
Arizona Parent Resource Guide

For Children who are Deaf or Hard of Hearing



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Arizona Early Hearing Detection and Intervention (AzEHDI)

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Introduction



This resource guide was designed to provide assistance to parents of children who are deaf or hard of hearing (deaf/HH) within the state of Arizona. Many parents who discover that their child is deaf/HH have typical hearing themselves and have questions about how to best to meet their child's unique needs. These questions might include: "What is the most effective way to communicate with my child?" or "What is the best educational placement for my child who is deaf/HH?"

While we will not promise to have the answers to all of the tough questions, we have designed this resource guide to give unbiased information on these and other topics pertaining to children who are deaf/HH. We will also highlight resources available to assist parents as they make decisions about what is best for their child, from the time they are born to when they are in preschool, particularly in the state of Arizona. An article published by the American Society for Deaf Children (available at www.deafchildren.org) states,

"If you are looking for information about how to raise a child with hearing loss, there is good news and bad news. The good news is there is a lot of information available. The bad news is...there is a lot of information available!"

How does one sort through the information provided in books, articles, websites, from professionals, family, friends, and other sources to arrive at decisions that are right for your child and family?"

This resource guide is an attempt to sort through the information available for parents in Arizona. To accomplish this task, we searched over 90 websites, many of which are included in this guide, and reviewed over 200 guidebooks, information packets, and articles. Much of the information available on these sites is similar, but almost every time a ‘nugget’ of information was found that we thought would benefit parents. We would like to make it clear, however, that this was not an extensive review of websites. Rather, the information in this resource guide includes information that was deemed relevant at the time this guide was written, and was available to those reviewing it.

The authors of this guide do not endorse any of the resources or service providers listed in this publication and cannot verify the continuation of information and/or services past the publication date. It is the reader’s responsibility to determine the validity and availability of the resource or service listed in this guide. With that said, we are excited to share what we have found with parents of children who are deaf/HH, and hope that the resources in this guide are helpful to them as they make decisions about what is best for their child and family.

This guide is structured by topic, beginning with hearing screenings and evaluations and understanding the types and degrees of hearing loss. The second section pertains to making the best choices for your child and your family post-diagnosis. Here we discuss communication opportunities, seeking advice and support from others, and amplification and technologies for children who are deaf/HH.

The topic of the third section is early intervention for children from birth to 3 years of age, including understanding your child’s rights and participation in an Individualized Family Service Plan (IFSP). Transition to preschool for children who are at least 3 years old follows, paying specific attention to the Individualized Education Plan (IEP) process and educational placements and modifications. In each of these sections, state and national resources are woven into the text as they pertain to each particular topic. The final section of this resource guide provides an alphabetical listing and short description of each resource listed discussed in this guide.

Understanding Hearing Loss



HEARING SCREENING AND EVALUATION

We cannot overemphasize the importance of early detection when it comes to determining if a child is deaf/HH. As the United States Department of Health and Human Services (HSS, 1990) report states,

“If hearing impaired children are not identified early, it is difficult, if not impossible, for many of them to acquire the fundamental language, social, and cognitive skills that provide the foundation for later schooling and success in society.”

Early detection and intervention, along with early amplification and/or use of sign language, helps to prevent significant delays in communication development. Thus, it is critical to detect hearing loss in children as soon as possible, preferably before the child is one month of age. If a child is born prematurely, this would be calculated by the child’s corrected age. The Joint Commission on Infant Hearing recommends a 1-3-6 plan: newborn screening by 1 month of age, identification before 3 months of age, and early intervention before a child reaches 6 months in age. This plan is highlighted in the following diagram, ‘A Family’s Checklist- Infant Hearing’ which will be discussed further in this resource guide.

Please note: Although it is recommended that the child receive intervention services before 6 months of age (as indicated in this checklist), it is highly suggested that these services are sought simultaneously with the child's fitting for an amplification device, so that the early intervention specialist can provide instruction and support for using this device in the home setting.

A Family's Checklist – Infant Hearing

Child's Name: _____

Child's Date of Birth: ____/____/____

Normal Milestones	Before 1 Month	Before 3 Months	Before 6 Months
<p>Many babies meet normal milestones even if they have a hearing loss in one or both ears. You should only use these milestones to monitor your baby's hearing and development if your baby has PASSED the hearing screening or been evaluated by a Pediatric Audiologist...</p>	<p><input type="checkbox"/> Hospital Inpatient Screen</p> <p>Place: _____ Screen Date: ____/____/____</p> <p>Results: Left Ear <input type="checkbox"/> Pass <input type="checkbox"/> Right Ear <input type="checkbox"/></p> <p><input type="checkbox"/> Refer <input type="checkbox"/></p> <p><input type="checkbox"/> Repeat Screen</p> <p>Place: _____ Screen Date: ____/____/____</p> <p>Results: Left Ear <input type="checkbox"/> Pass <input type="checkbox"/> Right Ear <input type="checkbox"/></p> <p><input type="checkbox"/> Refer <input type="checkbox"/></p> <p>If your baby does not pass the screening in one or both ears, talk to your doctor about seeing a Pediatric Audiologist as soon as possible.</p> <p>If your baby passes, testing is done. Watch for normal milestones. Be sure your doctor gets the results. www.AZNewborn.com</p>	<p><input type="checkbox"/> Evaluation by Pediatric Audiologist. Be sure your doctor gets the results.</p> <p>Place: _____ Date: ____/____/____</p> <p>Results: Right Ear <input type="checkbox"/> Normal <input type="checkbox"/> Left Ear <input type="checkbox"/></p> <p><input type="checkbox"/> Hearing Loss <input type="checkbox"/></p> <p>If your baby has a HEARING LOSS, the next steps are:</p> <p><input type="checkbox"/> Evaluation by an ENT (Ear, Nose, and Throat) doctor</p> <p>Place: _____ Date: ____/____/____</p> <p><input type="checkbox"/> Hearing aid fitting (if appropriate) of loaner or permanent hearing aids by a Pediatric Audiologist.</p> <p><input type="checkbox"/> Contact Hands & Voices for family support: by phone at 866-685-1050 or www.AZHV.org</p>	<p><input type="checkbox"/> Enroll in Early Intervention program, if hearing loss in both ears</p> <p>Program: _____ Date: ____/____/____</p> <p><input type="checkbox"/> Learn about communication Options</p> <p><input type="checkbox"/> Learn about cochlear implants, if applicable</p> <p><input type="checkbox"/> Regular visits to a Pediatric Audiologist</p> <p>Evaluations:</p> <p><input type="checkbox"/> Ophthalmologist (eye doctor)</p> <p>Place: _____ Date: ____/____/____</p> <p><input type="checkbox"/> Genetic Specialist</p> <p>Place: _____ Date: ____/____/____</p> <p>You may need a referral from your doctor to see these specialists.</p>
<p>Months of Age</p> <p>2 Quiets when hearing a familiar voice. Makes vowel sounds like ahh, ohh</p> <p>4 Looks for sounds with his eyes. Uses sounds such as squeals, whimpers, chuckles</p> <p>6 Turns head toward sound. Babbles ba-ba, ma-ma, da-da</p> <p>9 Imitates speech sounds of others. Understands no-no or bye-bye. Turns head toward soft sounds.</p> <p>12 Correctly uses ma-ma or da-da.</p>			

TAKE THIS TO YOUR BABY'S DOCTOR

Source: Arizona Department of Health Services. Reprinted with permission.

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Every state and territory in the United States has established an Early Hearing Detection and Intervention (EHDI) program to ensure that all babies are screened for hearing loss before they leave the hospital or birthing center. Appropriate follow-up is given for babies who do not pass the screening, and intervention services are provided before the child reaches 6 months in age. The National Center for Hearing Assessment and Management serves as the national resource center for the implementation and improvement of comprehensive and effective EHDI services. Their website provides links to information about the EHDI programs in every state and territory, and also contains a wealth of information and resources related to early detection and intervention.

National Center for Hearing Assessment and Management

www.infanthearing.org

435-797-3584

The initial screen conducted at the hospital is called the “Universal Newborn Hearing Screening” (see following brochure). The procedures used in this screening are typically Otoacoustic Emissions (OAEs) and/or Automated Auditory Brainstem Response (AABR), both of which will be described later in this section of the guidebook. Both of these screens can be performed quickly, typically within 10-15 minutes if the baby is quiet or asleep. The Arizona Department of Health Services Office of Newborn Screening provides information on the newborn screening program, including specific information about the hearing portion of the screening.

Arizona Department of Health Services Office of Newborn Screening

www.aznewborn.com

602-364-1409



Many babies with hearing loss will react to loud sounds. The only way to know if your baby's hearing is normal is to have the screening done with special equipment.

Before you leave the hospital, be sure you know the results of your baby's hearing screening and what the next steps are.



CAN MY BABY HEAR?

Your Baby's First Hearing Test Arizona EHDI

Why is hearing screening important?

- Hearing loss is one of the most common newborn conditions.
- Most babies with hearing loss have no signs or symptoms.
- The first three years are the most important for learning language and how to communicate.

You need to know if your newborn baby has a hearing loss so you can get the help your baby needs. If hearing loss is found early, your child will have the best chance to learn the skills needed to be ready for school.

How is hearing screening done?

- Your baby will be screened for hearing loss in the hospital soon after birth.
- The screening takes 10-15 minutes if the baby is quiet or asleep.
- The screening is done with special equipment and is safe and does not hurt.

If your baby PASSES the screening...

It means that your baby's hearing was in the normal range during the screening. Hearing loss can develop after you leave the hospital. It is important to check your baby's hearing and communication development during the first year.

If your baby DOES NOT PASS the screening...

- **By one month of age:** Make an appointment to come back to the hospital for an outpatient hearing screen within one to two weeks after birth. If your baby was in the neonatal intensive care unit (NICU) for more than 5 days or has a risk factor, talk to your baby's doctor. Make the outpatient appointment with a pediatric audiologist, as soon as possible.
- **By three months of age:** Make sure that your baby has been tested by a pediatric audiologist by three months of age.
- **By six months of age:** If a hearing loss is confirmed, your baby should be enrolled in an early intervention program by six months of age.

Is my baby at risk for hearing loss?

Yes, if your baby has one or more of the following risk factors or conditions at birth:

- Stayed in the NICU for more than 5 days
- Had an infection before or after birth such as CMV, herpes, rubella or meningitis.
- Has a family member with hearing loss from birth or childhood

These babies at risk can pass a hearing screening at birth but will need more testing later. Talk with your baby's doctor and make an appointment with a pediatric audiologist or hearing specialist for further testing.

Use this milestones chart to help you check your baby's hearing, speech and language development.

By **2 months** of age a baby with normal hearing should be able to:

- Quiet when hearing a familiar voice
- Make sounds like ah and ohh

By **4 months** of age a baby with normal hearing should be able to:

- Look for sounds with his eyes
- Make sounds like squeals, whimpers or chuckles

By **6 months** of age a baby with normal hearing should be able to:

- Turn his head toward a sound
- Make sounds like ba-ba, ma-ma, da-da

By **9 months** of age a baby with normal hearing should be able to:

- Imitate speech sounds made by others
- Understand no-no or bye-bye
- Turn his head toward a soft sound

By **12 months** of age a baby with normal hearing should be able to:

- Correctly use ma-ma or da-da
- Respond to singing or music

A baby with mild hearing loss may also be able to do these things.



For more information about the Newborn Hearing Screening Program, please contact:

Arizona Department of Health Services
Office of Newborn Screening
Arizona Early Hearing Detection and Intervention Program (EHDI)



250 N 17th Ave, 1st floor
Phoenix, AZ 85007-3231
Phone: (602) 364-1409

or
(800) 548-8381 (within Arizona)

Deaf and Hard of Hearing call 711 for AZ Relay Service

Visit our website at:
www.AZNewborn.com

Talk to your baby's doctor if you have any concerns or questions.

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NBS-EHDI1 (4/13)

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If your baby passes the newborn screening performed at the hospital or birthing center, it means that the sensory cells of the ear were found to be working properly during that screen. No further follow-up is typically needed unless there are known risk factors for hearing loss, or if there are further concerns. There is no single screening procedure that rules out all types and degrees of hearing loss. If you have concerns about your child's hearing, discuss this with your child's primary care doctor so that a plan of care can be implemented.

Some children pass the newborn hearing screening and develop a hearing loss after they leave the hospital. In this case, it is important for parents to be aware of potential signs that the child might have a hearing loss, and also be aware of any factors or conditions that may contribute to hearing loss. Please refer to the two previous documents for a description of the typical milestones in child development and a list of some of the conditions that might contribute to hearing loss developing later in a child's life.

If you are told that your baby did not pass the initial screen or is referred for further testing after the hearing screening, it may not necessarily mean that your child has a hearing loss. Rather, this initial screen is an indicator that the child needs to have his or her hearing checked again before one month of age. Babies may be referred for further testing after the newborn hearing screening because there is fluid in their ears or because the child was not asleep or quiet during the testing. A child may also be referred for further testing due to equipment problems, technical errors, or due to a true hearing loss. Based on statistics from the Arizona Department of Health for the year 2006, four percent of all babies who were screened in a hospital were referred for a second screen. Of these 3,922 babies, 35 babies were diagnosed with a confirmed hearing loss. Thus, the only way to confirm that the initial screen was accurate is to re-screen the baby within the recommended time frame.

The Arizona Department of Health Services Office of Newborn Screening is notified by the hospital when a child is referred for further testing after the newborn hearing screening. This office follows up with families and provides education and information to parents. However, you do not need to wait to hear from this office to get your child's hearing rescreened. This follow up, which is an outpatient procedure, is performed at many locations throughout Arizona. Simply contact one of the locations listed on the following link to make an appointment. You may want to contact your insurance plan member services representative to determine which

locations/providers are covered by your plan and if a referral from your primary care provider is needed.

Local Resource for Parents:

Available at: <http://azdhs.gov/lab/aznewborn/parents/hearing-screening.htm>

There are several hearing tests that an audiologist can perform to detect if sound is being transmitted efficiently through the auditory system and true hearing levels. The most commonly used tests are briefly described below.

- Otoacoustic Emission Test (OAE)- A small probe is inserted into the ear canal of a calm or sleeping child and presents soft sounds to measure echoes from the peripheral portion of the ear, as a means of determining if the cochlea is stimulated with audible sound. This test does not measure what the child hears, but simply tells whether the outer hair cells in the cochlea are functioning. If the cochlea does not respond to sound, there might be a hearing loss and further testing is needed.
- Auditory Brainstem Response (ABR)/Brainstem Auditory Evoked Response (BAER)- Sensors (small electrodes) are placed on the child's head and clicks or tones are presented through ear phones and/or a bone conduction headband to record brain activity in response to sound. This test can be performed while a small baby is asleep. It is often recommended that a baby older than four months be sedated because the test requires the child to remain still to rule out any other muscle reaction that could be interpreted as hearing. The ABR is considered to be highly accurate in detecting hearing loss when combined with other audiological test results.
- Auditory Steady-State Response- Like the previous test, electrodes are placed on the head during a state of sleeping or sedation, yet a continuous tone is emitted to elicit a response. This test is beneficial in determining the degree of hearing loss in the severe-to-profound range; however, it is not widely used clinically. However, it may be used in conjunction with an ABR to further confirm a diagnosis.
- Immittance testing- Immittance testing is comprised of tympanometry and acoustic reflex testing. Tympanometry is a measure of eardrum movement as a function of pressure and is used to determine if the middle ear is functioning properly. Abnormal tympanograms are indicative of possible middle ear pathology such as fluid, infection, or problems with the bones

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of the middle ear (ossicles). Acoustic reflex testing is a measure of the stapedial reflex in the middle ear which contracts the stapedius muscle and ossicles in response to intensely loud sound. Acoustic reflexes may be absent in persons with conductive hearing loss, significant sensorineural hearing loss, acoustic nerve tumors, or facial nerve injuries. A patient must remain very still and quiet for accurate testing.

- Behavioral Observational Audiometry (BOA)- An audiologist watches an infant's face and body language to determine if he/she is responding to sound (such as changing sucking pattern, widening eyes, or searching for the source of the sound). This test is primarily used with infants and children with developmental delays.
- Visual Reinforcement Audiometry (VRA)- A sound is emitted through a loud speaker and the audiologist observes the child's behavior. If the child turns toward the speaker, a toy lights up or moves. This test is commonly conducted with children between 6 months and two years of age.
- Conditioned Play Audiometry (CPA)- Frequency (tone)- specific signals are delivered to an older child's earphone and the child is asked to respond with some action whenever a sound is heard (i.e. throwing blocks in the bucket or adding a piece to a puzzle). A speech test often accompanies this test. Words are spoken into headphones and the child is asked to repeat the words or point to pictures of the objects mentioned. Audiologists use these tests to determine the softest level at which the child can detect sounds and recognize speech.
- Bone conduction response- The audiologist places a bone conduction oscillator on the child's mastoid bone to bypass the outer ear and middle ear and stimulate the cochlea directly.
- Masking- If there is a suspicion that one cochlea hears better than the other, or is doing the work for them both, a noise from a headphone occludes one ear while the other ear is tested.

If your baby passes the second screening test, you still need to be aware of indicators that your child might have a hearing loss. Many babies with undetected hearing loss have a delay in language development. If you are concerned about your child's hearing and/or language development, you should contact your child's pediatrician and discuss your concerns. However, if you are not satisfied with the pediatrician's response, you can take your child to an Ear, Nose and Throat doctor (ENT or otolaryngologist), who will most likely have your child's hearing

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evaluated by an audiologist specializing in pediatric care. Your insurance plan member representative can help you find an ENT if a referral from your primary care physician is needed.

If your baby does not pass the second screening, you should talk to your child's pediatrician about requesting a referral to an audiologist who specializes in pediatric care as soon as possible. An audiologist is a health care professional with a master's degree (M.A.) or doctorate (Au.D. or Ph.D.) from an accredited university program. Audiologists are trained to know the functions of the ear, how to determine if a person has a hearing loss, and what to do when a hearing loss is diagnosed.

When choosing an audiologist, or talking to your child's pediatrician about the audiologist he or she recommends, you will want to ensure that the audiologist you choose works primarily with children. The American Academy of Audiology is the world's largest organization of, by, and for audiologists with over 10,000 members. Their mission is to promote quality hearing and balance care by advancing the profession of audiology.

American Academy of Audiology

www.audiology.org

800-222-2336

If a hearing loss is confirmed by the child's audiologist, an evaluation by an ENT is the needed. The sooner the child visits the ENT, the sooner services can be administered. In some cases, an ENT and an audiologist work together at the same location, as many ENTs have on-site audiologists. For children who are diagnosed at an older age, pediatricians will often refer the child directly to an ENT.

An ENT specializes in ear, nose, throat, and head and neck disorders. As with audiologists, it is recommended that you find an ENT who works with children. The American Academy of Otolaryngology- Head and Neck Surgery, is the world's largest organization representing these specialists. Although their website is primarily for these doctors, there is a section for parents that gives health information on hearing-related topics.

American Academy of Otolaryngology - Head and Neck Surgery

www.ent.org

703-836-4444

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A visit to the ENT is necessary to find out if there is a biological or medical reason for the hearing loss and if there is a medical treatment. It is often difficult to determine if a child has fluid in his or her ears that may be preventing the child from hearing within the normal ranges. If the child is over 12 months of age, an ENT might recommend a quick out-patient procedure to place tubes in the child's ear drums to drain any fluid that can interfere with hearing. Often this process may be frustrating for parents who are anxious to know if their child's hearing loss is temporary or permanent. Other setbacks like ear infections or sickness might also prevent a timely and accurate diagnosis of the child's hearing. This is another reason why it is essential to have a complete diagnostic hearing evaluation by the time the child is 3 months old in cases when the outpatient hearing rescreen is failed. A link to the list of Arizona providers for completing this diagnostic evaluation follows.

Early Hearing Detection & Intervention- Pediatric Audiology Links to Services (EHDI-PALS)

www.ehdipals.org

Children with a diagnosed hearing loss should have their hearing tested frequently, typically every 3-4 months for babies up to 2 years old and every six months for 3-5 year olds. Once children reach the age of 6, they need to have their hearing tested annually. After diagnosis, you will most likely be contacted by an Early Intervention specialist who will be assigned to work with your child from birth to three years of age. The goal of the early intervention program is to provide support and instruction to families within the natural learning environments that facilitate the child's successful engagement in relationships, activities, routines, and events of everyday life. This occurs in the context of the family's typical routines and activities so that information is meaningful and directly relevant to supporting the child in meeting the expectations of his or her environment. Early intervention is discussed in greater detail in the third section of this guide.

Parents may find the time of waiting and wondering during the screenings and evaluations to be very unsettling. Many parents who have children with hearing loss have typical hearing themselves, so it can be difficult to understand the unique experience of raising a child who is deaf or hard of hearing. Many parents say that it is helpful to connect with other parents who have already been through a similar experience. Arizona Hands & Voices (AZHV) is the state

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chapter for the national Hands & Voices organization, which is a non-profit and parent-driven organization dedicated to supporting families and their children who are deaf or hard of hearing. AZHV also participates in the Guide By Your Side (GBYS) program, which provides emotional support and unbiased information to families by pairing them with trained Parent Guides who are or have been in similar situations, all free of charge.

Arizona Hands & Voices

www.azhv.org

866-685-1050

The American Society for Deaf Children (ASDC) was founded as a parent-helping-parents network and is now a national independent non-profit organization whose purpose is providing support, encouragement and information to families of children who are deaf or hard of hearing. ASDC provides resources, publications, and national family conferences.

