

Babies & Hearing Loss

**An Interactive Notebook for Families With
Young Child Who is Deaf or Hard of Hearing**

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This Notebook exists only because families with young children who are deaf and hard of hearing asked for it. Committee members have talked with, and more importantly, listened to many families who have struggled with the diagnosis of their child's hearing loss. Through these discussions, it became clear that what families wished for most was clear and unbiased information. Some of those family members became valuable members of the Wisconsin Sound Beginnings Parent Notebook Committee.

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Our thanks to the many additional parents who shared stories and photographs of their beautiful children with us and allowed us to display them throughout the notebook.

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Dear Parents,

Every expectant parent plans on a healthy child and begins building hopes, dreams and expectations for their new baby. These dreams can be altered when a child is diagnosed with a hearing loss or impairment. Many parents have suggested the diagnosis of their child's hearing loss initiated a mourning process, as well as a new sense of responsibility. With the realization of your child's hearing loss comes the responsibility to gather information, make decisions, and help your baby to grow the best you can.

We understand the dedication, time commitment and sense of overwhelming that comes with this responsibility. The ***Babies and Hearing Loss Notebook*** was created through the collaborative efforts of parents who have been where you are now and professionals who have dedicated their lives to making the "systems" work for you and your child. After a year of loving commitment, enthusiasm, and perseverance, The Wisconsin Sound Beginnings Parent Notebook Committee hopes that this resource will help guide you and your family during this emotional and busy time as well as in the years to come. Even though you may not be ready to use it all right away, it is here for you when you are.

We are very interested in your thoughts on what you found useful or not about this resource and how we can continue to make this notebook more helpful to families. We have included a feedback form at the back of the notebook or you may write to the Wisconsin Sound Beginnings Program at:

Department of Health and Family Services
Attn: Elizabeth Seeliger
One West Wilson Street
P.O. Box 2659
Madison, WI 53701-2659

Best Wishes,

Elizabeth Seeliger
Wisconsin Sound Beginnings
Program Director
Parent Notebook Committee Co-Chair

Loraine Lucinski
Wisconsin CSHCN Program
Parent Consultant
Parent Notebook Committee Co-Chair

Celebrating Your Child

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Celebrating your Deaf or Hard of Hearing Child



I'm scanning my memory, reaching back to December 1981, when our daughter Emily was identified as profoundly deaf. It was September when I first suspected our 10-month old baby couldn't hear. Three months and many professionals later we had a definitive diagnosis of profound deafness. Celebrate? Impossible, I thought. I doubted I'd ever smile again, never mind feel joy or contentment.

This is written for parents in a similar place: discovering their child is deaf or hard of hearing. Today there are more options and new technologies available, yet I know the response in the hearts and minds of parents is not so very different. The knowledge that one's child will face difficulties is never easy to accept or welcome information. A thousand questions run through a parent's mind: How will my child learn? Can we communicate fully? How will this impact our family? How much will this cost, and where will the money come from? Where will I find the time to get my child to therapy? I don't have a car, how can I transport her to therapy and school? What will my child's life be like? Is she sad? Will I muster the strength cope? What about my other child or children? Why did this happen? Who is to blame?

The best advice I can give is to live one day at a time. Learn all you can about what it means to be deaf or hard of hearing. Make every effort to meet other parents with deaf and hard of hearing children. Make every effort to meet older children and adults who are deaf and hard of hearing. Be a smart consumer and seek professionals who will provide honest, unbiased information – consider what might motivate a provider to recommend one approach, treatment or therapy over another. Information leads to power, confidence and comfort for you as parents.

This spring my daughter will graduate from a state university and is applying to graduate schools. Twenty-one years ago I would have given anything to make her deafness disappear; today, her dad and I know we would not want her to be anything other than the deaf person she is. For us, sign language has been the most effective way to relate to each other and for her to learn. She showed us what she needed, what was best for her. It was our job as parents to pay attention to what she communicated. Falling in love with our child was easy, falling in love with the part of her that was "deaf" took some time, but it did happen. Learn, accept support, reject negativism and trust yourself above all.

