

Resource Guide

For Families of Children with Hearing Loss

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



No baby is too young for
a hearing test...

Notes

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

1-800-606-0215 (TTY)

John Elias Baldacci
Governor



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Commissioner

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Dear Parents,

You have just found out that your baby has a hearing loss. You may have many questions.

This booklet may help answer some questions and give you some basic information about childhood hearing loss. We hope this information helps you and your family.

You still may have questions about your own child's hearing loss after reading this booklet. There are many resources in Maine that can help answer questions and offer support. One program, "Early Childhood and Family Services" (ECFS) is available to help all families who have children with hearing loss. A professional from this program can meet with you to answer your questions, provide information, and offer support. 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. This builds a solid foundation for communication.

Sincerely,
The Maine Newborn Hearing Program
Advisory Board Members



Childhood Hearing Loss

In Maine, 40 to 60 babies are born each year with a hearing loss. Hearing loss in infants happens more often than you would think.

Early identification is important. Children with hearing loss are more likely to develop normal language and communication skills with early diagnosis and support services.

Educating yourself about hearing loss, knowing its effects and the things you can do to help your baby is important. Each family member reacts in his/her own way when told their child has a hearing loss. Families may experience feelings of loss, sadness, and uncertainty. This is natural.

Some children with hearing loss may need extra help in the important early years of life. This extra help is called *early intervention*. Early intervention is any service or therapy that helps a child develop. Your audiologist and ECFS consultant can help you with technology, support, and information. Meeting other families who have children with a similar hearing loss may help you understand what can work best for your child and your family.

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 without hearing loss generally develop spoken language naturally. We also know that any degree of hearing loss can interfere with the easy development of spoken language. The bigger the hearing loss, the more help the baby needs.

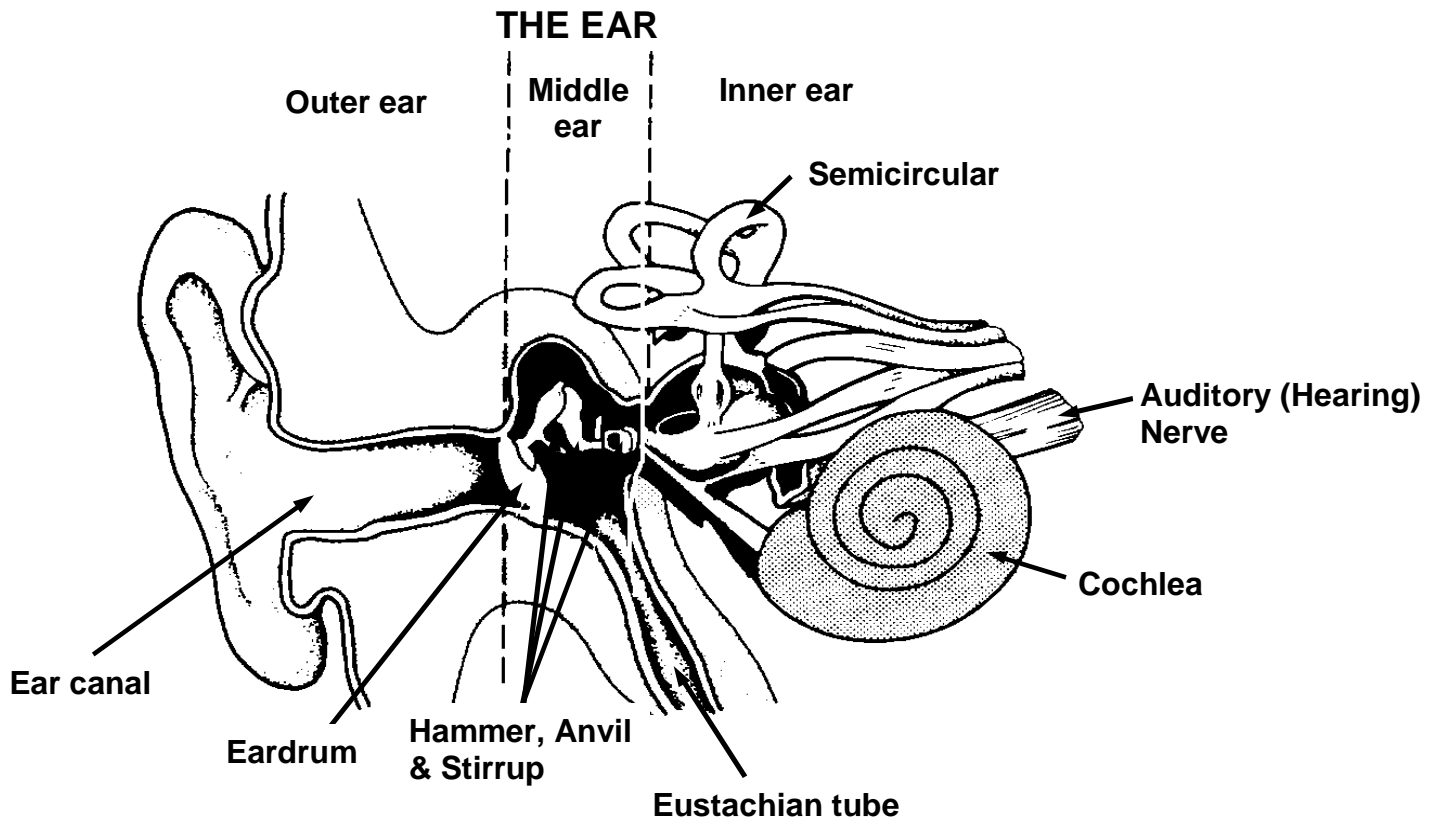
Communication and language grow out of relationships. Children learn best from adults and family members who talk with them and interact with them. Babies with hearing loss need their family to help them learn to communicate.