The American Society for Deaf Children

www.deafchildren.org

800-842-2732

An online resource that can be helpful is My Baby's Hearing, developed by a team of professionals at Boys Town National Research Hospital. This website is divided into two sections: 'First steps' for newborn screening information, and 'Next steps' for when the child has been diagnosed with a hearing loss. The 'Next steps' portion has a 'parent to parent' section in which you can hear the views of parents with children who are deaf or hard of hearing.

My Baby's Hearing

www.babyhearing.org

402-498-6511



A Message from the Office of Newborn Screening

[Hearing Loss: Online Directory for Parents and Providers](#)



What is EHDI PALS (Early Hearing Detection & Intervention Pediatric Audiology Links to Services)?

An easy-to-use online directory matching hearing services to children's needs. For hearing tests and other hearing related services, go to: <http://www.ehdipals.org>

What information does EHDI PALS provide?

This site has information about hearing (audiology) services for children of all ages. The services and staff listed have the right equipment and skills to serve children.

How can I access it?

EHDI PALS is easy to use. Click "[Find a Facility](#)" to answer a few questions that take you to the services and staff closest to you.

What are some of the resources the website provides?

Click on "[Parent Resources](#)" to find questions to ask about your child's appointment. It also tells you about hearing programs in Arizona.

Click on "[Other Helpful Websites](#)" for national and state parent support groups and other resources related to childhood hearing loss and testing.

Each year in the United States, more than 12,000 babies are born deaf or hard of hearing; most have two hearing parents. Hearing loss can affect a child's ability to develop communication, language, and social skills. The earlier children with hearing loss start getting services, the more likely they will reach their full potential*.

*Adapted from the Centers for Disease Control and Prevention website – www.cdc.gov

TYPES AND DEGREES OF HEARING LOSS

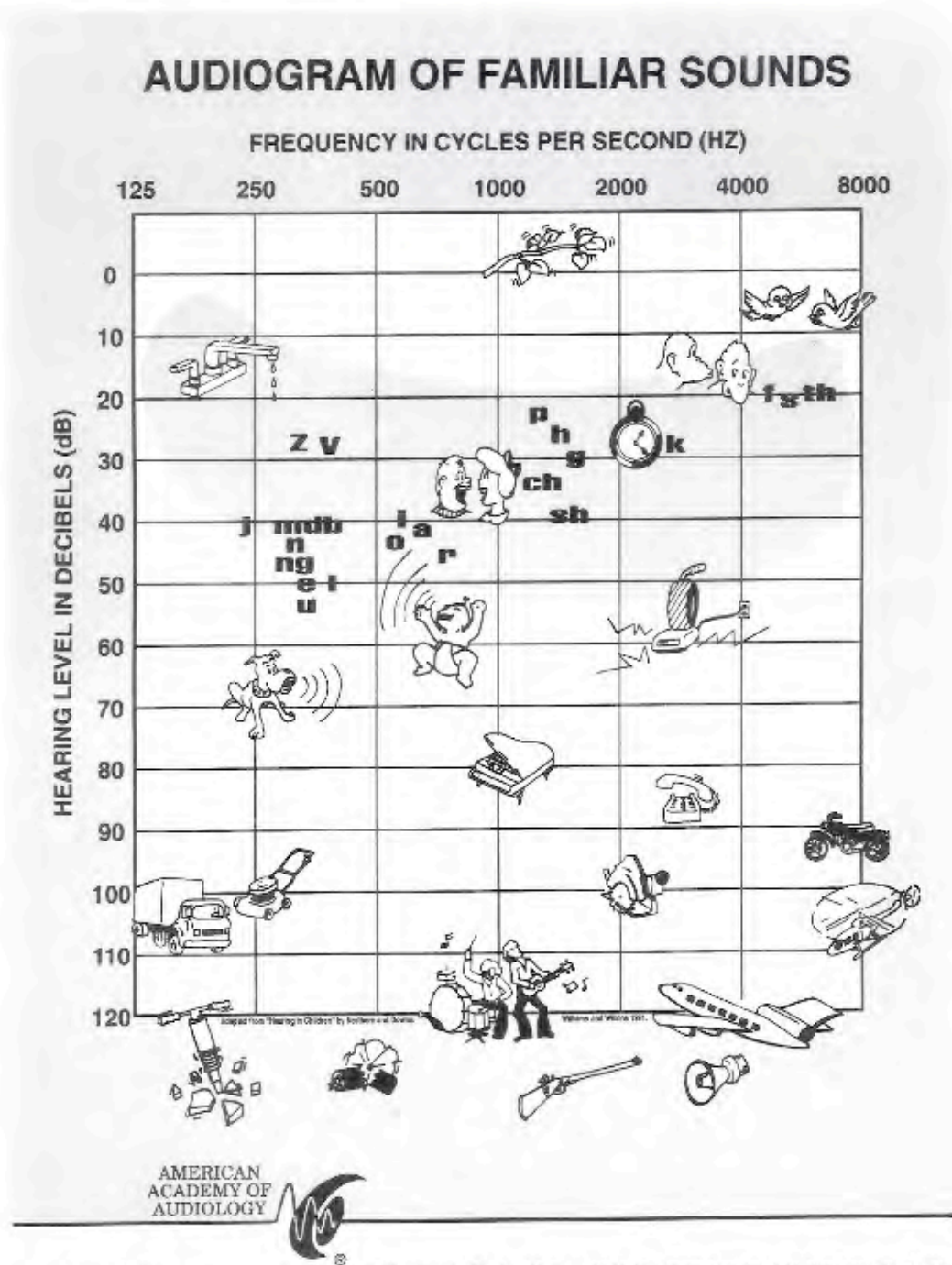
Results from the hearing testing methods mentioned in the previous section may be presented on an audiogram. An audiogram is a graphic illustration of the responses obtained during a hearing test. Audiograms are essential for understanding the degree of a child's hearing loss, monitoring for any changes in auditory status over time, and determining whether the child will benefit from hearing aids or cochlear implants. However, an audiogram is not an accurate predictor of how a child perceives the speech sounds that he or she hears. Two children with the same audiogram may learn language, and develop speech and auditory skills, in very different manners.

On an audiogram, the frequency of cycles per second (Hz) are shown horizontally. To the layperson, this can be described as pitch, or notes on a musical scale. Frequency is measured by the number of waves or cycles that a sound makes in a single second. Frequency increases on an audiogram from left to right, or from low to high frequency. Children with typical hearing can detect very low frequency of sound (i.e. a fog horn at 20 Hz) to a very high frequency (i.e. a whistle at 20,000 Hz). An audiogram shows test results in the range of frequencies that must be heard for development of speech and language, and thus its range is limited to frequencies between 250-8000 Hz.

The intensity, or loudness, of a sound (measured in decibels or dB) is shown on the vertical scale of an audiogram. The scale moves from soft on the top of the audiogram down to loud on the bottom of the scale. This measures how loud or soft a sound is heard. Children with typical hearing can hear each frequency at a level of 15-20 dB or less. Many audiograms that are presented to children have pictures representing sounds that can be heard by a person with normal hearing. For example, the following are sounds that can be heard at the corresponding decibels (dB):

Sound	dB Level
Whisper	about 20 dB
Refrigerator humming	about 40 dB
Normal conversation	about 60 dB
City noise	about 80 dB
Lawnmower	about 90 dB
Chainsaw	about 110 dB
Firecracker	about 140 dB

Audiograms for children also usually include a shaded area (that looks like a banana) that depicts the approximate frequency at which a specific sound is typically heard. Many speech sounds are produced in frequencies between 250 and 5000 Hz, and spoken between 20 to 60 dB. The softest sound is the ‘**th**’ as in the word ‘**with**,’ and the loudest speech sound is ‘**aw**’ as in the word ‘**saw**.’ The speech area on the audiogram is used to illustrate the child’s hearing thresholds (or what they are capable of consistently hearing). The child’s thresholds are marked with an ‘x’ or blue pen for the left ear, and with an ‘o’ or red pen for the right ear. An example of a child’s audiogram (without the threshold markings) follows:



Source: Adapted from the Northern and Downs textbook, *Hearing in Children* (2002). Reprinted with permission.

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The degree of an individual's hearing loss is determined by his or her hearing thresholds. In general, the following terms are used to categorize the levels of hearing loss:

- Minimal (16 to 25 dB)- This degree of hearing loss can be compared to people with normal hearing lightly plugging their ears with their fingers. A child with this degree of hearing loss typically has few difficulties with communication, but may have difficulty hearing soft speech or speech from a distance. It will most likely be difficult for them to hear speech in loud environments. A child with a hearing threshold of 16 dB can miss up to 10% of speech at a 3-foot distance. A hearing loss that is a few decibels greater can cause the child to hear inconsistent or distorted parts of speech, particularly with word endings like -s and -ed. If this degree of hearing loss is undetected, the child's behavior might be confused for immaturity or inattention.
- Mild (26 to 40 dB)- With this degree of hearing loss, it is often difficult to hear faint or distant speech, and a child cannot hear a whispered conversation even if it is in a quiet environment. A child with this type of hearing loss may hear speech, but tends to not be able to hear word fragments, endings, and indistinct word sounds. With a 30 dB hearing loss, a child can miss 25-40% of the speech signals, and often experiences difficulty learning early reading skills such as letter and sound association. The child may be more fatigued due to the extra effort needed to listen. Hearing instruments are usually recommended for children with this degree of hearing loss.
- Moderate (41 to 55 dB)- A child with this degree of hearing loss has difficulty hearing at conversational levels, and speech must be loud to be understood. The child's speech may also be affected, as some have unclear pronunciation and a flat quality to their voice due to their inability to monitor their own voice. A child with 50 dB hearing loss may miss up to 80% of all speech. In addition to hearing aids, an FM system is often recommended for children to overcome classroom noise and distance. Sign language or visual communication may help to improve language development.
- Moderately Severe (56 to 70 dB)- This degree of hearing loss inhibits a child from hearing conversational speech at conversational levels, as he or she may be able to hear a loud voice from about one foot from the ear. A child's speech and language will most likely be affected, as it is difficult to detect many speech sounds, especially vowels. If this degree of hearing loss is

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present before the child is one year of age, speech and language will not develop spontaneously without amplification and intervention. Even with the aid of a hearing device, children with this degree of hearing loss may be aware of conversation around them but miss parts of words. A 55 dB hearing loss can result in missing up to 100% of speech without amplification. For children with this degree of hearing loss, hearing aids and an FM system are recommended, along with intense speech and language therapy and/or sign language or visual communication and early language development.

- Severe (71 to 90 dB)- A child with this degree of hearing loss cannot hear conversational speech or loud speech, and may be more aware of vibrations than tonal patterns. Even with hearing aids, the child may be unable to perceive high pitch speech sounds sufficiently. At this level of hearing loss, a child may be a candidate for a cochlear implant and can use sign language to communicate and promote early language development.
- Profound (91 dB or higher)- With this degree of hearing loss, a child cannot hear loud speech and will have difficulty hearing loud sounds. Twenty percent of infants diagnosed with hearing loss are considered to have a profound loss. For most children with this degree of hearing loss, they will not be able to perceive most speech sounds even with the use of traditional hearing aids. A child with profound hearing loss may be a candidate for a cochlear implant or need to rely upon sign language to communicate.

There is not a technical cut off for when a child with hearing loss is considered to be “deaf” or “hard of hearing,” but often a child is considered to be “deaf” if there is a hearing loss from severe to profound in which speech is not understood even with the use of hearing aids. A child is considered to be “hard of hearing” if the degree of hearing loss is in the range where speech is commonly used. Children considered to be “hard of hearing” typically can benefit from the use of hearing aids. As children get older, they may feel more comfortable identifying themselves as being deaf or hard of hearing, based on their own feelings, the language they use, and the groups of people they tend to socialize with. Often the word Deaf is capitalized to signify identification with others who are Deaf and share similar language, experiences, and a sense of common history and “culture.”

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Even with the assistance of hearing aids and/or cochlear implants, a child who is deaf/HH will not have hearing equivalent to their peers with typical hearing. It is also important to remember that many children who use hearing aids or cochlear implants cannot hear when their hearing device is not being used (i.e. at bedtime or in the pool).

There are several websites that will allow you to experience the sounds with various degrees of hearing loss. For example, the website for the Phonak brand of hearing aids has demonstrations of how everyday sounds would be heard by a person with normal hearing, mild hearing loss, and moderate hearing loss.

www.phonak.com/us/b2c/en/hearing/understanding_hearingloss/how_hearing_loss_sounds.html

Each child's hearing is unique. Different things will impact how a child will use their available hearing. Below are some of the various factors that can impact a child's hearing, and some common terms used to discuss hearing loss.

- **“Age of onset”** is the age in which the hearing loss occurred. A loss that occurred before the child understands and uses language is called “pre-lingual,” while a loss that occurred after the child has some understanding of and is already using language (usually around the age of 2 years) is called a “post-lingual” loss.
- **Bilateral hearing loss** is a hearing loss in both ears.
- **Unilateral hearing loss** affects only one ear. These children typically have difficulty locating the source of sounds. Childhood illnesses, such as mumps, are often the cause of this type of loss.
- **Sensorineural hearing loss** is usually present when there is damage in the inner ear or cochlea and the hair cells are not functioning properly. There is often some distortion of nerve sound signals processed by the brain. This damage may occur during pregnancy or delivery, or it can be caused by genetics, exposure to excessive loud or sudden impulse sounds, ototoxic medications or infections such as measles, mumps, and meningitis. Often permanent hearing loss is classified as sensorineural loss because the way the brain and cochlea are contributing to

the loss of hearing cannot be established. This type of hearing loss cannot be treated medically because the hair cells are not functioning properly. Cochlear implants might be a choice for children with severe to profound sensorineural hearing loss, as those devices bypass the missing or damaged hair cells.

- **Conductive hearing loss** is caused by blocked or reduced movement of sound waves along the route from the outer or middle ear to the inner ear, preventing sound from being conducted normally. A conductive loss could be caused by blockage in the ear or damaged anatomical structures in the ear or ear canal. The causes of a conductive loss include earwax (cerumen) or other debris in the ear canal, fluid behind the ear drum, a middle ear infection (which could lead to a ruptured eardrum if not treated), trauma to the ear drum, a growth (cholesteatoma) on the ear drum, or a problem with the ossicles (middle ear bones). Conductive hearing loss can also result from birth defects in the head and neck, genetics, low birth weight, exposure to loud noises, head injury, and/or repeated middle ear problems.
- **Otitis Media** is an inflammation of the middle ear, commonly referred to as an ear infection. If the fluid is infected, it is often accompanied by a fever and earache. Middle ear fluid without infection is called “otitis media with effusion” (OME) and is usually treated with antibiotics. OME often has no other symptoms other than hearing loss due to a blockage created by the fluid in the middle ear. It can take up to six weeks for this fluid to drain, or tubes may be placed in the ears. The tubes are inserted during a short surgery, and they usually fall out on their own.
- **Mixed hearing loss** is a combination of conductive and sensorineural hearing loss. In this case, sound is not transmitted normally to the inner ear and there are also problems with the inner ear and/or neural parts of the auditory system.
- **Central hearing impairment** is caused by injury, disease, tumor, or unknown problems affecting the auditory centers of the brain. With a central hearing impairment, loudness of sound is not always affected, but the understanding of speech (also called clarity) often is impacted.
- **Central Auditory Processing Disorder (CAPD)** can also be present. This is not a hearing loss, but a problem in the brain that interferes with the ability to interpret sounds correctly.

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With a CAPD, it is difficult to localize the origin of sound or distinguish between two similar sounds. This condition is worse in a noisy environment and/or when a child is listening to complex information.

- **Auditory Neuropathy/Auditory Dyssynchrony (ANAD)** is a specific type of hearing loss in which the cochlea appears to be functioning normally, but sound cannot travel to the hearing center of the brain because the auditory nerve is not working properly. This is sometimes referred to as Auditory Dyssynchrony. Children with this condition may be able to hear sounds but cannot understand what those sounds mean, leading to difficulties in understanding speech clearly. To this child, sounds may fade in and out or seem out of sync. Children with this type of hearing loss can hear better on some days and not others, for no discernible reason. There is an increased risk of this condition if the child is born prematurely, has RH incompatibility, or had severe jaundice as a newborn. The following pages describe this type of hearing loss in greater detail and give specific resources for this condition.

Auditory Neuropathy/Auditory Dyssynchrony (ANAD)

What is ANAD?

Auditory Neuropathy/Auditory Dyssynchrony (ANAD) is a hearing disorder in which sound enters the inner ear normally but the transmission of signals from the inner ear to the brain is impaired. Although ANAD is not yet fully understood, scientists believe the condition probably has more than one cause. In some cases, it may involve damage to the inner hair cells located within the cochlea—specialized sensory cells in the inner ear that transmit information about sounds through the nervous system to the brain. Other causes may include faulty connections between the inner hair cells and the nerve leading from the inner ear to the brain, or damage to the nerve itself. A combination of these problems may occur in some cases.

Although outer hair cells—hair cells adjacent to and more numerous than the inner hair cells—are generally more prone to damage than inner hair cells, outer hair cells seem to function normally in people with auditory neuropathy. Outer hair cells help amplify sound vibrations entering the inner ear from the middle ear. When hearing is working normally, the inner hair cells convert these vibrations into electrical signals that travel as nerve impulses to the brain, where the impulses are interpreted as sound.

Risk Factors

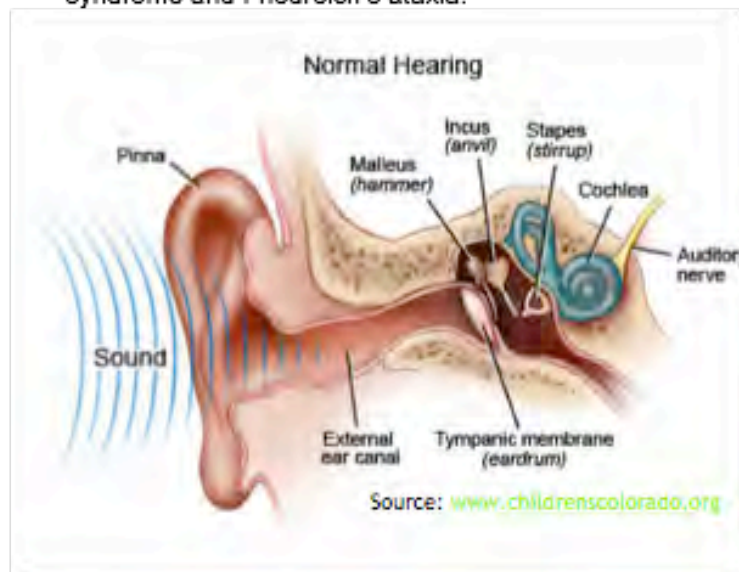
A variety of risk factors and etiologies have been linked to ANAD in children including:

- Anoxia (lack of oxygen) at birth
- Hyperbilirubinemia requiring blood transfusion (associated with severe jaundice during the newborn period)
- Infectious diseases (e.g. mumps)
- Immune disorders (Guillain-Barré syndrome)
- Hereditary (OTOF and DFNB59 gene mutations, Charcot-Marie-Tooth Syndrome, Friedreich's Ataxia, hereditary sensorimotor neuropathy, mitochondrial defects)
- Unknown

There are large individual differences among children with this hearing disorder. For some, hearing may improve over time. This is most common when the cause of the disorder is hyperbilirubinemia.

Genetic Link

The prevalence of ANAD is estimated to be 7-10% of sensorineural hearing loss and 10-14% of severe-profound sensorineural loss. ANAD runs in some families, which suggests that genetic factors may be involved in some cases. Some people with ANAD may have neurological disorders that also cause problems outside of the hearing system. Examples of such disorders are Charcot-Marie-Tooth syndrome and Friedreich's ataxia.



Clinical Presentation

Children with ANAD present with:

- Normal or near normal cochlear hair cell function indicated by present otoacoustic emissions, (OAE's)
- Absent or abnormal auditory nerve function as indicated by an auditory brainstem response (ABR) test
- Present cochlear microphonic response in the ABR where its direction reverses with stimulus polarity changes
- Absent or elevated middle ear muscle reflexes
- Audiometric hearing thresholds that may range from normal to a severe hearing loss and/or may fluctuate
- Difficulty understanding speech, especially in noise
- Speech perception worse than would be predicted by the degree of hearing loss.

Symptoms

Children with ANAD may have normal hearing, or hearing loss ranging from mild to severe. These individuals typically have difficulty understanding speech, especially in noise. Often, speech perception is worse than would be predicted by the degree of hearing loss. For example, a person with ANAD may be able to hear sounds, but would still have difficulty recognizing spoken words. Sounds may fade in and out for these individuals and seem out of sync and hearing may appear to fluctuate from day-to-day or even hour-to-hour. Additionally, other neuropathies may be present that can affect coordination for activities like writing, running, or talking.

Diagnosis

Audiologists use a combination of methods to diagnose ANAD. These include tests of auditory brainstem response (ABR) and otoacoustic emissions (OAE). The hallmark of ANAD is a negligible or very abnormal ABR reading together with a normal OAE reading. A normal OAE reading is a sign that the outer hair cells are working normally.

An ABR test monitors brain wave activity in response to sound using electrodes that are placed on the person's head and ears. An OAE test uses a small, very sensitive microphone inserted into the ear canal to monitor the faint sounds produced by the cochlea's outer hair cells in response to stimuli. Both tests are painless. Other tests may also be recommended as part of a more comprehensive evaluation of an individual's hearing and speech-

Genetic Testing

The genetic inheritance pattern of ANAD is autosomal recessive. This means that the parents of an affected child are unaffected, but carry a single mutation in the gene. Detection of pathogenic mutations in both copies of a child's OTOF (Otoferlin) or DFNB59 (Pejvakin) gene is considered a positive test result for ANAD.

