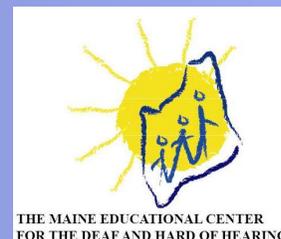


A Parent's Guide for Deaf & Hard of Hearing Infants & Children



Maine CDC Newborn Hearing Program



Dear Parents,

In the days and weeks following the confirmation of your child's hearing loss, you may find yourself searching for answers everywhere. You may suddenly feel the need to become an expert on the subject of hearing loss in order to make the right decisions for your child. It can seem overwhelming because there is so much to learn and consider and so many decisions to make. You might take on roles that had never been considered before learning of your child's hearing loss. You may interact differently with your husband, wife or partner. These are all very normal experiences when you are adjusting to having a child with hearing loss.

We have designed this notebook as a resource for all Maine families who have an infant or child newly diagnosed as deaf or hard of hearing. It is our hope that this notebook guides you and your family as you begin your journey toward understanding your child's hearing loss. There is a lot of information in this resource guide. With the help of other parents, we have tried to make this resource guide family-friendly and easy to read. Even though you may not read all of it right away, keep this notebook handy and refer to it when you need more information.

We have organized the resources in the following sections:

- 1. Getting the Facts on Hearing Loss:** includes the types of hearing loss, the levels of hearing loss, how to read the results of the hearing test, assistive technology and many other facts about hearing loss.
- 2. Support and Advocacy:** includes professionals and organizations that support children and families and methods and tips on coping with a hearing loss diagnosis.
- 3. Early Intervention:** includes the professionals that may interact with you and provide early intervention services, what an Individual Family Services Plan (IFSP) is and what that means.
- 4. Communication and Language:** includes language milestones and the different communication modalities available to families.
- 5. Family Stories:** from several families who are willing to share their journeys with you.
- 6. Resources:** a list of resources available both within Maine and nationally. The list includes support for families, where to find information on your rights and professional resources.
- 7. Glossary:** common terms and acronyms.
- 8. Keeping Track:** a place to keep track of business cards, notes and other items.

Maine CDC Newborn Hearing Program

Phone: 207-287-8427 or 1-800-698-3624 Ext 8427 (voice)

Website: www.mainepublichealth.gov/MNHP

Maine Educational Center for the Deaf and Hard of Hearing

Phone: 207-781-6335

Website: www.mecdhh.org

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Section 1

Getting the Facts on Hearing Loss

Did you know that 90 percent of children who are deaf or hard of hearing are born to parents who have normal hearing? Many parents of children who are deaf or hard of hearing did not know much about hearing loss before they were told that their child was deaf or hard of hearing.

This section of the notebook contains information that may help you better understand the ear, the types of hearing loss, the types of tests used to diagnose hearing loss, the medical exam and assistive technology.



Description of the Ear

Professionals that take care of the ear include:

Otolaryngologist (Ear, Nose and Throat – ENT)

provide medical care for the ear.

Audiologists test for hearing loss and work with the families and ENTs when assistive technology is needed or wanted.

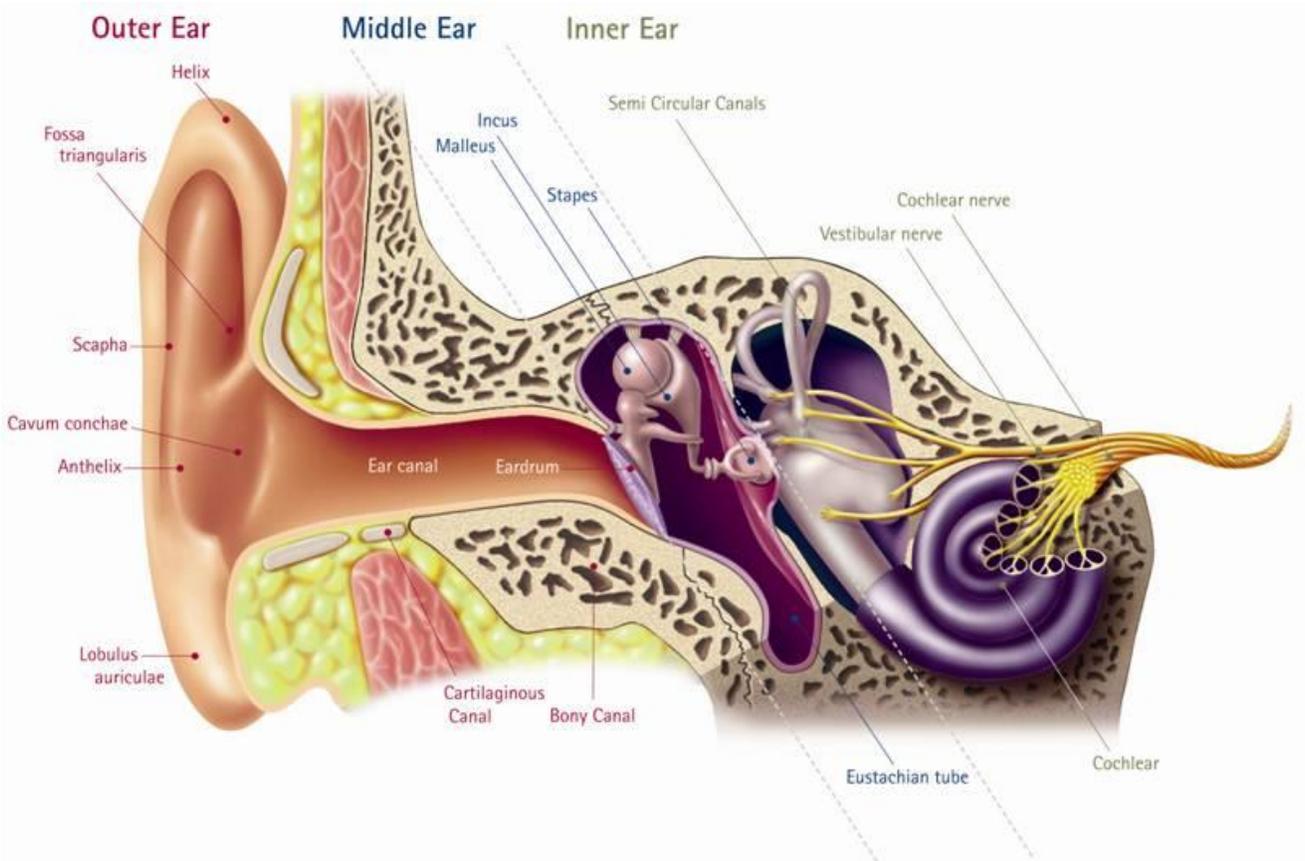
The ear is divided into three parts: **the outer ear, the middle ear,** and **the inner ear.** Working together, the three sections of the ear help us hear. Sound passes through all three parts of the ear before it goes to the brain. The brain interprets the sound and tells us what we are hearing.

Sounds go into the **outer ear.** The part of the outer ear that we can see is called the pinna. It catches sound from outside the ear and the sound travels to the ear canal. The sound pushes against the eardrum. The eardrum separates the outer ear from the middle ear.

The **middle ear** contains the three smallest bones in the body. They are so small they can fit on a dime. These bones are called the malleus, incus, and the stapes. They are commonly called the hammer, anvil and stirrup. When the eardrum moves, it makes the three bones in the middle ear move.

The **inner ear** is in the skull bone on the side of the head. This part of the ear contains the cochlea and the hearing nerve. The cochlea is shaped like a snail and contains fluid, thousands of tiny hair cells and nerve endings. These hair cells are tuned somewhat like the keys on a piano. Some of the hair cells respond to low pitch sound and some of the hairs respond to high pitch sounds. These hair cells connect to the hearing nerve which connects the cochlea to the brain.

The Ear



Types of Hearing Loss

Hearing loss can happen in any part of the ear. This includes the outer ear, the middle ear, and the inner ear. Hearing loss can happen in any one of these places or in more than one place. Each type of hearing loss has a different name and different possible treatments.

Types of hearing loss are classified by where and how the loss occurs in the ear and include:

- **Conductive Hearing Loss**
- **Sensorineural Hearing Loss**
- **Mixed Hearing Loss**
- **Auditory Neuropathy Spectrum Disorder**

Conductive Hearing Loss

A conductive hearing loss occurs when one or more of the structures of the outer or middle ear are not working properly and prevents sound from reaching the nerves of the inner ear.

Conductive hearing loss may be caused by:

- Fluid in the middle ear
- Problems with the bones of the middle ear
- A hole in the eardrum
- A blockage of the ear canal

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

Sensorineural Hearing Loss

Sensorineural hearing loss is caused by damage to the nerves of the inner ear that prevents sounds from reaching the brain. Sensorineural hearing loss may be caused by:

- Faulty development of the inner ear structures
- Damage to the inner ear and/or hearing nerve (from illness or infection before birth)
- Certain medications
- Family history of hearing loss

A sensorineural hearing loss is generally perceived as a loss of both loudness of sound and clarity of sound. Sensorineural hearing loss is more likely to be permanent. Many children with sensorineural hearing loss have some useable hearing, called “residual” hearing that allows access to sound with amplification.

Mixed Hearing Loss

This type of hearing loss is a combination of both conductive and sensorineural hearing losses. An example of a mixed hearing loss is sensorineural loss with an additional conductive loss due to an ear infection or fluid in the middle ear. Changing fluid levels can cause the conductive loss to fluctuate.

Auditory Neuropathy Spectrum Disorder (ANSD)

This type of hearing “loss” is caused by a miscommunication between the parts of the ear, the auditory nerve, and the listening center in the brain. The basic parts of the ear are able to detect sound, but there is a ‘bad connection’ between the external parts of the hearing system and the auditory nerve. The ‘bad connection’ prevents the information about the sound from being sent to the brain in a synchronized or organized way. A child with this hearing problem may be able to hear that sounds are present at times, but the sounds are not heard clearly or consistently.

Sometimes hearing loss can be associated with other conditions or symptoms. A geneticist may be consulted to test for certain conditions or symptoms that are not identifiable by appearance alone.

Hearing loss can occur in one or both ears. When it occurs in one ear, it is called a **unilateral hearing loss**. When it occurs in both ears, it is called a **bilateral hearing loss**. Sometimes, one’s hearing loss stays the same over the years of one’s life and this is called a stable hearing loss. There are also some types of hearing loss that gradually change or progress over time. This type of hearing loss is called a **progressive loss and should be monitored by a child’s audiologist and physician over time**.

Which Ear?	What does that mean?
Unilateral Hearing Loss	The hearing loss is in one ear
Bilateral Hearing Loss	The hearing loss is in both ears
Progressive Loss	The hearing loss gradually becomes worse over time

Degrees of Hearing Loss:

Potential Effects

How loud is that Sound?	
Item	dB
Leaves Rustling	15
Birds at 10 feet	50
Conversational speech	55
Barking dog	75
Telephone dial tone	85
Lawn mower	85
Train	105
Baby crying	110
Jet taking off	140
Loudest sound possible	194

One way to describe the severity of a hearing loss is by talking about the “degree” of loss. Hearing levels are measured using a decibel scale. Decibels (dB) measure the intensity or loudness of a sound; the larger the number, the louder the sound. To measure hearing loss, audiologists determine the softest sound your child can hear. The softest sound that can be heard at a certain frequency or pitch is called threshold.

The chart on the following page explains what sounds your child may and may not hear with amplification based on the degree of hearing loss. It identifies how amplification may help your child and the potential effects the hearing loss might have on the ability to hear and recognize spoken conversation and environmental sounds.

This is only a guide. Each child has unique potential and uses it differently. Only time will tell how your child uses their hearing potential and how they may or may not benefit from the use of amplification.

Degrees of Hearing Loss & Potential Effects

Degree of loss	Decibels	Potential Effects
Slight Hearing Loss	16-25 dB	Minimal loss of some sounds. May have difficulty hearing quiet or distant conversations especially in noisy environments.
Mild Hearing Loss	26-40 dB	Without amplification, can hear most conversations up close and in quiet environments, but is likely to miss parts of words, leading to misunderstanding. A child may be described as “hearing when they want to.” Amplification and speech reading may supplement the understanding of what is said.
Moderate Hearing Loss	41-55dB	Without amplification, a child has difficulty hearing spoken conversations. Much of the energy of speech may be missed. Consistent use of amplification and language intervention may increase the likelihood of learning to hear and recognize sounds and developing speech and language at a normal rate.
Moderately Severe Hearing Loss	56-70 dB	Conversation must be very loud to be heard without amplification. Proper amplification provides access to spoken language. Age when amplification is used, consistent use of amplification and intervention are important to help the child learn to use their hearing.
Severe Hearing Loss	71-90 dB	Without amplification, a child may hear the presence of loud voices and sounds close to the ear; speech is not be clear. With early and consistent use of amplification and intervention, many children have access to spoken language.
Profound Hearing Loss	91 dB or greater	Without amplification, the child is more aware of sounds as vibrations. The child may rely on vision rather than hearing as the primary means for communication and learning. Technology such as hearing aids and/or cochlear implants may or may not be useful for hearing spoken conversation.
Unilateral Hearing Loss (one sided loss)	The loss can occur at any decibel	May have difficulty hearing faint or distant spoken conversations. A child usually has difficulty knowing where sounds are coming from, has difficulty understanding speech directed toward the affected side or listening successfully in places with background noise.

Frequently Asked Questions

Below are some of the most common questions families ask when a child is diagnosed with hearing loss.

Q. Who does the hearing testing?

Hearing testing is usually done by an **audiologist** to find out how well a child can hear. **Audiologists** are health care professionals who have special training in the evaluation of hearing loss and balance disorders.

Q. How do I find a place to test my child's hearing?

The person you see for your child's health care may make a referral to an audiologist. In addition, the Maine CDC Newborn Hearing Program has developed a list of the audiology facilities and audiologists that test infants and young children.

Q. How many tests will my child need?

The audiologist may need to do several tests to find out more about the kind of hearing loss your child has, the degree of the loss and the reason for the loss.

Q. What are the types of hearing tests?

Different hearing tests may be done depending on the age of the child and the information the audiologist needs. The next several pages provide some basic descriptions of the different types of tests that can be done for infants and young children.

Types of Hearing Tests

The following describes the various tests audiologists may use to test hearing. This is provided to you as a simple guide; please consult with your child's audiologist for detailed information regarding the testing completed and planned for your child.

Otoscopic Exam:

A lighted tool called an otoscope is used to look in the ear canal and at the eardrum. This exam can help find out if there is fluid in the child's middle ear or if something is blocking the ear canal.

Tympanometry:

A small, soft probe is placed at the opening to the child's ear canal. The audiologist changes the pressure in the ear canal and sends some sound into the ear to test how the eardrum moves. This test is used to see how the middle ear is functioning and can help find out if there is fluid in the middle ear, a hole in the eardrum or other problems with middle ear structure. The same testing may be used to find out about your child's middle ear muscle reflexes, "acoustic reflexes." Tympanometry is also known as impedance testing or emittance testing.

