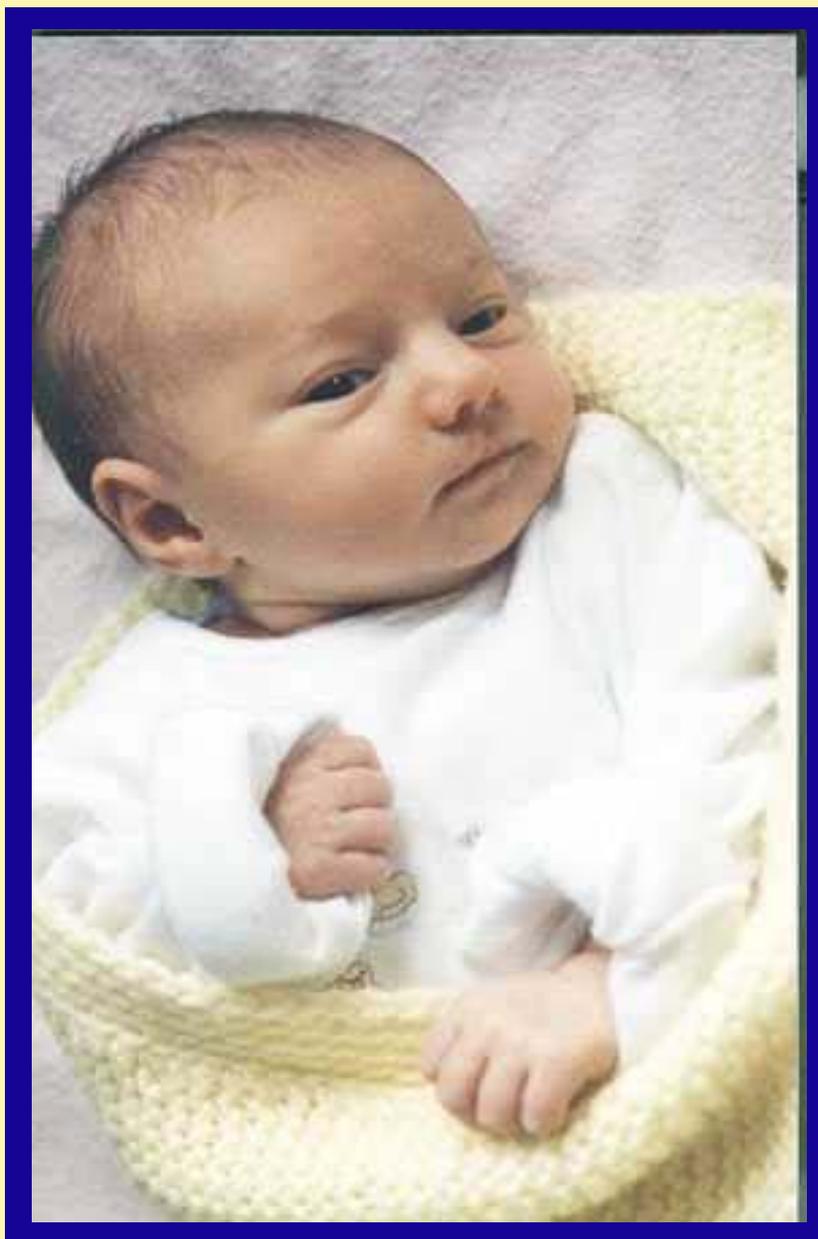


A Parent's Guide for Infants & Children with Hearing Loss



**Maine Newborn Hearing Program
Bureau of Health, Division of Family Health
Maine Department of Health and Human Services**

Dear Parents,

This notebook is designed to give the same clear and accurate information to the families in Maine who have just found out that their infant or young child is deaf or hard-of-hearing. We hope families will use this resource to find out about the professionals and people who are available for support and information.

This resource was created through the dedication, enthusiasm, and hard work of the Maine Newborn Hearing Program Advisory Board. The people who worked on this notebook include parents who have a deaf or hard-of-hearing child, professionals who work with deaf and hard-of-hearing infants and children, and Deaf and hard-of-hearing people.

We hope this notebook will help guide you and your family as you begin your journey towards understanding your baby's hearing loss. We have included a lot of information and we tried to keep it as easy to read as possible. Even though you may not read all of it right away, keep this notebook handy and refer to it as you need it.

A program in Maine, "Early Childhood and Family Services" is available to meet with you if you have questions or want more information. Their contact information is on page 86.

We are very interested in what you think. We would like to know what was helpful and what could be changed to make it more helpful. We have included a feedback form at the end of the notebook. Please send it back to us or contact us at:

Maine Newborn Hearing Program
Bureau of Health, Division of Family Health
Maine Department of Health and Human Services
11 State House Station
Augusta, Maine 04333

Telephone: (207) 287-5357 OR 1-800-698-3624 (Voice)
(207) 287-8015 OR 1-800-438-5514 (TTY)

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FAMILY
STORIES
CELEBRATING
CHILDREN



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

- *Please see page 59 for description of an FM system*

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.



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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.

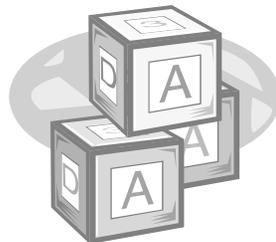
Is our daughter cured? No. There is no magical cure for deafness. Although she has learned to listen and speak utilizing a cochlear implant, she is unable to hear when she removes her processor for bath time, bedtime and swimming activities. In addition, if any component of her cochlear implant fails, 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. If you need someone to talk about it, please do not hesitate to contact us.

Phone: (207) 827-8696 E-mail: shayden742@yahoo.com

Scott, Lori and Jessica Hayden



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.

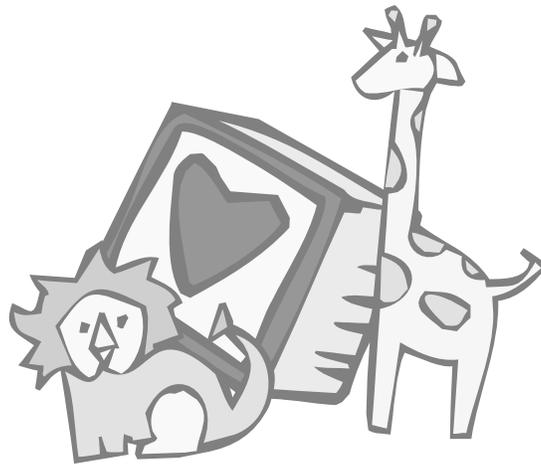
My family is now complete, two deaf sons and two hearing daughters. I am so fortunate and I tell them that every day. We now have a bilingual and bicultural home. This simply means that we respect two languages and two cultures in our home. We try to balance our home very carefully so that everyone's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





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 Baxter School have had such a tremendous impact on our lives. Child Development System, Baxter 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 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

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 whomever 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, main stream preschool two days a week, speech two times per week and sign language two times per week.

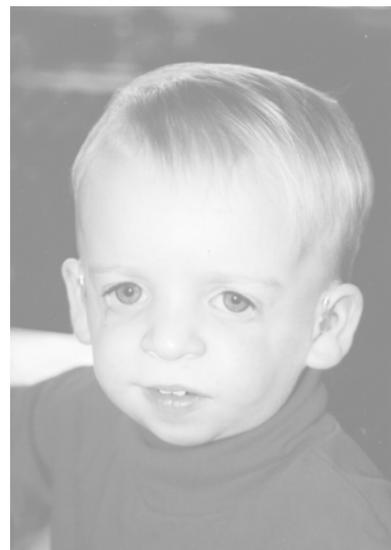
She is talking wonderfully and is the happiest kid around. We've made adjustments to her programs as her frustration has built and she's learned to tell us what she needs.

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





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. & Ricky W. Jamieson, Sr.

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.



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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

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.

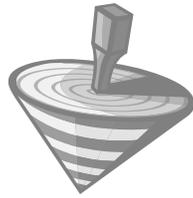
We found out that meningitis had taken our daughter's hearing. We were faced with a challenge and a future we were not expecting. Today she is a 22 year old living happily and independently as a college student.

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



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?

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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.

Please feel free to contact us: nvick@earthlink.net 207-829-2171

Gregg and Tina Novick



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.

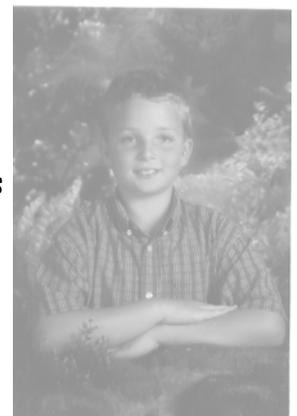
We chose Cued Speech as a communication mode for Ryan. Ryan has a full time Cued Speech Transliterator at school. At home and outside of school, he uses what hearing he has, lip-reading and some cues to understand what is being said to him. He wears his hearing aids all the time and loves them - they're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

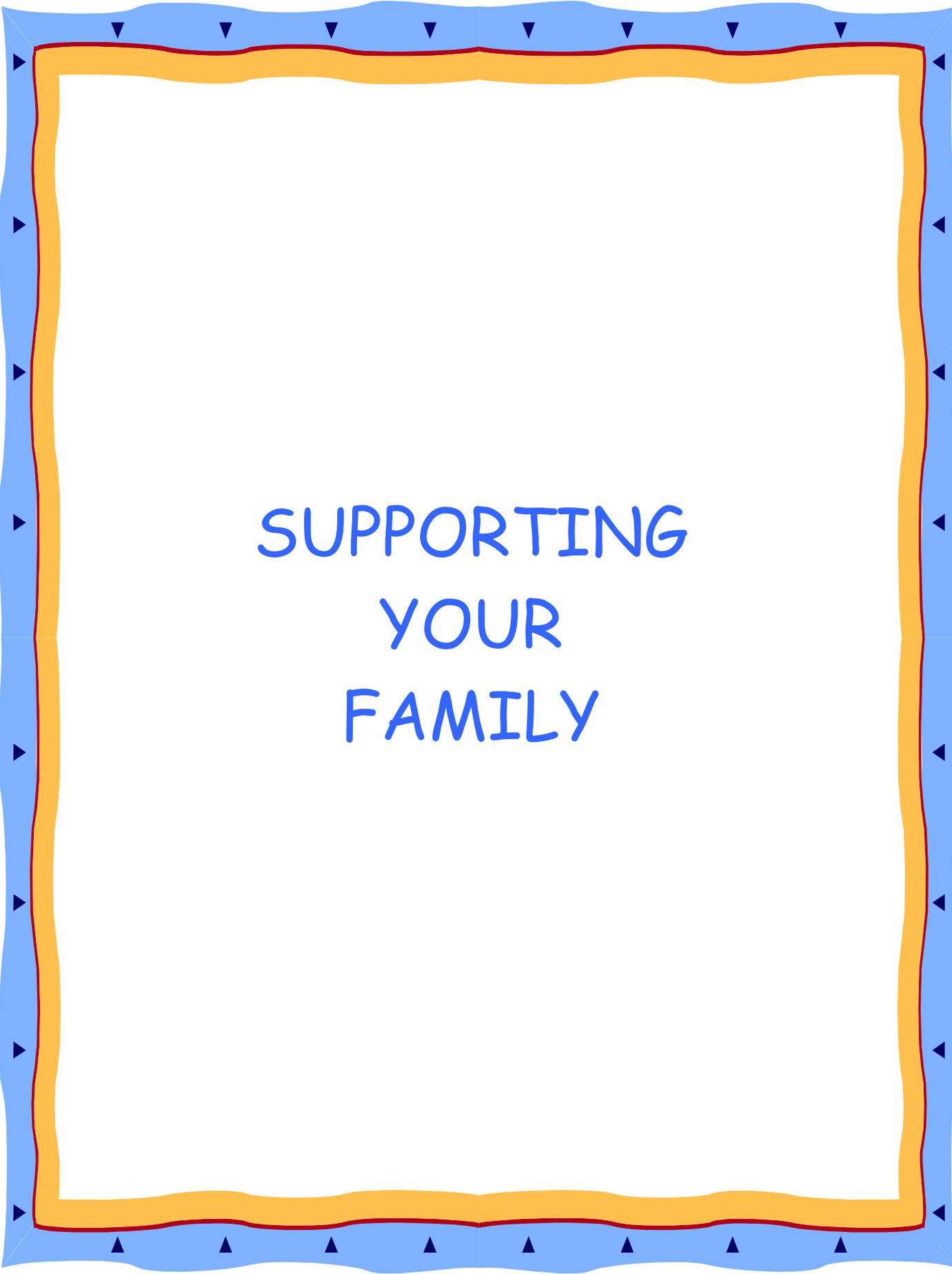
Ryan has been mainstreamed since preschool. He is going into the 5th grade this September and he is on or above grade level in all subjects. He has a wonderful group of peers (all of whom are hearing) that understand his hearing loss and respect him. Ryan is a great advocate for himself, explaining that 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 & Jeff Banger





SUPPORTING
YOUR
FAMILY



Acceptance

If you are like most parents of children with hearing loss, you probably did not know much about hearing loss before you were told your child was deaf or hard-of-hearing. 90% of children who are found to be deaf or hard-of-hearing are born to parents who have normal hearing.

It is normal for parents of a child with hearing loss to experience a period of adjustment. During this period of time, your feelings may be up and down.

It is natural to feel many emotions when you first find out your child has a hearing loss. These feelings may include shock, fear, sadness, confusion, anger, guilt, relief and disbelief. Many parents find that these emotions return at each new stage of their child's development, so that adjusting to their child's hearing loss is a continuing process.

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 will be taking on roles that you may never have 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.

It is important to be open about hearing loss. Promote education of deafness for your family and community. This will lead to acceptance.

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:

- Recognizing and sharing feelings 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
- 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 coped with similar experiences will help you learn more about the joys and challenges of parenting a child with hearing loss.
- Develop a support network and seek professionals who will provide honest and unbiased information and support you as you decide what will work 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 will help you get a fresh view of a situation and allow you to cope better.

For some people, feelings of frustration, helplessness and disbelief do not get better with time, but even seem to get worse. If this seems to be happening to you or a family member, it is important to seek outside support such as a mental health provider, a support group or clergy.

If you feel you or a family member needs immediate help, you can call the Crisis Hotline at 1-888-568-1122 (Voice/TTY) . A trained counselor will help you find the services you or a family member needs.

Your Family

The child's grandparents, brothers and sisters, extended family and community members will also experience a period of adjustment. Each person reacts differently and will need 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 baby is not "normal" or appear afraid of your baby's hearing loss.
- Feelings of sadness because your baby 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 relief. If other family members are deaf/Deaf, they may be comfortable, familiar and even happy about deafness. And feelings of relief can happen when the hearing loss has finally been identified because then family members can start learning about hearing loss and how to help.
- 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 baby.



Brothers and Sisters

Brothers and sisters may also need time to adjust. They will want to know about what it means to have a new family member with hearing loss and how this will affect them. They may have extra questions as they try to adjust to hearing loss as well as having a new brother or sister. As a parent, it is important to know that much time and energy will be spent dealing with the hearing loss.

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 brother or sister'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.

These experiences can be challenging. At the same time, with support and information, the brother or sister of a deaf or hard of hearing child can gain powerful skills and understanding.

When they 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.



Recognizing and talking about the feelings and attitudes of brothers and sisters toward the child with hearing loss will help them adjust and cope.

Here are some tips that can help:

- 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 the 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.



Grandparents

(The following section was adapted from Wisconsin's Family Guide "Babies and Hearing Loss".)
(Included with permission from Connie Stevens, parent of a deaf child with Down Syndrome)

Grandparents often have added worries. Their concern will not be just for the child who is deaf or hard of hearing, but for their own son or daughter and his or her husband, wife or partner and for any other grandchildren in the family. They may worry about what their responsibilities will be to the child and their family. They may want to help but may not know how.

You may want to invite the grandparents to therapy sessions, appointments or to family training. This will help them feel more involved and informed.

Helping grandparents to learn what they can do to help you and their new grandchild will help them to stay connected to their new grandchild and to have an open mind about their grandchild's hearing loss.





Who Will Help Us?

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

"How much does my baby hear?"

"Why does my baby have a hearing loss?"

"Can we fix the hearing loss?"

"What does the audiogram (hearing test) mean?"

"Will she be able to talk? Or do we have to learn sign?"

"How will this change our life?"

Who can help answer your questions?

You will be meeting 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 will be 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.

Different people have different roles and sometimes their information may conflict with each other and cause more confusion. Give yourself time to make decisions that feel right for you and your family as you begin your journey with your baby.

Some of the people you may meet on this journey are:

Audiologists.

The Audiologist will:

- Have the skills and equipment to test your baby's hearing, diagnose hearing loss and explain the test results using words you can understand.
- Recommend and fit hearing aids or other equipment to help your baby hear better and teach you how the equipment works.
- Discuss other equipment that might help your baby hear better (cochlear implant, FM system).
- Teach you about ways to help your baby develop his listening skills.
- Work with you and your baby through ongoing testing to make sure that the hearing aids are working well.

