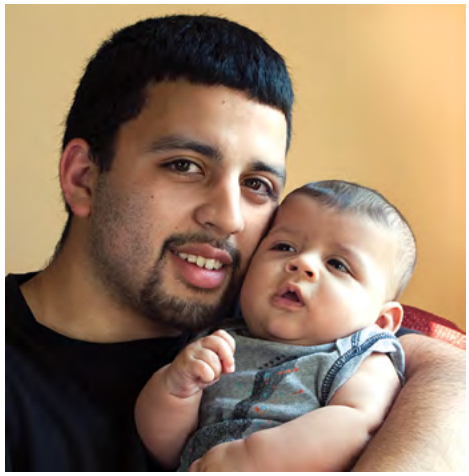

RESOURCE NOTEBOOK

for Families of Children Who are Deaf or Hard of Hearing

Resource Notebook for Families of Children Who are Deaf or Hard of Hearing

This publication was developed by the Washington State Department of Health's Early Hearing-loss Detection, Diagnosis and Intervention (EHDDI) Program.

You can view and download this notebook online at:
www.doh.wa.gov/earlyhearingloss

For additional copies, contact the EHDDI program at:

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For persons with disabilities this document is available on request in other formats. To submit a request, please call 1-800-525-0127 (TTY/TDD 711).

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Introduction

Dear Family,

You have just learned that your child is deaf or hard of hearing. We have prepared this notebook as a resource for your family, since you likely have many questions about what to expect and who can help you on this journey. In this notebook you will find information about hearing, communication options and resources available to you.

I hope this information helps you feel confident about finding resources and advocating for your child. Many families find that taking this notebook to their child's appointments makes it easy for them to keep their resources and appointments organized. Please personalize this book as much as you like—it was made especially for you and your family.

Some of the information in this book may be helpful now and some of it will be helpful later. Please use the Table of Contents to find the information that will help you the most. If you have questions about topics covered in this guide, please ask someone in your early support team.

Your child has an exciting future ahead and being deaf or hard of hearing is just one part of that journey. I hope this resource helps you get started and I wish you all the best.

Sincerely,

Janna Bardi, MPH
Assistant Secretary, Prevention & Community Health
Washington State Department of Health

Getting Started

Feelings About Your Child Being Deaf or Hard of Hearing

Learning that your child is deaf or hard of hearing may have confirmed what you already suspected or it may have been a surprise. Families react to this news in different ways. Know that whatever your reaction, it is normal. Please remember that you are not alone.

You will have many important decisions to make about your child's care and this might feel overwhelming. Keep in mind that parents make decisions based on the information they have at that time and what works best for their child and family. As your child develops and grows and your family gathers new information, your plans can change to meet your family's needs or in response to new information.

This notebook provides resources from organizations that have experience working with families like yours (see Resources section). These organizations will happily help you address current and future concerns. We have also included stories from families from Washington State. We hope you find their words helpful.

Much of what we "say" shows through nonverbal communication, such as facial expressions and body language.

What Can You Do Right Now?

The first few weeks and months after learning your child is deaf or hard of hearing can be a busy and overwhelming time. Here are some ideas to help you:

Interact and communicate with your child

Start communicating with your baby now. Much of what we "say" shows through nonverbal communication, such as facial expressions and body language. Bonding between a baby and family happens naturally through close face-to-face interactions, playing and communicating during daily routines. Your baby can learn how to read your face and body, even if she can't fully hear your spoken words.

Babies learn from things you do and say in everyday life. Communicate with your child as you do daily tasks such as changing a diaper, giving a bath, or feeding a meal. Your child will also learn when you sing songs, do finger plays, and play games like peek-a-boo, pat-a-cake, and so-big.

On the next page are some early communication ideas to try with your child.

Things to Try	Examples of What to Do
Use a natural voice when speaking to your child. Talk and sing to your child. Make eye contact with your baby.	While rocking or cuddling your baby, sing lullabies and tell him how much you love him. Make sure your baby can see your face when you're talking.
Use facial expressions that match your words and actions.	While playing peek-a-boo, say "Peek-A-Boo!" with a surprised, happy look on your face. Say, "Do you need your diaper changed?" with a questioning look on your face. Include signs and facial expressions during the diaper routine.
Use sign language or gestures and hand movements while speaking.	When saying, "Let's go change your diaper," point to the child's diaper. Wave your hand or your baby's hand when saying, "Hello" or "Goodbye."
Explain when it's time to do something.	Say, "It's time for a nap. Let's go take a nap."
Make lots of eye contact and use touch, hugs and kisses to help your baby learn how to interact with you and your family.	Look at your baby's face and say/sign "I Love You." Then, give lots of hugs and kisses. Guide your child's hand as she gently pets your family dog. At the same time, look your baby in the face and say, "Gentle" or "Nice doggy." Your baby will learn how it feels to pet the dog gently.
Watch and listen for your child to sign or say words and respond to them.	If your child is making an "M" sound, respond by saying, "Mmmm… Milk!" and pointing to your child's bottle/cup or signing "milk". If your child makes the sign for milk, repeat the sign while saying "Milk" and pointing to your child's cup or bottle. Signing Savvy (www.signingsavvy.com) is a great online resource that has videos to help you learn some common signs.
Respond to your child's facial expressions. *This may also be a good time to help your child learn the word or sign for his feelings too.*	Say, "You look like you're having fun!" with a big smile and the sign for fun. Say, "Uh oh. You look sad." with a sad face and the sign for sad.
Have fun together and play with toys to support communication and vocabulary development.	Give your baby words for difference concepts like big and small. Talk about and point to what your baby is looking at. Sign or say things again and again. Repetition is very important.
Make a scrapbook of your baby's favorite people and things.	Talk and sign about the pictures that interest your baby. Be expressive. Make eye contact with your child then look at the book together and make eye contact again. Pause long enough for your child to respond to encourage turn-taking. Respond to your baby's gestures and vocalizations as a conversation.

Contact the Family Resources Coordinator (FRC) for your county

An FRC is a very valuable resource who can help with everything from getting connected in your community to financing hearing aids or transitioning to school. Learn how to contact your FRC in the Resources section of this guide.

People who are close to you can be a great support.

Keep a journal or notebook for your child

We have included some writing topics (below) and a goal setting worksheet in the Staying Organized section to help you get started. Journal writing ideas include:

- Sounds that your child responds to or makes—as your child grows, this may help you see how far she has come!
- Questions or concerns that you have.
- Your feelings and experiences during this process.
- Hopes, dreams and thoughts about the future.

Stay organized

You can use this notebook to help you stay organized. In the Staying Organized section we include a checklist of steps to consider (Care Plan for Infants who are Deaf or Hard of Hearing). This section also has pages where you can write down important information. We encourage you to bring this notebook with you to appointments and when you visit with your early support team.

Seek support from family and friends

People who are close to you can be a great support. Invite the support people in your child's life to participate in visits to the audiologist, early intervention meetings and parent groups.

Start learning about communication options for your child

There are many different communication options for children who are deaf or hard of hearing and their families. The Communication Options section of this book has information on some of the options.

Your Child's Hearing

This section may help answer questions about your child's hearing and what your child's hearing loss means.

Approximately 33 babies are born with hearing loss in the United States every day.

Parts of the Ear

There are three parts to the ear—the outer ear, the middle ear and the inner ear. Each of the three main parts has several smaller parts:

Outer ear

- The part we see (pinna or auricle)
- Ear canal

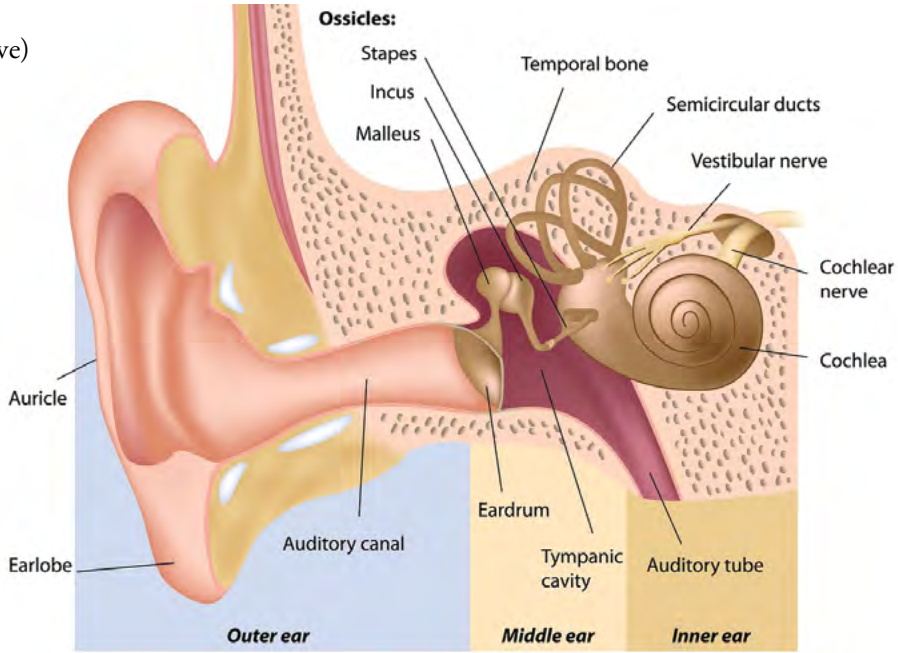
Middle ear

- Eardrum
- Three tiny bones (ossicles):
  - Hammer (malleus)
  - Anvil (incus)
  - Stirrup (stapes)
- Auditory tube (Eustachian tube)

Inner ear

- Parts that help with balance (vestibular system including semicircular ducts)
- Balance nerve (vestibular nerve)
- Hearing organ (cochlea)
- Hearing nerve (cochlear nerve)

Anatomy of the Ear



How Does My Child Hear Sound?

- Sound comes into the ear and travels down the ear canal to the eardrum (tympanic membrane). This is where it reaches the middle ear.
- The sound causes the eardrum to vibrate, which causes the three middle ear bones (ossicles) to move.
- The movement of the middle ear bones causes pressure changes in the fluid of the inner ear or cochlea.
- These pressure changes cause a structure in the inner ear (basilar membrane) to stimulate hair cells in the cochlea.
- The movement of the cochlear hair cells sends the signal through the hearing (auditory) nerve to the brain.

MED-EL and Siemens have helpful videos on YouTube that show how hearing works:
https://www.youtube.com/watch?v=flIAxGsV1q0
https://www.youtube.com/watch?v=0NJ_EAQjR3c

About Hearing Loss

Hearing loss is more common than many people think. Approximately 33 babies are born with hearing loss in the United States every day. The American Academy of Pediatrics (AAP) recommends that all babies have a hearing screen before leaving the hospital or before one month of age. For babies found to be deaf or hard of hearing at birth, the AAP recommends starting early intervention services by six months of age to ensure that language will develop at the same rate as those children who are not deaf or hard of hearing.

What is hearing loss?

Hearing loss is a reduced ability to detect sounds. A hearing loss can be described in various ways, including by its type and degree.

You may hear different terms used for people who are deaf or hard of hearing. The appropriate term to use depends on how the person identifies himself, rather than a specific degree of hearing loss.

- **deaf**, when spelled with a little or lower case **d**, means "audiologically deaf." This term is used to describe a severe to profound degree of hearing loss. This term is often used when a child cannot hear speech sounds.
- **Deaf**, spelled with a capital or upper case **D**, is used to identify a member of the Deaf community who is "culturally Deaf." The Deaf community is a diverse group of people who share a language, a common heritage and similar experiences. Members of the Deaf community primarily use sign language to communicate. A person can have any degree of hearing loss to be a member of the Deaf community. Hearing people who know sign and/or work with individuals who are deaf or hard of hearing can take part in the Deaf community as allies (for example, family members, ASL interpreters, children or siblings of those who are deaf or hard of hearing or deaf education professionals).

- **hard of hearing** is used if a child has a mild to severe degree of hearing loss.
- **hearing impaired** is a term that is considered to be negative by the Deaf community. Deaf or hard of hearing are the preferred words to describe an individual with a hearing loss.

Types of hearing loss

Your child's type of hearing loss depends on where it occurs in the ear. The three main types are conductive, sensorineural or mixed.

Conductive means the decreased hearing level is due to issues with the outer or middle parts of the ear. Often something in the middle or outer ear blocks the sound from passing through the structures. Medicine or surgery can sometimes improve hearing with this type of hearing loss.

Sensorineural means the decreased hearing level is due to issues with the inner ear (cochlea) or the hearing (auditory) nerve. Often this type of hearing loss is permanent. Medicine or surgery are usually unable to improve hearing levels with this type of hearing loss. Hearing aids or cochlear implants are often helpful.

Mixed means the decreased hearing level is due to issues with both the outer or middle ear and the inner ear. Medicine, surgery or hearing aids can sometimes help this type.

Your child's decreased hearing levels may affect one ear or both ears.

- **Unilateral** means hearing loss in one ear.
- **Bilateral** means hearing loss in both ears.

Degrees of hearing

Your child's hearing level is measured in degrees. There are six degrees of hearing loss. Degrees of hearing loss are measured in decibels (dB). Decibels refer to the intensity or loudness of the sound. The larger the number is, the louder the sound.

Slight decrease in hearing level:	Sounds softer than 16–25 dB are not heard, for example, leaves rustling
Mild decrease in hearing level:	Sounds softer than 26–40 dB are not heard, for example, a dripping faucet
Moderate decrease in hearing level:	Sounds softer than 41–55 dB are not heard, for example, a clock ticking
Moderately severe decrease in hearing level:	Sounds softer than 56–70 dB are not heard, for example, a dishwasher
Severe decrease in hearing level:	Sounds softer than 71–90 dB are not heard, for example, a dog bark
Profound decrease in hearing level:	Sounds softer than 91 dB are not heard, for example, a lawnmower

Your child's hearing may not fall into just one of these categories. For instance, his hearing level could be called mild to moderate or severe to profound. The table on the next page shows how different degrees of hearing levels can affect your child's spoken language. With hearing levels up to moderately severe your child is likely to be able to hear your voice but may not hear all the sounds in your words. This can make it hard to learn words and also say certain sounds.

Keep in mind that the same hearing level can affect children in different ways and hearing technology (hearing aids, cochlear implants, FM systems) can help many children access sound and spoken language. Also, many people use sign language or "baby sign" to help early communication with their babies, regardless of their hearing level. Learning to sign does not mean your child will not learn how to talk. Starkey Hearing Technologies has a hearing level simulator you can use to understand how things might sound to someone who is deaf or hard of hearing: www.starkey.com/hearing-loss-simulator.

Table showing how decreased hearing levels can affect spoken language.

Degree of Hearing Level	What It Means	Without Amplification and Early Intervention	With Amplification and Early Intervention*
Slight	The softest sounds a child hears are at levels of 16 dB – 25 dB. Softer sounds than these are not detected.	• Very soft sounds like leaves rustling in the wind or whispering and some very soft speech sounds may not be heard. • A child may have trouble hearing very distant speech and hearing in a noisy environment.	• Most children can recognize and understand soft sounds of speech and the world around them. • Most children will not use hearing aids but may need special accommodations or other technology, especially in school, to compensate for the challenges that distance and background noise present.
Mild	The softest sounds a child hears are at levels of 26 dB – 40 dB. Softer sounds than these are not detected.	• Soft sounds such as a faucet dripping, birds chirping and some speech sounds may not be heard. • Sounds that are moderately loud to a person without hearing loss (such as speech) will be soft. • A child will have trouble hearing faint or distant speech and may have trouble hearing in a noisy environment.	• Most children can recognize and understand soft sounds of speech and the world around them.
Moderate	The softest sounds a child hears are at levels of 41 dB – 55 dB. Softer sounds than these are not detected.	• Most speech sounds and louder sounds such as a clock ticking or a vacuum cleaner may not be heard. • Sounds that are loud to a person without hearing loss will be soft. • Speech can only be understood if it is loud. • A child may have limitations in vocabulary, language comprehension, and language usage. • A child may have errors in her speech.	• Most children can recognize and understand soft sounds of speech and the world around them. • Most children develop age-appropriate vocabulary, language comprehension and language usage. • Most children learn to monitor their own speech production and to speak clearly. • Most children will need support, for example with FM systems, in noisy environments in order to succeed.

continued

* Some children may not meet these expectations, especially if they have medically complex issues or have other developmental delays.

Degree of Hearing Level	What It Means	Without Amplification and Early Intervention	With Amplification and Early Intervention*
Moderately Severe	The softest sounds a child hears are at levels of 56 dB – 70 dB. Softer sounds than these are not detected.	• Most speech sounds and louder sounds such as a dishwasher may not be heard. • Speech may only be heard if it is loud and close to child. • Most children will not develop speech and language on their own. • Most children will have poor speech.	• Most children can detect and understand most sounds. • Most children can learn to understand and use spoken conversation. • Most children will need help in school, for example FM systems, due to difficulties hearing in noisy places or hearing sounds that are far away.
Severe	The softest sounds a child hears are at levels of 71 dB – 90 dB. Softer sounds than these are not detected.	• Most speech sounds will not be understood and other loud sounds such as a phone ringing or a dog barking may be missed. • Sounds that are very loud to a person without hearing loss will be very soft. • Speech will only be heard if it is shouted in the ear. • Spoken language comprehension and speech will not develop spontaneously. • A child with severe hearing loss will have mostly unintelligible speech.	• The majority of children can detect and understand most sounds. • Most children can learn to understand and use spoken conversation, even though they will not hear speech the way people without hearing loss do. • Most children will need special accommodations, for example FM systems in school, to compensate for the challenges that distance and background noise present.

continued

* Some children may not meet these expectations, especially if they have medically complex issues or have other developmental delays.

Degree of Hearing Level	What It Means	Without Amplification and Early Intervention	With Amplification and Early Intervention*
Profound or Severe-Profound	• The softest sounds a child hears are at levels of 91 dB or more. Softer sounds than these are not detected. • A child with a profound or severe-profound hearing loss may be called deaf. • Your child may be a candidate for cochlear implants. Ask your audiologist.	• Very loud sounds, such as an airplane flying overhead or a lawnmower, will not be detected. • A child will rely on vision rather than hearing for primary communication. • A child will have unintelligible speech.	• Most children will need special accommodations, for example FM systems in school, to compensate for the challenges that distance and background noise present. • Children can develop age-appropriate language comprehension and language usage. • With appropriate fitted technology and early intervention, most children can learn to understand and use spoken conversation, even though they will not hear speech and language the way people without hearing loss do. **With Hearing Aids Only:** • Many children use visual communication to assist them in understanding spoken conversation. • Many children can detect moderately loud sounds and spoken conversation under ideal listening conditions (no background noise and facing the speaker). **With Cochlear Implants:** • Most children can detect sounds within the "mild hearing loss" range (see Mild in this table). • Most children can develop the ability to use listening and spoken language to communicate. • To learn more about cochlear implants, see our Communication Options section or talk to your child's audiologist.

* Some children may not meet these expectations, especially if they have medically complex issues or have other developmental delays.

Questions You May Have About Your Child's Hearing

What percentage of hearing does my child have?

Hearing is difficult to describe in terms of percentage. Instead, you will hear it defined in terms of the type, degree and configuration of hearing loss. If someone refers to your child's hearing as a percentage, talk to your audiologist for a better description.

Will my child's hearing get better or worse?

This is difficult to determine. If your child has a conductive loss, it can sometimes get better. If your child has a sensorineural hearing loss, it will probably not get better. Some hearing losses can get worse over time. These are called "progressive hearing losses." Checking your child's hearing on a regular basis helps to make sure that any change in hearing is known and that he is getting appropriate amplification. Your audiologist or Ear, Nose, and Throat (ENT) doctor may be able to give you more information about the chances of your child's hearing getting worse over time.