Otoacoustic Emissions:

(Also known as OAE, DPOAE, TEOAE)

During an Otoacoustic Emission (OAE) test a small, soft probe containing a microphone and receiver is placed in the ear canal. The microphone makes sounds and the sounds reflected back from the cochlea are recorded and measured by a computer. It is necessary for a child to be quiet and calm for this test to be completed. This test can find a hearing loss that occurs in the inner ear.

Auditory Brainstem Response

(Also known as ABR, AABR, BAER)

This test measures the ear and the brain's response to sound. Small sensors are put on the child's head and small earphones are placed over the child's ears.

Different sounds are sent through the earphones. A computer measures and analyzes the brain's response to the different sounds. The responses are measured in the form of waves on a graph. This gives more information about the degree and type of hearing loss across frequencies in both ears.

The child must be quiet, sleeping, or perhaps sedated for this type of testing to be done.

(Other tests that may be done as part of the ABR are:

Tone Pip and Auditory Steady State Response)

Behavioral Tests:

Behavioral Observation Audiometry Visual Reinforced Audiometry Conditioned Play Audiometry

Behavioral hearing tests require the child to respond to sound. This testing needs to be done by an audiologist who has been trained to observe behavioral responses in infants and to teach a young child to respond to sound with reinforcement or through play. The type of behavioral testing used by the audiologist is determined by the age of the child.

Behavioral observation testing provides an estimate of a child's hearing levels as the audiologist observes the response to a variety of sounds. After about 6 months of age, another behavioral test, visual reinforcement audiometry, is used: the child is taught to respond to sound through head turns that are reinforced by animated lighted toys. As the child gets older, they are taught to repeat an action such as placing a block in a container in response to sound; this is called conditioned play audiometry.

With both visual reinforcement and conditioned play audiometry, accurate information about hearing "thresholds" or how loud speech and sounds need to be to be heard is obtained. Children have fun playing these listening games as the audiologist tests hearing.

For behavioral hearing testing, your child is placed in a special room that is soundproof. Depending on age, your child may sit on your lap or in an infant/child seat. There may be two testers working with your child. The sounds may be delivered to your child through earphones or special insert earphones or speakers in the testing room.



After doing different tests, the audiologist uses different symbols to mark the softest levels at which your child is aware of sound. The symbols are connected to make a line on the graph for each ear.

This line is called the configuration of the audiogram. Configurations are different for each child's individual hearing loss. Some configurations go somewhat straight across. These are called flat hearing losses. Some configurations angle downward; either gently or sharply, these are called sloping losses. Your audiologist will describe your child's hearing loss to you.

An audiogram can show several things:

- If both ears have the same level of hearing or different levels
- The amount of hearing loss
- If there is different hearing loss for some frequencies

You will probably have many visits to an audiologist when you are finding out about your child's hearing loss. Your audiologist will talk to you about the hearing tests and discuss the audiogram with you. Do not be afraid to ask questions about anything you don't understand, and keep asking until you are sure you understand.

The Medical Evaluation

An Ear Nose and Throat doctor (ENT) is a physician who specializes in the diagnosis and treatment of disorders of the ear and related structures of the nose and throat. This physician is also called an Otolaryngologist. If your child has been confirmed to have a hearing loss, a medical evaluation by this physician is recommended in order to determine the cause of the possible hearing loss and to make treatment recommendations to you.

A complete medical evaluation helps the ENT identify any physical differences of the ear, possible infections, or other medical conditions that are known to be associated with childhood hearing loss. The ENT works with your child's primary care provider and possibly a genetics doctor to determine what additional tests are needed for a complete medical evaluation.

This medical evaluation assists your child's health care provider to diagnose the type and severity of hearing loss and whether or not there may be other associated medical conditions. If your child has been found to have a hearing loss, monitoring is generally needed every six months after the initial evaluation until the age of three.

The ENT makes treatment recommendations for your child based upon the findings of the medical evaluation, the audiologic testing, and any additional testing and evaluations that may have been ordered.

A medical examination may include a complete family and medical history; a head and neck examination; a microscopic ear examination and a review of prior testing

Suggested testing and additional evaluations may include:

- Repeat or additional testing, such as Otoacoustic Emissions (OAE) or Auditory Brainstem Response (ABR)
- Imaging Studies (Such as a CT Scan or MRI scan)
- Laboratory Testing
- Eye Examination
- Genetic Evaluation
- Cardiac Evaluation / EKG testing
- Kidney Evaluation (Urinalysis, blood tests and ultrasound)

Treatment recommendations may include repeating hearing testing and observation, medications, ear tube placement and/or amplification.

Hearing Assistive Technology

Hearing assistive technology refers to any kind of equipment used to help a person hear. This section gives you an overview of the various types of hearing assistive technologies available to infants and children with hearing loss. Your audiologist and ENT will assist you in determining if assistive technology is appropriate for your child. The specific technology will be decided by your audiologist based on the child's hearing loss and access needs.

Hearing Aids:

Hearing aids are instruments that make sounds louder. When sound is made louder it is called amplification. Hearing aids make all sounds in the environment louder (speech, as well as other sounds like TV, vacuum cleaner or air conditioner). They cannot "cure" a hearing loss or make a person hear sounds at frequencies where there is no hearing.

Audiologists usually recommend hearing aids for a child as soon as possible after a hearing loss is identified. Before a hearing aid can be purchased, the audiologist must determine the degree of your child's hearing loss and receive medical clearance from an otolaryngologist (ENT doctor). There are many different options and types of hearing aids, but all have the following four basic parts:

- A microphone to pick up sound
- An amplifier to change sound waves into electrical signals and make them louder
- A power supply (battery)
- A receiver to change electrical signals back into sound waves and deliver them to the ear

Hearing aids have changed quite a lot over the years. Today, there are many wonderful options. The audiologist can help you choose the right hearing aid for your child, program the instruments to work best for the hearing loss in each ear, and work with you and your child to ensure that the aid(s) are adjusted best for the hearing loss and access needs over time.

Earmolds are an important part of many types of hearing aids. The earmold delivers the amplified sound into the ear. The earmold is custom made, specifically molded to the shape of the child's ear and made of a soft material that is safe and comfortable for little ears. Earmolds need to be replaced fairly often as your child's ear grows. Earmolds for young children can come in many different colors.

Several types of hearing aids and many different features are available. Your child's individual needs and skills are considered in selecting the best hearing aid and features. The behind-the-ear (BTE) hearing aid is the type of hearing aid most commonly recommended for infants and young children.

Cochlear Implants:

A cochlear implant (CI) is a device that helps some profoundly deaf children to hear. A CI has two parts. One part is surgically implanted and includes an electrode system and a receiver. The other part is worn externally and has a microphone, a sound processor, and a transmitter coil that communicates with the internal part. The external part is most commonly worn on the ear and looks like a hearing aid behind the ear. Sometimes, it may be worn in a pocket, pouch or harness, or clipped to the clothing.

A CI does not correct hearing loss. It bypasses the normal hearing pathway and stimulates the auditory nerve directly, allowing the listener access to sound.

If a child has a severe to profound sensorineural hearing loss and does not benefit from conventional hearing aids, they may be a candidate for an implant. Your audiologist and health care provider can give you more information about CI surgical centers, benefits, risks and other requirements.

Remote Microphone Hearing Assistance Technologies (HAT), sometimes called: FM System (Frequency Modulation System)

Some listening situations are more difficult because of background noise or because the sound is soft or far away. An infant or toddler may benefit from a remote microphone HAT system when riding in the car, when at child care, or when the parent and child are at a distance greater than three to six feet or in noisy environments.

The HAT system has two components. The person speaking wears a microphone and transmitter that sends speech across the space to the receiver. The child wears a receiver that sends sound through the hearing aid or cochlear implant. The system is designed to amplify the speaker's voice so that it can be heard clearly, even at a distance and is louder than competing background noise.

When using this type of system, the child can still hear their own voice and environmental sounds through the hearing aid or cochlear implant, if they use personal amplification. Some children may use the HAT system as the primary form of amplification while others may use it only in settings that are particularly noisy or during therapy sessions.

Section 2:

Support and Advocacy

When you first find out that your child has a hearing loss, many questions may run through your mind.

1. How much does my child hear?
2. Can we fix the hearing loss?
3. What do the hearing test results mean?
4. Who can help answer your questions?

You will meet many new people because of your child's hearing loss. Each person has a different role in helping you and your family.

Some of these people are focused on what your child needs in terms of medical services, hearing tests, hearing aid services, language development and educational services. Other people are focused more on what the family may need in terms of information and support.

Give yourself time to make decisions that feel right for you and your family as you begin your journey with your child.



Professionals You Will Meet

Below is a description of some of the people and resources who are dedicated to helping children and families with hearing loss. This list includes audiologists, physicians, Child Development Services, Early Childhood and Family Services, therapists, counselors, and other parents who have a child with hearing loss.

Audiologist:

- Has the skills and equipment to test your child's hearing, diagnose hearing loss and explain the test results using words you can understand.
- Recommends and fits hearing aids or other equipment to help your child hear better.
- Discusses other equipment that might help your child hear better (cochlear implant, FM system).
- Teaches you about ways to help your child develop listening skills.
- Works with you and your child through ongoing testing to make sure that the hearing aids are working well.

Doctors:

Most children with hearing loss have a primary care provider, who is often a pediatrician or a family physician. In addition, you may meet an Ear Nose and Throat (ENT) or Otolaryngologist doctor.

Ear Nose & Throat (ENT) or Otolaryngologist:

- Diagnoses medical problems with your child's ears.
- Suggests possible treatments related to your child's ears/hearing.
- Provides medical clearance for hearing aids.
- Helps you connect with audiologists and other professionals.

Geneticist:

- Helps determine the cause of the hearing loss and any related health issues.

Child Development Services (CDS):

Child Development Services is a statewide agency under the supervision of the Maine Department of Education that provides early intervention services to the children of Maine.

CDS:

- provides “case management.” They help keep track of all the people working with you and your child.
- helps you and your family plan what services you need with an Individualized Family Service Plan.

Early Childhood and Family Services (ECFS):

ECFS is a statewide organization under the Maine Educational Center for the Deaf and Hard of Hearing (MECDHH). ECFS provides unbiased services to children from birth to five years of age with any degree of hearing loss.

ECFS:

- answers questions about how your child’s hearing loss affects communication, participation in family activities, and learning.
- gives basic information about hearing loss in everyday language
- suggests helpful tips from other families raising a child with hearing loss
- suggests ways to help your child learn about what is happening around them
- helps you learn about communication options
- reinforces what you learned from your audiologist about your child’s hearing aids
- helps other people in your child’s life understand hearing loss (grandparents, cousins, friends and day care providers)
- helps you connect with other supports, such as communication therapists, counselors and other parents of children with hearing loss

Specialty Providers (also known as Therapists/Educators):

Some of the specialty providers with whom you may work include: speech and language therapists (SLP), teachers of the deaf (TOD), occupational therapists (OT), physical therapists (PT), special educators, parent-infant specialists and/or cued speech, listening and spoken language or sign language specialists.

Depending on your child's needs, your provider can:

- Monitor your child's development (language, cognitive and motor skills).
- Explain where your child's skills may need some help and show you how to help your child during every day play.
- Help your child learn language.

Counselors, Social Workers and Psychologists

Counselors can:

- Listen to you and other family members as they sort through their feelings about having a child with hearing loss.
- Help family members develop additional coping skills to meet their new challenges.
- Offer ways to help individual family members deal with the changes in the family environment relating to the hearing loss.

Organizations

Guide By Your Side (GBYS)

Maine Guide By Your Side (GBYS) is a program of Maine Hands & Voices that is dedicated to supporting families with deaf or hard of hearing children, without bias, around communication opportunities, modes or methodology. A trained parent Guide is connected with the family of a newly-diagnosed deaf or hard of hearing child to provide emotional support and unbiased information about state and local resources. The Guide is a parent of a deaf or hard of hearing child. Maine also has a Deaf/Hard of Hearing Guide program where parents meet Deaf and Hard of Hearing adults for the opportunity to ask questions, information sharing and support.

Maine Hands & Voices:

A non-profit parent organization dedicated to supporting Maine families and their children who are deaf or hard of hearing and the professionals who serve them, regardless of their communication choices.

Maine Center on Deafness:

A resource center for deaf and hard of hearing people that provides general information and advocacy on hearing loss. The Maine Center on Deafness also has a telecommunications equipment program for specialized telephones for deaf and hard of hearing people.

Maine Parent Federation (MPF):

MPF is a non-profit organization that provides information, support and training to parents and professionals statewide. Information about specific disabilities, parenting, education, services, support groups and resources are available.

Supportive People

Listed below are people who are available to provide additional support to you and your family.

Other Parents of Children Who are Deaf or Hard of Hearing:

- Share their stories: What did they experience and what might you expect?
- Share resources and helpful hints that helped them during those first years with their child.
- Listen to you and answer your questions based on their experiences.
- Get your children together for playtimes and social interaction.

People who are Deaf or Hard of Hearing:

- Share their life stories
- Are role models
- Are language models

Supporting Your Family

A child's grandparents, brothers, and sisters, extended family and community members also experience periods of adjustment. Each person reacts differently and needs time to adjust to their changing feelings.

The following are some of the feelings that any member of your family could experience:

- Feelings of isolation because those close to you don't understand what you are experiencing.
- Feeling angry and hurt if relatives and people close to you react as if your child is not "normal" or appear afraid of your child's hearing loss.
- Feelings of sadness, because your child may miss some of the auditory experiences you enjoy such as music, laughter, sounds of nature, or others.
- Feelings of excitement or anxiety if the family needs to learn a new language.
- Feelings of uncertainty because the family network of friends may be changing because there are different opinions, interests and/or priorities now.
- Feelings of being closer, stronger and more united as your family learns more about living with a child who is deaf or hard of hearing and learns to enjoy the unique person that has come into the family.
- Feelings of pride in your strength and your ability to meet challenges as you make decisions for your family and your child.

Siblings

Brothers and sisters may also need time to adjust. They might want to know what it means to have a new family member with hearing loss and how this affects them. They may have extra questions as they try to adjust to hearing loss as well as having a new brother or sister.

Here are some of the feelings that a brother or sister may experience:

- Feeling jealous or resentful of the attention the deaf or hard of hearing child receives.
- Feelings of guilt. They may think that they somehow “caused” their sibling’s hearing loss.
- Feelings of embarrassment when their friends ask questions about their brother or sister’s hearing loss. They may need to learn to handle insensitivity.
- They may begin to see themselves as an unofficial guardian and feel especially protective towards their brother or sister.

When siblings are helped to understand the hearing loss and are included in the decisions about communication, they often learn early empathy for others and become more mature and independent than other children their age.

