Resource Guide

For Families of Children Who Are Deaf or Hard of Hearing

No baby is too young for a hearing test

Department of Health & Human Services
Maine Center for Disease Control & Prevention (Maine CDC)
Maine Newborn Hearing Program

The Maine Educational Center for the Deaf and Hard of Hearing / Governor Baxter School for the Deaf, Earliest Interactions

Please contact us with comments or questions.

Maine Department of Health & Human Services
Maine Center for Disease Control & Prevention
Newborn Hearing Program

11 State House Station
Augusta ME 04333-0011

207-287-5357 or *1-800-698-3624* (Voice)
Or
TTY: *Call 711* (Maine Relay)

Maine Educational Center for the Deaf and Hard of Hearing/
Governor Baxter School for the Deaf

1 Mackworth Island
Falmouth, Maine 04105

207-781-3165 (Voice)
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This project was supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of an award totaling $235,000 Award number H61MC30766 Maine Educational Center for the Deaf and Hard of Hearing, "Earliest interactions: Supporting 1-3-6 and Family Engagement". The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS or the U.S. Government.

Last Update: September 2023

Welcome!

You have just found out that your baby is deaf/hard of hearing. We are happy to welcome you to our community! You may have many questions. This booklet may help answer some questions and give you some basic information that we hope is helpful to you and your family.

During your family's journey, you will hear your child's hearing described in many different ways (hearing difference, hearing loss, deaf, hard of hearing, etc.). Because children who are born with hearing differences have not experienced a "loss" in hearing, the Deaf/Hard of Hearing Community chooses not to incorrectly use the term "hearing loss" when discussing the hearing of those who are born deaf/hard of hearing. Instead, the terms "hearing levels", "hearing difference", and "deaf/hard of hearing" are commonly used. You'll see this terminology used interchangeably throughout this booklet when referring to your child's hearing.

You still may have questions about your child being deaf/hard of hearing after reading this booklet. There are many resources in Maine that can help answer questions and offer support. Two programs, Child Development Services (CDS) and Early Intervention and Family Services (EIFS) collaborate to provide Early Intervention Specialists (EIS) who are trained to support families with deaf or hard of hearing children. A professional from EIFS can meet with you to answer your questions, provide information, and offer support. Many families also find comfort and support in talking to a parent who has been through this process. Maine Hands & Voices has a program called Guide By Your Side that offers support from a Parent Guide to help you navigate through this new journey with your baby. Contact information is in the back of this booklet.

Remember to take the time to enjoy your baby. Smile, talk, sing, read, and play with your child. These simple actions and activities build a solid foundation for communication and language development.

First Steps

In Maine, 20 to 25 babies who are deaf/hard of hearing are born each year; it happens more often than you would think. Each family member may react differently when learning the baby is deaf/hard of hearing. Families may experience feelings of sadness and uncertainty. This is natural.

When deaf or hard of hearing children are young, providing access to language is important. Early intervention services are provided to families in Maine to support this process. Your audiologist and early interventionist will work together to provide information and resources to support your family. Meeting other families who have children that are deaf or hard of hearing may help you understand what can work best for your child and for your family. Children who are deaf/hard of hearing are more likely to develop age-appropriate language and communication skills with early identification support services.

Learning how you can support your child in developing language is an important part of this journey. Raising children may be the most rewarding and challenging job you will ever have. For every challenge, there are joys and surprises you may never have imagined.

Hearing and the Learning of Language

The ability to share feelings and thoughts with other people using language is one of the most important skills we learn as infants.

We know that children's brains learn language best in the early years, from birth to age three. Young children with typical hearing generally develop spoken language naturally, through repeated exposure to language as part of their family's daily routines. We also know that when young children do not have typical hearing, language development doesn't happen as naturally.

