that all data are documented and considered and that decisions are made by a group of persons knowledgeable about the student, evaluation data, and placement options. Section 504 requires periodic reevaluations, but does not specify any timelines for placement. Section 504 requires that students be educated with their non-disabled peers to the maximum extent appropriate. Section 504 does not require a meeting or any change in placement.

What is due process?

Section 504 requires local education agencies to provide impartial hearings for parents who disagree with the identification, evaluation, or placement of a student. It requires that parents have an opportunity to participate in the hearing process and to be represented by counsel. Beyond this, due process details are left to the discretion of the local education agency. It is recommended that districts develop policy guidance and procedures.

Early Hearing Loss Detection, Diagnosis, & Intervention Act

An exciting piece of legislation was introduced by Representative James Walsh (R-NY) in 1997. The “Early Hearing Loss Detection, Diagnosis, and Intervention Act of 1997” (H.R.2923) provided grant support to individual states so that they could establish screening and intervention programs for newborns and infants with hearing loss. The legislation called for:

1. Screening all babies born in hospitals or birthing centers for hearing loss prior to discharge.
2. Screening all babies not born in hospitals within the first two months of life.
3. Diagnostic audiologic testing performed in a timely manner when hearing loss is suspected.
4. Linkage with a community system of early intervention for those infants diagnosed with hearing loss.
5. Establishment of public policy for the early identification and intervention of newborns with hearing loss.

The benefits of early diagnosis and intervention are well documented. Representative Walsh’s bill has moved the country toward universal newborn hearing screening (UNHS) and benefited countless children and families.



TERMINOLOGY

*“I’ve learned that kids need hugs
more than kids need things.”*

—Anastasia



Acquired Hearing Loss

Hearing loss that is not present at birth, but picked up later in life.

Adjusted Age

Adjusted age is the time (for example, days) between the date of premature birth and the actual due date of the full term pregnancy.

Alerting Devices

Term used to describe devices that are available to help people who are deaf or hard of hearing increase, maintain, or better communicate within their surroundings and society.

American Sign Language (ASL)

American Sign Language is language in which the placement, movement, and expression of the hands and body are part of the language. Research has shown that ASL is a complete language with its own grammar and language rules. ASL is considered by the Deaf community to be the native language of people who are deaf. It is often the chosen language for people who are deaf, even when they are fluent (understand) in both ASL and English. 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 who “speak” ASL to learn the language in order to give their infant/child the best opportunity to learn ASL. (For more information see Deaf Culture section.)

Amplification

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

“At risk”

This is a term that refers to a medical condition or event that is known to be connected with a hearing loss.

Auditory Trainer

A communication device that can be used with a hearing aid, and is made to increase the main sound source and reduce any other noise for the listener.

Auditory Brain Stem Response (ABR)

This is a hearing test that can record and tell what the brain’s response to sound is. During the test, small electrodes are placed on your infant/child’s head and a computer is used to figure out the brain’s response to sound. The test does not hurt and is usually done while infants/children are sleeping. The screening form may be used before the infant/child leaves the hospital. There is a longer form for infants/children that is usually one part of a complete diagnostic audiological evaluation, or work up by a hearing loss specialist.



Audiogram

This is a graph, or picture, of how a person hears different sounds at different levels of loudness. The numbers across the top show pitch, from low on the left to high on the right. The numbers going from top to bottom of the audiogram on the left side show the level of loudness.

Audiological Evaluation

Tests done by a licensed audiologist to figure out whether or not there is a hearing loss, how much of a hearing loss there is, and what type of a hearing loss. The evaluation also includes suggestions for the best way of dealing with the hearing loss. If a hearing aid is suggested, procedures, or ways, to figure out the best hearing aid may also be part of this evaluation.

Audiologist

An audiologist specializes in the study of hearing disorders. Audiologists figure out the hearing loss, measure it, and help the deaf and/or hard of hearing person, by suggesting certain hearing aids or other assistive devices. Most are also licensed to sell and fit hearing aids.

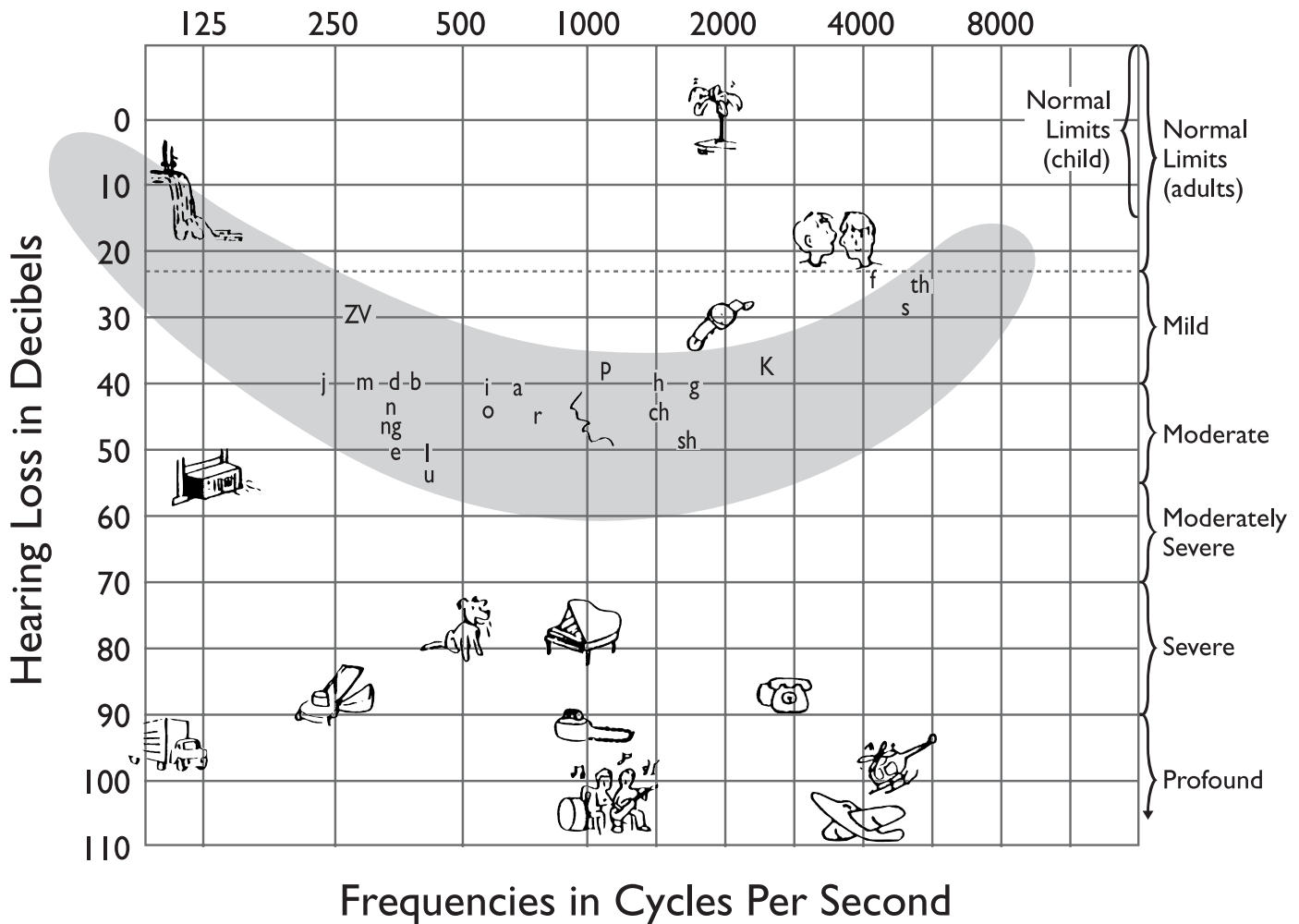
Auditory Discrimination

The ability to pick up differences in sounds and words.

Auditory Neuropathy (Auditory Dyssynchrony)

An defect in the auditory (hearing) system caused by improper firing of auditory nerve cells (dyssynchrony). This affects the ability to understand

Comparison of the Frequency and Intensity of Various Environmental and Speech Sounds



speech signals clearly. The condition is diagnosed using sophisticated (high technology) diagnostic tests (otoacoustic emissions, acoustic reflex, and auditory brain stem response). There may or may not be a hearing loss.

Auditory Nerve

This nerve is called the VIIIth (eighth) cranial nerve. It is found in the inner ear and leads to the brain. It is responsible for carrying nerve signals, resulting from sound stimulation, to the brain.

Auditory-Verbal

This method follows a specific philosophy within the broader aural-oral category. Development of language through listening and the use of existing hearing are very important to this method. Use of hearing aids and/or cochlear implants will be the same as in the aural-oral method. One-on-one teaching with a specially trained auditory-verbal therapist is an important part of this method. There is little, if any, emphasis on visual clues such as speechreading or gesture during therapy sessions. Parents participate in all therapy sessions and use the same techniques 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. The goal of auditory-verbal practice is to assist children who are deaf or hard of hearing to grow up in regular learning and living environments, allowing them to become independent, participating, contributing citizens in mainstream society. The method's philosophy supports the idea that children with all degrees of hearing loss deserve a chance to develop the ability to listen and to use their voice to communicate.