Doctors (Otolaryngologist or Ear, Nose, Throat (ENT))

The ENT Doctor will:

- Diagnose any medical problems with your baby's ears.
- Suggest possible treatments relating to your baby's ears/hearing, such as, putting in ventilation tubes if your baby has chronic middle ear infections.
- Provide medical clearance for hearing aids if recommended.
- Help you connect with audiologists or other professionals.

Early Childhood and Family Services (ECFS) Consultants.

ECFS will:

- Answer your questions about how your baby's hearing loss affects communication, participation in family activities, and learning.
- Give you basic information about hearing loss in everyday language.
- Suggest helpful tips from other families raising a baby with hearing loss.
- Suggest ways to help your baby learn about what is happening around him.
- Help you learn about communication options.
- Reinforce what you learned from your audiologist about your baby's hearing aids.
- Help other people in your baby's life understand his hearing loss (Grandparents, cousins, friends, and day care providers).
- Help you connect with other supports, such as communication therapists, counselors, and other parents of children with hearing loss.

Child Development Services (CDS)

CDS will:

- Help you keep track of all the different people working with you and your baby ("case management").
- Help you and your family plan what services you need with an Individualized Family Service Plan (IFSP). Please see more information about the IFSP on pages 28 through 38.
- Help you find the money to pay for hearing aids, FM systems, and other equipment.
- Help you understand your baby's development.

Therapists (Speech Therapists, Sign Language Specialists, Occupational Therapists, Developmental Therapists, Physical Therapists).

Depending on your child's needs, the therapists will:

- Make sure your baby is developing her skills at the right speed (spoken language, signing, cognitive and motor skills).
- Explain where your baby's skills may need some help and show you how to help your baby during everyday play.
- Help your baby learn to pay attention to language.
- Help your baby learn to speak or sign.

Counselors (Social Workers and Psychologists).

Counselors can:

- Listen to you and other family members as they sort through their feelings about having a baby with hearing loss.
- Help family members develop new 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.

Other Parents of Children Who are Deaf or Hard of Hearing

Other parents can:

- Share their stories. What did they experience and what should you expect?
- Share people, resources, and helpful hints that have 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

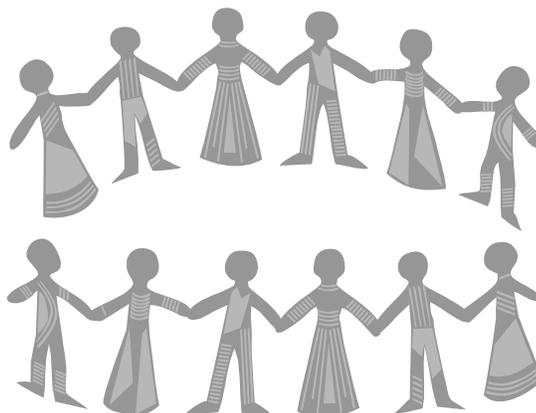
Deaf or Hard-of-Hearing people can:

- Share their life stories.
- Be a role model.
- Be a language model.

“Supportive People”

Supportive people can be friends, grandparents, ministers, rabbis, and they can:

- Lend an ear when you need to talk.
- Share a shoulder to lean on, a hug, a joke, a smile, laughter and sometimes tears.
- Come into your home for an hour to give you time for yourself.
- Let brothers and sisters talk about their feelings and emotions with someone who is not Mom or Dad.
- Give brothers and sisters special time.



As soon as possible after you have found out that your baby is deaf or hard of hearing, a plan should be developed to help your baby and family get the support and early intervention that is needed. An agency called Child Development Service (CDS) will work with your family to make sure you get the services you need.

Child Development Services & The Individualized Family Service Plan (IFSP)

CDS is a part of the Department of Education. There are 17 sites located all over Maine that serve a local area. The Child Development Service System coordinates early intervention services, special education and related services for eligible children (birth to school age five) with developmental delays and/or disabilities.

Services that CDS may help coordinate could include special help such as, speech therapy, developmental therapy, physical therapy, occupational therapy, ongoing audiological evaluation and other related services.

In Maine, the Child Development Service System (CDS) works with families to develop the Individualized Family Service Plan (also called IFSP). The IFSP is a team developed, written plan for children between the ages of birth to five with developmental disabilities and their families. Here are the steps in the IFSP process:

- After your baby is referred to your local CDS agency, a CDS worker will contact you to set up a comprehensive screening of your baby's development. Your CDS worker will review the screening results with you and explain how your baby's development compares to other babies of the same age.

- Sometimes, more evaluations/testing are needed to find out more about your baby's development. Your CDS worker will work with you to set up any recommended evaluations/ testing.
- After all evaluations and testing are completed, your CDS worker will set up a meeting called an Early Childhood Team (ECT) meeting. At this meeting, the team will discuss the results of any evaluations/testing. If the results of the evaluations/testing show a developmental delay and it is decided that the child needs early intervention, then the Individual Family Service Plan (IFSP) will be developed.
- The IFSP will include the strengths and needs of your child and family. The plan will identify the supports and services that will be needed meet the developmental needs of your child and any support services the family may need.
- After the first IFSP is developed, the team will meet periodically to review it and make sure your baby and family are getting the support you need and make any needed changes to the plan.

Some of the agencies may use a document known as an Individualized Education Plan (IEP) for children ages 3 to school age 5. The IEP looks a little different and has a different focus than the IFSP. Your local CDS agency will provide you with information so that you can discuss which form will best meet the needs of your child.

The Individualized Family Service Plan (IFSP)

Each local agency may develop their own paper and record keeping forms to document the IFSP. However, all CDS agencies in Maine must include the following things in the IFSP:

- A statement of the family's resources, priorities and concerns about helping the development of their child (included with parent's permission).
- A statement of the major goals expected for the child's development.
- What procedures or criteria will be used to measure the child's developmental progress.
- How often the child's developmental progress will be evaluated.
- The specific intervention services that will be used to address the identified needs.
- How much and how often the child will receive services.

The following pages (31 through 38) are a sample of what an IFSP looks like.



**Each regional site can provide information specific to the local area. Please see the listing of the CDS sites in the appendix on page 115 to find your local agency.*

Maine Individualized Family Service Plan

Today's Date: _____

For Office Use Only

1. General Information

Child's Name: _____ DOB: _____ M / F Date of Referral: _____

SS# _____ CDS ID# _____ Medicaid: Yes No

Parent/Foster Parent(s): _____ Guardian: _____

Mailing Address: _____

Town of Residence _____

Telephone: (H) _____ (W) _____

Administrative Case Manager (through Childfind) or Site Contact: _____ Telephone: _____

Service Coordinator assigned ECT: _____ Telephone: _____

Primary Health Care Provider: _____

Eligibility Criteria: _____ Diagnosis: _____

6 Month Review Date: _____ Annual Review Date: _____

90 Days prior to 3rd Birthday: _____ Other: _____

4. Description of Child Strengths and Concerns

(Please address present level of functioning in each domain)

Levels of Functioning	Documentation
Cognitive: Physical: (Vision, Hearing, Health) Gross Motor Fine Motor Communication: Expressive Receptive Articulation Pragmatics Social/ Emotional: Adaptive: (Self-Help)	

Strengths: _____

Significant health factors which may be affecting this child's development:

5. Family(s) Concerns	Resources/Strengths	Needs
Please Prioritize	Family's ability to help in area of disability	Resources needed by family to continue helping child

Maine Individualized Family Service Plan

<u>6. Outcomes/Goals</u>	Major Outcomes/Annual Goals Expected*	Procedure or Instrument to Evaluate Progress	Expected Date of Completion
I. Outcome/Goal:	Objectives (Criteria for achieving outcomes):		
II. Outcome/Goal:			
Objectives:			
III. Outcome/Goal:			
Objectives:			
IV. Outcome/Goal:			
Objectives:			

* Outcomes are statements written in everyday language

Maine Individualized Family Service Plan

7. Early Intervention Services:

Meeting the Unique Needs of the Child/Family to Achieve the Identified Outcomes

Intervention Services	Method of Service	Provider	Location	Frequency	Intensity	Start Date	End Date	Method of Payment

8. Least Restrictive Environment The natural environment in which the recommended services will be provided given the age of the child. This environment is, to the extent appropriate to the child's needs, one in which children without disabilities would participate.

9. Transition Planning:

PHP:	Y/N
Medical:	Y/N
Dental:	Y/N

Early Intervention Certification Signature: _____ Date: _____

10. Other Services— Not Required under IDEA

Services	Steps to Secure Services Through Public and Private Resources

Maine Individualized Family Service Plan

11. **Financial Resources:** Resources that may be used to support the services specified in this plan

Medicaid: _____ Katie Beckett# _____

If Prime Care, P.A. needed from _____

SSI# _____

DMCH/Coordinated Care Services# _____

BCSN/Wrap Around Funds# _____

Private Insurance:

Company Name: _____ Policy #: _____

Telephone: _____

Policy Holder's Name: _____

Policy Holder's SS #: _____ Policy Group #: _____

My rights concerning use of third party financing for my child's services have been explained to me in writing.

I authorize _____ do not authorize _____ the use of the financial resources information to access third party payment.

Parent/Guardian Signature

Date

SLIDING FEE SCALE (For children ages Birth through 2)

I have been provided with a written explanation of the Department of Education Policies and Procedures related to payment for Services to Children Birth through Two. My parent contribution has been set at _____ per fiscal year for early intervention services documented in this plan.

Parent/Guardian Signature

Date

I have read this plan. I approve of this service plan for my child and family.

Parent/Guardian Signature

Date

I do not approve of this service plan for my child and family and request the following:

_____ Another ECT _____ Evaluation

Comments:

I have received in writing, an explanation of my legal rights, including my right to an independent evaluation, to be notified of any meetings regarding my child, to have access to my child's record and to request that inaccurate information be deleted, to give written permission for information on my child to be given to other agencies or therapists, to transition activities when my child becomes age three and/or five, to make a complaint regarding my rights under the Americans with Disabilities Act and to make a complaint to CDS or to the Department of Education regarding my child's services.

Parent/Guardian Signature

Date

Maine Individualized Family Service Plan

Physician Approval (Needed for Medicaid)

Child's Name: _____

D.O.B.: _____

I have read the Individualized Family Service Plan for this child, and as of _____
(IFSP/Amendment Date)

I authorize, with signature below, provision of these services, per plan, as a medical necessity.

Primary Health Care Provider/ Physician Signature

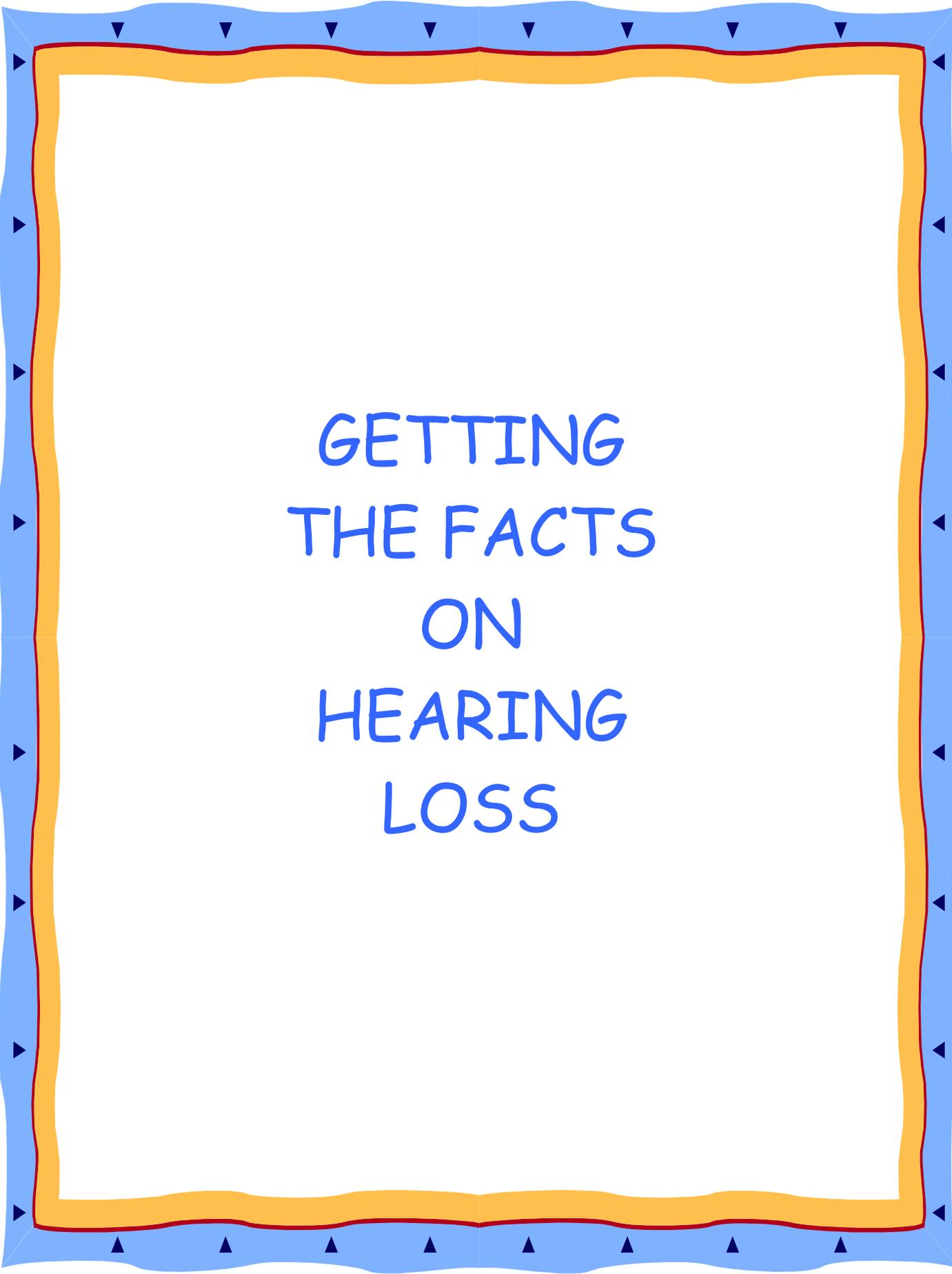
Date

Primary Health Care Provider/ Physician Signature **TYPED**

Comments:

Please return this form to the address listed below as soon as it is signed. Thank You.

C/O:



GETTING
THE FACTS
ON
HEARING
LOSS



Getting the Facts

Trying to understand a medical diagnosis of any kind can be very overwhelming. Professionals will talk with you about this information, and you may read about it. You may feel that you cannot understand or remember much of what you have been told. This is a common experience. It takes time to learn new information.

It is O.K. if you do not understand something. Please ask the professional that you are working with to explain it another way. You can ask them to explain it, as many times as is necessary for you to feel comfortable with the new information.

In this section of the notebook, you will find information that will help you better understand the ear, the types of hearing loss, the types of tests used to diagnose hearing loss, and assistive technology.

Description of the Ear

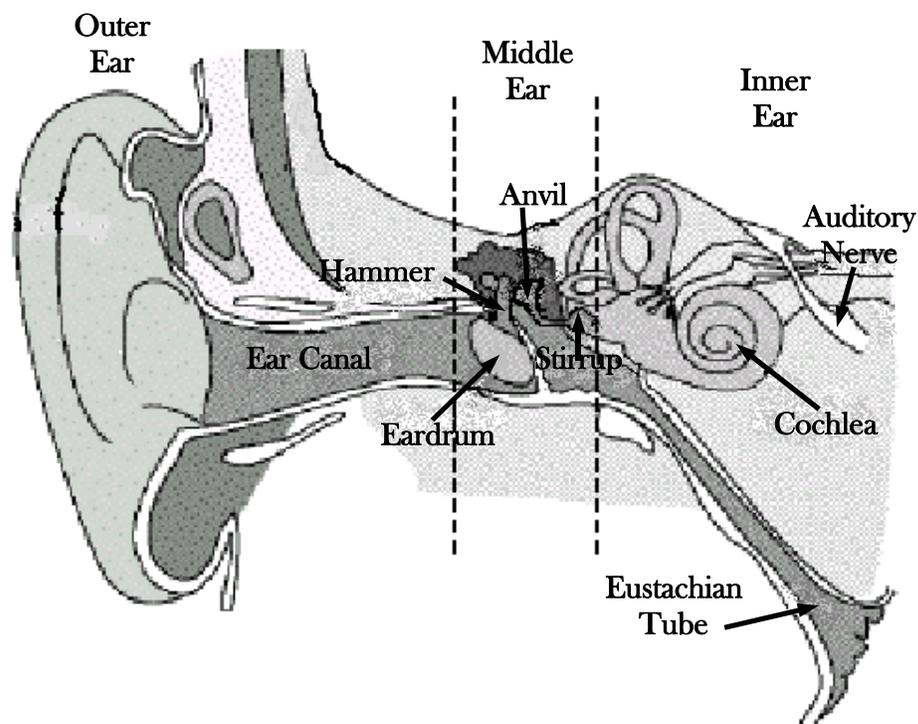
The ear is divided into three main sections: **the outer ear**, **the middle ear** and **the inner ear**. Sound passes through all three sections of the ear before it goes to the brain. The brain interprets the sound and tells us what we are hearing. It tell us if we are hearing music, noise, a voice, a car horn, a dog, or other sounds.