What caused my child to be deaf or hard of hearing?

Although over 50 percent of infants who are born deaf or hard of hearing have no known risk factor for hearing loss, there are some common risk factors:

- Family history of childhood hearing loss.
- A genetic cause, even if there isn't a family history.
- A syndrome that is known to affect hearing.
- Craniofacial abnormalities, such as a cleft lip or palate, ear pits or ear tags.
- Infections during pregnancy with CMV (cytomegalovirus), toxoplasmosis, herpes, rubella or syphilis.
- Admission to a neonatal intensive care unit for more than five days.
- Bacterial meningitis.
- Certain medications used to treat cancer or severe infections.
- Repeat ear infections.

These are just some of the most common risk factors that can affect hearing. Your audiologist or doctor can give you more information about other risk factors and causes of hearing loss.

Early Intervention and Your Support Team

Early Intervention

You may have already begun talking to your audiologist and early support team about services that are available for your child. Washington State has many programs to help children who are deaf or hard of hearing. Two important terms are defined below: early intervention and IFSP. You might hear these terms when talking to people about services for your child.

Early intervention programs are special programs designed to support your child's learning and development.

What is early intervention?

Early intervention programs are for children ages birth to three and their families. These are special programs designed to support your child's learning and development and will teach you how to help your child develop and learn. These programs provide specialists trained in working with children who are deaf or hard of hearing.

- When you enroll in an early intervention program, you will be assigned an early intervention specialist who works with you and your child.
- You may also have the option to participate in play groups and parent meetings.
- You may live in a community that has one or more programs from which to choose. Often programs have different strategies and ideas about how to communicate with children who are deaf or hard of hearing (see Communication Options section).
- You may be able to receive services from early intervention specialists outside your community through telehealth or virtual services.

What is an IFSP?

An Individualized Family Service Plan, or IFSP, helps a family build a plan of programs and services to meet the needs of their child and their family. The IFSP team will work with you to identify your child's specific needs and then build a plan to ensure she receives the services necessary to reaching her goals.

The IFSP team is usually made up of family members, professionals (therapists, social workers, developmental specialists or other specialists), and others who are involved in the child's life (caregivers or close friends/relatives).

Your early support team will help you explore options.

To learn more about making an IFSP, contact your Family Resources Coordinator (FRC). Learn how to contact your FRC in the Resources section.

How do we prepare for transition to preschool?

Making the transition from early intervention to preschool services can be an emotional process simply because your baby is growing up so quickly. As your child gets closer to age three, your FRC and your early intervention provider will help you make a transition plan for moving into the next chapter of your child's education and preschool.

A transition plan will lay out steps that help the team decide if your child needs to attend a special education or community-based program. You can find more information about transitioning to preschool in our Advocacy section.

Early Support Team

You will meet many professionals and other people who can help you and your child. Your early support team will help you explore your options, find qualified specialists, and discover the combination of tools and approaches that work best for your child and family. This section briefly describes who may be a part of your family's team and how each of them can help.

Doctors and Medical Providers

Pediatrician or Family Practitioner

- Refers you to an audiologist who works with infants and young children.
- Answers questions you may have about medical treatment.
- Helps you access early intervention services.
- Treats your child or refers to ear specialists for middle ear problems, such as ear infections, that can affect your child's hearing.

Audiologist (pediatric audiologists specialize in working with infants and young children)

- Has the proper education, training and equipment to test and evaluate hearing.
- Obtains detailed information about your child's hearing.
- Recommends and fits assistive technology (hearing aids, FM systems, cochlear implants) if appropriate.
- Works with you and your team to assess how well your child responds to sounds at home.
- Provides information about early intervention options for your family.
- Works with your family and team to adjust and maintain your child's amplification, if appropriate.

Otologist, Otolaryngologist or Ear, Nose, and Throat (ENT)

- Checks your child's outer and middle ear in case there is a medical cause for your child's hearing loss.
- Explains and talks with you about possible medical or surgical treatments for hearing loss, including cochlear implants.
- Diagnoses and treats ear infections and other medical problems that can affect your child's hearing.
- Gives approval or "medical clearance" for your child to wear hearing aids.
- Schedules other tests to find out more about the cause of your child's hearing loss.

Medical Geneticist/Genetic Counselor

- Reviews possible genetic causes for your child's hearing loss to help make sure there are no other underlying health concerns (for example, kidney or heart problems).
- Counsels families about the implications of a genetic hearing loss.
- Discusses options for genetic testing.

Specialists and Counselors

Family Resources Coordinator (FRC)

- Helps your family access services for your child from birth to three years of age.
- Assists you in finding resources to pay for services.
- Provides information about your rights as a parent or guardian.

Center for Childhood Deafness and Hearing Loss (CDHL) Consultant

- Helps the FRC find family-centered services locally available for your child that support your family's goals.
- Provides expertise in language and early communication development if a deaf or hard of hearing program is not available in your community.
- Makes sure that your child is included in the CDHL registry. The CDHL and Office of Superintendent of Public Instruction (OSPI) use this registry to help determine where services are needed to best support children who are deaf and hard of hearing and their families.

Early Intervention Specialist

- May be a teacher of the deaf, audiologist or speech-language pathologist.
- Works with you and your child (birth to three years of age) to provide support in the communication approach your family has chosen.
- Provides you and your child with individualized and family-centered services that will help your child learn communication and language skills.
- Helps assess your child's and family's strengths and needs.
- Talks with you about your observations and concerns about your child.
- Keeps records of your child's progress in communication and development.
- Gives you opportunities to meet with other adults and children who are deaf or hard of hearing.
- Helps define your child's educational needs when your child transitions to preschool.

Teacher of the Deaf

- Has special certification to teach children who are deaf or hard of hearing.
- Works with your family to help you understand your child's hearing and the potential impact hearing loss can have on language, social and cognitive development.
- Helps you learn to observe and monitor your child's responses to communication (through listening, vision, vocalizing and signing and/or gesturing).
- Gives you information about your child's amplification equipment (e.g., hearing aids, ear molds, batteries) and possible future amplification options (e.g., cochlear implants).

Children with Special Health Care Needs (CSHCN) Coordinator

For children ages birth to 18:

- Helps you with accessing services and service providers.
- Helps you coordinate services and resources in your community.
- Authorizes hearing aids for children covered by Medicaid.

Aural Rehabilitation Specialist

- Develops your child's listening skills to help your child learn speech and language.
- May be an audiologist or speech-language pathologist and can be a teacher of the deaf with specialized training.

Speech Language Pathologist

- Provides speech and language therapy to help make your child's speech more understandable.
- Evaluates your child's speech and language skills.

American Sign Language (ASL) Specialist

- Helps you and your family learn ASL.
- Recommends specific services to support language acquisition.
- Has credentials in ASL instruction, assessment and advocacy.

Counselor/Therapist

- Gives emotional support for your child and family.
- Helps you or your family work through difficult emotions about your child's hearing loss.

All children must have a way to communicate their needs and wants.

Social Network

Other Families of Deaf and Hard of Hearing Children

- Share experiences they have had.
- Tell you about helpful people and resources they have found.
- Listen to you.
- Share their feelings about parenting a child with hearing loss.
- Tell you about their child's achievements.
- Meet with you so your children can play together.

Deaf and Hard of Hearing Adults

- Share information about the Deaf community and cultural perspectives.
- Share personal experiences about being deaf or hard of hearing.
- Act as a language model for your child and family.
- Connect you to other deaf adults who use other methods of communication.
- Act as a role model for your child.
- Provide encouragement for your family in meeting challenges and raising a successful child.

Children Who Are Deaf/Hard of Hearing Plus

Many children who are deaf or hard of hearing have other needs affecting their development. The term "deaf/hard of hearing plus" refers to children who have a hearing loss in addition to other conditions. Your child might have spent time in the Neonatal Intensive Care Unit (NICU), been diagnosed with a syndrome or cerebral palsy, or become deaf or hard of hearing because of an illness or accident. If this is the case, you are not alone. As many as 40 to 60 percent of all children who are deaf or hard of hearing have additional special needs.

You may be wondering where to start. What's most important?

Your early support team can help you sort out what areas of need your child might have. They can help you determine whether he might benefit from services such as physical or occupational therapy, services of a teacher of the visually impaired, or nutrition consultation. Only you and your family can answer the question of what's most important at this point in time.

Keep in mind: All children must have a way to communicate their needs and wants. If your child is deaf or hard of hearing, regardless of what additional disabilities or medical issues he may have, make sure that your early support team includes a specialist who can help you address communication and language.

How do I know if my child has other developmental issues?

Certain factors raise a child's risk for physical, vision, motor or intellectual disabilities. This does not mean that your child **will** have these issues, but it does mean that your early support team should take a closer look to rule out other challenges (see chart on next page).

Other factors that can happen in early childhood may cause hearing loss, visual impairment or other disabilities. These include:

- Asphyxia (for example, from near-drowning)
- Direct trauma (to the eye and/or ear)
- Encephalitis
- Severe head injury (for example, from a car crash or fall)
- Stroke
- Tumors

Risk factors for hearing loss and other issues

Common Risk Factors for Hearing Loss	Is There a Risk Factor for Other Issues?	Take a Closer Look
Family history of childhood hearing loss.	Possibly. If there is a family history of visual impairment as well, make sure to monitor your child's vision.	"InfantSee" provides free vision screenings for children age 6–12 months. To find a participating doctor, go to: www.infantsee.org Seek a genetic evaluation.
Syndrome known to have hearing loss.	Many syndromes known to be associated with hearing loss are also associated with vision impairment.	If your child has any of these syndromes, have a specialist check her vision as well: • CHARGE • Cornelia de Lange • Dandy Walker • Down • Goldenhar • Norrie • Pfeiffer • Refsum • Usher • Wolf-Hirschhorn (Note: This is only a partial listing.) Seek a genetic evaluation.
Craniofacial abnormalities, such as a cleft lip or palate, ear pits or ear tags.	Some craniofacial abnormalities can cause visual impairment as well.	Ask your primary care provider to check your child's vision.
Infections of the mother during pregnancy, such as cytomegalovirus (CMV), toxoplasmosis, herpes, rubella and syphilis.	These infections can cause visual impairment as well as other disabilities.	Your early support team will assess all developmental areas. **Also**, ask for a consultation by a Teacher of the Visually Impaired to screen your child's vision.
Admission to a neonatal intensive care unit for more than five days.	Yes, especially if your child was born prematurely or weighed less than $5^1/_2$ lbs.	Your early support team will assess all developmental areas. **Also**, ask for a consultation by a Teacher of the Visually Impaired to screen your child's vision.
Bacterial meningitis	Yes, for some children who have a severe case.	Your early support team will assess all developmental areas. **Also**, ask for a consultation by a Teacher of the Visually Impaired to screen your child's vision.

My child is deaf or hard of hearing and has one of the risk factors above. What should I do?

Make use of your early support system, via your Family Resources Coordinator, to ensure that your baby gets all of the screenings, assessments and services that he might need.

If your child has a visual impairment in addition to hearing loss, or you are concerned about that possibility, contact Washington Sensory Disabilities Services (WSDS) to ask for help:

Phone: 1-800-572-7000
Email: wsds@psesd.org
Web: www.wsdsonline.org

Hearing Tests for Your Child

There are many ways to test your child's hearing. The kind of test your child has depends on your child's needs and abilities.

Your child's hearing may be tested using air conduction, bone conduction or both. Using both air conduction and bone conduction helps the audiologist determine the location of your child's hearing loss.

> **Air conduction** tests the entire auditory system—including the outer ear, middle ear, inner ear—and the brain. Your child hears sounds through earphones or speakers.
>
> **Bone conduction** is where sound vibrations travel through the skull to the inner ear and to the brain. It bypasses the outer ear and middle ear and only tests the inner ear to the brain. Sounds are presented to your child with a small vibrator (bone oscillator) that is placed on the bone behind the ear.

Objective hearing tests are done while your child is sleeping or resting quietly.

Objective Hearing Tests

Objective hearing tests are done while your child is sleeping or resting quietly. They don't require your child to respond to sound. There are three main kinds of objective tests: BAER, EOAE and tympanometry.

BAER Test (pronounced "bear")

This test measures how well your child's hearing nerve responds to sound.

BAER stands for Brainstem Auditory Evoked Response. You may also see this test called ABR (Auditory Brainstem Response) or BER (Brainstem Evoked Response).

It is used for infants and young children who are too young to respond to sounds by turning their heads. It may also be used for older children who cannot do behavioral hearing tests. Sometimes a BAER test can confirm results of a behavioral hearing test.

During a BAER test:

- Your child must be asleep. If your child is tested before six months of age, the test is done while she sleeps naturally. Children over six months of age usually fall asleep with a mild sedative prescribed by a doctor.

- Your child's skin is cleaned and sensors are put on her forehead and behind each ear.
- Sounds are played into each ear through a soft foam or rubber earphone.
- A computer records the response of your child's hearing nerve.
- Your child's audiologist looks for the softest sound your child's hearing nerve responds to.

EOAE Test

This test measures how well your child's cochlea—or inner ear—works.

EOAE stands for Evoked Otoacoustic Emissions. You may also see this test called OAE (Otoacoustic Emission), TEOAE (Transient Evoked OAE), or DPOAE (Distortion Product OAE).

It is usually done during the same visit as a BAER test. Your child needs to be still and very quiet for this test.

During an EOAE test:

- A soft foam or rubber earphone is placed in each of your child's ears.
- Sounds play through the earphones.
- A computer measures the response of your child's inner ear to the level of the hearing organ or cochlea.
- The audiologist evaluates the response.

Tympanometry Test

This test helps the audiologist find out how well your child's middle ear is working.

During a tympanometry test:

- The audiologist puts a rubber tip in your child's ear.
- The tip is connected to a machine that changes the air pressure in your child's ear canal. The machine prints out a graph.
- The graph gives information about whether the eardrum is moving well. If the eardrum is not moving well, it could mean that fluid is present in the middle ear space which can temporarily affect hearing.

Behavioral Hearing Tests

Behavioral hearing tests require your child to respond to sound. Your child will respond by turning his head, playing a simple game or raising his hand.

Your child must be at least 6–7 months developmental age to do a behavioral hearing test. He needs to be able to sit up by himself and have good head control.

There are five main kinds of behavioral tests for infants and children:

- Visual Reinforcement Audiometry
- Conditioned Play Audiometry

- Speech Awareness Threshold
- Speech Reception Threshold
- Speech Recognition

There are five main kinds of behavioral tests for infants and children.

Visual Reinforcement Audiometry (VRA)

- This test happens in a soundproof room called a sound booth. The test requires your child to turn her head in response to sounds.
- Your child sits on your lap in the middle of the room.
- A helper sits in front of you and your child. The helper keeps your child's attention forward by using toys.
- On each side of your child are darkened boxes. These boxes contain toys that the audiologist can light up when your child responds to sounds.
- Your child will hear sounds through a speaker or earphones.
- The audiologist teaches your child to turn her head toward the sound she hears by reinforcing her response with the toys in the light boxes.
- The audiologist finds the softest sounds to which your child responds.

Conditioned Play Audiometry (CPA)

- Conditioned play audiometry is usually used for children who are three years and older.
- Your child will sit on your lap or a chair in a soundproof room called a sound booth.
- Your child will hear sounds through a speaker or earphones.
- The audiologist will teach your child to play a simple game, such as putting a block in a bucket or a peg in a board each time he hears the sound.
- The audiologist will find the softest sounds to which your child responds.

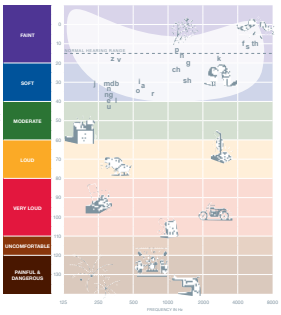
Speech Awareness Threshold (SAT)

- This test measures your child's awareness to speech.
- It is helpful because some very young children respond to speech before they respond to tones used to test hearing.
- The audiologist will present speech sounds to your child through a speaker or earphones.
- The audiologist will find the softest level of speech to which your child responds.

Speech Reception Threshold (SRT)

- This test measures your child's ability to recognize words.
- Your child must know the names of some common objects to be able to do this test.
- The audiologist will present words to your child through a speaker or earphones.
- The audiologist will ask your child to repeat the words she hears or to point to pictures of the objects.

Image courtesy of MED-EL Corporation
www.medel.com



- The audiologist will find the softest level at which your child can recognize the words.

Speech Recognition

- This test measures your child's ability to recognize speech in words with and without hearing technology.
- The audiologist will present a list of words through a speaker or earphones.
- Your child will point to pictures of the word presented.

Understanding Your Child's Audiogram

An audiogram is a graph of the softest sounds your child hears. Your child's audiogram can answer these questions:

- Is the hearing the same in both ears or is it different?
- How much hearing loss does your child have? (degree of hearing loss)
- Is there more hearing loss in some frequencies (pitches) than others?
- Is there a difference in air conduction and bone conduction hearing? (air-bone gap)

Your audiologist will be able to explain your child's audiogram in full detail, but below are a few tips that will help you understand the graph.

Across the top of the graph are the frequencies, or pitches.

- The frequencies are organized like a piano keyboard. The low tones are on the left and the high tones are on the right.
- An example of a low pitch is a drum and an example of a high pitch is a bird chirp.
- These pitches or frequencies are measured in Hertz (Hz).

Down the side of the graph is the intensity, or loudness of sounds.

- The sounds at the top of the graph are soft.
- The sounds at the bottom of the graph are loud.
- Loudness is measured in decibels (dB).

The marks on your child's audiogram represent the softest sounds your child responded to during the hearing test.

If your child wore earphones during the test, you will find blue X's and red O's on the graph.

X = left ear
O = right ear

If your child didn't wear earphones during the test, you will find S's on the audiogram.

S means your child was tested using speakers.
When using speakers, only your child's better-hearing ear is tested.

You may also see these symbols:

< and > means your child was tested using bone conduction.
A means your child was tested with hearing aids.

The audiogram on the next page shows pictures that represent what sounds might be heard at different frequencies or pitches and at different intensities or loudness. If you put your child's hearing test results on this audiogram, you can see what sounds he can and cannot hear.

- The purple/blue shaded area in the Faint and Soft ranges is called the "speech banana."
- The speech banana shows where the different sounds of speech fall on the audiogram.
- Even a mild hearing loss may affect your child's ability to learn speech and language.

Even a mild hearing loss may affect your child's ability to learn speech and language.