Aural-Oral

In this method, listening is the main method for learning language. Speech is the main method of expressing language. The use of existing hearing is very important. Children are encouraged to use aided hearing (hearing aids or cochlear implants) during their waking hours. For this method to work, aided hearing must be within a range where speech can be heard. If an infant/child cannot hear speech, even with hearing aids, then a cochlear implant may be an option. In addition to listening, an infant/child is encouraged to watch the speaker to get more information from speechreading or lipreading, facial ex-

pressions, and gestures. Hearing through hearing aids or through a cochlear implant, even in the best of cases, is not the same as typical hearing. Early intervention will include certain strategies for increased emphasis on listening and communication. This approach does not include the use of sign language. The philosophy behind this method is to prepare children to work and live in a hearing society.

Babbling

Term used to describe your infant's first use of speech sounds. With this early babbling, there is no communication or language plan. However, later babbling may be used as a part of your infant/child's beginning communication system.

Behavioral Testing

With this test, your infant/child is taught to respond to hearing a sound by looking towards the person or thing making the sound.

Behavioral Observation Audiometry (BOA)

During this hearing test, an audiologist studies an infant/child's response to sound by looking at his/her facial expressions, or looks, body movements, and other actions. Different sounds from high levels to low levels may be used with the infant/child. This test is only one part of a complete audiological evaluation, or work up by an audiologist.

Bilateral Hearing Loss

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

Bilingual/Bicultural

Being fluent in two languages and comfortable in two cultures. For a person who is deaf, these words mean people who "speak" both American Sign Language and English, and are comfortable in both the Deaf Culture and the Hearing Culture.

Bilingual Language Development

Bilingual means knowing or being fluent in two languages. For a person who is Deaf, the two languages are usually American Sign Language (ASL) and English. When an infant/child is born to parents who are Deaf, the language of the home and the first language of the infant/child is usually ASL with English as a second language. When an infant/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 and adds English as a second language as the child gets older.

Binaural

Regarding hearing with both ears.

Binaural Hearing Aids

Hearing aids worn on both ears.

Body Aids

An amplification unit (equipment) that is worn on the body. Provides increased gain (power) and less feedback for people with a severe hearing loss. Used in situations where ear level hearing aids cannot be used.

Bone Conduction

The process through which sound is sent to the inner ear by the movement of the bones of the skull when responding 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, passing by 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

An amplification device (equipment) that is worn behind the ear and usually put on with a headband. It allows sound to be moved through bone directly to the inner ear.

Child Service Coordinator

The person who is in charge of managing all services for the infant/child and will serve as the person for parents to contact when trying to get needed services and assistance. The child service coordinator is also needed to help parents in discovering and locating available services and service providers, and to inform parents (and families) of the availability of advocacy (support) services.

Chronological Age

Chronological is how old the infant/child is based

on his/her date of birth. It is referred to when comparing him/her to other infants/children born at the same time. If an infant was born early, however, his/her development (growth) may be measured at his/her adjusted age.

Closed Captioned

A process in which the text version of what is being said on a TV or video is either coded in the video or in real time (for news broadcasts, etc.) and is printed at the bottom of the television screen when the “caption” option is on. This is provided on a standard television through an electronic chip. By law, TV’s that are 13 inches and larger, and are manufactured after 1993, must have closed caption capability.

Cochlea

A hearing organ found in the auditory (hearing) portion of the inner ear that sends sounds from the middle ear to the auditory nerve.

Cochlear Implant

An electronic device that excites nerve endings in the inner ear (cochlea) in order to pick up and process sounds, including speech. A microphone, a speech processor (miniature computer that changes sound waves into special coded signals), and a transmitter (coil that sends coded signals to inner parts) are worn externally. A small receiver (changes coded signals into electrical pulses) and an electrode array (carries decoded electrical signals to the hearing nerve) are surgically implanted.

Cognitive

The ability to think, learn, and remember.

Communication

The exchange of information through spoken or non-spoken means. Communication can include gestures, facial expressions, words, and/or signs. Children’s earliest communication with parents or other caregivers starts before they use either words or signs.

Conditioned Play Audiometry

During this hearing test, the audiologist measures a young child’s response to sound through the use of a game. For example, the child may be taught to drop a block in a container whenever a sound is heard. A variety of sounds from high to low pitch may be presented at various levels of loudness (intensity). This

test is only one part of a complete audiological evaluation, or work up by an audiologist.

Conductive Hearing Loss

A hearing loss resulting from a disorder of the outer or middle ear.

Conductive Hearing Loss

Conductive hearing loss is the result of something affecting the outer or middle ear, such as ear infections associated with fluid in the middle ear space. Middle ear infections are the second-most common reason children see doctors. Any time children have middle ear infections with fluid in their ears, they have an accompanying hearing loss. Other common causes of conductive hearing loss include excess wax, foreign bodies, or swelling of the auditory (hearing) canal. In most cases, conductive hearing losses can be treated either medically or surgically, and are not permanent.

Congenital Hearing Loss

Hearing loss at birth or connected with the birth, or which forms within the first few days of life.

Connexin 26

A protein that plays an important role in the working of the cochlea. The instructions for this protein are found in many genes including one known as the GJB2 gene. Genetic research shows that a large number of infants with hearing loss who do not have a syndrome/condition, may have a difference in the GJB2 gene.

Consonants

The sounds made by stopping the outgoing breath such as b, p, r, s, t, v, f, g, k, p.

Consonant Blend

Two or more consonant sounds spoken together, such as “sn”, “tr”, and “bl”.

Continuum of alternative placements

School districts must provide various settings in which to educate children with disabilities, including regular classes, special classes, and special schools.

Continuum of alternative placements

School districts must provide various settings in which to educate children with disabilities, includ-

ing regular classes, special classes, and special schools. This variety of settings is referred to as the continuum of alternative placements.

Cued Speech

This is a visual communication system combining eight hand shapes (cues) that represent different sounds of speech. These cues are used together with speaking. The hand shapes will help your infant/child differentiate sounds that look the same on the lips – such as “p” or “b”. This system is designed to clarify lip reading by using the simple hand movements around the face to indicate the exact pronunciation of any spoken word. Since many spoken words look exactly alike on the mouth (for example, pan, man), cues will allow your infant/child to see the difference between them. This is a particularly good system for an infant/child who may not be able to learn entirely through amplified (increased) hearing. For the method to work, both the speaker and the listener must know the system.

Deaf

Spelled with a small “d,” the word “deaf” refers to the phenomenon of being audiotologically deaf. A child who is audiotologically deaf has a hearing loss so severe that the child cannot adequately process information through hearing, with or without amplification (increasing the sound). Spelled with a capital “D,” the word “Deaf” refers to a specific linguistic and cultural identity, namely a person whose primary language is American Sign Language, and considers himself/herself to be part of the Deaf community. Members of the Deaf community share common identity, culture, and experiences.

Deaf Blindness

Educationally significant combined loss or no residual (existing) hearing.

Deaf Community

A group of people who share common interests and a common heritage. Their method of communication is through American Sign Language (ASL). The Deaf community in the United States may have a wide range of feelings and opinions on certain issues, but stress remains on Deafness as a positive way to live.

Deaf Culture

A view of life made up of certain traditions, beliefs, artistic expressions, understandings and language (ASL) particular to Deaf people. A capital “D” is often used in the word Deaf when it refers to community or cultural features of Deafness.

Deaf Educator

A person trained in the education of deaf and hard of hearing people.

Deafness

This term is defined by the Individuals with Disabilities Act (IDEA) as “a hearing impairment that is so severe that the child is impaired in processing linguistic information through hearing, with or without amplification.” That is, a hearing loss that is great enough to cause an infant/child to be unable to learn at a normal pace without help like hearing aid/s.

Decibel

The unit of measurement for the loudness of a sound. The higher the decibel, the louder the sound and greater the hearing loss.

Developmental Delay

A delay in the appearance of some phases of growth in motor skills, cognitive (thought) ability, social-emotional growth, or language use and understanding.

Ear mold

An individually fitted plastic or vinyl piece that is worn in the outer ear and connects with a hearing aid. It has a channel that carries sound from the hearing aid to the ear.

English-only approaches

These approaches include:

- Auditory-verbal approach
- Auditory-oral approach
- Cued Speech

Environmental Sounds

All sounds that take place around us. These usually do not include speech sounds.

Etiology of Hearing Loss

The cause of, or reason for, the hearing loss.

Expressive Language

Symbolic communication such as vocalization, speech, gestures, signs, or body movement, and spontaneous utterance as opposed to imitation.

Feedback

The whistling sound made when amplified sound (made louder) goes back into the microphone. In a hearing aid, feedback can occur when an ear mold does not fit well and the amplified sound goes back into the hearing aid microphone. There are additional causes for feedback and if feedback lasts it should be discussed with your health care provider.