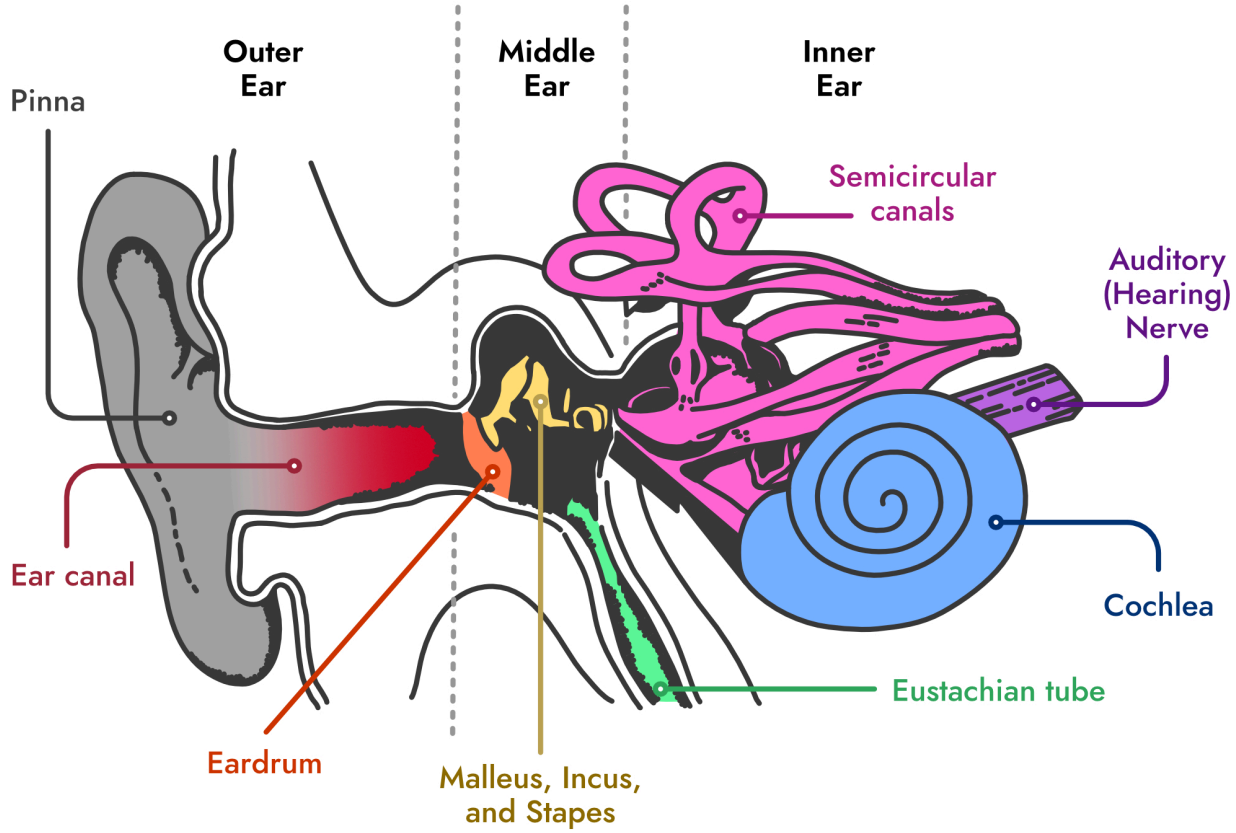
Communication and language grow out of relationships. Babies learn best from adults and family members who interact with them.

Families may need support to help their babies learn language. That support is available from many agencies and providers in Maine and nationwide. You can find information about some of the agencies in Maine in the back of this booklet. These agencies have professionals who can share information on a variety of topics and provide ongoing support to guide you.

The first step is getting to know your baby and learning as much as you can about how babies learn language. The most important goal is that your baby develops language, and your involvement is critical in meeting that goal.

Helpful hints for supporting your child's language development can be found in the "Communicating with your Baby" section.

How Hearing Works



Parts of the Ear

The ear is divided into three parts: **the outer ear**, **the middle ear**, and **the inner ear**. 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.