Configuration of your child's hearing loss

Your child's hearing loss will most likely not look like a straight line. Your child's hearing will vary at different pitches. Some examples of typical hearing losses include:

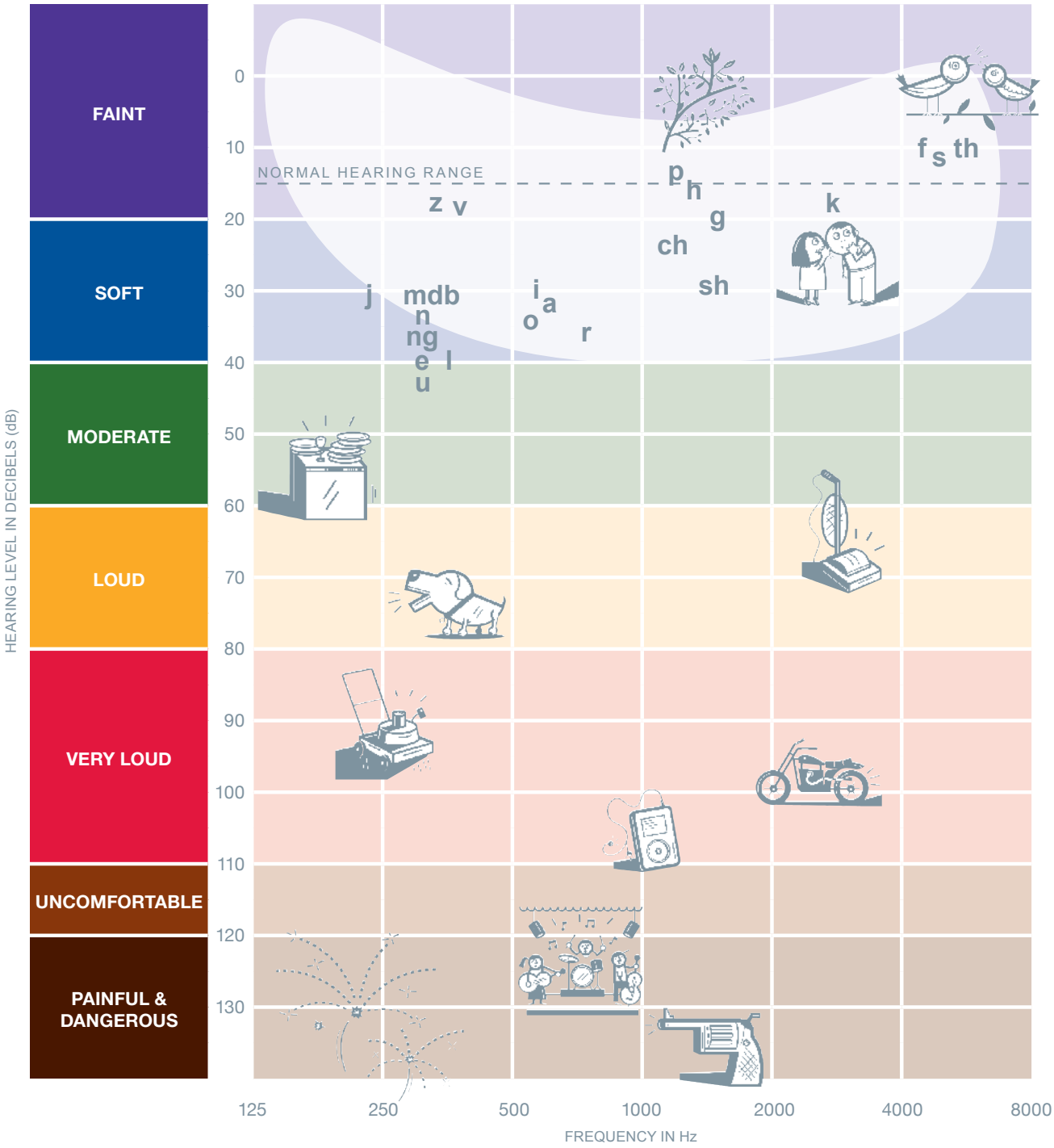
Sloping hearing loss:
Your child's hearing is better in lower frequencies.

Reverse sloping or rising hearing loss:
Your child's hearing is better in higher frequencies.

Precipitously sloping hearing loss (steep and rapid slope):
Your child's hearing drops off dramatically in high frequencies.

Cookie bite:
Your child hears better in the lower and higher frequencies, and worse in mid frequencies.

AUDIOGRAM OF FAMILIAR SOUNDS



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WWW.AUDIOLOGY.ORG | WWW.HOWSYOURHEARING.ORG

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Questions You May Have About Your Child's Hearing Tests

How do I know the diagnosis is correct?

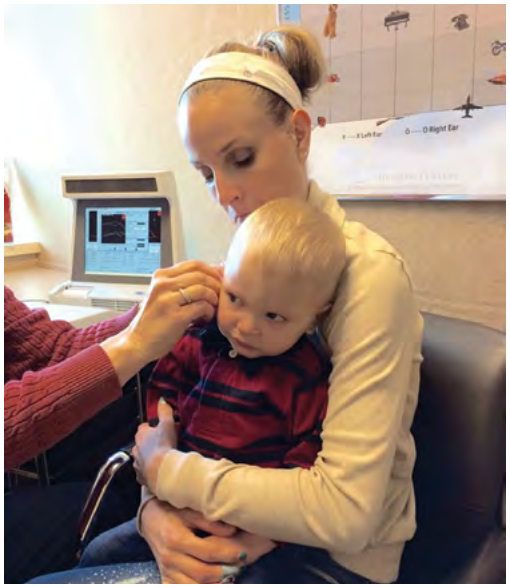
Newborn hearing screening allows us to find infants who are deaf or hard of hearing at a very young age. It is very difficult to tell how well a very young child is hearing just by watching. At such a young age, your child cannot simply tell you what she does or doesn't hear clearly. It would be helpful if she could!

The hearing tests used to identify hearing loss are very accurate. It may take more than one visit with an audiologist to determine if your child is deaf or hard of hearing. If your child has a hearing loss, she will also have more hearing tests in the future. These tests will provide more information about your child's hearing. If you are concerned that your child has not had an accurate or complete hearing evaluation or if a second opinion would make you feel more comfortable about the diagnosis, make an appointment with another pediatric audiologist.

The EHDDI program has a list of pediatric audiology clinics on its website: http://www.doh.wa.gov/infantaudiology. These audiologists specialize in testing and treating infants and young children with hearing loss. All the audiologists indicated as "Level 1 Clinics" on this list meet the Washington State Best Practice Guidelines for the Diagnostic Audiological Assessment of Infants. If you would like information about audiology clinics outside Washington State, EHDI-PALS has an online directory that will let you search for audiology clinics nationwide: www.ehdipals.org

How often will my child's hearing be tested?

Your audiologist will decide how frequently your child needs his hearing tested. These tests will make sure that his hearing has not changed. Your child may also have hearing tests while wearing his hearing aids.



Communicating with Your Child

Communicating with your child is important. Responding to your child and encouraging her to respond to you is the key to your child's language development. There are many ways for children who are deaf or hard of hearing and their families to communicate. Your family may have many different opinions and discovering what works best for your family may take time. We hope this section gives you the information you need to begin learning about options for communicating with your child.

As your child's needs change, it is okay to make different decisions later on.

The communication options you choose should provide your child with full access to communication. It should also use the primary language spoken in your home (such as English, Spanish, American Sign Language, etc.). Some families may wish to practice a bilingual approach where there is a time for signing and time for speaking. **When trying an option, keep in mind that no one option is best for all children. As your child's needs change, it is okay to make different decisions later on.**

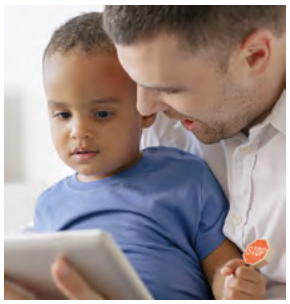
How Hearing Loss Affects Communication

With the proper elements, children who are deaf or hard of hearing can develop, learn and achieve on par with their peers with hearing. The impact of decreased hearing levels is different for a child than for an adult. This is because a young child has not learned or had access to speech and language skills. Adults with decreased hearing levels already know the rules of language and can apply them in daily conversations.

For a child of families who use spoken language in the home, even a mild hearing loss can affect his ability to develop speech and language. Children need to hear all of the sounds of their language to learn how to talk. Similarly, a child needs to see a lot of visual language, such as sign language, if his family wants sign language to be part of his life.

How much a hearing loss affects communication for your child depends on things like:

- The type, degree and configuration of the hearing loss.
- Your family's involvement in your child's communication development.
- The age at which your child became deaf or hard of hearing.
- The age at which your child's hearing loss was found.



- The age at which intervention began, how often it occurred and the quality of the intervention provided.
- Other health conditions your child may have.

Factors that contribute to a child successfully learning to listen and speak include:

- Consistent use of appropriately fit amplification (hearing aids, cochlear implants, FM systems) in order to have access to sound.
- Being surrounded by fluent speakers of the child's language and engaging the child most waking hours.
- Guidance and coaching by an early intervention provider knowledgeable in how to help children develop the ability to communicate and learn through listening and spoken language.

Factors that contribute to a child successfully learning to use sign language:

- Being surrounded by fluent users of your chosen sign language and engaging the child most waking hours.
- Guidance and coaching by an early intervention provider knowledgeable in how to help children develop the ability to communicate and learn through the particular language or visual support system.

Choosing Communication Options

Many families say that choosing communication options is one of the hardest decisions they have ever made. Every option requires a commitment from your family to help your child learn language. Many people may tell you their method is best. **Keep in mind that no one option is best for all children.** For some children, a combination of methods may be best. **Also, remember that you can always change your decision later.** Here are some things to think about as you explore communication options:

- Make decisions based on the needs of your child and family.
- Ask questions. Talk to teens, young adults and adults who are deaf or hard of hearing, as well as to other families with children who have a hearing loss.
- Get as much information as you can about your options by talking to others, reading, and doing your own research.
- Watch your child's progress and re-evaluate your choice from time to time.

Remember that you can change your decision later if the option you chose isn't working as well as you think it should. Your early intervention specialist will give you the tools to measure your child's progress. Guidance and coaching from your early support team will provide you with specific tools and training on how to support your child.

The option(s) you choose should allow your child to:

- Communicate with the entire family (siblings and extended family).
- Have a relationship with all family members and feel like part of the family.
- Enjoy meaningful, two-way conversations.
- Know what is going on.

- Express their feelings clearly.
- Join in the world of imagination and play.
- Develop a positive self-identity and healthy self-esteem.

For some children, a combination of communication options may be best.

Communication Options

Below are some of the different ways your child can learn language. You can use this information as a starting point to learn about the options. Your child's audiologist or Family Resources Coordinator can provide more information about early intervention programs that may be available for each option. You can also visit programs and watch how other children, teachers and families communicate.

American Sign Language (ASL) — English Bilingual

- Families learn to communicate with their child using American Sign Language (ASL) as the first language, while also teaching their child English via reading, writing and speaking.
- ASL is a rich and full language that uses the body, face and hands to communicate.
- ASL is a separate language from English. Like all world languages, ASL has specific language components, including its own sentence structure.
- Some homes that use ASL-English bilingual use spoken English in the home during designated times. The family sets aside a specific time for ASL and a time for speaking English.
- Your child does not have to wear amplification to communicate this way.
- The use of ASL is part of the Deaf community, but is not limited to the Deaf community. ASL is a fast-growing language that extends beyond the reach of the Deaf community and is recognized as a vibrant visual language.
- Members of the Deaf community also include hearing people who know ASL and respect Deaf culture and people. Members of the Deaf community have a cultural identity that is based on a rich heritage of shared experiences. Children who are deaf or hard of hearing can have healthy, meaningful relationships from both within their families and the Deaf community.

Cued Speech

- Cued speech uses eight hand shapes near the mouth that represent different sounds in spoken language.
- The hand shapes represent sounds that are hard to tell apart from each other with just lip reading.
- The hand shapes, combined with lip reading, give your child visual access to spoken language.
- Amplification is recommended, but not required.
- Families learn to communicate with their child using hand cues while speaking.
- Cued speech is not often used in Washington State.

Listening and Spoken Language

- Sometimes referred to as oral, auditory/oral and auditory-verbal.
- Relies on access to sound and speech.
- Your child may need amplification (hearing aids or cochlear implant) with this approach.
- Provides visual cues, like lip reading and gestures, when needed to help a child understand and develop language.
- Does not use sign language.
- In combination with appropriate amplification, the child can develop listening skills and, in turn, learn to speak, communicate and learn through listening and spoken language.

Total Communication

- Families learn to communicate with their child using a combination of signed and spoken language.
- Children are encouraged to use their eyes, ears, voices and hands to communicate.
- The family learns a sign system, such as Signing Exact English (S.E.E.). S.E.E. was designed to be used together with spoken language to help your child understand and use language. It is a tool for making English accessible through listening and vision. In Washington State many Total Communication programs use S.E.E.. It can support age-appropriate development of listening, speech, reading and writing. Other sign methods include Pidgin Signed English (PSE) and Manually Coded English (MCE).

Hearing, Listening and the Brain

You may have questions about how hearing and listening are different or if your child will be able to listen to spoken language. These questions may become important as you consider communication options or communication goals. We hope this is helpful, but talk with your audiologist if you have more questions.

Hearing is a sensory response to sound where the ear transmits information to the brain. Hearing develops before birth.

Listening begins with hearing. A person who is deaf or hard of hearing may use amplification to hear (hearing aids, cochlear implant or other device). Over time, listening skills develop as the brain begins to understand what it hears.

The brain can develop the ability to understand what it hears and enable understanding and learning through listening.

A child who is deaf or hard of hearing needs specialized therapy and education to develop effective listening skills. Teachers of the deaf, audiologists and speech language pathologists can provide educational and therapy services to develop these skills. Some professionals are certified as Listening and Spoken Language Specialists (LSLS) through the AG Bell Academy for Listening and Spoken Language.

In the past, a child's education or therapy was often referred to as "auditory training" but now is more accurately described as aural habilitation, auditory-verbal therapy, auditory-verbal education or listening therapy. The name of the service provided may depend on:

- The focus of the service (skills learned).
- The training of the professional providing the service (audiologist, therapist, teacher of the deaf, etc.).
- Where the services take place (school, hospital, home, etc.).

Children and families will often receive a combination of these services to help a child who is deaf or hard of hearing develop listening and spoken language.

Children with hearing loss may benefit from learning some form of visual communication.

Questions Families Might Ask about Communication

Will my child be able to talk?

This question is difficult to answer. It can depend on the how well hearing technology provides access to sound and spoken language, how well your child is able to use her remaining (residual) hearing and other factors. With the right elements, most children who are born deaf or hard of hearing can learn to listen and, in turn, learn to speak and communicate through listening and spoken language. Appropriately fit amplification and qualified early intervention providers teaming with families are key elements for helping a child to develop the ability to speak and listen.

Many children with mild and moderate losses learn to talk well with the help of hearing aids and specialized services for children who are deaf or hard of hearing.

Children with more severe hearing losses will rely on hearing technology in order to develop spoken language and it may take more time to develop spoken language. Your child's team of doctors, therapists and teachers of the deaf will help your family try to achieve your communication goals for your child.

Things that may help your child learn to talk are:

- Consistent use of amplification (see Assistive Technology section).
- Checking your child's amplification devices to make sure they are working.
- Attending follow-up appointments with your child's audiologist.
- Receiving regular services from professionals trained in working with children who are deaf or hard of hearing.
- Consistent use of strategies that give your child access to spoken language.
- Giving your child many opportunities to practice their skills.

Will my child and family learn to sign?

This is also a difficult question to answer. Deciding to learn to sign is up to your family. Here are some things to consider when thinking about this decision:

- Children who are deaf or hard of hearing may benefit from learning some form of visual communication. This can include ASL, S.E.E. and Cued Speech (see Communication Options section). Including visual communication may help your child get speech and language information in more than one way.
- Learning to sign does not mean your child will not learn how to talk.

Your child will learn how to sign by watching you and others sign. Families can use sign or "baby sign" to facilitate early communication with their babies, regardless of their child's hearing level. If you and your family do not already know how to sign, there are classes available to help you learn. Community colleges, Deaf centers and local service organizations provide ASL courses for everyone. Ask your FRC about these classes.

When making a choice in communication for my child, will this decision be for life?

You can always change your decisions about communication. In fact, it is important for your family to remain flexible and open-minded about your choices in communication. The needs of your child and family may change over time. As you gain more information and knowledge about deafness and your child's hearing, you may choose a different communication option. Monitor your child's progress in order to understand the growth he is making in his language development.

Can my child's environment affect communication?

There are some situations where listening through a hearing aid or cochlear implant can be very challenging. Background noises such as TV, multiple conversations, air conditioning or fans can reduce your child's ability to listen. An audiogram estimates what your child can hear in a quiet environment. Home, grocery stores, parks and playgrounds and other areas can have poor listening environments. Visual "noise" can also be distracting, such as a cluttered or busy environment, repetitive movements and bright or dark lighting. Talk with your early intervention specialist about options to help lessen problems related to noise.

My child who is deaf or hard of hearing has vision problems and delayed motor development. How will that affect her ability to communicate?

Your family's approach to communication will involve some of the same considerations you've read about in this section, as well as some unique to your child. Families of children who are "Deaf/Hard of Hearing Plus" also need to consider assistive technology options such as hearing aids or cochlear implants, as well as use of signing. However, depending on your child's functional abilities, she may benefit from different strategies to support her ability to

communicate (for example, touch cues and tangible symbols). Ask your early intervention specialists about seeking help from people who have experience working with young children who are Deaf/Hard of Hearing Plus. If your child has a diagnosed visual impairment in addition to hearing loss, or you are concerned about the way she uses her vision, contact Washington Sensory Disabilities Services (WSDS) to discuss next steps:

Phone: 1-800-572-7000
Email: wsds@psesd.org
Web: wsdsonline.org

The process to fit your child with hearing aids will take a few weeks.

Assistive Technology

This section provides information about hearing aids, cochlear implants, FM systems and other tools for communication access. Your audiologist will be able to give you more information and answer your questions. Assistive technology is also called amplification.

Does my child need assistive technology?

Hearing loss decreases the amount of sound your child's ears and brain receive. If your child isn't able to hear some or all the sounds of speech, then he will have difficulty learning spoken language.

- If you want your child to learn to communicate with listening and spoken language, your child will most likely need to use hearing aids, cochlear implants and/or an FM system.
- The sooner you get amplification, the sooner your child can begin hearing speech sounds.
- A child can wear hearing aids at any age.
- If you are considering cochlear implants, it is important to begin the cochlear implant candidacy process early. Speak with your child's audiologist about this process.
- Some families may choose a communication option that uses only sign language and doesn't require the use of hearing aids or cochlear implants.

Hearing aids

What is a hearing aid?

- A hearing aid is a small electronic device that your child wears behind her ear(s). It makes some sounds louder.
- A hearing aid has three basic parts:
  - Microphone
  - Amplifier
  - Speaker
- The hearing aid receives sound through a microphone, which breaks it into smaller segments (digitizes) and sends them to an amplifier. The amplifier increases the power of the segments and then sends them to the ear through a speaker.
- Hearing aids are secured to your child's ears with earmolds.

Hearing aid image courtesy of Phonak – www.phonak.com

What are earmolds?

- An earmold is a small piece of soft plastic that is custom made for your child's ear.
- Earmolds fit inside your child's ear canal.
- The earmold helps hold the hearing aid in place.
- Because young children grow very fast, earmolds may need to be replaced every three to six months.
- Earmolds will last longer for older children.

How can a hearing aid help my child?

- Hearing aids make all sounds louder. This includes speech and other sounds, such as the television, doorbell, vacuum, etc.
- Hearing aids can help improve speech and language development for your child.
- They can help your child interact with family and peers who use spoken language.

What are some different kinds of hearing aids?

There are many hearing aid styles. Your audiologist will help you select the best hearing aid for your child.

- Small children usually wear behind the ear (BTE) hearing aids.
- Smaller, in the ear (ITE) hearing aids are not recommended for small children.
- Some children with conductive hearing losses, who can't wear a traditional hearing aid, may be fitted with a soft band retained sound processor.

Hearing aid technology

There are also several kinds of technology for hearing aids. Types of hearing aids are:

Hearing aids

- Increase sound digitally.
- Your audiologist adjusts them using a computer.
- The hearing aid program can be customized to fit your child's hearing loss.
- Processes noise and speech in a way that may help your child understand speech better.
- Offer increased flexibility to accommodate changes in your child's hearing over time.