Fingerspelling

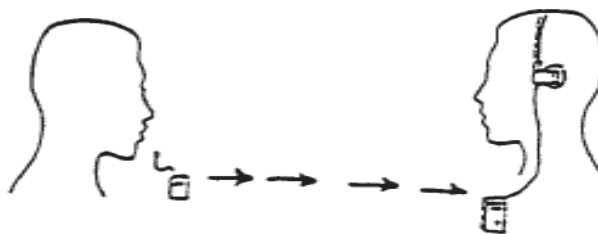
A standardized series of hand shapes to form letters.

Frequency

The pitch (level) of a sound.

Frequency Modulation (FM) System

An assistive listening device, often referred to as an auditory trainer, which is used to help with the problem of background noise interference, and/or distance between the speaker and the person with the hearing loss. Increasing the loudness of speech relative to background noise is also referred to as improving the signal to noise ratio. One type of FM system consists of a microphone/transmitter (worn by the speaker) and a receiver (worn by the child). The signal is sent from the speaker to the child through an FM signal. FMs are used most commonly in the classroom.



Functional Hearing

This means how helpful a person’s residual (remaining) hearing is in hearing and understanding information through hearing only, when amplified (increased) with hearing aids.

Gain

Term that describes the amount of amplification provided by a hearing aid. For example, a child with unaided hearing at 70 decibels who, when amplified, hears at 30 decibels, is experiencing a gain of 40 decibels.

Genetic Counseling

Provides genetic diagnoses and counseling for people with birth defect and genetic disorders that may be connected with hearing loss or have a chance of hearing loss returning.

Genetic Hearing Loss

Hearing loss that is caused by one of more than a hundred genes that are known to be responsible for hereditary hearing loss and deafness. The hearing loss can be part of a syndrome (meaning the infant/child has other medical problems) or non-syndromic (meaning that the infant/child has no other medical problems).

Gesture

The movements of the hands or body that express an idea. Gestures include pointing, head nodding, waving good-bye and many others. Gestures can be used alone or can be combined with words to communicate thoughts and ideas.

Hard-of-Hearing

A hearing loss, whether permanent or changing, which affects a person's ability to detect or understand some sounds including speech. Hard-of-hearing is preferred by the Deaf and hard-of-hearing community over the term "hearing impaired" when referring to people who have hearing loss and also have, and use, residual (remaining) hearing to communicate.

Hearing Aid

An electronic device that increases sound and directs it into the ear. A hearing aid has a microphone, an amplifier (makes the signal louder), and a receiver (loudspeaker). Sound usually enters the ear through an ear mold worn in the ear. The most common style of hearing aid for children is a behind-the-ear hearing aid in which the hearing aid fits behind the top and back part of the ear and connects through a small tube to the ear mold.

Hearing Carry Over

Hearing carry over (HCO) allows a person with a speech disability to type his/her part of the conversation on a TTY. The operator reads these words to the called party, and the caller hears responses directly from the other party.

Hearing Impaired

Clinical or medical term used to describe an infant/child whose hearing is less than the normal range. It is not the term generally preferred by people who have a hearing loss. (For more information, see Deaf, Hard-of-Hearing.)

Hearing Impairment

A clinical or medical term used to describe an infant/child whose hearing is less than the normal range. It is not the term generally preferred by people who have a hearing loss. (For more information, see Deaf, Hard-of-Hearing.)

Hearing Loss

This describes a hearing level that is less than that heard by most people. The range of hearing loss is shown in the table below. (The range of numbers attached to the specific word labels may vary slightly.)

Normal Hearing	0 decibel to 15 decibel
Mild Loss	16 decibel to 35 decibel
Moderate Loss	36 decibel to 50 decibel
Moderate/Severe Loss	51 decibel to 70 decibel
Severe Loss	71 decibel to 90 decibel
Profound Loss	91 decibel or more

Hearing Screening

A pass/refer (no pass) type of hearing test that is designed to pick up infants/children who require more audiological evaluation (tests by a hearing specialist) to figure out whether or not there is a hearing loss.

Hertz (Hz)

This is generally used for measuring frequency, expressing the vibrations or cycles per second. Most speech sounds fall within the so-called "speech range" of about 300 to 3000 Hz.

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 the hearing aid snugly in place behind the ear.

IDEA

The Individuals with Disabilities Education Act (IDEA), formerly the Education of the Handicapped Act (PL 94-142), includes “hearing impairment” and “deafness” as two of the categories under which children with disabilities may be eligible, or qualify, for special education and related service programming.

IEP (Individualized Education Plan)

A team developed, written program, that identifies therapeutic and educational goals and objectives, needed to appropriately address the educational needs of a school-aged student with a disability. An IEP for a child with a hearing loss should take into account the following factors:

- a) communication needs and the child’s and family’s preferred mode of communication,
- b) linguistic needs,
- c) severity of hearing loss,
- d) academic progress,
- e) social and emotional needs, including opportunities for peer interactions and communication, and
- f) appropriate accommodations to facilitate learning.

IFSP (Individualized Family Service Plan)

A written plan developed by parents/guardians with input from a multidisciplinary team. An IFSP includes the following:

- a) addresses the family’s strengths, needs, concerns, and priorities,
- b) identifies support services available to meet those needs, and
- c) empowers the family to meet the developmental needs of the infant or toddler with a disability.

Impedance Testing

These are tests that tell whether or not the middle ear is working correctly. These tests can be done while your infant/child is awake and alert.

Inclusion

Also referred to as “mainstreaming”. This refers to the concept that students with disabilities should

be included with their “typically developing” classmates in the educational setting to the maximum extent possible.

Infrared Systems

Infrared systems transmit sounds by invisible light beams. To be effective, the receiver must be within direct line of sight of the light beam from the transmitter. These systems cannot be used outside because of interference from sunlight.

Intensity

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

Language

A series of words communicated through speech, sign, and writing that are used to express thoughts shared with people in a community.

Least Restrictive Environment

Term in the Individuals with Disabilities Education Act (IDEA) used to describe the educational setting requirement in which a child with disabilities is educated with non-disabled peers for as much time as possible, and still receives services that meet his/her special needs. The least restrictive environment will not be the same for every child.

Listening Age

Term used to describe how long an infant/child has worn a hearing aid and therefore, had the opportunity to “listen.” For example, after an infant/child has worn a hearing aid for one year, his/her listening age will be one. An infant/child with a listening age of one ear, might be just beginning to use words even though his chronological age may be older.

Localization

Turning in the direction of a sound or finding where it is coming from.

Manual Babbling

Term used to describe the early hand shapes used by infants or toddlers who see sign language in their everyday surroundings. As with speech babbling, early manual babbling may not represent any true signs or words. Later manual babbling may be used as part of a young child’s beginning communication system.

Manually Coded English (MCE)

This method uses a visual (signed) form of the English language. English is visually represented (coded) through manual signs. There are a number of systems for manually coding English and each one has its own rules and variations. Most of the systems use American Sign Language signs as a base and also use English word order. Since manually coded English follows English language rules, it is easier for hearing parents to learn and use with their infants/children. All sign language methods require a commitment from all family members to learn and use signs for all communication with the infant/child. If you choose sign communication, it is important for you to learn sign as quickly as possible so that your infant/child can learn language from you in the same natural way that an infant/child with hearing learns from his/her parents.

Mixed Hearing Loss

A type of hearing loss that has is both conductive and sensorineural. (See conductive and sensorineural hearing loss.)

Monaural

Referring to hearing with only one ear.

Monaural Amplification

The use of one hearing aid instead of two.

My TTY

Like a TTY or teletypewriter. A typing piece of equipment that attaches to a phone line as well as a personal computer and allows callers to type conversations back and forth. It is sometimes known as a TDD, or telecommunications device for the deaf, or TT, text telephone.

Native Language

The language spoken in an infant/child's home.

Natural Environment

Term in the Individuals with Disabilities Education Act (IDEA) used to describe the location for early intervention services. IDEA describes the natural surroundings as a home or community setting that is natural and normal for same age peers who have no disabilities.

Oral

A term that is used when referring to people with hearing loss and deafness who talk but do not necessarily use sign language. Emphasis is placed on use of remaining hearing, lip-reading, and background clues to communicate using spoken language.

Oral Method

A teaching approach that uses listening skills and speech-reading to develop understanding and communication skills.

Otitis Media

A middle ear infection. Infants/children with many repeating ear infections may have fluctuating (changing) hearing loss and there may be a chance for speech and/or language delays. Fluid can also be in the ear with or without infection, and may cause temporary (not lasting) hearing loss, which can advance into permanent hearing loss.

Otoacoustic Emissions (OAE)

A hearing test that is used to make sure that the cochlea (part of the inner ear) is working. During the test, a small instrument (probe) is placed in your infant/child's ear and a computer records the response. The test is very simple and does not hurt. An OAE test is often done as one type of hearing screening test before the baby leaves the hospital. A hearing specialist should do it as part of a complete diagnostic audiological evaluation, or review, for infants and young children.

Otorhinolaryngologist/ENT/Otologist

A doctor who specializes in diseases of the ear, nose, and throat. An ENT must examine a child to rule out any medical problems before parents purchase a hearing aid. An ENT should check every infant/child on a routine basis. Some of these doctors also give out hearing aids.

Parent/Infant program

A program offered by a local school district or a school for deaf children that provides learning opportunities for the child age 0-3 and parents. Parent infant programs may include home visit, center-based, and/or parent group components.

