WASHINGTON STATE HEARING LOSS HELPER

for Families of Children with Hearing Loss

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INTRODUCTION

Have you just learned that your child has a hearing loss? If so, the diagnosis of hearing loss is often a very emotional time for parents and families. You likely have a lot of questions too. This notebook includes information designed to help you learn about your child's hearing loss, communication options, and resources near your home.

We hope this notebook empowers you and helps you feel confident about finding resources and advocating for your child. Many families find that taking this notebook to all of their child's appointments makes it easy for them to keep their medical papers and appointments organized. Please personalize this book as much as you would like, as 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 your child's audiologist or doctor.

Resource Worksheet

As you use this guide, you may want to keep track of the different resources you have contacted in the tables below.

Program	Contact Name	Phone	Date of Visit	Notes

Books read, videos watched, websites visited	Notes

Parent of Deaf or Hard of Hearing Child	Phone	Name & Age of Child	Notes

GETTING STARTED:

Feelings About Your Child's Hearing Loss

Learning about your child's hearing loss may have confirmed what was already suspected or it may have come as a shock. Some parents easily accept a diagnosis of hearing loss. Others have a hard time accepting it, sometimes for a long time. Whatever your reaction is, it is *normal*. Please remember that you are not alone.

You will find that there are many decisions to make about your child's care. You may also need to make important decisions while still feeling overwhelmed. 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. Most importantly, be prepared to make or change decisions as your child develops and his or her needs change.

This book provides resources from organizations that are experienced in working with families who are similar to yours (see *Resources*). These organizations will happily help you address current and future concerns. We have also included stories from local families and suggestions from two children who have grown up with hearing loss, Sawyer and Tess. We hope you find their words helpful.

What Do We Do Today?

The first few weeks and months after learning about your child's hearing loss 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. Some studies indicate that over 90% of what we "say" is shown through nonverbal communication, such as facial expressions and body language. Your baby can learn how to read your face and body, even if he or she can't hear your spoken words.

Babies learn from the routines you have and things you do or say in everyday life. Talk to 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.

Below 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.	While rocking or cuddling with your baby, sing lullabies and tell him how much you love him.
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.
Use 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 he 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/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.
Respond to your child's facial expressions. *This may also be a good time to help your child learn the word or sign for their 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.

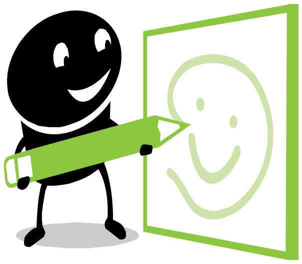
- **CONTACT THE FAMILY RESOURCES COORDINATOR (FRC) FOR YOUR COUNTY.**

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 (Gold tab).

- **KEEP A JOURNAL OR NOTEBOOK FOR YOUR CHILD.**

We have included some writing topics (below) and a goal setting worksheet (next page) 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.**

This notebook is the perfect place for keeping copies of clinical reports and important forms. Take this notebook to your child's appointments too. If the doctor needs copies of reports, you will have them with you, and you will have a place to store new materials too.

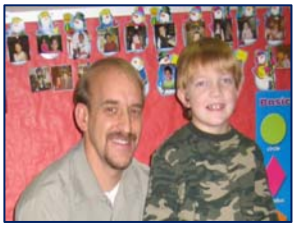
- **SEEK SUPPORT FROM FAMILY AND FRIENDS.**

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 methods for children with hearing loss and their families. The *Communication Options* section of this book has information on some of the options. We have also included personal stories and a few photos from local families.

An Awesome Team! – A family's story



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.

Family Goals

Dreams for our child:

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Concerns for our child:

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What we want to learn:

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Family Goals:

1.)____
2.)____
3.)____
4.)____

Updated Goals:

Date:__________ 1.) ____
Date:__________ 2.) ____
Date:__________ 3.) ____
Date:__________ 4.) ____

YOUR CHILD'S HEARING

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

- How the ear works.
- How your child's hearing is tested.
- Types and degrees of hearing loss.
- The audiogram.
- Frequently asked questions about hearing loss.

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 tympanic membrane to vibrate, which causes the three middle ear bones (ossicles) to move.
- The movement of the ossicles causes pressure changes in the fluid of the inner ear, or cochlea.
- These pressure changes cause a structure in the inner ear, called the basilar membrane, to stimulate cochlear hair cells.
- The movement of the cochlear hair cells sends the signal through the auditory (hearing) nerve to the brain.

"Always make eye contact when you communicate. That way your child can see your expressions and get a better idea of what you are saying. Like with my sister, I always have to make sure she sees my face when I'm talking to her." – Sawyer, age 15

How Does the Ear Work?

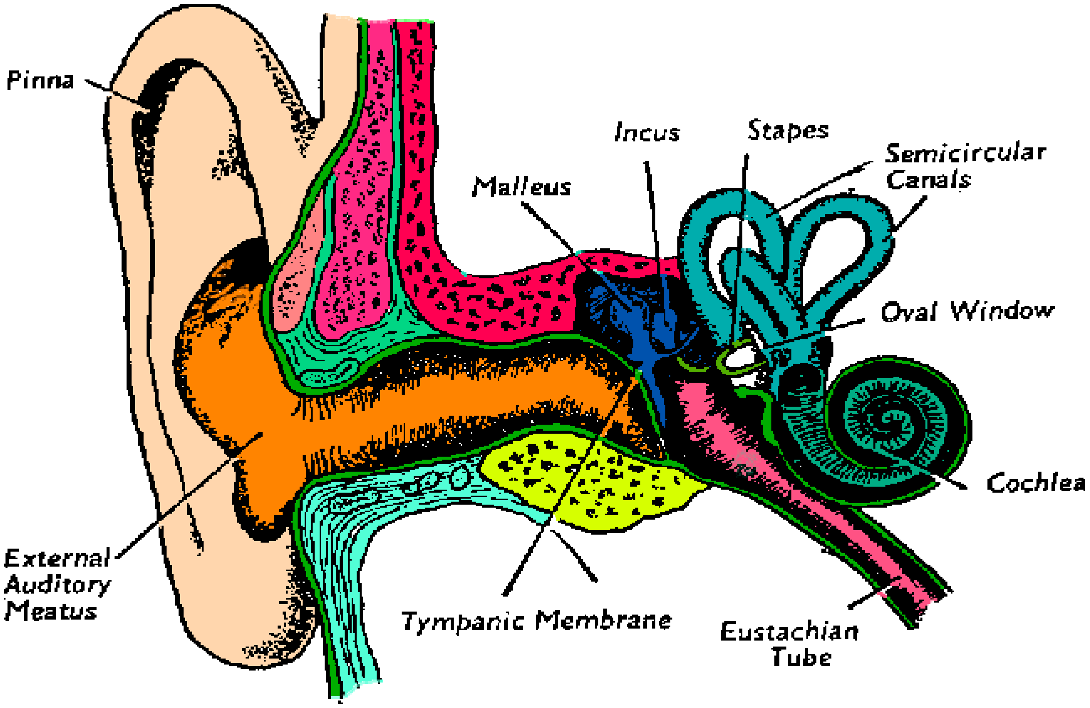
PARTS OF THE EAR

There are three parts to the ear – the external ear, the middle ear, and the inner ear. Each of the three main parts has several smaller parts.

OUTER EAR:
- Pinna (the part we see).
- Ear canal (external auditory meatus).

MIDDLE EAR:
- Tympanic membrane (eardrum).
- The ossicles (malleus, incus, stapes; also referred to as the hammer, anvil, and stirrup).
- Eustachian tube.

INNER EAR:
- Vestibular system (used for balance).
- Vestibular (balance) nerve.
- Cochlea.
- Auditory (hearing) nerve.



The structure of the Ear.

ABOUT HEARING LOSS

"When your child asks about their hearing loss, be open and honest. Having this information helps them understand and become better advocates for themselves when they grow up." – Tess, age 11 ¾ & Sawyer, age 15

FACTS:

- Hearing loss is the most common birth defect found in American children, but not all newborns are tested for it.
- Approximately 33 babies are born with hearing loss every day in the United States.
- Educating children who don't receive early identification and intervention services is estimated to cost schools an additional $420,000 per child.
- The American Academy of Pediatrics (AAP) recommends that all babies be screened for hearing loss before leaving the hospital.
- For babies found to have a hearing loss, the AAP recommends early intervention services by six months of age for speech and language development.

WHAT IS HEARING LOSS?

Hearing loss is a reduced ability to detect sounds. Many people try to describe hearing loss as a percentage. This is not the most accurate way to describe it. It is better to describe it by the type and the degree of hearing loss.

TYPES OF HEARING LOSS

The type of hearing loss depends on where it occurs in the ear. Your child's hearing loss can be described as conductive, sensorineural, or mixed.

- **CONDUCTIVE HEARING LOSS** means there are problems with the outer or middle parts of the ear. Most times, there is something in the middle or outer ear that blocks the sound from passing through the structures. Medicine or surgery can sometimes help this type of hearing loss.
- **SENSORINEURAL HEARING LOSS** means there is a problem with the cochlea (inner ear) or the auditory nerve. Most times this type of hearing loss is permanent. It is not usually fixed by medicine or surgery. Hearing aids are often helpful.
- **MIXED HEARING LOSS** means there is a problem in both the outer or middle ear and the inner ear.