Continue reading this section of your notebook for reflections from other Wisconsin families who have deaf or hard of hearing children. Be inspired and trust that you are exactly the parent your child needs.

Barbara Aschenbrenner
Smiling Mother of Emily, born 11/80

Personal Stories of Celebration



Here is your chance to meet a few Wisconsin families who have children who are deaf or hard of hearing. They have shared personal celebrations of their children.

Jack, born 9/97



When our deaf son was very young, people would ask, “How’s Jack?” We knew they were most curious about his progress relative to his hearing loss; however, we were bothered when the deafness overshadowed the fact that he was really just a healthy, normal little boy. So, in response to people’s questions, we would tell a story about what Jack was doing. For example, we’d say, “oh, he walks now and is getting into everything.” We think of Jack as a child first, and his deafness is just part of who he is. We try to guide others into seeing him as we do. We must also add that when he was a year and a half old, Jack received a cochlear implant and is making fantastic progress in his speech, listening and language skills.

-- Paul & Molly Martzke, Green Bay

Catherine & Ian, born 8/93



Our twins, Catherine and Ian, are deaf and we have two older boys who are hearing. We suspected first that Catherine couldn’t hear. Ian had us fooled because when I (mom) would rock and sing to him, he’d hum back. Both were tested, and identified with profound hearing losses. Within minutes of the diagnosis, right there in the audiologist’s office, we learned the signs for “ball” and “baby.” I knew our children were ready for language; Catherine was already showing frustration at 13 months of age. We use CASE (Conceptually Accurate Signed English), speaking and signing at the same time in order to include everyone in our family. Within a week or two, the twins were signing back to us. Our older boys are proud to know sign language. Catherine leans more toward using ASL (American Sign Language) while Ian readily acquires English through signs and speech reading. They attend our neighborhood school with the accommodation of an interpreter and keep pace with their peers. At age seven, they were diagnosed with a heart condition called “Long Q-T Syndrome,” which sometimes exists in conjunction with profound deafness. The syndrome is rare, but we encourage parents to speak with their doctor about ruling it in or out. More information can be found on this website: SADS.org

Willa, born 5/97



Willa is our first child, our only child. She failed the newborn hearing screening, and was diagnosed with certain hearing loss a year and a half later. She uses hearing aids and has learned to speak. She does well in school, being mainstreamed into a regular kindergarten class. She loves books and qualifies to attend reading instruction in the first grade classroom at school. We go to the library one or two times per week and read with her every night. Willa even has her own library card! About six months ago, she lost more hearing in her right ear and we hope she will receive a cochlear implant soon. Of course we worry about her future, her education and communication, but we've been through the hardest part. Her grandparents, the whole family, and we all love her very much. She's really no different than any other kid.

-- Allen Tsao & Aiping Gu, Milwaukee

Emma, born 4/97



We've always believed that it's important for people to perceive the deaf or hard of hearing child as a child! So many consider deafness to be a disability. We don't see it that way – our daughter Emma will live a different way. She will require some special accommodations, but basically she just uses different ways to communicate and to learn or approach information and situations. When Emma was young, we suspected that she couldn't hear and thought, "If all we have to do is learn sign language, that's no big deal." We participate in Wisconsin's Deaf Mentor Program and appreciate the education and encouragement we receive from our deaf mentor.

-- Don & Lori Menzel, Kewaskum

Claire, born 11/98



Our daughter Claire was diagnosed at 17 months with a moderate to severe hearing loss. It was hard to believe at the time because she is such a smart little girl who was already speechreading and focusing on visual cues. Once fitted with hearing aids and given access to communication through speech therapy and sign language, she made incredible strides. By age 3 years, her expressive speech was delayed by only six months and her receptive language skills exceeded her actual age! Those are "clinical" statistics that provide a narrow view of Claire. In fact, she is an energetic, inquisitive and affectionate girl who often seems wise beyond her years. She has a sense of humor and loves "knock down hugs." She has taught us to appreciate little things. We'll never forget the look on her face when she realized that our cats, which she'd seen daily since she was born, made noises! She is like any other child in so many ways, yet just a little more special from our perspective.