Management

Management of ANAD is often complex due to the varied presentation of the disorder. Some patients benefit from hearing aids. However, many patients get limited hearing aid benefit or no benefit at all. At this time, there is no reliable way to predict who will and will not benefit. Some professionals recommend the use of Frequency Modulated (FM) systems. FM systems can improve listening in noisy backgrounds.

Some patients benefit more from a cochlear implant than from hearing aids. Those with some types of genetically inherited ANAD may benefit more from cochlear implants than patients with other causes of the disorder. Further research in this area is needed.

It is safe to say that no single teaching approach fits all patients with ANAD. It is helpful to work closely with a team of professionals. Some patients benefit from teaching that focuses only on learning to listen and speak. Others benefit from visual communication approaches (i.e., sign language or cued speech).

Resources For Parents/Patients:

1. **Boystown National Research Hospital:** <http://www.babyhearing.org/HearingAmplification/Causes/Neuropathy.asp>
2. **National Institute on Deafness and other Communication Disorders:** <http://www.nidcd.nih.gov/health/hearing/neuropathy.asp>
3. **Hands and Voices:** http://www.handsandvoices.org/comcon/articles/aud_neuropathy.htm
4. **Cued Speech.org:** <http://www.cuedspeech.org.uk/auditory-neuropathy-auditory-dys-synchrony>
5. **Como, Italy Conference ANAD Guidelines:** <http://www.childrenscolorado.org/conditions/speech/danielscenter/ANSDD-Guidelines.aspx>

Information adapted from:

1. National Institute on Deafness and Other Communication Disorders. *Auditory Neuropathy*. (2011). <http://www.nidcd.nih.gov/health/hearing/neuropathy.asp>
2. Boystown National Research Hospital. *My Baby's Hearing*. (2011). <http://www.babyhearing.org/HearingAmplification/Causes/Neuropathy.asp>
3. The Children's Hospital Guidelines Development Conference. (2008). *Guidelines for Identification and Management of Infants and Young Children with Auditory Neuropathy Spectrum Disorder*.
4. Partners Healthcare Center for Personalized Genetic Medicine and Harvard Medical School. *Auditory Neuropathy Spectrum Disorder*. (2011). <http://pcpgm.partners.org/Imm/tests/hearing-loss/ANSDD>

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Two other hearing related conditions are cochlear dysplasia and enlarged vestibular aqueducts (EVA) syndrome or large vestibular aqueducts (LVA) syndrome. Cochlear dysplasia is a condition in which the cochlea is malformed or has not developed normally. There are several common versions of cochlear dysplasia or malformation: Mondini malformation is the most common and results in only 1.5 turns in the cochlea, instead of the normal 2.5, as well as incomplete development of the membranous and bony labyrinths. Common cavity is the second most common version and occurs when the cochlea and vestibule are merged together forming a single cavity. Michel dysplasia/aplasia is the complete absence of inner ear anatomy and is the most severe form of congenital inner ear malformation, but also the least common. Cochlear implantation in malformed cochleas comes with its' own set of challenges, as does mapping post-implantation, and should be discussed at length with an ENT and audiologist familiar with difficult cases.

Vestibular aqueducts are narrow and bony canals that travel from the inner ear to deep inside the skull. Running through the vestibular aqueduct is a fluid-filled tube called the endolymphatic duct, connecting the inner ear to a balloon-shaped structure called the endolymphatic sac. A child's vestibular aqueducts are considered to be enlarged if they are greater than 1.5 millimeters in diameter. If this is the case, the duct and sac usually grow large as well. Although the function of the vestibular aqueduct and sac is not yet fully understood, the theory is that they ensure the fluid in the inner ear has the correct amount of ions. Most children with EVA develop some degree of hearing loss, and 5-15% of children with sensorineural hearing loss have this condition. Sometimes a diuretic is prescribed in an effort to reduce hearing loss associated with EVA. However, surgery is not considered to be a viable option as it can destroy the child's hearing. Steroids are sometimes given to treat sudden hearing loss, like if a child suffers a head injury and loses his or her hearing. However, no studies currently support the effectiveness of steroid treatments for children with EVA. You can minimize the effects of EVA by having your child avoid contact sports, wear head protection, and avoid extreme changes in pressure (like submerging in very deep water or engaging in any free-fall activities).

Making the Best Choices for Your Child and Your Family



COMMUNICATION OPPORTUNITIES

The goal for all children is to learn how to communicate. Communication is the sharing of information, and can occur through signed or spoken language, gesturing, and even through technology. It is the process of understanding other people and having them understand you. Every child is unique, and so is what works best for him/her to learn to communicate with others. There is no single method of communication that has been scientifically proven to be the best option for ALL deaf and hard of hearing children.

Other parents may have different opinions on what is the best way to provide these communication opportunities for their child and what will be best for their family. You will also encounter many professionals who have different advice, and you may see examples of children who have been very successful using different methods of communication. But you know your

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child the best. You understand what helps your child learn, and what works best for your family. The best decision you can make is to use whatever opportunities make communication successful for your child and your family.

Language is a system that is used to communicate, such as spoken English, written English, American Sign Language, and other spoken or written languages. Family involvement and early intervention have been identified as the most influential factors in language development for children with a hearing loss (Moeller, 2000). Thus, a family must be committed to consistently communicating with their child using the communication approach that works best for their child and their family, and work to support their child's development in all possible ways.

It is important to realize that you don't have to choose only one communication approach for your child, and whatever communication approach(es) you use may change over time. A communication method can change as the child's needs and preferences vary, or as the child gets older. There have been children who have chosen to take off their hearing aids and use sign language as their primary means of communication, while other children who are fluent in sign language choose to get a cochlear implant later in life.

You must have an understanding of critical periods of development while making decisions, as not all opportunities are available at all times. In addition, one approach does not preclude another. Some families adopt more than one communication approach for their child. Other families will choose one communication approach, find it is not working as well as they had hoped, and will make adjustments or changes later.

The most important thing is that families work as much as possible to develop their child's ability to communicate, and to have the language to understand and learn from the world around them. Some parents may not feel qualified, educated enough, or ready to make communication decisions for their child. Others may be afraid that they will make a wrong decision.

Talk to other parents about their experiences. Just remember that what works for their child and their family might not work as well for your child and your family, and that is when you need to rely on your judgment as a parent. Hopefully you will also be working with a team that can help you evaluate and assess the progress your child is making with the choices you have made and the opportunities you have provided for your child.

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If your child is not progressing as quickly as you desire in spoken and/or signed language development, you can make changes. In any case it is important that you and your child are successfully communicating.

There are several different communication approaches for children who are deaf/HH. The Communication Approaches Chart that follows shows communication modes as a continuum, ranging from a fully visual approach to a fully auditory approach with many combinations in between. It is useful to view these approaches as communication opportunities that can be combined rather than choosing one communication method and eliminating all others. Each communication approach will then be explained a bit further, and resources will be provided for learning more about each approach.

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COMMUNICATION APPROACHES CHART

BEGINNINGS for Parents of Children Who Are Deaf or Hard-of-Hearing, Inc :: www.ncbegin.org

	AMERICAN SIGN LANGUAGE	ENGLISH OR OTHER SPOKEN LANGUAGE			
	AMERICAN SIGN LANGUAGE (ASL) / ENGLISH AS A SECOND LANGUAGE (Visual Approach)	AUDITORY VERBAL (AV) (Auditory Approach)	CUED SPEECH (CS)	AUDITORY ORAL (A-O) (Combined Visual & Auditory Approaches)	SIMULTANEOUS COMMUNICATION (SimComm or Total Communication)
DEFINITIONS	<p>A bilingual approach which includes the development of both ASL and English. ASL is a natural, visual/manual language totally accessible to children who are deaf, that has its own grammar and linguistic principles.</p> <p>The acquisition of English is addressed through the use of teaching strategies for English as a Second Language.</p>	<p>An approach emphasizing spoken language development through listening.</p> <p>Child develops spoken language through one-on-one therapy and use of residual hearing with optimal amplification.</p> <p>Strives to make the most of a child's ability to learn through listening; therefore, the child does not rely on visual cues.</p>	<p>An auditory-visual communication approach combining a system of hand cues with the natural mouth movements of speech, specifying each sound (phoneme) of spoken language clearly.</p> <p>A hand shape (consonant groups) at a location (vowel groups) cues a syllable. This integration provides clear access to all the phonemes (sounds) as parents coo, babble and talk.</p>	<p>An approach that teaches a child to use his/her remaining hearing through amplification and the use of speechreading/natural gestures/visual cues to aid the child's understanding of language.</p> <p>The use of any form of sign language communication is not encouraged.</p>	<p>An educational philosophy that uses spoken language and sign language simultaneously.</p> <p>Uses an English-based sign language system which can include speech, speechreading, fingerspelling, natural gestures and the use of residual hearing.</p>
PRIMARY GOALS	<p>To acquire an age-appropriate internal language as a basis for learning a second language and opportunities for academic achievement.</p> <p>To develop a positive self-image and cultural identity providing access to the Deaf community.</p> <p>To provide a basis for learning written and, when possible, spoken English as a second language.</p>	<p>To develop spoken language through listening by following the stages and sequence of typical development.</p> <p>To develop the skills necessary for successful mainstreaming in school and integration into the hearing community.</p> <p>To promote a positive self-image through natural family and social interactions using spoken language.</p>	<p>To provide clear communication in the spoken language of the home.</p> <p>To develop the phonemic language base to achieve full literacy in conversation, reading and writing.</p> <p>To support speechreading, speech and auditory skill development.</p>	<p>To develop spoken language through listening and visual cues.</p> <p>To develop spoken language and communication skills necessary for school success and integration into the hearing community.</p>	<p>To provide a bridge to the development of spoken language in the very young child.</p> <p>To provide communication between the child and his/her family, teachers and peers using sign language.</p> <p>To support integration into both the hearing and the Deaf communities.</p>
LANGUAGE DEVELOPMENT (RECEPTIVE)	<p>The child develops early language concepts as well as higher order cognitive skills by utilizing the visual nature of ASL.</p>	<p>The child develops understanding of spoken language through early and consistent intervention that emphasizes learning through listening in a developmentally appropriate sequence.</p> <p>Optimal listening opportunities require the use of appropriate hearing technology.</p>	<p>The child absorbs language through early, consistent, clear communication using Cued Speech, speechreading and hearing.</p> <p>Cueing boosts auditory awareness, discrimination and understanding.</p>	<p>The child develops internal language through early, consistent listening experiences and developmentally appropriate therapy, which includes speechreading and the use of hearing technology.</p>	<p>The child develops language through speechreading, listening and exposure to a combination of speech and sign-based systems in English order.</p>
EXPRESSIVE LANGUAGE	<p>ASL fluency and written English.</p> <p>Ability to code switch from ASL to English (signed, spoken or written as needed).</p>	<p>Spoken and written English.</p>	<p>Cued, spoken and written English or other languages (60+ cued languages).</p>	<p>Spoken and written English.</p>	<p>Spoken English using sign language in English word order, and written English.</p>
HEARING (AUDITION)	<p>Encourages individual decision about amplification.</p> <p>Amplification may provide access to spoken language and allow the child more opportunity to become bilingual.</p>	<p>Early, consistent and appropriate use of hearing technology (hearing aids, cochlear implant(s), FM system) is critical to this approach.</p> <p>Requires ongoing auditory management.</p>	<p>Early, consistent and appropriate use of hearing technology (hearing aids, cochlear implant(s), FM system) is important with this approach.</p> <p>Requires ongoing auditory management.</p>	<p>Early, consistent and appropriate use of hearing technology (hearing aids, cochlear implant(s), FM system) is important with this approach.</p> <p>Requires ongoing auditory management.</p>	<p>Consistent and appropriate use of hearing technology (hearing aids, cochlear implant(s), FM system) is strongly encouraged.</p>
FAMILY/PRIMARY CAREGIVER RESPONSIBILITIES & GUIDANCE	<p>Parents are committed to learning and using ASL consistently.</p> <p>Families emphasize literacy in the home.</p> <p>Families provide opportunities for interaction with the Deaf community to help ensure a future independent and fulfilled Deaf citizen.</p> <p>ASL is learned through classes, media, websites, and interaction with members of the Deaf community.</p>	<p>Parents are expected to actively participate as partners in sessions with therapist(s) in order to learn strategies and techniques that promote the auditory learning of goals.</p> <p>Families need to carry over the goals established in therapy into the child's daily routines and play activities.</p> <p>Parents learn to create an optimal "listening" learning environment.</p> <p>Parents must also provide a language-rich environment, to make learning through listening a meaningful part of all experiences.</p>	<p>Parents are expected to learn to speak-and-cue at all times in order for children to absorb the phonemes critical to language and reading readiness.</p> <p>Families need to provide consistent use of cues and speech during daily routines and play activities.</p> <p>The system is taught in less than 20 hours through multi-media, classes, and Family Cue Camps. Consistent daily use and practice leads to conversational ease within a year.</p>	<p>Families are expected to provide appropriate carry-over of goals, strategies and techniques from the child's classroom setting and/or individual therapy sessions into daily routines and play activities.</p> <p>Parents need to work with the child's teacher(s) and/or therapist(s) to learn strategies and techniques for developing listening, speechreading and speaking skills in an oral learning environment.</p>	<p>Families are expected to learn and consistently use the chosen English-based sign language system.</p> <p>Parents need to work with the child's teacher(s) and/or therapist(s) to learn strategies that promote language expansion.</p>

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American Sign Language (ASL)

As with all signed language, ASL is a manual language communicated through hand signs, facial expressions, and gestures. American Sign Language is a true language, with its own grammar and syntax rules. Early and consistent exposure is needed for all language development. Parents and early intervention professionals must utilize the first years of life to foster this type of communication, as this is a critical time during which children develop language skills. Early language learning experiences affect other areas of development and are critical to children's future success (ie. learning a first language early allows one to more easily acquire skills in a second language). Sign language is visual and therefore fully accessible to children who have typical vision. Using sign language, even with babies who can hear, promotes earlier expressive communication and language development. Studies have shown that children can benefit from the use of sign language, with no risk to other language skills (Malloy, 2006). There are no studies that support the myth that learning sign language will prevent a child from learning spoken language.

Children who are learning American Sign Language need access to adults who are fluent in ASL, and thus most hearing parents may need to learn ASL if they don't know it already. This will take a serious commitment to learn a second language. Many sign language classes are available throughout the state of Arizona. Several classes are free of charge to parents of children who are deaf/HH. See the following page for a non-exhaustive list of these classes, with more information available on the Arizona Commission for the Deaf and the Hard of Hearing (ACDHH) website.

Sign Language Classes

ASDB Early Childhood & Family Education	520-770-3464
ALOHA-Tucson	520-795-9887
Easter Seals Society	520-745-5222
Phoenix Day School for the Deaf	602-771-5300
LDS Church: Phoenix	602-242-0694
LDS Church: Mesa	480-964-8335
St. Mathew Methodist Church	602-838-7309
Tri-City Baptist	602-838-5430
Valley Center of the Deaf	602-267-1921
Community Parks/Recreation Programs	
Local Community Colleges, Universities, and Churches	
Arizona Commission for the Deaf and the Hard of Hearing (ACDHH) www.acdhh.org 602-542-3323	

There are also several websites available that provide resources for ASL. For example, Sign2Me is a site promoting ASL tools for early literacy, and also offers courses and baby sign language products for purchase.

Sign2Me

www.sign2me.com

425-493-1903

Other websites serve the needs of the ASL Educational community by providing free reference and learning tools to enhance in-classroom learning for ASL educators and their students. Signing Savvy is one example.

Signing Savvy

www.signingsavvy.com

There are also a variety of free and paid ASL or sign language applications for tablets and smart phones.

The National Association of the Deaf is a civil rights organization of, by, and for deaf and hard of hearing individuals in the United States. The organization supports the right of the American Deaf community to use American Sign Language, and their website includes extensive information on law and advocacy.

National Association of the Deaf

www.nad.org

301-587-1788

Auditory-Oral (AO) or Auditory-Verbal (AV)

Although the communication approaches chart separates these two approaches, they are similar in that the goal of each is to teach children who are deaf/HH to learn to use listening and spoken language. With newborn hearing screening and improvements in technology (hearing aids, FM systems, and cochlear implants) this is becoming a far more attainable goal for children with significant hearing loss than it has been in the past. However, technology alone will not enable this to happen. Again, early and continual access to sound and intentional intervention is needed for spoken language development. Parents and providers trained in this approach must utilize the first years of life, as this is the critical window for developing natural spoken language skills through listening. Those early experiences will affect a child's ability to receive and use auditory information later in life. The later the child is amplified, the greater the need for didactic intervention.

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In the Auditory-Oral approach, speech reading, natural gestures, and visual cues are also used to communicate. Factors that influence a child's ability to succeed with oral-auditory skills are: a) age of identification and amplification, b) presence of other disabilities, c) consistent use of hearing devices, d) strong family support, e) a team that shares common communication goals, and f) a language-rich environment. Oral Deaf Education is an organization devoted to the promotion of oral deaf education as a collaborative, family-centered education approach. Their website provides a list of oral deaf education schools, videos highlighting children who have been educated in this manner, and downloadable materials for parents, educators, and professionals.

Oral Deaf Education

www.oraldeafed.org

Cued speech

Cued speech employs 8 hand signs to give cues to the child about the sound a speaker is making and enable the child to read lips. This approach helps the child to distinguish between sounds that look the same when spoken (for example p, b, and m look the same when they are spoken) and is a visual system designed to support the development of spoken language. Parents can typically learn to cue in a relatively short period of time and should be expected to cue with their child at all times until it may no longer be needed. The National Cued Speech Association supports effective communication, language development, and literacy through the use of Cued Speech. They are primarily an advocacy organization, focusing on outreach, family and education support, and community-based education.

National Cued Speech Association

Susan Price, Arizona Cued Speech Representative

www.cuedspeech.org

520-770-3471

Simultaneous or Total Communication

In the simultaneous communication approach, sign language cues are given to the child along with spoken language, but these signs are presented in the syntax that the English language follows, not American Sign Language. In Signed Exact English (SEE), the signs are a literal

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word-for-word match to the spoken message, whereas Pidgin Signed English is a mixture of both ASL and SEE. Pidgin Signed English focuses more on conceptual accuracy, with some but not all of the words in the spoken message signed to the child. This approach is also called Total Communication when every means is used to communicate with the child such as SEE, finger spelling, speech reading, natural gestures, and amplification. The Signing Exact English Center is a non-profit organization established to work with parents and educators to promote an understanding of the principles of SEE and its use.

Signing Exact English Center

www.seccenter.org

562-430-1467

Bilingual ASL-English

This approach, which is considered to be both a bilingual and bicultural approach, stresses the development of two languages, American Sign Language (ASL) and the native language of the family. ASL is usually taught as the first language, and the second language is taught through reading, writing, speech, and the use of residual hearing. The American Society for Deaf Children is a national independent non-profit organization dedicated to supporting and educating families of children who are deaf/HH. They believe deaf children should be fluent in both sign language and English for optimal academic success. They emphasize that research consistently demonstrates that fluency in sign language and in English offers deaf children (including those with cochlear implants) and hard-of-hearing children optimal opportunities for social and academic success, and should both be part of their language-rich environment.

American Society for Deaf Children

www.deafchildren.org

1-800-942-2732

The following “Decision Guide to Communication Options” was designed to guide you through the steps in deciding about communication.

Arizona Parent Resource Guide for Children who are Deaf or Hard of Hearing

Step Three: Plan the Next Steps Based on Your Needs

This final table will suggest specific steps that may help you feel confident about your decision. Don't give up. Keep looking for the resources you need to get to a level of comfort with this process. You will begin developing an understanding of your long term goals for your child, which may in turn shape your decisions and provide motivation. *You can do it!*

If you are having difficulty	What you can do
Do you feel you do not have enough support?	<ul style="list-style-type: none"> • Discuss your options with a trusted person • Find out what help is available to support your choice
Do you feel pressure from others to make a specific choice?	<ul style="list-style-type: none"> • Focus on the opinions of others that matter most to you • Share your guide with others • Ask others to complete this guide • Find a neutral person to help you and the other people involved
Do you feel you do not have enough facts?	<ul style="list-style-type: none"> • Find out about the advantages and limitations • List your questions and note where to find the answers
Are you not sure which advantages and limitations matter most to you?	<ul style="list-style-type: none"> • Review the stars in the Advantages and Limitations table to see what matters most to you • Find people who know what it is like to experience the advantages and limitations • Talk to parents who have made the decision • Read stories of what mattered most to others • Discuss with others what matters most to you

Are there other factors that make the decision difficult? If so, list them here:

.....

.....

.....


Here are some of the resources available to help in your decision-making process:

- Early Hearing Detection and Intervention Program at Centers for Disease Control and Prevention www.cdc.gov/nchddd/ehdi/default.htm
- National Center for Hearing Assessment and Management www.infantheating.org
- Boys Town National Research Hospital and National Institute on Deafness and Other Communication Disorders (NIDCD) www.babyhearing.org/
- Hands & Voices www.handsandvoices.org

Disclaimer:
We provide links to other web pages if you want to learn even more about a topic. One of these pages is on the CDC web site and others are on outside web sites. Links to organizations outside of CDC are included for information only. CDC has no control over the information at these sites. The views and opinions of these organizations are not necessarily those of CDC, the Department of Health and Human Services (HHS), or the U.S. Public Health Service (PHS).
Format is based on the Ottawa Personal Decision Guide, University of Ottawa, Canada

V-42020203


Decision Guide to Communication Choices



For Parents of Children Who Are Deaf or Hard of Hearing

"I wish I knew when my son was little that the decisions I made for him were my decisions for that time. I wish I knew I could change course and that was okay. It would have taken a lot of pressure off. I wish I realized that as he grew older, he would become the decision-maker and I would become his consultant and biggest fan."