Your child’s hearing loss may affect one ear or both ears.

- **UNILATERAL** means the hearing loss is in just one ear.
- **BILATERAL** means the hearing loss is in both ears.

DEGREES OF HEARING LOSS

The severity of hearing loss is measured in degrees. There are four 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.

MILD HEARING LOSS: Sounds softer than 25-40 dB are not heard (dripping faucet).
MODERATE HEARING LOSS: Sounds softer than 40-65 dB are not heard (clock ticking).
SEVERE HEARING LOSS: Sounds softer than 65-90 dB are not heard (dog bark).
PROFOUND HEARING LOSS: Sounds softer than 90 dB are not heard (lawnmower).

Your child’s hearing loss may not fall into just one of these categories. For instance, it could be called mild to moderate or severe to profound. The chart on the next page shows the impact that different degrees of hearing loss can have for your child in learning spoken language. Keep in mind that the same hearing loss can affect children in different ways.

TERMS USED FOR HEARING LOSS

Many people confuse the terms hearing impaired, hard of hearing, deaf, and Deaf.

- **hearing impaired** is used for a child with any degree of hearing loss. (Many people don’t like this term and prefer to use the term *hard of hearing*.)
- **hard of hearing** is used if a child has a mild to severe degree of hearing loss.
- **deaf,** when spelled with a little or lower case **d**, means “audiologically deaf.” This term is used to describe a profound or severe to profound degree of hearing loss.
- **Deaf**, spelled with a capital or upper case **D**, is used by the Deaf Community to mean “culturally Deaf.” A person can have *any* degree of hearing loss to be a member of the Deaf Community. Members of the Deaf Community communicate using sign language, and have a culture that they identify as their own.

***From The Hallway – A family’s journey*:**

> *…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…*

Degree of Hearing Loss	What it Means	Without Amplification and Early Intervention	With Amplification and Early Intervention
Mild	The softest sounds a child hears are at levels of 25 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 normal hearing person, 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 40 dB - 65 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 normal hearing person 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 his 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.
Severe	The softest sounds a child hears are at levels of 65 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 normal hearing person will be very soft. – Speech will only be heard if it is shouted in the ear.	– 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 normally hearing people do.

Continues on next page →

Degree of Hearing Loss	What it Means	Without Amplification and Early Intervention	With Amplification and Early Intervention
Severe		– Spoken language comprehension and speech will not develop spontaneously. A child with severe hearing loss will have mostly unintelligible speech.	– Most children will need special accommodations, especially in school, to compensate for the challenges that distance and background noise present.
Profound or Severe-Profound	The softest sounds a child hears are at levels of 90 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, especially in school, to compensate for the challenges that distance and background noise present. – Children can develop age-appropriate language comprehension and language usage. *With Hearing Aids Only:* – Many children still need 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). – To learn more about cochlear implants, see our *Communication Options* section or talk to your child’s audiologist.

YOUR CHILD'S TEAM

WHO CAN HELP?

You will meet many professionals and other people who can help you and your child. This section briefly describes who may be a part of your family's care team, and how each of them can help.

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.
- Keeps your child equipped with properly fitted earmolds.
- Adjusts your child's hearing aids when needed.
- Works with you to assess how well your child responds to sounds at home.
- Provides information about early intervention options for your family.
- Works with you and your early intervention specialist to maintain your child's amplification, if appropriate.

AURAL REHABILITATION SPECIALIST

- Develops your child's listening skills to help your child learn speech and language.

CHILDREN WITH SPECIAL HEALTH CARE NEEDS (CSHCN) COORDINATOR

For children ages birth to 18:
- Helps families with accessing services and service providers.
- Helps families coordinate services and resources in their community.
- Authorizes hearing aids for children covered by Medicaid.

COUNSELOR/THERAPIST

- Gives emotional support for children and families.
- Helps you or your family with emotional issues about your child's hearing loss.

EARLY INTERVENTION SPECIALIST FOR DEAF AND HARD OF HEARING (D/HH) INFANTS & TODDLERS

- Works with families of children (birth to three) with communication and learning needs.
- 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.
- Helps answer questions about how your child’s hearing loss affects communication, learning, and participation in school and society.
- Talks with you about your observations and concerns about your child.
- Works with your child’s audiologist to help you learn to use your child’s amplification. Also helps make sure your child’s hearing aids are working well.
- Keeps records of your child’s progress in communication and development.
- Gives you support during difficult times.
- Gives you opportunities to network with other adults and children with hearing loss.
- Helps define your child’s educational needs when your child is ready to “graduate” from early intervention.

FAMILY RESOURCES COORDINATOR (FRC)

Helps families with children birth to three:

- Access services they need.
- Find resources to pay for services.

MEDICAL GENETICIST/GENETIC COUNSELOR

- Reviews possible genetic causes for your child’s hearing loss.
- Counsels families about the implications of a genetic hearing loss.
- Discusses options for genetic testing.

OTOLOGIST, OTOLARYNGOLOGIST, OR EAR, NOSE, & THROAT (ENT) DOCTOR

- Makes sure there is not a treatable condition in your child’s outer or middle ear that is causing the 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 causes of your child’s hearing loss.

PEDIATRICIAN OR FAMILY PRACTITIONER

- Refers you to an audiologist who works with infants and young children.
- Answers questions you may have about medical treatment of your child's hearing loss.
- 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.

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.

OTHER PARENTS OF DEAF AND HARD OF HEARING CHILDREN

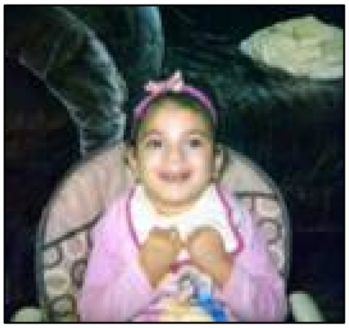
- Shares experiences they have had.
- Tells you about helpful people and resources they have found.
- Listens to you.
- Shares their feelings about parenting a child with hearing loss.
- Tells you about their child's achievements.
- Meets with you so your children can play together.

DEAF AND HARD OF HEARING ADULTS

- Shares personal experiences about being deaf or hard of hearing.
- Shares educational, social, and cultural perspectives.
- Shows you different methods of communication.
- Acts as a role model for your child.
- Provides encouragement for your family in meeting challenges and raising a successful child.

"Well, I think it's good that my classmates and teachers know about my hearing aids, that way they understand the reason for wearing them and how they work. When my friends and teachers know this then I am able to understand them better."

– Tess, *age 11 ¾*



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 (pictured, left). 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.

What is Early Intervention?

Early Intervention programs are for children ages birth to three and their families. These programs provide specialists who are professionally trained in working with children who have hearing loss.

- When you enroll in an Early Intervention program, you will be assigned a parent infant specialist who works with you and your child.
- You may also have the option to participate in play groups, parent meetings, and sign language classes, if appropriate.
- You may live in a community that has one or more programs to choose from. Often, programs have different beliefs and ideas about how to communicate with children with hearing loss. (see *Communication Options*)

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. The IFSP team works with the family to identify the child's specific needs and then builds a plan to ensure the child receives the services necessary to reaching his or her goals.

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

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

What About Preschool?

Making the transition from early intervention to preschool services can be an emotional process simply because your baby is growing up so quickly. Don't worry. As your child gets closer to age three, your FRC will help you make a transition plan for moving into the next chapter of your child's educational career and preschool.

A transition plan will lay out steps and services needed to move into special education or community-based programs.

Want to know more about transitioning into school?

The Wendorf family shares some of their experiences in *Team Wendorf – Growing Together*. Their story is actually a copy of their family statement, which was written and used for their first Individualized Education Program, or *IEP*, when Kai was three years old. They are thrilled to report that Kai is beginning Kindergarten at her neighborhood school this fall. Way to go!

Team Wendorf – Growing together

by The Wendorf family

We are Team Wendorf. We are a growing family of five, soon to be six and 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 untypical 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% 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 your 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 6 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 6 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, named 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 & 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 of Early Intervention Services and into the IEP process.

In accordance with our goal and dream for Kai to enter mainstream Kindergarten we desire Kai 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.

TESTS

How is My Child's Hearing Tested?

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. This section includes information on:

- Objective Hearing Tests
- Behavioral Hearing Tests
- Getting the Correct Diagnosis
- Frequency of Testing
- Understanding Your Child's Audiogram

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 to 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 bone oscillator (small vibrator) that is placed on the bone behind the ear.

"It's kind of good that I do have a hearing loss because I have a lot more friends than I would if I were only hearing, and I would never have met my friends from camp!"
– Sawyer, age 15

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.