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 provide 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 child develops language.

Helpful hints are 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. 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.

Middle Ear:

There are three bones in the middle ear commonly called the **hammer, anvil, and stirrup**. 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 **hearing nerve**. The cochlea contains hair cells that respond to sound. The hearing nerve connects the cochlea to the brain.

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

Hearing Loss

You have been told that your child has a hearing loss. You will learn more about the hearing loss over time. Your audiologist may have talked about how sound may be heard with amplification (hearing aids). Your audiologist may have also talked with you about the “degree” of hearing loss, which means how loud a sound needs to be for your baby to hear it. The “degree” of hearing loss can range from mildly hard of hearing to profound deafness.

Some children have more than one cause or site of hearing loss. Some common sites of hearing loss are:

- **Conductive Hearing Loss**

This type of hearing loss is caused by a problem in the outer or middle ear. A conductive loss prevents sound from reaching the nerves in the inner ear. A child with a conductive hearing loss usually has difficulty with hearing soft sounds.

- **Sensorineural Hearing Loss**

This type of hearing loss is caused by damage to the nerves in the inner ear that prevents sounds from reaching the brain. A child with a sensorineural loss has difficulty hearing sounds clearly and hearing sounds that are not loud enough.

- **Mixed Hearing Loss**

This type of hearing loss is a combination of both conductive and sensorineural losses. An example of a mixed hearing loss is sensorineural loss *and* an additional temporary conductive loss due to an ear infection or fluid in the middle ear.

- **Auditory Neuropathy / Auditory Dys-synchrony**

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.



Hearing Tests for Infants and Young Children

Preparing for Testing

Talk with your audiologist before you go so your baby is prepared for the specific tests to be done. **Some** of the tests require the baby to be asleep or quiet and calm, while others require an awake and cooperative baby. Bring extra diapers, a blanket and anything that will help your baby be more comfortable and calm during the testing.

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: This is a simple test where 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.

Tympanometry: This test is used to find out how well the middle ear is working. 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. There may be just a slight feeling of pressure in the ear. Some babies may fuss when they feel this pressure.

Otoacoustic Emissions (OAE): In an OAE test, 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. It is necessary for the baby to be quiet and calm for this test to be completed.