Sounds go into the **outer ear**. The part of the outer ear that we can see is called the pinna. It catches sound which travels from the pinna through 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 three sections of the ear work together to help us hear.



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 the loss occurs in the ear and include:

- **Conductive Hearing Loss**
- **Sensorineural Hearing Loss**
- **Mixed Hearing Loss**
- **Auditory Neuropathy/ Auditory Dys-synchrony**

- **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. Conductive hearing loss may be caused by :

- Fluid in the middle ear
- Problems with 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, sometimes referred to as nerve deafness, can occur if inner ear structures do not work correctly. 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 given in the Neonatal Intensive Care Unit
- 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, which will allow access to sound with amplification with hearing aids.

- **Mixed Hearing Loss**

Mixed hearing loss occurs in both the outer/middle ear and in the inner ear. It is a combination of both conductive and sensorineural hearing losses. An example of a mixed hearing loss would be a person with sensorineural loss and a temporary conductive loss due to an ear infection or fluid in the middle ear.

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

Auditory Neuropathy/ Auditory Dys-synchrony occurs when hearing is interrupted after it is picked up by the middle ear and the cochlea. The cochlea can detect sound but there is a "bad connection" to the auditory nerve which prevents the information from being sent to the brain in an organized way.

A child with this hearing disorder may be able to hear that sounds are present at times, but the sounds will not be heard clearly or consistently.

The specific causes of auditory neuropathy/dys-synchrony are currently being studied.

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**. Some hearing loss stays the same over the years. There are also some types of hearing loss that gradually develop over time; this is called a **progressive hearing loss**.

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.

Degrees of Hearing Loss and Potential Effects

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. In a decibel scale, the larger the number, the louder the sound. To measure hearing loss, audiologists determine the softest sound your child can hear. The softest sound your child can hear at a certain frequency or pitch is called a threshold.

The following chart was created to help explain 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 his ability to hear and recognize spoken conversation and environmental sounds.

However, this is only a guide. Each child has unique potential and uses that potential differently. Only time will tell how your child will use his hearing potential and how he may or may not benefit from the use of amplification.

<u>Degree of Loss</u>	<u>Decibels</u>	<u>Potential Effects</u>
Slight Hearing Loss	16 -25 dB	A 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, the child can hear most conversations up close and in quiet environments, but is likely to miss parts of words. The child may appear to be "hearing when he wants to". Amplification and lip-reading may supplement understanding of what is said.
Moderate Hearing Loss	41 -55 dB	Without amplification, the child will have difficulty hearing spoken conversation. Most of spoken conversations may be missed. Proper amplification and intervention should enable the child to hear and recognize sounds.

<u>Degree of Loss</u>	<u>Decibels</u>	<u>Potential Effects</u>
Moderately Severe Hearing Loss	56 -70 dB	Conversation must be very loud to be heard without amplification. Proper amplification will provide access to spoken language. Age of amplification, consistent use of hearing aids, and intervention are important to help the child learn to use his hearing.
Severe Hearing Loss	71 -90 dB	Without amplification, the child may hear loud voices and sounds close to the ear. With early and consistent use of hearing aids and intervention, many children will have access to spoken language. Most children will use visual information in addition to or in place of hearing.
Profound Hearing Loss	91 dB Or greater	Without amplification, the child will be more aware of sounds as vibrations. The child may rely on vision rather than hearing as the primary means for communication and learning. Hearing aids may or may not be useful for hearing spoken conversation.
Unilateral Hearing Loss (One Side Only)		May have difficulty hearing faint or distant spoken conversations. Usually have difficulty knowing where sounds are coming from. May have difficulty understanding spoken conversations on the affected side or listening successfully in background noise.

HEARING TESTS FOR INFANTS AND YOUNG CHILDREN

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. The Maine Newborn Hearing Program has developed a list of the audiology facilities and audiologists that are able to do the testing on infants and young children. Please see the list on page 116.

If a child does have a hearing loss, the audiologist may need to do several tests to find out more about

- What kind of hearing loss it is
- The degree of hearing loss
- The reason for the hearing loss

Different hearing tests may be done depending on the age of the child and the information the audiologist is looking for. Here are some basic descriptions of the different types of tests that can be done for infants and young children.

Types of Hearing Tests

Otoscopic Exam:

This is a simple procedure in which 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 in the child's middle ear or if something is blocking the ear canal.

Otoacoustic Emissions:**(Also known as OAE, DPOAE, TEOAE)**

Otoacoustic emissions are tiny sounds that are sent back by the healthy inner ear (cochlea). In an OAE test, a small, soft probe containing a microphone and receiver is placed in the ear canal.

The microphone sends sounds to the eardrum. The receiver listens for the "echo" back from the cochlea. The results are recorded and measured by a computer. This test can find a hearing loss that occurs in the inner ear.

Auditory Brainstem Response:**(Also known as ABR, AABR, BAER)****(Other tests that may be done as part of the ABR are:
Tone Pip and Auditory Steady State Response)**

An auditory brainstem response is a test which will measure the ear and the brain's response to sound. In this test, small sensors will be put on the child's head and tiny earphones will be placed in the child's ears.

Different sounds will be sent through the earphones. A computer will measure and analyze the child's electrical brain response to the different sounds. The brainstem 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.

High Frequency Immittance Tympanometry:

(Also known as Impedance testing or Immittance testing, Compliance or Acoustic Reflexes)

A small, soft probe will be placed at the opening to the baby's ear canal and the pressure will be changed in the ear canal. With compliance testing, a sound is sent through the probe and the amount of sound reflected back is measured. Acoustic reflex testing measures how loud the sound must be to cause the middle ear muscles to contract.

These tests are used to see how the middle ear is functioning. The results can help find fluid in the middle ear, a hole in the ear drum or other problems with middle ear structure.

Behavioral Tests:**Behavioral Observation Audiometry/ Visual Reinforced Audiometry/****Play Audiometry:**

Behavioral tests require the child to respond to sound and requires the expertise of a person trained to observe behavior responses in young children. These type of tests can give an estimate of how the child hears different pitches at different levels.

In these types of examinations, the child is placed in a small sound proof room called a sound booth (infants are usually in the mother's arms).

Different sounds are sent into the booth and the audiologist will observe the child's response (such as turning the head or startling). As children get older, they may be asked to repeat an action such as placing a block in a container or raise their hand.

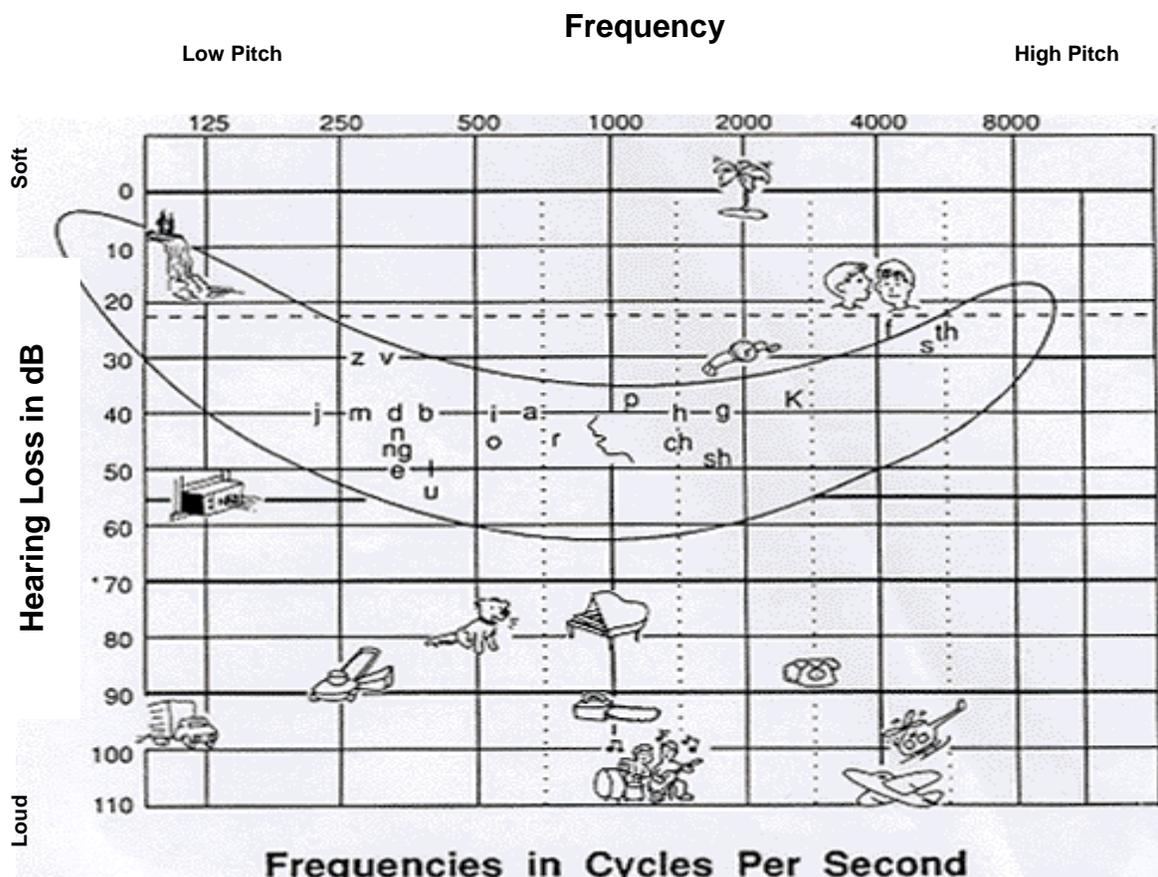
Toys that light up or make noise are often used in these types of examination. The audiologist will compare the child's response to the response of children with normal hearing.

THE AUDIOGRAM

The audiogram chart is a graph that shows a person's ability to hear. An audiologist will test a person's hearing threshold or the softest sound that a person can hear. It can be difficult to get enough information for a complete audiogram from a young infant in a single session. Often, it will take several appointments.

The numbers across the top of the chart show pitch (in frequencies) or how high or low a sound is. Treble and Bass are other names for high pitch and low pitch.

The numbers on the side show volume (in decibels- dB) or how soft or loud a sound is.



AUDIOGRAM OF FAMILIAR SOUNDS

After doing different tests, the audiologist will use different symbols to mark the softest levels at which your child is aware of sound. The symbols will be 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 will angle downward; either gently or sharply. These are called sloping losses. Professionals may use configurations to describe your child's hearing loss.

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 more hearing loss for some frequencies

You will probably have many visits to an audiologists 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. Don't be afraid to ask questions about anything you don't understand. And keep asking until you are sure you understand.

THE MEDICAL EVALUATION

The Otolaryngologist (also called an Ear, Nose and Throat Doctor)

An Otolaryngologist or Otologist is a physician who specializes in the diagnosis and treatment of disorders of the ear and related structures of the nose and throat. If your child has been confirmed to have a hearing loss, a medical evaluation by this physician will be recommended in order to determine the cause of the possible hearing loss and to make treatment recommendations to you, the parent.

A complete medical evaluation will help the otolaryngologist identify any structural abnormalities of the ear, possible infections, or other medical conditions that are known to be associated with childhood hearing loss. The otolaryngologist will work with your baby's primary care provider and possibly a genetics doctor to determine what additional tests are needed for a complete medical evaluation.

This medical evaluation will assist your child's doctors 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 will generally be needed every 6 months after the initial evaluation until the age of 3.

The Otolaryngologist will make treatment recommendations for your child based upon the findings of the medical evaluation, the audiologic testing, and any additional testing and evaluations which may have been ordered.

An Otolaryngology Medical Examination may include:

- Complete Family and Medical History
- Head and Neck Examination
- Microscopic Ear Examination
- Review of Prior Testing

Suggested testing and additional evaluations may include:

- Repeat or additional audiology testing
(Such as Otoacoustic Emissions or ABR)
- Imaging Studies (Such as a CAT 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:

- Repeat hearing testing and observation
- Medications
- Ear Tube Placement
- Hearing Aids

If your baby has a hearing loss and hearing aids are recommended, medical clearance must be given by the otolaryngologist before the audiologist can fit your baby with appropriate hearing aids.

ASSISTIVE TECHNOLOGY

Assistive technology includes a variety of tools that can help people with hearing loss. A listening or hearing device is a type of assistive technology that can be used to help a person hear more.

Hearing aids, cochlear implants and FM systems are types of assistive technology that are options for infants and children with hearing loss.

HEARING AIDS

A hearing aid is an instrument for the ear that makes 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 a TV, vacuum cleaner or air conditioner). They can not "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 audiologists 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 available. Although there are many options in hearing aids, they all have the following three basic parts:

- A microphone to pick up sound waves
- An amplifier to change sound waves into electrical signals and make them louder
- 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 options for hearing aids. Hearing aids can have remote controls, built-in volume control, computer programming and many other types of adjustments.

Hearing aids have different types of electronic technology. Types of electronic technology include conventional, programmable and digital. Styles include behind-the-ear, in-the-ear, body style and bone conduction.

There is a lot to consider when selecting the best hearing aid for your child. Your audiologist will help you choose the hearing aid that is best for your child.

Earmolds are an important part of the hearing aid. The earmold makes sure the amplified sound is delivered into the ear. The earmold must fit tightly into the ear canal or the amplified sound will *leak* out. Sound that is *leaked* will go back into the hearing aid and be amplified again. This sound is called feedback and is the squealing or whistling sound you can hear from a hearing aid.

The earmolds for an infant or young child should be checked and replaced every few months because they are growing so fast. Ear molds for young children can come in many different bright colors.

Hearing Aid Tips

- Hearing aids should always be kept dry and in a safe place when not worn. Pets or toddlers can chew or play with a hearing aid and break it.
- Hearing aid batteries are small and are toxic if swallowed. Seek medical attention immediately if your child or pet swallows a battery. Always store extra batteries in a safe, dry, child-proof place.
- Infants and young children may pull out their hearing aid. This is a very common problem for parents. Persistence and patience will pay off. There are things available to help keep the hearing aids in place such as, clips, hats and headbands. Ask your audiologist or consultant from Early Childhood and Family Services for information and advice.
- Sometimes, it may be difficult to insert an earmold into a little ear. There are lubricants that are specially made for this. Your audiologist can help you find them.
- Feedback can become a problem if the child is growing out of the earmolds. You may be tempted to turn down the volume to reduce feedback but this will reduce the strength of the hearing aid. At the first notice of feedback, schedule an appointment with your audiologist to get new earmolds made.
- Sometimes newly made earmolds have uneven spots that can cause redness or sore spots. These uneven areas can be filed down by the audiologist. Check your child's ears for redness often whenever she gets new earmolds.
- If your child gets an ear infection, she may fuss or pull them off her hearing aids more than usual. Be sure to talk to your healthcare provider or audiologist if you think your child has an ear infection or seems to be having any unusual discomfort or pain when wearing her hearing aids.



Tips and comments about hearing aids from Nicholas (age 7) and Seth (age 5), brothers who have worn hearing aids for 4 years.

- Always use fresh batteries.
- Hearing aids are electronic so you have to take them out when you play with water and go to sleep at night.
- If your hearing aids don't work, you have to take them to get them fixed.
- When your earmolds are loose, go have new ones made.
- The best thing about hearing aids is they help you hear.
- The worst thing about hearing aids is the batteries can stop working.
- It is easy to hear when you have hearing aids.... People get your attention first and don't just start talking "out of the blue".
- The best thing about an FM System is that you can hear directly without the background noise. I get dizzy and cannot concentrate sometimes because of the background noise.



Comments from their parents, Jason and Deb:

Everything in our house is done to help provide the best listening environment and promote use of residual hearing. Here are some examples:

- We don't run the dishwasher while the T.V. is on because it causes too much background noise.
- The children have to work together and choose to use either the T.V. or play a computer game. If both are on at the same time, neither one of the boys can hear.
- The air conditioner is in the kitchen away from the T.V. and computer that are in the living room.
- We are sure to tell the boys when we go outside or downstairs into the cellar because they don't hear footsteps or doors closing. More than once, a frantic boy has said "Mom, I couldn't find you. Why didn't you tell me where you were?".