BAER TEST (PRONOUNCED: BEAR)

- BAER stands for Brainstem Auditory Evoked Response. You may also see this test called ABR, BER, or AABR.
- This test measures how well your child’s hearing nerve responds to sound.
- 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 is used to confirm the results of a behavioral hearing test.
- The steps for a BAER test are:
  1. Your child must be asleep. If your child is tested before 6 months of age, the test is done while he or she sleeps naturally. Children over 6 months of age usually fall asleep with a mild sedative prescribed by a doctor.
  2. Your child’s skin is cleaned and sensors are put on his forehead and behind each ear.
  3. Sounds are played into each ear through a soft rubber earphone.
  4. A computer records the response of your child’s hearing nerve.
  5. Your child’s audiologist looks for the softest sound your child’s hearing nerve responds to.

EOAE TEST

- EOAE stands for Evoked Otoacoustic Emissions. You may also see this test called OAE, TEOAE, or DPOAE.
- This test measures how well your child’s cochlea, or inner ear, works.
- It is usually done during the same visit as a BAER test.
- Your child needs to be still and very quiet for this test.
- The steps for an EOAE test are:
  1. A soft rubber earphone is placed in each of your child’s ears.
  2. Sounds are played through the earphones.
  3. A computer measures the response of your child’s inner ear.
  4. The audiologist evaluates the response.

TYMPANOMETRY TEST

- This test helps the audiologist find out how well your child’s middle ear is working.
- The steps for a tympanometry test are:
  1. The audiologist puts a rubber tip in your child’s ear.
  2. The tip is connected to a machine that changes the air pressure in your child’s ear. The machine prints out a graph.
  3. The graph gives information about whether there is fluid in the middle ear, or if the eardrum is not moving well. This test can be done at any age.

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 to 7 months developmental age to do a behavioral hearing test. She needs to be able to sit up by herself and have good head control.

VISUAL REINFORCEMENT AUDIOMETRY (VRA)

- This test is done in a soundproof room called a sound booth. The test requires your child to turn her head in response to the sounds she hears.
- Your child sits on your lap in the middle of the room.
- A helper sits in front of you and your child. This 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 the sounds he hears.
- 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 your child responds to.

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 your child responds to.

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 pure tones.
- The audiologist will present speech sounds to your child through a speaker or earphones.
- The audiologist will find the softest level of speech that your child responds to.

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 he hears or to point to pictures of the objects.
- The audiologist will find the softest level at which your child can hear the words.

How Do I Know the Diagnosis is Correct?

Newborn hearing screening allows us to diagnose infants with hearing loss at a very young age. Hearing loss is often not obvious in young infants. 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 he does or doesn't hear clearly. It sure would be helpful if he could!

The hearing tests used to diagnose hearing loss are very accurate. Your child will also have more hearing tests in the future. These tests will provide more information about your child's hearing loss. 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.

In the *Resources* section, you will find a list of pediatric audiologists who specialize in testing and treating infants and young children with hearing loss. All of the audiologists on this list have indicated that they meet the Washington State Best Practice Guidelines for Diagnostic Audiologic Follow-up to Newborn Hearing Screening.

How Often Will My Child's Hearing be Tested?

Your child's hearing will be tested on a schedule determined by your audiologist. These tests will make sure that his hearing hasn't changed. Your child may also have hearing tests while wearing his hearing aids.

Your Child's Audiogram

WHAT IS AN AUDIOGRAM?

An audiogram is a graph of the softest sounds your child hears. A few tips 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 **X**'s and **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 ear is tested.

- You may also see these symbols:

  ^ or **Π** means your child was tested using bone conduction.
  A means your child was tested with hearing aids.

What does my child's audiogram tell me?

Your audiologist will be able to explain your child's audiogram in full detail. 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)
- How well does your child hear with hearing aids?

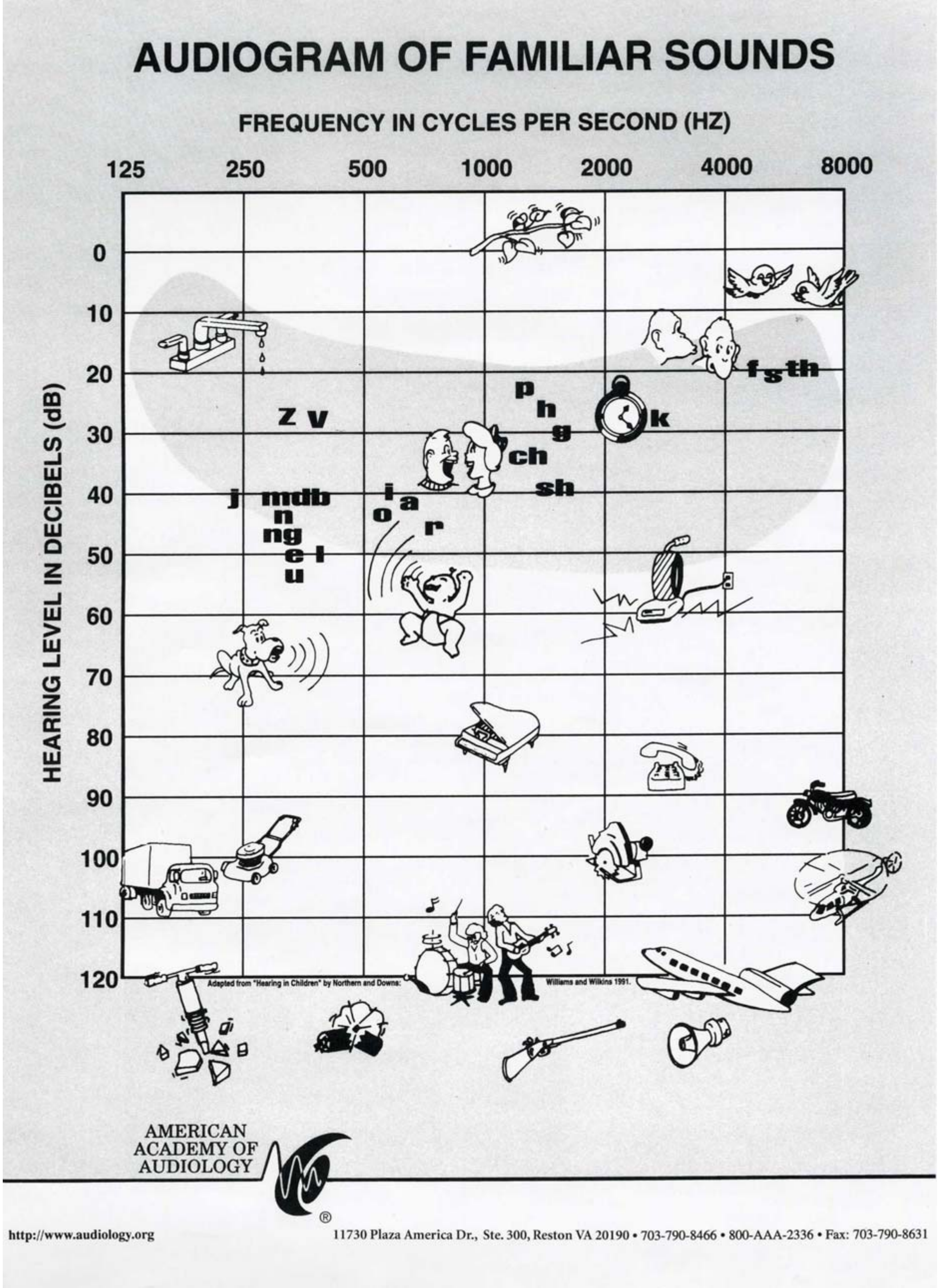
The audiogram on the next page has pictures that represent what sounds might be heard at different frequencies or pitches, and at different intensities or loudness.

- The gray shaded area is called the "speech banana."
- The speech banana shows where the different sounds of speech fall on the audiogram.
- Even a mild hearing loss will 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 the lower frequencies.
- Reverse sloping hearing loss -- Your child's hearing is better in the higher frequencies.
- Precipitously sloping hearing loss (steep and rapid slope) -- Your child's hearing drops off dramatically in the high frequencies.
- Cookie bite -- Your child hears better in the lower and higher frequencies, and worse in the mid frequencies.



The" Audiogram of Familiar Sounds" is used with permission from the American Academy of Audiology – www.audiology.org.

FREQUENTLY ASKED QUESTIONS ABOUT HEARING LOSS

WHAT PERCENTAGE OF HEARING LOSS DOES MY CHILD HAVE?

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

WILL MY CHILD'S HEARING LOSS 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 her hearing is not getting worse and that she is getting appropriate amplification. Your audiologist or ENT doctor may be able to give you more information about the chances of your child's hearing loss getting worse over time.

WHAT CAUSED MY CHILD'S HEARING LOSS?

Over 50% of infants born with hearing loss have no known risk factors for hearing loss. Some of the more common reasons for hearing loss are:

- Family history of hearing loss.
- A genetic cause, even if there isn't a family history of hearing loss.
- A syndrome that is known to have hearing loss.
- Craniofacial abnormalities, such as a cleft lip or palate, ear pits, or ear tags.
- Certain infections in the mother during pregnancy such as CMV (cytomegalovirus), toxoplasmosis, herpes and rubella.
- Admission to a neonatal intensive care unit for more than 48 hours.
- Bacterial meningitis.
- Repeat ear infections.