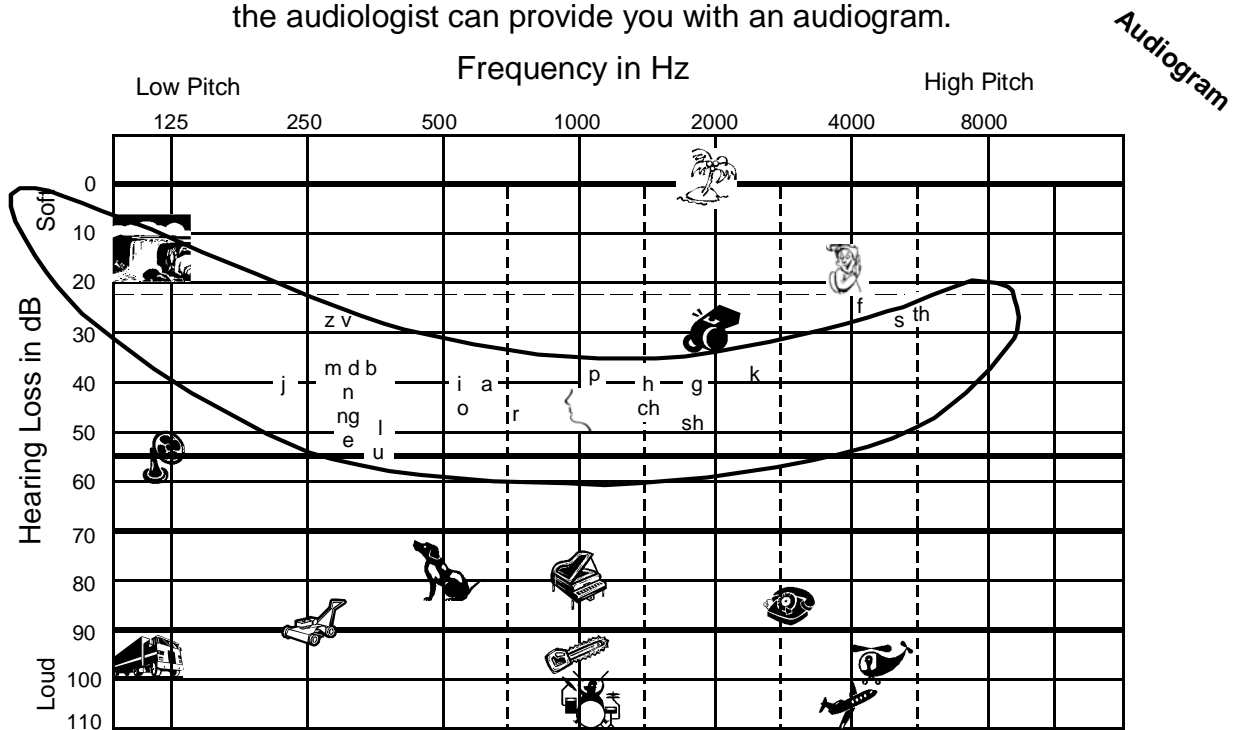
Auditory Brainstem Response (ABR): This test measures the baby's brainwave activity in response to sounds. Small sensors are put on the baby's head and earphones are placed over the baby's ears. Different sounds are sent through the earphones. A computer measures and analyzes the baby's electrical brain response to the different sounds. Some different types of ABR testing are Tone Pip and Auditory Steady State Response (ASSR). The baby must be asleep for this type of testing to be accurate. Natural sleep is preferred, however, sedation is used at times.

Visual Reinforcement Audiometry (VRA): In this test, the baby is taught to respond to sound by turning to a lighted animated toy. The test can be done with the sound coming through earphones, speakers or through hearing aids. It gives information about the degree of hearing loss for tones and for speech. The results of this test are highly accurate. This test is generally fun for the baby. He/she needs to be awake and alert.

Medical Evaluation: An otolaryngologist (ENT) is a special doctor who works with your baby's doctor, audiologist and possibly a genetics doctor to determine the possible cause of the hearing loss. Together, they will work to make recommendations for more testing, treatment and hearing aids, if needed. The ENT examines the baby's head, neck and ears and asks about your family's and baby's medical history. The ENT must give medical clearance before hearing aids can be issued.

The Audiogram

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



The audiogram tells what your child can hear. The numbers across the top of the chart show pitch - how high (treble) or low (bass) a sound is. The numbers on the side show volume - how soft or loud a sound is.

Pictures on the audiogram represent the sounds objects make. For example, the tree represents the high, soft sound of wind and the lawnmower represents the low, loud sound of a lawnmower engine.

The shape that looks like a banana is often called the “speech banana.” People with normal hearing can hear the sounds shown by the letters and pictures in the “speech banana.”

After testing your baby’s hearing, the audiologist marks X’s and O’s on the chart. The X is used for the left ear and the O is used for the right ear. The audiologist looks at the pattern of the X and O marks and determines the level of your baby’s hearing. Your baby will usually be able to hear the sounds **below** the X and O marks.