Trying to put ourselves into "their ears" has been a valuable experience. Both of us have sat and listened to the T.V. using the stetheset and each boy's hearing aids as well as the FM system. This was how we realized how distracting the dishwasher in the kitchen is when people are watching T.V. in the living room.

There are so many stories and memories involving our boys that bring a smile, a tear or a sigh. We are looking forward to a lifetime more of making memories with Nicholas and Seth.

Cochlear Implants

A cochlear implant is a surgically implanted device that transforms sound into electric impulses. A cochlear implant does not correct hearing loss. It bypasses the normal hearing pathway and stimulates the auditory nerve directly. The brain then learns to take this electrical stimulation and interpret it.

A cochlear implant has parts that are surgically placed inside the head and external parts that are worn on the outside of the body. The internal parts are an electrode and a receiver/stimulator. The external parts include a speech processor, transmitter coil and microphone.

There is an approval process for cochlear implant surgery. For a child to be considered for cochlear implant surgery certain conditions must be met. Some conditions are:

- The child has a profound sensorineural hearing loss in both ears
- Hearing aids are not enough to improve the child's hearing
- The child is at least 1 year old
- The auditory nerve is normal (as seen by CT or MRI scans)
- The child is healthy enough to have surgery

Also, the child's family must understand the benefits and limitations of a cochlear implant. The family must understand and commit to the time needed to travel to the cochlear implant center for pre-implant evaluations and postoperative follow-up services.

Cochlear implant surgery is performed under general anesthesia and lasts for approximately 2 1/2 hours. It has the normal risks of major ear surgery requiring general anesthesia. Cochlear implant surgery destroys any residual hearing in the ear.

About 4 to 6 weeks after the surgery, the child must have the cochlear implant programmed to fit their own particular special needs. After the cochlear implant is programmed, the child will require intensive speech and auditory training. The cochlear implant will have to be reprogrammed periodically.

Your audiologist and healthcare provider can give you more information about cochlear implant surgery risks and benefits and where it is done. A limited number of centers around the country specialize in cochlear implant surgery in toddlers and young children.



Young child getting her cochlear implant "turned on" or programmed after surgery.

FM Systems (Frequency Modulation System)

Some listening situations are more difficult because of background noise or because the sound is too far away. An infant or toddler may benefit from an FM system when riding in the car, at child care and when the parent and child are in different rooms or in other noisy environments.

An FM system is a like a radio station. The FM system has two components, the receiver worn by the child and the microphone transmitter worn by the person speaking. The system is designed to amplify the speaker's voice so that it is louder than any competing background noise and reduces the distance between the speaker and listener.

When using an FM system, the child can still hear his own voice and environmental sounds. Some children may use the FM system as the primary form of amplification while others may use it only in settings that are particularly noisy.

Assistive Devices for Environmental Awareness

For a young child who is deaf or hard of hearing, it is very important to make sure that they understand the environment around them. There are many devices that can help your baby or young child make a connection with ordinary everyday happenings around them.

The following things may help your deaf or hard of hearing infant or young child better understand the world around him:

- Doorbell Flashers and Telephone Visual Alert Systems
- Vibrating Clocks
- Closed Captioning
- Hearing Dog

- **Doorbell Flashers and Telephone Visual Alert Systems**

These are special bright lights that are programmed to flash when the doorbell or phone rings. They will help the child connect the flashing light to their mother going to the door or answering the phone. It can help the young child begin to know what will happen next.

- **Vibrating Clocks/ Wake Up Alarms**

Specialized clocks that can vibrate, flash light or have an adjustable loud buzzer with tone control can help a young child learn about the concept of time.

- **Closed Captioning**

Young children who watch TV may benefit from the use of closed captioning. Most TVs now have built-in captioning chips which allows text to be displayed on the TV screen (usually on the bottom of the screen).

- **Hearing Dog**

These are specialized dogs that are trained to assist in responding to sounds such as, a baby crying, doorbell signals or smoke alarm signals. They are trained to alert the owners to where the sounds are coming from.





COMMUNICATION
AND
LANGUAGE

(BIRTH TO 2 YEARS)

We All Have A Dream

by

Ayola Manolson

*We all have a dream, we all have a hope,
We all have an expectation that one day
our child will learn to talk, naturally and
effectively, But learning to talk means
much more than learning the right words.
It means learning to recognize feelings.
It means learning to understand thoughts.
It means learning to be a person, and how
to connect with another person.*

*A child doesn't learn to communicate by
himself. He learns through involvement with his
world. We, his parents, are the largest part of
that world, and it's what we do and how we do
it that affects our child's opportunities to learn.
It takes two to talk.*

(The MNHP Advisory Board interpreted "talk" as either spoken or signed communication.)

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Communication and Language

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

Communication grows out of relationships. Your baby was born with the ability and the need to relate to others. In the first hours of your child's life, she communicated with loud cries when she was hungry and a peaceful expression when her tummy was full. Parents quickly learn to know different cries from their own baby, that may sound the same to someone else.

Babies 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 do. All of this is communication. If they cannot fully use one of those 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 to your baby in *every* way that you can. Talk, gesture, echo her sounds and movements, play games. Responding to your baby and encouraging her 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.

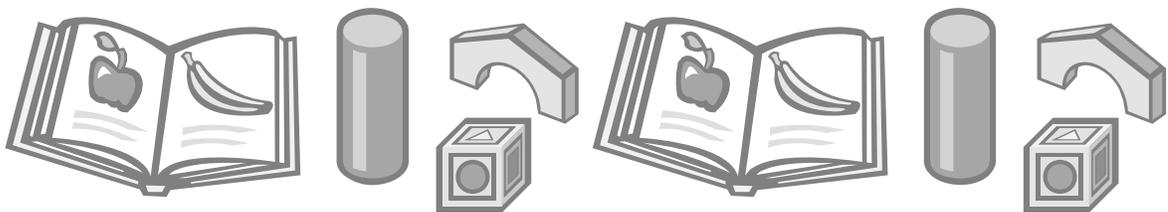
When we are born, our brains are "ready" to learn language—any language that we are exposed to. And once we learn a first language, we can learn a second or even third language. But our brain is only "ready" to learn a first language during the first three or four years of life. After that, the brain 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 baby gets the 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 her own speed and in her own way.

The important thing is that your baby is continuing to make progress in learning language.

The next few pages will help you learn about the steps your baby will go through as she learns to communicate and learns language. We also have included some helpful tips from other parents of children with hearing loss.



Communication and Language

As babies grow and develop, there are steps that all babies will experience when they are learning to communicate. Each step builds upon the other. Remember, every baby is different and develops at his own speed and in his own way.

Below are some descriptions of the different steps or levels and some of the sounds and actions you can look for as your baby begins to take more in and communicate in the first years of life.

Level 1 (Birth to Three Months)

Babies make their needs and desires known through their body language, facial expressions (including eye movements) and the crying, cooing and burbling sounds they make. As parents, we interpret their sounds and actions as communication.

Look for:

- Cries
- Looks around
- Eye contact
- Smiles
- Screams
- Vowel like sounds
- Changes in skin tones
- Movement of the body



Level 2 (Three to Eight Months)

Babies take a great deal of joy in all the discoveries they make. They become interested in the people and things that they see and hear and can touch and move. As they continue to experience, grow and explore, their facial expressions and their gestures are easier for us to understand.

Look for:

- Facial expressions
- Looks at objects and/or people
- A variety of sounds and noises
- Developing the ability to focus on objects and/or people
- Reaching and moving towards people and/or objects
- Smiling at faces
- Imitation of facial expressions, sounds or hand/body movements.

Level 3 (Eight to Thirteen Months)

Young children's communication skills increase, and they are able to connect and interact more easily with us. They direct more and more of their efforts toward trying to get our attention, help or approval. They also begin to look to us for information

Look for:

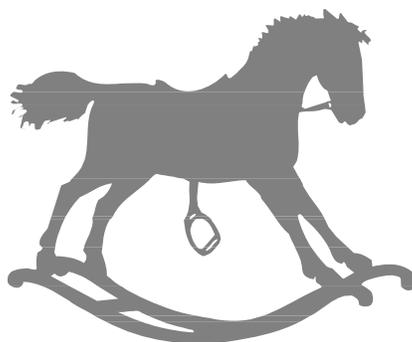
- Pointing at specific objects or people
- Pointing, nodding and waving
- Acting out what they mean
- Making sounds or gestures that stand for words
- Occasionally using single words/signs
- Combining eye gaze, vocalization and gesture
- Uses gestures and body movements to request favorite activities.

Level 4 (Thirteen to Twenty-four Months)

Young children begin to use words or signs consistently. Their body language and facial expressions still help us to interpret their feelings.

Look for:

- Frequent use of single words /signs
- Combining words that may be difficult for us to understand
- Combining two or more words/signs in phrases
- Beginning pretend play



A Word About 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" ("I'll huff and I'll puff and I'll ...") or "Goldilocks and the Three Bears" ("But this one is too small and this one is just right").

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 can't overhear these same conversations and get information 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 baby know" about what you are doing. Your family may have to teach your deaf or hard of hearing child about concepts or events that a hearing child might automatically pick up.

The communication tips on the following pages will give you some ideas on how to keep your baby informed about all the "little things" that we experience every day.

"The biggest difference I have found is that if your child is deaf, everything has to be deliberately taught. Nothing is picked up through osmosis. They do not automatically pick things up from conversations around them, or from the radio or television like our hearing children do."

Quote from a parent, Parent-to-Parent, WWW. Betterhearing.org

Given close relationships with sensitive, caring adults, young children generally develop spoken language naturally, without any conscious effort. 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.

Any degree of hearing loss can interfere with the easy development of spoken language. A baby with hearing loss needs some extra help to learn language in the early years of life.

Here are some communication tips that may help:

- 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.
- Make sure your baby can see the objects you are talking about.
- Touch and hold your baby as often as possible.
 - * Touch is the most basic form of communication that needs no words, no signs, no cues.
 - * Babies thrive on touch. It alerts them that communication is happening , or is about to happen.
 - * Touch helps calm your baby. Touch keeps a physical connection even when you are not directly looking at your baby.
- Communicate with your baby.
 - * Positioning is important. Move your baby; move yourself. Make sure your baby can see your face and what is going on while you are communicating with him.
 - * Speak in every day tones. Keep communication simple. Sign/say one or two words at a time. Try not to exaggerate your lip movements or talk loudly.
 - * Follow your baby's lead.
 - Give your baby time to look up at you and then communicate with him.
 - Notice where he is looking and talk about that.
 - When you talk about an object: touch/point at the object, sign/say the name of the object, and then touch/point at the object. This lets your baby know about the connection between the word and the object.

- Communicate with your baby (*continued*)
 - * Watch your baby playing and interacting with the world. Comment on what your baby is doing and what you are doing.
 - * Using facial expressions, body language and gestures helps hold your baby's interest and adds meaning.
 - * Babies learn through repetition. Repeat words or signs often and again in different situations so your baby hears the word or sees the sign/cue many times.

- Be aware of the environment around you to help your baby know what is going on.
 - * There are many times during the day when you may have to make extra effort for your baby to see you. These times include when your baby is in the crib, in the car seat or during tummy time.
 - * Remember to keep your baby facing away from a light source. When your baby has bright light in his face, it is harder to see you.
 - * Keep background noise and distractions to a minimum at those times when you are communicating or playing with your baby.
 - Turn OFF the TV
 - Turn OFF the radio
 - Turn OFF the dishwasher/washing machine/dryer/ vacuum cleaner while you are talking.
 - * Move closer to your child to help him understand you better.
 - * Place a mirror in the car so your baby can see you.
 - * Inform your baby
 - When leaving the room, let your baby know
 - When you go to answer the phone or door/door bell, let your baby know
 - When someone comes into the room or the house, let your baby know
 - If something unusual happens, let your baby know
 - Your baby needs to know what is happening in his day, let your baby know.

- Books and reading are important.
 - Look at pictures and books with your baby 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 with reading!



Communication Systems

There are many ways for children who are deaf or hard of hearing to learn language. Communication systems differ in how they expect children will learn language; some systems focus more on the use of hearing while others focus more on the use of vision.

Choosing a communication system for your baby will require time and many thoughtful decisions. What works for one family may not work for another.

It is important to check your child's progress often. Remember that it is okay to change what you are doing if your child isn't 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 most important goal is that your child develops language.

The following boxes include a simple description of different communication systems and a bit about family involvement in alphabetical order.

American Sign Language (ASL)

Description

American Sign Language is 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, complex thoughts and feelings as spoken languages.

Goal

To allow your child to learn a language that is visually accessible and does not rely on the ability to hear.

Family Involvement

Family members will need to learn to sign. Some members may choose to learn ASL and some members may choose to learn Manually Coded English.

Auditory Oral

Description

This system focuses on the use of hearing for the development of listening skills through the consistent use of cochlear implants or hearing aids, in order to maximize the child's ability to learn English. Speech reading is used. Signing is not used.

Goal

To encourage your child to use listening and speaking skills to communicate in English.

Family Involvement

Parents will need to be consistently involved in the development of their child's speech, language and auditory skills.

Auditory Verbal

Description

This system focuses on the use of hearing, using cochlear implants or hearing aids, in order to learn English. Speech reading is discouraged during individual therapy sessions in order to teach the child to "listen" and use what hearing they have. Signing is not used.

Goal

To allow your child to learn to speak English through the use of hearing.

Family Involvement

The Auditory-Verbal therapist partners with the parents to teach the parents how to teach speech and language to their child at home. Structured listening sessions and ongoing language work are incorporated into daily life.

Cued Speech

Description

A (sound based) visual communication system that uses a combination of hand shapes and locations (called cues) with the natural mouth movements of speech, to make all the sounds of spoken language look different from each other.

Goal

To allow your child to learn to communicate in the language of the home through the use of amplification, lip-reading and cues.

Family Involvement

Family members will need to learn to use hand shape cues during speaking. Cued speech can be learned through classes taught by certified instructors or therapists.

Manually Coded English

Description

There are several signed systems which use signing to produce "English on the hands". Unlike ASL, manually coded systems use signs in English word order and add special signs to show the grammar of English. Some examples of manually coded systems are Signed English (a.k.a Manually Coded English), Seeing Essential English (SEE I), and Signing Exact English (SEE II).

Goal

To teach your child to use signs as words and to learn to sign using the word order and grammar of English. Communication does not depend on your child's ability to hear.

Family Involvement

Family members will need to learn the vocabulary of American Sign Language, and the "sign markers" that correspond to English grammar.

The following boxes are descriptions of communication approaches or philosophies that combine communication systems to teach children language.

Total Communication

Description

Total communication uses a mix of communication systems. It uses signs, the manual alphabet from ASL, Manually Coded English as well as speaking and speechreading from Auditory Oral approaches. Often people will speak and sign at the same time (also called simultaneous communication) so that both auditory and visual cues are available to the child.

Goal

To allow your child to communicate by using both visual and auditory information.

Family Involvement

Family members will need to learn to sign and learn how to speak and sign at the same time.