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

COMMUNICATION OPTIONS

We all know that communication is important for families, but choosing the best way to do it can be hard. Your family may have many different opinions about what is best for your child. We hope this section gives you the information you need to begin learning about the options for your child and family.

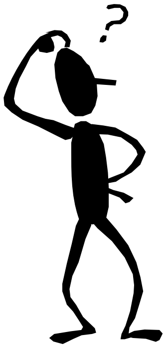
The communication method you choose should provide your child with full access to communication. It should also use the primary language spoken in your home (such as English, Spanish, American Sign Language, etc.). **When choosing a method, keep in mind that no method is best for *all* children. As your child's needs change, it's okay to make different decisions later on.**

How Hearing Loss Affects Communication

Hearing loss in a young child is different from hearing loss in an adult. This is because a young child hasn't learned many speech and language skills. Adults with hearing loss already know the rules of language and can apply them in daily conversations. For a child of parents 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 of Deaf parents who use sign language to communicate will learn language by watching sign language.

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

- The type of hearing loss.
- The degree of hearing loss.
- The configuration of the hearing loss.
- Your family's involvement in your child's communication development.
- The age at which your child's hearing loss occurred.
- The age at which your child's hearing loss was identified.
- The age at which intervention was started, how much was provided, and the quality of the intervention provided.
- Other health conditions your child may have.



COMMON QUESTIONS ABOUT COMMUNICATION

Will My Child Be Able to Talk?

This question is difficult to answer. It can depend on the severity of your child's hearing loss, how well your child is able to use his residual (remaining) hearing, and other factors.

- Many children with mild and moderate losses learn to talk well with the help of hearing aids and speech therapy.
- Children with more severe hearing losses may have more difficulty learning to talk, but your child's team of doctors and therapists will help your family try to achieve your communication goals for your child.
- Families may choose amplification for their children (see *Assistive Technology*, next section). If choosing amplification, and working with your child's team of professionals, many children develop age-appropriate speech and language skills.
    - Helping your child to achieve communication goals with amplification includes:
        - Attending follow-up appointments with your child's audiologist.
        - Receiving regular services from professionals trained in working with children who have hearing loss.

Will My Child and Family Learn Sign Language?

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

- Children with severe to profound hearing loss may benefit from learning some form of sign language. Even with powerful hearing aids, they may not be able to hear all the sounds of speech. This doesn't mean that children with severe to profound hearing loss will never learn to talk. It means they may need to get speech and language information in more than one way. For example, some families consider cochlear implant candidacy testing for their child, which may give their child greater access to the sounds of speech and reduce the need for sign language.
- Children with milder degrees of hearing loss may also benefit from knowing some form of sign language. There may be times such as swimming or bathing when your child is not wearing hearing aids, but needs to communicate.
- Some families, especially those with at least one Deaf parent, may choose to use sign language as the main communication mode for their child.

Choosing a Communication Method

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 with hearing loss and their families to communicate. Every method requires a commitment from your family to help your child learn language.

Many families say that choosing a communication method is one of the hardest decisions they have ever made. Many people may tell you their method is best. **Keep in mind that no method is best for *all* children.** For some children, a combination of methods may be best. **Also, remember that *any decision you make can be changed later*.** Here are some things to think about as you choose a communication method:

- Decisions should be based on your own observations about the needs of your child and family.
- Ask questions. Talk to 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 choices 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 method you chose isn't working as well as you think it should.

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

- Communicate with the entire family (siblings and extended family).
- Have a relationship with all family members.
- Enjoy meaningful conversations.
- Feel like part of the family.
- Know what is going on.
- Have control over the environment.
- Express feelings.
- Join in the world of imagination and play.

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 3 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 bi-lateral 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 that 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 3 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.

Communication Methods

The next few pages briefly describe some of the communication methods to explore before making your decision. Your audiologist or Family Resources Coordinator (FRC) can provide more information about early intervention programs that may be available for each method. Use this information as a starting point.

AUDITORY/ORAL:

- The auditory/oral approach uses your child's aided hearing and lip reading to teach spoken language.
- Lip reading means your child uses both hearing and sight to help him understand spoken language.
- Your child may need amplification (hearing aids or cochlear implant) with this approach.
- Families learn how to communicate with their child using spoken language.
- This approach doesn't use sign language.

AUDITORY/VERBAL:

- The auditory/verbal approach is similar to the auditory/oral approach, except it doesn't use lip reading.
- Your child is taught to use his hearing and listening skills without relying on visual cues.
- Your child may need amplification (hearing aids or cochlear implant) with this approach.
- Families learn how to communicate with their child using spoken language.
- This approach doesn't use sign language.

BILINGUAL/BICULTURAL (AMERICAN SIGN LANGUAGE):

- The bilingual/bicultural method focuses on teaching your child American Sign Language (ASL).
- ASL uses the body, face, and hands to communicate language.
- ASL is a separate language from English. It doesn't follow the same sentence structure as English.
- English is taught as a second language.
- Your child doesn't have to wear amplification to communicate this way.
- The Deaf community uses this method of communication.
- Members of the Deaf community have a strong cultural identity of their own.

From *Olivia's Story*:

> *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.*

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.

SIMULTANEOUS COMMUNICATION:

- This method involves speaking and signing the same words at the same time.
- Amplification is recommended, but not required.
- The family learns a sign language system, such as Signing Exact English (SEE). SEE is designed to be used together with speech to help your child understand and use language.
- SEE is different from ASL, because SEE follows spoken English exactly.
- The goal of this method is to develop your child’s language, listening, and speech skills.
- Families learn to communicate with their child using the primary language of the home (English, Spanish, Russian, etc.) and signing at the same time.

TOTAL COMMUNICATION:

- The total communication approach combines many methods.
- Families learn how to use spoken language and some form of sign language, gestures, facial expressions, finger spelling and pantomime to communicate.
- Signs and speech are usually used together. Sometimes they are used separately.
- Your child doesn’t have to use amplification to communicate this way.
- Families learn to communicate with their child using a combination of signed and spoken language.

Hearing vs. Listening

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 methods 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 deaf or hard of hearing person 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.

When a person has a hearing loss, specialized therapy and education are usually needed 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 may be certified as Listening and Spoken Language Specialists (LSLS through the AG Bell Academy for Listening and Spoken Language).

A child's education or therapy may be referred to as *auditory training*, *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 being learned).
- The training of the professional providing the service (audiologist, therapist, etc.).
- Where the services take place (school, hospital, 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.

ASSISTIVE TECHNOLOGY

Baby in photo is wearing a hearing aid.

This section provides information about hearing aids, cochlear implants, FM systems, and other assistive listening devices. Your audiologist will be able to give you more information and answer your questions. *Assistive technology and assistive listening devices are also called amplification.* Topics covered in this section include:

- Hearing Aids – What they do, how to get them, and how to help your child wear them.
- Hearing Aid Technology
- Troubleshooting Hearing Aids
- Cochlear Implants, FM Systems, and Other Devices
- Financial Assistance

Does My Child Need Assistive Technology?

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

- If the communication method you choose requires your child to wear hearing aids, the sooner you get hearing aids the sooner your child can begin hearing speech sounds.
- A child can be fit with hearing aids at any age.
- If you are considering a cochlear implant, it is important to begin the cochlear implant candidacy process early. Speak with your child's audiologist about this process.
- Some parents may choose a communication method that uses only sign language and doesn't require the use of hearing aids.

Hearing Aids

HOW DO HEARING AIDS WORK?

- Hearing aids for young children rest behind the ear. They attach to an earmold that fits inside the ear canal.
- An earmold is a small piece of soft plastic that is custom made for your child’s ear. It helps hold the hearing aid in place.
- The hearing aid is adjusted by the audiologist to fit your child’s needs.
- Hearing aids pick up sound through a microphone to make sound louder.
- The sound is sent through a tube in the earmold into your child’s ear.

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 improve your child’s interactions with family and peers.

WHAT CAN’T A HEARING AID DO?

- A hearing aid can’t cure your child’s hearing loss.
- It can’t help your child hear sounds at frequencies where she has no hearing.
- It can’t make only speech sounds louder. Hearing aids make *all* sounds louder, including background noise.
- It can’t make sounds clear if they are distorted by the cochlea.

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 are usually fit with behind the ear, or 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 fit with a bone conduction hearing aid.

REASONS WHY SMALL CHILDREN ARE FIT WITH BTE HEARING AIDS:

- Earmolds for BTE aids are made from soft materials. They are more comfortable for children. They are also less easily broken, especially for active children.
- Earmolds for BTE aids can be replaced as your child grows. The hearing aid itself will not need to be recased as your child grows.
- BTE aids are often more reliable and less easily damaged.
- BTE aids can easily be connected to an FM system or other assistive listening device.
- BTE aids and earmolds come in many fun colors for children. They also come with accessories specially designed for children.
- Tamper-resistant battery doors can be put on BTE aids. This is important because hearing aid batteries can be toxic to children, if swallowed.
- Volume control covers can be put on BTE aids. This helps make sure the volume is not accidentally changed.