--Jack & Christine Herden, Monches

Erik, born 2/93



Erik has a severe to profound hearing loss, but with hearing aids, is able to hear in that “speech banana” range at 20-35 decibels. Erik has a fun sense of humor. If you ask him to describe himself he’ll tell you he’s good at video games. His positive, cheerful disposition was helpful for me as his mother when we first discovered his hearing loss at 13 months of age. He continued to be his happy, cheerful self and wondered why I was crying. Today he has a sign language interpreter in school to insure that he doesn’t miss curriculum content, but likes using his speech and hearing to communicate with friends. Erik is an above average reader, a skill we credit to early use of closed captions on television and videos. He’s our third child, so it’s been natural for us to see him as a “whole child” and look beyond the hearing loss to the young, smart, charming person he truly is.

--Frank & Angela Pintar, Wauwatosa

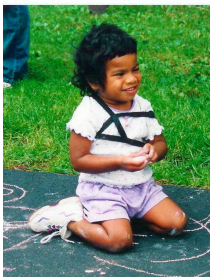
Janeva Mosher, born 8/01



We are deaf, and whether our child was deaf or hearing didn't matter. Neva is deaf and a true blessing. For us this is normal, she is normal, her development is normal and she proves that hearing and deaf children are very much the same. She achieves developmental milestones that are typical of most children. Our daughter is assertive, independent and a delight! A deaf child is a child first and we advise parents of deaf children to relax and enjoy their kids. We love Neva and everyday feel thankful for all the great things she brings to our life, she is such a joy and lights up the world for everyone who meets her. We hope you will meet her someday! All that being true, raising a deaf child is still a process full of decisions - as much so for deaf parents as for hearing parents. We who are deaf may make different decisions, but make them we must, and we encourage parents to get support from other parents to make the process easier.

--Jeff Mosher & Amy Rowley, Franklin

Jennifer, born 9/98



We adopted Jennifer as a newborn, from the Marshall Islands. We knew she was tiny and might have some problems, but didn’t know she was deaf until she was 15 months old. She also has cerebral palsy. People ask us if we’d have adopted her if we’d known about her medical concerns and deafness. Our answer is definitely, “yes! It would never have changed our minds.” Around four months after identifying her deafness and starting to communicate using sign language it “clicked” for us that this was a kind of special way to get to know Jennifer. We believe there’s a reason for this to happen and that her being deaf is just a “different way.”

--Brian & Tammy Hogan, Mukwanago

Jacob, born 7/01



Our son Jacob's hearing loss was identified through a newborn hearing screening. At 13 months he received a cochlear implant. At 17 months he now runs around, pointing and grunting – his way to ask for the names of things. We're involved in a playgroup with hearing kids and observe little difference between him and the other children except that he seems much more expressive non-verbally and often gets his point across more effectively. He's in the oral playgroup at the Center for the Deaf & Hard of Hearing and receives speech therapy at Children's Hospital of Wisconsin. We still use a few signs and if he knows the name of something in sign language, he uses it. It's fun to see the "wheels turning" in his head as he learns. Through Wisconsin's Deaf Mentor Program we've been exposed to Deaf culture, an awesome new experience for us.