Outer Ear

The outer ear is the part of the ear that is visible outside the body. The **pinna** catches sound from outside the ear and the sound travels to the **ear canal**. The sound pushes against the eardrum.

Middle Ear

The **eardrum** separates the outer ear from the middle ear.

There are three bones in the middle ear commonly called the **malleus, incus, and stapes**. When the eardrum moves, it makes the three bones in the middle ear move.

Inner Ear

The inner ear is connected to the middle ear bones. This part of the ear contains the **cochlea** and the **auditory nerve**. As the middle ear bones move, they create movement in the inner ear which cause the cilia, or tiny hair cells, to react, transmitting sound via the auditory nerve to the brain.

The three parts of the ear work together to help us hear.

Categorizing Hearing Differences

Your audiologist has informed you that your child is deaf/hard of hearing. Over time, additional tests will provide further information about the type and degree of your child's hearing differences. The type and degree of your child's hearing differences are important for your audiologist to know, as these details help them to understand what hearing technology may be appropriate for your child, and how your child's hearing differences might impact their spoken language development, if one of your family's goals is spoken language. The "degree" of hearing levels refers to how loud a sound needs to be for your baby to hear it, and can range from slight to profound. The degree of hearing levels can change over time; it is important that your child's hearing be monitored regularly. Degree categories will be explained further in the Audiogram section.

The "type" of hearing difference refers to where along the auditory system there may be a difference in structure, or blockage, that is impacting how sound is transmitted to the brain. The three types of hearing differences are sensorineural, conductive, and mixed.

- **Conductive:**
  Conductive hearing differences occur when there is something that physically prevents sound from traveling through the outer and/or middle ear. This can occur when the child has an ear infection, or in cases where the outer ear does not fully develop.

- **Sensorineural:**
  Sensorineural hearing differences are caused by a difference in development of the inner ear that changes the way the inner ear and auditory system interpret sound. A child with a sensorineural hearing difference has difficulty hearing sounds clearly.

- **Mixed:**
  Mixed hearing differences describe a combination of sensorineural and conductive hearing differences. An example of a mixed hearing difference is an existing sensorineural hearing difference and an additional temporary conductive component due to an ear infection or fluid in the middle ear.

- **Auditory Neuropathy Spectrum Disorder (ANSD):**
  This type of hearing difference is caused by a miscommunication between the parts of the ear, the auditory nerve, and the listening center in the brain. A child with ANSD may be able to hear that sounds are present, but the sounds are not heard clearly or consistently.

Hearing Tests for Infants and Young Children

Preparing for Testing

Contact your audiologist's office before you go to ask questions about how you and your baby can prepare for the specific tests to be done. Some of the tests require the baby to be asleep or quiet and calm, while others require the baby to be awake. Bring extra diapers, a blanket, and anything that will help your baby be more comfortable and calm during the testing. None of these tests are painful for your baby.

These are the types of tests used to measure a baby's hearing. The audiologist may recommend one or more of these tests.

Otoscopic Exam: A lighted tool called an otoscope is used to look inside the ear canal and see the eardrum. This exam can help find out if there is fluid or an infection in the baby's middle ear or a blockage in the outer ear.

Tympanometry: A small, soft probe is placed at the opening to the baby's ear canal and a tiny puff of air is pumped in and out to see how well the eardrum moves, and how well the middle ear is working. There may be just a slight feeling of pressure in the ear and some babies may fuss, but this does not hurt.

Otoacoustic Emissions (OAE): A small, soft probe containing a microphone and receiver is placed in the baby's ear canal. The microphone makes sounds and the sounds reflected back from the cochlea are recorded and measured by a computer. These sounds reflected back by the cochlea are called Otoacoustic Emissions. It is necessary for the baby to be quiet and calm for this test to be completed. This test tells us how the cochlea is working.