Hearing Aid Technology

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

CONVENTIONAL HEARING AIDS:

- Increase sound electronically.
- Your audiologist adjusts them by adjusting external screw controls.

PROGRAMMABLE HEARING AIDS:

- Increase sound electronically.
- Your audiologist adjusts them by programming an internal microchip.
- Might have several channels or programs for different hearing environments.
- Might come with a remote control to adjust the settings.

DIGITAL 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.

BONE CONDUCTION HEARING AIDS:

- Bone conduction hearing aids are used by some children with conductive hearing losses that cannot be medically or surgically corrected. Often, these children can't wear a behind the ear (BTE) hearing aid.
- These hearing aids transmit sound via a bone oscillator (vibrator) that sits on the bone behind the ear.

What Are Some 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 microphone – telecoil (M-T) switching 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 the audiologist to make adjustments to them as more information is learned 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, safety clips, and volume control covers.

What is the Process for Getting Hearing Aids?

**** Before you buy any hearing aids, speak with your Family Resource Coordinator (FRC).***

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.

1. Your child must have approval, or "medical clearance," from an otolaryngologist to wear hearing aids. Medical clearance is required by law.
2. The audiologist must make impressions of your child's ears. These impressions will be used to make custom earmolds for your child.
3. Your child must have a special measurement called the RECD (Real Ear to Coupler Difference) made with his earmolds in place. Your child's RECD measurement helps the audiologist adjust his hearing aids. The RECD measurement should be made before or at the time of the fitting of your child's hearing aids.
4. 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 the hearing aids. Make sure to teach your child that only adults are allowed to 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 with the hearing aids on.
- Little hands like to pull out hearing aids. Things such as Huggie Aids, alligator clips, hats and headbands can help keep the hearing aids on. Your audiologist can help you choose something that works for your child.
- 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 Vaseline.)*

- Try to have your child wear the hearing aids whenever he is awake. This way, hearing sounds will become part of her daily routine. You may need to start with small amounts of time and build up to longer periods.

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 high-pitched squealing or a fluttering sound. Talk to your audiologist if there are problems with feedback. Some causes of feedback can be:

- An earmold that is not inserted all the way into your child's ear.
- An earmold that fits poorly or that your child has outgrown.
- An earmold, tubing, or earhook that is damaged.
- A hat or blanket that covers the hearing aid and microphone (feedback will stop when you remove the hat or blanket).
- A hearing aid that is damaged.
- An earmold or an ear canal blocked by wax or discharge from an ear infection.

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 she 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.

OVER AMPLIFICATION

Over amplification means a hearing aid is too loud. Your audiologist should use a technique called real ear measures to find the settings that are appropriate for your child. If your child repeatedly pulls the hearing aids out of his ears, or blinks more than normal with his hearing aids on, they may be too loud. Loud sounds should be loud with hearing aids, but they shouldn't cause discomfort for your child. Talk to your child's audiologist if you think he is being over amplified.

Cochlear Implants, FM Systems & Other Assistive Listening Devices

COCHLEAR IMPLANTS

In picture: Daxx (smelling tulip) has a cochlear implant with a zebra print ear level sound processor.

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 otolaryngologist (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. Here are a few points about cochlear implants:

- Cochlear implants are for children with a severe to profound hearing loss.
- A cochlear implant is surgically placed into the inner ear.
- Not all children can have a cochlear implant.
- The implant doesn't correct hearing loss.
- The implant bypasses the normal auditory pathway (outer ear, middle ear, inner ear). It also stimulates the auditory nerve directly. Then, the brain learns to interpret this electrical stimulation as speech.
- With proper follow-up therapy, a cochlear implant can help children with severe to profound hearing loss develop better speech and language skills.
- A cochlear implant “synthesizes” hearing of sounds. Your child will need training to learn to attach meaning to the sounds. This is called aural habilitation.
- Federal guidelines say that a child with a profound hearing loss should be at least 12 months old at the time of surgery. However, it is important to start the cochlear implant candidacy process early.
- With implantation there is a risk of losing some or all of the residual hearing in the implanted ear. This is a good thing to discuss with your audiologist and surgeon.

FM SYSTEMS

FM Systems make speech louder without making background sounds louder. This allows your child to hear the speaker's voice better. This is really 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. Here are a few points about FM systems:

- One person (the parent, 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.
- FM systems are used when you want your child to be able to hear the speaker over background noise.

OTHER LISTENING DEVICES

CLOSED CAPTIONING

This device can either be attached to a television or built into the television. It provides written text of the spoken words at the bottom of the television screen.

TTY

TTY stands for teletypewriter. You may also see it called a TDD (Telecommunications Device for the Deaf). A TTY allows a person with hearing loss to use a telephone by typing rather than speaking. A person using a TTY can call another TTY user direct, or use a relay service to call someone who doesn't have a TTY.

TELEPHONE AMPLIFIER

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

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, door knockers, bed vibrators, and phone flashers.

VIDEO PHONES

Video phones are available for your home in a variety of prices. New technology is also providing free and low-cost video chat cell phone apps and computer software. These are great tools for children and adults, with or without hearing loss.

In the picture:
Daxx (sitting on counter) has a cochlear implant and Hadlie is wearing a hearing aid. (see *A Rewarding Journey* for story)

The Boling Family – Full of Love!

by The Boling Family

Our family draws attention where ever we go – people do double-takes and start counting...

We have nine children, no twins, ranging in age from 4 months to ten. 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 also 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 2 ½ 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 3 ½ 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). It turned out in the end, that our primary insurance covered 97% 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 7 months now since he began “hearing” and he is almost 3 ½ 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 and then every two weeks for a couple of months and 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 that are a total of 2 ½ 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 anyway 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 (9 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.

FINANCIAL ASSISTANCE

Choosing a Health Plan that Works

Most people don’t have many choices about their health care plan. If you have health care coverage, it is very frustrating to learn that your plan doesn’t cover the things your family needs. For people who are deaf or hard of hearing, this often means that the costs of hearing aids, cochlear implants, and other medical equipment and services aren’t covered by the health plan.

Coverage of Hearing-Related Technology & Procedures

Getting your health plan to pay for cochlear implants or hearing aids can be a challenge. This is common, but don’t give up. Some health plans cover the full cost of hearing aids and cochlear implants, while others won’t 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.

Are you trying to get the costs of cochlear implants covered? You may need to teach your health plan about two things:

- How cochlear implants are different from hearing aids.
- Why cochlear implants are “medically necessary” for some people.

If your health plan doesn’t 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.

Finally, 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 infants and toddlers under three years old. In Washington, the Part C system is called the Early Support for Infants and Toddlers (ESIT) program. Ask your Family Resource Coordinator (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.

ADVOCACY

Trying to make sure your child receives the services and education he or she deserves may feel like a fight, at times. Remember that you're not alone. There are many people who will help you find the services and opportunities your child needs to succeed.

The Law & Your Rights

There are laws that guarantee you and your child certain rights. The Washington State Department of Early Learning (DEL) has brochures that may help you learn more about our state and federal laws. Summaries of the brochures are below.

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

BIRTH TO SIX PRESCREEN WHEEL

This wheel will help parents learn about their child's age appropriate milestones for vision, hearing, and development from birth to six years old.

INFANTS AND TODDLERS WHO ARE DEAF OR HARD OF HEARING

This pamphlet will help you find answers to some of your first questions. It has information about where to begin looking for answers, interventions and treatment options, and communication methods.

A FAMILY'S GUIDE TO EARLY INTERVENTION SERVICES IN WASHINGTON STATE

This brochure has information about services for children ages birth to three. You will learn about the Individuals with Disabilities Education Act (IDEA), Washington State early intervention services, and creating an Individualized Family Service Plan (IFSP).

TRANSITION: THE NEXT STEP: WHAT HAPPENS WHEN MY CHILD TURNS THREE?

Early intervention ends when your child turns three. This brochure will answer questions about what happens as your child approaches three and transitions out of early intervention services. Tips for making a smooth transition plan and an Individualized Education Program (IEP) are also included.

Your Responsibilities as a Parent

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

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, ask your Family Resources Coordinator (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 he should, talk with his 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, and 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 for your child's teachers at the next IEP planning meeting.

This notebook is the perfect place to keep notes. We have included a few pages for writing notes in our *Staying Organized* section. If needed, add extra pages or a spiral notebook for your 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's 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.

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 ten 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 set backs 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 someday 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.

RESOURCES

NOTE: The inclusion of any resource, service, or website does not imply endorsement by the Washington State 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.

In this section you will find details about:

- How to contact your Family Resources Coordinator (FRC).
- Early Intervention programs that specialize in working with children with hearing loss and their families.
- Helpful organizations & websites.
- Schools for children with hearing loss.
- Common terms and definitions.
- Audiologists who evaluate and treat infants and young children with hearing loss.

Contacting Your Family Resources Coordinator

One of the first steps to take in helping your child is contacting your Family Resources Coordinator, usually known as your FRC. Your FRC will help your family get the early intervention services your child needs.