Bilingual/Bicultural

Description

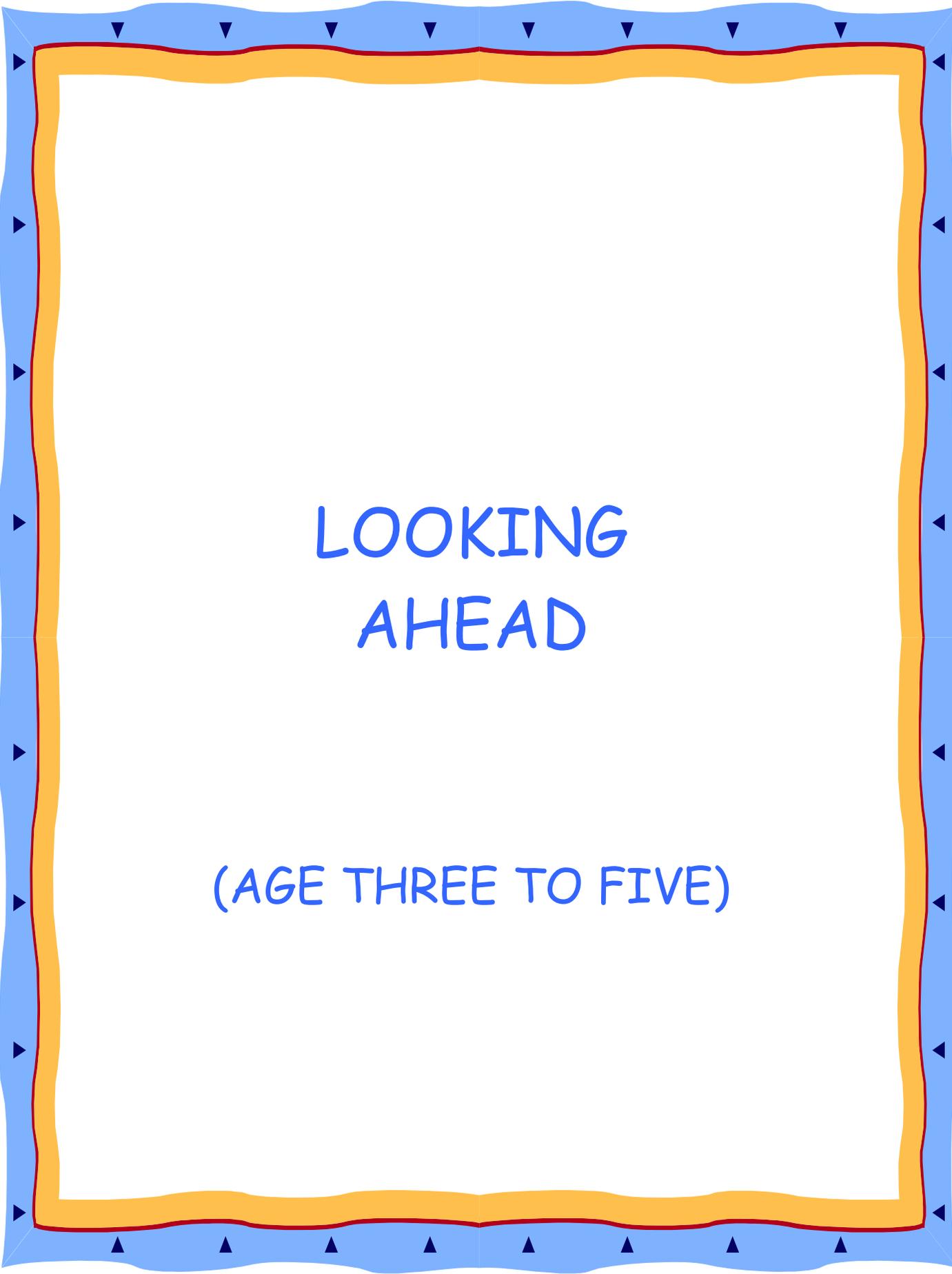
The Bilingual-Bicultural approach uses American Sign Language as a first language and English is learned through reading and writing. Spoken English/speech services are encouraged separately. A bilingual-bicultural approach supports knowledge of and respect for American Deaf and hearing cultures.

Goal

To allow your child to develop American Sign Language as a first language and English as a second language. The bilingual-bicultural approach emphasizes the importance of fluency in a first language in order to learn another language.

Family Involvement

Family members will need to learn American Sign Language and get to know deaf and hard of hearing adults who are part of the Deaf community.



LOOKING
AHEAD

(AGE THREE TO FIVE)

Language Milestones

Children learn language in their day to day exchanges with caregivers. Remember, every child is unique and follows an individual rate of development. There is, however, a natural progression of skills for language development. The milestones listed below can serve as a guide to normal English language development.

By Three Years

A child's language is made up of simple sentences that often leave out small, unstressed words. He understands many concepts, such as, the names of groups of things, words that describe size, opposites, and prepositions like "in", "on", "under".

He can take a number of turns in conversation and knows that a pause in the conversation is a signal for him to take his turn. He is getting to know language rules: he asks for "what" and "where"; he often uses "a" and "the", adds an -s for more than one thing and uses the negatives "can't" and "don't".

- Uses an expressive vocabulary of 900 to 1,000 words
- Uses "sentences" with simple subject and verb ("I see a kitty.").
- Plays with words and sounds (repeats funny sounds and silly words).
- Follows two-step commands ("Take off your shoes and put them in the closet").
- Talks about what is happening in the moment.
- Repeats overheard expressions ("swears" or "Now listen here young man").

By Four Years

The 4 year old uses many sentences that have 4 or more words and is using more grammar to talk about when things have happened and to tell simple stories. She begins to link two ideas together in complex sentences and uses language to find out about the world and to have conversations with adults and playmates.

- Uses an expressive vocabulary of 1,400 to 1,600 words
- Asks many, many questions
- Talks about activities at school or at friend's homes
- Understands most questions about the here and now
- Has some difficulty answering "how" and "why"

By Five Years

The five year old uses language as a tool for learning, thinking and problem-solving. The child uses language to direct his own and other's behavior, to plan what he is going to do, to think about what he likes to do, and to create imaginary situations. The five-year old uses the same grammar as the rest of the family. He can tell stories that stick to the topic, has a growing sense of humor, can tease and discuss emotions

- Uses a vocabulary of well over 2,000 words
- Discusses feelings
- Understands "before" and "after" regardless of word order
- Follows three step commands
- Uses sentences that give lots of details ("I like to read my books.")

Group Activities for Young Children

As your child begins to explore the world around him, he may enjoy participating in group activities with other children his own age.

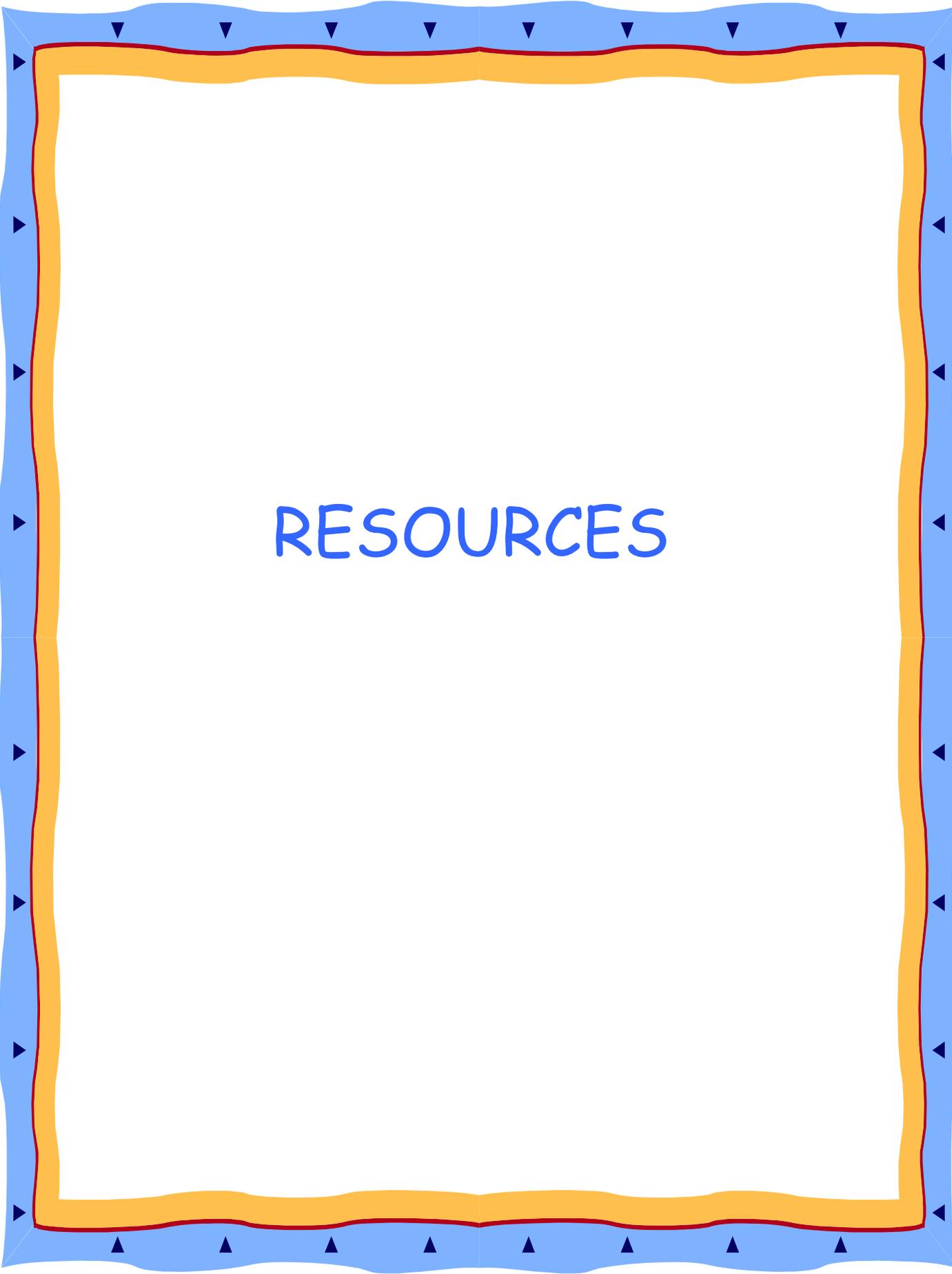
Group activities you may want to consider include preschool programs, playgroups, library story hour for young children, camp experiences for children with hearing loss, and athletic activities like gymnastic or swimming classes and others.

There are many other activities for young children that you may discover in your local community. You should visit the programs and find out as much as possible before enrolling.

Here are some questions you may want to ask to find out more about a particular program or activity:

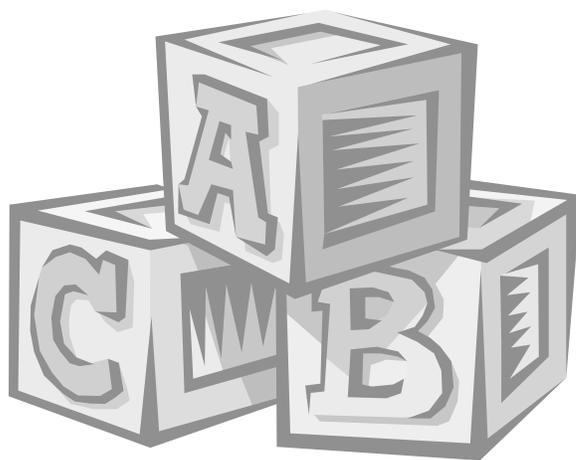
- Does this particular activity meet the goals I have for my child?
- Does the staff have specific knowledge and skill in working with children who have a hearing loss? And if they don't, will they accept training?
- What accommodations will be provided to include your child with hearing loss?
- What transportation is involved? Is transportation provided?
- Is there a cost involved with this program?
- Do the children participating appear happy and active?
- Does the program have fluent language models in your chosen language mode for your child?





RESOURCES

STATE & LOCAL RESOURCES



Alpha One

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

Alpha One administers the **MPower Loan Program**. This is a state bond funded program through which individuals and businesses can obtain long-term, low interest loans for assistive technology. Possible technology relating to families include hearing aids, flashing fire alarms, and other alerting devices

Alpha One Deaf Services
127 Maine Street
South Portland, ME 04106

E-mail: info@alphaonenow.com
Website: www.alphaonenow.com

Telephone:
1-800-640-7200 (V/TTY)
767-2189 (V/TTY)
799-8346 (FAX)

Child Development Services (CDS)

A state agency that is a part of the Department of Education. It is a statewide network of regional sites which 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 services are provided on the basis of a sliding fee scale. Special education and related services are provided to eligible children at no cost to families.

Department of Education
CDS Central Office
146 State House
Augusta, ME 04333

Telephone: 624-6660 (V) 624-6800 (TTY) 624-6661 (FAX)

***Please see appendix for a complete listing of contact information for individual sites**

Children with Special Health Needs Program (CSHN)

A program within the Department of Human Services, Bureau of Health & Human Services, Division of Family Health. This program can pay for specialty medical care, assist with insurance co-payments and deductibles, may pay for lodging and transportation to attend medical visits and can offer assistance with care coordination for those children who meet the income and medical guidelines. While hearing loss alone is not a covered medical condition, other conditions associated with hearing loss may be covered.

Children with Special Health Needs Program

Key Bank Plaza

11 State House Station

Augusta, Maine 04333

Telephone:

287-5139 or 1-800-698-3624 (V)

287-8015 or 1-800-438-5514 (TTY)

Community Counseling Center

Therapy and case management for families with a deaf member in Cumberland and York counties. Please contact the Portland office for information about services for the Augusta, Lewiston and Bangor areas. Fluent in American Sign Language. Provides in-home behavioral management work for children and their families. MaineCare accepted. Mentoring services also available. A support group for parents of deaf/Hard of Hearing children meets every other Wednesday.

Community and Counseling Center

343 Forest Avenue

Portland, ME 04101

Website: www.commcc.org

Telephone:

874-1030 (V)

874-1043 (TTY)

874-1044 (FAX)

Cued Speech Association of Maine

The Cued Speech Association is an organization formed to foster the growth and educational application of Cued Speech in Maine. Information is available on early intervention options for newly deafened children; learning workshops for teachers, parents, interpreters, and support persons; and an annual Cued Speech Camp for Children and Families.

Cued Speech Association of Maine
RFD 2, Box 728
Chelsea, ME 04330

E-mail: CuedSpeechMaine@cs.com

Telephone:
622-2564 (V/TTY)

The Office of Deaf Services

A program within the Department of Health & Human Services responsible for program planning, policy development, professional training and community education to ensure equal access to programs for deaf children and adults in need of mental health/mental retardation services.

Limited consultation on communication needs is available for deaf and nonverbal children served by Bureau of Mental Health & Mental Retardation who communicate via non-traditional communication modes.

Bureau of Mental Health and Mental Retardation and Office of Substance Abuse

40 State House Station
Augusta, ME 04333

E-mail: Meryl.Troop@maine.gov

Telephone:
287-4240 (V/TTY)
287-1022 (FAX)

Division of Deafness

The Division of Deafness (DOD) is a division of Department of Labor, Bureau of Rehabilitation. The DOD provides a program of services to deaf, late-deafened, and hard-of-hearing citizens of Maine. This includes information and referral, advocacy, publication of the "Guide to Services for People who are Deaf or Hard of Hearing", a quarterly newsletter "Maine Lines for the Deaf", ongoing TTY and other training programs for state agencies, Certification of Hearing Dogs and accessibility promotion.

Division of Deafness
Bureau of Rehabilitation Services
150 State House Station
Augusta, ME 04333-0150

E-mail: Jan.A.Devinney@maine.gov

Telephone:

624-5963 or 1-800-698-4440 (V Toll-Free within Maine only)

624-5965 or 1-888-755-0023 (TTY Toll-Free within Maine only)

624-5980 (FAX)

Dorothy Ames Trust Fund

A privately funded trust dedicated towards hearing impaired children in New England. Funds are used to purchase hearing aids, auditory trainers, and to teach them to use their voices as distinguished from using sign language.

To be considered for a grant from the trust, a child must be a resident of Maine, New Hampshire, Vermont, Massachusetts, Connecticut or Rhode Island. Preference is given to any children from North Haven, Maine. Benefits are limited to once per lifetime and some income eligibility guidelines apply. Grants will not reimburse for equipment/services that have already been paid for.

Dorothy Ames Trust Fund
Key Trust Company of Maine
P.O. Box 1054
Augusta, ME 04332-1054

Telephone:

Christine L. Cook, Assistant Vice President & Trust Officer

623-5527 (V) 623-5662 (FAX)

Early Childhood and Family Services (ECFS)

A program that is a part of Statewide Educational Services, a state funded, independent agency.

The ECFS program provides information, support and training to families and professionals statewide for children (newborn to five years of age) who are deaf, hard of hearing, or have a suspected hearing loss. Their services include home visits and are provided without cost to families.

Telephone:

Central Office: 1-866-231-8910 (V/TTY statewide toll-free)

Aroostook & Washington Counties: 472-0502 (V/TTY)

Greater Bangor Area: 989-2305 (V/TTY)

Greater Portland Area: 781-6293 (V/TTY Newborn to age 5)
781-6335 (V/TTY 3 to 5 yrs)

Geoffrey Foundation

A privately funded family foundation that can provide financial support in four categories:

- Families committed to Auditory-Verbal therapy for their child (newborn through college age) with a severe to profound (80 dB) hearing loss.
- College students who attend schools with hearing students and communicate using spoken language.
- Hearing research that advances amplification and/or seeks cures to hearing loss.
- Discretionary giving of funds that the Board chooses at its discretion.

Geoffrey Foundation
P.O. Box 422
Portsmouth, NH 03802

Telephone:
(603) 431- 3400 (V)

Governor Baxter School for the Deaf (GBSD)

GBSD is dedicated towards meeting the educational needs of deaf and hard of hearing children. A school program operates for deaf and hard of hearing students kindergarten through eighth grade.

Several programs are available through the GBSD including, statewide outreach with children, birth to age 5, technical assistance to educational programs for children who are deaf and hard of hearing, and assistance with education and audiological evaluations for referred children.

Parent/infant/toddler and preschool programs are available on Mackworth Island and in the greater Bangor area. Services include play groups, family support group meetings, speech therapy, occupational therapy and family sign language classes.

Governor Baxter School for the Deaf
Mackworth Island
Falmouth, ME 04105

Telephone:
781-3165 (V) 781-6201 (TTY) 781-6260 (FAX)

hear ME now!

An Auditory-Oral Learning Center for children (Birth to Age 5) who are hard-of-hearing or deaf that focuses on teaching children to learn to listen and speak without the use of sign language.