Soft band retained sound processor

- Soft band retained sound processors are used by some children with conductive hearing losses that cannot be medically or surgically corrected. Often, these children can't wear a BTE hearing aid.
- The processor transmits sound via a bone oscillator (vibrator) that sits on the bone behind the ear. This is mounted on a soft band.

Baha® Softband image courtesy of Cochlear Americas

Important features of hearing aids for infants and toddlers

- The hearing aid should have enough power to allow your child to hear speech sounds.
- It should have Direct Audio Input (DAI) and FM programming options. These options allow the hearing aid to be paired with other listening devices, such as FM systems.
- It should be flexible to make changes in tone, output and gain. This allows audiologists to adjust them as they learn more information about your child's hearing.
- It should have tamper-resistant battery doors. This is important because hearing aid batteries are toxic and can harm your child, if swallowed.
- The hearing aid should have a microphone that is right for your child's listening needs:
  - **Directional microphones** pick up sounds coming from the front of your child.
  - **Omni-directional microphones** pick up signals from all directions. They can be more helpful for a child who is mobile.
  - **Multiple microphones** will let you switch between omni and directional settings.
- It should have comfortable, customized earmolds.
  - Because young children grow very fast, the earmolds may need to be replaced every 3 to 6 months.
  - Earmolds will last longer for older children.

Your audiologist can talk to you about other accessories for your child's hearing aids. Accessories include battery testers, dehumidifiers, hearing aid stethosets (so you can listen to your child's hearing aids), safety clips and volume control covers.

Process for getting hearing aids

The process to fit your child with hearing aids will take a few weeks. This may seem like a long time but several steps must happen first.

- By law, your child must have approval or "medical clearance" from an Ear, Nose and Throat (ENT) doctor—an otolaryngologist—to wear hearing aids.
- The audiologist must make impressions of your child's ears. These impressions will be used to make custom earmolds for your child.
- Your child must have a special measurement called the Real Ear to Coupler Difference (RECD) made with his earmolds in place. Your child's RECD measurement helps the audiologist adjust his hearing aids. The RECD measurement are made before or at the same time as your child's hearing aid fitting.
- Sometimes your child may have medical clearance and earmolds, but you may still be waiting for funding for the hearing aids. In these cases, your child's audiologist may fit her with a "loaner" hearing aid during the waiting period.

This is because it is important that your child start wearing amplification as soon as possible.

Tips for keeping hearing aids on infants and small children

Keeping hearing aids on your small child can be a challenge, especially at first. As your child gets used to his hearing aids, and learns that he hears better with them on, it will get easier. Here are a few tips that can help:

- You should be in control of when and where your child wears his hearing aids. Make sure to teach your child that only adults can take off the hearing aids.
- Give your child reinforcement for wearing her hearing aids. Have a reward, such as a special toy or game, that your child can only have when the hearing aids are on.
- Little hands like to pull out hearing aids and cochlear implants. Things such as Huggie Aids, alligator clips, hats and headbands can help keep hearing aids on. Your audiologist can help you choose something that works for your child. You can also get tips from other families and on the internet (for example, Facebook groups like Parents of CI Kids Who Sign or Parents of Children with Cochlear Implants).
- Sometimes putting the earmold in your child's ear can be tricky. Using a special lubricant and having good technique can help. Your audiologist can teach you proper technique and help you get special lubricant. (Use a water-based lubricant—don't use petroleum jelly.)
- Try to have your child wear the hearing aids whenever he is awake. This way, hearing sounds will become part of his daily routine. You may need to start with small amounts of time and build up to longer periods.

The website for Supporting Success for Children With Hearing Loss has good advice on how to help keep hearing aids on children at different ages.

Babies (0–12 months):
http://successforkidswithhearingloss.com/wp-content/uploads/2013/07/Babies-0-to-12-months-Final-3_11_14.pdf

Toddlers (12–24 months):
http://successforkidswithhearingloss.com/wp-content/uploads/2013/07/Toddlers-12-to-24-months-Final-3_11_14.pdf

Preschoolers (2 to 5 years):
http://successforkidswithhearingloss.com/wp-content/uploads/2013/07/Preschoolers-2-to-5-years-final-3_11_14.pdf

Possible issues with your child's hearing aids

Be sure to talk with your child's audiologist if you have questions or any of the problems listed below.

Feedback

Feedback is a normal function of any sound system. It occurs when sound travels through a microphone to a speaker and is reamplified. This creates a

feedback loop that sounds like a squeal or fluttering sound. It happens when the hearing aid is turned on but not in the ear or if the hearing aid is touched while in the ear. Earwax can also cause feedback. Your audiologist, nurse or physician can look in your child's ear and check to see if wax needs to be removed. If feedback occurs when your child has her hearing aids on, you can try these troubleshooting tips:

Cochlear implant image courtesy of MED-EL Corporation www.medel.com

- Check to see if the earmold or earhook is damaged.
- Remove anything that is touching the hearing aid (for example a hat or blanket).
- Feedback can also be caused by an earmold that no longer fits your child or if your child has wax in her ear or earmold. Your audiologist can help you troubleshoot these issues.
- If you notice any redness or irritation from the earmold or hearing aid, notify your audiologist for adjustment.

Sore spots

Sometimes new earmolds have uneven areas that can cause redness or a sore spot in your child's ear. If this happens, your audiologist can often file the earmold smooth. Check your child's ears for redness whenever he gets new earmolds. A sore spot may be the reason your child doesn't want to wear his hearing aids.

Ear infections

If your child has an ear infection she may not want to wear her hearing aids because her ears hurt. If you think your child has an ear infection, be sure to talk to your child's doctor or audiologist. They may recommend that your child doesn't wear her hearing aids until the infection clears. If your child's ears are actively draining, remove the hearing aids until the ear infection clears.

Cochlear implants and FM systems

Cochlear implants

You may have heard or read about cochlear implants. If you are interested in a cochlear implant for your child, talk to your audiologist or ENT doctor. They can tell you if a cochlear implant might be helpful. They can also help you find a pediatric cochlear implant program near you.

There are a few things to know about cochlear implants:

- Cochlear implants are for children with a severe to profound hearing loss.
- A cochlear implant has an internal part that is surgically placed into the inner ear and an external part that your child wears behind his ear.
- Not all children are candidates for cochlear implants.
- The implant bypasses the normal auditory pathway (outer ear, middle ear, inner ear). It stimulates the auditory nerve directly and the brain learns to interpret this electrical stimulation as speech and other meaningful sounds.
- A cochlear implant "synthesizes" hearing of sounds. Your early intervention provider will help you help your child learn to listen and understand through their cochlear implants.

Image courtesy of MED-EL Corporation www.medel.com

Cochlear implant with a remote control to check and adjust settings. Image courtesy of Cochlear Americas www.cochlear.com.

- With proper follow-up therapy, cochlear implants can help children with severe to profound hearing loss develop better speech and language skills.
- Federal guidelines say that a child with a profound hearing loss should be at least 12 months old at the time of surgery. It is important to start the cochlear implant candidacy process early and speak with the implant team about your child's potential candidacy.
- Speak with your implant team surgeon and audiologist about the potential risks and benefits of cochlear implantation.

FM systems

FM Systems are wireless electronic devices that send speech directly to the person wearing the receiver, thus helping overcome listening challenges such as distance and background noise. This allows your child to hear the speaker's voice better. It is helpful in places with a lot of background noise, like school or on the playground.

If you think an FM system would be helpful for your child, talk to your audiologist. Sometimes places where children get their cochlear implants or hearing aids have loaner programs for FM systems. When your child enters preschool, you can request that your home school district supply this equipment.

There are a few things to know about FM systems:

- One person (the parent or guardian, therapist or teacher) wears a microphone and transmitter.
- Your child wears a receiver.
- The microphone picks up the speaker's voice.
- The speech sounds are sent to your child's ears through radio waves.
- FM systems can be used alone, with hearing aids or with cochlear implants.
- FM systems are helpful in the classroom or at home.

Other tools for communication access

Technology exists to help people who are deaf or hard of hearing become aware of things like the telephone ringing or an alarm going off. Devices can also help someone access speech through text displayed on a screen. Here are some examples that your family may find helpful when your child is older.

Alerting devices: These devices help to alert your child of sounds such as the doorbell or telephone ringing. They might provide a visual signal such as a flashing light, or a tactile signal such as a pocket receiver that vibrates. Some of the most common devices used are alarm clocks, smoke alarms, doorknockers, bed vibrators and phone flashers. The Hearing, Speech & Deaf Center (HSDC) Store, and companies such as Harris Communication or ADCO Hearing Products, have on-line stores or catalogs of alerting devices.

Captioning: Captioning is the text of the audio portion of a video or film displayed directly on the screen. Usually you see captioning on the bottom of the screen. Captioning may include not only the words, but also sounds that are important to understand and the source of the sounds. Open

captions cannot be turned off and closed captions are not visible unless they are turned on for display.

Communication Access Realtime Translation (CART): CART is verbatim text of spoken presentations provided for live events. Only the text is provided on a computer screen or projected for display on a larger screen. CART is beneficial in large group settings such as classrooms, meetings, workshops, live theater and other events.

Telephone amplifier: This device makes the telephone signal louder. It can be used with or without a hearing aid.

Video phones and Video Relay Service (VRS): Video phones are available for your home in a variety of prices. VRS allows people to communicate over video telephones or similar technologies. Convo, Purple and Sorenson are popular VRS providers. There are also free and low-cost video chat cell phone applications and computer software (for example, FaceTime and Skype). These are great tools for children and adults, with or without hearing loss.

The TED Program distributes special equipment for people who are deaf or hard of hearing.

Getting assistive listening equipment

Telecommunications Equipment Distribution (TED) Program

The Washington State Office of Deaf and Hard of Hearing (ODHH) has a Telecommunications Equipment Distribution (TED) program. TED distributes special equipment for people who are deaf or hard of hearing. They offer the equipment on a sliding fee scale based on your income and family size. Many people receive the equipment at no cost.

The equipment the TED program provides changes as new technology becomes available. You can visit their website to learn about the equipment they offer and how to apply for services:
www.dshs.wa.gov/altsa/odhh/telecommunications-equipment-distribution

You can also try out different pieces of equipment at the ODHH Regional Service Centers located in Bellingham, Seattle, Tacoma, Vancouver and Spokane. (See the table on the next page for contact information.)

Hearing, Speech and Deaf Center (HSDC)

The Hearing, Speech and Deaf Center in Seattle offers assistive listening technology through the HSDC Store. You can purchase communication devices for the home, classroom and other meeting places. The store carries over 300 products, including amplified phones and alarm clocks, as well as signaling and safety equipment for common sounds such as doorbells, baby cries or fire alarms. In addition, they stock supplies to maintain and protect hearing aids and cochlear implant processors.

You can see the equipment in their showroom in Seattle. They also have an online catalog: http://hsdcstore.com/

HSDC Store Contact Information:

Seattle Area (V/TTY): 206-328-6872
Nationwide (V/TTY): 888-328-2974

Image courtesy of Phonak (www.phonak.com)

Office of Deaf and Hard of Hearing (ODHH) Regional Services Centers

You can try different pieces of assistive listening equipment at these ODHH Regional Service Centers.

Regional Service Center	Address	Phone Number	Email and Website
Hearing, Speech and Deaf Center Bellingham	114 W. Magnolia Street Suite 106 Bellingham, WA 98225	Voice: 360-647-0910 Voice Toll-free: 866-647-0910 Video Phone: 360-255-7167 TTY: 360-647-8508 Toll-free: 877-647-8508	Email: bellingham@hsdc.org Website: www.hsdc.org
Hearing, Speech and Deaf Center Seattle	1625 19th Avenue Seattle, WA 98122	Voice: 206-323-5770 Voice Toll-free: 888-222-5036 Video Phone: 206-452-7953 TTY: 206-388-1275	Email: seattle@hsdc.org Website: www.hsdc.org
Hearing, Speech and Deaf Center Tacoma	621 Tacoma Avenue Suite 505 Tacoma, WA 98402	Voice Toll-free: 866-421-5560 Video Phone: 253-292-2209 TTY: 253-474-1748 Toll-free: 866-698-1748	Email: tacoma@hsdc.org Website: www.hsdc.org
Southwest Washington Center of the Deaf and Hard of Hearing	301 SE Hearthwood Blvd. Vancouver, WA 98684	Voice: 360-695-3364 Voice Toll-free: 866-695-6777 Video Phone: 360-334-5740 TTY: 360-695-9720	Email: frontdesk@swcdhh.org Website: www.swcdhh.org
Nexus	1206 N. Howard Street Spokane, WA 99201	Voice/TTY: 509-328-9220 Video Phone: 509-315-2288	Email: info@nexusinw.com Website: www.nexusinw.com
Deaf-Blind Service Center	1620 18th Avenue Suite 200 Seattle, WA 98122	Voice: 206-323-9178 TTY: 206-323-3644 Video Phone: 206-455-7932	Email: info@seattledbsc.org Website: www.seattledbsc.org

Financial Assistance

There are several possible sources of coverage for hearing aids or other hearing-related technology and procedures. The amount of coverage for hearing healthcare varies depending on your family's medical insurance plan, financial need and other factors. In this section, the following possible coverage sources will be introduced:

- Private insurance
- Washington Apple Health (Medicaid) insurance
- IDEA Part C funding
- Charitable organizations or associations

Coverage of hearing-related technology and procedures

Private insurance

Getting your health plan to pay for hearing aids or other hearing devices can be a challenge. This is common, but do not give up. Some health plans cover the full cost of hearing aids, while others will not pay at all. In the middle, some plans cover a portion of the costs. For example, a plan may cover up to $1,000 per hearing aid, every two years.

If your health plan does not cover hearing aids, ask if they have an option for an additional premium. Some plans charge as little as an extra 50 cents per month to offer the coverage for a family plan.

If you get health benefits through your job, try working with your employer's benefits administrator rather than dealing directly with your health plan. Your benefits administrator may be a very helpful resource for these issues. Your doctor's office may also be willing to help you work with your health plan.

Washington Apple Health (Medicaid) insurance

Currently, Medicaid insurance covers the cost of hearing aids for people 20 years of age and younger when they are determined medically necessary by a licensed audiologist or otolaryngologist. For more information and the most recent updates to Medicaid insurance coverage, please visit:
www.hca.wa.gov/medicaid/billing/pages/hearing_aids.aspx

IDEA Part C funding

Your family may qualify for additional assistance through the Individuals with Disabilities Education Act (IDEA), Part C funding. IDEA is a federal law that includes early intervention services for eligible children under three years of age. In Washington, the Part C system is called the Early Support for Infants and Toddlers (ESIT) program. Ask your FRC if you are able to receive help with purchasing assistive technology through the IDEA Part C funding program. Strict guidelines are in place for receiving these funds and all other funding options must have been examined and attempted prior to using Part C to pay for hearing aids or related services.

Charitable Organizations or Associations

There are sometimes other financial assistance options available within a person's community. For example, the Northwest Lions Foundation and the Washington Assistive Technology Act Program may be able to provide a device on a short-term or long-term basis depending on need.

For more information on a few such organizations, please see:

Northwest Lions Foundation:
www.nlfoundation.org/hearing/hap.php

Washington Assistive Technology Act Program:
http://watap.org/loan

Sertoma Hearing Aid Assistance:
http://sertoma.org/ways-to-help/hearing-aid-resources

Summary

When looking for financial assistance for hearing healthcare, including hearing aids, make sure you look into all possible funding sources. For example, your family's health plan, Part C funding (note this is a payor of last resort) and other offerings from charitable organizations or associations. Lastly, be sure to discuss your options with your child's audiologist, as she may be aware of additional resources for which your child may be eligible.

Advocacy

Trying to make sure your child receives the services and education he deserves may feel like a fight at times. Remember that you are not alone. There are many people who will help you find the services and opportunities your child needs to succeed. This section covers laws related to children who are deaf or hard of hearing and things you can do to protect your child's rights.

There are laws that guarantee you and your child certain rights.

If you have more questions, talk to your Family Resources Coordinator (FRC). Find out how to contact your FRC in our Resources section.

The Law and Your Rights

There are laws that guarantee you and your child certain rights. Knowing these laws can help you advocate for your child's education and ensure that your family receives services that meet your needs.

Individuals with Disabilities Education Act

The Individuals with Disabilities Education Act (IDEA) is a federal law that outlines standards that states need to follow for providing early intervention services to families with children who have disabilities, including children who are deaf or hard of hearing. The specific laws in place for children birth to three years of age are included under Part C of IDEA. In Washington State, the Early Support for Infants and Toddlers (ESIT) program runs the Part C system. (See chart of next page for details.)

The ESIT program has Family Resources Coordinators (FRCs) in each county in Washington. The FRC's role is to help your family get the early intervention services your child may need and help you understand your rights under Part C. Find out how to contact your FRC in our Resources section.

The ESIT program created an informative brochure that describes your rights according to Part C of IDEA. This brochure has an overview of your rights as a parent or guardian and gives details about the following safeguards to which you are entitled, including:

- Early intervention providers should give you prior written notice before they propose or refuse early intervention services.
- You have the right to parental consent.
- Information related to your child and family should be kept confidential.

- You have options for dispute resolution if you disagree with your early intervention provider's identification, evaluation or placement of your child or their delivery of appropriate early intervention services.

The English version of the brochure is here:
www.del.wa.gov/publications/esit/docs/parents_rights_brochure_english.pdf

Individuals with Disabilities Education Act (IDEA)

Section of IDEA	Section Contains	Services Called	Who Administers in Washington
Part A	Introduction and definition of terms used in the Act	Not applicable	Not applicable
Part B	Educational guidelines for school children 3–21 years of age	Early childhood special education	Office of Superintendent of Public Instruction
Part C	Guidelines for the funding and services for children from birth to 3 years of age	Early intervention	Early Support for Infants and Toddlers (ESIT) program
Part D	Description of national activities that should be carried out to improve the education of children with disabilities	Not applicable	Not applicable

Who is eligible for Part C services in Washington?

After an FRC contacts you, she will begin gathering information to determine if your child is eligible for Part C early intervention services. services.
In Washington State, children who are deaf or hard of hearing are automatically eligible for early intervention services. To be eligible, a child must have at least one of the following:

- An identified condition, like hearing loss, that is likely to result in delay.
- A 25 percent delay or show a 1.5 standard deviation below his age in one or more of the developmental areas.
- An informed clinical opinion (rarely used as the only reason for eligibility).

You can find more information on assessment and determining eligibility on the ESIT program's resources page: www.del.wa.gov/publications/esit

Individualized Family Service Plan (IFSP)

After your child is determined to be eligible for Part C services, your family will work with your FRC and other service providers to create a plan called an IFSP. This written plan includes services you have chosen to improve your child's learning and development and support your ability to meet your child's needs. Early intervention services begin when you have agreed to the IFSP and the services outlined.

Work with your FRC and early support team to ensure the plan reflects your family's concerns, interests and values. The IFSP is an ongoing process that meets the changing needs of your child and family. It is reviewed at least every six months and rewritten on a yearly basis.

The ESIT program's Individualized Family Service Plan Process and Resource Guide has more detailed information about the IFSP:
www.del.wa.gov/publications/esit/docs/IFSP_Resource_Guide.pdf

Transitioning out of Part C

When your child turns three, Part C early intervention services end and your child will transition into preschool special education services (Part B) if needed. Your FRC and early support team will help through this transition. About six to nine months before your child's third birthday, you will begin working with your team to create a transition plan. Guide By Your Side™ (GBYS) is a great resource for support and information during this time.

Your school district will determine if your child qualifies for preschool special education services. Special education and related services will be provided through an Individualized Education Program (IEP). The school district will set up a meeting to develop your child's IEP.