-- Ron & Chris Jahnke, Wauwatosa

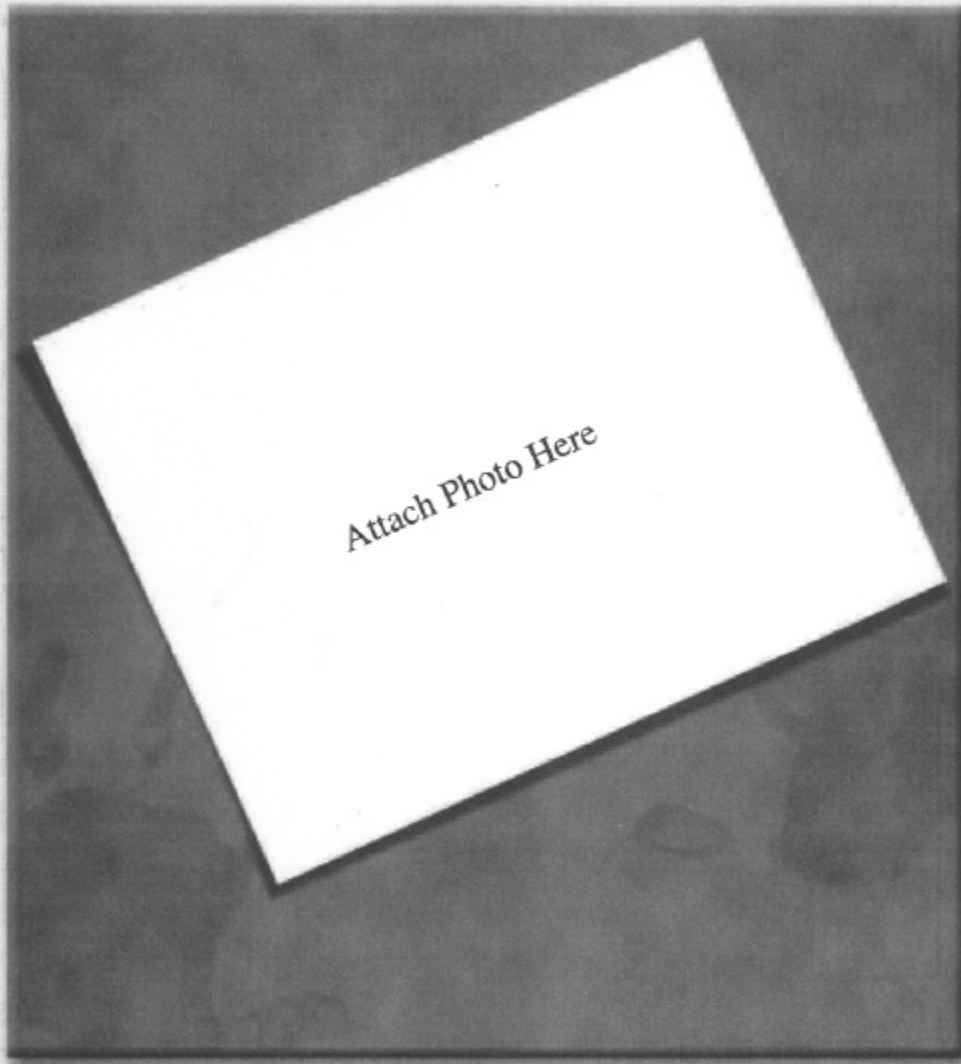
Tess, born 3/98



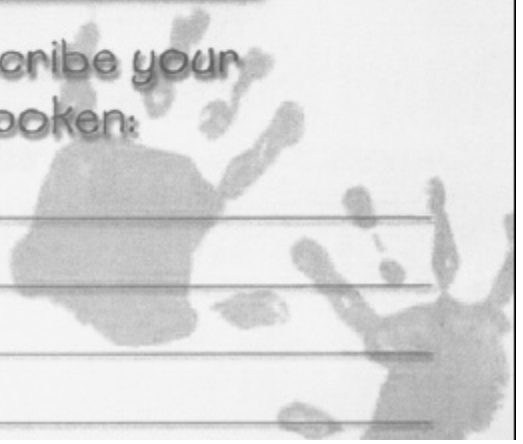
Some people say that a deaf kid is "just a kid." But, our daughter Tess is still a *deaf kid*; we can't separate the deafness from her. She also has Down Syndrome, so for her, things take more time. Moments to celebrate are when she shows that spark of understanding, then uses signs. She tells us a story, her hands flying, and we understand bits and pieces. When things "click" for her it's a thrill because it's taken us so long to get to that point.