Pediatrician

A doctor who treats only infants/children. He/she may treat inflammations and infections of the ear and the upper respiratory system (breathing) that can change hearing, as well as other conditions that occur in infants/children.

Post-Lingual Deafness

Hearing loss that develops after learning a first language.

Pre-Lingual Deafness

Hearing loss that is congenital (at birth) or develops before learning a language.

Progressive Hearing Loss

A hearing loss that increases over time.

Public Access Devices

Also called Audioloops or Induction Loops and Infrared Systems, Public Access Devices improve the use of hearing aids in theaters, churches, classrooms, and public meetings. The Americans with Disabilities Act (ADA) make it a law to include these systems in a host of public settings. Government agencies are the first to provide such access devices.

Real Ear Measurement

An audiological test that measures how well sound is amplified, made louder, by the hearing aid for an infant/child. During this test a small device (probe microphone) is placed in the ear canal while the hearing aid and ear mold are being worn.

Receptive Language

The understanding of spoken, written, and/or signed language.

Relay Telephone Service (Relay Alaska)

A service that involves an operator “relaying” conversation between a text telephone user (generally a person with a hearing loss and/or speech impairment) and a hearing/speaking individual using an ordinary, non-adapted phone.

Residential Schools

Schools for deaf and hard of hearing that provide room, board, and care for deaf and hard of hearing children in addition to educational services.

Residual Hearing

The amount of hearing that a person with a hearing loss uses.

Sensorineural Hearing Loss

A hearing loss that occurs when the inner ear, the auditory (hearing) nerve, and/or the brainstem do not work correctly.

Sensorineural Hearing Loss

This is permanent and is the result of something affecting the inner ear, or the nerve that deals with hearing called the auditory nerve. There are many different causes of sensorineural hearing loss, including congenital infections, medications, noise, and genetics. In fifty percent of congenital hearing loss cases, a cause is never found. Congenital hearing loss is present in three to six out of every 1000 newborns and is detectable at birth through universal newborn hearing screening. Sensorineural hearing loss can also develop later in life for various reasons, one of which is excessive exposure to loud noise.

Sign Language

Communication using movements rather than spoken words.

Signed English

These sign systems use signs from American Sign Language along with invented signs to represent English word order and rules. The systems are not languages but are a code meant to be used to support spoken English. Some examples are Seeing Essential English (SEE I) and Signing Exact English (SEE II).

Simultaneous Communication (Sim-com)

See Total Communication.

Total Communication

Spoken English combined with a Manually Coded English Sign System. (For more information, see Manually Coded English Sign System.)

Sound Field Systems

A sound field system is designed to give teachers the edge over poor classroom sound and unwanted background noise. Through the use of an FM transmitter, and the portable speakers strategically positioned in the classroom, the teachers voice is projected at a

level where students can hear comfortably without straining. Speech/sounds are increased 10-12 decibels above room noise through a single ceiling speaker or through speakers placed around the room. Unlike the FM systems, a sound field system does not require listeners to wear receivers.

Spanish Relay Services

Telephone companies must provide interstate (between states) relay services in Spanish. While Spanish language relay is not required for calls within (intrastate) states, many states with large Spanish-speaking populations already offer this service on a voluntary basis.

Special Lights

These are linked electronically to doorbells, telephones, alarm clocks, and alarm systems (for example, smoke detectors), and can be used as alerting devices. Some schools use them.

Speech

The ability to express thoughts through sounds (words).

Speech Awareness Threshold

The softest level that speech is heard.

Speech and Language Pathologist

A person who specializes in the diagnosis and habilitation of speech and language problems. This specialist may meet with a child on a regular basis to work on the fine points of speech and language development/growth and speech correction. He/she will explain how parents can help with the infant/child's speech and language development/growth.



Speech Area or Zone

This is an audiological graph, or picture, using decibels and frequencies, to show the area where most sounds of spoken language take place. This area is called the "speech banana" because of the shape this area forms on the graph. One purpose of wearing hearing aids is to amplify, or make louder, the sound into the speech area. This is not possible with all types and/or amounts of hearing loss.

Speechreading

The skill of understanding spoken language through movements seen on the mouth, facial expression and body language, and background clues.

Speech Reception Threshold

The softest level that familiar two-syllable words are understood.

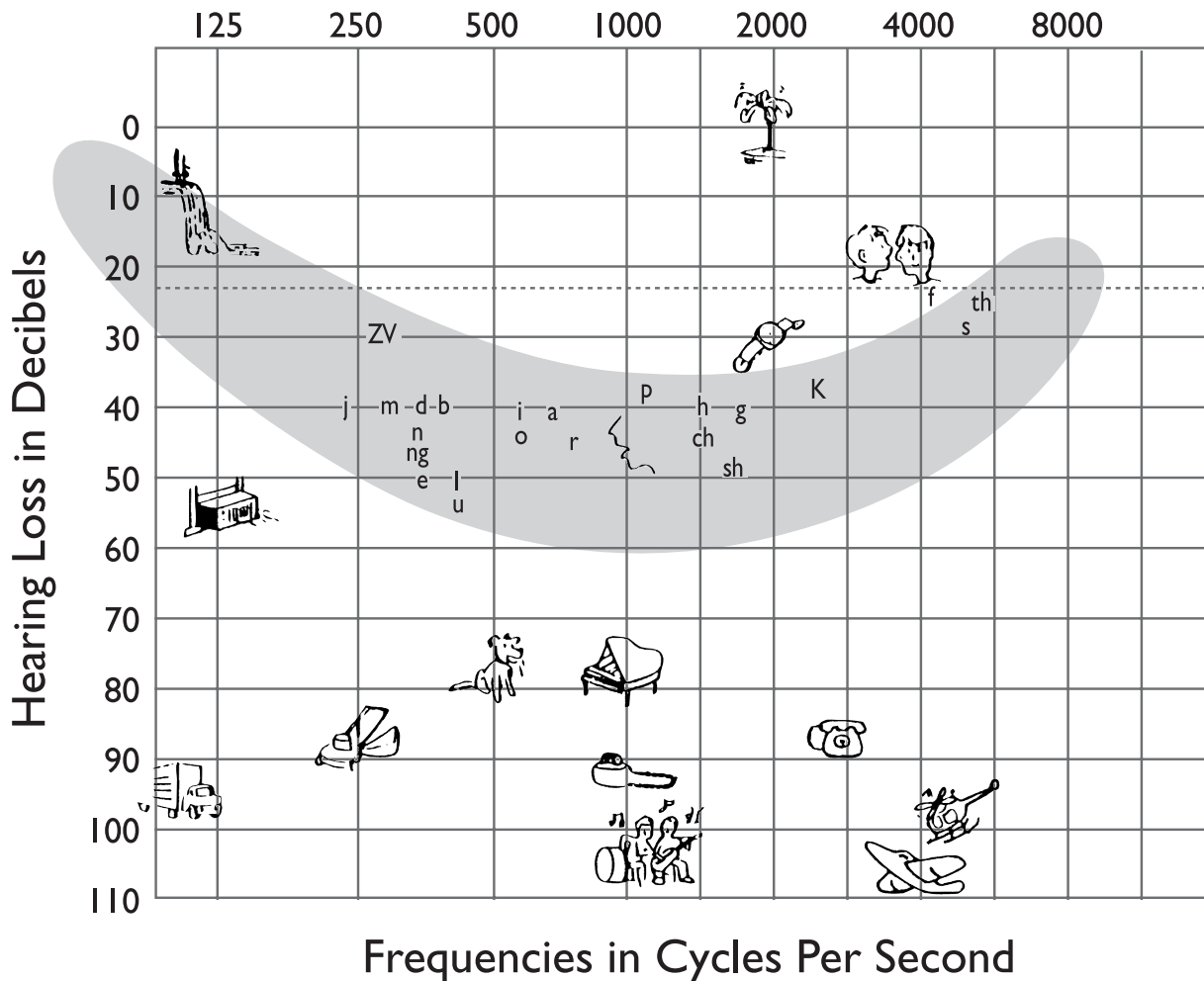
Speech-to-Speech Relay

With this option, a person with a speech disability uses a Communication Assistant (CA) who is specially trained in understanding a variety of speech disorders. The CA repeats what the caller says in a manner that makes the caller's words clear and understandable. No special telephone is needed for this option.

Speech Visualizers

These are electronic devices that can stand for different aspects of speech like pitch and volume. They are helpful in speech production.

The "Speech Banana"



Tactile Aids

A type of assistive communication device that sends out a vibration or “tactile” signal to point out the presence of sound/s.

Teacher of the deaf or hard of hearing

This person is certified by the State Department of Education to teach the deaf or hard of hearing. Parents should begin talking to these special teachers, from programs in their area, even if the child is only an infant. This person can help parents get started right away with communication and language development/growth, even if the hearing aids have not yet arrived. Most areas have programs for infants/children and their parents. Teachers in these programs will become one of the most important members of the team, providing home visits and one-on-one early intervention for parents and infants/children.

Telecommunications Devices for the Deaf (TTDs)

Originally, and often still referred to as TTY’s, these electronic devices allow the deaf and hard of hearing to communicate through a text telephone system.