Levels of Hearing Loss

As your child’s hearing is plotted on the audiogram, the audiologist determines your child’s hearing loss by matching it to one of the following general categories:

Category	Level
Hearing within normal limits:	0—15 dB HL
Slight Hearing Loss:	16—25 dB HL
Mild Hearing Loss:	26—40 dB HL
Moderate Hearing Loss:	41—55 dB HL
Moderately-Severe Hearing Loss:	56—70 dB HL
Severe Hearing Loss:	71—90 dB HL
Profound Hearing Loss:	91 dB HL or greater

Amplification Choices

Amplification describes the way sound is made louder for your child. Some of the choices are described below.

Hearing Aids

When a baby is found to have a hearing loss, audiologists often recommend hearing aids. Hearing aids can be used by tiny babies. Hearing aids make sounds louder but they do not provide normal hearing. The audiologist will recommend a hearing aid that matches your baby's hearing loss.

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.

FM Systems

An FM system has two parts, a microphone that the talker wears and a receiver that the baby wears. The FM system is designed to amplify the talker's voice so that it is louder than any competing background noise. It makes the speech "close," as if the talker were right next to the baby. This is useful when your baby begins to play at a distance, at home, at daycare, or at preschool.

Cochlear Implants

Cochlear implants are mostly used by people with severe to profound hearing loss. The implant, which involves surgery, works in the inner ear. Usually, cochlear implants are not recommended for children younger than 12 months of age. Your audiologist and health care provider can give you more information.

Using the Amplification

Your baby's amplification is special for him/her. It is custom fit and adjusted for his/her specific hearing loss. It must be worn as recommended by your audiologist. It is difficult for a baby to learn to listen, but learning to listen comes before learning to talk. Help your baby use the amplification consistently and allow many good opportunities to listen. Try to keep the room quiet so that your voice is not lost in noise. You should talk with your baby face-to-face. For example, play on the floor so the baby does not have to look up to see your face.

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 amplification 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 responding behaviors, so remember to share what you notice with your audiologist at each appointment. This will help them make the best adjustments to your baby's hearing system and to help him/her learn to listen.



Communicating with Your Baby

Talking to your baby:

- Hold, touch, rock, gesture, sing, and play with your baby.
- Read aloud to 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 he/she is born. Tell your baby what you are doing. Your baby was born ready to communicate.
- 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 amplification, be sure to use it consistently.
- Listen to your environment. You can make it quiet by moving away from background noises such as TV's, fans or blowers.
- Lighting is also important. Remember to keep your baby facing away from the light source. When your baby has bright light or sunshine in his/her face, it makes it harder for your baby to see you.
- Playing on the floor is important. All babies need time to play on their tummies. A baby with hearing loss may cry more on their tummy if they cannot see you. Get down to your baby's level as often as possible and change your baby's position frequently.

Words of Advice:

- Keep good records of everything to do with your baby's hearing loss (medical records, notes, audiograms, etc.). Ask for copies when you take the baby to a provider. Put them in one notebook or box. Bring all of this information with you when you bring your child to a new doctor, audiologist or specialist.
- Ask questions.
- Meet other families who share your concerns about babies and children with hearing loss.

If you want more information, contact one of the agencies listed in the back of this booklet. They are here to help you.

Communication Methods

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 methods focus on the use of hearing while others focus on the use of vision. Choosing a method for your child and your family takes time and thought. What works best for one family and child may not work for others. No one method has been proven to be best for all children with hearing loss.

When you begin thinking about what methods might work best for you and your child, you need to consider what kind of hearing loss your child has.

Children with a mild to moderately-severe hearing loss usually learn the spoken language that is natural to their family with some "supports." These supports might include using hearing aids, speech reading (also called "lip reading"), and some extra help from speech and language professionals.

Children with a severe or profound hearing loss may learn language in different ways depending on the methods used. Professionals will work with you to help you decide what might work best for your child. Some families choose to follow just one method while other families combine methods. What choices you make depend on your child and your family.

A good way to decide what will work best for your child and family is to be open about all the modes. Learn as much as you can about how children learn language and how you can best help your child. Ask questions; talk with adults who are Deaf and Hard of Hearing and other families with children who have a hearing loss. Discuss and read as much information as you can about the different methods. The first method you choose is not final. It is important for families to be flexible and open-minded about their choices. The needs of the child and the family may change over time.