Candace Lindow-Davies, Lukes mom. © 2008 HPI - Hands & Voices



Arizona Parent Resource Guide for Children who are Deaf or Hard of Hearing

This pamphlet will help guide you through the steps in deciding about communication. Deciding which communication method(s) will be best for your child can be stressful. The right choices are up to your family. Discovering what works for your child is truly a work in progress. Your child's needs, and those of your family, along with your long-term goals for your child, may change with time and you'll want to review your choices regularly. The communication method you choose first may not be your last or only choice.

The keys to making a good decision for your child and your family are:

- Knowing all of the options,
- Learning all you can about those options, and
- Resisting pressure to make a decision until you have enough information and you feel ready to choose.

Learn all you can about the different communication options. You can get information from organizations that support children with hearing loss. You may also want to talk to professionals, other parents of children with hearing loss, and adults who have grown up with hearing loss. Check out books, journals, and quality web sites, too. A list of resources at the end of this pamphlet will help you get started.

This pamphlet will guide you through three steps:

1. Find your starting point in the decision-making process,
2. Identify and explore your decision making needs, and
3. Plan your next steps.

Step One: Find your starting point

This step will help you describe your starting point in exploring communication options. Please remember, this decision about communication involves the whole family.

How far along are you with your decision?

- I do not know what my options are.
- I am considering the options.
- I am close to making my choice(s).
- I have already made my choice(s).

Are you leaning toward certain communication option(s)?

- No
- Yes. Which option(s)? Why?

Step Two: Identify and explore your decision-making needs

This step will help you move forward in the decision-making process. It will help you assess the knowledge you already have about the communication options and weigh the advantages and limitations of each one. It will also help you evaluate your support system and identify any pressure you might be feeling to choose certain options.

Families that answer "No" to one or more of the questions in this section may be more likely to:

- Delay their decision,
- Feel regret about their choice or
- Blame others for bad outcomes.

Therefore, it is important to focus carefully on your needs. Ideally, after working through this guide, you will be able to answer "Yes" to each of the questions posed. Likewise, if you've already made your decision, you should be able to answer "Yes" to each question.

A. Support

- Do you have family members, caregivers, and others who support you and who can help you make an informed choice for your child and family?
 - Yes No
- Are you choosing without pressure from others?
 - Yes No

You may use separate sheets if you need more space.

From whom have you received support?	Name:	Name:	Name:
Which option does this person prefer?			
Is this person pressuring you?			
How can this person support you?			
What part of the person's background affects their opinion?			

The following questions refer to the "Comparison" table below.

Advantages and Limitations of Communication Options

This chart helps you work through your needs in the four categories (A, B, C and D) in Step 2 above.

You may use separate sheets if you need more space.

	Advantages: Reasons to choose this option	How much it matters. Add ★ to ★★★★★	Limitations: Reasons to avoid this option	How much it matters. Add ★ to ★★★★★
Option 1				
Option 2				
Option 3				
Combination of Options				

B. Knowledge

- Are you confident that you know all the options available? Yes No
- Have you considered the advantages and limitations to each option for your family? Yes No
- Have you looked for more information or talked with others who can help you find more information? Yes No

In the Advantages and Limitations table above: List the options and the main advantages and limitations that you already know. Underline the advantages and limitations that you think you are most likely to experience.

C. Values

Are you clear about which advantages and limitations matter most to you? Yes No

In the Advantages and Limitations table above: Use stars (★) to show how much each advantage and limitation matters to you. Five stars (★★★★★) means that it matters "a lot." Zero stars means it matters "not at all."

D. Certainty

- At this point do you feel confident that you know enough about each option and how it might affect your family? Yes No

In the Advantages and Limitations table above: Circle the option or combination of options with the advantages that (1) matter most to you and (2) you believe are most likely to happen.

See **Step Three** on next page...

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Arizona Parent Resource Guide for Children who are Deaf or Hard of Hearing

For children from birth to age three, the Arizona Early Intervention Program (AzEIP) provides services to families of children who are deaf and hard of hearing through a division of the Arizona Schools for the Deaf and Blind (ASDB), called the ASDB Early Childhood and Family Education Program. The early intervention program provides support to families and children using any individual approach, or combination of communication approaches. There are also private and non-profit organizations that support individual approaches.

Arizona Early Intervention Program (AzEIP)

<https://www.azdes.gov/AzEIP/Family-Information>

602-532-9960; 888-439-5609

Arizona State Schools for Deaf and Blind Early Childhood and Family Education

http://www.asdb.az.gov/asdb/index.php/home/Early_Childhood_and_Family_Education

520-770-3464

ADVICE AND SUPPORT FROM OTHERS

Parents may feel overwhelmed when trying to make the best decisions for their child, and may have several questions that need to be answered. The important thing to remember is that you are not alone. Each year approximately 12,000 children in the United States, or 3 in every 1,000 children are born with hearing loss. This makes hearing loss the most frequently occurring birth defect (White, 1997). Although you will undoubtedly receive advice and support from your extended family and friends, there are also many other parent groups and organizations that would love to offer advice and support.

A great place to start when looking for support from others is to find other parents of children who are deaf or hard of hearing through organizations such as The American Society for Deaf Children and Hands and Voices. The websites for these organizations offer a wealth of information and resources, and the organization offers printed materials. Members of the American Society for Deaf Children receive a quarterly publication, *The Endeavor*, and members of Hands & Voices also received a quarterly newsletter, *The Communicator*. The American Society for Deaf Children hosts a Biennial National Conference for parents and professionals. It is also partnered with the parent-founded organization called Deaf Autism America.

The American Society for Deaf Children

www.deafchildren.org

800-942-2732

Hands & Voices

www.handsandvoices.org

303-492-6284

As the state chapter of Hands & Voices, Arizona Hands & Voices (AZHV) holds several events throughout the year to provide opportunities for parents to meet and talk with other parents of children who are deaf/HH, or gain information on topics that are unique to this population. Arizona also offers the Guide By Your Side (GBYS) program that links families to parent guides who can offer advice and support on a variety of topics. Parent guides are parents of children

Arizona Parent Resource Guide for Children who are Deaf or Hard of Hearing

who are deaf/HH who have completed special training programs and have become knowledgeable about related issues. Every effort is made to connect families with parent guides who have chosen similar communication approaches with their own children. Parent guides work with families at no charge. You can find out more about the GBYS program on the Arizona Hands & Voices website. There you can also view upcoming events in our state, see a list of the board of directors, read family stories from members, and register to join the organization.

Arizona Hands & Voices

www.azhv.org

866-685-1050

There are several other organizations throughout Arizona that offer support to parents of children who are deaf/HH. The ASDB Early Childhood and Family Education (ECFE) Program is the Arizona Early Intervention Program (AzEIP) provider of early intervention services for children who have bilateral hearing or vision loss, under Part C of the Individuals with Disabilities Education Act (IDEA). They provide services to families living all over Arizona, in order to meet the needs of families in their local communities. They recognize that the relationship between parents and their child is of primary importance to a child's physical, mental and emotional development. Educational mentoring and therapy services are provided in the home or other natural environments by professionally trained staff. ECFE also works with families by providing information, education, and support during the transition into preschool.

ASDB Early Childhood and Family Education (ECFE)

http://www.asdb.az.gov/asdb/index.php/home/Early_Childhood_and_Family_Education

520-770-3464

The EAR Foundation of Arizona provides services to people who are deaf, have a hearing loss, or a balance impairment. The EAR Foundation sponsors several programs for persons with hearing loss and rallies for early detection of hearing loss. The "Hear for Kids" program provides loaner or permanent hearing aids to children from birth to 18 years of age whose families are without insurance or in financial need.

EAR Foundation of Arizona

www.earfoundationaz.com

602-685-1050

The Arizona Association of the Deaf is organized and operated exclusively to promote the welfare of deaf/HH residents in the state of Arizona. They are concerned with educational and economic rights, security, social equity, and just privileges for citizens. Their website contains legislative information, a newsletter, and links to Arizona activities including the Arizona Deaf Festival.

Arizona Association of the Deaf

www.azadinc.org

Every year in Flagstaff, Arizona the Northern Arizona Deaf Expo features exhibits, interpreter and family workshops, and opportunities to practice sign language. Anyone who is interested in learning more about services available for individuals who are deaf/HH are invited to attend this event.

Northern Arizona Deaf Expo

www.nazdeafconnection.com

The Arizona Commission for the Deaf and the Hard of Hearing (ACDHH) is a statewide information referral center for issues related to hearing loss. The organization strives to ensure accessibility for the deaf and hard of hearing to improve their quality of life. Their website includes a searchable resource directory with information on many topics related to deafness and hearing loss. In addition, the website includes a section with responses to frequently asked questions and a list of upcoming events.

Arizona Commission for the Deaf and the Hard of Hearing

www.acdhh.org

800-352-8161; 602-542-3323

Arizona Parent Resource Guide for Children who are Deaf or Hard of Hearing

The Arizona Blind Deaf Children's Foundation began as a foundation to support programs at the Arizona Schools for the Deaf and Blind, and are now committed to ensuring that all children who are blind, deaf, or hard of hearing in Arizona have access to experiential learning in key areas that encompass and expand upon traditional education including art, fitness, and literacy.

Arizona Blind Deaf Children's Foundation

www.azblinddeafchildren.org

520-577-3700

There are also other local organizations that provide support for children with special needs, not just those who are deaf/HH. The Arizona Department of Health Services Office for Children with Special Care Needs (OCSHCN) is Arizona's Title V Program for children and youth with special health care needs. This program works to improve systems of care, provides information and referrals to families who would like assistance in finding services available to their child, and provides advocacy to help maximize existing benefits. Their website contains links to many programs and services available to children with special needs and their families.

Arizona Department of Health Services Office for Children with Special Care Needs

www.azdhs.gov/phs/ocshcn

602-542-1860; 800-232-1676

Raising Special Kids is a non-profit organization of families helping families of children with disabilities and special needs in Arizona, through parent-to-parent programs, special education information, and community outreach. The organization is Arizona's Parent Training and Information Center (PTI) authorized under the Individuals with Disabilities Education Act (IDEA) to provide assistance in special education to families and schools. The organization has recently combined the PTI program with the Parent Information Network, known as PINS, to strengthen and improve the delivery of parent training and assistance in special education across

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the state. Their website contains information on special education and a list of workshops and courses available online or at their facility in the Phoenix area.

Raising Special Kids

www.raisingpecialkids.org

800-237-3007

Pilot Parents of Southern Arizona was created by a small group of interested parents and professionals who are committed to providing encouragement and support to families who have children with special needs in Arizona. Services include peer-to-peer support, a parent training and information center, and a library of books and videos addressing issues related to a child's special needs.

Pilot Parents of Southern Arizona

www.pilotparents.org

520-324-3150

Many organizations outside of Arizona also offer information and support for parents of children who are deaf or hard of hearing. For example, Beginnings for Parents of Children Who are Deaf or Hard of Hearing, Inc. is a non-profit agency providing an impartial approach to meeting the diverse needs of families with children who are deaf or hard of hearing. The agency was created to be a central resource for the state of North Carolina, but their website also includes information for all families and professionals and covers a range of topics from early intervention to school issues.

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

www.ncbegin.org

919-715-4092

Arizona Parent Resource Guide for Children who are Deaf or Hard of Hearing

The Laurent Clerc National Deaf Education Center was mandated by Congress in the Education of the Deaf Act (EDA) to provide information, training, and technical assistance for parents and personnel throughout the nation to meet the needs of children who are deaf/HH. Their mission is to improve the quality of education for this population throughout the United States, and they maintain two demonstration schools for elementary and secondary students. Their website contains a resources section with a centralized source of information related to children who are deaf/HH, formerly known as the National Deaf Education Network Clearinghouse. They also provide trainings and technical assistance, publications, and cochlear implant education.

Laurent Clerc National Deaf Education Center

www.gallaudet.edu/clerc_center.html

202-651-5855

The Better Hearing Institute is a not-for-profit corporation that educates the public about hearing loss. Their website provides a wealth of information on hearing loss, including a special section for children with information for parents, and a list of hearing loss resources by topic.

Better Hearing Institute

www.betterhearing.org

202-449-1100

Raising Deaf Kids is a website created by the Deafness and Family Communication Center at the Children's Hospital of Philadelphia. Their goal is to provide a wealth of information and resources on hearing loss and to help parents make better decisions for their child. The website includes a section of parent talk on a range of issues pertaining to hearing loss and communication opportunities.

Raising Deaf Kids

www.raisingdeafkids.org

215-590-7440

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The John Tracy Clinic provides free worldwide parent-centered services to young children from birth to five years old with a hearing loss. The organization was founded by parents of a child with a profound hearing loss who studied how deaf children could be taught to communicate in the hearing and speaking world. The clinic provides distance education courses for parents, international onsite summer sessions for families, and professional education. Their website also features information on common concerns, and an “Ask the Expert” section with issues that might be of interest to families.

John Tracy Clinic

www.jtc.org

213-748-5481

The House Research Institute works closely with physicians from the House Clinic. The institute’s Children’s Auditory Research Evaluation (CARE) Center is devoted to improving the communication ability of infants and children with auditory disorders. The center provides comprehensive evaluations of children’s hearing abilities to determine appropriate treatments and make recommendations for long-term care. Their website also includes a section with educational resources for parents.

House Research Institute

www.hci.org

800-388-8612

The Deafness Research Foundation is a national source of private funding for basic and clinical research in hearing and balance science. The foundation publishes a magazine called Hearing Health, to keep persons who are deaf/HH informed of the latest discoveries in the field. Their website features a dictionary of hearing conditions and options, with a glossary of associated medical terms.

Deafness Research Foundation

www.drf.org

866-454-3924

The Rochester Institute of Technology Center for Education Research and Partnerships was created to serve as a source of factual information for parents, teachers, and others interested in the education of children who are deaf or hard of hearing. Questions posed on this site are answered by either members of the Editorial Board of the Journal of Deaf Studies and Deaf Education or other experts. Current and past responses are listed by topic.

Rochester Institute of Technology Center for Education Research and Partnerships

www.rit.edu/ntid/educatingdeafchildren

585-475-2411

There are other sites that are concerned with larger issues, such as health and communication disorders, but also include hearing loss. The Centers for Disease Control and Prevention includes a webpage with information on hearing loss in children. This division of the Department of Health and Human Services features articles, materials, and statistics about hearing loss, as well as issues related to hearing loss in the A-Z index.

Centers for Disease Control and Prevention

www.cdc.gov

800-232-4636

In addition, the National Institute on Deafness and Other Communication Disorders is part of the National Institutes of Health (NIH), the federal government's focal point for support of biomedical research. This particular institute is mandated to conduct and support research and

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training programs in the processes of hearing, balance, smell, taste, voice, speech, and language. Their website has a section on health information that includes issues related to hearing loss.

National Institute on Deafness and Other Communication Disorders

www.nidcd.nih.gov

301-496-7243

Finally, other organizations offer special services and information to their members. One example is the Alexander Graham Bell Association for the Deaf and Hard of Hearing, a membership organization and information center for families, health care providers and educational professionals. Their mission is to advocate for independence of people with hearing loss through listening and talking.

Alexander Graham Bell Association for the Deaf and Hard of Hearing

www.agbell.org

202-337-5220

AMPLIFICATION AND TECHNOLOGY

Your child's needs for amplification and assistive technologies will depend on his/her type and degree of hearing loss, and the communication approach(es) your family will use. This section will begin with a discussion of hearing aids and cochlear implants. While we are not promoting the use of these amplification devices over any other communication approach, we include this discussion because many parents have questions about what these technologies do and how they might benefit their child. Following this discussion, we will present examples of other assistive technologies that might be appropriate for assisting your child's communication needs.

The first carbon-type hearing aid was produced in 1898, and the first wearable digital signal processing hearing aid became available in 1988. A hearing aid is a small amplifier cased in molded plastic. A microphone picks up sound from the environment and converts it into an electric signal. This sound is filtered, electronically processed, and amplified. A loudspeaker converts the electrical signal back into an audible signal and delivers it to the ear canal. Most hearing aids that are fitted to children are digitally programmed and adjusted by an audiologist to meet the child's hearing needs. An audiologist will set the hearing aid for a child's specific hearing loss, as determined by an audiogram or ABR test. A hearing aid enhances the child's residual hearing and the benefit received from a hearing aid will depend on the type and degree of hearing loss and any other medical or developmental challenges the child may have.

Children are typically fitted with a behind-the-ear (BTE) hearing aid(s) because they are safe, versatile and compatible with other devices. They also can be easily found if they should fall off the child. With a BTE device, an earmold is molded to fit snugly into the child's ear, and the processing device sits behind the ear, connected to the ear mold tubing. When placing the earmold in the child's ear, you should place the longest part of the mold in the ear canal first, and then twist the mold back until it slides gently into the ear. If the earmold sticks out (which can give feedback as sound is escaping between the ear and mold), you should gently pull the back of the ear forward to allow the mold to slide into the ear. Behind-the-ear hearing aids must have a custom earmold that fits properly into the child's ear. This means that as a child grows, they must be frequently fitted for new earmolds by an audiologist. A four-month old child might return to the audiologist every 6-8 weeks for new earmolds, but this need for new molds will slow down as the baby grows.

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There are several different hearing aid manufacturers and hearing aid models made for children, all with a unique set of features. For example, some hearing aids have a volume control for a child to adapt the volume to each unique listening situation. Some have different programs for use in different situations, usually triggered by pushing a button on the hearing aid to change programs, while others have the capability to recognize different hearing environments and automatically select the most appropriate hearing program. Many audiologists recommend a hearing aid that has frequency modulated (FM) technology, so that the child can use an FM system in a classroom setting. Some hearing aids require a boot or special battery door to attach an FM to the unit. Other features that might be considered for older children include: a telecoil function for talking on the phone without feedback and compatibility with inductive loop systems, EasyPhone/AutoPhone that automatically selects a telephone program when a handset is close to the ear, and Bluetooth capability for connecting to mobile devices and enabled devices like MP3 players, computers and televisions. Some hearing aids are also water resistant or waterproof. Additional things to consider when purchasing a hearing aid for your child are as follows.

- Does the hearing aid have most current technologies available?
- Is the hearing aid manufacturer reputable?
- Is the hearing aid durable?
- How often does the audiologist have to send that model in for repair?
- Is the hearing aid FM compatible?
- Does the hearing aid have a telecoil?
- What hearing aid does the audiologist recommend for my child?
- Have others been satisfied with its performance?
- What is the total cost of the hearing aid?
- Will the cost of the aid be covered by insurance?
- Is there a trial period to test and return the hearing aids if not satisfied?
- What is the cost to return hearing aids during the trial period?
- How long is the warranty, and can it be extended?
- Does the warranty cover loss and damage?
- How long will this particular aid last my child?
- What happens if the hearing aid needs to be repaired?

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An audiologist who specializes in pediatrics is the best person to consult with when making a decision about what type of hearing aid to purchase for your child. The audiologist will be able to assess your child's needs and help you select the most appropriate hearing aid.

Once a child is fitted with hearing aids, he or she will not be able to hear everything immediately. Children who have not had normal hearing may not be able to hear all sounds clearly, and may continue to hear fragments of sounds until they become accustomed to the hearing aid and "learn" to hear sounds. However, some children with a significant degree of hearing loss may show little or no benefit from using the hearing aids. This is why early intervention, as discussed in the next section, is essential for helping the child to adapt to this new technology. Even with the best intervention and experience using hearing aids, some children may continue to have difficulty hearing under certain circumstances. To make sure your child is getting the maximum benefit from his or her hearing aids, you should continue to have his or her hearing checked regularly. The audiologist can make adjustments to the hearing aid programs if necessary. For a child with a non-progressive hearing loss, evaluations by an audiologist should occur every 3 months for a child under two years of age, every 6 months until age 5, and once a year after that. An audiologist may recommend more frequent visits for children with a progressive hearing loss.

For information about paying for hearing aids for your child, please see the following document provided by the Arizona Early Hearing Detection and Intervention (EHDI) program. Please note:

This list was compiled to assist families in obtaining funding to cover the costs of hearing aids. The information should be verified before decisions are made as programs, funding and eligibility may change over time. Talk with your audiologist about other options.

If you have questions or would like to update the information you can contact:

Arizona Early Hearing Detection and Intervention

State Coordinator:

Lylis E Olsen, MS, MPH

602-690-3975

lylisolsen@msn.com

Hearing Aids - Resources for Parents

Hearing aids as well as other audiological services can be quite expensive and unaffordable for many families. Fortunately there are programs in Arizona that can help families and children that are in need of assistance.

Loaners:

Your first option would be to check with your audiologist about loaner hearing aids. Loaner hearing aids are also available to any Arizona family, through the HEAR for Kids Program with the EAR Foundation of Arizona. Loaners are usually available for up to six months. Longer loan periods are possible for special circumstances such as assessment for cochlear implantation. The program is funded by grants and donations.

Purchasing Equipment:

Research on how to purchase and pay for permanent hearing aids should begin as soon as possible. It may take several months to determine eligibility for some programs. The answers to some of the questions listed below may help you find the assistance that is right for your family.

Q. Is your child enrolled in an AHCCCS or KidsCare health plan?

NO ► You may be eligible for other programs as described below.

YES ► Your child may be eligible for hearing services through Children's Rehabilitative Services (CRS). Information about CRS services and how to apply are on the next page.

Q. Does your health plan cover hearing aids?

NO ► There may be an appeals process to challenge limits or restrictions on coverage. You may be eligible for other programs described below.