Grandparents

(The following section was adapted from Wisconsin’s Family Guide “Babies and Hearing Loss” and is included with permission from Connie Stevens, parent of a deaf child with Down syndrome)

Grandparents often have added worries. Their concern is not just for the child who is deaf or hard of hearing, but for their own son or daughter, their spouse or partner, and extended family.

They may want to help but may not know how. You may want to include them in therapy sessions, appointments or in family training. This may help them feel more involved and informed. It also helps them stay connected to their grandchild and understand their grandchild’s hearing loss.

Helpful Tips:

Here are some helpful ways to cope and adjust in the weeks and months after you have found out about your child's hearing loss:

- Find out as much as you can about childhood hearing loss and how children learn language.
- Get to know other parents who have children with hearing loss. Parents who have similar experiences may help you learn more about the joys and challenges of parenting a child with hearing loss.
- Develop a support network and seek professionals who provide honest and unbiased information and support you as you decide what works best for your child and family.
- Care for yourself by taking a break or a brief time away to renew and refresh if you are feeling overwhelmed. Sometimes a brief break helps you get a fresh view of a situation and allows you to cope better.
- Recognize and share your feelings. It is a good way to deal with them. Dealing with your feelings takes time. Support is available from many sources, including family, friends, and professionals.

Tips for Brothers and Sisters

- Allow for special one-on-one time with each child in your family and strive to make each child feel special, important and loved as much as possible.
- Talk to your children about hearing loss. Ask them about their feelings and allow them time to express them.
- Include them and their questions in the therapies and programs.
- Talk about how **all** your children can help each other in different ways. Let each brother and sister have a say in how much they would like to help with the new baby.
- Once in a while, satisfy their curiosity by taking them with you to the places that you go with the child who is deaf or hard of hearing (such as the audiologist or therapy sessions). This is an acceptable practice with many professionals, if you ask permission before a session.
- Read books together about children who are deaf or hard of hearing

Section 3:

Early Intervention

This section is dedicated to providing an overview of the early intervention services available to children in Maine. The section describes the Maine Department of Education's Child Development Services and the roles they play, what the Individualized Family Service Plan and the Individual Education Plan are, and how to navigate through the system.

Trying to understand a medical diagnosis of any kind can be very overwhelming. It is common that you might not understand or remember what you are being told. It is okay. When that happens, please stop the professional and ask for them to explain it in a different way. You may also wish to bring someone with you who can listen and take notes. Remember the professionals spend their days talking about hearing loss and they do not expect you to know the information right away. As with anything new, it takes time to learn. Do not be afraid to ask questions and to do your own research.



Maine Department of Education-Child Development Services

(CDS)

Overview:

This section describes CDS's responsibilities, services and processes as the lead agency for providing early intervention, special education, and related services to eligible Maine children, birth to kindergarten-age five.

What is CDS:

CDS is a quasi-state agency which is overseen by the Maine Department of Education (DOE), and has nine regional sites across the state. The agency provides Part C (birth through age two) and Part B 619 (ages three to kindergarten-age five) services as identified by both Federal (Individuals with Disabilities Education Act) and State (Maine Unified Special Education Regulations) regulations.

CDS's Part C program provides services to infants and toddlers with significant developmental delays or established conditions which may result significant developmental delays. All eligible infants and toddlers and their families receive service coordination and may receive special instruction, speech-language therapy, occupational therapy, physical therapy or other services depending on the needs of the child and family. Services are identified on the family's Individualized Family Service Plan (IFSP) and are delivered in the child's natural environment – typically the home or childcare. CDS's Part C program focuses on building the caregiver's capacity to meet the child's needs to ensure that intervention occurs not only during sessions but throughout the child's daily routines and activities.

CDS's Part B 619 program provides a free and appropriate public education (FAPE) to children, ages three to kindergarten-age five, who are identified as having a disability and for whom the disability has an adverse effect on the child's educational performance. Special education and related services are identified on the child's Individual Education Plan (IEP) and are provided in the least restrictive environment (LRE) as determined by the IEP team.

How Does CDS Work?

1. Audiologists are required to refer any child that has been identified as deaf or hard of hearing to CDS. This may occur after the newborn hearing screening at the birthing hospital or after subsequent audiological evaluations.
2. Once CDS has received a referral, a service coordinator or case manager will contact the family to schedule a comprehensive evaluation of your child's development. For infants and toddlers, an assessment of the family's strengths, needs, concerns and priorities is also completed. In some cases, additional evaluations may be needed. For

children three to kindergarten-age five, an observation of the child in an educational setting is required.

3. If the child is age two or younger, CDS will arrange an IFSP meeting at which team members will discuss the results of evaluations. Depending on those results or the presence of an existing condition, the team may develop an IFSP based on the child's development and the family's concerns and priorities. The team will identify a primary service provider based on those concerns and priorities.
4. Through a memorandum of understanding, a Deaf and Hard of Hearing Early Childhood Specialist from MECDHH/GBSD will be assigned to each family, either as primary service provider or consultant to the primary service provider. Following the IFSP, they will begin the process of supporting the family's outcomes and providing information on supporting early language development, hearing levels, communication opportunities and statewide resources. .
5. If the child is three to kindergarten-age five, CDS will arrange an IEP meeting at which team members will discuss the results of evaluations and observation. Based on those results, the IEP team may determine that the child is eligible for services and develop an IEP based on the team's recommendations.
6. Through a memorandum of understanding, a Deaf and Hard of Hearing Early Childhood Specialist from MECDHH will be assigned to each child, to provide ongoing consultation to service providers and classroom teachers, or provide direct service to the child.
7. Both the IEP and IFSP are living documents and are required to be reviewed periodically. Any team member may request a meeting for the purposes of review and to propose changes as appropriate.

Who is on the IFSP or IEP Team?

IFSP and IEP team meetings can be overwhelming as they typically include many professionals who are discussing evaluations, services, progress, etc. Oftentimes, professional jargon and acronyms may make it challenging to have a clear understanding of the discussion. Families should not hesitate for clarification if necessary. Families may invite whomever they choose to the meeting.

The IFSP/IEP team may include:

- The family
- An ECFS Deaf and Hard of Hearing Early Childhood Specialist.
- The CDS service coordinator and/or case manager
- The teacher or primary service provider
- Therapists
- Audiologist
- Others as requested by the family

What are the differences between an IFSP and an IEP?

The chart below describes the differences between the Individualized Family Service Plan (IFSP) and the Individual Education Plan (IEP).

IFSP or Part C (Birth—2 years old)	IEP or Part B (3—21 years old)
Part C of IDEA applies to infants and toddlers and their families.	Part B of IDEA applies to children age three to 21, while Section 619 of Part B applies specifically to children three to five years.
Provides Early Intervention Services (birth to age two) to every eligible child and their families under the federal grant program.	Provides Special Education and Related Services under the Free and Appropriate Education Act (FAPE).
Utilizes an Individualized Family Service Plan (IFSP) with children and their families.	Utilizes an Individual Education Program (IEP) with children and their families.
Provides family support services and education to children in their Natural Environment and in the context of everyday activities.	Provides services and education to children in the Least Restrictive Environment.
Ensures Local Service Access to all children.	Ensures Local Service Access to all children.
Encourages Active Parent Involvement.	Encourages Active Parent Involvement.

Please use the following links to view the IFSP and IEP forms online:

<http://maine.gov/education/forms/specialservices/progreview/ifsp.doc>

<http://www.maine.gov/doe/specialed/forms/IEP-2014.pdf>

Section 4:

Communication and Language

This section describes the typical milestones for language development and the different communication options and opportunities available to children with hearing loss.



Introduction to Language:

As human beings, we cherish our ability to communicate our feelings and thoughts using language.

Communication grows out of relationships. Your child was born with the ability and the need to relate to others. In the first hours of your child's life, they communicated with loud cries when hungry and with a peaceful expression when full. Parents quickly learn to know what different cries mean.

Children communicate in many ways; they use their eyes, ears, and bodies. They recognize signals from what they see, what they hear, how they are touched, and what people around them are doing. All of this is communication. If they cannot fully use one of their senses, they depend even more on the others.

Sometimes when parents discover their child has a hearing loss, they feel unsure and they may ask themselves "How can we communicate?" Communicate with your child in *every* way that you can. Talk, gesture, and echo their sounds and movements, play games. Responding to your child and encouraging them to respond to you is an important stepping-stone to language.

Languages are special—they have words and unique grammar rules for how to put words together. Language allows us to talk about what we feel, describe what we experience; explain how things work, and make plans for the future. Language is one of our most important possessions.

When we are born, our brains are "ready" to learn language—any language to which we are exposed. Once we learn a first language, we can learn a second or even third language. But our brain is only "ready" to learn a first language during the first three or four years of life. After that, the brain becomes less able to learn a first language naturally.

Babies who are deaf or hard of hearing have a harder time getting enough exposure to language. Your family may have to make special efforts to make sure your child gets the necessary language exposure she needs and that she is developing her language skills. Remember that children learn to communicate and learn language over time. Each child's ability develops gradually and each child— with normal hearing and with hearing loss— develops at his/her own speed and in his/her own way.

Language Milestones

Your Child Should:	What you should be doing:
<p><i>Birth to 3 months:</i></p> <ul style="list-style-type: none"> • Startle to sudden noises • Sooth or calm to your voice • Squeal, coo, laugh 	<p><i>Birth to 3 months:</i></p> <ul style="list-style-type: none"> • Whenever your baby makes sounds, try to imitate them. Use a pleasant voice when talking to your baby. • Hold your baby close to you, often rocking, singing, talking quietly and reading. • Talk to your baby using his/her name while you work around the house.
<p><i>3-6 Months:</i></p> <ul style="list-style-type: none"> • Turn head or move eyes to find a familiar voice • Play at making noises and sounds • Like sound-making toys <p><i>6-9 Months:</i></p> <ul style="list-style-type: none"> • Respond to his/her name • Begin to understand common words like “no” and “bye-bye” • Imitate speech by making sounds like coughing, clicking tongue, smacking lips • Watch you and listen when you read nursery rhymes. 	<p><i>3-9 months:</i></p> <ul style="list-style-type: none"> • Keep imitating your baby’s sounds, talk a lot with him/her • Hold your baby close to you often singing, reading nursery rhymes, stories or talking • Talk with your baby about his/her toys and play games like “Peek-a-boo” or “Pat-a-cake”

Language Milestones

Your Child Should:	What you should be doing:
<p>9-12 months:</p> <ul style="list-style-type: none"> • Repeat simple words & sounds that you make; jabber • Point or reach for familiar objects when asked • Respond differently to happy or angry talking • Follow simple directions 	<p>9-12 months:</p> <ul style="list-style-type: none"> • Make simple speech sounds to see if your child imitates you • Pay attention to see if your child says “Mama” or “Dada” • Talk with your child about his/her toys and items in your home • Point to pictures in his/her books and talk about them
<p>12-18 Months:</p> <ul style="list-style-type: none"> • Bounce to music • Talk in what sounds like sentences, with a few understandable words • Identify people, body parts and toys • Enjoy listening to stories read aloud 	<p>12-18 Months:</p> <ul style="list-style-type: none"> • Show your child his/her body parts, “Here’s your nose, eye, ear” • Show simple picture books, helping to turn the pages, talk about the pictures • Play “Where’s Daddy or Mommy?” and point to Daddy or Mommy
<p>18-24 Months:</p> <ul style="list-style-type: none"> • Understand you when you call from another room • Point to body parts when asked • Begin to speak in two-word combinations, such as “Mommy more” • Has favorite books 	<p>18-24 Months:</p> <ul style="list-style-type: none"> • Read simple stories to your child and ask questions “Where’s the kitty?” and point out the picture • Give instruction, “Put the doll on the chair,” “put the ball in the box”

Language Milestones

Your Child Should:	What you should be doing:
<p>24-30 Months:</p> <ul style="list-style-type: none"> • Begins to take turns • Responds to simple questions • Understands descriptive words such as wet, hungry, tired 	<p>24-30 Months:</p> <ul style="list-style-type: none"> • Give your child time to explore materials and encourage them to do this in their own way • Respond to your child's comments • Expand on what your child says by repeating their message and adding a few words
<p>30-36 Months:</p> <ul style="list-style-type: none"> • Understands questions who, when and why • Has mastered many of the basic rules of grammar such as plural -s, -ing, -ed, and articles (a, the) • Tells stories • Talks about their own experiences 	<p>30-36 Months:</p> <ul style="list-style-type: none"> • Let your child participate with you in daily tasks and talk about what you are doing together • Provide information and brief explanation about what is happening. Think out loud sometimes! • Listen carefully to stories

By age three and a half, children typically speak in full sentences and have the basic grammar of their language.

Incidental Learning

Most of what we learn is never “taught” to us. We learn from hearing conversations and hearing the news and commercials on the television or songs on the radio.

Children learn a great deal from just playing and listening to what is going on around them. We also constantly “update” our children with information about what we are doing and all the “little things” that happen every day.

Children learn when they watch television shows such as *Sesame Street* and *Blues Clues*. They listen to conversations around them and hear songs on the radio. When they are read to, they get to know cherished stories such as, *The Three Little Pigs* or *Goldilocks and the Three Bears*.

Incidental information includes all the things you know that you learned “accidentally” rather than being formally taught. It is an important part of the set of things children “know about” as they enter school.

Deaf and hard of hearing children often do not overhear these same conversations clearly or get information through listening as easily. They miss out on incidental learning and depend on you and your family to provide information and “fill in the blanks”.

You may have to make a special effort to let your child know about what you are doing. Your family may have to teach your child about concepts or events that a hearing child might automatically pick up.

The communication tips on the following pages may give you some ideas on how to keep your child informed about all the “little things” that we experience every day.

Communication Tips

Young children generally develop spoken language naturally through close relationships with sensitive, caring adults. Most of us learned language as babies by hearing it spoken to us and around us. This cannot happen automatically for children who have a hearing loss.

TIPS:

- Babies who have hearing loss are visual learners. They need to be able to see who is talking and what objects are being talked about to learn about their world.
- If your child has amplification (hearing aids, cochlear implant) be sure it is worn during all waking hours of the day so your child has the best access to your voice.
- Touch and hold your child as often as possible.
 - Communicate with your child.
 - Notice where your child is looking or what seems to interest them.
 - Positioning is important. Move your child; move yourself. Make sure your child can see your face and what is going on while you are communicating.
 - Use your normal conversational voice. Do not talk loudly or slowly. Just speak clearly with short sentences.
 - For both signing and talking, keep communication simple. Sign/say one or two words at a time.
 - Follow your child's lead.
 - Give your child time to look up at you and then communicate with them.
 - Notice what they are looking at and talk about that.
- Watch your child playing and interacting with the world. Comment on what your child is doing and what you are doing.
- Using facial expressions, body language and gestures helps hold your child's interest and adds meaning.
- Babies learn through repetition. Repeat your words or signs often and again in different situations so your child hears the word or sees the sign/cue many times.