Contact your FRC as soon as possible. If you don't have a Family Resources Coordinator (FRC), call the "Family Health Hotline" at: 1-800-322-2588 (TTY: 1-800-833-6384). You will be given 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 at: http://www.del.wa.gov/development/esit/Default.aspx.

Early Intervention Programs Specializing in Hearing Loss

The Early Intervention Programs listed below specialize in working with children who are deaf or hard of hearing and their families. The program staff have special training in working with children with hearing loss. Your FRC will also be able to help you contact resources near your home.

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 Super Market, 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 I. 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 that the ends of the DNA strand actually fray and begin to unwind cutting 5 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.

HELPFUL ORGANIZATIONS IN WASHINGTON STATE

There are many local and national resources to help you. We have only listed some of the resources below. Your audiologist or Family Resources Coordinator (FRC) can also help you find more resources and programs to fit your needs.

FAMILY CONVERSATIONS
2525 220th Street SE, Ste 100
Bothell, WA 98021
(425) 482-4185 (voice)
e-mail: Family_Conversations@seattlechildrens.org
website: http://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 parents, 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.

GUIDE BY YOUR SIDE™
2001 H Street
Bellingham, WA 98225
(425) 268-7087 (voice)
e-mail: GBYS@WAhandsandvoices.org
website: www.wahandsandvoices.org

Guide By Your Side was created by Hands & Voices. Their "Parent Guides" are all parents of a child with hearing loss. The trained parent guides provide unbiased information about communication options, help families navigate through systems, link families with local and national parent-to-parent resources, and assist parents 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.

HEARING SPEECH AND DEAFNESS CENTER, NORTH SOUND
Family Program
Crown Plaza Building
114 West Magnolia Street, Suite 106
Bellingham, WA 98225
(360) 647-0910 or 1-866-647-0910 (voice) / (360) 647-8508 or 1-877-647-8508 (TTY)
(360) 255-7166 (video phone)
e-mail: bellingham@hsdc.org
website: www.HSDC.org

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

LISTEN AND TALK
8610 8th Avenue NE
Seattle, WA 98115
(206) 985-6646 (voice)
e-mail: 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 supports the work of a child's clinical audiologist. Consultation services are provided in partnership with the Washington State Center for Childhood Deafness and Hearing Loss (CDHL). Long-distance therapy, coaching, and support through technology based programs, such as Skype are also available.

PARENT INFANT PROGRAM (PIP) - SEATTLE
Hearing Speech and Deafness Center
1625 19th Avenue
Seattle, WA 98122
(206) 323-5770 or 1-888-222-5036 (voice) / (206) 388-1275 or 1-800-761-2821 (TTY)
(206) 452-7953 (videophone)
e-mail: seattle@hsdc.org
website: www.HSDC.org

The PIP program offers family-centered services for deaf and hard of hearing children from birth to three years old in King, Snohomish, & Pierce counties. They provide a (ASL)/English bilingual approach to meet each family's needs. Included in the program *are home visits which include the Shared Reading Program and weekly "Family Night" activities which include the "Kids Club" playgroup (for PIP children and siblings), parent support groups, parent education nights, and American Sign Language (ASL) classes.*

PARENT INFANT PROGRAM (PIP) - TACOMA
Parent Infant Program, Birney Elementary School
1202 South 76th Street
Tacoma, WA 98408
(253) 475-0782 or 1-866-421-5560 (voice) / (253) 474-1748 or 1-866-698-1748 (TTY)
(253) 292-2209 (videophone)
e-mail: tacoma@hsdc.org
website: www.HSDC.org

The Tacoma PIP program offers family-centered services for children from birth to three years old and their families in Pierce, Grays Harbor, Thurston, Mason, & South Kitsap counties. Services include home visits, play groups, parent groups, and one-on-one communication therapy sessions

WASHINGTON SCHOOL FOR THE DEAF – FAMILY INFANT & TODDLER PROGRAM
611 Grand Blvd.
Vancouver, WA 98661
(360) 696-6525 (Voice/TTY) / (800) 613-4228 (Voice/TTY Toll free)
website: http://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)
(425) 917-7827 (Voice/TTY) / (800) 572-7000 (Voice/TTY Toll free)
e-mail: wsds@psesd.org
website: http://www.wsdsonline.org

Washington Sensory Disabilities Services (WSDS) is here to assist 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 Deaf/Hard of Hearing Services (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 *is having trouble finding supports relating to birth-to-three year olds who are deaf or hard of hearing, contact WSDS for help.*

WASHINGTON STATE CENTER FOR CHILDHOOD DEAFNESS & HEARING LOSS (CDHL)
611 Grand Blvd.
Vancouver, WA 98661
(360) 418-0401 (voice)
website: www.wsd.wa.gov

CDHL collaborates with the Office of Superintendent of Public Instruction (OSPI), Educational Service Districts (ESDs), local school districts, and other public and private agencies to provide statewide leadership for the coordination and delivery of educational services for children who are deaf, deaf-blind, and hard of hearing, including the full range of communication modalities.

WASHINGTON STATE HANDS & VOICES
PO Box 4022
Bellevue, WA 98009
e-mail: info@wahandsandvoices.org
website: www.wahandsandvoices.org

Hands and 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.

YAKIMA VALLEY HEARING AND SPEECH CENTER
PARENT-INFANT-TODDLER PROGRAM
Hearing and Speech Center
303 South 12th Avenue
Yakima, WA 98902
(509) 453-8248 (voice)
e-mail: info@hearingandspeechcenter.com
website: http://hearingandspeechcenter.com/

The Parent-Infant-Toddler Program serves children and families in the upper and lower Yakima Valley, Tri-Cities area, Ellensburg, and Goldendale areas. Individualized therapy, counseling, and parent participation are key 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 your child's doctors and school districts to provide ongoing services for your family.

SCHOOLS FOR CHILDREN WITH HEARING LOSS

Public School

If your child is over three years of age, contact your local school district and ask what options it offers for children with hearing loss. By law, any child with a hearing loss and a need for services is entitled to special education services.

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 can provide you with more information and help you explore your options and other resources.

Residential School

WASHINGTON SCHOOL FOR THE DEAF
611 Grand Blvd
Vancouver, WA 98661
(360) 696-6525 (V/TTY) / 800-613-4228 (V/TTY Toll free)
website: http://www.wsd.wa.gov/

The Washington School for the Deaf (WSD) is a residential state school, located in Vancouver, WA. 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.

Private Schools

CEDAR PARK CHRISTIAN SCHOOLS
(PROGRAM FOR CHILDREN AGES 2.5-5 YEARS OLD AND THEIR SIBLINGS)
Kayce Aspen, Language Services Director
Lynnwood Campus
425-742-9518
Website: http://www.cpcsschools.com/lynnwood/preschool-childcare/languageservices

LISTEN AND TALK (PROGRAMS FOR CHILDREN AGES 3 – 5 YEARS)
8610 8th Avenue NE
Seattle, WA 98115
(206) 985-6646 (Voice)
e-mail: suzanneq@listentalk.org
website: www.listentalk.org

NORTHWEST SCHOOL FOR HEARING IMPAIRED CHILDREN (PROGRAMS FOR CHILDREN AGES 3 – JUNIOR HIGH)
P.O. Box 31325
Seattle, WA 98103
(206) 364-4605 (Voice)
website: http://northwestschool.com/

SPOKANE HOPE SCHOOL (**H**EARING **O**RAL **P**ROGRAM OF **E**XCELLENCE)
(PROGRAMS FOR CHILDREN BIRTH – 5 YEARS)
University Hearing & Speech Clinic
310 N. Riverpoint Blvd, Box V.
Spokane, WA 99202-1675
(509)-828-1379 (Voice)
website: http://www.oraldeafed.org/schools/hope/index.html

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 2 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!

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)
http://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)
http://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 parents of children from birth through age 21. This website contains information about the Academy's many programs and activities, their policy statements and practice guideline, and publications and other child health resources.

AMERICAN SPEECH-LANGUAGE-HEARING ASSOCIATION (ASHA)
http://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 comprised of audiologists, speech-language Pathologists, teachers of the deaf, geneticists, doctors and parents of deaf and hard of hearing children at Boys Town National Research Hospital in Nebraska. It has a wealth of information about newborn hearing screening and infant hearing loss.

BEGINNINGS FOR PARENTS OF CHILDREN WHO ARE DEAF OR HARD OF HEARING
http://www.ncbegin.org

BEGINNINGS was established to provide emotional support and access to information as a central resource 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) (formerly the Infant Toddler Early Intervention Program (ITEIP)) provides early intervention services, including Family Resources Coordination, for eligible children from birth to age 3 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.

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.

NATIONAL CENTER FOR HEARING ASSESSMENT & MANAGEMENT (NCHAM)

http://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 a wealth of 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)

http://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 individuals in the United States. This website provides information about legal rights, advocacy issues, frequently asked questions, news and outreach.

NORTHWEST LIONS FOUNDATION FOR SIGHT & HEARING

http://www.nlfoundation.org/hearing

The Northwest Lions Foundation for Sight & Hearing has several programs to accomplish its mission of protecting and restoring hearing. These programs include: Lions Affordable Hearing Aid, Lions Hearing Aid Bank, Lions Health Screening Unit, Lions Patient Care Program and Lions Special Project Grants.