A parent-infant program is available for children three years of age and younger and is offered on site or by appointment in the home. It provides parents with auditory-oral techniques to enhance their child's communication using meaningful sound, language and play.

A toddler and preschool program is also available. Services include developmental therapy, speech therapy, audiological support and family training. Tutoring and consultation services are available for school age children.

hear ME now!
19 Yarmouth Drive
Suite 201, Yarmouth Hall, Pineland Farms
New Gloucester, ME 04260
www.oraldeafed.org/schools/hearmenow/index.html

Telephone:
688- 4544 (V/TTY) 688-4548 (FAX)

Howard & Espa Michaud Charitable Trust

(Administered through the Department of Behavioral and Developmental Services)

A privately funded trust dedicated towards assisting "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."

Children do not need to be a client of BDS to be eligible. 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.

Howard and Espa Charitable Trust
Dept of Behavioral and Developmental Services
P.O. Box 1285, 642 Main St.
Presque Isle, ME 04769

Telephone: 554-2127 or 1-800767-9857 (V) 764-2000 (TTY)

Lion's Club

Your local Lion's Club may donate toward hearing aids and adaptive equipment. Not every club has a hearing health focus but many will consider a one-time request for assistance. The Lion's Club will accept donations of old hearing aids in their eyeglass collection boxes. Call the chapter nearest you to inquire about their hearing program by calling the number below or search online at www.lionsclubs.org/EN/content/resources_club.shtml.

Lion's Club
John Kustron, State Chair of Speech & Hearing Telephone: 247-3314 (V)
HCR 72, Box 8018
North Waterboro, ME 04061

For a list of other Service Organizations that might provide funding for hearing aids and other adaptive equipment in Maine, see "Service Organizations".

Maine Association of the Deaf

The Maine Association of the Deaf (MeAD) is a state chapter of the National Association of the Deaf and is the Central deaf organization for statewide activities for the Deaf in Maine. The MeAD distributes a newsletter to members.

Maine Association of the Deaf
Rod MacInnes, President
P.O. Box 1014
Portland, ME 041-4
Telephone: 871-5903 (TTY)

MaineCare

MaineCare is the name for Maine's medicaid program. It is a free or low-cost health insurance program for Maine families and children. Many services are covered, such as, doctor visits and therapies. MaineCare does provide a limited (\$400) hearing aid benefit for children (0-21).

There are eligibility requirements, such as, income guidelines, but special rules may apply for children with disabling conditions. Call the number below to find out how to apply for enrollment. The Katie Beckett Medicaid Eligibility Option for disabled children can be applied for through the same application process.

Department of Health and Human Services, MaineCare Program
Website: www.state.me.us/dhs/beas/medicaid
1-877-543-7669 (V statewide toll-free) 532-5001 (TTY)

Maine Center on Deafness (MCD)

A non-profit, community resource center which provides general information on deafness, deaf advocacy, consumer information, outreach & support services, and auxiliary aid information. MCD works with deaf individuals in any area in Maine and with service providers who wish to work with this group. Services include education and referral services for HIV/AIDS and other health related matters, substance abuse, telecommunications equipment distribution program, civil rights office and the Maine telephone relay service outreach program.

Maine Center on Deafness
68 Bishop Street, Suite 3
Portland, ME 04103

www.mainecenterondeafness.org

Telephone: 797-7656 (V/TTY) or 1-800-639-3884 (V/TTY) 797-9791 (FAX)

Maine Newborn Hearing Program

A program within the *Genetics Program*, Bureau of Health, Department of Human Services. This program is responsible to coordinate hospital newborn hearing screening programs and coordinates the follow-up of infants identified with hearing loss.

Several materials are available, including this Parent Notebook.

A registered nurse is available for resource and referral information.

Maine Newborn Hearing Program

Key Bank Plaza

11 State House Station

Augusta, ME 04333-0011

Telephone:

287-5357 or 1-800-698-3624 (V)

287-8015 or 1-800-438-5514 (TTY)

287-4743 (FAX)

Maine Parent Federation

A private, non-profit organization that provides information, support and training to parents and professional statewide through numerous grant funded projects.

People can receive information about specific disabilities, parenting, education, services, support groups and resources available to assist families and professionals within the home, school and community.

Maine Parent Federation

P.O. Box 2067

Augusta, ME 04338-2067

Telephone

623-2144 (V/TTY) or 1-800-870-7746 (V/TTY)

Website: www.mpf.org

E-mail: parentconnect@mpg.org

New England Center Deafblind Project

The New England Center Deafblind Project provides technical assistance and consultation to infants, children and youth (ages 0-22) who are deafblind. The project works with families, schools, and other programs to provide the support and training necessary to serve deafblind individuals in their communities. The project is funded by a federal grant, through Catholic Charities of Maine.

New England Center Deafblind Project
P.O. Box 84
Thomaston, ME 04861

www.necdbp.org

Telephone:
596-6209 (V)
594-4183 (FAX)

Public Health Nursing Program

A state program that is a part of the Bureau of Health, Department of Health and Human Services. Public Health Nurses are registered professional nurses and their services include home visits to families, clinics and educational services. Services are provided at no cost.

Public Health Nursing Program
Key Bank Plaza
11 State House Station
Augusta, ME 04333-0011

Telephone:
287-3259 or 1-800-698-3624 (V)
287-8015 or 1-800-438-5514 (TTY)

287-5355 (FAX)

Service Organizations

The following is a list of different Service Organizations that may have a hearing aid donation program or who might fund a one-time request for financial assistance. Each region has its own chapters, so call your local chapter of the organization to find out more information. Check your local phone listings to find the phone number.

Elks Club	Masons Lodge
Fraternal Order of the Eagles	Moose Lodge
Kiwanis	Optimist Club
Lions Club	Rotarians

Social Security Administration (Augusta Office)

The Social Security Administration is a nation-wide federal agency that is responsible for the Social Security (SSI) and Supplemental Security Income Disability (SSDI) Program.

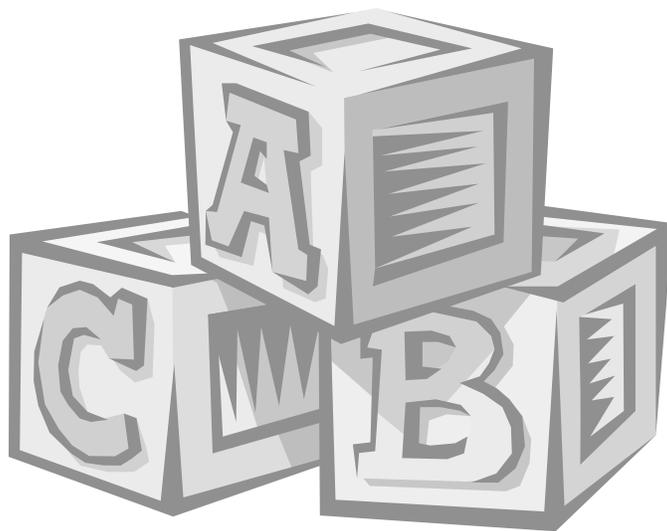
These programs are sometimes known as SSI and SSDI and may provide assistance to children and adults with disabilities. Children and adults who have a disability and meet medical and certain income criteria may qualify for benefits under these programs.

Telephone:

Augusta Office: 622-1451 (V) or 623-4190 (TTY)

Nationwide Toll Free 1-800-772-1213

NATIONAL RESOURCES



Alexander Graham Bell Association for the Deaf and Hard of Hearing

3417 Volta Place, NW
Washington, D.C. 20007-2778
(202) 337- 5220 (V) (202) 337-5221 (TTY)
Website: www.agbell.org

An international organization of parents, professionals, and oral deaf/hh children and adults that provides newsletters, journals, and information relating to oral education. Financial aid programs available for children with hearing loss. Mentoring programs, leadership opportunities for deaf/hh teens and young adults and Advocacy services available for members.

American Academy of Audiology (AAA)

8300 Greensboro Dr, Suite 750
McLean, VA 22102
(703) 790-8466 (V/TTY) 1-800-222-2336
Website: www.audiology.org

A professional membership organization dedicated to providing high quality hearing care to the public. Provides consumer information and locates certified audiologists in a specified area. Website contains, "Ask the Audiologist", designed to enhance parental and public understanding of audiology.

American Speech-Language-Hearing Association

10801 Rockville Pike
Rockville, MD 20852
(301) 897-3279 (V) Toll Free 1-800-638-8255
(301) 897-0157 (TTY)
Website: www.asha.org

The national professional, scientific, and credentialing association for audiologists, speech-language pathologists, and speech, language and hearing scientists. Provides brochures, fact sheets, and information packets to the general public at no cost. A computerized referral database of audiology and speech-language pathology programs is available to meet individual consumer needs.

American Society for Deaf Children

1820 Tribute Road, Suite A
Sacramento, CA 95815
(916) 641-6084 (V/TTY)
Toll free: (800) 942-2732
Website: www.deafchildren.org

A non-profit parent organization that provides a positive attitude toward signing and Deaf culture. Provides current information, support and encouragement to parents and families with children who are D/HH. Prints the Endeavor (a parent newsletter).

Auditory-Verbal International, Inc.

2121 Eisenhower Avenue, Suite 402
Alexandria, VA 22313
(703) 739-1049 (V)
(703) 739-0874 (TTY)
Website: www.auditory-verbal.org

An international organization providing resources and information to parents and professionals on teaching children who are D/HH to speak using residual hearing and amplification.

Beginnings for Parents of Children Who are Deaf or Hard of Hearing, Inc.

3900 Barrett Dr., Suite 100
Raleigh, NC 27609
(800) 541-4327 (V/TTY)
(919) 571-4843 (V/TTY)
Website: www.beginningssvcs.com/

A resource and reference organization that produces materials and videos oriented toward helping families make choices about communication methods.

Better Hearing Institute

P.O. Box 1840
Washington, DC 20013
1-800-327-9355 (V/TTY)
Website: www.betterhearing.org

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

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

Children's Hospital LO-301
300 Longwood Avenue
Boston, MA 02115
(617) 355 -7404 (V)
(617) 355- 6603 (TTY)

An interdisciplinary clinical and research group within the Department of Otolaryngology and Communication Disorders at the Boston Children's Hospital. The clinical team includes specialists in psychology, audiology, education, medicine, speech and language, psychiatry, and communications.

BCDC provides comprehensive evaluation and consultative services to deaf and hard of hearing children, and their physicians, families, and schools. Staff work with children and families from diverse locations and backgrounds covering the full pediatric age spectrum, from infants to teens. BCDC serves as a center for coordination of evaluations, referrals, research, guidance and information for families and agencies.

**Boystown National Research Hospital
Center for Childhood Deafness**

555 N. 30th Street
Omaha, Nebraska 68131
(402) 498-6521 (V/TTY)
Website: www.babyhearing.org

A non-profit hospital that is internationally recognized for research and treatment of childhood deafness and communication disorders. Provides information on childhood hearing loss to parents, children, other family members, and the public at large.

Cochlear Implant Association, Inc. (CIAI)

5335 Wisconsin Avenue NW, Suite 440,
Washington, DC 20015-2052
(202) 895-2781 (V)
(202) 895-2782 (FAX)
Toll free: (800) 942-2732
Website: www.cici.org

An non-profit organization that distributes educational materials, organizes national and international meetings and conventions, promotes cochlear implant technology and deafness research, and advocates on all governmental levels for the rights and services of people who have hearing loss. Provides information and support to cochlear implant users and their families, and professionals.

Deafness Research Foundation

1050 17th St NW, Suite 701
Washington, DC 20036
(202) 289-5850(V)
1-800-535-3323
(202) 293-1805 (FAX)
Website: www.hearinghealth.net

A privately funded research foundation committed to finding the causes, treatment, and prevention of all types of hearing loss. Organizes a national campaign aimed at public outreach, professional education, and government relations. Provides parents with a website detailing current research findings.

Deafpride

1350 Potomac Ave. SE
Washington, DC 20003
(202) 675-6700 (V/TTY)

Advocacy for the rights of deaf people and their families.

Families for Hands and Voices

P.O. Box 371926
Denver, CO 80237
(866) 422-0422 Toll Free
Website: www.handsandvoices.org

A national, parent-driven organization dedicated to non-biased support to families who have children with deafness or hearing loss. Activities include outreach events, educational seminars, advocacy lobbying efforts, parent-to-parent support network, and a newsletter.

**Gallaudet University
Laurent Clerc
National Deaf Education Center**

800 Florida Avenue NE
Washington, DC 20002-3695
(202) 651-5000 (V)
Website: www.clerccenter.gallaudet.edu

Gallaudet is the only four-year liberal arts university in which all programs and services are designed specifically to accommodate students who are deaf or hard of hearing. Centralized source of information on topics dealing with deafness and hearing loss.

The Hearing Exchange

P.O. Box 689
Jericho, NY 11753
(516) 938- 5475(V)
Website: www.hearingexchange.com

An on-line community for the exchange of ideas, information, stories, and support relating to hearing loss. Great place to read stories from children with hearing loss and their parents

**The Hearing Impaired Kids Endowment (HIKE) Fund
International Center for Job's Daughters**

10115 Cherryhill Place
Spring Hill, FL 34608-7116
(352) 688-2579 (voice & fax)
Website: www.missouriiojd.org/HIKE/index.htm

Provides hearing devices for children with hearing impairment from newborn through 20 years of age, whose parents are financially unable to meet this need. Funding is raised through Job's Daughters, and typically takes six months from application to receiving funds. Large amounts are possible.

Hear Now

4248 Park Glen Road
Minneapolis, MN 55416
1-800-648-4327
Website: www.sotheworldmayhear.org

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

**Helen Keller National Center
For Deaf-Blind Youths and Adults**

111 Middle Neck Road
Sands Point, NY 11050
(516) 944-8900 (V)
(516) 944-8637 (TTY)
(516) 944 -7302 (FAX)
Website: www.hknc.org

The national center and its 10 regional offices provide diagnostic evaluation, comprehensive vocational and personal adjustment training, and job preparation and placement for people who are deaf-blind from every state and territory. Field services include information and referral and advocacy and technical assistance to professionals, consumers, and families.

Marion Downs National Center for Infant Hearing

University of Colorado at Boulder,

Campus Box 409

Boulder, CO 80309

(303) 492-6283 (V)

(303) 492-4124 (TTY)

Website: www.colorado.edu/slhs/mdnc

Information on universal newborn hearing screening, assessment, diagnosis, and early intervention. Research information available.

Miracle-Ear Children's Foundation

P.O. Box 59261

Minneapolis, MN 5545900261

1-800-234-5422 (V)

Website: www.miracle-ear.com

The Miracle-Ear Children's Foundation works in cooperation with local Miracle-Ear Centers nationwide to provide free Miracle-Ear hearing aids, services, and support materials to children age 16 and under whose families do not qualify for public assistance, yet cannot cover the expense of hearing aids.

Check the website to find local Miracle-Ear centers.

(Miracle-Ear Centers in Maine are located within a Sears store).

National Association of the Deaf (NAD)

814 Thayer Avenue

Silver Springs, MD 20910 -4500

(301) 587-1788 (V)

(301) 587-1789 (TTY)

(301) 587-1791 (FAX)

Website: www.nad.org

A nonprofit consumer organization safeguarding the accessibility and civil rights of persons who are deaf/hard of hearing in education, employment, health care, and telecommunications. Provides grassroots advocacy and empowerment, deafness related information and publications, legal assistance, policy development, public awareness, and youth leadership development.

National Center for Hearing Assessment & Management (NCHAM)

National Center for Hearing Assessment & Management (NCHAM)

Utah State University - 2880 Old Main Hill - Logan, UT 84322

Tel: (435) 797-3584

Website: www.infanthearing.org

The goal of the **National Center for Hearing Assessment and Management** (NCHAM - pronounced "en-cham") at **Utah State University** is to ensure that all infants and toddlers with hearing loss are identified as early as possible and provided with timely and appropriate audiological, educational, and medical intervention. NCHAM's research, training, and technical assistance activities contribute to this goal by working to achieve the following objectives:

- Every child born with a hearing loss is identified before 3 months of age and provided with timely and appropriate intervention by 6 months of age.
- Every family of an infant with hearing loss receives culturally-competent family support as desired.
- All newborns have a "medical home."
- State Departments of Health have effective newborn hearing screening tracking and data management systems which are linked with other relevant public health information systems.

National Cued Speech Association

23970 Hermitage Road

Shaker Heights, OH 44122

Website: www.cuedspeech.org

A nonprofit association that promotes and supports the use of cued speech for communication, language acquisition, and literacy. Provides information, referral, and support services for persons with language, hearing speech, and learning needs. Sponsors family camps, workshops, conferences and scholarships. Distributes a catalog, newsletter and journal on cued speech and hearing loss.