- Be aware of the environment around you to help your child know what is going on.
 - There are many times during the day when you may have to make extra effort for your child to see you. These times include when your child is in the crib, in the car seat or during tummy time.
 - Consider lighting. Remember to keep your child facing away from a light source. When your child has bright light in his face, it is harder to see you.
 - Move closer to your child to help them understand you better.
 - Place a mirror in the car so your child can see you.
 - Keep background noise and distractions to a minimum when you are communicating or playing with your child. While you are talking:
 - Turn **OFF** the TV
 - Turn **OFF** the radio
 - Turn **OFF** the dishwasher/washing machine/dryer/vacuum cleaner
 - Let your child know:
 - When you are leaving the room
 - When someone comes into the room or the house
 - What is happening in their day
- Books and reading are important.
 - Look at pictures and books with your child often
 - Point to the pictures and talk about them
 - Read books with real photographs
 - Young babies like books with rhymes, “lift the flaps” and repeated words
 - Have fun reading

Communication Options and Opportunities

This section contains descriptions of the various communication methods available to families. There are many ways for children who are deaf or hard of hearing to learn language.

Choosing a communication system for your child requires time and many thoughtful decisions. What works for one family may not work for another. All communication systems require lots of family involvement and a language-rich environment.

It is important to check your child's progress often. Remember that you can change what you are doing if your child is not learning language. Keep in mind that no choice is permanent. Professionals will be working with you and your child to make sure your child is learning to communicate well. The following is a description of the different communication methods or modalities.

American Sign Language (ASL)

American Sign Language (ASL) is a visual language. With signing, the brain processes linguistic information through the eyes. The shape, placement, and movement of the hands as well as facial expressions and body movements all play important parts in conveying information. ASL has its own grammar and word order. This approach uses American Sign Language as a first language and English is learned through reading and writing. Spoken English/speech services are encouraged separately. The goal is to provide the child with a fully accessible language.

Auditory Oral

(also known as AO or Listening and Spoken Language-LSL)

This approach focuses on the consistent use of hearing aids and/or cochlear implants to develop age-appropriate spoken language through listening. The development of listening skills is worked on systematically and naturally across all environments so that the child strengthens the auditory centers of his/her brain. Speech reading and natural gestures may be used, although listening is the primary focus. The goal is to develop listening and spoken language to the fullest extent. Signing is not used.

Auditory Verbal

(also known as AVT or Listening and Spoken Language-LSL)

Auditory-Verbal Therapy is one-on-one therapy that focuses on listening and spoken language through the consistent use of hearing aids and cochlear implants to develop age-appropriate spoken language skills through listening. Parents and caregivers actively participate in all sessions. The development of listening skills is worked on systematically, through play and routine activities, so that the child strengthens the auditory centers of his/her brain. Speech reading and signing are not used. The goal is to develop listening and spoken language to communicate, and to help parents/caregivers help their child learn to listen and speak the language of their home through everyday play activities and routines.

Bilingual Bimodal

The Bilingual Bimodal approach is one that supports the acquisition of both American Sign Language (ASL) and spoken English. It is based on the fact that a child's brain has the ability to learn both a visual and a spoken language at the same time without delaying the learning of either language. "Bilingual" refers to the fluent use of both languages. "Bimodal" refers to the use of language in two modalities: one signed language, one spoken language. This approach includes early access to visual language, while also pursuing the maximal use of hearing assistive technology and spoken language therapy. Both languages are valued equally in this approach, and the child should have consistent access to both. The languages are kept separate and whole. Speaking and signing are not presented simultaneously, but rather at separate times, or one after the other. The goal is to learn both languages and have the option of using either ASL or spoken English based on the child's preferences.

Cued Speech

Cued speech is a visual communication system of eight hand shapes (cues) and four positions that represent all of the different sounds of speech. These cues are used while talking to make the spoken language clear through a combination of lip and cue reading. This system allows the child to distinguish sounds that look the same on the lips. The primary goal of cued speech is to develop spoken language and literacy skills.

Manually Coded English

There are several signed systems that use signing to produce “English on the hands” such as Signed English. Unlike ASL, manually coded systems use signs in English word order and add special signs to show the grammar of English.

Combined Approaches

For some children using one communication approach is sufficient. For others, a combination of approaches is beneficial. Your child’s team will work with you to help you decide when more than one approach may be needed.

Section 5: Family Stories

This section is a collection of stories from families about their child's hearing loss. Each story has been told in the family's voice and has not been altered.



Silas' Story

Silas' story begins in May of 2004. I found out I was pregnant and got in touch with my midwife, Ellie Daniels. She and Donna Broderick of Morningstar Midwifery had been my midwives for my last home birth. Ellie was my midwife for 2 other homebirths as well. As my pregnancy progressed we discovered I was carrying twins! I had an ultrasound, which confirmed that two boys were growing in my womb. Ellie and Donna were wonderful supportive caretakers throughout my pregnancy, and we decided to continue with plans for a home birth.

On the night of January 26, 2005 I went into labor. Ellie and Donna arrived, and were with me while I labored in the birthing pool. Early in the morning of January 27th, 2005 Seth was born in the birthing pool. Silas was breech, so I came out of the pool for Ellie to deliver him. 8 minutes later we were holding Silas. The twins seemed fine, I was doing well, and our family got started on the newest chapter of our lives... life with twins.

Ken and I and eight brothers and sisters welcomed Seth and Silas into our home, and our lives would never be the same. Donna came back for a new baby check when Seth and Silas were four days old. Seth was doing well, but Silas



hadn't really been eating, had lost a pound, and was jaundiced. Donna was very supportive and came with me to the doctor's office. We ended up at the hospital in Damariscotta where arrangements were made for Silas to be transported to Maine Medical Center's NICU. During his hospital stay, Silas failed the newborn hearing screening.

Because of his other medical issues, Silas was 6 or 7 months old before we saw an audiologist who confirmed that Silas had a hearing loss, and told us to get a more thorough hearing test called an ABR. When Silas was 11 months old he had his ABR and we learned he has a profound loss in his left ear and a moderate to severe loss in his right ear. I can't say I was surprised by the result, but the answer left us with a lot of questions.

We were referred to an audiologist and Silas was fitted with a BTE digital hearing aid. I still remember seeing the light come on for Silas when he made the connection between the

hearing aid and being able to more clearly hear the world around him. At first he pulled the aid out frequently, I was always putting it back in. One morning after a few weeks of this, his eyes got really wide when I put his aid in, and turned it on. From that day we have not struggled to have Silas wear his hearing aid. He began asking for it if I forgot to put it in.

Our audiologist encouraged us to have Silas evaluated for a Cochlear Implant. I hoped that Silas could have the digital aid on the right ear and a CI on the left, but we found out Silas was not a good candidate. Our audiologist is very supportive and has always helped us with any technology needs for Silas. Silas uses an FM system as well, which is very helpful in situations where there is background noise or a distance issue.

The folks from Early Childhood and Family Services through the Maine Educational Center for the Deaf and Hard of Hearing are wonderful. A consultant came to our home, explained Silas' hearing loss in a way we could understand it, and explained the different options we could pursue in helping Silas to develop language. The consultant kept us up to date on technology, and workshops dealing with hearing loss in children. Our consultant from ECFS changed a couple of times, but everyone we worked with was extremely helpful. The consultant was always with me to help in IFSP and IEP meetings, helping us to get what we needed for Silas.

We decided to use a bi-lingual approach with Silas. We all learned ASL to help Silas communicate. We are a hearing family, so Silas is exposed to English all the time, and his speech therapy focuses on developing his spoken English skills. Both ECFS and CDS were supportive in this decision and provided ASL instruction in our home for the whole family. As Silas grows we continue to develop our sign language skills.

You will come across many opinions on the best way to educate a Deaf/hard of hearing child. Many will tell you that using sign language delays the development of speech, or that if a child has sign language, he/she will not desire to learn English. Our experience is the opposite. Silas had the desire to use spoken English from an early age, but he learned new vocabulary best with signs. He would



learn a sign, then a while later that word was added to his spoken vocabulary. Sign language made it possible to communicate with Silas when he had very few spoken words. There were very few words he learned to speak that he didn't learn the sign first. Silas' spoken English has improved greatly over the past two years, but sign language is still the language I use to teach new concepts, and to clarify what he is saying or thinking about. It has been a wonderful tool for us.

For preschool we enrolled Silas and Seth in the ASL room at the MECDDH. They had a wonderful year there, made many friends, and learned a lot. The preschool's bi-lingual approach matched what I was looking for, and I intend to continue for Silas' education. We are a home school family, and we intend to home school Silas. We have started Kindergarten, and he is doing well.

You have discovered that your child has a hearing loss. You have an exciting journey ahead of you! Ask questions about everything. Find out all you can about how to support your child. Don't spend time worrying about the decisions you make regarding communication. Try things! Communicate! If what you are doing isn't working, try something else. Just keep trying! Each child is different, and you will find the method that works best for your child as long as you keep trying. Make friends with other families who have children with hearing loss. It helps to know you are not alone.

This journey has taught me many things, there have been ups and downs, and we have made good decisions and not so good decisions. As I look back over the past five years the three most important lessons I have learned are: embrace your child for who they are, get language in them early (sign language worked wonders for us), and follow your child's lead.

Maya's Story

Maya was born Dec. 17, 2006. I counted fingers and toes, and felt gratitude for our healthy baby girl. On check out from the hospital we were told to follow up on two failed hearing screenings. The nurses said "no big deal it happens to lots of babies, fluid in the ears most times". So we went home and settled happily into parenthood. Two months later, after banging pots and pans over Maya's crib one naptime, with no alert; we agreed to dig out the referral card from the hospital. We followed up with a local ENT doctor and an audiologist each not accustomed to children as patients. They couldn't help us. We finally found a pediatric audiologist in Lewiston who performed a three hour ABR test (Auditory Brainstem Response) on Maya and delicately delivered the news that our 3 month old baby was "profoundly deaf". The audiologist gave us the number for Karen Hopkins and an amazing set of information then let it settle in for us. Our baby was Deaf.

I mourned; I got mad, sad, questioning, and then I took charge. Maya was fine, once we accepted this we could go ahead and accept Deaf.

Maya's pediatrician ordered tests to check for syndromic hearing loss (hearing loss associated with other medical malfunctions) and after a sedated EKG Maya was flagged as possibly having Jervell Lange-Nielsen /Long QT cardiac Arrhythmia associated with congenital deafness. This put deaf into the back seat to a possible, deadly problem. She was immediately put on Propranolol (a beta blocker or heart rhythm normalizer) this medicine was a precaution because they couldn't find the irregular heart rhythm on subsequent EKG tests.

We moved on to dealing with the hearing loss again and fitted Maya with loaner hearing aids and ladybug colored earmolds. We also began learning Sign Language in order to communicate with Maya and her budding personality, she was already very funny. After meeting Karen Hopkins, we were relieved to hear that culturally deaf people can, in fact, drive cars, have kids and be happily married... Phew! So if we chose that route for Maya she would be Fine.

While we were learning sign language, we were on the road to learning about Cochlear implants which could provide Maya access to sound. The info put out by the companies was a lot of marketing so, we dug deeper, met kids with implants and, became intrigued. Was Maya an implant candidate?

At 10 months, we took Maya to Boston Children's Hospital and we started the candidacy process. Preparing for a no on the implant candidacy, we kept with the sign language and by 12 months our baby had 25 signs and a keen sense of humor. We were so pleased.

She also got a clean bill of health from her cardiologist and went off of her cardiac meds. She likely did not have Jervell Lange-Nielsen Syndrome and it was probably a different genetic cause. We were joyful, Deaf is not death! The heart thing put that in perspective for us.

On December 28th 2007 Maya got her first Cochlear implant. It was activated 6 weeks later when the incision healed and her first sounds were anticlimactic in clinic but the next day she did, in fact, turn to her name during therapy. Nobody expected this from her and we were really excited!

From this point we did LOTS OF THERAPY! Speech therapy was three times a week. Exhausting and also, really fun. Her second implant came at 22 months, a week before her little sister. By age 2, Maya was on par with her peers for speech milestones. She also had a great foundation in sign language that we still build on now that she is almost 4 years old.

Maya can now sing most songs from the movie "Mama Mia", she narrates her life with her voice all day long (comes in handy when she is doing things she shouldn't). She repeats embarrassing things out loud in public, she can sign to deaf adults and seamlessly move on to say she hears an airplane passing high overhead. Maya whispers with friends and signs when she meets a baby who doesn't talk yet because she assumes they are deaf.

We want the best of life for her and we always hope we do what is right for her, so far, we think we have.

Maya is a dancer, a singer, a little actress and she happens to also be deaf. She is one of our amazing girls!

A lot of parents continue to inform our choices as Maya grows, many of them also have Deaf or hard of hearing children, if we can inform on anybody's questions or interest we would love to be here for you like others are here for us. Parent to parent networks can be wildly helpful.

Valerie & Nathan Dukhey



Parker's Story

On April 21, 2009, our son Parker was born via emergency C-section at Maine Medical Center in Portland. He was not breathing, his heart was not beating, and his organs had begun to fail due to severe anemia. After multiple blood transfusions, 8 days on a ventilator, more medication than I can name, we came to the realization that our first born would be a miracle baby. On day eight we were finally allowed to hold him.

We juggled wires and tubes, IV poles and electrodes and we sat. We counted 10 perfect little fingers, 10 perfect little toes, 2 perfect little ears. He has his mother's eyes, his father's nose, and wow...so much hair!

We celebrated with the nurses as he grew strong enough to move out of an incubator and into a "real crib". After 3 weeks in the NICU, we were told Parker was finally well enough to be moved to the step down unit called "continuing care" to start working on our "going home checklist". There was finally an end in sight. The only thing that stood in our way was a finite list of things Parker had to do successfully before we could take our little miracle baby home. Eat all meals by mouth, gain weight every day, breath on his own for 5 days straight, and pass the car seat test. Finally all that was left was his Maine newborn hearing screening.

As with all of his other tests, we stood by his crib, but this time we were confident. There was no hearing loss on either side of our family and we knew that this test would be the only test so far that was a "non-issue". So we stood confidently and watched as our favorite nurse placed sticky electrodes on Parker's tiny head and fit tiny ear phones into his tiny perfect ears. Then we watched as she stood behind a computer and waited...and waited...and adjusted the ear phones...and waited some more. "Hmmp...well, he's had a busy day," she said, her voice oozing with fake positivity, "Let's try again tomorrow."

That night we talked to Parker, we held him, and we looked at his tiny, seemingly perfect ears, and we wondered. The next day came and his second hearing test went just like the first and at that point we were told that they would add a referral to an audiologist to our growing list of follow up appointments. A few days later we bundled our little miracle up into his car seat and carefully carried him down to the lobby, nurse in tow, and carefully clipped him into the car.