OFFICE OF THE DEAF AND HARD OF HEARING (ODHH)

http://www1.dshs.wa.gov/hrsa/odhh/

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 and training, and outreach services to clients and their families

PARENT TO PARENT
http://www.arcwa.org/parent_to_parent.htm

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

SEATTLE CHILDREN'S
http://www.seattlechildrens.org/classes-community/community-programs/newborn-hearing-screening/

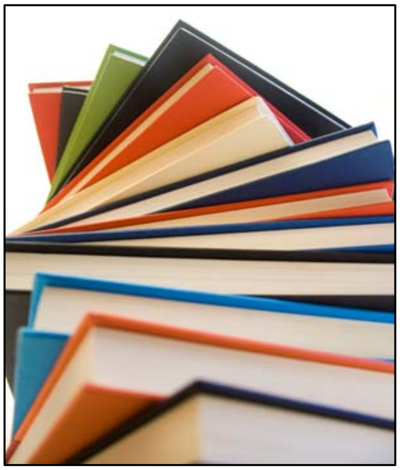
Seattle Children's is working in partnership with the Washington State Department of Health *and* Washington Chapter of the American Academy of Pediatrics *to implement comprehensive Universal Newborn Hearing Screening Programs across Washington.*

WASHINGTON SENSORY DISABILITIES SERVICES (WSDS)
http://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/Family

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 the state of Washington are screened for hearing loss before hospital discharge or by one month of age, that they receive diagnostic audiological assessment by three months of age if needed, and that they are enrolled in early intervention services by six months of age or earlier, if the infant is found to have a hearing loss.



TERMS & DEFINITIONS

Over time, and 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.

ABR/AUDITORY BRAINSTEM RESPONSE: A non-invasive test that measures responses in the brain waves to auditory stimulus. This test can indicate whether or not sound is being detected, even in an infant. This test may also be referred to as BAER, BSEP, and BSER.

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 are assured you by the law and actively participating in the decision-making process to ensure that the services are delivered in line with your goals for your child's development and education.

AMBIENT NOISE: Background noise, which competes with the main speech signal.

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.

ASL: American Sign Language (ASL) is a separate language from English. It doesn’t follow the same sentence structure as English. ASL uses the body, face, and hands to communicate language.

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.

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 also 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.

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.

AUDITORY NEUROPATHY: 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 TRAINING: The process of training a person to use residual hearing for awareness, identification, and interpretation of sound. A speech language therapist or audiologist usually does this training.

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 mild to profound hearing loss in both ears.

BINAURAL HEARING AIDS: Hearing aids worn on both ears.

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 or her 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: 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, by-passing 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 he heard a sound. Play audiometry is generally used when the child is at least 18 months old.

CONDUCTIVE HEARING LOSS: Sound waves don't 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. In this context, it applies to people who mostly use visual communication.

DEAF COMMUNITY: A group of people, both deaf and hearing, who share common interests and a common heritage. In this community, the most common language is American Sign Language (ASL). The Deaf community in the United States may have a wide range of perspectives on issues, but emphasis remains on Deafness as a positive state of being.

DEAF CULTURE: A view of life manifested by the mores, 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 impacts 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.

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.

ENT: A medical doctor, who specializes in the ears, nose and throat. Sometimes referred to as an otolaryngologist or otologist.

ESIT: ESIT stands for Early Support for Infants and Toddlers (formerly the Infant and Toddler Early Intervention Program, or ITEIP). This program provides individualized, quality early intervention services to children from birth to 3 who have disabilities and/or developmental delays.

FINGERSPELLING: Finger spelling uses a standardized series of handshapes to form words. Each letter has its own particular shape. Usually it is used when there is no sign for a certain word.

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

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.

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: The following hearing levels are typically described as follows

Normal Hearing	0 dB to 15 dB
Mild Loss	16 dB to 35 dB
Moderate	36 dB to 50 dB
Moderate/Severe	51 dB to 70 dB
Severe Loss	71 dB to 90 dB
Profound	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.

I.D.E.A.: The Individuals with Disabilities Education Act, Public Law 108-446. Part C (See “Part C”) provides services to children birth to three years of age with disabilities. Part B of IDEA covers educational mandates for students age three through high school graduation or age-out of the system.

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 1) describes the family's strengths, needs, concerns and priorities; 2) identifies support services available to meet those needs; and 3) 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: 1) communication needs in the child's and family's preferred mode of communication; 2) linguistic needs; 3) severity of hearing loss; 4) academic progress; 5) social/ emotional needs, including opportunities for peer interactions and communication; 6) appropriate accommodations and assistive communication devices to facilitate learning; 7) opportunities to interact with peers and adults who use the same communication mode; 8) the proficiency of the staff delivering services identified on the IEP; and 9) opportunities for direct instruction in the child's communication mode; 10) all educational placement options, and 11) how extra-curricular activities will be made communication-accessible.

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. Examples include: 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: A basic principle of 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.

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."

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 are any delays or conditions that would indicate a need for special services.

NATIVE LANGUAGE: The language of the home, i.e. the native language of children who are deaf with deaf parents is often American Sign Language.

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, 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 produces. Measured in decibels.

PART B: The section of I.D.E.A. about special education and support services available to eligible children from three to 21 years of age.

PART C: The section of I.D.E.A. 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. Since ear canals are shaped differently, 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.

SEE: Signing Exact English (SEE) is different from ASL. SEE follows spoken English exactly and is designed to be used together with speech to help your child understand and use language.

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 ASL, Fingerspelling, SEE).

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% 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% 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 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, 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.

TACTILE AIDS: A type of assistive communication device that vibrates or gives a "tactile" signal to indicate the presence of sound(s). It is worn on the body and triggers the sense of touch or feeling to draw attention to information that cannot be heard by the individual with hearing loss.

TELECOMMUNICATION DEVICES FOR THE DEAF (TDD'S): Originally and often still called TTY's, these electronic devices allow the people with hearing loss to communicate via a text telephone system. This term appears in ADA regulations and legislation.

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: Video Relay Service (VRS) 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.

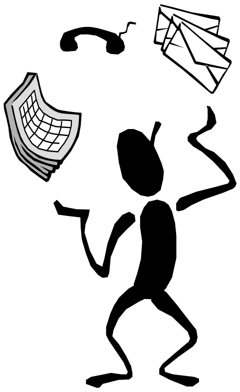
VISUAL REINFORCEMENT AUDIOMETRY (VRA): A method used to test hearing in young children. For example, the child learns to look at a toy that lights each time he hears a sound.

STAYING ORGANIZED

This section is a place to keep everything you will need for attending your child's appointments, and a place to store all of the information you may collect at each visit.

In this section you will find:

- Important Numbers Worksheet
- Appointment Schedule Worksheet
- Tips for Preparing for Your Child's Appointments
- Notes Pages
- *Learning about Hearing Loss – A Roadmap for Families* & *A Family's Checklist* – created by NCHAM
- *Communicate with Your Child* brochure – created by NCHAM
- *Questions You May Want to Ask* brochures – created by CDC
- *Business Card Holder* (for professional cards)
- Plastic Sheet Protectors (for important documents)
- Divider with Pockets (for brochures and other information you collect)



Important Numbers

Please take time to fill-in 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.

Insurance Information:

Insurance Company: ______________________________

Group/Policy #: ______________________________

Phone #: ______________________________

Other Insurance Information:

Insurance Company: ______________________________

Group/Policy #: ______________________________

Phone #: ______________________________

Child's Medical Providers:

Title	Name	Address	Phone	Email/Website
Primary Care Dr.				
Audiologist				
ENT				
Geneticist				
Ophthalmologist				
Other				
Other				
Other				

Child’s Early Intervention Contacts:

Title	Name	Address	Phone	Email

Family Support Organizations:

Organization	Contact Name	Phone	Website	Email

Local and State Resources:

Organization	Contact Name	Phone	Website	Email

Public School Contacts:

School	Contact Name	Position	Phone	Email

Additional Contacts:

Organization	Contact Name	Phone	Email	Comments

Child’s Amplification Information (if chosen by family):

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 Fit:		
Accessories:		
Accessories:		
Accessories:		

Amplification Contacts:

Type of Contact	Contact Name	Phone	Email
Repair			
Programming			
Insurance			
Other			

Appointment Record

Use this Appointment Record to keep track of your child's appointments and any follow-up instructions given by the provider. This record may also be useful when requesting copies of medical records for yourself or another provider.

Date/Time	Provider's Name	Phone #	Reason for Appt	Instructions

Date/Time	Provider’s Name	Phone #	Reason for Appt	Instructions

Preparing for Your Child's Appointments

Below are some helpful hints about getting ready for your child's appointments. This notebook also includes the *Questions You May Want to Ask* brochures, created by the Centers for Disease Control (CDC). They are also available on the CDC website: http://www.cdc.gov/ncbddd/hearingloss/freematerials.html.