YES ► Call your health plan Member Services and ask for information about your hearing service benefits.

Q. Are your financial resources limited?

NO ► Ask your audiologist if the office or facility where you receive audiological services can arrange a payment plan.

YES ► There are several programs available to those with financial needs.

Your audiologist may participate in some of the following programs, which are described in more detail on the next few pages. Your audiologist may be helpful in deciding which program/s best suit your needs. Please note that some programs may require you to change providers.

- HEAR for Kids
- UnitedHealthCare Foundation for Children (higher income levels)
- Starkey Foundation's HEAR Now Program
- Lions Affordable Hearing Aid Program
- Sertoma Clubs

Children's Rehabilitative Services (CRS)

CRS provides medical care and support services to children and youth who have certain chronic or disabling conditions. CRS recipients can get hearing related services in one of four Multi-Specialty Interdisciplinary Clinics (MSICs) located in Flagstaff, Tucson, Yuma and Phoenix.

The Arizona Health Care Cost Containment System has contracted with Arizona Physicians IPA (APIPA) to administer the CRS program, as APIPA-CRS.

Eligibility:

To be eligible for APIPA-CRS services you must:

- Have an eligible medical condition (Most hearing impairments are eligible conditions)
- Live in Arizona
- Be under age 21
- Be a U.S. citizen or qualified alien.

APIPA-CRS recipients must also be enrolled in an AHCCCS acute health plan or ALTCS (Arizona Long Term Care System) plan. You may call Member Services toll-free at 1-866-275-5776 for more information.

Hearing Aids and Cost to the Family

APIPA-CRS covered services are provided at no cost to recipients. Hearing services, including hearing aids, earmolds and fitting are covered for qualified APIPA-CRS recipients. Hearing aids may be replaced every three years or more often if there is a significant change in hearing. Hearing aids are covered for loss or damage by a two year replacement warranty. If the original hearing aid(s) are lost or damaged, families are encouraged to purchase insurance for the replacement aid(s).

For some types of hearing aids, prior authorization may be needed before APIPA-CRS can provide them. Your APIPA-CRS hearing services provider will take care of this for you.



For families who have ALTCS, APIPA-CRS and private insurance

APIPA-CRS will coordinate benefits with your private insurance and you will not be billed for any remaining cost, when you get hearing services at an MSIC or APIPA-CRS provider.

Additional Services

APIPA-CRS recipients who receive hearing services may also be eligible for additional medical specialty services like ENT, Genetics, Ophthalmology, among others at their MSIC.

Apply by Filling Out an Application:

To get an application or information:

- Call Member Services toll-free at: 1-866-275-5776.
- Visit the APIPA-CRS web site at www.myapipacrs.com,
- Call the Office for Children with Special Health Care Needs (OCSHCN) at 602-542-1860,
- Call 1-800-232-1676 and ask for the CRS Program, or
- Download an application from the OCSHCN web site at www.azdhs.gov/phs/ocshcn/crs/crs_az.htm.

HEAR for Kids

HEAR for Kids is a program of the EAR Foundation of Arizona. Most of the funding is provided by St. Luke's Health Initiatives and private donations as well as grants from Arizona Community Foundation, Nina Mason Pulliam Charitable Trust and others. Authorization is generally available within 48 hours of the application.

Eligibility:

Eligibility is based on family income, household size/dependent care, and expenses. If the child is covered by AHCCCS or KidsCare or other insurance that covers hearing aids, they are not eligible for HEAR for Kids. Children must be currently living in Arizona to be eligible.

- **Income:** Total Household income for the past 12 months: Wages/Salary, Pension, Social Security, Child Support and any other income.
- **Expenses:** Total Allowed Deductions for the past 12 months include medical/dental not paid for by health insurance or third party, annual rent or mortgage payments, annual payments for primary vehicle.
- **Dependent Care:** Use the following calculations:
 - Number of children in childcare _____ x \$200 x number of months _____ = \$ _____
 - Number of incapacitated adults receiving care _____ x \$100 x number of months _____ = \$ _____

Using the amounts you calculated above, find **Annual Income**. Take **Income** minus **Expenses** minus **Dependent Care** = **Annual Income**. Using the chart below, find the number of people in your family and the corresponding maximum **Annual Income** to be eligible. (current as of 3/2010).

Number in Family	Annual Income
1	\$16,245
2	21,855
3	27,465
4	33,075
5	38,685
6	44,295
For each additional person, add \$5,610	

Cost to the Family:

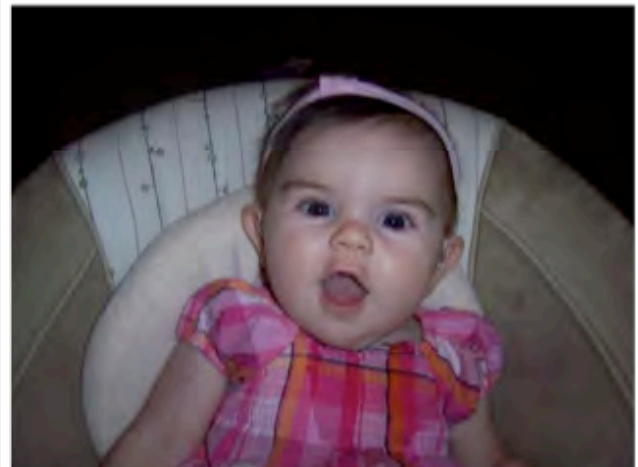
As long as the family qualifies under the financial criteria above, there are no costs. Earmolds are covered for the first year as many times as needed. Earmolds may be covered after the first year if the family continues to meet the financial criteria. Repairs or new aids are covered as needed if the family qualifies.

Hearing Aids:

Any aid selected by the audiologist will have a 1 or 2 year warranty. There is no restriction on type of hearing aid although the least expensive aid available with the features needed is generally purchased to ensure that the funding is available for all in need. Some repairs and replacement of cochlear implant parts may also be available.

Applications can be downloaded on the EAR Foundation website at www.earfoundationaz.com but must be submitted by the audiologist who will be helping select and fit the hearing aid(s).

The Ear Foundation can be contacted directly by calling 602-690-3975, or e-mail to: lylolsen@msn.com



UnitedHealthCare Children's Foundation

The UnitedHealthCare Children's Foundation is a 501(c)(3) non-profit charity dedicated to facilitating access to medical-related services that are not fully covered by the available commercial health benefit plan. This "support" is in the form of a medical grant to be used for medical services not covered or not completely covered by commercial health benefit plans.

The applicant must be covered by a commercial health benefit plan and limits for the requested service are either exceeded, or no coverage is available and/or the copayments are a serious financial burden on the family. The UnitedHealthCare Children's Foundation requires a commercial health benefit plan. If your health plan is an AHCCCS, ALTCS or KidsCare plan, you will not be eligible for this grant, but you may be eligible for CRS. Read more about CRS on page 2.

Eligibility:

The applicant must be 16 years old or younger and live in the United States and receive and pay for care/items in the United States.

Financial need of the child's family will be evaluated and documented through information provided on the application and by submission of a photocopy of the most recently filed Federal tax return (Internal Revenue Service 1040, 1040-A, or 1040-EZ). The following scale will be used to determine financial eligibility:

Your Family Size As reported on your IRS 1040	Adjusted Gross Income As reported on your IRS 1040
2	\$40,000 or less
3	\$60,000 or less
4	\$80,000 or less
5 or more	\$100,000 or less

NOTE: Awards will NOT be granted to individuals in families whose Adjusted Gross Income (AGI) exceeds the scale.

An application must be submitted to the Foundation prior to the receipt of services. The Foundation does not pay for past medical expenses

Exclusions:

The UnitedHealthcare Children's Foundation has a specific set of items that are excluded from grant consideration. For a complete list of exclusions see www.uhccf.org.

Hearing Aids:

There does not appear to be any restriction on types of hearing aids other than a limit of \$5,000 or 85% of the fund balance, whichever amount is less per year. Awards to any one individual are limited to a lifetime maximum of \$7,500.

If a grant is approved by the Regional Board of Directors for your child, the grant will help pay for approved medical services/items after your commercial health benefit plan submits payment, if any. The grant funds are not paid to you or the child outright - you work with the Foundation on submitting invoices/bills for approved medical services/items after your commercial health benefit plan submits initial payment (if any) to the health care provider



Applications:

Applications and further information on criteria and services can be found at the link below or by calling (952) 992-4459.

www.uhccf.org

Starkey Foundation's HEAR Now Program

HEAR Now is a national non-profit program committed to assisting those permanently residing in the U.S. who are deaf or hard of hearing, who qualify under the National Poverty Guidelines for assistance and have no other resources to acquire hearing aids.

Eligibility:

All applicants are asked to call HEAR Now to discuss eligibility for the program. Please call 800-648-4327.

Income Guidelines: All income figures are based on take-home wages (net income) from all members of the household

Size of Family Unit	HEAR NOW Income Guidelines	Size of Family Unit	HEAR NOW Income Guidelines
1	\$17,867	4	\$36,137
2	\$23,957	5	\$42,227
3	\$30,047	6	\$48,317

NOTE: For family units with more than 6 members, add \$6,090 for each additional member.

HEAR Now also considers family assets such as savings, retirement funds, life insurance and annuities.

Cost to the Family

The family is responsible for finding a hearing health care professional willing to work with them and the HEAR Now Program. HEAR Now does not provide a list of hearing health care professionals or make referrals to practitioners. Check the listings in your local phone book under "Audiologists" and/or "Hearing Aids" and call to ask if they are a HEAR Now provider. If they are a provider, ask if they can take you on as a new client. Most Pediatric Audiologists in Arizona are not participating providers and you may be responsible for the cost of the fitting and programming of the hearing aids.

The family is responsible for the cost of the evaluation/assessment and the non-refundable processing fee to HEAR Now. Once the aids are provided, the family is responsible for the purchase of batteries and extended warranty coverage for the aids.

The Hearing Aids are selected by the Foundation and will be Starkey products. Starkey makes behind-the-ear, in-the-ear and bone conduction hearing aids. A one year warranty is provided. Check with the audiologist to make sure that these hearing aids will meet your child's needs before pursuing this option.

Additional Information and Application:

This information is current as of March 2010. You can access the website link below for more current information and to access the application process or call 1(800) 328-9602.

www.sotheworldmayhear.org



<p>Lions Affordable Hearing Aid Program (AHAP)</p>	<p>Sertoma Clubs</p>
<p>The Lions AHAP is rooted in a continuum of care model involving hearing care professionals and focuses on low-income beneficiaries. The hearing aid is one part of the solution to hearing impairment.</p> <p>Also needed are the services of hearing care professionals to conduct tests, order ear molds, program the hearing aids and do follow-up care.</p> <p>Currently Lions AHAP is distributing two hearing aids through a partnership with Rexton, Inc. in cooperation with participating Lions foundations, districts and clubs, and hearing care professionals. Lions clubs, districts and hearing programs are able to order one or both aids from Lions AHAP.</p> <p><u>How does the Lions AHAP program work?</u></p> <p>A Lions club decides the eligibility of a person, and the person is tested by a hearing care professional. The Lions club sends the order to Lions AHAP, who notifies the manufacturer. The hearing aid is shipped to the hearing care professional listed on the order form. The hearing care professional fits the hearing aid for the person. Individuals cannot apply directly to Lions Club International Foundation; he/she must work through his/her local Lions club.</p> <p><u>Eligibility</u></p> <p>The criteria for eligibility are income-based. This includes using the federal government's poverty guidelines and adjusting it to the local economy. The hearing aids are for the segment of the population who would never be able to purchase hearing aids.</p> <p>Each club has their own criteria and application process. For further information on the program, contact the Lions AHAP office at (630) 468-6771 or e-mail LionsAHAP@lionsclubs.org You can also contact a club near you by going to the Lions International website: www.lionsclubs.org</p>	<p>Sertoma stands for SERvice TO MAnkind. Sertoma's primary focus is on assisting the more than 50 million people with hearing health issues and educating the public on the issues surrounding hearing health. In order to achieve these goals Sertoma has undertaken a multi-faceted approach by launching programs that address both the treatment and prevention aspects of hearing health.</p> <p><u>Communicative Disorders Scholarships</u></p> <p>There is a \$1,000 Scholarship for hard of hearing or deaf students that have clinically significant bilateral hearing loss. Graduating high school seniors or undergraduate students must be pursuing a four year degree.</p> <p>There is also a \$1,000 Scholarship for graduate students who have been accepted into a graduate level program in audiology or speech-language pathology at institutions in the United States. Sertoma provides more funds nationally for graduate level study in communicative disorders than any other single organization.</p> <p><u>Other Services:</u></p> <p>Sertoma Affiliates are non-profit hearing and speech facilities that have established a relationship with a Sertoma Club or have an independent relationship with Sertoma. This relationship results in greater service to people with communicative disorders by supporting the professional staff and programs of the affiliate.</p> <p>There are 7 Sertoma clubs in Arizona. Locations and contact information can be found on their website or by calling 1 (816) 333-8300.</p> <p>www.sertoma.org</p>

If over time and through audiological evaluations it is discovered that your child is not receiving adequate benefit for the development of spoken language from the use of hearing aids, he or she might be a candidate for a cochlear implant. A cochlear implant is a surgically implanted device that transmits coded electrical impulses to stimulate the hearing nerve within the inner ear, providing a sense of sound to a person who is profoundly deaf or hard of hearing. A microphone picks up sound from the environment and sends it through the speech processor that arranges those sounds and sends them to a transmitter. The transmitter converts these sounds into electric impulses, and an electrode array collects these impulses and sends them to different regions of the auditory nerve.

A cochlear implant does not amplify sound like a hearing aid does, but rather it bypasses the non-functioning parts of the ear to produce the sensation of sound. According to the Food and Drug Administration (FDA), as of April 2009 more than 180,000 people worldwide have received cochlear implants, including approximately 41,500 adults and 25,500 children in the United States.

The decision to implant a child is not taken lightly, as the implant is a surgical procedure under general anesthesia, and has some risks including the possibility that any residual hearing a child has may be lost. Implant design and surgical techniques are evolving in an effort to preserve residual hearing; however, it is by no means an exact science and preservation of hearing cannot be guaranteed. Also, a patient must have a hearing nerve and a cochlea that will permit successful implantation of the device's electrodes.

An audiologist can help provide information about whether a cochlear implant might be an option for the child, and an otologist (an ENT who has obtained additional training to perform cochlear implants and other specialized surgeries to the ear) should also be consulted. Typically, cochlear implant candidacy is determined by a team that includes the ENT, audiologist, speech therapist, early interventionist, social worker, and the child's parents. Further, in order to be considered a viable candidate for a cochlear implant, the child typically must meet the following FDA-approved criteria:

Arizona Parent Resource Guide for Children who are Deaf or Hard of Hearing

- Age 12 months and up (although exceptions are sometime made for younger children)
- Severe-to-profound sensorineural hearing loss (exceptions are made in cases of auditory neuropathy where audiogram thresholds have minimal bearing on auditory performance)
- Reception of little or no benefit from amplification devices (or a lack of progress made with hearing aids)
- No medical contraindications
- Strong patient motivation and family support
- Appropriate expectations
- Educational and home environments must be supportive of facilitating maintenance and care of the device and committed to the development and use of spoken language.

The perceived benefits from receiving a cochlear implant also vary from one individual to another. Factors that contribute to the degree of benefit a person receives from an implant include, but are not limited to: chronological age, duration of hearing loss, cognitive abilities, the number of surviving auditory nerve fibers, access to oral/auditory verbal speech/language therapists, other health or developmental disabilities, and the patient's motivation to learn to hear. You may wish to consult other parents who have a child who has been implanted prior to making this decision for your child.

If it is determined that your child is a viable candidate for a cochlear implant, you will want to look into whether the procedure is covered by your health insurance. You will then want to investigate which cochlear implant might best serve the needs of your child. One consideration is the device's Cumulative Survival Rate (CSR). This indicates the likelihood that a device will function properly during a given period of time. You should review the track record of each company's products, as the device you choose must be designed to last a lifetime. Some other considerations when selecting a cochlear implant include:

- Speech understanding performance in everyday situations
- Durability and versatility for everyday activities (ie. water-resistance)
- Batteries for the sound processor (rechargeable or disposable, or both)

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- Access to future technology upgrades without future surgery
- Manufacturer's commitment to investment in new and improved technologies
- Reputation of company
- Warranties available

More and more cochlear implant surgeons are recommending (and families are choosing) binaural cochlear implants as two implants are considered better than one, just as two ears are considered better than one. Some surgeons prefer to do both implants at the same time (simultaneous implant surgery) while other surgeons and families opt to do one implant at a time (sequential implant surgery). There are perceived advantages and disadvantages to both procedures, so you will need to discuss this with your implant team.

There are three major manufacturers of cochlear implants commonly used in the United States. They are listed below in alphabetical order.

Advanced Bionics Corporation

www.advancedbionics.com

877-829-0026

Cochlear Corporation

www.cochlearamericas.com

800-523-5798

Med-EL Corporation

www.medel.com

919-572-2222

After your child receives a cochlear implant, the external processor will typically be activated within 2-4 weeks of the surgery. The audiologist will then begin mapping the cochlear implant. Mapping is the process of programming the settings of the electrical stimulation limits necessary for the user to comfortably hear loud and soft sounds. This process varies by manufacturer and

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may include determining the threshold levels (T levels), comfort levels (C or M levels) and managing electrodes that may be causing problems. The audiologist will also make changes over time as the child becomes more comfortable with electrical stimulation. It could take six months or more for a child to fully adapt to using a cochlear implant, but the experience of listening with a cochlear implant improves over time. The younger the child, the more quickly they seem to adjust. With appropriate mappings, intentional listening practice and support from a speech therapist or listening and spoken language specialist, the child can quickly learn to maximize benefit from the cochlear implant.

There are many other assistive technologies to help those who are deaf or hard of hearing. For children who use hearing aids or have cochlear implants, FM systems are now being used in some birth to three-year old programs to help maximize the benefit the child receives from their hearing device(s) by closing the distance between the parent or caregiver and the child. With this system, one speaker (typically the parent or caregiver) wears a microphone connected to a small transmitter that can be clipped to their clothes. The sound from the microphone is transmitted by FM radio frequency to a receiver worn by the child either at the end of the child's hearing aid or around the neck. The virtual distance between the speaker and child is equal to the distance between the speaker's mouth and the microphone, allowing the child with hearing loss to hear the speaker's voice directly in his or her ear. Furthermore, FM systems are being used in many school systems to provide for communication needs beyond what the hearing aids can offer in crowded and loud classrooms. To find out about the capability requirements and/or inquire about use of an FM system for your child, you can either talk to your child's audiologist or contact the hearing aid or cochlear implant manufacturer. Once your child is in school, the school district will usually handle the process of procuring the device.

For children who use sign language, the Arizona Commission for the Deaf and the Hard of Hearing (ACDHH) offers services including a telecommunications relay service that allows a user to place text-based calls from their personal computer or mobile device to any standard telephone in the United States. The messages are sent via instant messaging to the relay service that contacts the telephone user and voices the text message in real time. This service is available 24 hours a day by calling 7-1-1 in Arizona. The ACDHH also offers a telecommunications equipment distribution program (AzTEDP) that provides amplified telephones, captioned telephones, and telecommunication devices for the deaf (TTY).

Arizona Commission for the Deaf and the Hard of Hearing, ACDHH

www.acdhh.org

602-542-3323

Video relay, a service that allows calls to be placed through a videophone appliance connected to a TV or personal computer and webcam, is also available through certain companies. The user signs to an interpreter who contacts the telephone user and voices the messages back to them.

Purple Communication

www.purple.us

877-885-3172

Sorenson Video Relay Service

www.sorensonvrs.com

866-756-6729

ZVRS

www.zvrs.com

727-254-5600

Described and captioned media is available to persons who are deaf/HH through the Described and Captioned Media Program, funded by the U.S. Department of Education and administered by the National Association of the Deaf. This program is dedicated to promoting and providing equal access to communication, and includes a free-loan media library available to those who are deaf, blind, hard of hearing or visually impaired.

Described and Captioned Media Program

www.dcmp.org

800-237-6213

Early Intervention

For children ages 0-3 years



IDEA 2004 AND CHILDREN WHO ARE DEAF OR HARD OF HEARING

Early intervention, serving children from birth to age 3, is required by law. Public law 94-142 was enacted in 1975 and was renamed the Individuals with Disabilities Education Act (IDEA) in 1990 and revised again in 2004. There are different sections of this law. Part C outlines early intervention services. Federal funding is available to states that have early intervention services under IDEA. A child between birth and 36 months of age, who is developmentally delayed or has an established condition with a high probability of a developmental delay, can qualify for IDEA Part C services. “Hearing Impairment” and “deafness” are two of the established conditions under this law.

Federal law requires each state to develop its own policies and a system to oversee and monitor IDEA Part C services. In Arizona, a division of the Department of Economic Security (DES)

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oversees all Part C service-providing agencies. That division is called the Arizona Early Intervention Program, or DES-AzEIP.