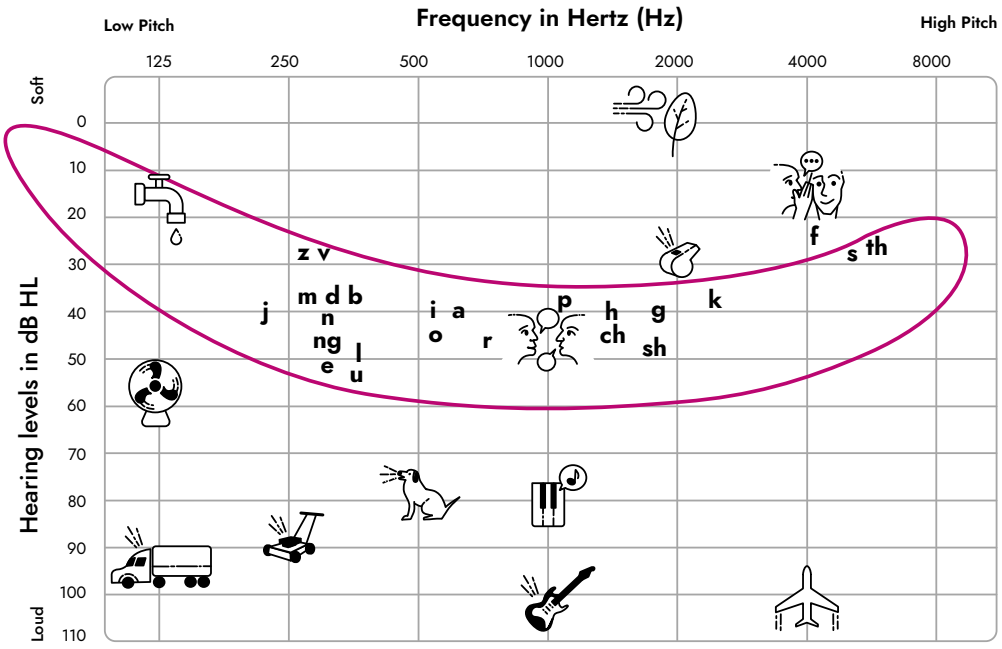
Auditory Brainstem Response (ABR): Small sensors are put on the baby's head and sound is sent through earphones. A computer measures and analyzes the baby's brain's response to sound, to help determine whether a hearing difference exists, and if so, what the type and degree is. The baby must be asleep for accurate test results. Testing can take a while; multiple sessions might be needed. Natural sleep is preferred; however, sedation is used at times.

Visual Reinforcement Audiometry (VRA): Your baby is taught to respond to sound by turning to a lighted animated toy or video. The test can be done with the sound coming through earphones, speakers, or through hearing aids. This helps determine the softest sounds your child can reliably hear. This test is generally fun for the baby. Multiple sessions might be needed to obtain accurate test results.

Ear, Nose, and Throat (ENT) Evaluation: The ENT doctor (otolaryngologist) examines the baby's head, neck, and ears and asks about your family's and baby's medical history. The ENT will work with your baby's doctor, audiologist, and a geneticist to determine the possible cause of the hearing difference, and make recommendations for more testing, treatment, and hearing technology, if needed. The ENT must give medical clearance before hearing technology can be issued.

The Audiogram

After a series of hearing tests, the audiologist can provide you with an audiogram.



The audiogram is a visual used to show how your child responds to sound. The numbers across the top of the chart refer to the frequency or pitch of the sound, also known as Hertz (Hz). The numbers on the side refer to the intensity or volume of the sound, also known as decibels (dB).

Pictures on the audiogram show the relative volume and pitch of familiar sounds. For example, the tree represents the high, soft sound of wind and the lawnmower represents the low, loud sound of the engine.

The area outlined in purple on the audiogram is often called the "speech banana." The speech banana represents all the sounds of speech at a conversational level, and can be heard by people with typical hearing.

After testing your baby's hearing, the audiologist marks Xs (left ear) and Os (right ear) on the chart. The audiologist looks at the pattern of the Xs and Os and determines the level of your baby's hearing.