It was at that time that we got the best advice we would ever get. "Don't get caught up in the tests and labels, just love him... no matter what, just love him. It's all he needs right now. The rest will fall into place." And it did.

At 8 weeks old, we sat with our fingers and toes crossed and willed Parker with all of our might to *hear*. We'd been practicing at home...making loud noises, showing him the dogs when they barked, and sitting in front of him and talking. His little eyes watched every move our faces made and we knew that the tests had to be wrong. He was just too small...there's no way they could accurately measure hearing on a baby that small.

We sat in the tiny, dark sound booth as the audiologist pumped sound into his ears and waited...and adjusted...and waited. After 3 hours of waiting...and adjusting...and waiting, we were brought into a brighter office and as our eyes adjusted to the light, we were informed that our son was deaf. *Profoundly deaf*. It was as if the audiologist had said a four letter word. Deaf. The official diagnosis was profound-sensory-neural-bilateral-hearing-loss, phew...to this day it is still a mouthful. Through the tears, I remember a box of tissues coming my way and the same wonderful advice we'd heard just a few weeks ago.

"Love him..." She said, "...take him home and love him. I'll have someone contact you to help you through the next steps, for now, just go home and love him." And we did.

Over the next month we added more acronyms to our growing list of alphabet soup...CDS, IFSP, MECDHH, ASL, LSL, SLP. We discovered that we had a broader support system than we ever knew existed and that for us, the term "it takes a village" would never be more true.

Parker would receive language at first through sign language at home, at daycare, and the grocery store...everywhere. We would start speech therapy at 12 weeks old, even though he could not hear. Our speech therapist (SLP) would come to the house and play games and show toys, and help us adjust to a new sense of language. Our support from the Maine Educational Center for the Deaf and Hard of Hearing (MECDHH) would help us understand the pros and cons of all language options and supported us as we slowly navigated into the unfamiliar waters of deaf culture. They were there to calm our fears about whether or not Parker would lead a happy life.

Would he ever get married? Yes. Would he be able to go to school and learn? Yes. Would he be able to play sports? Yes. Would he ever know that we loved him? Yes.

The next few months brought tiny hearing aids that would be fitted to his tiny perfect ears. And molds that would fit slightly less perfectly to his ears and would bring the soundtrack to our summer... feedback. Like a swarm of bees every time we tried to snuggle too closely, a constant reminder that our perfect son was deaf. The hearing aids brought the same homemade hearing tests that his early diagnosis had brought. We made loud noises, we

showed him when the dogs barked, and we sat in front of him and told him how much we loved him...still no response. This gave us some answers. The hearing aids didn't help and we knew then that our next step would be to consider cochlear implants.

We'd researched, we'd talked to other families, we knew that our choice would be considered controversial to some and a "no brainer" to others. We wondered...was it worth the risk...is it what future Parker would want? For us we knew that it meant the power of gaining access to sound and the power of having options. Away we went to Boston for more tests, more meetings, and more answers. Parker would be a candidate and would receive his first cochlear implant on July 10, 2010. On July 19, 2010, we sat once again with fingers and toes crossed, as an audiologist fit his brand new external cochlear implant processor to his tiny perfect right ear and waited...and within seconds Parker looked up with joy on his face as he heard his first sound. The video was passed around to family, friends, and anyone else that wanted to see and for the first time in a long time we had our answer. We knew, from the look on his face, that we had done the right thing for Parker.

The past few months have been a blur of speech therapy, a language centered playgroup for infants with hearing loss, meeting with CDS, trips to Boston for more testing and a second implant in 2011 and the addition of a listening and spoken language professional to Parker's ever growing list of providers.

The past few years have also been a blur of firsts. The first time Parker turned to the sound of his name, the first time he startled to the sound of the dogs barking, and the first time we sat in front of him and told him how much we loved him and knew that he heard us. More recently the first time he said, "No. Mama. Dad." And the first time he whispered, "I love you" back to us as we tucked him in for the night.

With the help of his team of speech therapists, listening and spoken language professionals, and us, he attends a mainstreamed preschool. His language improves each and every day, and with this, his connection to the community around him and his peers grows stronger. We know that Parker's journey, in his short 3 years, has been longer and more challenging than some, and easy compared to others, and we are so grateful for the team of professionals that support him. We are, once again, confident that Parker will succeed.

Chris & Katie Wellman

Makayla's Story

My daughter Makayla was born in January of 2000 with Down Syndrome and a heart defect. She was in the NICU for a month before she could come home. It was very scary when she was rushed to the hospital with bacterial meningitis and heart failure at 4 months of age.

I did some research and found out that bacterial meningitis can cause hearing loss. I got different answers from doctors and had to keep asking questions. My daughter had some different tests and after an ABR (Auditory Brainstem Response) test, I found out that she had a mild to moderate hearing loss. During this time, I had help and support from Karen Hopkins from the Early Childhood and Family Services Program. She helped me a lot.

I learned that my mother's instinct was never wrong from day one, I just was not sure what needed to be done. At this point, I always trust my instinct when it comes to my daughter's health and well-being. So should you. Dig deep for answers and get all the help you can. Don't be afraid to get a second opinion. Our children are tomorrow's future.

Today, Makayla has an FM system (Frequency Modulation System) to help her with her hearing loss. Since she has been using the FM system, I have found a dramatic difference in her hearing.

Deborah Wheelock



Jessica's Story

My wife and I had never known a person with hearing loss. Clouds gathered unseen on our horizon. Our only child, Jessica, was diagnosed with profound bilateral hearing loss. At 18 months of age, our family's world and dreams, as we knew them, came crashing down around us.

I am a strong "Mainer", yet this unexpected turn of events struck me to my knees with a force I could never have imagined. Frankly, I cried every time I thought of my daughter.



Fortunately, as quickly as despair began to overwhelm us, a group of wonderful early intervention specialists unselfishly provided my family with the support we so desperately needed. They gave us the critical tools and services that enabled my family to once again enjoy living.

Because of medical breakthroughs and the endless dedication of these early intervention specialists, Jessica is no longer silent and neither is the world around her. Our house is filled with sounds of laughter. The recitation of story book rhymes and the noises of an animated 4 year old surround my wife and I.

Jessica is learning to listen and speak with the aid of a cochlear implant. She is rapidly closing the communication gap with hearing children. Jessica is currently attending preschool and will begin kindergarten in another year. She is fully "mainstreamed", meeting the same academic and social standards as her hearing peers.

It has been a long journey which is far from over. However, our every thought is no longer consumed with the overwhelming and sometime tumultuous topic of deafness. We are living life once again.

Is our daughter cured? No. There is no magical cure for deafness. Although she has learned to listen and speak utilizing a cochlear implant, she is unable to hear when she removes her processor for bath time, bedtime and swimming activities. In addition, if any component of her cochlear implant fails, she still has a profound hearing loss.

As any parent, we are faced with an array of decisions concerning our child. The choices we

have made for Jessica are simply our family's story. Each family, parent, and child is unique. Your choices and your family's story will be too.

Although you may feel that your world has been shattered, give your child a big hug and rest assured; you too will again be pursuing your family's dreams and aspirations.

Scott, Lori and Jessica Hayden

Nicholas' Story

Nicholas was born to us sixteen years ago. He was born profoundly deaf with CHARGE Syndrome. CHARGE Syndrome affects many sensory systems and the majority of children are born deaf. Due to cranial nerve damage, the doctors were able to tell me almost immediately that there would be a neurological hearing loss.

Because I was more concerned with his survival, I accepted his deafness unconditionally. I immediately went to the experts (Deaf adults), not the medical community, for information and advice.

I started asking them questions regarding their childhood. I asked them if they had one wish, what would they have changed? Most all of them wished for a family they could communicate with. It did not take much more research to realize that my family would learn American Sign Language (ASL).

In my experience, American Sign Language is a deaf child's natural language. It is a visual mode of communication that comes without exhaustion to a child born without auditory sound. I knew I wanted my child to experience the beauty of his natural language before we immersed him with any other form of communication. I wanted him to feel successful, confident, and at ease with a language that only ASL could give him.

We continued to enlarge our family, adding two hearing daughters. We desperately wanted another deaf child, so we turned to adoption. Our final child was adopted from Hangzhou, China and is also profoundly deaf. He has been in our family for five years. He came to us at the age of five without any language, no knowledge of the world around him.

We immediately immersed him with Deaf culture and the language. This little boy has blossomed into a child who has had great influence in our community. He is a leader in many areas of his life because he has confidence in himself. I am sure he will do great things for this world someday.

My family is now complete, two deaf sons and two hearing daughters. I am so fortunate and I tell them that every day. We now have a bilingual and bicultural home. This simply means that we respect two languages and two cultures in our home. We try to balance our home very carefully so that everyone's needs are met.

If I could give new parents a piece of advice, sixteen years later, it would be love him and cherish him. He may not use your native language but you can use his, there may be some cultural differences, but what a gift. He will always be your son and you will always be his mommy and daddy. Enjoy the journey you are about to take.

I am so proud and pleased with the family I have been blessed with.

Terri Thompson

The Nadeau Family Story

When our oldest daughter was about 3 years old, we noticed that she wasn't progressing the same as other children her same age. Our pediatrician noticed as well and referred her for testing. We found out at that time that she had a hearing loss.

About two years later, our twin daughters were born premature and they both failed the newborn hearing screen in one ear. They were referred for more testing and we found out that they had the same kind of hearing loss as our older daughter. This prompted testing on our other child. Our 20 month old son was diagnosed with hearing loss (which explained some difficulty he'd been having).

When we first found out about our oldest daughter, we were a little overwhelmed but we were relieved to know what was wrong. When we found out about our other three children, we realized that we shouldn't have been overwhelmed when we had only one child with hearing loss. We are very thankful for finding out early so they could get the help they needed and be more closely monitored for progress.

All four of our children are hard of hearing in the mild to moderate range with similar patterns and the hearing loss is assumed to be of a genetic cause. They all have hearing aids and FM systems. We are learning sign language. This is a tremendous help, especially in relieving some of the frustration on each side of the communicants. I don't know what we would do without it!

The help we have received from our audiologists and the Early Childhood and Family Services have had such a tremendous impact on our lives. Child Development Services, Early Childhood and Family Services and all those involved through these two programs have made our life, and our children's especially, so much brighter because we can communicate.

We want other parents to know that although it may seem scary and overwhelming, there are rays of light and enlightening outlooks ahead and new perspectives on how thankful we should be.

Andrew & Jeanne Nadeau

Maria, Noah, Laura and Lucia

Wesley's Story

Wesley was born with bilateral ear canal atresia which means he was born with ear canals that did not form on both sides. So we knew right away that he would have at least some hearing loss. He has maximum conductive hearing loss in both ears.

When I first found out, I was O.K. that he might have some hearing loss. I was scared that he might be totally deaf, but also thought that as long as he was otherwise healthy, that I knew I was lucky. Wesley being deaf wasn't the worst thing that could happen and although it would be a challenge, our family would adjust just fine.

Because Wesley was born without ear canals, a traditional hearing aid would not work. He uses a bone conduction hearing aid. One side has a microphone and the other side vibrates against his skull, allowing him to get access to sound.

We use spoken and sign language with him and this works well for us. Wesley started signing at 10 months of age. It is so exciting to see that he is understanding and communicating.

I would like other parents to know that the wonderful people you meet when you are dealing with your own child's hearing loss will help you realize that there is such amazing support out there. I couldn't imagine Wesley's life without all the great people we've met who help us with his hearing loss. They are our extended family.

Take advantage of all the wonderful programs that Maine has to offer. It is amazing how much support is out there.

Kristin Young

Emma's Story

We found out that our daughter, Emma, was deaf when she was two days old. They told us that she would probably never hear or speak.

I immediately called my younger brother, Ralph, to share our shock. He said to us, "Emma is Emma, and whoever Emma is, that will be normal for Emma and that's what she'll know. Love her!"

So, we've always thought that we would never do anything invasive to Emma. We believed that should be her own decision. We've given her exposure to what is available and let her tell us what she would like us to do.

We've given her sign language, speech and boosted hearing aids, starting at nine months.

She is now 4 years old; she attends Governor Baxter School for the Deaf two days a week, mainstream preschool two days a week, speech two times per week and sign language two times per week.

She is talking wonderfully and is the happiest kid around. We've made adjustments to her programs as her frustration has built and she's learned to tell us what she needs.

She is awesome. It is all of us around her that needed to change, not Emma.

She may become deaf at any moment, but we are all where we need to be if ever that may happen. We've given her two languages and lots of love and support.

We have had a lot of frustrations along the way, but we've used our energy to advocate to make a difference (a change, hopefully), instead of getting mad at the system. We've always said "What can we do to help you help us?"

Robin L Foster

Cade's Story

We first knew there was an issue with Cade's hearing when he failed his newborn hearing screen. We thought it might be due to all his other birth related complications but further testing showed no response to sound. He was tested again at 6 months of age with a BAER test and he had "tubes" put in prior to his first birthday. By then, we were ready to hear the news.

When we were finally told, we were ready for it. We had seen the signs and noticed the differences and done our own little "tests" at home. So when the official word came, we certainly weren't shocked. He has profound bilateral hearing loss.

Cade has had hearing aids for 4 months now. There is still no sign that he hears anything but it is a stepping stone for us to get an implant so we're excited. We sign with him, but with all his other problems, he doesn't recognize or respond to or imitate signs. It is amazing to see our other three boys learn sign.

We would like other parents to know that everyone's experience is different. We had to concentrate on keeping Cade healthy for his first three years. We are just now able to "tackle" his hearing. He still has many health issues but we are moving towards a cochlear implant and we are so excited.

We don't see Cade's deafness as a problem, but as a gift. He gets to appreciate the visual beauty of things more than the rest of us. We're thankful that we're forced to stop and think of how we can help him benefit from things. When a good song comes on the radio, we not only enjoy listening to it, but we dance so Cade can enjoy it also.

Ann E. and Ricky W. Jamieson, Sr.

Isaac's Story

Isaac was born on October 2, 2002 after a normal pregnancy and planned cesarean section delivery. He was a beautiful baby boy. Everything was perfect.

Then we found out that our baby had failed the newborn hearing screening. The nurses told us not to worry because sometimes the fluid from birth is stuck in their ears and it can clear out in time. So, like they told us, we really didn't worry. In fact, we didn't even know what to worry about. As ridiculous as that sounds, it is true.

Isaac received further testing and that came back abnormal as well. It really didn't hit us until the audiologist came right out and told us that he had a hearing loss. We talked about cochlear implants, hearing aids, people to contact and medical centers. It was overwhelming. It was difficult accepting that something was wrong with my baby when he was right there and seemed just fine.

Isaac had four ABR tests along with additional testing to confirm that his hearing loss was severe to profound. He got hearing aids at 4 months old. They do not seem to provide any benefit but we continue to use them anyway.