Text-to-Voice TRS

This type of TRS uses a Communication Assistant (CA) who speaks what a TTY user types, and types what a voice telephone user replies. The first step of this type of TRS is the TTY user’s call to the TRS center. This is the same as getting a dial tone. The caller then gives the number of the party that he/she wants to call to the CA. The CA in turn places an outbound voice call to the called party. The CA serves as the “link” in the conversation, changing over all TTY messages from the caller into voice messages, and all voice messages from the called party into typed messages for the TTY user. The process is performed in reverse when a voice telephone user starts the call.

TRS

Telecommunications relay service, which allows communication between people who use TTY’s and people who use the general telephone network. A TRS is equipped with special equipment and staffed by communications assistants who relay conversation between the two parties. Each state has a TRS.

TTY (Text Telephone)

Teletypewriter. A typing piece of equipment that attaches to a phone line and allows callers to type conversations back and forth. It is sometimes known as a TDD, or telecommunications device for the deaf, or TT, text telephone. Also see myTTY.



Threshold

The softest level at which a sound is heard.

Total Communication (TC)

This method refers to a combination of oral communication and signed communication. In the simultaneous method, 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. Infants/children wear hearing aids and are encouraged to develop and use their existing hearing as well as sign and speech. The term total communication is a broader term and refers to speaking and signing as well as the use of speechreading and print. The belief behind TC is that your infant/child’s surroundings should provide access to language by making the full range of communication choices available.

Tympanometry

This test is used to measure the mobility of the eardrum. It is not a test of hearing but gives information on how well the ear canal, eardrum, Eustachian tube, and middle ear bones are working. It also tells if the middle ear is able to direct sound to the inner ear. Tympanometry is useful to a health care provider in figuring out whether or not there is a middle ear problem that needs special, medical treatment. This test may be one part of a complete audiological evaluation, or review by a hearing specialist.

Unilateral Hearing Loss

Concerning only one ear or one side of the head or body.

Vibrating Beepers and Alarms

These are now available and very popular, especially among deaf and hard of hearing teenagers.

Video Relay Services

This type of TRS allows people who use sign language to make relay calls through Communication Assistants (CA) who can explain their calls. The caller signs to the CA with the use of video equipment and the CA voices what is signed to the called party and signs back to the caller. This type of relay service is not required by law, but is offered on a voluntary basis by certain TRS programs. This option is helpful for people who use American Sign Language (ASL), and for people who cannot type on a TTY easily, such as children who are ASL users.

Voice Carry Over

Voice carry over (VCO) TRS allows a person who is hard of hearing, but who wants to use his/her own voice, to speak directly to the receiving party and to receive responses in text form through the CA. No typing is required by either the calling or the called party. This service is very useful to senior citizens who have lost their hearing, but who can still speak.

Vowels

The sounds coupled with the letters “a”, “e”, “i”, “o”, “u”, and sometimes “y”.

Wrist Vibrators

These are sometimes used to provide “tactile” sensation (physically feel) of speech and other sounds. Many children with a hearing loss like to place their foot or hand on the speakers of television, radios and stereos as they “listen”.

RESOURCES

*“I’ve learned that untold treasures
are found in the imagination
of a child.”*

— *Anonymous*



Organizations

Alexander Graham Bell Association for the Deaf and Hard of Hearing (A.G. Bell)

3417 Volta Place, NW
Washington, DC 20007-2778
Voice: (202) 337-5220
TTY: (202) 337-5221
Toll-free: 1-800-HEAR-KID (1-800-432-7543)
E-mail: info@agbell.org
Internet: www.agbell.org

Description: 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)

2020 E. Camp McDonald Rd
Mount Prospect, IL 60056
Voice/TTY: (847) 297-3206
E-mail: contact@aehi.org
Internet: www.aehi.org

Description: 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)

8300 Greensboro Dr, Suite 750
McLean, VA 22102
Voice: (703) 790-8466
TTY: (703) 790-8466
Toll-free: 1-800-AAA-2336 (1-800-222-2336)
Internet: www.audiology.org

Description: 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. Website contains, "Ask the Audiologist", designed to enhance parental and public understanding of audiology.

American Academy of Pediatrics (AAP)

141 Northwest Point Boulevard
Elk Grove Village, IL 60007-1098
Voice: (847) 434-4000
Fax: (847) 434-8000
Internet: www.aap.org/advocacy/archives/aprhear.htm

A professional membership organization of pediatricians whose efforts are dedicated to improving the physical, mental, and social well-being of all children.

American Society for Deaf Children (ASDC)

PO Box 3355
Gettysburg, PA 17325
Voice/TTY: (717) 334-7922
Toll-free: 1-800-942-ASDC (1-800-942-2732)
E-mail: ASDC1@aol.com
Internet: "http://www.deafchildren.org"
www.deafchildren.org

Description: A nonprofit organization designed to educate, empower and support 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.

American Speech-Language-Hearing Association (ASHA)

10801 Rockville Pike
Rockville, MD 20852
Voice: (301) 897-3279
TTY: (301) 897-0157
Toll-free: 1-800-638-8255
E-mail: actioncenter@asha.org
Internet: www.asha.org

Description: 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

2121 Eisenhower Avenue, Suite 402
Alexandria, VA 22314
Voice: (703) 739-1049
TDD: (703) 739-0874
E-mail: avi@auditory-verbal.org
Internet: www.auditory-verbal.org

Description: A nonprofit, international organization serving children with hearing impairment, their families, and the professional community. Provides information about the choice of listening and speaking 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)

P.O. Box 17646
Raleigh, NC 27619
Voice/TTY: (919) 850-2746
TTY: (919) 5 71-4843
Toll-free: 1-800-541-HEAR (1-800-541-5437)
E-mail: beginnings@beginningssvcs.com
Internet: www.beginningssvcs.com

Description: A nonprofit organization that provides support and information in an unbiased manner to parents and professionals dealing with deaf and hard-of-hearing issues in children. 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. Provides a weekly chat room for patients, called Parents Place.

Boystown National Research Hospital

555 North 30th Street
Omaha, NE 68131
Voice: (402) 498-6511
TTY: (402) 498-6543
Toll-free: 1-800-282-6657
E-mail: moeller@boystown.org
Internet: www.boystownhospital.org

Description: 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 signs and read effectively with young children who are deaf.

Callier Center for Communication Disorders at The University of Texas at Dallas

1966 Inwood Rd
Dallas, TX 75235
Voice: (214) 905-3000
TTY: (214) 905-3005
Internet: www.callierutdallas.edu

Description: 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. A Cochlear Implant 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.

Caption Media Program (CMP), National Association of the Deaf

1447 East Main Street
Spartanburg, SC 29307
TTY: 1-800-237-6819
Toll-free: 1-800-237-6213
E-mail: info@cfv.org
Internet: www.cfv.org

Description: A nonprofit program with a free-loan video collection of approximately 4,000 titles. Provides open-captioned 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. Funding for this program is provided by the U.S. Department of Education.

Central Institute for the Deaf (CID)

4560 Clayton Ave
St. Louis, MO 63110
Voice: (314) 977-0000
TDD: (314) 977-0001
E-mail: bfisher@cid.wustl.edu
Internet: www.cid.wustl.edu

Description: A private, nonprofit institute composed of: (a) research laboratories in which scientists study the normal aspects as well as the disorders of hearing, language, and speech, (b) a school for children who have hearing loss, speech, language, and hearing clinics; and (c) professional education programs in audiology, education of persons with hearing impairment, and communication sciences.

Cochlear Implant Association, Inc. (CIAI)

5335 Wisconsin Avenue NW, Suite 440,
Washington, DC 20015-2052
Voice: (202) 895-2781
Fax: (202) 895-2782
E-mail: ciainfo@cici.org
Internet: www.cici.org

Description: 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.

Council for Exceptional Children

1110 North Glebe Rd, Suite 300
Arlington, VA 22201-5704
Voice: (703) 620-3660
TTY(text only): (703) 264-9446
Toll-Free: 1-888-CEC-SPED (1-888-232-7733)
Internet: www.cec.sped.org

Description: A nonprofit organization that promotes information and programs for people with disabilities and/or gifted and talented populations. Advocates for appropriate governmental policy, sets professional standards, provides continual professional development, advocates for newly and historically underserved individuals with exceptionalities, and

helps professionals obtain conditions and resources necessary for effective professional practice.

Deafness Research Foundation

1050 17th St NW, Suite 701
Washington, DC 20036
Voice: (202) 289-5850
Fax: (202) 293-1805
Toll-Free: 1-800-535-DF-AF (1-800-535-3323)
Email: drf@drf.org
Internet: www.hearinghealth.net

Description: 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 website detailing current research findings.