Here are some tips for your child's IEP:

- An IEP meeting must occur before your child's third birthday.
- An IEP must be in place by your child's third birthday.
- You can request that your FRC be invited to the IEP meeting.

- You can bring a friend, family member or advocate, early intervention provider or other person with you for support during the IEP meeting.
- Families should research school options outside their home district that offer services for children who are deaf or hard of hearing.

The ESIT program's brochure *The next step: What happens when my child turns three?* has helpful information about the transition process: www.del.wa.gov/publications/esit/docs/transition_English.pdf

Section 504 plan

If your child does not qualify for special education services through an IEP, your school should work with you to determine if a Section 504 plan is appropriate. Section 504 of the Rehabilitation Act of 1973 is a federal law that ensures that a child with a disability has equal access to an education. Any school or program receiving federal funds must follow this law.

A Section 504 plan is a written plan that describes the special accommodations and modifications a child may need in order to receive equal access to an education. For a child with hearing loss, this may include preferential seating, captions on films, interpreters, tutors, note takers and acoustical adaptations.

To learn more about a Section 504 plan, talk to your early support team, family advocate or school district.

Your Rights and Responsibilities as a Parent or Guardian

Both you and your child have rights. Below are some suggestions for making sure that your child's rights are respected and protected.

Learn as much as you can about your rights and the rights of your child

Knowing about your rights under federal law will help you to make sure your child's school is honoring them. If you have any questions about your rights as a parent or guardian, ask your FRC, school or educational agency.

Become a partner with your child's preschool, school or educational agency

You know your child better than anyone, which makes you a key member of your child's educational team. Work together with your child's school. Your input is an important resource to the teachers and other professionals who work with your child.

Understand the program in your child's IFSP or IEP

Ask questions until you are sure you understand. Don't sign the IFSP or IEP until you understand all of it.

Keep track of your child's progress

If your child is not progressing as well as you think she should, talk with her teacher or providers. You have the right to ask for a review of your child's educational program at any time.

Keep records

Each year keep a notebook to write down questions or comments about your child's progress or educational program. Take notes whenever you meet with staff, talk on the phone or send notes to teachers or other staff. Write down dates, times, what happened and the names of the people involved. These notes can be a helpful reminder for you and your child's teachers at the next IEP planning meeting.

This notebook is the perfect place to keep notes. Staying organized and feeling prepared is a great way to reduce stress before, during and after your child's appointments or meetings.

Talk with your child's school or agency when you have concerns

It is important to tell your child's teachers, therapists and other professionals about your feelings and concerns. Sharing this information is a big part of creating a program that helps your child be successful.

You know your child better than anyone, which makes you a key member of your child's educational team.

Resources

The inclusion of any resource, service or website does not imply endorsement by the Department of Health's Early Hearing-loss Detection, Diagnosis and Intervention (EHDDI) program. Seek the advice of your child's health care provider before you act or rely upon any information from these resources.

Your FRC will help your family get the early intervention services needed.

Contacting Your Family Resources Coordinator

One of the first steps to take in helping your child is contacting your Family Resources Coordinator (FRC). Your FRC will help your family get the early intervention services needed.

Contact your FRC as soon as possible. If you do not have a FRC, call the "Family Health Hotline" at 800-322-2588 (TTY: 800-833-6384). They will provide you with the contact information for the Lead FRC in your area.

To learn more about the Early Support for Infants and Toddlers (ESIT) program, view their website: www.del.wa.gov/development/esit/

Family Support

Guide By Your Side™

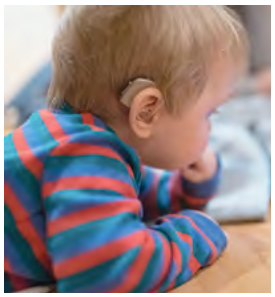
Phone: 425-268-7087 (voice)
Email: gbys@wahandsandvoices.org
Website: www.wahandsandvoices.org

Guide By Your Side (GBYS) was created by Hands & Voices™. Their parent guides are all parents of a child with hearing loss. The trained guides provide unbiased information about communication options, help families navigate through the system, link families with local and national parent-to-parent resources and assist families with advocating for their child in health care and school settings. Most importantly, GBYS encourages families, offering hope and the tools to fulfill the dreams they have for their children.

Hands & Voices™

Phone: 425-268-7087 (voice)
Email: info@wahandsandvoices.org
Website: www.wahandsandvoices.org

Hands & Voices is dedicated to supporting families by providing non-biased information about communication options and access to services and education.



They strive to empower deaf, hard of hearing and deaf-blind children in Washington to reach all of their future goals.

Washington State Father's Network

Phone: 425-653-4286 (voice)
Email: Louis.Mendoza@Kindering.org
Website: www.fathersnetwork.org

The Washington State Fathers Network (WSFN) connects men with other dads, resources, information and education, plus opportunities for "all family" celebrations. Focus is on assisting fathers as they become more competent and compassionate caregivers for their children with special needs. In addition to the WSFN state wide programs, each chapter runs their own set of local activities and programs.

Washington State Parent to Parent Support Programs

Phone: 1-800-821-5927 (voice)
Email: parent2parentwa@gmail.com
Website: www.arcwa.org/parent_to_parent.htm

Parent to Parent is a support network for families of children with disabilities. Services include local county coordinators, emotional support for families of children with disabilities, presentations to parent groups, professionals and other organizations, information on disabilities, community resources for the child and family, parent support meetings and trainings for parents who want to become a Helping Parent volunteer.

Early Intervention Programs Specializing in Children Who are Deaf or Hard of Hearing

The early intervention programs listed below specialize in working with children who are deaf or hard of hearing and their families. These programs have staff with special training in working with children with hearing loss. Your FRC will also be able to help you contact resources available to you.

Family Conversations

2525 220th Street SE, Suite 100
Bothell, WA 98021

Phone: 425-482-4185 (voice)
Email: family_conversations@seattlechildrens.org
Website: www.seattlechildrens.org/clinics-programs/audiology/

Family Conversations is for children up to age three and their families in Western Washington. They provide home-based, specialized instruction for families, supportive language development through listening, speaking and signing. Activities include weekly playgroups, parent education and informal support groups for the entire family, including extended family.

Hearing, Speech and Deaf Center, North Sound

Phone: 360-647-0910 or 866-647-0910 (voice)
360-647-8508 or 877-647-8508 (TTY)
360-255-7166 (video phone)
Email: bellingham@hsdc.org
Website: www.HSDC.org

The Hearing, Speech and Deaf Center, North Sound's Family Program offers services for families with deaf or hard of hearing children in Whatcom, Skagit, San Juan and Island counties. They provide a bilingual/bicultural approach to meet each family's needs including home visits, parent support groups, Individualized Education Program (IEP) and general advocacy, information and referral services and American Sign Language (ASL) classes.

Listen and Talk

8610 8th Avenue NE
Seattle, WA 98115

Phone: 206-985-6646 (voice)
Email: suzanneq@listentalk.org
Website: www.listentalk.org

Listen and Talk provides services for children and families throughout Washington using Auditory-Verbal Therapy and Education. Their goal is to teach children with hearing loss to communicate and learn through listening and spoken language. They provide families with individual therapy, parent support groups, children's playgroups and blended preschool and pre-K classes. Listen and Talk has on-site audiology services that support the work of a child's audiologist. They also provide consultation services in partnership with the Washington State Center for Childhood Deafness and Hearing Loss (CDHL). Services through a telehealth model (Virtual Home Visits) are also available for families seeking to help support their child's listening and spoken language development.

MOOSE Project

4001 North Cook Street
Spokane, WA 99207

Phone: 509-443-5905 (voice and text)
Email: mooseproject@comcast.net
Website: www.mooseproject.net

The MOOSE (Magic of Oral and Signing Education) project offers education, support and resources using both sign language and spoken word for children who are deaf or hard of hearing and individuals without hearing loss. MOOSE activities are open to those in the Spokane area who are interested in learning about and using total communication.

Parent Infant Program (PIP) – Seattle

Hearing Speech and Deafness Center
1625 19th Avenue
Seattle, WA 98122

Phone: 206-323-5770 or 888-222-5036 (voice)
206-388-1275 or 800-761-2821 (TTY)
206-452-7953 (videophone)
Email: seattle@hsdc.org
Website: www.HSDC.org

The PIP program offers family-centered services for children who are deaf and hard of hearing from birth to three years old in King, Snohomish and Pierce counties. They provide an American Sign Language (ASL)/English bilingual approach to meet each family's needs. Included in the program are:

- Home visits
- Shared reading program
- Weekly "family night" activities
- "Kids Club" playgroup (for PIP children and siblings)
- Parent support groups
- Parent education nights
- ASL classes

Spokane Hearing Oral Program of Excellence (Spokane HOPE)

(programs and services for children birth through five years)

310 N. Riverpoint Blvd, Box V
Spokane, WA 99202-1675

Phone: 509-828-1379
Email: info@spokanehope.org
Website: www.spokanehope.org

Spokane HOPE provides in-home services for infants, birth–3 and on-site Listening and Spoken Language programs for children 3–5 years who are deaf or hard of hearing in Eastern Washington and Northern Idaho. Their on-site programs for children with hearing loss who are fitted with hearing technology include small-group, language-enriched weekly toddler group and four days/week morning and afternoon preschool classrooms focusing on listening, learning, and speaking, with the goal to prepare children with hearing loss for the K–12 environment to learn on par with their hearing peers. HOPE provides activities for families to promote parent involvement and carryover of language skills at home. They also provide consultation services in partnership with the Washington State Center for Childhood Deafness and Hearing Loss (CDHL).

Washington School for the Deaf – Family Infant and Toddler Program

611 Grand Boulevard
Vancouver, WA 98661

Phone: 360-696-6525 (Voice/TTY)
800-613-4228 (Voice/TTY Toll free)
Website: www.wsd.wa.gov

The Family Infant Toddler Program offers a family-focused program to children and families living in Chelan, Clark, Cowlitz, Douglas, Grant, Okanogan and Skamania counties. They provide support and education through home visits, family support groups, play groups, exposure to a variety of communication options and access to adult and peer deaf role models.

Washington Sensory Disabilities Services (WSDS)

Phone: 425-917-7827 (Voice/TTY)
800-572-7000 (Voice/TTY Toll-free)

Email: wsds@psesd.org
Website: http://www.wsdsonline.org

Washington Sensory Disabilities Services (WSDS) assists children who are deaf or hard of hearing, blind or visually impaired or deaf-blind by providing training and other support to families and service providers.

WSDS has worked in collaboration with the Washington State Department of Health EHDDI program, Early Support for Infants and Toddlers (ESIT), Office of the Deaf and Hard of Hearing (ODHH), and the Statewide Center on Childhood Deafness and Hearing Loss (CDHL) to develop a state plan to improve access to specialized services for infants/toddlers with hearing loss. If your family or your Family Resources Coordinator (FRC) is having trouble finding support related to birth-to-three year olds who are deaf or hard of hearing, contact WSDS for help.

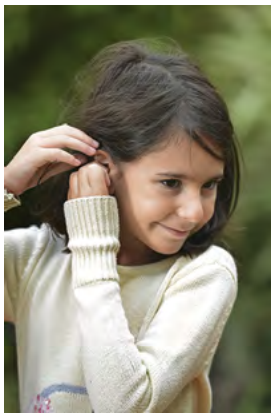
Washington State Center for Childhood Deafness and Hearing Loss (CDHL)

611 Grand Boulevard
Vancouver, WA 98661

Phone: 360-418-0401 (voice)
Website: www.wsd.wa.gov

The CDHL Statewide Outreach Team is a group of deaf education specialists who support children (birth–21), their families and the professionals and programs that serve them. CDHL early childhood specialists are available to provide initial information to families about early communication development and language acquisition, different listening and visual technologies and other information. CDHL also provides consultation services and technical assistance to direct service providers, school and program staff and others who work with children who are deaf or hard of hearing and their families.

CDHL is a state agency that works in collaboration with other state agencies (e.g., Department of Health, Department of Early Learning – Early Support for Infants and Toddlers, and the Office of Superintendent of Public Instruction),



public and private programs, and other stakeholder organizations to improve systems and regional services for children who are deaf, hard of hearing or deaf-blind.

Yakima Valley Hearing and Speech Center

Parent-Infant-Toddler Program
Hearing and Speech Center
303 South 12th Avenue
Yakima, WA 98902

Phone: 509-453-8248 (voice)
Email: info@hearingandspeechcenter.com
Website: http://hearingandspeechcenter.com

The Parent-Infant-Toddler Program serves children and families in the Yakima Valley, Tri-Cities, Ellensburg and Goldendale. Individualized therapy, counseling and parent participation are essential to this program's success. They provide education about spoken language, sign language, lip reading, auditory training and amplification devices. They also work closely with doctors and school districts to provide ongoing services for families.

Schools for Children Who Are Deaf or Hard of Hearing

Public school

If your child is over three years of age, contact your local school district and ask what options are available for children who are deaf or hard of hearing. By law, any child with a hearing loss who needs services is entitled to special education services. You can find a list of school districts, developmental centers and other agencies serving infants and children in your county here: www.doh.wa.gov/HearingCountyResources

Your child may qualify for services such as speech therapy or a specialized classroom for children with hearing loss. You will work with staff from your school district to develop an Individualized Education Program (IEP) for your child. Your audiologist or teacher of the deaf can provide you with more information and help you explore your options and other resources. If you live in an area that does not have a specialized deaf educator, you can contact the Center for Childhood Deafness and Hearing Loss (CDHL). The CDHL statewide outreach team provides evaluation, an Individual Family Service Plan (IFSP) and IEP support and consultation services for children ages 0–21, their families and school programs.

Day and residential school

Washington School for the Deaf

611 Grand Boulevard
Vancouver, WA 98661

Phone: 360-696-6525 (V/TTY)
800-613-4228 (V/TTY Toll-free)
Website: www.wsd.wa.gov/

The Washington School for the Deaf (WSD) is a day and residential state school located in Vancouver, Washington. WSD provides classes for students in preschool through high school. Students who live more than 60 minutes away from the WSD campus may live on campus. WSD is an ASL-English bilingual school that embraces a child-centered approach. Teachers and staff trained in bilingual strategies work to instill a love of learning and an understanding of self-identity for all students. The school's mission is "WSD Students are the BEST! – Bilingual-Empowered-Successful for Today and Tomorrow."

Private schools

Listen and Talk (programs for children ages 3–5 years)

8610 8th Avenue NE
Seattle, WA 98115
Phone: 206-985-6646 (Voice)

Email: suzanneq@listentalk.org
Website: www.listentalk.org

Blended preschool and pre-k classrooms provide children with hearing loss the skills necessary to fully participate in general education settings. Their classrooms also offer children with hearing the opportunity to learn about diversity while being taught by highly qualified teachers and assistants in a language rich environment.

Northwest School for Deaf and Hard-of-Hearing Children (NWSDHH) (play group for infants and toddlers and programs for children ages 3 through junior high)

15303 Westminster Way North
Shoreline, WA 98155

Phone: 206-364-4605 (voice)
Website: http://northwestschool.com

Northwest School for Deaf and Hard-of-Hearing Children offers classes for students who are deaf or hard of hearing in preschool through 8th grade. Mainstreaming begins in Kindergarten. NWSDHH uses simultaneous speech and Signing Exact English (S.E.E.) to prepare students to be self-confident, articulate and academically competitive learners and contributing community members. Tuition and transportation are paid by

local school districts. NWSDHH offers a Spanish-speaking families program and monthly Saturday play dates.

Spokane HOPE School – Hearing Oral Program of Excellence
(programs for children birth through five years)

University Hearing and Speech Clinic
310 N. Riverpoint Blvd, Box V
Spokane, WA 99202-1675

Phone: 509-828-1379 (voice)
Email: info@spokanehope.org
Website: http://spokanehopeschool.org

HOPE is proud to be housed within the Washington State University (WSU)–Eastern Washington University (EWU) Riverpoint Campus and has a strong partnership with the combined EWU Department of Communication Disorders and WSU Department of Speech and Hearing, allowing our preschoolers to access daily individual speech-language therapy. Our toddler group and preschool classrooms also include children with hearing as normal speech and hearing models for our preschoolers with hearing loss.

Websites

The following websites may be good resources for your family. This list only contains a small number of the websites available. Many families also use social media to connect with resources and support groups.

If you don't have internet access at home, check with your local library. Most libraries offer free access to the internet and training on how to use a computer.

Alexander Graham Bell Association for the Deaf and Hard of Hearing (AG Bell)

www.agbell.org

The Alexander Graham Bell Association for the Deaf and Hard of Hearing (AG Bell) is a lifelong resource, support network and advocate for listening, learning, talking and living independently with hearing loss. Through publications, outreach, training, scholarships and financial aid, AG Bell promotes the use of spoken language and hearing technology. With over a century of service, AG Bell supports its mission: Advocating independence through listening and talking.

American Academy of Pediatrics (AAP)

www.aap.org

The AAP is an organization of 60,000 pediatricians committed to the attainment of optimal physical, mental, and social health and well-being for all infants, children, adolescents and young adults. The AAP website contains general information for families of children from birth through age 21, and information about the Academy's many programs and activities, their policy statements and practice guidelines, publications and other child health resources.

American Society for Deaf Children

www.deafchildren.org

The American Society for Deaf Children (ASDC) is a national, non-profit organization whose purpose is to provide support, encouragement and information to families raising children who are deaf or hard of hearing. ASDC is committed to empowering diverse families with children who are deaf or hard of hearing by embracing full access to language-rich environments through mentoring, advocacy, resources and collaborative networks.

American Speech-Language-Hearing Association (ASHA)

www.asha.org

ASHA is the professional, scientific, and credentialing association for more than 114,000 members and affiliates who are speech-language pathologists, audiologists, and speech, language and hearing scientists in the United States and abroad. The mission of ASHA is to promote the interests of and provide the highest quality services for professionals in audiology, speech-language pathology, and speech and hearing science, and to advocate for people with communication disabilities.

Babyhearing.org

http://babyhearing.org

Babyhearing.org was developed by a team of professionals made up of audiologists, speech-language pathologists, teachers of the deaf, geneticists, doctors and families of deaf and hard of hearing children at Boys Town National Research Hospital in Nebraska. It has information about newborn hearing screening and infant hearing loss.

BEGINNINGS for Parents of Children Who Are Deaf or Hard of Hearing

www.ncbegin.org

BEGINNINGS was established to provide emotional support and access to information for families with deaf or hard of hearing children, ages birth through 21. The mission of BEGINNINGS is to help parents be informed, empowered and supported as they make decisions about their child.

Communicate with Your Child

http://communicatewithyourchild.org

The Communicate with Your Child website may help you answer questions about your child's hearing loss and find resources in your area.

Early Support for Infants and Toddlers (ESIT)

http://del.wa.gov/development/esit

The Early Support for Infants and Toddlers (ESIT) provides early intervention services, including Family Resources Coordination for eligible children from birth to age three and their families. ESIT, part of the Department of Early Learning, implements the Individuals with Disabilities Education Act (IDEA), Part C in Washington State.

Hands & Voices™

http://handsandvoices.org

Hands & Voices is a parent-driven, non-profit organization that provides unbiased support to families with children who are deaf or hard of hearing. They provide support activities and information about deaf and hard of hearing issues to parents and professionals that may include outreach events, seminars, advocacy, lobbying efforts, parent-to-parent networking and a newsletter. Hands & Voices strives to connect families with resources and information to make informed decisions around the issues of deafness or hearing loss.