Arizona Early Intervention Program, AzEIP

www.azdes.gov/azeip

888-439-5609

There are a total of five state agencies that are part of the Arizona Early Intervention Program:

1. The Arizona Department of Health Services (DHS)
2. The Department of Economic Security (DES)
3. The Arizona State Schools for the Deaf and the Blind (ASDB)
4. The Arizona Department of Education (ADE)
5. The Arizona Healthcare Cost Containment System (AHCCCS)

Of these five agencies, there are three state agencies responsible for providing the early intervention services in Arizona. These service-providing agencies are:

1. The Arizona State Schools for the Deaf and the Blind (ASDB)
2. The Department of Economic Securities: Division of Developmental Disabilities (DES/DDD)
3. The Department of Economic Security: Arizona Early Intervention Program (DES/AzEIP)

All of these agencies work together under a Team-Based Early Intervention model, but coordination of services for each child may be done by a different agency, depending on the child's eligibility. Children with a permanent, bilateral hearing loss are eligible for service coordination and specialized hearing-related services through ASDB and AzEIP. Children with a temporary or unilateral hearing loss causing a delay in development may be eligible for services through DES/AzEIP. Children with developmental delays receive services through DDD and may also qualify for services from ASDB if there is a permanent bilateral hearing loss. As AzEIP states: "Early Intervention is professionals working in partnership with parents and families of children with special needs, to support their children's growth, development, and learning. Early Intervention happens in places where children and families live, learn, and play; the families' natural environments."

What Is Child Find?

Child find is a component of the Individuals with Disabilities Education Act 2004 (IDEA '04) that requires states to *locate, identify, and evaluate* all children with disabilities, **aged birth through 21**, who are in need of early intervention or special education services. This includes children who are highly mobile, such as migrant or homeless children, children suspected of having a disability even though they are advancing from grade to grade, private school students, and homeschool students.

The Arizona initiative for child find is referred to as AZ FIND.

Local public education agency contact:

AZ FIND

1-800-352-4558 or 928-679-8106

azfind@azed.gov or

www.azed.gov/special-education/az-find

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Developmental and Educational Services for Children Ages Birth through 21 Years

Some children have more difficulty learning than others. They may have trouble achieving milestones in one or more of the following developmental or academic areas:

- Vision and Hearing
- Motor Control or Coordination
- Behavior or Social Skills
- Speech or Communication Skills
- Cognitive or Academic Skills

A referral for early intervention or special education services can come from a parent, guardian, foster parent, family member, teacher, counselor, or the student who finds learning difficult.

The earlier you express your concerns, the sooner your child's needs will be identified and the sooner he or she will receive the help needed to succeed.



Helping All Children Succeed



Do you have concerns about your child's development or progress in school?

Help for Infants and Toddlers

Children ages **birth to 2 years 10 1/2 months** are screened through the Arizona Early Intervention Program (AzEIP) to determine if early intervention services are needed.

Early intervention brings professionals, working in partnership with parents and families of children with special needs, together to support infants' or toddlers' growth, development, and learning.

If you have questions about your child's development an AzEIP specialist will talk with you about your concerns and observe your child. If your child is found eligible, a plan will be designed to include strategies, activities, and supports to achieve desired outcomes related to your child's needs.

Make an online referral at www.azdes.gov/azecip. For more information, call 1-888-439-5609 or (602) 532-9960.



Help for Preschool and School-Aged Children

Your local school district, or the charter school your child attends (for school-aged students), screens children ages **2 years 10 1/2 months through 21 years**. Public schools use an informal screening process to check your child's development and academic progress.

- Screening must be completed within 45 calendar days of the date you notify the school of your concerns.
- When a concern is identified through screening procedures, you must be notified within 10 school days and informed of procedures to follow up on your child's needs. For example:
 - Your child may be referred to the school's study team for pre-intervention services; or,
 - If screening results indicate your child may have a disability, a comprehensive evaluation will be necessary to determine your child's eligibility for special education and related services. A team, of which you will be a member, will meet to begin the process.

Screening and evaluation are free. All information contained in the screening or evaluation is confidential.

Contact your local school district or the charter school your child attends. For children attending private schools, contact the principal at the school district in which the private school is located.



Be Involved!

Family engagement has a positive influence on your child's academic success and emotional development.

- Set high expectations and establish goals.
- Communicate frequently with teachers to monitor your child's achievements.
- Ask for ideas and materials to help your child learn at home.
- Reward progress and celebrate accomplishments.
- Volunteer for classroom and schoolwide activities.
- Attend community events and workshops that promote learning and social growth.

Source: Arizona Department of Education, AZ FIND

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Hospitals, audiologists, medical providers, family members, caregivers, or even neighbors may refer a child to AzEIP. An online referral form is available on their website, as well as on the ASDB website. Additionally, audiologists who diagnose a hearing loss will send a referral to the Department of Health Services and ASDB's early intervention program. No matter who receives the referral, all of the AzEIP service providing agencies (ASDB, DDD and AzEIP) will coordinate together to make sure the family is contacted in a timely manner. Below are some of the key timelines in early intervention:

- The referring person should receive a notification that the referral was received within 2 business days.
- An early intervention provider will contact the family within 2 business days after notification. If the family cannot be contacted after several attempts, then a letter will be sent to the family notifying them that the referral is being closed. If the family is interested in pursuing eligibility or services, the family should receive a home visit from a provider within 10 business days.
- If the child is determined eligible for services by a review of medical records or an evaluation, an Individualized Family Service Plan (IFSP) will be written within 45 days of the initial referral.
- Any services on the IFSP should be expected to begin within 30 days of the writing of the IFSP.
- The IFSP should be reviewed and updated at least every 6 months, with a new IFSP being written annually.

More detailed information about Arizona Early Intervention services can be found on the AzEIP website.

Arizona Early Intervention Program, AzEIP, Family Information

www.azdes.gov/AzEIP/Family-Information

888-439-5609

Arizona Parent Resource Guide for Children who are Deaf or Hard of Hearing

The component of IDEA that requires states to locate, identify, and evaluate all children from birth to age 21 with disabilities who are in need of early intervention or special education services is called “Child Find.” In the state of Arizona, it is titled “AZ Find.” The website for AZ Find contains links and resources for parents of children at different ages.

AZ Find

www.azed.gov/special-education/az-find

800-352-4558

A child who has an established hearing loss is determined to be eligible for early intervention services following an evaluation of medical records. In some cases, a home evaluation may be conducted to determine if the child has a developmental delay greater than 50%.

The next step is for family members to meet with a few professionals from the early intervention team to complete a child and family assessment. The assessment is simply a discussion with the family about their daily routines and activities, priorities for their family and child, any resources they might have available to them outside of the early intervention program (i.e. community programs, church, family support, etc.) and any concerns about their child. If there are concerns about certain areas of the child’s development, the early intervention provider may use an approved tool or test to help gather more information.

Based on the family’s routines, resources, priorities, and concerns, the team (including the family members) will identify some desired outcomes and the services that might be needed to help the family and/or child to reach those outcomes. Some examples of services that may be available depending on the needs of the child and the desire of the family are: audiology services, sign language services, special instruction, speech language pathology, occupational therapy, physical therapy, social work, psychology, and vision services.

Arizona utilizes the Team-Based Model of early intervention, so expertise from a full range of Part C service professionals will be accessible to the team for every child. During the IFSP meeting, the family and other team members will select a Team Lead, who will be the primary contact for the family and the one who does the most visits with the family. Other team members may join the Team Lead for family visits and offer support and assistance, or may just be available if the Team Lead needs to ask them some questions by phone or during weekly team meetings.

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This support, however, depends upon the desired outcomes that the family and other team members have documented on the IFSP.

The Hearing and Vision Specialists (Teachers of the Deaf and Hard of Hearing; and Teachers of the Blind and Visually Impaired), and some audiologists are employed by ASDB. These professionals support all modes of communication.

ASDB Early Childhood and Family Education

<http://bit.ly/ASDBECFE>

520-770-3464; 855-822-5121

Service Coordinators for children who qualify for DDD services are employed by DES/DDD.

AzEIP contracts with different businesses in local communities across Arizona to hire local team members to serve families. These contracted teams have a core team including: a developmental special instructionist, a speech language pathologist, an occupational therapist, and a physical therapist. Additional team members include a social worker, psychologist, and the ASDB Hearing and Vision Specialists. A Service Coordinator, employed by the AzEIP team, may be utilized for children who do not receive service coordination from ASDB or DDD. All of these team members work together and meet as a group regularly to constantly improve the quality of services for families. Families are invited to participate in team meetings (in person or by phone) when their child is being discussed.

Evaluation and assessment, service coordination, and team meetings are provided at no cost to all families receiving AzEIP services. Arizona is a state that charges families a percentage of the cost for their other IFSP services, based on a sliding scale. This fee system is called Family Cost Participation. When a family first meets with their early intervention Service Coordinator, they will receive a copy of the Family Cost Participation paperwork. This paperwork must be completed and mailed to ASDB or AzEIP to determine the percentage of services, based upon their household income, the family will have to pay. Many families have 0% or a very low percentage of fees to pay. Knowing this percentage helps families decide which services to accept at the IFSP meeting. If a family chooses not to submit this information, their percent to

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pay is automatically 100%. Families may also consent to have AzEIP bill their private or public insurance companies for services first. If the insurance company does not pay, then the family must pay their percentage. Please see more details on Family Cost Participation on the AzEIP website listed below.

AzEIP Family Cost Participation

www.azdes.gov/AzEIP/Family-Cost-Participation

Families with public insurance programs are often approved for audiology and speech language pathology services through Arizona Children's Rehabilitative Services (CRS). CRS is a family-centered medical treatment, rehabilitation, and related support service center for children under the age of 21 with qualifying conditions and who are enrolled in the Arizona Health Care Cost Containment System (AHCCCS). Members may receive care and services in a clinic-like setting or from participating doctors in their office practice. AHCCCS has contracted with UnitedHealthcare Community Plan to administer the CRS Program.

United Healthcare- Arizona Children's Rehabilitative Services (CRS)

www.uhcommunityplan.com/az/medicaid/childrens-rehabilitative-services.html

800-348-4058

Families may choose to supplement the Early Intervention Services provided by the state through other local community resources. Additionally, participation in the Arizona Early Intervention Program is optional, and a family may choose to decline AzEIP services and use only community resources.

One community resource that may be considered is the private, not-for-profit school, Desert Voices in Phoenix, Arizona. The mission of the school is to teach deaf and hard of hearing children the oral language skills needed to speak and understand when others speak to them. The school is a certified Moog Center, seeking to prepare children who are deaf/HH to enter a traditional school setting with age appropriate speech and language skills and at the academic

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level of their hearing peers. Desert Voices Early Intervention Program typically serves children from 4 weeks to approximately first grade.

Desert Voices Early Intervention Program

www.desert-voices.org

602-224-0598

The IFSP team might also suggest that the child who is deaf or hard of hearing receive additional services from a speech pathologist, also called a speech-language pathologist or SLP, who works for a university program or is in private practice. The speech therapy approaches used with a child who has a hearing loss are different from those used with a child with normal hearing who has difficulty with speech and/or language. It is therefore important to find a speech pathologist who specializes in working with children who are deaf or hard of hearing. Each of the three large state universities in Arizona have speech and hearing clinics that provide speech, language, and hearing services for children. Please visit the website for each of these programs to investigate the special services these universities might be able to provide for your child with a hearing loss.

Arizona State University Department of Speech and Hearing Sciences

www.shs.asu.edu

480-965-2374

Northern Arizona University Department of Communication Sciences and Disorders

www.csd.nau.edu

928-523-2969

University of Arizona Department of Speech, Language, and Hearing Sciences

www.slhs.arizona.edu

520-621-1644

Transition to Preschool

For children who are at least 3 years old



Once a child who is deaf or hard of hearing turns 3, he or she may be eligible to receive special services when they attend school. Under federal law, school districts are responsible for providing services needed for school-aged children. All children are entitled to a free, appropriate, and public education (FAPE). The term “free” means that there is no cost to the child or parent for the child to be educated. An “appropriate” education means that the state has complied with procedures set forth in IDEA, and that an individualized education program has been reasonably calculated to enable the child to receive educational benefits.

Although the law does not directly state that the child is entitled to the best education possible, but rather one that is appropriately suited to meet his or her needs, families can be instrumental in deciding what is best for their child. The education is “public” as it is provided within the public school district. A public school district, however, is required to pay for a private education for a child when it is determined that the public school district cannot provide the education to which the student is entitled.

Finally, an “education,” is not medically related, but may include health care services related to the child’s special needs. However, a child who has been receiving Early Intervention Services is

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not automatically entitled to receive services once they reach the age of three. The child must first be evaluated by the school district through the Child Find process.

When your child reaches the age of three, and with your permission, the Service Coordinator will call a transition meeting with your IFSP team and your child's school district representative. Your child will then be referred to your school district's Child Find Team. The Child Find Team will review existing information and assessments provided by the IFSP team and will determine what, if any, additional assessments might be needed. If your child has not participated in the birth-to-three early intervention program, contact your home public school to begin the preschool placement process.

Parental consent is needed before the child is evaluated, and the evaluation must be completed within 60 days of parental consent. The evaluation may encompass all possible areas related to the suspected disability or identified diagnosis as in the case of a child who is deaf or hard of hearing. It is important to note that hearing loss, in and of itself, may not qualify a child for special education services. A child must have an educational need as a result of the hearing loss that will require special accommodations. This will be considered during the evaluation, and interpretations of this definition vary from school district to school district.

If the parents disagree with the evaluation, then it is their right to take their child for an Independent Educational Evaluation, and ask the school district to pay for the cost of this second evaluation. The child's eligibility for special services is then decided upon by a group of qualified professionals and the child's parents. If the parents are not satisfied with the eligibility decision, then they may request a hearing to challenge that decision.

Another law that covers your child's right to a public education is Section 504 of the Rehabilitation Act of 1973. Please see the following figure for an explanation of how Section 504 and IDEA work together to better assist your child's education team in making the most appropriate decision for your child's educational success.

Individual Education Plans (IEP) and 504 Plans

As a parent, you are your child's greatest advocate, supporter, and cheerleader. By becoming knowledgeable regarding educational laws as well as services and programs available within your community, you can ensure that your child receives a Free and Appropriate Public Education (FAPE). There are two primary laws that cover your child's rights to a public education:

1. Individuals with Disability Education Improvement Act (IDEA)
2. Section 504 of the Rehabilitation Act of 1973

Understanding how Section 504 and IDEA work with each other and complement each other allows you as the parent to better assist your child's educational team in ensuring your child's right to a Free and Appropriate Education (FAPE) is provided allowing for maximum educational success.

What is an IEP?

An IEP is an individual education plan, which is part of the special education laws of the IDEA 97 laws or educational benefit laws. IDEA allows for additional services and protections for disabled children not offered to other children such as accommodations, modifications, related and special education services to allow the child to be successful in school.

What is a 504 plan?

Section 504, of the Rehabilitation Act of 1973 is a civil rights law that prohibits discrimination against individuals with disabilities. Section 504 ensures that a child with a disability has equal access to an education. The child may receive accommodations and modifications even if he or she does not qualify for special education. Any school or program receiving federal funds must follow this law.

What are the similarities between the two plans?

Both plans can provide the student with certain accommodations and modifications to allow a disabled child to be more successful in school. Related services can be provided for students on either plan, such as occupational therapy, physical therapy, and speech and language therapy. Neither plan requires the student to have a change of placement. The child may stay in a regular classroom.

What are the main differences between the two?

A student receiving Special Education (SPED) through an IEP is protected under all Section 504 laws. The opposite is not true. Section 504 does require the school to come up with a system of safeguards such as:

- Parental notice of evaluation or placement decision
- Parental review of records
- Impartial hearing for appeals.

SPED has a more elaborate system of safeguards to protect the parent and child, such as:

- Prior Written Notice of all evaluations, changes to IEP and placement changes
- Right to an independent evaluation at the public school's expense
- Arbitration or mediation if the parent and school do not agree on the plan
- Administrative Complaint Process
- Due Process Hearing

A 504 plan includes only accommodations, modification, and related services as needed. It does not allow for direct or indirect services with the student, or consultation services regarding the student between the special education teacher and regular education teachers. IEP does provide for services through special education teachers with the student and consultation with the regular classroom teachers.

Qualifying for Special Education and an IEP

Special education allows a child to have an individual education plan (IEP) when the child's disability interferes with the student's education and performance. Special Education is available for all children that qualify from age 3 through age 21 or upon graduation from high school, whichever comes first. If a parent feels their child requires special education, the first step is to contact the school the child is attending and explain what how you feel your child's disability will affect education. The next step is the evaluation, which will include:

- a letter or form from the physician explaining the child's specific medical concern
- interview with parents
- interview with teachers
- information from parents
- specific testing, including all areas related to suspected disability

If the child is qualified as "other health impaired" it does not require that testing be performed to show a learning disability. However, this does require proof, from your physician, of a medical disability that affects the child's education.

After the evaluation is completed, the team will meet. The team consists of the parent, the student (if he/she is at least 14 years old), regular education teacher, a Local Educational Agency (LEA) representative (usually the principal) and a representative from any area that the child was tested in (i.e. speech pathologist, audiologist, psychologist). The parent may bring an advocate, such as a more experienced parent, to this and all team meetings. At the team meeting, all findings will be reviewed, including the teacher's observations, the physician's information, and any testing that has been completed. The parent may share any literature they have on the child's disability and how it will affect him or her in school at this time. After discussing the findings, the team will make a decision on eligibility.

Qualifying for a 504 Plan

Eligibility for a 504 plan requires a physical or mental disability, which substantially limits at least one major life activity (i.e. walking, writing, speaking, etc.) If the child qualifies for an IEP the parent cannot legally choose to use a 504 plan instead.

The first step is to contact the school the student is attending. Most schools will evaluate a student to see if the student will qualify for special education first. If the child does not meet eligibility criteria for special education, the school will evaluate for a 504 plan. The team will get information from the parents, classroom teachers, attending physician, and more, depending on the impairment. A 504 plan allows for many accommodations and modifications depending on the exact disability. Depending on various factors, an audiologist may recommend various accommodations and modifications for students with hearing loss, which may include any of the following listed on the next page. As needed, 504 plans also allow for related services such as speech and language therapy and/or audiology services. The final modifications and accommodations will be individualized, according to state regulations.

Reference:

1. American Partnership for Eosinophilic Disorders Website
http://www.apfed.org/downloads/IEP_and_504.pdf

THE IEP PROCESS

If it is determined that the child is eligible for special education services, an Individualized Education Plan (IEP) will be written according to the child's needs. When IDEA was reauthorized in 1997, it included specific language for students who were deaf or hard of hearing:

In Sec.300.346 Development, review and revision of IEP:

The IEP team shall also... (iv) Consider the communication needs of the child, and in the case of a child who is deaf and hard of hearing, consider the child's 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; and (v) consider whether the child requires assistive technology devices and services.

An IEP team must meet to write an IEP for your child within 30 calendar days after your child is determined to be eligible for services. The meeting will be scheduled by the school district, and the parents must receive advance notice to ensure that they have ample opportunity to attend. As a parent, you have the right to request for the school district to reschedule the meeting if it is not planned for a time that you can attend. You can also invite other people (such as your Service Coordinator or other IFSP team members) to attend the meeting who have special knowledge about the child. Typically, the following people will attend an IEP meeting (although some people may perform more than one role):

- Parent(s)
- School administrator- A member of the school district who knows about the general education curriculum and the resources available at the school. This person must also be qualified to provide or supervise special education services.
- General education teacher (if your child is participating in, or will be participating in, a general education class)
- Special education teacher- At least one special education teacher or provider who works with, or will work with, your child

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- Evaluation personnel- Someone who knows the child's evaluation results and what these results mean for instruction. This person could be a school psychologist, an administrator, or the child's teacher.
- Child- It is usually up to the parent to decide if the child will attend, but an older child must be invited to the transition meeting for life after high school.

The following people might also be present at your child's IEP meeting, depending on your child's needs and the situation:

- Interpreter/Translators- A person who can communicate with families or children using ASL or other language or communication mode.
- Transition personnel- A person who can ensure the continuation of services in the next stage or setting of a child's education. For example, this person might navigate the move from Early Intervention to preschool, or from preschool to elementary school).
- Others with knowledge or special expertise about your child- Any person who has knowledge of the child and may be able to contribute to the meeting (e.g. a private speech pathologist or a special care giver).

A child's first IEP meeting can be overwhelming to parents due to the large number of attendees and the sensitivity of the topics discussed when attempting to decide what is best for your child. It is highly suggested that parents discuss these issues with your Service Coordinator and/or research IEP meetings via websites or through parent-to-parent networking prior to the meeting. To further help you prepare for the first IEP meeting, please see the following suggestions.

Preparing for the IEP Helpful Hints for a Successful Meeting

Before the IEP Meeting

1. Review your child's current IEP.

What goals did your child reach? Which ones haven't been met? Are new goals needed?

Ask to review all of your child's school records.

2. Talk to your child about school.

What subjects and activities do they like or not like?

Pay attention to what seems to motivate and interest your child.

3. Visit your child's classroom(s) and other possible program options.

4. Make a list of your child's strengths and needs.

Consider academic, social, behavioral, and self-help skills for the next year and upcoming transitions.

5. Make a list of goals you would like your child to achieve.

What concerns and hopes do you have for your child now and in the future?

Share your expectations and dreams for your child.

6. Make a list of questions you have for the team.

Review samples of your child's work and progress reports to see if appropriate progress has been made.

Call your child's private therapist or doctor if you have any concerns. Take recent reports from them to the meeting.

7. Know what rights and responsibilities you and your child have for special education services.

Ask for information about IEP procedures.

Attend parent trainings, or contact a parent group for more information.

8. Be prepared to advocate for your child.

Know who will be attending the meeting.

Have someone with you for support.

Organize your thoughts and materials.

Maintain a positive attitude.

Assume that each team member has your child's best interest in mind and that everyone wants to work together.

During the Meeting

1. Get answers to your questions.

Get answers to your question(s) or ask that someone get back to you later.
Ask staff to clarify terms or programs which are unfamiliar to you.