Ear Foundation (EF)

1817 Patterson Street
Nashville, TN 37203
Voice/TDD: (615) 284-7807
Fax: 1-800-545-HEAR
Toll-Free: 1-800-545-HEAR (1-800-545-4327)
Email: earfound@earfoundation.org
Internet: www.earfoundation.org

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

Gallaudet University

800 Florida Avenue NE
Washington, DC 20002
Voice: (202) 651-5000
Email: public.relations@gallaudet.edu
Internet: www.gallaudet.edu

Description: World's only university in which all programs and services are designed specifically to accommodate students who are deaf or hard of hearing. Offers more than fifty undergraduate degree programs and numerous continuing education and summer

courses. It also houses the National Deaf Education Network Clearinghouse, which disseminates information about people who are deaf and hard of hearing and shares best practices in deaf education.

**Gallaudet University Regional Center -
Johnson County Community College**

12345 College Blvd
Overland Park, KS 66210-1299
Voice/TTY: (913) 469-8500
Internet: web.jccc.net/academic/gurc

Description: Affiliated with Gallaudet University, this Community College provides services to deaf and hard of hearing students, 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 deaf and hard of hearing students, family/parent education programs, needs assessment, technical assistance, and resource and referral.

Hear Now

4248 Park Glen Road
Minneapolis, MN 55416
Toll-Free: 1-800-648-4327
Email: cbetz@harringtoncompany.com
Internet: www.hearingaid.org

Description: A nonprofit domestic program of the Starkey Foundation involved in increasing 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.

Holley Ear Institute

28000 Dequindre
Warren, MI 48092
Voice: (313) 343-7484
TTY: (313) 343-8789
Email: ardis.gardella@stjohn.org
Internet: www.stjohn.org

Description: 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.

House Ear Institute (HEI)

2100 West Third St
Los Angeles, CA 90057
Voice: (213) 483-4431
TDD: (213) 484-2642
Email: webmaster@hei.org
Internet: www.hei.org

Description: 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. Website provides educational information related to hearing health.

**Infant Hearing Resource, Hearing and Speech
Institute**

3515 SW Veterans Hospital Road
Portland, OR 97201
Voice: (503) 228-6479
TTY: (503) 228-6479
Email: valeriesghearingandspeech.org

Description: A nonprofit organization that publishes 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.

John Tracy Clinic

806 W. Adams Boulevard
Los Angeles, CA 90007
Voice: (213) 748-5481
Toll-Free: 1-800-522-4582
Fax: (213) 749-1651
TTY: (213) 747-2924
Email: mmartindale@johntracyclinic.org
Internet: www.johntracyclinic.org

Description: A private, nonprofit organization that provides worldwide parent-centered services without charge to young children with hearing loss. Provides

correspondence courses and videotapes for parents of infants and children who are deaf or have hearing loss. Courses are available in English and Spanish.

Joint Committee on Infant Hearing Screening

Iowa EHDI Coordinator
Iowa Department of Public Health
321 E. 12th St.
Lucas State Office Building
Des Moines, IA 50319-0075
Voice: (515) 242-5639
Fax: (515) 242-6384
Email: dramsey@idph.state.ia.us
Internet: www.asha.org/infant_hearing
Listen-Up Website
Email: kay@listen-up.org
Internet: www.listen-up.org

Description: This is a one stop place for information, answers, help, ideas, resources, and anything else related to hearing-impairment. A listserv is included to assist parents and others to advocate for the rights of children with hearing loss.

Marion Downs National Center for Infant Hearing

University of Colorado at Boulder, Department of Speech, Language, and Hearing Science
Campus Box 409
Boulder, CO 80309-0409
Voice: (303) 492-6283
TTY: (303) 492-4124
Internet: www.colorado.edu/slhs/mdnc

Description: A university affiliated center that coordinates statewide systems for screening, diagnosis, and intervention for newborns and infants with hearing loss. Via its website, the center also provides information on parent participation in systems' building as well as a list of references for publications in early intervention.

National Association for the Deaf (NAD)

814 Thayer Avenue
Silver Spring, MD 20910-4500
Voice: (301) 587-1788
TTY: (301) 587-1789
Fax: (301) 587-1791

Email: NADinfo@nad.org
Internet: www.nad.org

Description: A nonprofit consumer organization safeguarding the accessibility and 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.

National Information Center for Children and Youth with Disabilities

P.O. Box 1492
Washington, DC 20013
Voice/TTY: (800) 695-0285
Fax: (202) 884-8441
Internet: <http://www.nichcy.org/>
Email: nichcy@aed.org

National Cued Speech Association

23970 Hermitage Road
Cleveland, OH 44122-4008
Voice: 1-800-459-3529
TTY: 1-800-459-3529
Email: curly@cuedspeech.org
Internet: www.cuedspeech.org

Description: 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.

National Deaf Education Network and Clearinghouse Info to Go - Gallaudet University

800 Florida Avenue, NE
Washington, DC 20002-3695
Voice: (202) 651-5051
TTY: (202) 651-5052
Email: clearinghouse.infotogo@gallaudet.edu
Internet: <http://clerccenter.gallaudet.edu>

Description: 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.

National Institute on Deafness and Other Communication Disorders (NIDCD)

National Institutes of Health
31 Center Dr. MSC 2320
Bethesda, MD 20892-2320
Voice: (301) 496-7243
Toll Free: 1-800-241-1044
TTY: (301) 402-0252
Toll Free TTY: 1-800-241-1055
Email: nidcdinfo@nidcd.nih.gov
Internet: www.nidcd.nih.gov

Description: 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, based on research, that educate the public and health professionals about its seven research areas in communication. Website contains sections for parents that cover topics related to hearing loss.

Oberkottter Foundation

PO Box 50215
Palo Alto, CA 94303-9465
Toll Free Voice: 1-877-ORAL DEAF
(1-877-672-5332)
TTY: 1-877-672-5889
Internet: www.oraldeafed.org

Description: 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.

Self Help for Hard of Hearing People (SHHH)

7910 Woodmont Avenue, Suite 1200
Bethesda, MD 20814

Voice: (301) 657-2248
TTY: (301) 657-2249
Fax: (301) 913-9413
Email: national@shhh.org
Internet: www.shhh.org

Description: 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. Website offers a listserv for parents on various aspects on deafness including support, counseling, and parental input.

Signing Exact English Center for Advancement of Deaf Children (S.E.E. Center)

PO. Box 1181
Los Alamitos, CA 90720
Voice: (562) 430-1467
TTY: (562) 430-1467
Fax: (562) 795-6614
Internet: www.seecenter.org

Description: A nonprofit organization that promotes early identification and intervention, the development of improved English skills, and the understanding of the principles of Signing Exact English and its use. The organization also strives to foster the positive development of self concept of the child who is deaf by promoting the interaction of the child and Family with the Deaf and hearing communities. Videotapes, research articles, and packets are also available to parents and educators for a minimal fee.

SKI-HI Institute - Utah State University

6500 Old Main Hill
Logan, UT 84322-6500
Voice: (435) 797-5600
TTY: (435) 797-5584
Fax: (435) 797-5580
Email: skihi@cc.usu.edu
Internet: www.skihi.org

Description: A nonprofit, grant funded institute that develops programs and materials and provides work-

shops for professionals working with families of infants and young children who have special needs. 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 both in the United States and Canada.

Starkey Hearing Foundation

6700 Washington Ave. S.
Eden Prairie, MN 55344
Voice: 1-800-328-8602
Internet: www.starkey.com

TDI (Formerly Telecommunications for the Deaf, Inc.)

8630 Fenton Street, Suite 604
Silver Spring, MD 20910-3803
Voice: (301) 589-3786
TTY: (301) 589-3006 Email: info@tdi-online.org
FAX: (301) 589-3797
Internet: www.tdi-online.org

Description: A national advocacy organization that promotes equal access to telecommunications and media for people who are deaf, late-deafened, hard of hearing, or deaf blind. Provides public education and promotes consumer involvement in policies

which support accessibility. Publishes an annual, national directory of TTY numbers.

U.S. Department of Education

400 Maryland Avenue, SW
Washington, DC 20202-0498
Voice: 1-800-USA-LEARN (1-800-872-5327)
Internet: <http://www.ed.gov/index.jsp>
Email: customerservice@inet.ed.gov

World Federation of the Deaf

PO Box 65, 00401
Helsinki, FINLAND
Fax: +358 9 580 3572
TTY: +358 9 580 3573
Email: info@wfdnews.org
Internet: www.wfdnews.org

Description: A nonprofit organization which works for human rights and equal opportunity for Deaf people everywhere. WFD promotes the right of Deaf people to use sign language to access education, information, and all other spheres of life. Priorities include deaf education, strengthening associations of Deaf people, assisting in the establishment of associations where none exist, and abolishing discrimination against Deaf communities and sign languages.