The website of the Washington chapter of Hands & Voices can be found at: www.wahandsandvoices.org

Harvard Medical School Center for Hereditary Deafness

http://hearing.harvard.edu

The Harvard Medical School Center for Hereditary Deafness website provides information on the genetics of deafness. This site also has links to their booklets for families and information about genetic tests for hearing loss and deafness.

Hearing First

www.hearingfirst.org

Hearing First is a multimedia website experience designed to connect families and professionals to the tools, relationships and learning they need to improve listening and spoken language outcomes for children who are deaf or hard of hearing.

National Center for Hearing Assessment and Management (NCHAM)

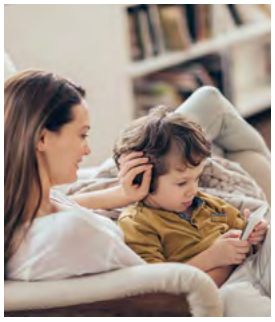
www.infanthearing.org

In 1995, the National Center for Hearing Assessment and Management (NCHAM) was established at Utah State University. NCHAM assists hospital-based Universal Newborn Hearing Screening and state-based Early Hearing Detection and Intervention (EHDI) programs. Their website contains information about newborn hearing screening and follow-up. It also includes a bulletin board, statistics and contact information for every state.

National Association of the Deaf (NAD)

www.nad.org

The mission of the National Association of the Deaf is to promote, protect and preserve the rights and quality of life of persons who are deaf and hard of hearing in the United States. This website provides information about legal rights, advocacy issues, frequently asked questions, news and outreach.



Northwest Lions Foundation for Sight and Hearing

www.nlfoundation.org/hearing.php

The Northwest Lions Foundation for Sight and Hearing has several programs to accomplish its mission of protecting and restoring hearing. These programs include:

- Lions Hearing Aid Program

- Lions All American Hearing Aid Program
- Lions Health Screening Unit
- Lions Patient Care Grants
- Lions Project Support Grants

Office of the Deaf and Hard of Hearing (ODHH)

www.dshs.wa.gov/altsa/office-deaf-and-hard-hearing

ODHH provides services to the deaf, hard of hearing and deaf-blind communities throughout Washington State. ODHH Regional Service Centers have professional staff working with children and their families to meet their language, technology and other communication needs. These centers also provide case management, advocacy, workshops, information and referral services, education, training and outreach services to clients and their families.

Seattle Children's

www.seattlechildrens.org/classes-community/community-programs/newborn-hearing-screening

Seattle Children's is working in partnership with the Washington State Department of Health and Washington Chapter of the American Academy of Pediatrics to implement comprehensive Universal Newborn Hearing Screening Programs across Washington. It sponsors Family Conversations, a birth to three program for children with hearing loss, the annual Signed Exact English (S.E.E.) Skillshop and weekly S.E.E. classes at several locations.

The S.E.E. Center

www.seecenter.org

The S.E.E. Center is a national resource for books, workshops, and other resources for Signing Exact English.

Supporting Success for Children with Hearing Loss

http://successforkidswithhearingloss.com

Supporting Success for Children with Hearing Loss is an organization for professionals and family members seeking information about learning and social issues of children who are deaf or hard of hearing. They provide resources, continuing education and member networking.

Visual Language and Visual Learning (VL2)

www.vl2parentspackage.org

The VL2 center studies bilingual communication—English and American Sign Language (ASL). The VL2 Parent Information Package *Growing Together* is a collection of resources for hearing parents of children who are deaf or hard of hearing that focuses on visual language and visual learning.

Washington Sensory Disabilities Services (WSDS)

www.wsdsonline.org

Washington Sensory Disabilities Services is an OSPI (Office of the Superintendent of Public Instruction) funded state needs project which provides information, training, technical assistance and resources to families

and educators statewide about children and youth with sensory disabilities—students who are deaf/hard of hearing, blind/visually impaired or deaf-blind.

Washington State Department of Health

www.doh.wa.gov/EarlyHearingLoss

The Early Hearing-loss Detection, Diagnosis and Intervention (EHDDI) program is part of the Washington State Department of Health. The main goals of the EHDDI program are to ensure that all infants born in Washington:

- Have their hearing screened before hospital discharge or by one month of age.
- Receive diagnostic audiological evaluation by three months of age, if needed.
- Are enrolled in early intervention services by six months of age or earlier, if the infant has hearing loss.

Terms and Definitions

Over time, as technology advances, the terms and definitions used with hearing loss will continue to change. Please ask your provider questions about any terms you hear that seem new or different to you.

Acoustics

Pertaining to sound, the sense of hearing or the science of sound. Often used to refer to the quality of the sound environment.

Acquired hearing loss

Hearing loss that is not present at birth. Sometimes referred to as adventitious loss.

Advocacy

This term refers to the role parents or guardians play in developing and monitoring their child's educational program. Advocating for your child means knowing what rights the law assures you and actively participating in the decision-making process to ensure that the services are in line with your goals for your child's development and education.

Ambient noise

Background noise that competes with the main speech signal.

American Sign Language (ASL)

As the third most used language in the United States, ASL is a complete, natural language with its own form, function and social usage. It is expressed through the movements of the hands, face, body and received through the eyes. Like all languages, ASL has its own distinct vocabulary and grammatical structure. It is the language preferred by the majority of the Deaf community.

American Sign Language (ASL) Specialist

A professional who has been specifically trained in ASL linguistics and language teaching and learning strategies. This person provides assessments to make professional recommendations for specific services supporting language acquisition. ASL specialists possess credentials in ASL instruction,

assessment and advocacy, and require a high proficiency in use and knowledge of ASL.

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

Assistive communication devices
Devices and systems that are available to help deaf and hard of hearing people improve communication, adapt to their environment, and function in society more effectively.

Audiogram
A graph that reads a person's ability to hear different pitches (frequencies) at different volumes (intensities) of sound.

Audiological assessment
A set of hearing tests to show the type and degree of hearing loss. They identify pure-tone thresholds and test impedance, middle ear function, speech recognition and speech discrimination. These tests can also assess how well a child hears with amplification.

Audiologist
A professional who treats and supports people with hearing loss or balance disorders. New graduates must get their Doctorate in Audiology. Audiologists may be certified by ASHA, AAA or ABA.

Audism
Discrimination or prejudice against individuals who are deaf or hard of hearing. It is the notion that one is superior based on one's ability to hear and results in a negative stigma toward anyone who does not hear.

Auditory brainstem response (ABR)
A non-invasive test that measures responses in the brain waves to auditory stimulus. This test can indicate if sound is being detected, even in an infant. This test may also be called BAER, BSEP and BSER.

Auditory Neuropathy Spectrum Disorder (ANSD)
A hearing disorder where sound enters the inner ear normally but the transmission of signals from the inner ear to the brain is impaired. It can affect people of any age.

Auditory steady state responses (ASSR)
Like the ABR, the ASSR measures the brainstem's responses to particular auditory stimuli. This non-invasive, painless test is done while the child is sleeping. ASSR technology gives the audiologist another way to determine your child's hearing across different frequencies. The equipment has higher upper limits than ABR equipment, allowing the audiologist to more accurately differentiate between severe and profound hearing loss in infants.

Auditory-verbal therapy (AVT)
A method for teaching children who are deaf or hard of hearing to listen and speak using their residual hearing and the use of amplification devices such as hearing aids, cochlear implants and FM devices. AVT emphasizes speech and listening.

Auditory-verbal education
A certified Listening and Spoken Language Specialist (LSLS) educator teaches children who are deaf or hard of hearing to listen and talk exclusively through listening and spoken language.

Aural habilitation
Training designed to help a person with hearing loss make productive use of residual hearing. Sometimes includes training in speech reading.

Bilingual/bicultural
Belonging to both a hearing/English language culture and Deaf Community/ASL culture.

Bilateral hearing loss
A hearing loss in both ears.

Binaural hearing aids
Hearing aids worn on both ears.

Bone anchored hearing aid (BAHA)
A type of hearing aid that conducts sound to the inner ear through the mastoid bone (the large bony mass just behind the ear) instead of by directing amplified sound at the ear drum. Since a BAHA bypasses the middle ear, people who have a conductive hearing loss may find a BAHA an effective way to hear.

Bone conduction
Sound received through the bones of the skull.

Chronological age/adjusted age
"Chronological" refers to a child's age based on date of birth. This is how we normally think of age. If a baby was born prematurely, however, his development may be measured with "adjusted" age. Adjusted age accounts for the time between premature birth and the actual due date of a full term pregnancy. This more truly reflects what the baby's developmental progress should be.

Cochlear implant (CI)
A cochlear implant is an electronic device that is surgically implanted in the cochlea of the inner ear. It transmits auditory information directly to the brain, bypassing damaged or absent auditory nerves. Technically, it synthesizes hearing of all sounds, but the wearer needs training to attach meaning to the sounds. This is called auditory habilitation. Typically, cochlear implant users have severe to profound hearing losses and do not get much benefit from hearing aids. Successful CI users gain useful hearing and improved communication abilities.

Cognitive
Refers to the ability to think, learn and remember.

Conditioned play audiometry (CPA)
In play audiometry, the audiologist helps the child understand the rules for playing a game. For example, the child learns to drop a block into a container to show that she heard a sound. Play audiometry is generally used when the child is at least 18 months old.

Conductive hearing loss
Sound waves do not reach the inner ear through the normal air conduction channels of the outer and middle ear. This is often caused by middle ear infections. In children, conductive loss is typically medically correctable.

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

Deaf
Medically, this means a severe hearing loss that prevents the child from hearing spoken language. Socially, "Deaf" with a capital letter "D" refers to the cultural heritage and community of deaf individuals, such as the Deaf culture or Deaf community.

Deaf community
A group of people, both deaf and hearing, who share common interests and a common heritage. In the United States, the most common language is American Sign Language (ASL). Members do not view being deaf as a disability, but rather as part of their identity and part of a rich and diverse human experience.

Deaf culture
A view of life manifested by the morals, beliefs, artistic expression, understanding and language (ASL) particular to Deaf people. A capital "D" is often used in the word Deaf when it refers to community or cultural aspects of Deafness.

Deaf blindness
A combined loss of vision and hearing that affects educational needs.

Decibel (dB)
The unit of measurement for the loudness of a sound. The higher the dB, the louder the sound.

Ear mold
A custom made plastic or vinyl piece that fits into the outer ear to connect with a hearing aid.

Ear, Nose and Throat (ENT)
A medical doctor, who specializes in the ears, nose and throat. Sometimes referred to as an otolaryngologist or otologist.

Early Support for Infants and Toddlers (ESIT)

Formerly the Infant and Toddler Early Intervention Program (ITEIP), this program provides individualized, quality early intervention services to children from birth to three who have disabilities and/or developmental delays.

Educational interpreter

A person who performs conventional interpreting and uses special skills for working in an educational environment.

Eligibility

A child qualifies for special education services based on specific disabilities and an exhibited delay in one or more of the following areas: cognitive ability, motor skills, social/adaptive behavior, perceptual skills and/or communication skills.

Finger spelling

Finger spelling uses a standardized series of hand shapes to form words. Each letter has its own particular shape.

FM system

An assistive listening device worn by the speaker to amplify his voice and transmit it directly to the listener's ears via an electronic receiver and special earphones or the listener's own hearing aids or cochlear implants. The device reduces background noise interference and the problem of distance between speaker and listener.

Free Appropriate Public Education (FAPE)

An educational right of children with disabilities in the United States that is guaranteed by the Rehabilitation Act of 1973 and the Individuals with Disabilities Education Act (IDEA).

Frequency

The number of vibrations per second of a sound. Frequency, expressed in Hertz (Hz), determines the pitch of the sound.

Gain

Describes how much the amplification helps. For example, a child with unaided hearing at 70 dB who hears at 30dB when amplified has a gain of 40 dB.

Genetic counseling

A health care professional with special training in genetics provides counseling and information about potential genetic causes or risks for birth defects or other disorders. For a child with hearing loss, the genetic counselor can review other health issues that could be associated with the hearing loss. The counselor can also discuss the likelihood of a progressive hearing loss (more loss over time) or the chances of the family having another child with hearing loss. The following website lists genetics clinics in your area: http://www.doh.wa.gov/GeneticClinics

Hard of hearing

1) A hearing loss, whether permanent or fluctuating, that makes it harder to detect and decipher some sounds.

2) The term preferred by the Deaf and hard of hearing community to refer to individuals who have hearing loss, but also have and use residual hearing.

Hearing screening

Tests the ability to hear selected frequencies at intensities above normal hearing. Aims to identify people with hearing loss quickly and to refer them for further testing.

Hearing aid

An electronic device that conducts and amplifies sound to the ear.

Hearing loss

Below is a description of typical hearing levels:

No Hearing Loss	0 dB to 15 dB
Slight Loss	16 dB to 25 dB
Mild Loss	26 dB to 40 dB
Moderate Loss	41 dB to 55 dB
Moderately Severe Loss	56 dB to 70 dB
Severe Loss	71 dB to 90 dB
Profound Loss	91 dB or more

Huggies

The brand name of a plastic-ringed device designed to "hug" the hearing aid to the ear. Popular for infants and toddlers whose ears may be too small to hold the hearing aid snugly in place.

Inclusion

Often used the same way as the term "mainstreaming." This term refers to integrating and including students with disabilities as much as possible with their (typically developing) peers in the school.

Individual Family Service Plan (IFSP)

The IFSP is a plan that parents or guardians write with input from a multi-disciplinary team (see "Part C").

The IFSP:

- Describes the family's strengths, needs, concerns and priorities.
- Identifies support services available to meet those needs.
- Empowers the family to meet the developmental needs of their infant or toddler with a disability.

Individualized Education Program (IEP)

A team-developed, written program to identify therapeutic and educational goals and objectives for a school-aged student with a disability.
An IEP for a child who is deaf or hard of hearing must include that child's Communication Plan. It should also address:

- Communication needs in the child's and family's preferred mode of communication.

- Linguistic needs.
- Severity of hearing loss.
- Academic progress.
- Social/ emotional needs, including opportunities for peer interactions and communication.
- Appropriate accommodations and assistive communication devices to facilitate learning.
- Opportunities to interact with peers and adults who use the same communication mode.
- The proficiency of the staff delivering services identified on the IEP.
- Opportunities for direct instruction in the child's communication mode.
- All educational placement options.
- How extra-curricular activities will be made communication-accessible.

Individuals with Disabilities Education Act (IDEA)

The Individuals with Disabilities Education Act (IDEA) is a federal law (108–446) that outlines standards that states need to follow for providing early intervention services to families with children who have disabilities, including children who are deaf or hard of hearing. Part C provides services to children birth to three years of age with disabilities. Part B covers educational mandates for students age three through high school graduation or age-out of the system.

Intensity

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

Interpreter

A person who facilitates communication between hearing and deaf or hard of hearing persons by interpreting spoken language into a signed language, or transliteration of a language into a visual and/or phonemic code. For example, oral interpreter, signed language interpreters and cued speech interpreters.

Intonation

The aspect of speech made up of changes in stress and pitch in the voice.

Least restrictive environment (LRE)

A basic principle of Individuals with Disabilities Education Act (IDEA) that requires public agencies to establish procedures to educate children with disabilities together with children who do not have disabilities whenever possible. This includes children in public or private institutions or other care facilities. Special classes, separate schooling or otherwise removing children with disabilities from the regular educational environment should only occur when the nature or severity of the disability is such that education in regular classes with assistive services cannot achieve satisfactory results. The federal "Deaf Students Education Services Policy Guidance" clarifies that the Least Restrictive Environment for children with a hearing loss is one in which students have direct communication with teachers and peers. For more information, see the Hands & Voices™ website.

Listening and Spoken Language
An approach that emphasizes speech and listening to teach children who are deaf or hard of hearing.

Listening and Spoken Language Specialist (LSLS)
LSLS are licensed speech-language pathologists, audiologists or educators of the deaf who have become specialists in supporting children who are deaf or hard of hearing develop spoken language and literacy primarily through listening.

Listening bubble
The circle of space within which a person can hear. Any sound that is made within the bubble is a sound a person can hear. Sounds outside the bubble cannot be heard.

Listening fatigue
A phenomenon that can occur after prolonged exposure to an auditory stimulus. Symptoms include tiredness, discomfort, pain and loss of sensitivity.

Mainstreaming
Educational placement of students with disabilities into typical, general education classrooms, for some or all parts of the school day, based on the student's IEP. This placement decision may be rooted in the philosophy that all children with "disabilities" should be integrated with their non-disabled peers to the maximum extent possible, when appropriate to the needs of the child with a disability. Mainstreaming is one point on a continuum of educational options. This term is sometimes used the same way as "inclusion."

Mapping
The term for programming a cochlear implant to optimize the cochlear implant user's access to sound.

Monaural amplification
Using one hearing aid instead of two.

Multi-disciplinary assessment and evaluation
Health care providers representing two or more disciplines, i.e., a speech therapist and an audiologist evaluate the child's development. This determines if there is a need for special services.

Native or home language
The primary language used in the home. Deaf families often use American Sign Language and reading/writing in English. Other native or home languages might include Spanish, Russian, Cantonese, etc.

Oral
An unspecific term that is sometimes used when referring to people with hearing loss and deafness who talk but don't necessarily use sign language. They use residual hearing, assistive technology, lip reading and contextual cues to communicate using spoken language.

Otitis media
A middle ear infection. Children with recurring episodes may experience fluctuating hearing loss and may be at risk for speech/language delays. Fluid can be present with or without infection and may cause temporary hearing loss, which can evolve into permanent loss.

Oto-Acoustic Emissions (OAE)
A test that verifies cochlear activity, often used to check a baby's hearing in the first day or two after birth. This test uses a probe placed in the ear canal releases quiet sounds and measures the response from the cochlea.

Otologist
A physician who specializes in medical problems of the ear.

Output
The amount of amplification (loudness) that a hearing aid produces. Measured in decibels.

Part B
The section of IDEA about special education and support services available to eligible children from three to 21 years of age.

Part C
The section of IDEA about diagnostic and early intervention services available to eligible children from birth through two years of age and their families.

Peri-lingual deafness
Hearing loss that happens while learning a first language.

Post-lingual deafness
Hearing loss that happens after learning a first language.

Pre-lingual deafness
Hearing loss that is present at birth or that happened before learning a first language.

Real-ear measurement
A test to measure the hearing aid output by using a "probe microphone" in the ear canal. It assesses how effectively the hearing aid amplifiers sound in the ear. Every ear canal is shaped differently so it is important to test actual hearing aid function in each person.

Relay telephone services
Relay Telephone Service/Relay Network. A service that uses an operator to "relay" conversation between a TDD/TTY user (generally a person with a hearing loss and/or speech impairment) and a hearing/speaking individual using an ordinary, non-adapted phone.

Residual hearing
The amount of usable hearing that a person with hearing loss has.

Signed Exact English (S.E.E.)

Signing Exact English (SEE) is a visual tool used to support spoken English. It is a system that uses manual representations of English vocabulary and grammar and is designed to be used together with speech.

Sensorineural

A type of hearing loss caused by damage to the inner ear (cochlea) and/or nerve of hearing. Sensorineural damage is usually irreversible.

Sign language

The use of sign patterns made with the hands, face and body to express the speaker's thoughts. There are different ways to use sign language—see American Sign Language (ASL), finger spelling, Signed Exact English (SEE).

Simultaneous communication

An approach for educating children who are deaf or hard of hearing that consists of the simultaneous use of both a spoken language and a manual (signed) form of that language (such as English and Signed Exact English).

Sound field system

An assistive listening device that can be helpful in classrooms. The teacher wears a microphone to transmit and amplify sound through strategically placed speakers.

Speech Reception Threshold (SRT)

The faintest level at which a person can identify 50 percent of the simple spoken words presented and repeat them correctly.