2. Steps to take if there are disagreements.

Work as a team to explore options.
Respect each other's opinions.
Repeat your requests and concerns, stating your reason(s), to make sure the team understands your position.
Sign the IEP to show your attendance, but do not give your approval for the IEP contents if you disagree.
Ask to hold another meeting at a later date if the team can't reach consensus.
Gather more information if needed.
Avoid emotional confrontations.
Ask for and review procedural safeguards. The school will give you the name of a parent advocacy group to help address your concerns.

3. School records are important.

Request a copy of the IEP document.

After the IEP Meeting

1. The IEP meeting is over, but your involvement continues.

Keep a copy of the current IEP on hand to review periodically and monitor progress.
Ask for an IEP review meeting if issues and concerns develop and cannot be easily resolved.

2. Continue to learn more about special education procedures and self-advocacy.

Contact parent groups for resources and training,
Call the Parent Information Network for additional information at 1-800-352-4558 or 602-542-3852.

This article was developed in January 1998 by Becky Raabe, Parent Information Network Specialist, Contract # AO-0012-003, with funding from the Arizona Department of Education under a grant from the U.S. Department of Education. Inclusion in this article does not constitute endorsement by either department. This article is in the public domain and may be freely reproduced and disseminated, provided credit is given to the Parent Information Network, Arizona Department of Education, Exceptional Student Services.

IE 11

Source: Parent Information Network, Arizona Department of Education, Exceptional Student Services

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The purpose of the meeting is to develop an IEP document that will outline the special services your child will receive in the preschool setting. Some team members might suggest IEP items, but the parents are equal members of the IEP team, and no services can be given to the child without parental consent. If you disagree with the decisions made by other members of the IEP team, you should voice your concerns and state the reasons why you feel the way you do to ensure that the others understand your position.

It also helps to maintain a positive attitude, as your ideas are more likely to be considered if they are conveyed in a constructive manner rather than an accusatory manner. You may need to create solutions and present them to the team for consideration. If the team continues to disagree on proposed services, you as a parent must sign the IEP to show that you were in attendance, but you do not have to give agreement to the IEP contents. You may ask for another meeting to be held at a later date if a consensus is not reached. If you are still in disagreement with the IEP team, you may file a complaint with the state agency and request a due process hearing. Mediation will be provided.

Each child's IEP must include:

- The child's present levels of academic achievement and functional performance
- Annual goals for the child
- How the child's progress toward each goal will be measured
- Statement of special education and related services to be provided to (or on behalf of) the child, including program modifications or support from school staff
- Explanation of the extent (if any) to which the child will not participate in the mainstreamed classroom and in school activities
- The child's communication and language mode (if an interpreter is required)
- Special modifications for student assessment procedures, including state and district-wide assessments, if needed
- Dates of services including frequency and location
- How and when the parents will be informed of the child's progress

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Once the child begins receiving services as defined by the IEP, the team must meet at least once a year, or more often if a parent or guardian requests a review of the IEP. The IEP may be revised as necessary, and parents have the right to request additional testing, independent evaluations, mediation, and a due process hearing. The child will be reevaluated at least every 3 years unless the parents and school system agree that such an evaluation is not necessary. Parents must give consent for this reevaluation.

The Arizona Department of Education (ADE), Office of Exceptional Student Services (ESS) provides information about the IEP process, and what to do if the school district and parents do not agree on the elements of the IEP.

Arizona Department of Education Exceptional Student Services

www.ade.az.gov/ess

1-602-542-4013

The Parent Education Network, within the Arizona Department of Education Exceptional Student Services, has Parent Information Network Specialists (PINS) who provide on-site and phone consultations, trainings, resources, and information to support parents of special education students, all free of charge. A free consultation is provided to help parents assess their needs and learn how to participate in the special education process including IEP meetings. However, PIN specialists cannot attend IEP meetings.

PINS has recently joined forces with the Arizona Parent Training and Information Center (PTI) at Raising Special Kids to improve the delivery of parent training and assistance in special education across the state. Other parents of students receiving special education services that have been nominated by PIN specialists or school district/charter school staff are called Partners Are Liaisons to Schools (PALS). These parents serve as contacts for families at the district or school level to educate parents and students about their special education rights and responsibilities. You can find information about PINS and PALS, as well as an extensive library of downloadable resources such as sample letter for requests for evaluations and records and information on subjects related to special education on their website.

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Arizona Department of Education Exceptional Student Services Parent Education Network
www.ade.az.gov/special-education/deputy-associate-superintendent/parent-information-network

877-230-7467

Assistance with IEP meetings is another service provided by the Pilot Parents of Southern Arizona, a group of interested parents and professionals serving families with children with special needs. Their website contains a list of services available, one of which is assistance with, and sometimes attendance at, a child's IEP meeting.

Pilot Parents of Southern Arizona

www.pilotparents.org

520-324-3150

EDUCATIONAL PLACEMENTS AND MODIFICATIONS

For every child who is three years of age or older, the IEP must specify the type of educational environment the team feels will best meet the child's needs. The IDEA specifies that all students with disabilities must be educated in the same environment as students without disabilities as much as possible. This is called the Least Restrictive Environment (LRE).

However, parents of a child with special needs and/or the IEP team might feel that the best placement for the child is NOT in the least restrictive environment. For example, a child who is learning to develop his or her speech and auditory skills might be best suited to attend an oral deaf preschool. The parents have the right to opt out of what would be the least restrictive environment, in this case a preschool with students without disabilities, for an educational experience that they feel would better meet their child's needs.

A child can be educated in classrooms that range from self-contained to full inclusion. A self-contained classroom is one in which the child spends 39% or less of the school day in the "regular" classroom with peers who do not have special needs. Instruction in the self-contained classroom is provided to a small class by a special education teacher.

A resource classroom is one in which the child spends 40-79% of the school day in the "regular" classroom with peers who do not have special needs. Special services are provided in both the regular classroom and the special education classroom as a "pull-out" depending on the parameters of the IEP.

A mainstreamed classroom is when a child is educated in the regular classroom in the same manner and with the same requirements as peers who do not have special needs. Inclusion, on the other hand, is when a child is educated in the regular classroom and support services are provided within this setting. Assignments in the regular classroom are adapted to fit the child's individual needs.

In the state of Arizona, your child's school district of residence is responsible for providing special education services for your child. There are special education preschools available throughout the state. The Arizona Department of Education has a searchable database of schools by name, city, county, zip code, county, or district number.

Arizona Department of Education/Find A School

www.azed.gov/edd

800-352-4558

Another option for children who are deaf or hard of hearing is to attend preschool at the Arizona State Schools for the Deaf and the Blind (ASDB). The Arizona School for the Deaf (ASD) is in Tucson, and the Phoenix Day School for the Deaf (PDS) is in Phoenix, with five satellite sites located from Queen Creek to Avondale. Both of these schools support a philosophy that includes the acquisition of both American Sign Language (ASL) and English. The preschool classrooms typically have 4-6 children with a certified Teacher of the Deaf and an Instructional Assistant. Speech therapy, occupational therapy, audiology, and physical and vision therapy (if needed) are provided on these campuses. Attendance at the Arizona State Schools for the Deaf and Blind is funded through the child's local school district, and transportation to and from their campus will also be provided without cost to the family if specified in the IEP. ASDB also has Regional Cooperatives, a voluntary partnership between public education agencies in northern Arizona and ASDB, to provide services within the local school setting. A list of the Cooperatives and member districts in Arizona by region can be found on their website, under (programs).

Arizona State Schools for the Deaf and Blind (ASDB)

www.asdb.az.gov

520-770-3863 Tucson; 602-771-5300 Phoenix

A child might also be educated in a private school, such as the Desert Voices Pre-School Program. This Phoenix-based private, not-for-profit school's mission is to teach children who deaf or hard of hearing the oral language skills needed to speak and understand when others speak to them. The preschool is a certified Moog Center, which prepares students to enter a mainstreamed classroom setting when they are ready, and with the age appropriate speech and language skills at the academic level of their peers. The preschool program at Desert Voices is a full day program for children ages 3 to approximately first grade.

Desert Voices Pre-School Program

www.desert-voices.org

602-224-0598

Another option is for the child to attend preschool at a public charter school. Although not an option for preschool students, the Sequoia School for the Deaf and Hard of Hearing is a public charter school located in Mesa, Arizona that serves students beginning in kindergarten. At Sequoia, students master both American Sign Language (ASL) and English so that they might succeed in both the hearing and deaf worlds.

Sequoia School for the Deaf and Hard of Hearing

www.sequoiadeafschool.org

480-890-4001

Special educational accommodations and modifications for children with special needs at any of these schools must be agreed upon by the IEP team, and listed in the IEP. Some of these accommodations can be found in the IEP checklist that follows:

THE IEP CHECKLIST:

RECOMMENDED ACCOMMODATIONS AND MODIFICATIONS FOR STUDENTS WITH HEARING LOSS

Name: _____ Date: _____

Amplification Options

- Personal hearing device (hearing aid, cochlear implant, tactile device).
- Personal FM system (hearing aid + FM).
- FM system/auditory trainer (without personal hearing aid).
- Walkman-style FM system.
- Sound-field FM system.

Assistive Devices

- TDD.
- TV captioned.
- Other.

Communication Accommodations

- Specialized seating arrangements:

- Obtain student's attention prior to speaking.
- Reduce auditory distractions (background noise).
- Reduce visual distractions.
- Enhance speechreading conditions (avoid hands in front of face, mustaches well-trimmed, no gum chewing).
- Present information in simple structured, sequential manner.
- Clearly enunciate speech. Allow extra time for processing information.
- Repeat or rephrase information when necessary.
- Frequently check for understanding.
- Educational interpreter (ASL, signed English, cued speech, oral).

Physical Environment Accommodations

- Noise reduction (carpet & other sound absorption materials).
- Specialized lighting.
- Room design modifications.
- Flashing fire alarm.

Instructional Accommodations

- Use of visual supplements (overheads, chalkboard, charts, vocabulary lists, lecture outlines).
- Captioning or scripts for television, videos, movies, filmstrips.
- Buddy system for notes, extra explanations/directions.
- Check for understanding of information.
- Down time / break from listening.
- Extra time to complete assignments.
- Step-by-step directions.
- Tutor.
- Note taker.

Curricular Modifications

- Modify reading assignments (shorten length, adapt or eliminate phonics assignments).
- Modify written assignments (shorten length, adjust evaluation criteria).
- Pre-tutor vocabulary.
- Provide supplemental materials to reinforce concepts.
- Provide extra practice .
- Alternative curriculum.

Evaluation Modifications

- Reduce quantity of tests.
- Use alternative tests.
- Provide reading assistance with tests.
- Allow extra time.
- Other modifications: _____

Other Needs? Considerations.

- Supplemental instruction (speech, language, pragmatic skills, auditory, speechreading skills).
- Counseling.
- Sign language instruction.
- Vocational services.
- Family supports.
- Deaf/Hard of Hearing role models.
- Recreational/Social opportunities.
- Financial assistance.
- Transition services.

Source: Johnson, Benson, & Seaton. (1997). *Educational Audiology Handbook*. Appendix 11-A, p.448. Singular publishing Group, Inc.

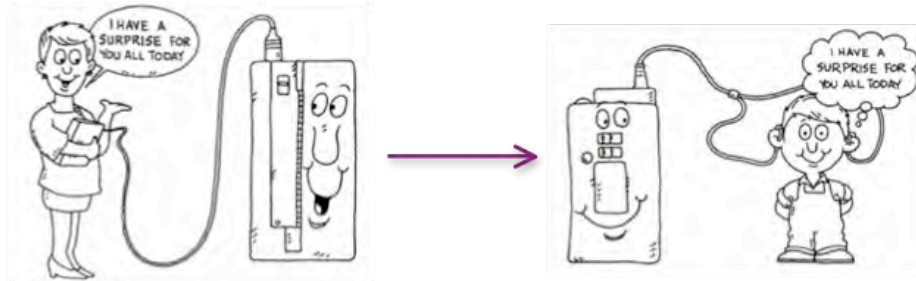
Although today's advanced hearing aids can improve the quality, audibility, and clarity of the speech signal, they cannot remove all obstacles to speech understanding. FM devices are an effective way to improve speech understanding in difficult listening situations. FM systems can be used with or without hearing aids to make hearing easier—reducing stress and fatigue.

What is an FM system?

FM systems work in tandem with the child's hearing aids by adding a special, remote microphone that can be placed much closer to the speaker. An FM system transmits sounds via radio waves, just like a miniature radio station. They operate on special radio frequencies assigned by the Federal Communications Commission (FCC). An FM device transmits the speech signal directly to the ear, thereby limiting the influence from noise, distance, or reverberation. Simply put, in poor listening conditions, FM systems can improve the *quality* of the sound reaching the student.

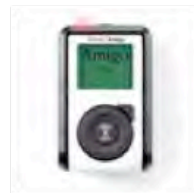
The teacher wears a small microphone and FM transmitter.

The student wears an FM receiver that is usually connected directly to their hearing aids, or the receiver can be an independent device. The FM transmitter relays the signal from the teacher's microphone directly to the FM receiver via radio signal.



There are a number of different makes and models of FM systems with different features and controls. The FM transmitters and receivers are small enough to allow for mobility for both the teacher and the student, and the FM system can be connected to devices such as television, radio, or CD player.

Transmitters:



Receivers:



- A. Classroom sound field receiver**
- B. Personal/portable sound field receiver**
- C. Direct Audio Input** (connected by a lead directly to the hearing aid via an audio shoe)
- D. Integrated FM receiver** (FM receiver built into the hearing aid)
- E. iSense®** (Specifically designed for children who experience speech comprehension problems, especially in noisy environments (e.g. children with auditory processing disorder))

References:

1. FM Systems: What Are They and What Do They Do? Australian Hearing Website. http://www.hearing.com.au/digitalAssets/4715_1173929641136_FM%20systems.pdf
2. Oticon USA Website: <http://www.oticonusa.com/Oticon/Consumers/Pediatrics/Amigo.html>
3. Phonak USA Website: http://www.phonak.com/us/b2c/en/products/fm/what_is_fm.html

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There are other services not listed on the previous checklist that might be necessary for a child with hearing loss to succeed in school. Some of these are listed below.

- Audiology- A child with a hearing impairment will need someone working at, or in conjunction with, the school district to meet any needs the child might have with hearing testing, assessment of classroom acoustics, and monitoring of hearing and/or assistive listening devices.
- Teacher of the Hearing Impaired- Many school districts have in-house teachers who work with children who are deaf or hard of hearing in their schools, or they contract for their services with Co-Ops such as the Arizona State Schools for the Deaf and Blind. These teachers can also help to teach other educators working with your child about his or her learning needs.
- Speech therapists- These professionals are trained to provide language and communication support for children who have hearing impairments.
- Educational Interpreter/Translator- This person could be a sign language interpreter who interprets spoken language into ASL for a child who uses sign language, or a language facilitator who facilitates communication between a child with hearing loss and others in the educational setting. Parents must make a clear case that their child will not be able to follow what is being communicated in the classroom without this resource in order for it to be included in an IEP. Although sign language interpreters who work in Arizona classrooms are exempt from needing to be licensed, state law does require minimum qualifications. See the Arizona Administrative Code, Title 7, Education, Chapter 2 State Board of Education, Article 6, Certification R7-2-620 which specifies the requirements for Professional, Non-teaching School Personnel. However, parents can request a Licensed/Certified Interpreter. You can also find an interpreter in Arizona who is a member of the Registry of Interpreters of the Deaf (RID), a national membership organization representing professionals who facilitate communication between people who are deaf or hard of hearing and people who can hear, by searching their website.

You can directly access the Standard Practice Paper for K-12 Educational Interpreting at:

[www.rid.org/UserFiles/File/pdfs/Standard Practice Papers/K-12 Ed SPP.pdf](http://www.rid.org/UserFiles/File/pdfs/Standard%20Practice%20Papers/K-12%20Ed%20SPP.pdf)

Registry of Interpreters of the Deaf

www.rid.org/content/index.cfm/AID/131

703-838-0030

Classroominterpreting.org was developed with funding from the U.S. Department of Education, Office of Special Education Programs and is maintained by Boys Town National Research Hospital. The website offers resources and information pertaining to classroom interpreting to administrators, teachers, parents, students, and interpreters.

Classroom Interpreting

www.classroominterpreting.org

402-452-5039

- Transportation- A child with special needs can be provided with free transportation to and from the school he or she attends if documented in the IEP.
- Training or Counseling for Parents- An IEP can also specify that the parent of a child with special needs be given training or counseling that will help their child benefit from his or her education. This can include, for example, instruction in sign language. This training or counseling is listed on the IEP under “Related Services.”

Classroom teachers vary on their experience and comfort levels in working with children who are deaf or hard of hearing. Some teachers are extremely knowledgeable about how to work with these children. Others are adaptable and willing to learn. Yet others have no experience and may be uncomfortable with this new role.

HELPING STUDENTS WITH HEARING LOSS IN THE CLASSROOM

The following list was created to give suggestions to classroom teachers in how they might maximize the learning experiences for students in their classroom who are deaf or hard of hearing.

- Teach your child to be their own advocate when it comes to telling the teacher if they can hear and/or understand what they need to in the classroom. Develop a hand signal—such as pointing to their ear—that can be used to tell the teacher if they missed something or would like the teacher to repeat information.
- Tell your child’s teacher that having the child repeat instructions to make sure s/he understands what was said is much more effective than simply asking the child if s/he can hear or understand.
- If an educational interpreter or translator is present in the classroom, instruct the teacher to speak directly to the child with hearing loss, rather than communicating with the interpreter.
- If hearing devices are worn by the child, have the child be in charge of his or her own equipment. Students can be taught to change their own hearing aid batteries (it is advisable to always have extra batteries on hand), charge their FM system, and remind the teacher when to use and turn off the FM system.
- If the child utilizes an FM system, request that the teacher take the time to understand all the functions of the FM system before the school year begins. The school audiologist or teacher of the deaf can help with this learning process, or the teacher could watch an FM system simulation (such as those that can be found on YouTube. See www.youtube.com/watch?v=1l37lzLIgQU).
- Encourage the teacher to use visual aids to assist in the learning process (such as overheads, charts, outlines, etc.)
- Ask the teacher to seat a child with hearing loss close to the teacher, although it is preferable that they also have children seated in front of them so that they might watch those children and pick up on signals from them as well.

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- Advise the teacher to obtain the child's attention prior to speaking to and/or giving the child directions.
- Encourage the teacher to reduce distractions or background noise as much as possible. Simple things like closing the classroom door and adding carpet or tennis balls to the legs of chairs can help a child who uses a hearing device tremendously.
- Some teachers may not realize that simply talking louder does not always help a student with hearing loss as much as speaking more clearly and precisely. Ask the teacher to make the effort to enunciate properly and/or rephrase statements for the child if needed.
- Encourage the teacher to maintain eye contact when speaking, as a student with hearing loss may depend on lip reading or facial cues to understand spoken language. This is especially important when the child uses an educational interpreter or translator. The child must be able to see both the teacher and the interpreter at all times.
- Teach the teacher (and possibly the entire class) some sign language for enhanced communication options. Show the teacher and class some signs that you use at home and many of these signs can be used for all students in the classroom (ie. yes/no, help, thank you).
- Consider having your child talk to the class about his or her hearing loss. Students typically respond well if they understand why an interpreter is needed or why a child needs to have hearing aids or a cochlear implant. Most children with hearing loss would rather this be discussed directly with the class rather than having to explain things to children who ask questions individually and/or make assumptions that might not be helpful.
- Ask the teacher to assign your child a buddy to assist him or her with tasks that might be overwhelming to a child with hearing loss, such as riding a bus before or after school, and during an activity that prohibits the use of hearing devices (such as water play).

ADDITIONAL RESOURCES FOR STUDENTS WITH SPECIAL NEEDS

There are several additional resources available for parents who need assistance, advice, or clarification on policies related to students with special needs. For example, if parents think that their child's school district needs to be supported and/or more educated about how to address the needs of their child, the parent could suggest that the district's Special Education Director make a request for SUPPORT Cadre Services. The SUPPORT Cadre offers experienced professionals who provide technical assistance to special education personnel when they lack the infrastructure to support their staff. Requests for SUPPORT Cadre Services can only be made by the Special Education Director by completing a Request for Service form and submitting it by fax to 602-364-1115. More information is available by calling 602-542-4831.

If a parent feels that the rights of a student with special needs are being violated, there are organizations to consult for help, both in and outside the state of Arizona. The Arizona Center for Disability Law advocates for the legal rights of people with disabilities to be free from abuse, neglect and discrimination and to gain access to services, maximizing independence and achieving equality. Their website contains a wealth of information on disability law and offers self-advocacy materials, trainings, and newsletters.

Arizona Center for Disability Law

www.acdl.com

520-327-9547 Tucson; 602-274-6287 Phoenix

Parents can also learn more about special education law and how to advocate for their child on the Wrightslaw website. This site was created for giving information about special education law, education law, and advocacy for children with disabilities. It includes both advocacy and law libraries on a wide range of special education topics, as well as the Wrightslaw Yellow Pages for Kids, a listing by state of educational consultants, advocates, health care specialists, academic tutors, educators, and attorneys.

Wrightslaw

www.wrightslaw.com

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The Council for Exceptional Children is an international professional organization dedicated to improving the educational success of individuals with disabilities. It advocates for appropriate governmental policies and for individuals with exceptionalities. There is a lot of information on their website, but much of it is restricted to their members.

Council for Exceptional Children: International

www.ccc.sped.org

888-232-7733

There are also a few national centers that provide information and technical assistance on issues related to children with disabilities. The National Dissemination Center for Children with Disabilities provides information, programs, services, and research-based information on effective practices for children with disabilities. This center also has a state specific link for locating organizations and agencies within your state that address disability-related issues.