As Isaac got a little older, we looked further into using a cochlear implant. We wanted to find out if it was the option that would fit us best. We thought it would give Isaac a better opportunity to hear and speak. We were using Total Communication with Isaac and could understand his name when spoken loudly even before he received his cochlear implant. However, he loved visual language and focused on anyone trying to communicate with him.

We went to Boston Children's Hospital for the Cochlear Implant Candidacy Program. It went smoothly and the people at the hospital were just as impressed with our little man as we were. We knew he was approved when they told us to choose which implant we wanted. Choosing a cochlear implant was difficult. Every brand had qualities that we liked for Isaac and each brand seemed to try and "out do" the other. When we finally decided on one, the big day couldn't come soon enough.

Isaac was fifteen months old at the time of his surgery. His surgery took about 5 hours and went extremely well. He did have some trouble because of his Von Willebrands clotting disease, but nothing to worry about. One month later we went back for his cochlear implant to

be activated. We were very nervous for his reaction to sound. As usual, Isaac fully enjoyed the noise and began to beat the drums. He has taken off since then and can hear at 25 dB across all frequencies after just one month of hearing. He is saying “hi” and is attempting to say other words. He surprises us all the time with his ability to comprehend a task or instruction. It is amazing!!!

It is an extremely hard and long process. I wish I had met and had support from people who had experience with hearing loss long before I did. Having a child with special needs is difficult and requires a lot of time and energy. It is so important to take advantage of early intervention and give babies the opportunity to learn and develop as much as they can.

There is one saying that we heard that has always stuck with our family. “The cochlear implant is 10% hardware and 90% software”. The hardware is the processor and the software is the support.

Jenny M. Saunders

Sarah C's Story

Our daughter, Sarah, contracted Bacterial Meningitis at the young age of 10 months. After two weeks of hospitalization, she was well enough to come back home. We returned to our family routines with the knowledge of how very, very fortunate we were because she almost died from this deadly disease.

At 10 months of age, she loved to scoot around in her walker. It was my husband who first noticed that she did not seem to recognize when the phone rang. Before she had meningitis, she would scoot over and laugh while pointing at this ringing box on the wall.

The doctors did not want to alarm us and we were told she may be retaining fluid in her ears and this could be causing a temporary decrease in her hearing.

We found out that meningitis had taken our daughter's hearing. We were faced with a challenge and a future we were not expecting. Today she is a 22 year old living happily and independently as a college student.

Truly, there are positives to everything. If Sarah had been a hearing child, we would have never met the wonderful people over the years.

Our daughter is PROUD DEAF and accepts herself for who she is, not what she could have been. Being Deaf is Sarah. If Sarah could hear, she would be a totally different person. We will keep Deaf Sarah, Deaf is a part of who she is.

Our advice is to take one day at a time, enjoy the moment and look forward to many more.

Suzette and Hal Carter

Sarah N's Story

When Sarah was 4 months old, we went to her well-baby visit. My pediatrician asked me the same 4 questions he asked all parents at their baby's 4 month check-up, "Do you think she can hear?" If there was one thing I was sure of as a new parent, my baby could hear. She turned when we entered the room; she looked up when she heard the beep of the ceiling fan turning on. Yes, she definitely could hear. What did I know?

Three months later, I was talking to the mother of twin 7 year-old boys. She said that one had had very bad ear infections when he was younger and that he really didn't hear well for the first 5 years of his life because of them. She hadn't known he wasn't hearing properly, she just thought he was quiet. "Sarah is quiet", I thought, "And I haven't heard a single consonant sound out of her". I spent the next week wondering if Sarah could hear & trying to convince myself that I was crazy. I finally said to my husband that I didn't think Sarah was hearing right. "You're crazy", was his response. "I know this child hears". He sat down to play with Sarah and 15 minutes later announced that, not only did Sarah not hear right, he didn't think she could hear at all.

Although unrelated to her hearing loss, Sarah had suffered multiple ear infections her first year. It was spring and she still had fluid in her ears & the doctors said to wait until the fluid cleared out. By June, when she still had the ear infections, we scheduled ear tube surgery. Several scheduling difficulties later, she got her ear tubes at the end of July. "Don't take her to any place loud tonight", we were told. "You will see a completely different baby".

My husband took her to her post-operative appointment & mentioned to the surgeon that we hadn't seen any change in her and that she still did not seem to hear. He recommended waiting 6 weeks before re-testing her in a sound booth; then, if there was no improvement, waiting another 6 weeks for more booth testing, then another 4 weeks before doing an ABR (auditory brainstem response). Gregg went home thinking, "Well, I guess that's what you do". Thank goodness for his good sense, the next day he called back and insisted on an ABR immediately. Gregg can be very persuasive & the appointment was scheduled.

The day after her ABR appointment, we had a party to go to. We had to tell all of our friends that Sarah was profoundly deaf. In general, they were very supportive, "OK, what do we do next?" But there was one friend who really understood how I felt, "My God, you must be so

relieved!", she said. Four months of worrying that her language wasn't where it was supposed to be. If she was deaf, that would explain it. We could get her help and start working. But, what if they told me she could hear? Why wasn't she developing language? What else could be wrong? How was I going to convince the doctors that something WAS wrong? And could I handle it?

I could handle deaf. I didn't know what to do next, but I knew there was something. We got her fitted with hearing aids and went to visit Baxter school for the deaf (the only deaf school in the state at the time). I listened to the teachers, I listened to the parents. They said only a few deaf children could learn to speak and we should teach Sarah sign language. It just didn't seem right for us. I knew Gregg and I could learn sign language, I knew her grandmothers would learn it and force her grandfathers to learn it. But what about extended family? What about our friends?

Then we heard about a conference about cochlear implants right here in Maine. I had no idea what a cochlear implant was, but it was a start. We heard about a therapist in Massachusetts (Lea Watson) who taught deaf children to listen and to speak. When we met her, I knew that was what I wanted for Sarah. Lea was just as uncompromising about her methodology as the people at Baxter. The difference was that she was telling me what I wanted to hear, that Sarah could communicate with the rest of the world on the same terms as everybody else.

When Sarah was 5, we heard that they were giving kids bi-lateral cochlear implants (an implant in each ear). The theory was that kids would be able to hear better in background noise and possibly be able to localize sound. Four years earlier, I couldn't quite understand why they were only going to give her one. Now, the only decision to be made was how to get a second implant for Sarah. We knew that the earlier we could get sound into her other ear, the better she would be able to use it. We called Boston Children's to begin the process. Exactly four years (to the day) after the first, Sarah's second cochlear implant was turned on. Today, she hears her friends whispering in her ear, talks on the telephone, and keeps up with a circle of friends gabbing before class starts. Sarah knows that she is deaf; she just defines "deaf" differently than others.

My best advice for other parents is, listen to the professionals but trust your heart. Your child will excel if you believe in what you are doing. Set high standards for your child, believe that she can achieve them, and then watch her exceed them. But most importantly, once you have

chosen a path, bathe your child in language and provide her with everything she needs to succeed in that path.

Gregg and Tina Novick

Ryan's Story

When Ryan was eighteen months old, we weren't sure he could hear well. I brought it up to his pediatrician during his 18 month check-up. As a result, we contacted an audiologist who performed an auditory brainstem response test (ABR) on Ryan. We discovered he had a severe to profound hearing loss (80 dB in the low frequencies and dropping off dramatically in the higher frequencies) in both ears.

As a result of genetic testing, we learned in February, 2002 that Ryan's hearing loss is caused by a problem with the Connexin 26 gene. Hearing loss caused by the Connexin 26 gene is an inherited autosomal recessive condition.

We were devastated. It was much worse than we had thought. We were also under the misunderstanding that hearing aids are like glasses – he could just put them on and he would have perfect hearing! When we realized we were wrong about how hearing aids worked, we were scared and overwhelmed.

Today, Ryan wears Phonak Supero, Behind the Ear (BTE), digital hearing aids. He also has a Phonak MicroLink Auditory Trainer that is used at school as well as at home and during sports activities. We also have a specialized phone.

We chose Cued Speech as a communication mode for Ryan. Ryan has a full time Cued Speech Transliterater at school. At home and outside of school, he uses what hearing he has, lip-reading and some cues to understand what is being said to him. He wears his hearing aids all the time and loves them – they're his ears. His speech is beautiful and he sounds like his hearing peers.

Ryan has been mainstreamed since preschool. He is going into the 5th grade this September and he is on or above grade level in all subjects. He has a wonderful group of peers (all of whom are hearing) that understand his hearing loss and respect him. Ryan is a great advocate for himself, explaining that he needs to see the person speaking and letting them know if he doesn't understand something. He works very hard—we are VERY proud of him and what he has accomplished.

Our advice to other families is—Don't take NO for an answer. Do lots and lots of research and choose what is best for your child. Get the best equipment you can. Find and use the best professionals. Ask lots of questions so you understand—there is no such thing as a stupid question.

Never stop talking to your child, reading to them, repeating back to them what they said to you. Get as much language into your child as soon as you can! Never give up!!

Anne and Jeff Banger

Section 6:

Resources

This section is divided into four sections: The first contains summary and contact information on local and state organizations and resources. The second section contains summary and contact information on national organizations and resources. The third lists additional resources for books, and videos. And the fourth lists transportation options throughout the state.



REGIONAL & STATE RESOURCES

Editor's Note: The authors of this guide do not officially endorse or certify any of the resources/services providers listed in this publication. It is the reader's responsibility to check the validity and references of anyone listed in this guide

Alexander Graham Bell Association for the Deaf and Hard of Hearing

Website:

<http://listeningandspokenlanguage.org/>
www.agbell.com

The chapter promotes early intervention and the use of hearing technology, education and advocacy and support for families.

Alpha One

South Portland Office

127 Main Street

South Portland, ME 04106

Voice: 207-767-2189

Toll Free: 800-640-7200

Presque Isle Office

66 Spruce St.

Presque Isle, ME 04769

Voice: 207-764-6466

Toll Free: 800-974-6466

Website: www.alphaonenow.org

Alpha One is a community-based enterprise directed and managed by people with disabilities and dedicated to providing the community with information, services and products that create opportunities for people with disabilities. Alpha One may be able to assist with assistive technology.

Alpha One - Bangor

11 Bangor Mall Blvd, Unit A

Bangor, ME 04401

Voice: 207-941-6553

Toll Free: 800-300-6016

Maine Department of Education

Child Development Services (CDS)

23 State House Station

Augusta, ME 04333-0023

Voice: 207-624-6600

TTY: 888-577-6690

Web site: <http://www.maine.gov/doe/cds/index.html>

Regional site locations in Maine:

<http://www.maine.gov/doe/cds/sitelocations.html>

A statewide network of regional sites that ensure coordination and delivery of early intervention services for children with development delays and disabilities.

Maine Department of Health and Human Services

Children with Special Health Needs Program (CSHN)

11 State House Station
286 Water Street, 7th Floor
Augusta, ME 04333
Voice: 207-287-5357
TTY: 711 Maine Relay
Website:

<http://www.maine.gov/dhhs/mecdc/population-health/mch/cshn/>

This program provides care coordination through a cooperative process that links children and families to services and resources.

Cued Speech Association of Maine

Nicole Dobson, Director
Sanford, ME 04073
207-602-0770 (v/text)
Offers information on early intervention, learning workshops, interpreters and support persons and an annual cued speech camp for children and families.

Maine Behavioral Healthcare

165 Lancaster St
Portland, ME 04101
Voice: 207-874-1030 Ext. 308-Portland
207-373-9417-Brunswick

Website: www.mainebehavioralhealthcare.org

Counseling and case management services for children with hearing loss and their family members. MaineCare accepted.

Guide By Your Side

Guide By Your Side Coordinator
207-400-0713

A family support program that connects a trained parent guide, who is the parent of a deaf or hard of hearing child with the family of a newly-diagnosed deaf or hard of hearing child to provide emotional support and unbiased information along with local resources as only a parent-to-parent program can accomplish. Parents can also access Maine's Deaf/Hard of Hearing Guide Program through Guide By Your Side as well.

Maine Department of Labor

Division for the Deaf, Hard of Hearing and Late Deafened

150 State House Station
Augusta, ME 04333
VP: 207-470-7668
Voice: 207-623-7958
TTY: 207-623-7957
TTY Users call Maine Relay 711

Website:

www.maine.gov/rehab/dod/index.shtml

Provides a program of services that include information and referral, advocacy, accessibility promotion, deaf identification cards and listings of qualified interpreters.

**Dorothy Ames Trust Fund
Key Bank Trust Client Services**

Mail Code NY-31-66-0942
66 South Pearl Street, 6th Floor
P.O. Box 22042
Albany, NY 12207
Edward DeLuccia
Toll Free: 866-238-8650
Fax: 518-257-8765

The Dorothy Ames Trust assists deaf children in New England to purchase hearing aids and auditory trainers and to teach them to use their voices as distinguished from sign language. You must provide copy of audiologist report, statement of need from parents, estimate of cost for equipment or services requested, and a copy of your most recent signed tax return.

hear ME now!

PO Box 896
Portland, ME 04104-0896
Voice: 207-781-7199
Website: www.hear-me-now.org

A nonprofit organization that provides information and support to families and professionals using a listening and spoken language approach. Services include home consultations, early intervention that focuses on coaching parents in promoting listening and speaking as part of their typical family day, family groups, preschool music program, and extensive consultation and coaching support to community preschools.

**Early Childhood and Family Services (ECFS)
Maine Center for the Deaf and Hard of Hearing**

1 Mackworth Island
Falmouth, ME 04105
207-781-6335

Website: <http://www.mecdhh.org/statewide-educational-services/early-childhood-family-services/>

ECFS provides services to families with children, newborn to age 5, who are deaf or hard of hearing. ECFS provides information to families and professionals statewide, supports the choices families make to benefit their children and assist them with identifying resources that may help them meet the individual needs of their child. Services include home visits, daycare and preschool consultation and collaboration with service providers. The ECFS consultants are trained in all communication modalities and assistive technologies available to children to offer support as needed. Services provided at no cost to families.

Howard & Espa Michaud Charitable Trust

30 Skyway Drive Unit 100
Caribou, ME 04736
Voice: 207-493-4132
TTY: 800-606-0215

Website:

<http://www.betterhearing.org/hearingpedia/hearing-loss-resources/children/howard-espa-michaud-charitable-trust>

This trust is designed to assist "children from the Aroostook County area, with special emphasis on children from the greater Presque Isle area, who are in need of special treatment related to audio disorders or deficiencies." Funds may be used exclusively for the care, treatment and/or furnishing of devices for children with hearing impairments or disorders. All other funding sources must be accessed first.