Speech Language Pathologist (SLP)

A professional who works with people who have specific speech and language needs.

Speech Awareness Threshold (SAT)

The faintest level at which a person can identify 50 percent of the spoken words presented and point to pictures or repeat them correctly.

Speech intelligibility

The ability to be understood when speaking.

Speech banana (speech zone)

The area on an audiogram (graph) that shows the range of decibels and frequencies where most of the sounds of speech occur. It's called the "speech banana" because of the shape of the area on the graph. The purpose of wearing hearing aids, cochlear implants and other assistive technology is to amplify sound into this zone.

Speechreading

A way to interpret and understand speech that relies on visual cues, sometimes called "lip reading." The speechreader watches lip and mouth movements, facial expressions and gestures, and considers structural characteristics of language and contextual clues. She may also use residual or aided hearing for extra cues.

Syntax
Defines the word classes of language, such as nouns and verbs, and the rules for which words can be combined and in what order.

Telecommunication Devices for the Deaf (TDD)
Originally and often still called Text Telephone (TTY), these electronic devices allow the people with hearing loss to communicate via a text telephone system. This term appears in Americans with Disabilities Act (ADA) regulations and legislation.

Tinnitus
The sensation of ringing, buzzing or other sounds in the ears. The noise can be intermittent or continuous and can vary in loudness.

Total communication
The philosophy of educating children who are deaf or hard of hearing that makes use of a number of modes of communication: formal signs, natural gestures, finger spelling, body language, listening, lip-reading and speech. Children in these programs typically wear hearing aids or cochlear implants.

Tympanogram
A pressure or "impedance" test that tells how the ear canal, eardrum, eustachian tube and middle ear bones are working. It is not a hearing test.

Unilateral hearing loss
A hearing loss in one ear.

Video relay/video phone (VRS)
Video Relay Service is a communication technology where the deaf and hearing consumers are in different locations and are linked through an interpreter provided through a relay center. Users of VRS must have equipment that allows them to send their image to the Relay Center. Once connected, a deaf caller can simply sign a message to the sign language interpreter, who conveys it to the person called. That person, in turn, can reply and the interpreter will transmit the message in sign language back to the deaf caller.

Virtual home visits
Services provided through two-way interactive video conferencing (tele-health/tele-intervention).

Visual Reinforcement Audiometry (VRA)
A method used to test hearing in young children. For example, the child learns to look at a toy that lights each time he hears a sound.

Staying Organized

This section has tips to help you prepare for appointments and stay organized. We include questions you may want to ask your early support team. You'll find pages where you can write down the names and phone numbers of the people you talk with, information about appointments, and details about amplification if your child wears hearing aids. You can also use the blank pages at the end of the notebook to write notes. We encourage you to bring this notebook with you to appointments and when you visit with your early support team.

Have a friend or family member take notes during the appointment.

Preparing for Your Child's Appointments

Below are some helpful hints about getting ready for your child's appointments. We also include questions you may want to ask your early support team. These questions were adapted from a resource from the Centers for Disease Control and Prevention (CDC) called *Questions You May Want to Ask*.

You can find the full list of questions on the CDC website: www.cdc.gov/ncbddd/hearingloss/freematerials.html

Before your visit

- Make a list of concerns or things you are worried about.
- Write down any questions you have (big or small). The *Questions You May Want to Ask* brochures have great ideas too!
- Take a friend or family member with you. They may help you remember questions or take notes.
- Keep this notebook with you. You can take notes in it, keep track of your appointments and organize information the doctor gives to you at the visit.

During your visit

- Ask the questions you prepared or let the doctor read your list and answer them.
- Have a friend or family member take notes during the appointment, so you can review the information later. You may also think about asking to record the conversation, especially if you are feeling nervous or scared.
- Ask the doctor to explain any words that you don't know or haven't heard before.
- Repeat what you heard, just to make sure you understood everything correctly.

- Find out who to call if you have questions when you get home.
- Ask the doctor for recommended resources, such as local organizations, books, videos or websites that might be helpful for you or your family.

After your visit

- Review your notes and talk with others who went to the appointment, just to make sure you understood what was said.
- If you have questions, contact your doctor.
- Review the resources your doctor recommended.
- Make an appointment for a second opinion, if needed.

Care Plan for Infants who are Deaf or Hard of Hearing

Child's Name _____ ***Child's Date of Birth*** _____

Now that you have learned your child has hearing loss, this care plan can help you understand the next steps.

- ○ **Continue to have your baby see his or her primary care provider** for well child exams.
- ○ **Ask your baby's audiologist about early intervention services.** The Early Support for Infants and Toddlers (ESIT) Program provides services for infants and toddlers who have disabilities, including hearing loss (birth to three years of age). A Family Resources Coordinator (FRC) can help you access services such as family training, counseling, and other early intervention services your child and family may need—including specialized help to meet the unique communication needs of infants and toddlers with hearing loss.

  Every community has an early intervention program (it may be called an early learning program). The FRC in your community will help you with early intervention services eligibility for your child. To locate the Lead FRC in your county, call the Family Health Hotline at **1-800-322-2588**. Or you can find your county's Lead FRC by visiting: **http://www.del.wa.gov/publications/esit/docs/ContactsDirectory.pdf**
- ○ ***Infants and Toddlers Who are Deaf or Hard of Hearing* is a state brochure for families** who have just learned their child has hearing loss. It can be found at: **http://del.wa.gov/publications/esit/**
- ○ **Contact family support groups:**

  Washington State Guide By Your Side: 425-268-7087
  Washington State Parent to Parent: 1-800-821-5927
  Washington State Father's Network: 425-653-4286
- ○ **Learn more about the type of communication options available.** The Center for Childhood Deafness and Hearing Loss (CDHL) can provide you with information about the different ways a child can learn language. Someone at the CDHL can work with you and your Family Resources Coordinator to help you explore communication options. Contact the CDHL at: 1-800-613-4228.

continued

Care Plan continued

- ○ **Make sure you have the Hearing Loss Helper Guide.** This notebook includes stories from other parents, tools to help stay organized, and information about hearing loss, communication options, and early intervention services. The Hearing Loss Helper Guide is a free resource. You can get it from your audiologist or download it at **www.doh.wa.gov/earlyhearingloss**.
- ○ **If you choose amplification for your infant**, have your baby fitted with hearing aids. If needed, find out about loaner hearing aids. An evaluation by an ear, nose, and throat (ENT) doctor needs to be done before your child can be fitted with hearing aids.

  ENT Clinic _____ Date _____

- ○ **Continue with regular visits to a pediatric audiologist** to check your baby's hearing and hearing devices. Pediatric audiologists are specially trained to evaluate and provide care for infants.
- ○ **Consider a genetic consultation.*** A genetic consultation will determine if your child has any other health issues that may be associated with hearing loss and can help you learn if your child's hearing loss may run in your family.

  Medical geneticist/genetic consultant _____ Date _____

- ○ **Contact other medical specialists*** (eye, heart, etc.) as needed.

  Specialist _____ Date _____

  Specialist _____ Date _____

To learn more, please visit: www.doh.wa.gov/earlyhearingloss and **www.babyhearing.org**

* You will usually need a referral from your health care provider to see these specialists.

The Early Hearing Loss, Detection, Diagnosis & Intervention (EHDDI) Program

Phone: 206-418-5613 • Fax: 206-418-5415 • E-mail: ehddi2@doh.wa.gov

Web site: www.doh.wa.gov/earlyhearingloss

Washington State Department of Health
DOH 344-033 May 2014

For persons with disabilities, this document is available on request in other formats.
To submit a request, please call 1-800-525-0127 (TTY/TDD 711).

Healthy Communities Washington
Partners promoting healthy people in healthy places
www.doh.wa.gov/healthycommunities

Important Contact Information

Please take time to complete the following information. You will need it from time to time, and you'll be glad to have it organized and easy to find in one location. Make sure you have your child's insurance card with you when you take your child to different medical services.

Doctors and Medical Providers

Pediatrician or Family Practitioner

Name: _____ Name: _____

Address: _____ Address: _____

City: _____ City: _____

Phone: (_____) _____ Phone: (_____) _____

Email: _____ Email: _____

Audiologist

Name: _____ Name: _____

Address: _____ Address: _____

City: _____ City: _____

Phone: (_____) _____ Phone: (_____) _____

Email: _____ Email: _____

Otologist, Otolaryngologist or Ear, Nose and Throat (ENT) Doctor

Name: _____ Name: _____

Address: _____ Address: _____

City: _____ City: _____

Phone: (_____) _____ Phone: (_____) _____

Email: _____ Email: _____

Medical Geneticist/Genetic Counselor

Name: _____ Name: _____

Address: _____ Address: _____

City: _____ City: _____

Phone: (_____) _____ Phone: (_____) _____

Email: _____ Email: _____

Other

Name: _____ Name: _____

Address: _____ Address: _____

City: _____ City: _____

Phone: (_____) _____ Phone: (_____) _____

Email: _____ Email: _____

Specialists and Counselors

Family Resources Coordinator (FRC)

Name: _____ Name: _____

Address: _____ Address: _____

City: _____ City: _____

Phone: (_____) _____ Phone: (_____) _____

Email: _____ Email: _____

Center for Childhood Deafness and Hearing Loss (CDHL) Consultant

Name: _____ Name: _____

Address: _____ Address: _____

City: _____ City: _____

Phone: (_____) _____ Phone: (_____) _____

Email: _____ Email: _____

Early Intervention Specialist

Name: _____ Name: _____

Address: _____ Address: _____

City: _____ City: _____

Phone: (_____) _____ Phone: (_____) _____

Email: _____ Email: _____

Teacher of the Deaf

Name: _____ Name: _____

Address: _____ Address: _____

City: _____ City: _____

Phone: (_____) _____ Phone: (_____) _____

Email: _____ Email: _____

Children with Special Health Care Needs (CSHCN) Coordinator

Name: _____ Name: _____

Address: _____ Address: _____

City: _____ City: _____

Phone: (_____) _____ Phone: (_____) _____

Email: _____ Email: _____

Aural Rehabilitation Specialist

Name: _____ Name: _____

Address: _____ Address: _____

City: _____ City: _____

Phone: (_____) _____ Phone: (_____) _____

Email: _____ Email: _____

Speech Language Pathologist

Name: _____ Name: _____

Address: _____ Address: _____

City: _____ City: _____

Phone: (_____) _____ Phone: (_____) _____

Email: _____ Email: _____

American Sign Language (ASL) Specialist

Name: _____ Name: _____

Address: _____ Address: _____

City: _____ City: _____

Phone: (_____) _____ Phone: (_____) _____

Email: _____ Email: _____

Counselor/Therapist

Name: _____ Name: _____

Address: _____ Address: _____

City: _____ City: _____

Phone: (_____) _____ Phone: (_____) _____

Email: _____ Email: _____

Social Network

Other Parents of Deaf and Hard of Hearing Children

Name: _____ Name: _____

Address: _____ Address: _____

City: _____ City: _____

Phone: (_____) _____ Phone: (_____) _____

Email: _____ Email: _____

Deaf and Hard of Hearing Adults

Name: _____ Name: _____

Address: _____ Address: _____

City: _____ City: _____

Phone: (_____) _____ Phone: (_____) _____

Email: _____ Email: _____

School District

School

Name: _____

Address: _____

City:_____

Phone: (_____) _____

Email: _____

School Nurse

Name: _____

Address: _____

City: _____

Phone: (_____) _____

Email: _____

Other Resources

Name: _____

Address: _____

City:_____

Phone: (_____) _____

Email: _____

Name: _____

Address: _____

City: _____

Phone: (_____) _____

Email: _____

Name: _____

Address: _____

City:_____

Phone: (_____) _____

Email: _____

Name: _____

Address: _____

City: _____

Phone: (_____) _____

Email: _____

Appointments Schedule

When you go to your child's appointments, it is helpful to make notes of your visit. Write down answers to your questions and any instructions given by the service provider. This is helpful when you may need to request medical records for another provider or for the school district. Make more copies of this page as needed.

Date, time and place of appointment: _____

Provider's Name: _____

Purpose of appointment: _____

Notes:

Date, time and place of appointment: _____

Provider's Name: _____

Purpose of appointment: _____

Notes:

Date, time and place of appointment: _____

Provider's Name: _____

Purpose of appointment: _____

Notes:

Amplification Information

If your child uses hearing aids, it may be helpful to write down details about your child's hearing aids. Having this information on hand can be useful when you are talking to your child's audiologist, the hearing aid manufacturer or your insurance company.

Hearing Aids Information

Type of Amplification	Right Ear	Left Ear
Make and Model:		
Serial Numbers:		
Date of Purchase or Fitting:		
Date Warranty or Guarantee Expires:		
Ear Mold Material and Style:		
Date the Ear Mold was Fitted:		
Accessories:		
Accessories:		
Accessories:		

Amplification Contacts

Type of Contact	Contact Name	Phone	Email
Repair			
Programming			
Insurance			
Other			

Questions For Your Early Support Team

Asking questions is always okay, but you might not necessarily know what to ask sometimes. Below are some possible questions you may want to ask your child's audiologist, Family Resources Coordinator (FRC), early intervention specialist or others in your early support team.

Questions About Hearing

How much hearing does my child have? Please explain the terms sensorineural, conductive, mixed, mild, moderate, severe, profound and auditory neuropathy spectrum disorder.

Is the loss permanent? Does my child need more testing? How often should my child's hearing be tested?

Can you tell me if my child's hearing level will change or get worse?

Do both ears have the same hearing level?

How will the hearing level affect my child's speech and language development?

What could have caused my child's hearing level?

Would you suggest genetic counseling for our family?

Please explain the audiogram or the report.

May I have a copy of the hearing test results?

Questions About Hearing Aids and Cochlear Implants

Would my child benefit from using hearing aids?

What are my choices for hearing aids? Should she have a hearing aid in both ears?

How much do hearing aids cost? Where can I get help to pay for the hearing aids?

Can you help me contact a program that can lend me hearing aids?

What can my child hear with the hearing aids?

How do you test if the hearing aids are working just right for my child?

How many hours should my child wear the hearing aids?

Should my child wear the hearing aids when playing sports?

What should I do if my child loses his hearing aids?

What should I do if my child does not want to wear the hearing aid?

How often do you need to check or adjust the hearing aids?

How often will my child need new hearing aids?

Which part of a hearing aid (such as the earmold and tubing) will need to be replaced regularly?

What is the difference between a hearing aid and a cochlear implant?

Should I consider a cochlear implant (an electronic device placed under the skin behind the ear)?
Where can I get more information?

Questions About Communication Options and Education

What are communication options (such as sign language, listening, and spoken language or total communication)?

When should I begin early intervention, sign language, speech or other therapy?
What is available in my area?

How do I know if my child is meeting important language milestones on time?

If my child is not meeting important language milestones on time, what should I do?

Questions about Support

Is there a parent group in my area? And who should I contact?

Can you help me meet another family with a child who has hearing loss similar to my child's?

Can you help me meet Deaf adults?

Where can I look up more information about hearing?

How do I share the hearing test result with my family?

Do you have tips for my family about how to communicate with my child at home?

Family Goals

Dreams for our child:

_____

_____

_____

_____

_____

Concerns for our child:

_____

_____

_____

_____

_____

What we want to learn:

_____

_____

_____

_____

_____

Family Goals:

1. _____

_____

2. _____

_____

3. _____

_____

4. _____

_____

Updated Goals:

Date: _____

1. _____

_____

Date: _____

2. _____

_____

Date: _____

3. _____

_____

Date: _____

4. _____

_____

Family Stories

This section contains real stories from families with children who are deaf or hard of hearing. They have agreed to share their experiences to help support and encourage other families.

We hope you enjoy reading these stories and encourage you to reach out to other families through Guide By Your Side™ or other parent support groups. Hearing from parents who have been through similar experiences is a great way to learn and be supported.

We hope you enjoy reading these stories.

Marc and James
An Awesome Team!

Marc and James are an amazing father and son team.

They both live in the Yakima Valley surrounded by their family. They are both bright and possess a quick wit. Marc is a college graduate and works as a graphic design artist. James is in the 3rd grade and works with LEGOs®.

Both Marc and James have been deaf since birth and, through dedicated work, they have learned to communicate with others. Marc began working with his local hearing and speech center in 1971, the year it opened. James began attending the same hearing and speech center in 2002, the year he was born.

Together with their local team of doctors, specialists, therapists and personal support network, they are continuing to grow and share their talents with their community.

A Communication Dream

by Natalia's family

The wish to communicate is a dream for many people. This is our story of making a dream come true.

Natalia is now three years old. She was born with several challenging medical conditions. She has a medical history of congenital cytomegalovirus (CMV), spastic cerebral palsy with quadriplegia, a feeding tube, progressive hearing loss, microcephaly and a developmental delay. Natalia is unable to speak or to move her hands for communication.

We continue learning to use a total communication approach with Natalia. Recently, Natalia was fitted with binaural hearing aids at a children's hospital. Our family participates in the Parent-Infant Child Program for deaf and hard of hearing children at our local speech and hearing clinic. We work closely with Natalia's team of professionals, including her resource teacher at our local public school, teacher of the deaf at our local speech and hearing clinic, the Special Education Technology Center at our local university, speech language pathologist and physical therapist. Natalia's team is working closely together to provide her with appropriate techniques and materials to enable her to achieve both receptive and expressive language as well as a sense of control and accomplishment. When school began in September, Natalia had a head switch attached to her wheelchair so that she can learn to play games and she will eventually use her head switch for communication.

We are committed to learning basic sign language to use in communicating with Natalia. We are also learning to monitor her hearing aids and to call attention to sounds as they occur. Natalia is much more content now that she has access to sounds. We will continue to bring language to her through speech and sign language.

Team Wendorf: Growing Together

by the Wendorf family

We are Team Wendorf—a family of six. We want to give you a quick snap shot of our family, our son and our life with hearing loss.

The Beginning

Our son Kai was born six weeks early and only 14 months after his big sister Lucia. We noticed immediate differences between Kai and Lucia, from the way they observed people to the way they responded to visual elements. We had several people tell us Kai was the most observant baby they had ever met. As an infant Kai would study people's faces intently, which seemed atypical to many.

Kai had failed his newborn hearing screen. At the time we did not really know what that meant, but we were not concerned. A nurse informed us that 90 percent of babies fail due to fluid that has not drained from their ear canals. Four months later Kai failed another hearing screen and, when the hospital called to follow up on Kai's inconclusive hearing screen, we finally took Kai to a children's hospital for a BAER test.

Two hours after his initial BAER test, we were told that Kai has a moderate bilateral sensori-neural hearing loss. We were given a pamphlet on hearing loss, a hug and another appointment scheduled in six weeks for more tests. The news was strange and unexpected; we didn't even know what all those words meant but we just kept going knowing this was all in God's plan for our family and our son.

After several phone calls, a providential family connection to a nationally-known hearing loss expert, and a handful of professionals who were willing to educate us, we found ourselves at the pediatric audiology department with our wonderful audiologist. By the time Kai was six months old, he had his first pair of loaner aids and had started auditory verbal therapy through a local organization.

The Blessing

When Kai was 18 months old, our third child, Otto, was born. Otto was thoroughly tested for hearing loss and the BAER showed normal hearing. It was not until we confirmed that Otto had normal hearing that we grieved the loss of "normal" in Kai. The emotion was difficult to process because it felt like we were denying who Kai is, or wishing for him to be different. We felt we had failed our son living in a world of denial and naivety.

In the midst of our emotion, we realized something beautiful—that we had come to view the "loss" not as such but rather the amazing blessing to live life with Kai in a wholly new and unexpected way. We jumped with both feet into a world we had never previously given thought to and, in the process, found a renewed beauty, admiration and love in the ability to listen and talk, in the gift of language.