Degree

As your child's hearing is plotted on the audiogram, the audiologist determines the degree of your child's hearing levels by matching it to one or more of the following degree categories:

Degree	Level in Decibels (dB)
Hearing within normal limits	0–15 dB HL
Slight	16–25 dB HL
Mild	26–40 dB HL
Moderate	41–55 dB HL
Moderately Severe	56–70 dB HL
Severe	71–90 dB HL
Profound	91 dB HL or greater

Hearing Technology

Hearing technology is used to provide increased access to certain sounds according to your child's hearing levels. Some of the choices are described below.

Hearing Aids

When a baby is deaf/hard of hearing, audiologists often recommend hearing aids. Hearing aids can be used by people of all ages, even tiny babies. Hearing aids make sounds louder but they do not provide typical hearing levels. The audiologist will recommend a hearing aid that matches your baby's hearing levels.

The most common type of hearing aid recommended for babies is Behind The Ear (BTE). This type of hearing aid fits behind the ear and directs sound into the ear with an earmold. Since babies and small children grow quickly, they usually need to have new earmolds made often so the hearing aid fits well.

Bone Conduction Hearing Devices

This type of amplification is used for children who may not benefit from traditional hearing aids coupled to earmolds. This can be worn on a special headband or attached directly to the skin with adhesive.

Remote Microphone (RM) Hearing Assistance Technologies (HAT)

The RM-HAT system has two components.

A microphone is worn by an adult (usually a parent or teacher), which transmits spoken language directly to a receiver, attached to the child's hearing technology or in the form of a soundfield speaker. As a result, the child accesses the spoken language transmitted through this system as if they are seated next to the parent/teacher, regardless of the distance between them. The spoken language transmitted through the system will also be louder than competing background noise.

Cochlear Implants (CIs)

CIs are used for children who have moderately severe to profound hearing levels and who may have difficulty accessing spoken language through their hearing aids. Children with mild hearing levels are likely not candidates for CIs, but could become candidates in the future if their hearing changes. An implant is placed in the inner ear during surgery, and provides electrical stimulation in response to sound picked up by the external processor, which is worn behind the ear. Children as young as 9 months may be eligible for a CI.

Using Hearing Technology

Your baby's hearing technology is custom fit and adjusted for their specific hearing levels. It is important to help your baby use their hearing technology consistently and successfully.

Some children with hearing technology can hear environmental sounds, some can hear speech sounds, and some can understand spoken language with their technology. This depends on their degree of hearing levels, their consistency of technology use, and other factors. Ask your audiologist about your child's ability to hear with hearing technology.

There will be many trips to your audiologist for testing. You will continue to learn more about how your baby hears with each appointment. The hearing technology will need to be adjusted as more is learned about the loudness and clarity of sound that your baby hears. Parents are the best observers of their baby's listening and communication/communicative behaviors, so remember to share what you notice with your audiologist at each appointment. This will help your audiologist make the best adjustments to your baby's hearing technology and to help them learn to listen.

Communicating with Your Baby

Talking to your baby:

- Hold, touch, rock, gesture, sing, and play with your baby.
- Share books with your baby every day. Be sure to show your baby the pictures. Even tiny babies can enjoy books.
- Talk often and gesture with your baby from the day they are born. Tell your baby what you are doing. Your baby was born ready to communicate and learn language.
- Remember to make sure your baby can see you while communicating. Eye contact and facial expressions are very important. Your baby loves to see your face.
- Listen and look as your baby communicates with you. Wait to give a response after your baby looks around or looks at an object and then looks back at you.
- Use a normal talking voice. Speak naturally.

Making it easier for your baby to listen:

- Bring your baby close to you. Always talk face-to-face.
- If your baby has hearing technology, be sure to use it consistently.
- Listen to your environment. You can make it quiet by turning off or moving away from sources of background noise such as TVs, fans, or blowers.
- Remember to keep your baby facing away from the light source. When your baby has bright light or sunshine in their face, it makes it harder for your baby to see you.
- Get down to your baby's level as often as possible and change your baby's position frequently.