Lion's Club

Website: <http://www.mainelions.org/>

Your local Lion's club may donate toward hearing aids and adaptive equipment

Maine Center on Deafness (MCD)

68 Bishop Street, Suite 3

Portland, ME 04103

Voice/TTY: 207-797-7656

Website:

www.thecommunityconnector.org/directory/profile/maine-center-on-deafness-mcd

A community resource center that provides general information on deafness, deaf advocacy, consumer information.

Maine Hands & Voices

Website: <http://mainehandsandvoices.wildapricot.org>

A non-profit parent organization dedicated to supporting Maine families and their children who are deaf or hard of hearing and the professionals who serve them regardless of their communication choices.

MaineCare (Medicaid)**Maine Department of Health and Human Services**

11 State House Station

Augusta, ME 04333-0011

Voice: 800-977-6740

TTY: Maine Relay 711

Website: <http://www.maine.gov/dhhs/oms/>

MaineCare provides limited coverage on hearing aids for children 21 years and under.

Maine CDC Newborn Hearing Program (MNHP)

11 State House Station

286 Water Street, 7th floor

Augusta, ME 04333

207-287-8427—voice

TTY: Maine Relay 711

Website: www.mainepublichealth.gov/MNHP

A program with the department of Health and Human Services, Maine Center for Disease Control. This program coordinates hospital newborn hearing screening programs and follow-up of infants with hearing loss. The program provides resource and referral information for families.

Maine Parent Federation (MFP)

484 Maine Ave., 2D

Farmingdale, ME 04344

207-588-1933—voice

800-870-7746 Maine only

Website: <http://www.startingpointsforme.com>

A non-profit organization that provides information, support and training to parents and professionals statewide. Information about specific disabilities, parenting, education, services, support groups and resources are available.

**New England Consortium of
Deafblind Projects**

175 North Beacon St.

Watertown, MA 02472

Voice: (617) 972-7514

Website:

<http://www.nec4db.org>

National:

<https://nationaldb.org>

Informational:

<http://www.perkins.org/community-programs/nec/>

Maine CDC Public Health Nursing Program

11 State House Station

286 Water Street, 7th Floor

Augusta, ME 04333

Voice: 1-888-644-1130

Website: <http://www.maine.gov/dhhs/mecdc/index.htm>

A program with the Maine Center for Disease Prevention. Public health nurses provide home visits, clinics and educational services at no cost.

Service Organizations:

The following is a list of different service organizations that may have hearing aid donation programs or might fund a one-time request for financial assistance.

Elks Club: www.maineelks.org

Fraternal Order of the Eagles: Contact local chapter

Kiwanis

www.newenglandkiwanis.homestead.com/directory.html

Lions Club www.lionsclub.org

Maine Academy of Audiology (MAA)

www.maineaudiology.org

Masons Lodge

www.mainemason.org/lodges/bydistrict.asp

Maine Academy of Audiology is comprised of audiologists from around the state who are focused on providing the utmost care, education, awareness, and advocacy for those with hearing loss.

NATIONAL RESOURCES

Editor's Note: The authors of this guide do not officially endorse or certify any of the resources/services providers listed in this publication. It is the reader's responsibility to check the validity and references of anyone listed in this guide.

American Academy of Audiology (AAA)

11480 Commerce Park Drive Suite 220
Reston, VA 20190
Voice: 800-222-2336
703-790-8466

Website: www.audiology.org

A professional membership organization dedicated to providing high quality hearing care information to the public. Provides consumer information and locates certified audiologists in a specified area.

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

3417 Volta Place, NW
Washington, DC 20007-2778
V: 202-337-5220

Website: www.agbell.org

An international organization whose mission is Advocating Independence through listening and talking. AG Bell works with families, and professionals to promote an understanding of childhood hearing loss and the importance of early diagnosis and intervention.

American Speech Language Hearing Association (ASHA)

2200 Research Blvd
Rockville, MD 20850
Voice: 800-638-8255
TTY: 301-296-5650

Website: www.asha.org

National accrediting association for audiologists, speech language pathologists. Provides information to the public.

American Society for Deaf Children (ASDC)

800 Florida Ave. NE #2047
Washington, DC 20002-3695
Voice: 800-942-2732 or 202-644-9204

Website: www.deafchildren.org

A national, independent parent organization that provides support, encouragement, and information to families raising children who are deaf or hard of hearing.

BEGINNINGS

156 Wind Chime Court, Suite A

Raleigh, NC 27615

Voice/TTY: 919-715-4092

Website: www.ncbegin.org

An organization that provides emotional, informational, and technical support to parents of children (birth—21) who are deaf or hard of hearing, deaf parent with hearing children and professionals who serve those families.

Boston Center for Deaf and Hard of Hearing Children (BCDC)

9 Hope Avenue

Waltham, MA 02453

Voice: 781-216-2215

TTY: 781-647-8913

Website:

<http://www.childrenshospital.org/centers-and-services/deaf-and-hard-of-hearing-program/>

Provides comprehensive evaluation and consultation services to children with hearing loss, their physicians, families, schools and other agencies.

Dawn Sign Press

6130 Nancy Ridge Drive

San Diego, CA 92121-3223

Voice/TTY: 858-625-0600 or 800-549-5350

Website: www.dawnsign.com

Features books, videos, printed materials on American Sign Language education and deaf culture.

Better Hearing Institute

1444 I Street, NW, Suite 700

Washington, DC 20005

Voice/TTY: 800-327-9355

Website: www.betterhearing.org

Provides information concerning hearing loss, hearing aids and where to get help.

Boys town National Research Hospital Center on Childhood Deafness

555 N. 30th Street

Omaha, NE 68131

Voice/TTY 402-498-6540

Website:

<http://www.boystownhospital.org/hearing-services/childhoodDeafness/Pages/default.aspx>

A nonprofit hospital that is internationally recognized for research and treatment of childhood deafness and communication disorders. Provides information on childhood hearing loss to parents and professionals.

Harris Communications

15155 Technology Drive

Eden Prairie, MN 55344

Voice: 800-825-6758

TTY: 800-825-9187

Website: www.harriscomm.com

Mail order catalog with many products including assistive devices, assistive listening devices, hearing aid accessories, books, videos and novelties.

Hands & Voices

PO Box 3093
 Boulder, CO 80307
 Voice: 303-492-6283
 Voice 866-422-0472

Website: www.handsandvoices.org

National non-profit parent organization dedicated to supporting families and their children who are deaf or hard of hearing and the professionals who serve them regardless of their communication choices.

The Hearing Impaired Kids Endowment (HIKE) fund

10115 Cherryhill Place
 Spring Hill, FL 34608-7116
 Voice: 352-688-2579

Website: <http://www.thehikefund.org/>

Provides hearing devices for children with hearing impairment from birth to 20, whose parents are financially unable to meet this need.

Hearing Loss Association of America (HLAA)

7910 Woodmont Avenue, Suite 1200
 Bethesda, MD 20814
 Voice: 301-657-2248

Website:

<http://www.hearingloss.org/content/understanding-hearing-loss>

Provides assistance and resources for people with hearing loss and their families. HLAA focuses on public awareness and the importance of regular hearing screens throughout life.

Hear Now

6700 Washington Ave South
 Eden Prairie, MN 55344
 Voice: 866-354-3254

Website:

<http://www.starkeyhearingfoundation.org/programs>

A program of the Starkey Foundation involved in increasing public awareness about the need for available and affordable assistive technology. Provides hearing aids to people with limited financial resources.

Helen Keller National Center

141 Middle Neck Road
 Sands Point, NY 11050
 Voice: 516-944-8900
 TTY: 516-944-8637

Website: www.hknc.org

Provides information, referrals, advocacy & technical support to professionals, families and consumers.

Laurent Clerc National Deaf Education Center—Gallaudet University

800 Florida Avenue NE
 Washington, DC 20002-3695
 Voice: 202-651-5000

Website:

http://www.gallaudet.edu/clerc_center.html

Gallaudet is a 4-year liberal arts university in which all programs and services are designed specially to accommodate deaf and hard of hearing students.

Marion Downs National Center for Infant Hearing

4280 Hale Parkway
Denver, CO 80220
Voice: 303-222-1871

Website: www.mariondowns.com

Information on universal newborn hearing Screening, assessment, diagnosis and early intervention

National Center for Hearing Assessment & Management (NCHAM) - Utah State

University
2615 Old Main Hill
Logan, UT 84322

Voice: 435-797-3584

Website: www.infanthearing.org

Ensures that all infants & toddlers with hearing loss are identified as soon as possible and provided with timely & appropriate audiological, educational & medical intervention.

National Institute on Deafness & Other Communication Disorders (NIDCD)

31 Center Drive MSC 2320
Bethesda, MD 20892-2320
Voice: 800-241-1044

TTY: 800-241-1055

Website: <http://www.nidcd.nih.gov/>

Conducts research & training on normal & disordered processes of hearing, balance, smell, taste, voice, speech and language.

National Association of the Deaf (NAD)

8630 Fenton Street, Suite 820
Silver Springs, MD 20910

V: 301-587-1788

TTY: 301-587-1789

Website: www.nad.org

Consumer organization that safeguards the accessibility and civil rights of person who are deaf/hard of hearing in education, employment, health care and telecommunications.

National Cued Speech Association

1300 Pennsylvania Ave NW Suite 190-713
Washington, DC 20004

Voice/TTY: 800-459-3529

Website: www.cuedspeech.org

Promotes & supports the use of cued speech for communication, language acquisition and literacy. Provides information, referrals and support services.

Oberkotter Foundation

1600 Market St Suite 3600
Philadelphia, PA 19103

V: 877-672-5332 TTY: 877-672-5889
215-751-2601

Website: www.oberkotterfoundation.org

Private family foundation that advocates oral deaf education.

Additional Resources

Books, Printed Materials, Videos and Websites

The following websites and organizations offer a broad spectrum of information on their website. Many have books, printed materials and videos. For more information on the organizations listed below, please consult the State and National Resources listed in the prior pages.

Alexander Graham Bell Association

Website: www.agbell.org

Cued Speech Association of Maine

Website: www.cuedspeechmaine.org

Dawn Sign Press

Website: www.dawnsign.com

Gallaudet University

Website:

http://www.gallaudet.edu/clerc_center.html

Hands & Voices

Website: www.handsandvoices.org

Harris Communications

Website: www.harriscomm.com

hearMEnow (hMn)

Website: <http://hear-me-now.org/>

Hearing Loss Association

Website: <http://hearingloss.org/>

Maine Educational Center for the Deaf & Hard of Hearing (MECDHH)

Website: www.mecdhh.org

Maine Parent Federation

Website: www.mpf.org

Supporting Success for Children with Hearing Loss

Website:

<http://successforkidswithhearingloss.com/about>

Section 7:

Glossary

The first part of this section contains a glossary that list words and definitions of terms you may encounter in your journey. The second part is a list of acronyms that you will see and hear.

Definitions

Acquired Hearing Loss – A hearing loss that develops during a person’s life and is not present at birth.

Advocacy – Advocating for your child means knowing what rights are assured your child by the law. Sometimes this role is played by parents or guardians and sometimes by someone else with special skills in advocacy.

Alerting Devices – Term used to describe devices that are available to help people who are deaf or hard of hearing use other senses such as, vision or touch, to adapt to their environment and improve communication.

American Sign Language (ASL) – A complete language with its own word order and grammar rules, used primarily by people who are deaf. ASL is a language that uses the hands, body and facial expressions to express the same kinds of words and thoughts as spoken languages.

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

Assistive Listening Device – Devices and amplification systems designed specifically to help people hear better in a variety of difficult learning situations. Hearing aids and FM systems are types of assistive listening devices.

Assistive Technology – A general term which includes all devices and systems which improve communication and help improve the listening environment. TTY’s, alert systems, FM systems, hearing aids and cochlear implants are all types of assistive technology.

“At Risk” – A term that refers to a medical condition or event that is known to be connected with a hearing loss.

Audiogram – A graph that shows how a person hears different sounds at different levels of loudness (intensity) and for all pitches (frequencies) used to hear speech.

Audiological Assessment – A complete evaluation of hearing that identifies the type and degree of hearing loss.

Audiologist – A health care professional who has special education and training in the evaluation of hearing loss and balance disorders. Most audiologists fit and dispense hearing aids and other listening devices.

Auditory Brainstem Response (ABR) test – A hearing test that can measure the electrical activity from the hearing nerve in infants and young children.

Auditory Neuropathy Spectrum Disorder (ANSD) - A hearing disorder caused by the abnormal conduction of auditory nerve impulses. A child with this hearing disorder may be able to hear that sounds are present at time, but the sounds cannot be heard clearly or consistently.

Auditory Nerve – A nerve responsible for carrying information about sound to the brain.

Auditory-Verbal – Auditory-Verbal therapy is one-on-one therapy that focuses on the consistent use of hearing aids and cochlear implants to develop age-appropriate spoken language skills through listening. Parents and caregivers actively participate in all sessions. The development of listening skills is worked on systematically, through play and routine activities, so that the child strengthens the auditory centers of his/her brain. Speech reading and signing are not used. The goal is to help parents/caregivers help their child learn to listen and speak through everyday play activities and routines.

Auditory-Oral –Focuses on listening and spoken language through the consistent use of cochlear implants or hearing aids to develop age-appropriate spoken language through listening. The development of listening skills is worked on systematically and naturally across all environments, so that the child strengthens the auditory centers of his/her brain. Speech reading and natural gestures may be used, although listening is the primary focus. Signing is not used. The goal is to develop listening and spoken language to the fullest extent.

Behavioral Observation Audiometry (BOA) – A hearing test during which an audiologist assesses an infant/child's response to sound by observing specific behaviors to sounds. This test is done in a sound proof room (sound booth).

Behind-the-Ear (BTE) Hearing Instrument – A type of hearing aid that fits behind the ear and directs sound into the ear with an earmold.

Bicultural/Bilingual – Participating in two cultures and being fluent in two languages. An example would be a person who is deaf who communicates in both ASL and English and is comfortable in both the Deaf culture and the Hearing culture.

Bilateral Hearing Loss – A hearing loss of any degree in both ears.

Bilingual-Bimodal– An approach that supports the acquisition of both American Sign Language (ASL) and spoken English. Both languages are valued equally in this approach, and the child should have consistent access to both. The languages are kept separate and whole.

Bone Conduction – Sound received through the bones of the skull. Bone conduction hearing testing bypasses the outer and middle ear and directly stimulates the cochlea by passing sound vibrations through the skull bone.

Bone-Conduction Hearing Aid – An amplification device that is worn with a headband. It allows sound to be moved through bone directly to the inner ear when ear structure prevents the use of an earmold.

Captioning/Closed Captioned – A written display of spoken words, used on a television or a movie screen.

Central Auditory Processing Disorder – A language disorder that involves the perception and processing of information that has been heard. Children with this disorder have problems following spoken instructions and usually show other language learning problems, even though the inner ear is functioning normally and there is no hearing loss.

Cerumen – Ear wax.

Child Development Services (CDS) - Statewide provider of early childhood intervention and services.