Hearing loss is a part of who Kai is, it shapes who he is and how he experiences every aspect of his world. It is now also part of who we are as a family. In the one minute it took to receive Kai's original diagnosis, everything about our life became different. Swim lessons, play groups, soccer, everyday trips to the grocery

store have become something entirely different for Kai and our family. We no longer take for granted the ease with which people communicate or the natural progression of language development.

Outside of his hearing loss, Kai is like any other little boy. He loves playing ball, skateboarding, reading, playing with trains and cars, slaying dragons, riding his new scooter and hanging out with Battle Cat (our cat). He loves playing with his sister and making his brother laugh. Kai seems to have an intrinsic love of music and has some impressive dance moves. In our own home, while playing games, sharing stories, dancing or painting, his hearing loss is often unrecognizable aside from his cute charcoal gray hearing aids.

However, once outside the comfort zone of our immediate family, Kai's differences become more apparent. If Kai walks into a large room with several people, if friends come to play or if a new face is introduced, he faces new challenges. He must adjust to the noise level, it is more difficult for him to localize sound (even our familiar voices) and he has to accustom himself to new voices. He often struggles to regain his confidence and assert himself as we know he can and want him to.

The Current Path and the End Goal

Upon his original diagnosis and our early meetings with both our audiologist and therapist, we were encouraged to create family goals for ourselves and Kai. These original goals, written in our IFSP, have intensified in nature but stick to the big idea that we desire Kai to be successful in a normal hearing world.

In order to achieve this goal, we desire for Kai:

- to be mainstreamed into our neighborhood Kindergarten along with his peers.
- to clearly articulate his speech so that someone unfamiliar with Kai can understand and respond to him.
- to be able to tell a sequential narrative in order to explain something that has happened.
- to be able to confidently play and converse with other children, aside from his siblings, during play.
- to be able to use words to articulate emotion.

Every day we are humbled, amazed and encouraged by Kai's language development. His encouraging growth is due in large part to the professionals who have helped us navigate the waters of having a child with hearing loss. We are excited and scared as we prepare to enter into a new season outside Early Intervention Services and into the IEP process.

In accordance with our goal and dream for Kai to enter mainstream Kindergarten, we want him to have continued support, direction and teaching by trained teachers of the deaf. There is still much work to be done before he is able to clearly and articulately communicate with someone unfamiliar to him, and can participate in our neighborhood Kindergarten classroom. In order to equip Kai with not only the language skills necessary to be successful, we know he will need to be taught to advocate for himself in a way that is specific to a child with hearing loss. We believe these needs can be best met by professionals who have been specifically trained and have experience working with other children (and families) with hearing loss.

A Million Miles Away: A Family's Journey

by the Spencer family

Unlike many parents our son's diagnosis didn't come with grief, fear or a sense of the unknown (that came much later). Our son, Nathan, was adopted from China when he was six years old with a known hearing loss. How bad it was we had yet to discover. Once we met Nathan and brought him home, our adventure really began.

We were arrogant and assumed information on raising a Deaf child would be readily available—on this we were mistaken. We got Nathan into see a specialist as soon as we could. It took three months from the time he came home. During that time we used some simple signs at home and worked with him to understand that this was a way of communicating. He had not been taught any formal communication previously. Nathan was diagnosed with bilateral profound hearing loss; essentially he heard a jet engine as a whisper.

Trying to decide how we were going to raise him was a challenge as well. Did we use ASL, SEE, obtain aids or even a Cochlear Implant? Unlike parents making a decision for a baby, we had a little boy who had thoughts of his own. We don't know Nathan's medical background, but we feel at one time he heard. Nathan asked for hearing aids and later a Cochlear Implant. Nathan now has one aid and one CI; he is in weekly therapy for sounds and speaking. Our home is using SEE to communicate; not ASL, as we had previously thought we would.

For a little over a year, my husband and I fluttered around on the outskirts of information. We have found it to be very difficult to get information once you are past the birth-to-three programs. Here is where the sense of the unknown really hit. The system is great for younger hearing loss identification; there are wonderful programs for the very young that help to transition children into school. Finding resources for a six-year-old is challenging. Getting entry into the Deaf community with an older child and hearing parents has also been a challenge. I've learned to trust my instincts and never give up.

Our family has attended Deaf Family Camp for the last two years and that has been a huge help. We've garnered information and met other families like ours, parents doing their best to meet their children's needs. After a year home, we finally have gotten some information and feel we are on the right path for our family.

Whether you have an infant or older child with hearing loss, know this—never give up, be your child's best advocate and be flexible. What you decide might change and that is okay. Take all the information that people give you—call all the numbers, get involved in play groups, research education options—and never be afraid to raise your hand and say that you need help.

Nathan is now just seven and the road before us is long. Nathan has made great progress in a short time. We have become the best advocates for our son. We still have much to learn but I have a feeling that will be a lifetime process as our son grows and his needs change.

The Luetke-Stahlman Family Story

by Barbara Luetke

After having two hearing children, we decided to adopt a deaf child. Mary Pattie (MP) came into our lives when she was 2½. Her older sisters were five and 10 years old at the time.

MP had hearing aids and vocalized but we couldn't understand what she was saying. She was just beginning to have some behavior issues, frustrated that she could not express her needs and desires. We began to sign as a family and chose Signing Exact English (SEE) because we were already an English speaking family. SEE was used by the speech therapist (SLP) and Teacher of the Deaf (TOD) in the school district where MP would be enrolled when she turned three years of age. They gave us published research that supported our desire to have MP educated using the same quality of language instruction that our hearing girls were receiving in school.

MP was enrolled in the preschool for children with hearing loss but mainstreamed with a SEE transliterator for Kindergarten (through college). A TOD consulted with her general education teacher to make sure that the modifications listed on her IEP were in place. She was implanted at four years of age and developed highly intelligible speech, graduated high school and college and earned a masters with honors.

MP and her deaf sister, Marcy (whom we adopted at four years of age) learned ASL as pre-teens. MP married a deaf man, has held a variety of professional and managerial jobs, and today is a happy young adult able to speak, sign, read and write grammatically accurate English and sign ASL when needed.

Marcy, who was in a self-contained (resource) room for students who were D/HH for preschool through 5th grade, began to mainstream into general education classes with a SEE transliterator in middle school. She also graduated HS and college and now works as a professional in the same SEE deaf education program in which she was enrolled as a HS student. Marcy married a hearing man, and also has articulate speech, signs SEE proficiently, and is able to socialize using ASL.

The Boling Family: Full of Love!

by the Boling family (written in 2011)

Our family draws attention wherever we go—people do double-takes and start counting!

We have nine children, no twins, ranging in age from four months to 10 years. Jonathan is our only adopted child and his story starts out differently than most others. He was born in the Fujian province of China. He was abandoned at a bus stop when he was eight months old. He was taken by a police officer to the local orphanage where he spent the next year of his life. At the orphanage he was put through rigorous tests to determine why he was abandoned by his parents. The tests revealed complete bilateral hearing loss. They even conducted a sedated ABR (uncommon over there) to confirm the results.

We had been trying to adopt a child from China for three years and were on a "waiting list" that seemed to be getting longer, not shorter, when we came across his name and picture on a list sent out by our adoption agency. It only took us a day to decide that he "was the one." We knew some sign language and were happy and willing to learn more as needed. The children also knew sign language to some extent and were excited about this new addition to our growing family. Jonathan then spent the next 11 months in a foster home while we waded through the rest of the red tape involved in a Chinese adoption.

When we brought him home at 2½ years old he had had no sign language training, but had his own gestures he used. We were sure he had some hearing because he responded so well to everything around him. No one could ever guess there was anything amiss with him after watching him in any setting. He played well with his new siblings (the one closest to his age is Steven, who is just 3½ months younger) and adapted to other children and adults well. We were surprised when his ABR—a month after we arrived home—came back stating that he was fully deaf. In the same breath, however, we were told that he was a prime candidate for cochlear implants. We knew right away that that was the path we wished to take. We could supplement with sign language as we went along, but providing him with the ability to hear was a gift we couldn't pass by. We truly felt prompted the entire way. The Lord was directing our footsteps as a family through this new world.

Everything was a whirlwind after the initial diagnosis the middle of October, with audiology appointments, an MRI, and trying to figure out how much insurance was going to cover. He was implanted the middle of December (only one week before we finally got the confirmation that our insurance company would cover it to some degree or another). In the end, it turned out that our primary insurance covered 97 percent of the total cost, which was a miraculous blessing. In January he had both implants activated. He was overwhelmed at first and cried, but after a few hours he was happy to keep them on. By that evening they were a part of him he only wanted off when it was time to sleep.

It's been seven months now since he began "hearing" and he is almost 3½ years old. Progress seemed slow to us at first, even though our audiologist and speech therapist kept telling us he was doing wonderfully. We went to see the audiologist every week for the first month, every two weeks for a couple of months, then once a month and now every few months. We homeschool and our speech therapist visits our home once a month to give us encouragement and advice. Much of his progress can be attributed directly to so many siblings constantly talking to and around him. He's in the middle of a group of four of our children who are a total of 2½ years apart, so he has constant verbal interaction with "peers." He can now say two

word sentences like "all done," "my turn," "more water" and "help please." He's learning things relating to his day-to-day life like "hold baby" and "dirty diaper" (he has a 4-month-old sister). He asked us his first question a few days ago—he said "Time for prayer?" when we were kneeling down together. He's learning his colors, numbers, letters and the names of his siblings. He has a great desire to learn to read so we're sure that will come soon as well. He is the most visual child we have **ever** seen. He could lip read when we first met him, to figure out what people were saying. He still watches mouths when he is talked to but, when we sit with him and read a book and he's facing away, he copies the sounds of the words he hears without seeing them formed.

People are very curious about the "devices" he wears, especially since they are on a headband. His ears were so incredibly floppy that there wasn't any way they could hold anything up. So his grandmother devised a headband that the cochlear devices fit in and it works wonderfully! People are really nice when they ask about them—even children—and we are happy to teach and educate others about this wonderful technology. Having a deaf child, before the implants, was only difficult when he needed to stop doing something and we had to run across the room to stop him or across the yard to catch him because he couldn't hear us. Other than that, he was a bright, active, "normal" two-year old. Now with the implants he stops when he's told to stop (as much as any 3-year-old does!) and turns around with a smile when he hears his name. We certainly have a long road ahead of us, and we know there will be bumps along the way, but our entire family has been blessed greatly having Jonathan be a part of us. The other children don't consider him "different" because of his devices any more than they do our oldest daughter (nine years old) who has worn glasses since she was five. We look forward to the future with great hope and excitement and wish the same for anyone else who has a deaf or hard-of-hearing child. There are so many recourses available now to aid those who are diagnosed with hearing loss.

Update: (written in 2016)

We now have eleven children, no twins, ranging in age from one to 15—and another is due this June!

By the time Jonathan was 4½, he no longer qualified for an IEP or special services—he had caught up! He started reading at four and hasn't stopped! He loves reading. He's almost eight and is well above his grade level in every subject. He also speaks **very** clearly; people are amazed when they learn he is totally deaf because he doesn't sound like it at all. He does struggle with hearing in a noisy environment and often asks us to repeat ourselves. He does sometimes sound like an "English as a Second Language Learner" when he puts sentences together in the wrong order. He also struggles more with idioms and sometimes pronounces words he's heard in conversation in funny ways, but he is self-confident and loves being around people. He interacts with both peers and adults well and he is full of love.

Often when his processors aren't on (like when he's getting in bed), he will speak clearly; someone listening would never know he was deaf. He's good at reading lips and knows a few signs for those times he can't hear (like in a swimming pool).

I talked of "bumps" along the road. One of those major bumps happened a couple of years ago when one of his internal implants failed. It took us almost a year to diagnose it properly because the failure was sporadic. It slowly got worse until the processor didn't work at all. We made the decision to have it re-implanted (another surgery). He recovered very quickly from the surgery but it put him back in his oral progression several months. It was stressful but we are glad we did it; it is very important to him.

He is still wearing the headband that his grandmother made him to keep his processors on his head (he's a very bouncy child) but he's come a long, long way. It hasn't been easy but it has been amazing and very rewarding. He is a miracle child!

Olivia's Story

by Bryan and Heather Milliren

It was a bright, sunny, spring afternoon and we drove eagerly to the university hearing center for some much anticipated news. We now realize how unprepared we were for what we were about to hear. Olivia was our only child, just 16 months old. As all-new parents, Olivia occupied the center of our thoughts and worries.

It was one year earlier that we gleefully attended our town's big, spring parade. Olivia, then five months old, sat in her stroller watching the cars, clowns and people eating cotton candy. In the distance a fire engine approached, delighting toddlers and startling babies. As the engine rolled passed. the driver gave a quick blast of the horn. While other babies stirred or cried with surprise, Olivia sat contentedly without notice, playing with her toy. Oddly, we had just watched a similar scene play out in the movie *Mr. Holland's Opus.* Needless to say, this experience produced many internal questions and unsettling doctor visits. One year later and weary from delays, referrals and repeated appointments, we sat in the hearing center eager for an answer. What answer, we had no idea. But when the doctor delivered the word that Olivia had a "severe-to-profound hearing loss in both ears," we sat puzzled and unsure. We left in silence. Tears came soon afterward. Grief set in quickly, as well as an overwhelming sense of "What's next?"

Now almost seven years have passed and what an adventure it has been. Those initial days of sadness and uncertainty have been filled with joy and gratitude. Initially, we knew we needed to make up for lost time, almost 17 months. We signed up for any and every early intervention possible: aural habilitation, birth-to-three playgroups, speech therapy, etc. We began working with a local audiologist to fit Olivia with digital hearing aids, and we enrolled in a sign language class. Olivia patiently endured her new regimen of five to seven appointments per week. We saw dramatic results almost immediately—Olivia's language exploded! She even impressed the speech therapist by learning 10 new signs in less than five minutes. Olivia was ready to learn and she needed us to dive right in with her. This turned out to be the best therapy for us as well.

Olivia's hearing aid usage changed dramatically over time. The audiologist's initial goal was for Olivia to wear her hearing aids 10 minutes, three times per day. We were lucky if they stayed in for 10 seconds! After 17 months of quiet, hearing-aid-free life, Olivia didn't want to cooperate. We persisted and slowly built up to 10 minutes. Then 15 minutes, 30 minutes, one hour. We had setbacks by way of illness, etc., but still we persisted. Yes, it was discouraging at times but, after several months, Olivia wore her hearing aids for the majority of her alert time. Our goal was, and still is, to stimulate Olivia's nerve endings and help her to access as much sound as possible through her residual hearing. We know that some day she may choose not to wear them but, until that time, we encourage Olivia to access sound through her hearing aids.

Olivia's sign language ability also blossomed rapidly in her new classes. Now, of course, she signs faster and more accurately than we do. She frequently teaches us new signs with a joyful smile. It is amazing how adaptable Olivia is using American Sign Language, Signed Exact English or Pigeon Signed English. Olivia learned to read lips early, "popcorn" being her first lip-read word. She also works very hard to use spoken language. She rarely lets on to others her challenge of hearing the soft frequency sounds of "s," "f" and "th." We often receive compliments on how well she speaks, but Olivia deserves most of the credit. She is a truly hard worker! We are so grateful for her supportive, flexible and exceptionally knowledgeable therapists and educators.

Olivia's hearing loss has opened up a whole new world for our entire family. We are learning a new language, building relationships with people we may have never known and listening. not just with our ears, but with eyes and hearts as well. It hasn't always been easy, and at times the stretches were difficult. Upon realizing that our small, rural community had few appropriate educational opportunities for Olivia, we moved to support her with a deaf and hard-of-hearing educational program. This meant leaving our first home, our church family, and added a lengthy commute to work. It meant establishing ourselves in another county and trying to find a way to reach out and connect with our local special needs community. Along the way, we have met with tremendous support. Our extended family and many in our church family have taken sign language classes in order to communicate with Olivia. We have found great love and encouragement as we learn the unique challenges of not only raising a child with a hearing loss, but also her younger siblings. In return, we offer our support and encouragement to other parents raising a child with a hearing loss or other special need.

We have come a long way in nearly seven years. We were so encouraged by a phone call from our local Parent-to-Parent coordinator in the first few days following that spring diagnosis. In our grief, we listened as she shared her journey of decision-making for her own daughter with a hearing loss. The most freeing statement she said that sunny May day was, "If you make a decision that doesn't work for your family, change it!" And, we have. We needed to find out for ourselves which hearing aids to choose, which communication method to embrace, which preschool to attend, which medical practitioner to select for Olivia and our family. Those decisions led to other decisions, like moving to a different community, selecting the best school program and advocating for Olivia's educational plan. We have made mistakes, but we have also met with great success and reward. Although initially we wanted to "fix" Olivia's hearing and make up for her first 17 months without sound, we now gratefully embrace the life we have. And that's a life where all the questions are not answered, the future is still uncertain, but the adventure is great and the growth potential is enormous.

The Hallway: A Family's Journey

by Christine Griffin

Perhaps you've heard the saying, "when one door closes another door opens" but no one tells us about the hallway. In this instance, the hallway represents the journey, a journey that starts from the first moment a parent or family member is told their child is hard of hearing or deaf.

When our two children were diagnosed ten years ago, we were shocked. We didn't know what to do, after all, no one in our family had a hearing loss. So, to help gain information, I talked to just about everyone who crossed my path, really—at the park, in the supermarket, over the phone, anywhere. And what I soon found out was that there weren't many people who knew specifics of supporting parents and a child with a hearing loss. Locating a "front door" to services was near impossible in our area, mostly because I didn't know what to ask. As it was, I barely could remember what the audiologist rattled off to me at our appointment, "Bilateral sensory neural hearing loss. What?"

When I finally had my first conversation with another parent, I was over the moon and, even though our experiences were different, she told me, "Be the best advocate for your child and trust your gut."

Shortly thereafter I was introduced to a parent support program that was housed in a local early intervention center where our daughter attended. This is where I could finally express myself to other parents, learn about resources and, most importantly, felt heard and understood for the first time in many months. No longer did I feel isolated; I soon found acceptance and validation from other parents that enabled me to take the next steps to help our children.

We soon learned that the success of our children lay within our hands as involved parents. Yet, learning new information in a very short period of time, along with balancing other parts of our lives, was also very stressful for my husband and me. In the PBS documentary *Stress – A Portrait of a Killer*, parents of children with disabilities were studied and found to be some of the most stressed out beings on this planet. It was found that, with long periods and high levels of stress, the ends of the DNA strand actually fray and begin to unwind, cutting five years off for every one year of these parents' lives. Thankfully, there is a natural healing to the DNA, which is found by parents supporting one another. We believe that parent-to-parent support is not a nicety, it is a necessity.

Therefore, if I can offer anything to you on this day, it would be to reach out to others and ask for help or clarification when you need it. Stay connected, if it only means signing up for a newsletter or joining a list serve. There is so much hope for your child; the joys will far outweigh the challenges and the hallway is a place to learn and grow.

A Rewarding Journey

by Natalie Delucchi

We have a 5-year-old son with a cochlear implant and a 2-year-old daughter who was just diagnosed with progressive hearing loss. It has been quite the journey but so rewarding.

Our son is going into our local kindergarten, testing out two years above age level. Before his implant, he had maybe 15 words. Our son attends a deaf oral school that has changed our life. Our daughter will start there next year.

Hearing loss is who we are and it makes our children so special and unique. They amaze us every day and have taught us to never take hearing for granted—from listening to the birds sing to the flushing of the toilet. Their disability is a blessing!

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