Other Considerations:

- Keep good records of everything to do with your baby's hearing (medical records, notes, audiograms, etc.). Ask for copies when you take the baby to a provider. Put them in one notebook, box, or electronic file. Bring all of this information with you when you bring your child to a new doctor, audiologist, or specialist. You may also sign up for the online patient portal at your baby's provider's office whenever possible for easier access to records.
- Ask questions.
- Take advantage of opportunities to meet other families with children who are deaf/hard of hearing.
- Many families find it helpful to meet deaf/hard of hearing adults.
- If you want more information, contact one of the agencies listed in the back of this booklet. They are here to help you.

Communication and Language Options and Opportunities

Communicating with your child is very important. Two-way communication, responding to your child, and encouraging your child to respond to you and others is key to your child's language growth. There are many ways to communicate with your child. Some approaches focus on the use of hearing while others focus on the use of vision. Choosing an approach for your child and your family is like going on a journey and takes exploration. What works best for one family and child may not work for others. No one approach has been proven to be best for all children who are deaf or hard of hearing.

Children need language to learn. All communication and language approaches require lots of family involvement and a language rich environment. Your team of providers will work with you and your child to complete ongoing assessments to determine if your child is making good progress. Families are encouraged to think of this time as an on-going exploration as to what works for your child. Changes to your child's language and communication plan are common and may be necessary in the process of supporting your child's language development. The needs of your child and your family may change over time.

The following are some of the communication and language opportunities/approaches your family will learn about:

- **American Sign Language (ASL)**: ASL is a language that uses the hands, body, and facial expressions to communicate the same kinds of words and thoughts as spoken languages. It is the language used by the Deaf community. Children who have a strong first language base in ASL are better able to learn the natural spoken language of the family as a second language. If the family does not already know ASL, family training and practice are critical to learn the language.

- **Auditory Approaches/Listening and Spoken Language (LSL):** These methods focus on maximizing the use of residual hearing and hearing technology in order to learn the spoken language of the family. The child is encouraged to use listening to understand spoken language in their environment in order to communicate. Auditory skill development is built into the child's daily life, as are speech and language goals. There are two therapy approaches:

  - **The Auditory Oral (AO)** approach encourages the use of visuals as a supplement to listening, such as gestures and sign support.

  - **The Auditory Verbal (AV)** approach emphasizes listening, without visual support. Supplementary visual support may be added as needed.

- **Bilingual/Bimodal:** The Bilingual Bimodal approach supports the acquisition of both American Sign Language (ASL) and spoken language. "Bilingual" refers to the fluent use of both languages. This approach includes early access to visual language, while providing use of hearing technology for access to spoken language. The languages are kept separate, and not used simultaneously. The family prioritizes learning and using both ASL and spoken language throughout their day to day activities.

- **Cued Speech:** Cued speech is a visual system of eight hand shapes used in one of four positions around the face (called cues) that a speaker uses to clarify speech sounds and words that look alike or are not visible on the lips. Cued speech provides complete visual access to the sounds of spoken language, regardless of hearing levels, and is an effective tool for literacy development.

- **Manually Coded Language Systems:** Manually Coded Language Systems were developed to provide visual access to spoken English. Many families utilize Sign Supported Speech, which involves the addition of signs to support understanding of spoken language. Unlike ASL, manually coded systems use signs in English word order and may add certain signs to show the grammar of English.

- **Combined Communication and Language Approaches:** For some children using one communication approach is sufficient. For others, a combination of approaches is beneficial. Your child's providers will work with you to help you decide when more than one approach may be needed.