**National Institute on Deafness and
Other Communication Disorders (NIDCD)**

National Institutes of Health
31 Center Dr. MSC 2320
Bethesda, MD 20892-2320
(301) 496-7243 (V) 1-800-241-1044 (V)
(301) 402-0252 (TTY) 1-800-241-1055 (TTY)
Website: www.nidcd.nih.gov

A nonprofit organization affiliated with the National Institutes of Health. Conducts research and research training on normal and disordered processes of hearing, balance, smell, taste, voice, speech, and language. Provides a newsletter and other materials, based on research that educates the public and health professionals about its seven research areas in communication. Website contains sections for parents that cover topics related to hearing loss.

Oberkotter Foundation

P.O. Box 50215
Palo Alto, CA 94303-9465
1-877-672-5332 (V toll free)
1-877-672-5889 (TTY toll free)
(516) 944 -7302 (FAX)
Website: www.oraldeafed.org

A private family foundation that advocates oral deaf education. The foundation distributes a variety of free educational materials (videos and pamphlets) for parents and professionals.

Self Help for Hard of Hearing People (SHHH)

7910 Woodmont Avenue, Suite 1200

Bethesda, MD 20814

(301) 657-2248 (V)

(301) 657-2249 (TTY)

(301) 913-9413

Website: www.shhh.org

A nonprofit educational, volunteer, and international organization composed of people who are hard of hearing and their relatives and friends. Offers education, support, and advocacy for persons who are deaf or hard of hearing, their families, and friends. Some states have local chapters. Website offers a listserv for parent support.

A chapter of SHHH meets the third Thursday of every month at 6:30 p.m., at the Barron Center, Brighton Ave. , Portland, Maine

Please contact Jodi Wendt for more information. E-mail: mrs828@attbi.com

NOTES

Use this space to write down any other resources you may find or hear about.

Books and Printed Materials

There are many books on hearing loss. Here is a brief listing. Ask your local library to help you find these books. Even if your local library does not have a copy available right away, many local libraries have lending agreements with other libraries throughout the state.

Two other great places to find books, videos and other materials are:

Governor Baxter School for the Deaf

Telephone: 781-6237 (V/TTY)

Website: www.gbsd.org

The Governor Baxter School for the Deaf has an extensive library of books and printed materials that can be borrowed. Please contact the librarian to find out more.

The Maine Parent Federation

P.O. Box 2067

Augusta, ME 04338-2067

Website: www.mpf.org

E-mail: parentconnect@mpg.org

The Maine Parent Federation has an extensive lending library. Please contact them to find out more.

Reference

American Sign Language Dictionary

By: M.L.A. Sternberg

Published By: Harper and Row, New York

(202) 651-5001 , <http://clerccenter.Gallaudet.edu>

A Personal Quest for Educational Excellence for a Hard of Hearing Child

Published By: Self Help for Hard of Hearing

www.shhh.org

ASL Basics for Hearing Parents of Deaf Children

By: Jess Freeman King and Jan Kelley-King

Published By: Butte Publications, Hillsboro, Ore., 1996

Auditory Verbal Therapy for Parents and Professionals

By: Warren Estabrooks (1994)

Www.agbell.org, (202) 337-5220

Caring for Young Children: Signing for Daycare Providers and Sitters

Beginning Sign Language Series

Published By: Garlic Press, Eugene, Oregon, 1996

Choices in Deafness: A Parent's Guide

Edited by: Sue Schwartz, Ph.D.

Published By: Woodbine House, 1996

Cochlear Implantation for Infants and Children

Senior Editor: Graeme M. Clark, Editors, Robert S.C. Cowan, Richard C. Dowell

Published By: Sand Diego: Singular Pub. Group, 1997

Cochlear Implants: A Handbook

By: Bonnie Poitras Tucker

Published By: Jefferson, N.C.: McFarland, 1998

Cued Speech Resource Book for Parents of Deaf Children

Second Edition, Orin R. Cornett and Mary Elsie Daisey

Published By: Cued Speech Discovery, 2001

Www.cuedspeech.org

Dancing Without Music: Deafness in America

By: Beryl Leiff Benderly

Published By: Anchor/Doubleday, 1980

Early Childhood Deafness

By: Ellen Kurtzer-White and David Luterman

Published By: York Press, 2001

Facilitating Hearing and Listening in Young Children

By: Carol Flexer

Published By: Singular Publishing Group, 1994

Www.agbell.org, (202) 337-5220

50 FAQ's about AVT

Edited by: Warren Estabrooks

Published By: Learning to Listen Foundation, 2001

Hearing Impaired Infants: Support in the First Eighteen Months

Edited by: Jacqueline Stokes, 1999

www.agbell.org, (202) 337-5220

Hearing Loss in Children

Pediatric Clinics of North America, Vol 46, 1999

It Isn't Fair! : Siblings of Children with Disabilities

By: S. Klein, and M. Schleifer

Published By: Bergin & Garvey, Westport, Connecticut, 1993

It Takes Two to Talk: A Parent's Guide to Helping Children Communicate

By: Ayala Manolson in English and Spanish

www.agbell.org, (202) 337-5220

Keys to Raising a Deaf Child

By: B. Frazier-Maiwald and L. Williams

Published By: Barron's Educational Series, Inc., Hauppauge, NY, 1999

Kid-Friendly Parenting with Deaf and Hard of Hearing Children

By: Daria Medwid and Denise Chapman Weston

Published By: Gallaudet University, Washington, D.C., 1995

Movers and Shakers: Deaf People who Changed the World

By: Cathryn Carroll and Susan M. Mather

Published By: Dawn Sign Press, San Diego, 1997

Not Deaf Enough: Raising a Child who is Hard of Hearing with Hugs, Humor and Imagination

By: Patricia Ann Morgan Candlish

www.agbell.org, (202) 337-5220

Raising and Educating a deaf child

By: Marc Marschart

Published By: Oxford University Press, New York, 1997

Signs for me: Basic sign vocabulary for children

By: B. Gahan and J. Dannis

Published By: CA Dawn Sign Press, Berkeley, CA, 1990

So Your Child has a Hearing Loss: Next Steps for Parents

By: AG Bell

www.agbell.org, (202) 337-5220

The Silent Garden

By: Paul Ogden

Published By: Gallaudet University Press, Washington, D.C., 1996

The Young Deaf Child

By: David M. Luterman

Published By: York Press, 1999

When Your Child is Deaf: A Guide for Parents

By: David M. Luterman and Mark Ross

Published By: York Press, 1991

Books for Children

Here is a short list of children's books that are written for or about children with hearing loss. There are many, many others not listed here. Any book for children can be read to your young child with hearing loss.

The most important thing to remember is to read to your child from a very young age. Even tiny babies can enjoy books. Reading together with your child is a building block for communication and learning.

Animal Signs: A First Book of Sign Language

By: D. Slier

Published by: Gallaudet University Press, Washington, D.C., 1995

A Very Special Friend

By: Dorothy Levi

Published By: Gallaudet University Press, Washington, D.C., 1989

Cosmo Gets a Hearing Aid

By: G. Clemente and E. Yelchin

Published By: AG Bell, Washington, D.C.

www.agbell.org, (202) 337-5220

Dad and Me in the Morning

By: Patricia Lakin

Published By: Albert Whitman & Company, Morton Grove, Ill., 1994

Dina the Deaf Dinosaur

By: C. Addabbo

Published By: Hannacroix Creek Books, Stanford, CT., 1998

Hooray for Harold: Dealing with Hearing Loss

By: T. Peters

Published By: Tim Peters & Co., Gladstone, N.J., 1997

I Have A Sister- My Sister is Deaf

By: Jeanne Whitehouse Peterson

Published By: Harper Collins, New York, 1977

Mandy

By: Booth, Barbara D.

Published By: Lee Lothrop and Shepherd Books, 1991

My First Book of Sign

By: Pamela J. Baker,

Published By: Gallaudet University Press, Washington, D.C., 1986

Patrick Gets Hearing Aids

By: M. Riski and N. Klakow.

Published By: Phonak, Inc., Warrenville, IL, 1994

Where's Spot

By: E. Hill

Published By: G.P. Putnam's Sons, (In consultation with Gallaudet University), 1995

Word Signs: A First Book of Sign Language

By: D. Slier

Published By: Gallaudet University Press, Washington, D.C., 1995

Videos

Captioned Media Program

The Captioned Media Program loans media without rental fees. The films are open-captioned and there is no need for a decoder. Funding is provided by the U.S. Department of Education. Deaf and hard of hearing persons, teachers, parents and others may borrow materials. Prepaid return labels are included. Other services include provision of free captioning information.

Over 4,000 educational and general-interest open-captioned titles are available. Educational titles include topics in school subject areas, preschool through college. Lesson guides accompany educational videos. General-interest titles include classic movies and special-interest topics such as, travel, hobbies, recreation, and others. Approximately 300 new titles are added each year based on users' recommendations.

Captioned Media Program
National Association of the Deaf
1447 E. Main Street
Spartanburg, SC 29307
(800) 237-6213(V) or (800) 237-6819 (TTY)

American Culture: The Deaf Perspective

(4 Tapes) Available from the San Francisco Public Library,
(415) 557-4433 (TDD) or (415) 557-4434 (V)

Auditory-Verbal Therapy for Parents and Professionals

Introduces AV Therapy, speech-language development, etc. via parent stories and taped therapy sessions,
Available from AG Bell (202) 337-8767

Beginnings

A Program that examines all communication choices without bias
Available from Beginnings, V/TDD (919) 733-5920

Building Conversations

(2 tapes) A family sign language curriculum.
Produced by Boystown National Research Hospital
Www.boysandgirlstown.org

Do You Hear That?

Shows auditory-verbal therapy sessions with children who have hearing aids or cochlear implants.

Available from AG Bell (202) 337-8767

Dreams Spoken Here

A film exploring oral deaf education from infancy through adulthood

Available at www.oraldeaf.org

(877) 672-5332

Families with hard of hearing children: What if your child has a hearing loss?

Parents and professionals talk about having a hard-of-hearing child.

Available from Hope, Inc.

809 North 800 East

Logan, Utah 84321

(801) 752-9533

Home Total Communication Video Tapes

Shows over 1000 signs

Available from Hope, Inc.

809 North 800 East

Logan, Utah 84321

(801) 752-9533

I See What You Say

A 12 minute introduction to Cued Speech from the Cued Speech Center

(919) 828-1218

Read with Me Series

Brenda Schick and Mary Pat Moeller

Available from Boystown Press

www.Girlsandboystown.org/products

Show `N Tell Stories

Bilingual Storytelling for Deaf Children and Their Families

Marlee Matlin introduces Brown Bear, Brown Bear, What Do You See?

And This is Me

Available at Center for Education of Deaf Infants, Berkeley, CA

Signed Cartoons

Includes Superman, Casper, Raggedy Ann, Three Bears, Popeye and The Three Little Pigs

Available from Hope, Inc.

809 North 800 East

Logan, Utah 84321

(801) 752-9533

Sound and Fury

A documentary film about a family's experiences with a decision to have a cochlear implant for their child. Some members of the family are hearing while others are Deaf.

Available from Sound and Fury

PO Box 2284

South Burlington, VT 05407

[Www.pbs.org/wnet/soundfury/film](http://www.pbs.org/wnet/soundfury/film)

Catalogs

AG Bell

3417 Volta Place, NW
Washington, D.C. 20007-2778
Phone: (202) 337- 5220 (V) / (202) 337- 5221 (TTY)
Www. Agbell.org
E-mail: publications@agbell.org

Publishes books and videos. Distributes a wide variety of educational materials.

Dawn Sign Press

6130 Nancy Ridge Drive
San Diego, CA 92121-3223
Phone (858) 625-0600
Fax (858) 625-2336
Www.dawnsign.com
Email info@dawnsign.com

Features books, videos, printed materials on American Sign Language education. Materials and information available on Deaf culture.

Garlic Press

1312 Jeppesen Ave.
Eugene, OR 97401
(541) 345-0063 Fax (541) 683-8767

Features a wide range of educational materials.

Gallaudet University Press

Clerc Center Catalog

Gallaudet University
800 Florida Avenue, NE
Washington, DC 20002
202-651-5000 TTY/V

The Clerc Center catalog offers a comprehensive listing of educational products and services available from the Laurent Clerc National Deaf Education Center. Clerc Center products include books, manuals, curricula, occasional papers in print and online, videotapes, and training programs that provide valuable tools and information for parents, students, professionals, and other people involved in the education of deaf and hard-of-hearing children.

Harris Communications

www.harriscomm.com

1-800-825-6758

A mail order catalog company with many products available including:

- **Assistive Devices:** TTYs, visual or vibrating signalers, closed-captioned decoders, alarm clocks, etc.
- **Assistive Listening Products:** amplified telephones, Pocketalkers, FM systems, Television listeners, etc.
- **Hearing Aid Accessories:** batteries and more.
- **Books, videotapes, CDs, and DVDs:** topics include Deaf culture, sign language, hearing loss, etc.
- **Novelties:** greeting cards, clothing, jewelry, games, posters, etc.

Child Development System, Regional Sites

CDS State Office
State House Station # 146
Augusta, ME 04333
Tel: 624-6660 Fax: 624-6661

CDS- Androscoggin County
377 Main St.
Lewiston, ME 04240
Tel: 795-4022 Fax: 795-4082

CDS- Aroostook County
122 Academy St.
Presque Isle, ME 04769
Tel: 764-4511 Fax: 769-2275

CDS- Cumberland County
50 Depot Rd
Falmouth, ME 04105
Tel: 781-8881 Fax: 781-8855

CDS- Franklin County
144 High St. , Ste 2
Farmington, ME 04938
Tel: 778-6262 Fax: 778-5548

CDS- Hancock County
190 Banor Rd., Ste A
Ellsworth, ME 04605
Tel: 667-7108 Fax: 664-0461

CDS- Knox County
111 Tillson Ave.
Rockland, ME 04841
Tel: 594-5933 Fax: 594-1925

CDS- Lincoln County
P.O. Box 1114
Damariscotta, ME 04543
Tel: 563-1411 Fax: 563-6312

CDS Opportunities
P.O. Box 272
Norway, ME 04268
Tel: 743-9701 Fax: 743-7063

Satellite Office
117 Main St.
Mexico, ME Tel: 369-0312

CDS- Penobscot County
376 Harlow St.
Bangor, ME
Tel: 947-8493 Fax: 990-4819

CDS- Piscataquis County
P.O. Box 312
Dover Foxcroft, ME 04226
Tel: 564-3115 Fax: 564-0019

CDS Project Peds
159 Silver St.
Waterville, ME 04901
Tel: 877-2498 Fax: 877-7459

CDS Search
35A Gurnet Rd.
Brunswick, ME 04011
Tel: 725-6365 Fax: 725-4211

CDS- Southern Kennebec County
263 Water St., Ste 500
Augusta, ME 04330
Tel: 623-4989 Fax: 622-9798

CDS- Waldo County
139 Northport Ave
Belfast, ME 04915
Tel: 338-1177 Fax: 338-9978

CDS- Washington County
P.O. Box 718
Machias, ME 04654
Tel: 255-4892
Fax: 255-6457

CDS- York County
39 Limerick Rd.
Arundel, ME 04046
Tel: 985-7861
Fax: 985-6703

**Maine Newborn Hearing Program , Division of Family Health, Bureau of Health, Department of Human Services
AUDIOLOGY EVALUATION FACILITIES FOR INFANTS**

CATEGORY A

The following facilities have indicated they are able to provide **complete audiological diagnostic testing** recommended by the MNHP for infants referred from hospital newborn hearing screening programs.

(#) = facility has indicated medical center affiliation for sedated testing if needed.

(*) = facility able to provide high frequency tympanometry testing.

BANGOR

Eastern Maine Medical Center (#) (*)

489 State Street, PO Box 404

Bangor, ME 04401

Phone: (207) 973-7365

Fax: (207) 973-5246

LEWISTON

Hearing Healthcare Associates, Inc. (#) (*)

10 High Street, Suite 201

Lewiston, ME 04240

Phone: (207) 786-9949

Fax: (207) 786-9948

PORTLAND

Maxwell, Knowland & Kluger

ENT Associates

43 Baxter Blvd

Portland, ME 04101

Phone: (207) 775-6381

Fax: (207) 775-3378

PORTLAND

Head & Neck Surgical Associates

1250 Forest Avenue

Portland, ME 04101

Phone: (207) 797-5753

Fax: (207) 797-9571

SOUTH PORTLAND

Maine Ear, Nose & Throat (#) (*)

210 Western Ave, 3rd Floor

South Portland, ME 04106

Phone: (207) 780-6000

Fax: (207) 842-6000

WATERVILLE

MaineGeneral Medical Center (*)

30 Chase Avenue

Waterville, ME 04901

Phone: (207) 872-4383

Fax: (207) 872-4222

CATEGORY B

The following facilities have indicated they are able to provide **pediatric audiological testing procedures** for infants referred from hospital newborn hearing screening programs and from diagnostic facilities. Services may include, but are not limited to, sound field testing, screening prior to electrophysiologic testing, otoacoustic emission testing and support services for hearing aid fitting.