National Dissemination Center for Children with Disabilities

www.nichcy.org

800-695-0285

More specific to children from birth to five years of age, the National Early Childhood Technical Assistance Center's mission is to strengthen service systems to ensure that all young children with disabilities and their families receive and benefit from high quality, culturally appropriate, and family-centered supports and services. This center is supported by the U.S. Department of Education's Office of Special Education Programs (OSEP) and their website gives contact information for agencies and responsible parties.

Early Childhood Technical Assistance Center

www.ectacenter.org

919-962-2001

Alphabetical List of Resources

Advanced Bionics Corporation, www.advancedbionics.com (877-829-0026)- Site of one of the three most popular cochlear implant suppliers in the United States.

Alexander Graham Bell Association for the Deaf and Hard of Hearing, www.agbell.org (202-337-5220)- One of the largest membership organizations and information centers that help families, individuals, health care providers, and educational professionals understand hearing loss and the importance of early diagnosis and intervention. Its mission is to advocate independence for people with hearing loss through listening and talking. There are 31 U.S. state membership chapters and the former company, Auditory-Verbal International, joined this association in 2005. Membership has an annual fee and benefits include a bimonthly magazine, a peer-reviewed scholarly journal (The Volta Review), a national convention, and educational opportunities.

American Academy of Audiology, www.audiology.org, (800-222-2336)- The world's largest organization of, by, and for audiologists with an active membership of more than 10,000. Their mission is to promote quality hearing and balance care by advancing the profession of audiology.

American Academy of Otolaryngology-Head and Neck Surgery, www.ent.org (703-836-4444)- The world's largest organization representing specialists who treat the ear, nose, throat, and related structures of the head and neck. Although the website is primarily aimed at ENTs, there is a section for parents that gives health information on hearing-related topics.

American Society for Deaf Children, www.deafchildren.org (800-942-2732)- Founded in 1967 as a parent-helping-parent network, this is now a national, independent non-profit organization dedicated to supporting and educating families of deaf and hard of hearing children and advocates for high quality programs and services. The society believes deaf children should be fluent in both sign language and English for optimal social and academic success. This is a paid membership organization and benefits include networking, representation, access to articles and a lending library.

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Arizona Association of the Deaf, www.azadinc.org- Organized and operated exclusively to promote the welfare of deaf and hard of hearing residents of the state of Arizona in education, economic, security, social equity, and just rights and privileges as citizens. Their website contains legislative information, a newsletter, as well as links to Arizona activities including the Arizona Deaf Festival.

Arizona Blind Deaf Children's Foundation, www.azblinddeafchildren.org (520-577-3700)- This organization began as a foundation to support programs at the Arizona Schools for the Deaf and Blind. It is now committed to ensuring that all children who are blind, deaf, or hard of hearing in Arizona have access to experiential learning in key areas that encompass and expand upon traditional education including art, fitness, and literacy. The foundation works to assess the needs of these children, bring together related agencies, and serve as an information source and funding source for grants that support the needs of children who are deaf or hard of hearing in Arizona.

Arizona Center for Disability Law, www.acdl.com (520-327-9547 Tucson; 602-274-6287 Phoenix)- This organization advocates for the legal rights of people with disabilities to be free from abuse, neglect and discrimination and to gain access to services, maximizing independence and achieving equality. The website contains a wealth of information on disability law and offers self-advocacy materials, trainings, and a newsletter.

Arizona Commission for the Deaf and the Hard of Hearing, ACDHH, www.acdhh.org (602-542-3323)- This organization serves as an Arizona statewide information referral center for issues related to people with hearing loss and strives to ensure, in partnership with the public and private sector, accessibility for the deaf and hard of hearing to improve their quality of life. Services include a telecommunications relay service, telecommunications equipment distribution program (AzTEDP), ASL interpreter licensure, outreach and education. Their website includes a searchable resource directory with information on many topics related to deafness and hearing loss, a section with Frequently Asked Questions (FAQ's) and a list of upcoming events.

Arizona Department of Education Exceptional Student Services, www.ade.az.gov/ess (602-542-4013)- The ADE Exceptional Student services department's mission is to promote the development and implementation of quality education for students with disabilities. Listed on

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the website is the contact information for the included departments, as well as a searchable database of reports and resources on many topics pertaining to special education.

Arizona Department of Education Exceptional Student Services Parent Education Network, www.ade.az.gov/special-education/deputy-associate-superintendent/parent-information-network (877-230-7467)- This website contains a list of Parent Information Network Specialists (PINS) who provide on-site and phone consultation, training, resources, and information to support parents of special education students. All services are free of charge. Their website also contains a list of downloadable resources, such as sample letters for requests for evaluation and records, and information on subjects related to special education, such as IEPs and assistive technology.

Arizona Department of Education/Find A School, www.azed.gov/edd (800-352-4558)- This site provides a searchable database of schools by name, city, county, zip code, county or district code number.

Arizona Department of Health Services Office for Children with Special Care Needs, www.azdhs.gov/phs/ocshcn (602-542-1860)- This is Arizona's Title V Program for children and youth with special health care needs, and is an office within the Bureau of Women's and Children's Health. This program works to improve systems of care, provide information and referrals to families needing assistance in finding services available for their child, and provide advocacy to maximize existing benefits. The website contains links to many programs and services available to children with special health care needs and their families.

Arizona Department of Health Services Office of Newborn Screening, www.aznewborn.com (602-364-1409)- This website provides information about the newborn screening program, including specific information about the hearing portion of the screening.

Arizona Early Intervention Program, (AzEIP), www.azdes.gov/azeip (888-439-5609)- Arizona's statewide, interagency system of supports and services for infants and toddlers with developmental delays or disabilities and their families. The website contains information on the AzEIP policies and procedures, referral processes, eligibility and family cost participation, and an online referral system.

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Arizona Hands & Voices, www.azhv.org (866-685-1050)- This is the state chapter for the national Hands & Voices organization. On the website, you can view upcoming events in our state, see a list of the AZHV board of directors, read family stories from our members, get links to resources, and register to join the organization.

Arizona State Schools for the Deaf and the Blind, www.asdb.az.gov (520-770-3863 Tucson; 1-602-771-5300 Phoenix)- ASDB is committed to excellence in education of all children and youth with hearing and vision loss throughout Arizona. It houses two schools for children with hearing loss from ages 3-22: Arizona School for the Deaf (ASD) in Tucson, and the Phoenix Day School for the Deaf (PDS) in Phoenix. These schools support a philosophy that includes the acquisition of both American Sign Language (ASL) and English. ASDB also has regional cooperatives (co-ops), a voluntary partnership between public education agencies in northern Arizona and ASDB. A list of co-ops and member districts in Arizona by region can be found on this website.

Arizona State University Department of Speech and Hearing Sciences, www.shs.asu.edu (480-965-2374)- The ASU Speech and Hearing Clinics provide high quality professional services to individuals of all ages with needs in communication and hearing improvement. The Speech Clinic offers a child-directed early literacy program in the summer and training opportunities for children through the public schools and at the Infant Child Research Program. (See <http://icrp.asu.edu> for more information on this program).

AZ Find, www.azed.gov/special-education/az-find (800-352-4558)- This is the Child Find Agency for the State of Arizona charged with providing the necessary information and resources to educate parents, public education agencies, state agencies, and professional organizations so that effective policy, procedures and practices for identifying, locating, and evaluating children with disabilities aged birth to 21 are developed and implemented. Their website contains links and resources for parents of children at different ages.

Beginnings for Parents of Children Who are Deaf or Hard of Hearing Inc., www.ncbegin.org (919-715-4092)- This non-profit agency provides an impartial approach to meeting the diverse needs of families with children who are deaf or hard of hearing and the professionals who serve them. The agency was created to provide a central resource for the state of North Carolina, and services are free to parents in that state. Their website includes

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information for all families and professionals covering a range of topics such as early intervention, communication options, and school issues.

Better Hearing Institute, www.betterhearing.org (202-449-1100)- This not-for-profit corporation educates the public about hearing. Their website provides a wealth of information on hearing loss (including a special section for children and information for parents) and treatments, as well as a list of hearing loss resources.

Centers for Disease Control and Prevention, www.cdc.gov (800-232-4636)- One of the major operating components of the Department of Health and Human Services, the CDC's mission is to create the expertise, information and tools that people need to protect their health. Issues related to hearing loss in children can be found in the A-Z index. Included in their website is a wealth of information, articles, materials and data and statistics about hearing loss.

Classroom Interpreting, www.classroominterpreting.org (402-452-5039)- This site was developed with funding from the U.S. Department of Education, Office of Special Education Programs and is maintained by Boys Town National Research Hospital. The website offers resources and information pertaining to classroom interpreting to administrators, teachers, parents, students, and interpreters.

Cochlear Corporation, www.cochlearamericas.com (800-523-5798)- One of the three most popular cochlear implant suppliers in the United States.

Council for Exceptional Children: International, www.cec.sped.org (888-232-7733)- A professional organization dedicated to improve the educational success of individuals with disabilities and/or gifts and talents. The organization advocates for appropriate governmental policies for individuals with special needs. There is a wealth of information available on their website, but most is available only to members.

Deafness Research Foundation, www.drf.org (866-454-3924)- This organization is the largest source of private funding for basic and clinical research in hearing and balance science. This organization publishes a magazine, called Hearing Health, a free consumer resource for hearing loss, technology, and research. Their website features a dictionary of hearing conditions and a glossary of associated medical terms.

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Described and Captioned Media Program, www.dcmp.org (800-237-6213)- Funded by the U.S. Department of Education and administered by the National Association of the Deaf (NAD), this program is dedicated to promoting and providing equal access to communication through described and captioned educational media. The program offers free-loan media to those who are deaf, blind, hard of hearing and/or visually impaired.

Desert Voices School, www.desert-voices.org (602-224-0598)- This Phoenix based private, not-for-profit school's mission is to teach deaf and hard of hearing children spoken language. The school is a certified Moog Center, seeking to prepare these children for entering a traditional school setting with age appropriate speech and language skills and at the academic level of their hearing peers. Their Early Intervention Program serves children from 4 weeks to 3 years of age, and the pre-school and elementary program is a full day program for children ages 3 to approximately first grade.

Ear Foundation of Arizona, www.earfoundationaz.com (602-685-1050)- This organization provides services to people who are deaf, have a hearing loss, or those who have a balance impairment. The Ear Foundation sponsors several programs for those who are deaf/HH and for the detection of hearing loss. "Hear for Kids" is a program for children 0-18 years of age in Arizona. This program provides loaner hearing aids and permanent aids for families without insurance or in financial need.

Early Childhood Technical Assistance Center, www.ectacenter.org (919-962-2001)- The national Early Childhood Technical Assistance Center is supported by the U.S. Department of Education's Office of Special Education Programs (OSEP). Their mission is to strengthen service systems to ensure that children with disabilities (birth through 5 years) and their families receive and benefit from high quality, culturally appropriate and family-centered programs and services. This is a technical assistance center, and thus the information available on the website is primarily information regarding laws and mandates with agency contact information.

Hands & Voices, www.handsandvoices.org (303-492-6284)- This international non-profit organization is dedicated to support families and their children who are deaf or hard of hearing, as well as the professionals who serve them. This parent-driven, parent and professional collaborative group is unbiased towards communication modes and methods. Chapters exist or are in the start-up process in 37 U.S. states. The Guide By Your Side (GBYS) program provides

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emotional support and unbiased information from trained parent guides to other families. An alphabetical list of topics for communication considerations, with information and additional resources listed for each, is available on their website. Members also receive a quarterly newsletter, *The Communicator*.

House Research Institute, www.hei.org (800-388-8612)- The House Research Institute is a non-profit organization dedicated to improving the quality of life for people with hearing loss and related disorders through scientific research, patient care, and the sharing of knowledge. The institute works closely with the House Clinic physicians to directly benefit patients. The House Research Institute's Children's Auditory Research and Evaluation (CARE) Center is devoted to improving the communication ability of infants and children with auditory disorders. The center provides a comprehensive evaluation of a child's hearing abilities to determine appropriate treatments and make recommendations for long-term care. Their website also includes a section with educational resources for parents.

John Tracy Clinic, www.jtc.org (213-748-5481)- This organization provides worldwide parent-centered services to young children five years old and under with a hearing loss without cost. Founded by parents of a child with a profound hearing loss, they have devoted their time and energy to studying how deaf children could be taught to communicate with the hearing and speaking world. The organization provides online educational courses for parents, international onsite summer sessions for families, and professional education. Their website also features pages with common concerns, an "Ask the expert" section, and chatterbox sections with information of interest to families.

Laurent Clerc National Deaf Education Center, www.gallaudet.edu/clerc_center.html (202-651-5855)- Mandated by Congress in the Education of the Deaf Act (EDA), this organization provides information, training, and technical assistance for parents and personnel throughout the nation to meet the needs of children who are deaf or hard of hearing with a broad spectrum of needs. Their mission is to improve the quality of education afforded to the population of students from birth to age 21 throughout the United States and maintains two demonstration schools for elementary and secondary students. Their website contains a resources section with "Info to go," a centralized source of information related to deaf and hard of hearing children formally

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known as the National Deaf Education Network Clearinghouse. They also provide training and technical assistance, publications, and cochlear implant education.

Listen and Talk, www.listentalk.org (206-985-6646)- A therapy center with a staff in the community of western Washington. Their website includes a section called “Voices of Listen and Talk” which features several videos of children with various degrees of hearing loss.

Med-EL Corporation, www.medel.com (919-572-2222)- One of the three most popular cochlear implant suppliers in the United States.

My Baby’s Hearing, www.babyhearing.org (402-498-6511)- An organization developed by a team of professionals at Boys Town National Research Hospital. Their website is divided into two sections: “First Steps” for newborn screening, and “Next Steps” for when the baby has been diagnosed with a hearing loss. Articles and information are provided in both areas. The “Next Steps” portion offers a nice section pertaining to developing language and learning with children with hearing loss and also has a “parent to parent” section in which you can hear the views of parents with children who are deaf/HH.

National Association of the Deaf, www.nad.org (301-587-1788)- A national civil rights organization of, by, and for deaf and hard of hearing individuals in the United States. They support the right of the American deaf community to use sign language. Their website includes extensive information on law and advocacy.

National Center for Hearing Assessment and Management, www.infanthearing.org (435-797-3584)- This organization serves as the national resource center for the implementation and improvement of comprehensive and effective Early Hearing Detection and Intervention (EDHI) Services. Their goal is to ensure that all infants and toddlers with hearing loss are identified early and provided with timely and appropriate audiological, educational, and medical intervention. Their website provides links to information about the EDHI programs in every U.S. state and territory as well as other resources related to early detection and intervention.

National Cued Speech Association, www.cuedspeech.org (800-459-3529)- This organization supports effective communication, language development, and literacy through the use of Cued Speech. The organization is primarily an advocacy organization, focusing on outreach, family

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and education support, and community-based education. They also provide certification for cued speech classes, instructors and translators.

National Dissemination Center for Children with Disabilities, www.nichcy.org (800-695-0285)- This center serves the nation as a single source of information on disabilities in children and youth (birth to age 22). The center offers information on the policies of the Individuals with Disabilities Education Act (IDEA) and No Child Left Behind (NCLB). There is also a link to research-based information on effective educational practices for children with disabilities. The website gives helpful information on early intervention, basic steps in special education, and IEPs for all children with special needs. In addition, the website has a state specific link to locate local organizations and agencies that address disability-related issues.

National Institute on Deafness and Other Communication Disorders, www.nidcd.nih.gov (301-496-7243)- This organization is one of the institutes that comprise the National Institutes of Health (NIH), which is the federal government's focal point for the support of biomedical research. NIDCD is mandated to conduct and support biomedical and behavioral research and training in hearing, balance, smell, taste, voice, speech and language. Their website has a section on health information that includes hearing, ear infections, deafness, voice, speech and language.

Northern Arizona Deaf Expo, www.nazdeafconnection.com- This is an annual event held in Flagstaff, Arizona for anyone interested in learning more about services available for individuals who are deaf or hard of hearing and their families. The expo features exhibits, interpreter and family workshops, and opportunities to practice and advance sign language skills.

Northern Arizona University Department of Communication Sciences and Disorders, www.csd.nau.edu (928-523-2969)- The NAU Speech and Hearing Clinic provides a full range of speech, language, and hearing services for individuals of all ages. The clinic also offers specific services for children with language disorders.

Oral Deaf Education, www.oraldeafed.org- This organization is devoted to the promotion of oral deaf education as a collaborative, family-centered educational approach to develop a child's speech and listening abilities along with confidence and life skills needed to meet the challenges of a greater world. Their website provides a list of oral deaf education schools, videos

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highlighting children who have been educated in this manner, and downloadable materials for parents, educators, and professionals.

Pilot Parents of Southern Arizona, www.pilotparents.org (520-324-3150)- This program was created by a small group of interested parents and professionals to serve southern Arizona. The group is committed to providing encouragement and support to families who have children with special needs. Services include peer-to-peer support, a parent training and information center, and a library of books and videos addressing issues related to disabilities. The website lists the programs and services available, one of which is assistance with (and sometimes attendance at) a child's IEP meeting.

Purple Communication, www.purple.us (877-885-3172)- This company provides video relay services by placing calls between a user who signs to an ASL interpreter. The interpreter then contacts the telephone user and voices the message back to them.

Raising Deaf Kids, www.raisingdeafkids.org (215-590-7440)- This is a website created by the Deafness and Family Communication Center at the Children's Hospital of Philadelphia. Their goal is to provide a wealth of information and resources on hearing loss, and help parents make better decisions for their child. The website is divided into information about children with hearing loss from infancy to teenage years, as well as featured topics such as growing up with hearing loss, learning, and communicating. It also includes a section of parent talk with a range of issues pertaining to hearing loss and communication choices.

Raising Special Kids, www.raisingpecialkids.org (800-237-3007)- This is a non-profit organization of families helping families of children with disabilities and special health needs in Arizona, through parent-to-parent programs, special education information, and community outreach. The organization is Arizona's Parent Training and Information Center (PTI) authorized under the Individuals with Disabilities Education Act (IDEA) to provide assistance in special education to families and schools. The site contains information on special education and a list of workshops and training programs available online or at their facility in the Phoenix area.

Registry of Interpreters of the Deaf, www.rid.org (703-838-0030)- This is a national membership organization representing the professionals who facilitate communication between

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people who are deaf or hard of hearing and people who can hear. Their website allows a user to locate a registered interpreter by searching by city and/or state.

Rochester Institute of Technology Center for Education Research and Partnerships, www.rit.edu/ntid/educatingdeafchildren (585-475-2411)- This website was created to serve as a source of factual information for parents, teachers, and others interested in the raising and educating of children who are deaf/HH. Questions are posed on the site and answered by members of CERT, members of the Editorial Board of the Journal of Deaf Studies and Deaf Education, or international experts.

Sequoia School for the Deaf and Hard of Hearing, www.sequoiadeafschool.org (480-890-4001)- Sequoia is a public charter school located in Mesa, Arizona that serves students from kindergarten to 12th grade. Students master both American Sign Language (ASL) and English to succeed in both the hearing and deaf worlds.

Sign2Me, <http://sign2me.com> (425-493-1903)- This website is designed to promote ASL tools for early literacy. They offer baby sign language products for purchase and courses taught, using only true-to-ASL signs.

Signing Exact English Center, www.seecenter.org (562-430-1467)- A non-profit organization established to work with parents and educators of hearing impaired children and promote understanding of principles of Signing Exact English (SEE) and its use. The website includes a message board forum for people to connect with others in the SEE community.

Signing Savvy, www.signingsavvy.com- An online sign language resource for educators, students, or anyone interested in American Sign Language. This site provides tools to enhance sign language education and assist with day-to-day sign language communication needs. The website offers free basic features and paid access to premium member features.

Sorenson Video Relay Service, www.sorensonvrs.com (866-756-6729)- This company provides video relay services by placing calls between a user who signs to an ASL interpreter. The interpreter then contacts the telephone user and voices the message back to them.

United Healthcare- Arizona Children's Rehabilitative Services, (CRS),

www.uhcommunityplan.com/az/medicaid/childrens-rehabilitative-services.html (800-348-4058)- This organization provides family-centered medical treatment, rehabilitation, and related support services for children under the age of 21 with qualifying chronic and disabling conditions, who are enrolled in the Arizona Health Care Cost Containment System (AHCCS). Members can get care and services in a clinic-like setting or from participating doctors in their office practice. AHCCS has contracted with United Healthcare Community Plan to administer the CRS Program.

University of Arizona Department of Speech, Language, and Hearing Sciences,

www.slhs.arizona.edu (520-621-1644)- The University of Arizona hearing clinics provide evaluation and rehabilitative audiological and communication disorder services to infants and children through the Grunewald-Blitz Clinic for Communication Disorders in Children. The clinic provides specialized programming for children with cochlear implants, and a summer camp for children using speech generating devices and services through the Child Language Center, also known as Wings on Words. (See <http://clctucson.org/services/wings-on-words-program> for more information about this program).

Wrightslaw, www.wrightslaw.com- A website created for issues related to special education law, education law, and advocacy for children with disabilities. The organization provides advocacy and law libraries with articles, cases, and resources about topics including No Child Left Behind, IDEA 2004, and a wide range of special education topics. Their website also includes the Wrightslaw Yellow Pages for Kids, a state listing of educational consultants, advocates, health care specialists, academic tutors, attorneys, and FetaWeb, the companion site to their published special education survival guide.

ZVRS, www.zvrs.com (727-254-5600)- This company provides video relay services by placing calls between a user who signs to an ASL interpreter. The interpreter then contacts the telephone user and voices the message back to them.

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