Cochlea – The bony structure of the inner ear that is named for its shape. It is called the end organ of hearing and contains hair cells that communicate directly with the auditory nerve sending information about sound to the brain.

Cochlear Implant - A surgically implanted device that transforms sound into electric impulses. Cochlear implants bypass the damaged parts of the ear and send electric signals directly to the hearing nerve (auditory nerve), which relays this information to the part of the brain that is responsible for hearing. Cochlear implants are mostly used for children with severe to profound hearing loss who are not able to benefit from hearing aids.

Cognitive (cognition) – The ability to think, learn and remember.

Communication – The give and take of information between people. Communication can happen in many modes, words, signs, gestures, hand and body movements, emotions, and facial expressions.

Conductive Hearing Loss – A hearing loss caused by a problem in the outer or middle ear. Problems can be caused from ear infections, fluid in the middle ear, ear wax build-up in the ear canal, a hole in the eardrum or damage to the tiny bones of the middle ear. People with a conductive hearing loss have a loss of sensitivity to sound and have difficulty with hearing soft sounds.

Congenital Hearing Loss – Hearing loss present at birth or hearing loss that develops in the first few days of life.

Cued Speech – A visual system that uses the mouth movements of speech in combination with cues. The cues are a combination of 8 hand shapes and 4 locations that make all the sounds of spoken language look different. When cueing spoken language, the 8 handshapes distinguish among consonant sound and the 4 locations near the mouth distinguish among vowel sounds. A handshape and a location together cue a syllable.

Cytomegalovirus (CMV) - One group of herpes viruses that can infect a person and cause a variety of problems, including hearing loss. Cytomegalovirus is known to be a cause of childhood hearing loss. A child can be infected with the virus before, during or after being born.

Deaf – A word that is used when a person has a severe to profound hearing loss greater than 90 dB HL. When it is spelled with a capital “D” (Deaf), it is used to refer to people who consider themselves to be a part of the unique cultural heritage and beliefs of deaf individuals known as “the Deaf culture or community”.

Deafblind - Also called Dual Sensory Impairment, Sight and Sound.

Deaf-Blindness occurs when a person has both a hearing loss and a visual loss. Some deaf-blind people have "low vision" or are blind combined with moderate to severe hearing loss. Some are deaf with poor vision and some are both blind and deaf. Since people with one type of loss tend to use the other sensory system to "make up for the loss", having losses in both sensory systems has a strong impact on communication, access to information, and mobility.

Deaf Community – A group of people who share common interests and a common heritage and who use ASL to communicate. The Deaf community has people who are both deaf and hearing. The Deaf community may have many opinions on different issues, but they agree on the importance of Deafness as a positive state of being.

Deaf Culture – A view of life that shares certain traditions, beliefs, common identity, artistic expression, experiences and language (ASL) particular to Deaf people.

Decibel (dB) – The unit of measurement for the loudness of a sound. A higher number of a decibel means a louder sound.

Developmental Delay – A term used when there is a delay in certain aspects of a typical childhood development (physical, cognitive or sensory).

Ear Canal – The passageway from the outer ear to the eardrum.

Eardrum – A thin tissue that separates the outer ear from the middle ear. It is also known as the tympanic membrane.

Ear Infection (or otitis media) – The presence or growth of bacteria or viruses in the middle ear.

Earmold – A custom made piece of plastic or vinyl that is needed to connect and fit a hearing aid or FM system in a person's ear.

Ear Wax – A normal substance produced from glands in the outer ear to help keep the ear healthy and protect it from infections. It is also called cerumen.

Educational Audiologist – An audiologist who has special training to help children with hearing loss in school settings. An educational audiologist can identify appropriate accommodations to facilitate learning.

ENT physician (or otolaryngologist or otologist)– A medical doctor who has special training and provides specialty medical care focused on the ears, nose and throat.

Environmental Sounds – All the sounds that take place around us. For example, the sound of a plane flying overhead, the sound of birds and insects, phones, the refrigerator.

Eustachian Tube – A small passageway from the back of the throat to the middle ear that allows air into the middle ear.

Expressive Language – How well a person can use language to communicate thoughts, ideas and feeling.

External Ear (pinna)– The outer portion of the ear that is visible and the ear canal.

Feedback – The shrill sound made when amplified sound from a hearing aid receiver goes back into the microphone of the hearing aid. Feedback can be caused by an earmold that does not fit properly or a damaged hearing aid.

Fingerspelling – A standardized series of hand shapes made to form letters of the alphabet and words.

Fluctuating Hearing Loss – A hearing loss that can change unpredictably. Sometimes conductive loss from middle ear infections is called fluctuating hearing losses.

FM System (Frequency Modulation System) - An assistive listening device that amplifies the speaker's voice transmitted via radio waves. The device reduces the problem of background noise interference and the problem of distance between a speaker and a person with hearing loss.

Frequency – Frequency, expressed in Hertz (Hz) determines the pitch of a sound. Treble and Bass are other names for high pitch and low pitch.

Functional Hearing – A term that refers to how helpful a person's residual (remaining) hearing is in hearing and understanding information through listening only, when amplified with hearing aids.

Gain – A term that describes the amount of amplification provided by a hearing aid. For example, a child with unaided hearing at 70 dB who, when amplified hears at 30 dB, is experiencing a gain of 40 dB.

Genetic Counseling – A series of discussions, evaluations, and testing with genetic professionals regarding a specific disorder (such as hearing loss). Information reviewed may include the possible causes of a birth defect or genetic disorder, any possible associated medical conditions and the risk of hearing loss for other family members or future pregnancies.

Gesture – The movements of the hands or body that express an idea. Gestures include pointing, head nodding, waving good-bye and many others. Gestures can be used alone or can be combined with words or signs to communicate thoughts and ideas.

Hair Cells – The hair-like structures in the cochlea of the inner ear that transform the mechanical energy of sound waves into nerve impulses.

Hard of Hearing – A term to describe mild to severe hearing loss.

Hearing Aid – An electronic device that conducts and amplifies sound to the ear. Hearing aids make sounds louder; they do not provide normal hearing. It is also called a hearing instrument.

Hearing Screening – A basic measurement of hearing ability that is designed to determine the likelihood of a hearing loss. Infants who do not pass the newborn hearing screen require further testing to find out if a hearing problem exists.

Hertz (Hz) - The measurement of frequency, or cycles per second of sound waves.

I.D.E.A. – The Individuals with Disabilities Education Act, Public Law PL 105-17 (formerly known as 101-476, PL 94-142 and PL 99-457). This federal law includes the description of the categories under which children with disabilities may be eligible, or qualify, for special education and related service programming.

Implantable Hearing Aid - Implantable hearing aids are designed for people with moderate to severe sensorineural hearing loss. Part, or all, of the device is surgically placed in the middle ear space. Rather than amplifying sounds before they reach the eardrum, implantable hearing aids bypass the ear canal and the eardrum and provide sound vibrations to the bones of the middle ear. This reduces the problem of feedback and increase the clarity of sounds.

Individualized Education Program (IEP) – A written statement for a child (between the ages **three to twenty-one**) with a disability. A program is developed, reviewed, and revised by a team that is composed of the child’s parents, regular education teacher, special education teacher, and a representative of the local education agency. Other people who have knowledge or expertise about the child or the particular disability may also become a part of the team.

Individualized Family Service Plan (IFSP) – A team developed, written plan for children ages **Birth to Two** with developmental delays/disabilities and their families. The plan includes: An assessment of the strengths and needs of the child and family, identification of the supports and services necessary to meet the developmental needs of the child and any services needed to help support the family.

Inner Ear – The part of the ear that has the organ for hearing (cochlea) and the organ for balance (labyrinth).

Interpreter – A person who facilitates communication between people who are hearing and those who are deaf or hard of hearing. Maine law requires that all interpreters be licensed by the State of Maine.

Language – A system of communication based on a common set of words and a common set of rules for how words are put together to express thoughts and feelings. Each language has its own grammar (rules) for how words and sentences are formed and all users of the language use the same rules. Languages can be spoken, signed, or expressed through writing.

Lip-reading (Speechreading)– Understanding speech through watching facial movements/expressions in conjunction with use of contextual information and situational cues.

Listening and Spoken Language Specialist (LSLS) - An LSL professional helps children who are deaf and hard of hearing develop spoken language and literacy primarily through listening. LSL professionals focus on education, guidance, advocacy, family support and the rigorous application of techniques, strategies and procedures that promote optimal acquisition of spoken language through listening by newborns, infants, toddlers and children who are deaf and hard of hearing. An LSL specialist is either an audiologist, a speech-language pathologist or a deaf educator who has completed advanced training through the Alexander Graham Bell Academy.

Microtia – A term that refers to any abnormal growth of the outer ear. Microtia includes abnormalities such as, minor skin tags, different ear shapes, or a completely missing outer ear.

Middle Ear – The part of the ear that includes the eardrum and three tiny bones (ossicles, also called hammer, anvil and stirrup).

Mixed Hearing Loss – A hearing loss that is a combination of both sensorineural and conductive causes.

Native Language – The language spoken in an infant/child's home.

Natural Environment – Term in the Individuals with Disabilities Education Act (IDEA) used to describe the location for early intervention services. IDEA describes the natural environment as a home or community setting that is natural and normal for same age peers who have no disabilities.

Otitis Externa – An inflammation or infection of the outer part of the ear and sometimes in the auditory canal.

Otitis Media – Fluid or infection behind the eardrum of the middle ear.

Otitis Media with Effusion – An infection of the middle ear with abnormal fluid.

Otoacoustic Emissions Test (OAE) – Otoacoustic emissions are tiny sounds that are reflected by the healthy inner ear (cochlea). In an OAE test, a small, soft probe containing a microphone and receiver is placed in a child's ear canal. The microphone makes sounds and the sounds reflected back from the cochlea are recorded and measured by a computer.

Otolaryngologist – A doctor who has specialized training in disorders of the ear, nose throat, head and neck. May also be called an ENT (ear, nose and throat) doctor.

Otologist (ENT doctor)– A doctor who has specialized training in disorders of the ear, nose, throat, head and neck.

Outer Ear – The external portion of the ear that collects sound waves and directs them into the ear. The outer ear consists of the pinna and the ear canal.

Part B - Early intervention services, special education and related services provided under the 2004 IDEA law for children 3-21years of age.

Part C - Early intervention services, special education and related services provided under the 2004 IDEA law for children birth to two years of age.

Receptive Language – A person’s ability to understand what other people are saying or signing using language.

Residual Hearing – The amount of hearing that a person with a hearing loss can use.

Sensorineural Hearing Loss – A hearing loss caused by damage or abnormality of the inner ear (cochlea) and/or the hearing nerve.

Simultaneous Communication (Sim-com) - A way of communicating in which a person speaks in English and uses signs in English word order at the same time.

Sound Field System - A term that refers to an adaptive system designed to help reduce unwanted background noise in an area or room. Through the use of speakers and microphones, a teacher or speaker’s voice can be projected to a level where students can hear comfortably without straining.

Speech Awareness Threshold - The lowest level at which a person can identify spoken words 50% of the time.

Speech Banana - A term that refers to a section of an audiogram (shaped like a banana) where people with normal hearing can identify the conversational sounds of spoken language.

Speech Language Pathologist (SLP or speech therapist) - A person who has special training to evaluate and provide treatment for speech, language, cognitive communication and swallowing problems in children and adults. Speech-Language Pathologists hold a master’s degree and must be licensed to practice by the State.

Speech Reading (lip reading)– A communication strategy that understands spoken language by interpreting lip movements, facial expressions, and body movement.

Sudden Deafness – The loss of hearing that occurs quickly due to such causes as an explosion, a viral infection, or the use of some drugs.

Tactile Aids – A type of assistive communication device that sends out a vibration or “tactile” signal to indicate the presence of sounds. It is worn on the body and through the sense of touch or feeling, draws attention to information that cannot be heard by a person with hearing loss.

Teacher of the Deaf - Teachers who specialize in language acquisition and the unique learning and communication needs of deaf or hard of hearing children.

Threshold – The softest level at which a sound can be heard 50 % of the time.

Total Communication – A communication method that focuses on using multiple methods to communicate. Total communication uses signs from ASL, fingerspelling (spelling out English words on the hands), speaking, speech reading, and the use of any hearing a person might have.

TTY/TTD – TTY = Teletypewriter. TDD = Telecommunication Device for the Deaf.

Originally and often still called TTY’s, this is a machine that allows people who are deaf or hard of hearing to send or receive written messages transmitted through telephone lines.

Tympanogram – A chart of the results of tympanometry.

Tympanometry – A test that is used to measure how well the ear canal, ear drum, Eustachian tube and middle ear bones are working. It does not directly measure hearing ability.

Unilateral Hearing Loss – A hearing loss in one ear only.

Visual Reinforcement Audiometry (VRA)– A method of assessment often used with very young children in which the child is conditioned to look at a toy that lights up each time they hear a sound.

Acronyms

ABR: Auditory Brainstem Response test

ASL: American Sign Language

ANSD: Auditory Neuropathy Spectrum Disorder

AVT: Auditory Verbal Therapy

BOA: Behavioral Observation Audiometry

BTE: Behind The Ear hearing aid

CDS: Child Development Services

CI: Cochlear Implant

CMV: Cytomegalovirus

dB: Decibel

DHHS: Department of Health and Human Services

ECFS: Early Childhood and Family Services

ENT: Ear Nose & Throat doctor; also known as an Otolaryngologist

FM System: Frequency Modulation System

HL: Hearing Loss

D/HH: Deaf/ Hard of Hearing

Hz: Hertz

I.D.E.A.: Individuals with Disabilities Education Act

IEP: Individualized Education Program

IFSP: Individualized Family Service Plan

MNHP: Maine Newborn Hearing Program

Section 8:

Keeping Track

Over the next few years, you and your child will be meeting many people and receiving many business cards, reports, and other written materials.

Here is a place to put those things and help you stay organized.

Notes

Notes

Maine CDC Newborn Hearing Program
Division of Disease Prevention
Children with Special Health Needs Program
11 State House Station
Augusta ME 04333-0011
(207) 287-8427 or (800) 698-3624 – Voice
All TTY users call Maine Relay 711

Maine Educational Center for the Deaf
& Hard of Hearing
Statewide Education & Family Services
One Mackworth Island
Falmouth, ME 041055
(207) 781-6335

Printed with the support of
U.S. Department of Health & Human Services
Health Services & Resource Administration
Maine Educational Center for the Deaf and Hard of Hearing Grant # H61MC30766
2018



Paul R. LePage, Governor

Ricker Hamilton, Commissioner



THE MAINE EDUCATIONAL CENTER
FOR THE DEAF AND HARD OF HEARING

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Supported by federal grant funds from the U. S. Department of Health and Human Services, Health Resources and Services Administration, Maine Educational Center for the Deaf and Hard of Hearing, Grant #H61MC030766