BEFORE YOUR VISIT

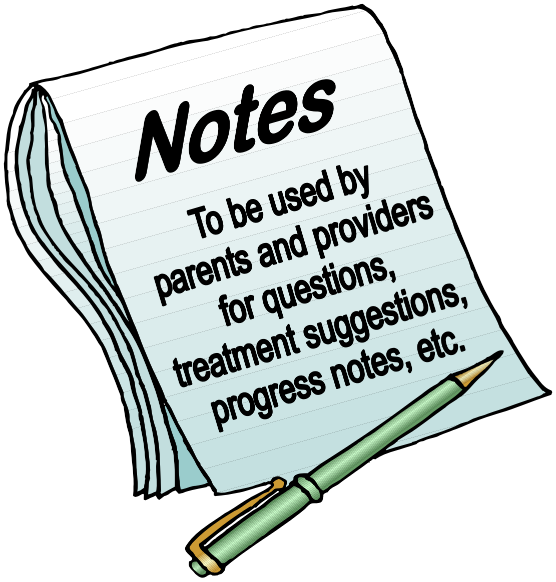
- Make a list of concerns or things you are worried about.
- Write down any questions you have (big or small).
    - The *Questions You May Want to Ask* brochures have great ideas too!
- Take a friend or family member with you. They may help you remember questions or take notes.
- Keep this book with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

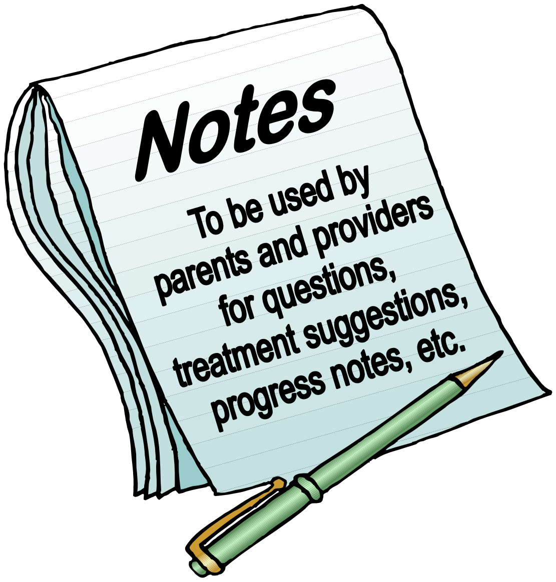
DURING YOUR VISIT

- 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 a 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 with you, 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.


Notes
To be used by parents and providers for questions, treatment suggestions, progress notes, etc.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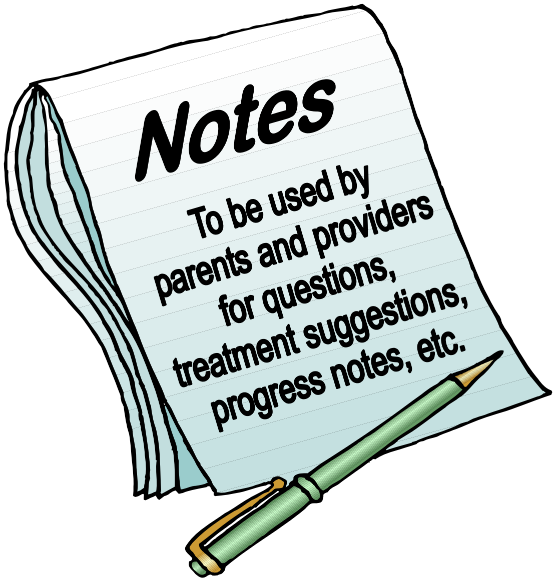
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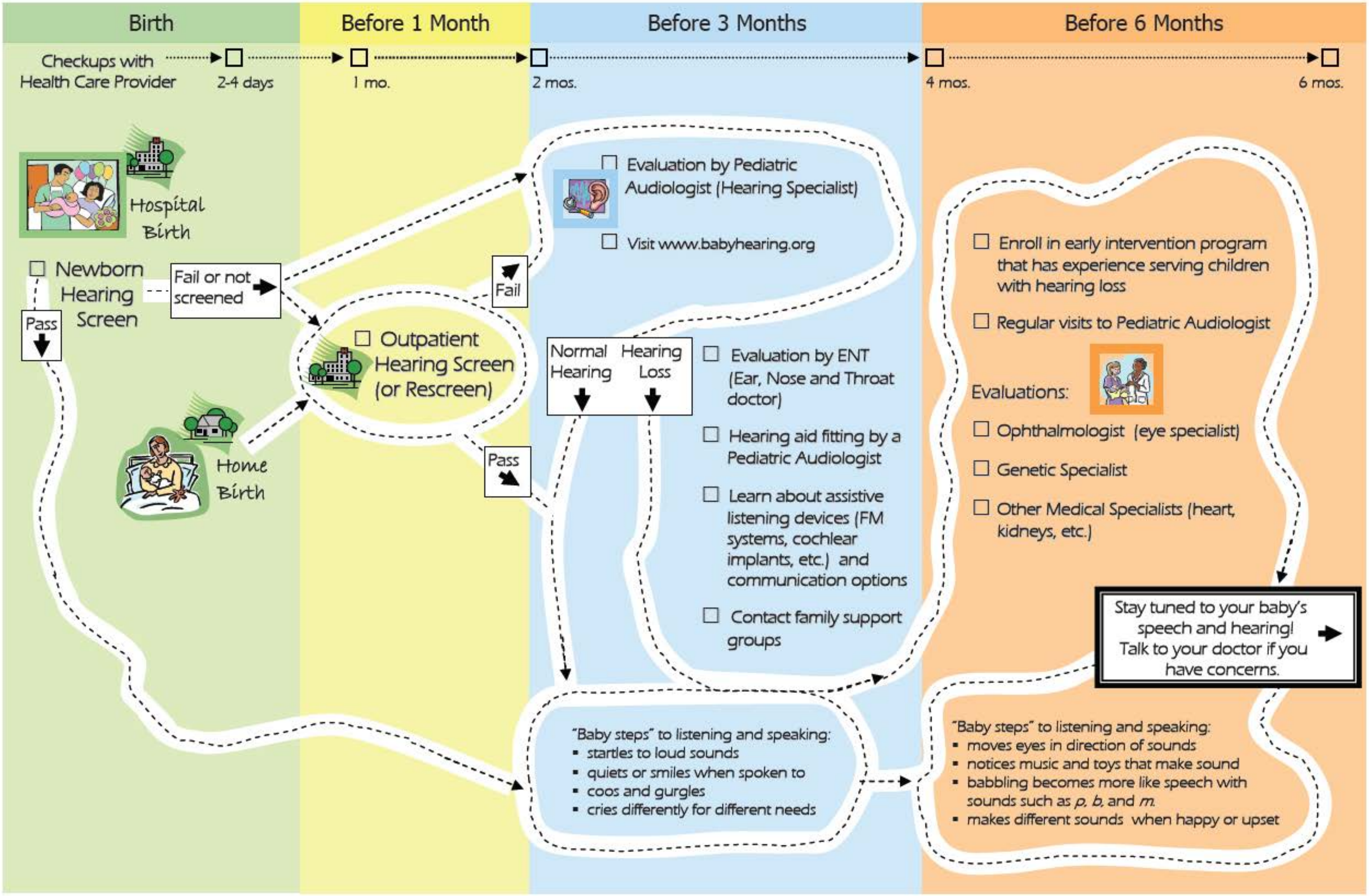
Universal Newborn Hearing Screening, Diagnosis, and Intervention

Learning about Hearing Loss -- A Roadmap for Families



Birth

Checkups with Health Care Provider → ☐ 2-4 days → ☐ 1 mo. → ☐ 2 mos. → ☐ 4 mos. → ☐ 6 mos.

Hospital Birth

☐ Newborn Hearing Screen

Pass

Fail or not screened

Home Birth

Before 1 Month

☐ Outpatient Hearing Screen (or Rescreen)

Fail

Pass

Before 3 Months

☐ Evaluation by Pediatric Audiologist (Hearing Specialist)

☐ Visit www.babyhearing.org

Normal Hearing

Hearing Loss

☐ Evaluation by ENT (Ear, Nose and Throat doctor)

☐ Hearing aid fitting by a Pediatric Audiologist

☐ Learn about assistive listening devices (FM systems, cochlear implants, etc.) and communication options

☐ Contact family support groups

"Baby steps" to listening and speaking:
- startles to loud sounds
- quiets or smiles when spoken to
- coos and gurgles
- cries differently for different needs

Before 6 Months

☐ Enroll in early intervention program that has experience serving children with hearing loss

☐ Regular visits to Pediatric Audiologist

Evaluations:

☐ Ophthalmologist (eye specialist)

☐ Genetic Specialist

☐ Other Medical Specialists (heart, kidneys, etc.)

Stay tuned to your baby's speech and hearing! Talk to your doctor if you have concerns. →

"Baby steps" to listening and speaking:
- moves eyes in direction of sounds
- notices music and toys that make sound
- babbling becomes more like speech with sounds such as *p*, *b*, and *m*.
- makes different sounds when happy or upset