Financial Support

Child Development Services: Child Development Services (CDS) is the Lead Agency in the state of Maine that is responsible for providing Early Intervention (birth-2 years) and Special Education and Related Services (ages 3-5) per the Individuals with Disabilities Education Act (IDEA) under the supervision of the Maine Department of Education. CDS will help you find funding for Early Intervention Services. For more information and to find your local CDS agency contact:

Central Office, Augusta
207-624-6600
TTY: *Call 711* (Maine Relay)

Child Development Services
146 State House Station
Augusta, ME 04333

MaineCare: a free or low-cost health insurance program for Maine families with children. Many services are covered. There are eligibility requirements, such as income guidelines, but special rules may apply for children with disabling conditions. For more information contact:

Statewide Toll Free
1-800-977-6740 option 3 (Voice)
TTY: *Call 711* (Maine Relay)

Office of Medical Services
442 Civic Center Drive
Augusta, ME 04333-0011

Social Security & Supplemental Security Income Disability Programs:

(Sometimes called SSI and SSDI) are federal programs that provide assistance to children and adults with disabilities. There are eligibility requirements, such as income and medical guidelines. For more information contact:

Augusta Office
207-622-1451 (Voice)
Nationwide Toll Free
1-800-772-1213 (Voice)

Disability Determination Services
Department of Health & Human Services
330 Civic Center Drive
Augusta, ME 04330-8035

Statewide Family Support Agencies

Child Development Services (CDS) is the Lead Agency in the state of Maine that is responsible for providing Early Intervention (birth-2 years) and Special Education and Related Services (ages 3-5) per the Individuals with Disabilities Education Act (IDEA) under the supervision of the Maine Department of Education. Early Intervention is provided under Part C of IDEA using evidence-based services in the natural environment for infants and toddlers with developmental delays and disabilities and their families. The Early Intervention Team from the regional CDS site supports the family and other primary caregivers in increasing the child's engagement, independence, and social relationships within the context of everyday routines and activities. Special Education and Related Services are provided under Part B of IDEA and ensures that identified children receive a Free Appropriate Public Education (FAPE). Services are provided at no cost to the family.

Central Office, Augusta
207-624-6600
TTY: *Call 711* (Maine Relay)

Child Development Services
146 State House Station
Augusta, ME 04333

Guide By Your Side is a Hands & Voices program that gives families with children who are Deaf or hard of hearing the same support as the Maine Hands & Voices chapter but does this in an individualized, personal way. We understand the importance of parent-to-parent and Deaf/hard of hearing adult to parent support from someone who knows how if feels to raise a child who is Deaf or hard of hearing. We are here to celebrate the successes of our children and offer information, strategies and just be there to listen in times that may be challenging. We are here so no one has to feel alone on this journey to our kids becoming happy, well-adjusted, successful adults, whatever that looks like for your child.

mainehandv@gmail.com *https://bit.ly/mhv-gbys*

Early Intervention and Family Services (EIFS), a department of the Maine Educational Center for the Deaf and Hard of Hearing (MECDHH), focuses on supporting families with children who are deaf/hard of hearing or are suspected to be deaf/hard of hearing. In collaboration with CDS, EIFS supports families and professionals statewide to ensure optimal services for children who are deaf/hard of hearing and their families. EIFS provides comprehensive, unbiased information to support families in making informed decisions that match their values and priorities, and ensure supports are in place to help meet the family's goals. EIFS is available to families of deaf/hard of hearing children from birth until their third birthday. Services are provided at no cost to the family.

207-749-8133 (Voice)
207-449-1476 (VP)

Early Intervention & Family Services
1 Mackworth Island
Falmouth, ME 04105

The Maine Newborn Hearing Program (MNHP) is part of the Maine CDC, Department of Health and Human Services. The MNHP coordinates newborn hearing screening programs and follow-up of infants who are deaf/hard of hearing.

A parent packet with information about state and national resources, programs, websites, and publications is available by request without cost to families and providers. The MNHP Coordinator is available for resource and referral information. For more information contact:

207-287-5357 or
1-800-698-3624 (Voice)
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