Government Agencies

United States Senators

Honorable Ted Stevens (R)
United States Senate
Washington, DC 20510-0201
Voice: (202) 224-3004

Honorable Appointee (R)
United States Senate
Washington, DC 20510-0202

Governor

Honorable Frank Murkowski
P.O. Box 110001
Juneau, AK 99811-0001
Voice: (907) 465-3500
E-mail: governor@gov.state.ak.us
Web: www.gov.state.ak.us

State Department of Education: Special Education

Greg Maloney, Director
Office of Special Education
Alaska Department of Education
801 W. 10th Street, Suite 200
Juneau, AK 99801-1894
Voice: (907) 465-2972
E-mail: greg_maloney@eed.state.ak.us
Web: www.eed.state.ak.us/tls/sped/

Programs for Infants and Toddlers with Disabilities: Ages Birth through 2

Karen A. Martinek, Unit Manager
State of Alaska, Dept. of Health & Social Services
Special Needs Services Unit
3601 C Street, Suite 934
P.O. Box 240249
Anchorage, AK 99524-0249
Voice: (907) 269-3423
E-mail: Karen_Martinek@health.state.ak.us

Programs for Children with Disabilities: Ages 3 through 5

Karen Sato, Program Manager
Office of Special Education and Early Development
Alaska Department of Education
801 W. 10th Street, Suite 200
Juneau, AK 99801-1894
Voice: (907) 465-2824
E-mail: Karen_Soto@eed.state.ak.us
Web: www.eed.state.ak.us/tls/sped/

State Vocational Rehabilitation Agency

Duane French, Director
Division of Vocational Rehabilitation
801 W. 10th Street, Suite A
Juneau, AK 99801
Voice: (907) 269-3573
TTY: (907) 269-3570
E-mail: Duane_French@labor.state.ak.us

Office of State Coordinator of Vocational Education for Students with Disabilities

Helen Merhkens, Program Manager
Office of Adult and Vocational Education
800 W. 10th Street, Suite 200
Juneau, AK 99801-1894
Voice: (907) 465-8704
E-mail: Helen_Merhkens@eed.state.ak.us

State Mental Health Agency

Walter Majoros, Director
Division of Mental Health/
Developmental Disabilities
Department of Health and Social Services
P.O. Box 110620
Juneau, AK 99811-0620
Voice: (907) 465-3370
TTY: (907) 465-2225
E-mail: Walter_Majoros@health.state.ak.us
Web: www.hss.state.ak.us

Richard Rainery, Executive Director
Alaska Mental Health Board
431 N. Franklin Street, Suite 200
Juneau, AK 99801
Voice: (907) 465-3072
E-mail: Richard_Rainery@health.state.ak.us

State Mental Health Representative for Children and Youth

Kathryn Craft, Children's Mental Health
Coordinator
Division of Mental Health/
Developmental Disabilities
Department of Health and Social Services
751 Old Richardson Highway, Suite 123
Fairbanks, AK 99701-7802
Voice: (907) 451-2017
E-mail: Kathryn_Craft@health.state.ak.us
Web: www.hss.state.ak.us

State Mental Retardation Program

David Maltman, Program Administrator
Developmental Disabilities Section
Division of Mental Health/
Developmental Disabilities
Department of Health and Social Services
P.O. Box 110620
Juneau, AK 99811-0620
Voice: (907) 465-3370
TTY: (907) 465-2225
E-mail: David_Maltman@health.state.ak.us
Web: www.hss.state.ak.us

State Developmental Disabilities Planning Council

Millie Ryan, Director
Governor's Council on Disabilities and Special
Education
P.O. Box 240249
Anchorage, AK 99524-0249
Voice: (907) 269-8990
E-mail: Millie_Ryan@health.state.ak.us
Web: www.hss.state.ak.us/htmlstuf/BOARDS/boards.htm

Protection and Advocacy Agency

Dave Fleurant, Director
Disability Law Center of Alaska
3330 Arctic Boulevard, Suite 103
Anchorage, AK 99503
Voice/TTY: (907) 344-1002, (907) 565-1002
E-mail: akpa@dlcak.org

Client Assistance Program

Pam Stratton, Director
ASIST
2900 Boniface Parkway, Suite 100
Anchorage, AK 99504-3195
Voice/TTY: (907) 333-2211, (800) 478-0047
E-mail: akcap@alaska.com
Web: <http://home.gci.net/~alaskacap/>

Programs for Children with Special Health Care Needs

Karen Martinek, Unit Manager
Department of Health and Social Services
Division of Public Health, Section of Maternal
Child and Family Health
Special Needs Services Unit
3601 C Street, Suite 934
P.O. Box 240249
Anchorage, AK 99524-0249
Voice: (907) 269-3423
E-mail: Karen_Martinek@health.state.ak.us
Web: www.hss.state.ak.us/dph/mcfh/default.htm

Regional ADA Technical Assistance Agency

Toby Olson, Executive Director
Northwest Disability and Business Technical
Assistance Center
Washington State Governor's Committee on
Disability Issues and Employment
P.O. Box 9046, MS 6000
Olympia, WA 98507-9046
Voice/TTY: (360) 438-4116
E-mail: tolson2@esd.wa.gov
Web: www.wata.org/NWD

University Centers for Excellence in Developmental Disabilities (formerly University Affiliated Programs)

Karen M. Ward, Director
University of Alaska Anchorage
Center for Human Development
2210 Arca Drive
Anchorage, AK 99508
Voice: (907) 272-8270
Web: www.alaskachd.org

Technology-Related Assistance

Jim Beck, Program Manager
Division of Vocational Rehabilitation
1016 W. Sixth Avenue, Suite 205
Anchorage, AK 99501
Voice: (907) 269-3570
E-mail: james_beck@labor.state.ak.us

State Mediation System

Gregory Maloney, Director
Alaska Department of Education
801 W. 10th Street, Suite 200
Juneau, AK 99801
Voice: (907) 465-2972
E-mail: greg_maloney@eed.state.ak.us
Web: www.eed.state.ak.us/tls/sped



Special Disabilities Organizations

Attention Deficit Disorder

To identify an ADD group in your state or locality, contact either:

Children and Adults with Attention-Deficit/
Hyperactivity Disorder (CHADD)
8181 Professional Place, Suite 201
Landover, MD 20785
Voice: (301) 306-7070
Voice: (800) 233-4050 (Voice mail to request
information packet)
E-mail: national@chadd.org
Web: www.chadd.org

National Attention Deficit Disorder Association
(ADDA)
1788 Second Street, Suite 200
Highland Park, IL 60035
Voice: (847) 432-2332
E-mail: mail@add.org
Web: www.add.org

Autism

To identify an autism group in your state, contact:

Autism Society of America
7910 Woodmont Avenue, Suite 300
Bethesda, MD 20814
Voice: (301) 657-0881, (800) 3-AUTISM
Web: www.autism-society.org

Cerebral Palsy

UCP of Alaska/Parents Inc.
4743 E. Northern Lights Boulevard
Anchorage, AK 99508
Voice: (907) 337-7678
E-mail: parents@parentsinc.org
Deaf Blind
Voice: (800) 438-9376
TTY: (800) 854-7013
Email: dblink@tr.wou.edu

Special Education Service Agency (SESA)
2217 East Tudor Road, Suite 1
Anchorage, AK 99507
Phone: (907) 562-7372
Fax: (907) 562-0545
TTD: (907) 563-8284
Email: sesa@sesa.org
Web: www.sesa.org

SESA is a public agency which provides assistance to Alaskan school districts and early intervention programs serving students with low incidence disabilities. Also available through SESA, is Alaska Dual Sensory Impairment (DSI) Services. DSI Services is a part of a SESA, but is federally funded to provide free assistance and support to families, infant learning programs, school districts, and other service providers involved with children, birth to 22 years old, experiencing both a vision and hearing loss.

Learning Disabilities

Pamela Bickford, Acting President
Learning Disabilities Association of Alaska
16840 Tideview Drive
Anchorage, AK 99516
Voice: (907) 345-7731

Mental Health

Jan McGillivray, CEO
Alaska Mental Health Association
4045 Lake Otis Parkway, Suite 209
Anchorage, AK 99508-5221
Voice: (907) 563-0880
E-mail: mhaa@alaska.net
Web: www.alaska.net/~mhaa

Jill Ramsey, Executive Director
NAMI Alaska
144 W. 15th Avenue
Anchorage, AK 99501
Voice: (907) 277-1363; (800) 498-4462 (In AK)
E-mail: jramsey@nami-alaska.org
Web: www.nami-alaska.org

Mental Retardation

Gwendolyn Lee, Executive Director
The Arc of Anchorage
2211 Arca Drive
Anchorage, AK 99508
Voice: (907) 277-6677
E-mail: glee@arc-anchorage.org
Web: www.arc-anchorage.org

Physical and Cognitive Disabilities

V. Gutierrez-Osborne, Executive Director
Easter Seals Alaska
126 W. 15th Avenue
Anchorage, AK 99501
Voice: (907) 277-7325
E-mail: vgosborne@gci.net
Web: www.easter-seals.org

Speech and Language

Kelly Scannell-Brewer
Alaska Speech-Language-Hearing Association
3211 Starboard Lane
Anchorage, AK 99516
Voice: (907) 261-5800, ext. 4340
E-mail: Kbrewer@provak.org

Visual Impairments

Gil Johnson, Director
American Foundation for the Blind
111 Pine Street, Suite 725
San Francisco, CA 94111
(415) 392-4845
E-mail: sanfran@afb.net
Web: www.afb.org



Organizations Especially for Parents

Support Centers for Parents of Children with Hearing Loss

Anchorage School District
Special Education Parent Resource Center
5530 East Northern Lights Boulevard
Anchorage, AK 99504
Phone: (907) 742-3972
Fax: (907) 742-3867

Special Education Service Agency (SESA)
2217 East Tudor Road, Suite 1
Anchorage, AK 99507
Phone: (907) 562-7372
Fax: (907) 562-0545
TTD: (907) 563-8284
Email: sesa@sesa.org
Web: www.sesa.org

SESA is a public agency which provides assistance to Alaskan school districts and early intervention programs serving students with low incidence disabilities. Also available through SESA, is Alaska Dual Sensory Impairment (DSI) Services. DSI Services is a part of a SESA, but is federally funded to provide free assistance and support to families, infant learning programs, school districts, and other service providers involved with children, birth to 22 years old, experiencing both a vision and hearing loss.