(*) = facility able to provide high frequency tympanometry.

AUGUSTA

Hearing Healthcare Associates, Inc. (*)

89 Hospital Street, Suite 3

Augusta, ME 04330

Phone: (207) 622-5922

Fax: (207) 622-6052

BANGOR

Warren Center

For Communication & Learning

175 Union Street

Bangor, ME 04401

Phone: (207) 941-2850

Fax: (207) 941-2852

BELFAST

Hearing Solutions, PA

147 Northport Ave

Belfast, ME 04915

Phone: (207) 338-6770

Fax: (207) 338-3488

BRUNSWICK

Midcoast Hospital

123 Medical Center Drive

Brunswick, ME 04011

Phone: (207) 373-6176

Fax: (207) 373-6180

CAMDEN

MidCoast Speech & Hearing

6 Glencove Drive

Rockport, ME 04856

Phone: (207) 230-6394

Fax: (207) 230-6578

FARMINGTON

Sparkes Hearing Services

201 Front Street

Farmington, ME 04938

Phone: (207) 778-9545

Fax: (207) 778-0003

ORONO

University of Maine

Conley Speech & Hearing Center

5724 Dunn Hall

Orono, ME 04469

Phone: (207) 581-2011

Fax: (207) 581-2060

PORTLAND

Northeast Speech & Hearing Center

43 Baxter Blvd.

Portland, ME 04101

Phone: (207) 874-1065

Fax: (207) 874-1068

PORTLAND

Sound Advice Audiology

1685 Congress Street

Portland, ME 04102

Phone: (207) 828-9590

Fax: (207) 828-1049

PRESQUE ISLE

Aural Rehabilitation Services (*)

6B Martin Street

Presque Isle, ME 04769

Phone: (207) 764-8401

Fax: (207) 768-5749

PRESQUE ISLE

Northern Maine ENT Associates

181 Academy Street, #5

Presque Isle, ME 04769

Phone: (207) 760-8100

Fax: (207) 760-8188

WATERVILLE

Anne Giroux Audiology (*)

124 Silver Street

Waterville, ME 04901

Phone: (207) 872-0320

Fax: (207) 872-0330

YARMOUTH

Yarmouth Audiology

163 Main Street

Yarmouth, ME 04096

Phone: (207) 846-1380

Fax: (207) 846-9701

Facility information is accurate as of July 2003. Information may change due to changes in staffing and diagnostic capacity. Please notify the Maine Newborn Hearing Program with any corrections and updates.

Transportation Agencies

Listing of agencies providing transportation to medical and related appointments for people enrolled in MaineCare.

Aroostook Regional Transportation System

P.O. Box 552
Presque Isle, ME 04769
Mileage Reimbursement:
764-5246 or 1-800-621-1011
Local Bus Service:
764-3384 or 1-800-442-3320

Coastal Transportation Services

46 Summer Street
Rockland, ME 04841
Bath Area: 443-6207 or 1-800-442-3320
Rockland Area: 596-6605 or 1-800-289-6605

Community Concepts Transportation

P.O. Box 278
South Paris, ME 04281
Auburn: 795-6073
Rumford: 364-3685
South Paris: 743-6905

Downeast Transportation

P.O. Box 914
Ellsworth, ME 04605
667-5796

Freeport Taxi (Provide a Ride)

72 Pleasant Hill Rd.
Freeport, ME 04032
865-9400 or 1-800-590-9400

Kennebec Valley Community Action Program (KVCAP) Transportation Agency

P.O. Box 1529
Waterville, ME 04903
Augusta: 622-4761
Waterville: 873-2122
Skowhegan: 474-8487 or 1-800-542-8227

Penquis Community Action Program (Project Ride)

P.O. Box 1162
Bangor, ME 04402-1162
Penobscot County: 973-3695
Piscataquis County: 564-7116 or 1-800-682-1003

PROP (People's Regional Opportunity Program)

510 Cumberland Avenue
Portland, ME 04101
874-1140 or 1-800-698-4959

Western Maine Transportation Services, Inc.

56 Pine Street
Mexico, ME 04257
Norway, South Paris, Lewiston, Auburn: 784-9335
Or 1-800-393-9335
Rumford: 364-2135
Mexico: 1-800-339-9687

Regional Transportation

127 St. John Street
Portland, ME 04102
774-2666 or 1-800-244-0704

Waldo County Transportation

P.O. Box 130
Belfast, ME 04915
338-4769 or 1-800-439-7865

Washington-Hancock Community Agency

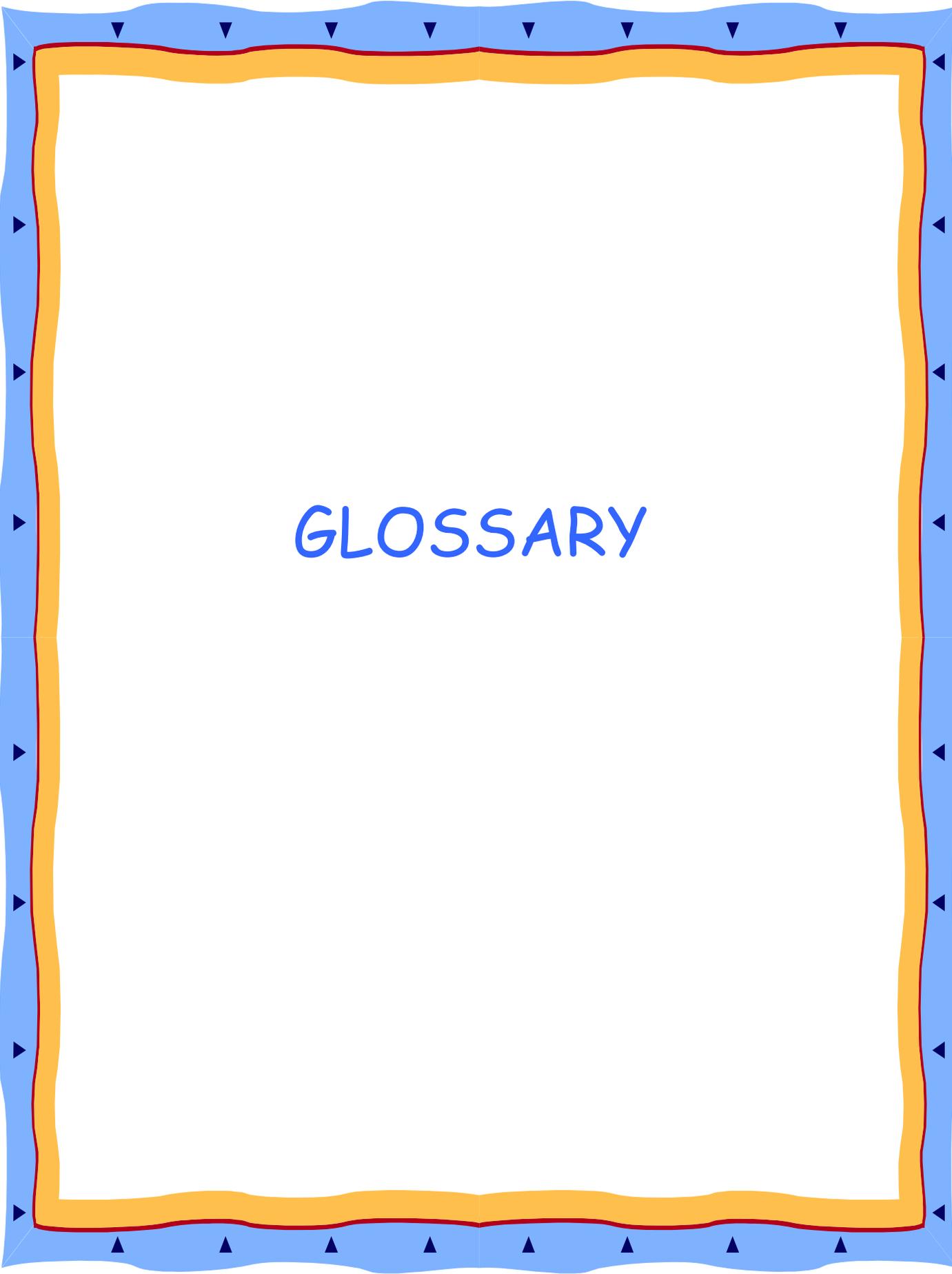
P.O. Box 280
Milbridge, ME 04658
546-7544 or 1-877-374-8396

West Transportation, Inc.

P.O. Box 82
Milbridge, ME 04658
1-800-596-2823 or 546-2823

York County Community Action Program

P.O. Box 72, 11 Cottage Street
Sanford, ME 04073
Biddeford: 283-1446 Buxton: 247-3665
Kittery: 748-1776 Sanford: 324-5762



GLOSSARY

DEFINITIONS

Acquired Hearing Loss - Hearing loss that develops during a person's life and is not present at birth.

Advocacy - The role parents or guardians play in monitoring their child's development and education. Advocating for your child means knowing what rights are assured you by the law and actively participating in the decisions to make sure that your child receives services in line with your goals for your child's development and education.

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 and intensity.

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 which can measure the electrical activity from the hearing nerve in infants and young children.

Auditory Nueropathy/Dysyncrony - 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 will not be heard clearly or consistently.

Auditory Nerve - A nerve found in the inner ear that leads to the brain. The auditory nerve carries nerve signals from sound stimulation to the brain.

Auditory-Verbal - A communication method that focuses on the use of hearing, using cochlear implants or hearing aids, in order to learn English. Speech reading is discouraged during individual therapy session in order to teach a child to "listen" and use what hearing they have. Signing is not used.

Aural-Oral - A communication method that focuses on the use of hearing, using cochlear implants or hearing aids, in order to learn English. Visual supports, such as speech reading, are encouraged as a supplement to listening in order to maximize a child's ability to learn English. Signing is not used.

Behavioral Observation Audiometry (BOA) - A hearing test in 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 - Being fluent in two languages and participating in two cultures. 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 that is in both ears.

Bone Anchored Hearing Aid - Hearing aids designed for conductive hearing losses or mixed hearing losses. The transducer is implanted into the mastoid bone and a removable sound processor makes the transducer vibrate the mastoid bone to stimulate the cochlea so it can "hear" the sound.

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 behind the ear and usually put on with a headband. It allows sound to be moved through bone directly to the inner ear.

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.

Cochlea - A part of the inner ear that is shaped like a snail shell. It changes sounds to nerve impulses and sends them to the auditory nerve.

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 - 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 which 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 English, 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 - 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 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 the appearance of certain phases of a typical childhood.

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 - The presence or growth of bacteria or viruses in the middle ear. It is also called Otitis Media.

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 - A medical doctor who has special training and provides specialty medical care focused on the ears, nose and throat. They are also called an Otolaryngologist or an Otologist.

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 - 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 are 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 hearing 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 with a disability (between the ages **three to twenty-one**). 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 strengths and needs of the child and family and 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 of hearing (cochlea) and the organ of 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 modified and 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 - A communication strategy that understands spoken language by interpreting lip movements, facial expressions, and body movement. It may also be called speech reading.

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 baby'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 - A doctor who specializes in diagnosis and treatment of hearing loss and other disorders of the ear.

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.

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 - 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 are commonly called SLP's and hold a master's degree and must be licensed to practice by the State.

Speech 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 can not be heard by a person with hearing loss.

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.

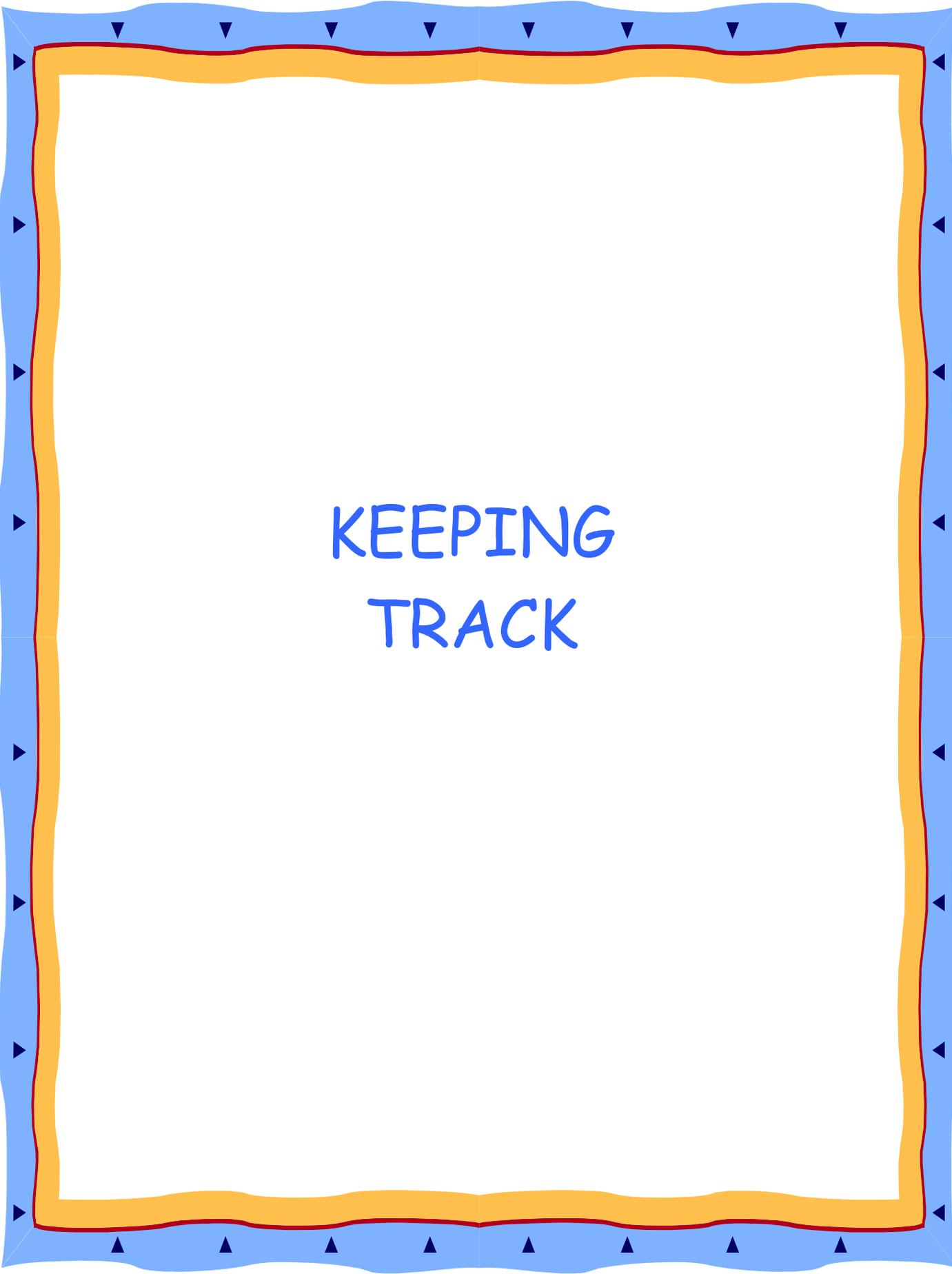
TTY/TTD - TTY = Teletypewriter. TDD = Telecommunication Device for the Deaf. Originally and often still called TTY's, this is a machine that allows people who are deaf or hard of hearing to send or receive written messages transmitted through telephone lines.

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 - 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 he or she hears a sound.



KEEPING
TRACK

Keeping Track

Over the next few years, you and your baby 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.

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Pocket Folder

NOTES

NOTES

FEEDBACK FORM

- Was the Family Information Notebook useful to you and your family?
(Please circle your answer)

Not Useful

Somewhat Useful

Very Useful

Comments:

- Has the information in this notebook helped you to understand the impact of hearing loss on your child and family?
(Please circle your answer)

Not Useful

Somewhat Useful

Very Useful

Comments:

- Did you find this notebook helpful in making decisions about your child's hearing healthcare?
(Please circle your answer)

Not Useful

Somewhat Useful

Very Useful

Comments:

- Did you find the Keeping Track Section of this notebook useful?
(Please circle your answer)

Not Useful

Somewhat Useful

Very Useful

Comments:

- Please rate the sections of this notebook for their usefulness.

(1= most useful 2=somewhat useful 3=least useful)

_____Family Stories Celebrating Children

_____Supporting Your Family

_____Getting the Facts

_____Communication and Language

_____Looking Ahead

_____Keeping Track

_____Resources

_____Glossary

- What other information should be added to make this notebook even more useful to you?

- Additional Comments:

Please mail to:

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Department of Health and Human Service
Bureau of Health
11 State House Station
Augusta, Maine 04333

OR FAX TO: (207) 287-4743

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John Elias Baldacci
Governor

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