The following communication modes are some of the choices you may 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. Children who have a strong first language base in ASL are better able to learn English or the natural language of the family, as a second language. Some children who receive cochlear implants may learn ASL as a first communication mode prior to implant and may keep signing as a second language. If the family does not already know ASL, training and practice are needed to learn the language.

AUDITORY ORAL (AO): This method focuses on maximizing hearing, using cochlear implants or hearing aids, in order to learn the spoken language that is natural to the family. Auditory skill development is built into the child's daily life, as are speech and language goals. Visual supports, such as speech reading, are encouraged as a supplement to listening. Signing is not used. Children may attend a specialized preschool to learn to listen and speak with other children with hearing loss.

AUDITORY VERBAL (AV): This method focuses on maximizing hearing, using cochlear implants or hearing aids, in order to learn the spoken language that is natural to the family. Use of visual supports, such as speech reading, are not encouraged during therapy sessions in order to strengthen the auditory parts of the child's brain. This encourages the child to "listen" in order to communicate. Families are actively involved in sessions. Attending mainstream preschools as early as possible is encouraged.

CUED SPEECH: This is a visual method that helps children learn the natural language of the family. It is a system of hand shapes and movements called cues that are used with speech reading. Since many spoken words look exactly alike on the lips, cues help clarify the spoken sounds and words. Cued speech can be learned through classes taught by trained teachers or therapists.

SIGNED ENGLISH: This method uses signing to produce "English on the hands". Unlike ASL, Signed English uses signs in English word order and adds special signs to show the grammar of English.

TOTAL COMMUNICATION (TC): This method uses many modes of communication. Total communication uses ASL, finger spelling (spelling out words on the hands), speaking, speech reading, and the use of any hearing the child has. TC often uses simultaneous communication or "sim com" in which the person speaks in English and uses signs in English word order at the same time.

It is important to check your child's progress often. It is okay to make a change in the communication method if your child isn't learning language. Professionals will work with you and your child to make sure your child is learning to communicate well.

Financial Support

The agencies listed below may help your family with the extra expense related to your child's hearing loss.

Child Development Services:

The Child Development Service (CDS) System is a part of the Department of Education. CDS is a statewide network of regional sites that ensures the coordination and delivery of early intervention services, special education and related services for eligible children (birth to school age five) with developmental delays and/or disabilities. Each regional site can provide information specific to the local area. CDS will help you find funding for Early Intervention Services. For more information and to find your local CDS agency contact:

**Central Office, Augusta: 207-624-6660 (Voice)
1-888-577-6690 (TTY)**

Child Development Services
146 State House Station
Burton Cross State Office Building, 5th Floor
Augusta, ME 04333

MaineCare:

MaineCare is 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)
1-800-977-6741 (TTY)**

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

The Child Development System (CDS) is a part of the Department of Education. CDS is a statewide network of regional sites that ensures the coordination and delivery of early intervention services, special education and related services for eligible children (birth to school age five) with developmental delays and/or disabilities. Each regional site can provide information specific to the local area. Early intervention, special education, and related services are provided to eligible children. For more information and to find your local CDS agency contact:

Central Office, Augusta: 207-624-6660 (Voice) Child Development Services
1-888-577-6690(TTY) 146 State House Station
Burton Cross State Office Building, 5th Floor
Augusta, ME 04333

Early Childhood and Family Services

Statewide Educational Services (SES), a division of the Maine Educational Center for the Deaf and Hard of Hearing offers support through its Early Childhood and Family Services (ECFS) program to children newborn to five years of age who are deaf, hard of hearing, or have a suspected hearing loss. ECFS is a state-funded, independent agency providing information, support and training to families and professionals throughout Maine. Their services include home visits and are provided without cost to families. For more information contact:

Statewide Toll Free: 1-866-231-8910 (Voice) Early Childhood Family Services
(207) 781-6335 (Voice) Mackworth Island
Falmouth, ME 04105

Maine Newborn Hearing Program

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 with hearing loss.

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) Maine Newborn Hearing Program
1-800-606-0215 (TTY) Key Bank Plaza, 7th Floor
286 Water Street
Augusta, ME 04333-0011