ARC (Association of Retarded Citizens) of Anchorage
2211 Arca Drive
Anchorage, AK 99508
Phone: (907) 276-3456
Fax: (907) 272-2161
TTY: (907) 277-3345
Email: wivy@arc-anchorage.org
Web: www.arc-anchorage.org

ARC's mission is to secure for all people with developmental and other disabilities the opportunity to choose and realize their goals of where and how they learn, live, work, and play. As a local chapter of The Arc of the United States, a nationwide organization of 140,000 parents, consumers, and professionals in the field, we are active in pursuing national legislation that promotes the rights and welfare of people with disabilities. The Arc of Anchorage is a non-profit, non-sectarian organization.

Parent Training and Information Project

PARENTS, Inc.
Faye Nieto, Executive Director
4743 E. Northern Lights Boulevard
Anchorage, AK 99508
Phone: (907) 337-7678 (Voice/TTY)
(800) 478-7678 (in AK only)
Fax: (907) 337-7671
E-mail: parents@parentsinc.org
Web: www.parentsinc.org

PARENTS, Inc. is a partnership of Alaskan families of children with disabilities, which provides support, training, resources, and advocacy statewide.

Southeast:
P.O. Box 32613
Juneau, AK 99803
Phone: (907) 586-6171
Fax: (907) 586-6433
Email: jan@parentsinc.org

Fairbanks/Interior:
P.O. Box 74922
Fairbanks, AK 99707
620 5th Avenue
Fairbanks, AK 99701
Phone: (907) 456-6770
Fax: (907) 451-1169
Email: Kathie@parentsinc.org

Matsu Valley, Southwest, Kenai/Soldotna,
Ketchikan, Barrow, and other locations call:
1-800-478-7678

Parent Teacher Association (PTA)
Janice Loudon, President
Alaska Congress of Parents and Teachers
P.O. Box 201496
Anchorage, AK 99520-1496
Phone: (907) 279-9345
E-mail: ak_office@pta.org
Web: www.akpta.org

Recommended Readings for Parents

A Basic Course in American Sign Language

Description: A primer used in many sign language classes.

Authors: Humphries, Tom, Padden, Carol Silver Spring, Md., T.J.

Publishing: Publishers, Inc., 1994.

Spanish

version: *Un Curso Basico de Lenguaje Americano de Senas*

Authors: Rubio, Lourdes, translator, Delgado, Gilbert, editor

Publishing: Silver Spring, Md., T.J. Publishers, 1991.

ASL Basics for Hearing Parents of Deaf Children

Description: Introduces the basics of ASL in an easy format. Video also available.

Authors: King, Jess Freeman and Kelley-King, Jan

Publishing: Hillsboro, Ore., Butte Publications, 1996.

Deaf and Hard of Hearing Students Educational Service Guidelines

Description: Describes needed program elements and features which must be considered when designing appropriate services for individual students.

Publishing: National Association of State Directors of Special Education (NASDSE), Alexandria, Va., NASDSE, 1994.

Deaf Culture, Our Way

Description: An entertaining glimpse of life in the Deaf community.

Authors: Holcomb, Roy, Holcomb, Samuel, and Holcomb, Thomas

Publishing: San Diego, Dawn Sign Press, 1995.
A portion of sales of this is donated to ASDC.

Deaf Like Me

Description: A family's story of educating and communicating with their daughter.

Authors: Spradley, T.S. & Spradley, J.P.

Publishing: Silver Spring, Md., National Association of the Deaf, 1978.

Educating Deaf Children Bilingually

Description: Practices in educating deaf children to achieve grade-level mastery and fluency in the languages of the deaf community and general society.

Author: Mahshie, Shawn Neal

Publishing: Washington, D.C., Gallaudet University Press, 1995.

Kid-Friendly Parenting with Deaf and Hard of Hearing Children

Description: A step-by-step guide to, and reference for, raising a deaf or hard of hearing child.

Authors: Medwid, Daria and Weston, Denise Chapman

Publishing: Washington, D.C., Gallaudet University Press, 1995.

Movers & Shakers: Deaf People Who Changed the World

Description: A collection of Deaf success stories

Authors: Carroll, Cathryn and Mather, Susan M.

Publishing: San Diego, Dawn Sign Press, 1997.

Raising and Educating a Deaf Child

Description: Information on deaf children's needs.

Author: Marschark, Marc

Publisher: New York, Oxford University Press, 1997.

A portion of sales of this is donated to ASDC.

Speak to Me

Description: A down-to-earth account of how a single mother copes to accept her 18 month old son's deafness.

Author: Forecki, Maria Calhoun

Publishing: Washington, D.C., Gallaudet University Press, 1995.

The Joy of Signing

Description: A popular dictionary of approximately 1,500 signs.

Author: Riekehof, Lottie L.

Publishing: Springfield, Mo., Gospel Publishing House, 1987.

The Other Side of Silence

Description: Classic book on American Sign Language and the Deaf community.

Authors: Neisser, Arden

Publishing: Washington, D.C., Gallaudet University Press, 1983.

The Silent Garden

Description: Provides parents with a firm foundation for making decisions for their child.

Author: Ogden, Paul

Publishing: Washington, D.C., Gallaudet University Press, 1996.



Recommended Readings for Children

(For children birth to age five)

A Very Special Friend

Description: Six-year-old Frannie finds a very special friend in Laura, who “talks” in sign language.

Author: Levi, Dorothy

Publishing: Washington, D.C., Gallaudet University Press, 1989

Come Sign With Us: Sign Language Activities for Children

Description: This illustrated activities manual contains more than 300 line drawings of people signing familiar words, phrases, and sentences using ASL in English word order. Video also available.

Author: Hafer, Jan and Wilson, Robert

Publishing: Gallaudet University Press, 1996. (In Spanish and English.)

Dad and Me in the Morning

Description: Beautifully illustrated story of a boy and his father on the beach.

Author: Lakin, Patricia

Publishing: Morton Grove, Ill., Albert Whitman & Company, 1994.

I Have A Sister - My Sister is Deaf

Description: An empathetic, affirmative look at the relationship between siblings, as a young Deaf child is affectionately described by her older sister.

Author: Peterson, Jeanne Whitehouse

Publishing: New York, Harper Collins, 1977

Mandy

Description: Mandy, a young Deaf girl, is delightfully presented in a lively, picture-book format.

Author: Booth, Barbara D.

Publishing: New York, Lothrop, Lee & Shepard Books, 1991.

My ABC Signs of Animal Friends

Author: Bahan, Ben and Dannis, Joe

Publishing: San Diego, Dawn Sign Press, 1994

My First Book of Sign

Description: Gives signs for 150 of the words most frequently used by young children.

Author: Baker, Pamela J.

Publishing: Washington, D.C., Gallaudet University Press, 1986.

My Signing Book of Numbers

Description: Children learn the signs for numbers 0 through 20, and 30 through 100.

Author: Gillen, Patricia Bellan

Publishing: Washington, D.C., Gallaudet University Press, 1988.

Sesame Street Sign Language ABC

Description: With Deaf actress Linda Bove, Muppet scenes depict letters and words.

Author: Children’s Television Workshop.

Publishing: New York, Random House, 1985.

Signs for Me: Basic Sign Vocabulary for Children, Parents and Teachers

Description: Vocabulary primer with the basics for preschoolers

Author: Bahan, Ben and Dannis, Joe

Publishing: San Diego, Dawn Sign Press, 1990.

Silent Lotus

Description: Vivid watercolor drawings bring to life the thousand-year-old tradition of Cambodian court ballet and the quiet triumph of a young Deaf dancer.

Author: Lee, Jeanne M.

Publishing: Farrar, Straus, and Giroux, 1991.

The Handmade Alphabet

Description: Celebrates the beauty of the manual alphabet.

Author: Rankin, Laura

Publishing: New York, Penguin, 1991.

Word Signs

Description: Delightful board book with full color photos of objects important to babies.

Author: Slier, Debbie

Publishing: Washington, D.C., Gallaudet University Press, 1995.

Additional Resources

Adco Hearing Products

5661 South Curtice Street
Littleton, CO 80120
Voice/TTY: 800-726-0851
Web: www.adcohearing.com

Assistive Communication Center

7346 South Alton Way, Suite E
Englewood, CO 80012
Voice/TTY: 800-859-8331
Web: www.assistcenter.com/ear
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Butte Publications

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Institute for Disabilities Research and Training

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Family Outreach Center for Understanding Special Needs, Inc. (FOCUS)

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KANA

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