--Dan Ruetten & Connie Stevens, Spring Green

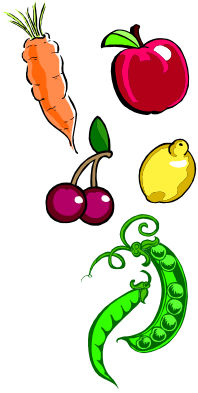
Celebrate your Child's First Word



Here is a place for you to describe your
child's first word, signed or spoken:



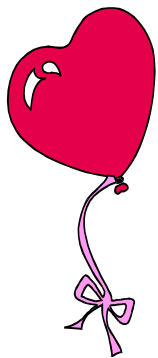
Celebrating Your Child



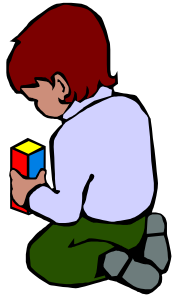
Food and Drink	Likes	Dislikes



Likes	Dislikes	People and Friends



Toys, Blankets and other Things	Likes	Dislikes



Likes	Dislikes	Games and Activities



Books and Songs	Likes	Dislikes

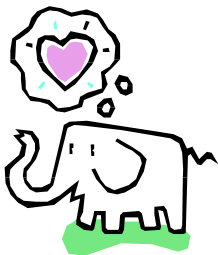
Likes	Dislikes	



How does your child let you know what he/she likes?	How does your child let you know what he/she doesn't like?

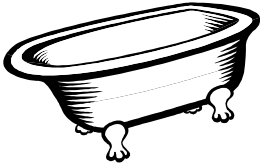


When is your child the most cooperative?	When is your child the least cooperative?



What frightens your child?	What soothes your child?

How do you and your child participate in the following daily routines together?



Feeding	Dressing	Bathing



Naptime/Bedtime	Playtime	Other



What do you do to help your child learn?	What do you do to help your child communicate?

Journal Pages

Just for You



Journal Pages

Just for You



Journal Pages

Just for You



Journal Pages

Just for You



Lined writing area consisting of 20 horizontal lines.

Journal Pages

Just for You



Supporting Your Family

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Supporting your Family



In Wisconsin there are resources and programs to support families of children who are deaf or hard of hearing. The first place we recommend you call or visit is the FirstStep Hotline. This is the State of Wisconsin, Department of Health and Family Services funded hotline. The goal of the hotline is to assist families of children with special needs statewide in identifying appropriate resources and supports. To contact FirstStep call 1-800-FIRSTSTEP or visit <http://www.mch-hotlines.org>.

One of the main programs to assist families of young children who are deaf or hard of hearing in Wisconsin is the Birth to 3 Program. This Program serves children ages birth to three years of age in Wisconsin who have developmental delays or conditions known to result in a developmental delay. The Birth to 3 Program works with each child and family to provide individualized services and supports such as education, therapy, and other supportive services. Many children who are deaf or hard of hearing are eligible for the Birth to 3 Program; eligibility is based on a child's need and not on family income. The FirstStep Hotline can connect you with the Birth to 3 Program in your county.

The ***Supporting your Family*** section will introduce you to local, state, and national resources to support your child and family. It will also share tips and strategies for ways to support, nurture, and interact with your child who is deaf or hard of hearing and strengthen the bond within your family. It was developed because your child's hearing loss impacts everyone he or she is connected to –mothers, fathers, siblings, grandparents and extended family.

Amanda's story of her son Bailey summarizes one person's experience with the process of grief, acceptance, and seeking support:

“I think your son might have hearing problems,” the neurologist told me. I had suspected this, but the blow hit me like a ton of bricks. After audiograms and an MRI we learned his loss was very profound. And yet I was in denial.

I sat in my denial corner for about a year, doing almost nothing to help him in his language development. We were prescribed hearing aids, which Bailey hated and loved to chew on. Then the ENT told me hearing aides were useless and it was time to go total visual language. From that day forward I thanked him and hated him for the news.

I had no prior experience with deaf people. Although I was no longer in denial about Bailey being deaf, I was ignorant as to just what deaf people can do. I had little exposure to deaf people, in fact none. It wasn't until our “in home parent teacher” walked through the door that my impression of deaf people changed. She was a hearing woman married to a deaf man. I had so many questions for her: Can deaf people drive, get jobs, get married, raise children...and how can they if they can't hear? How can someone function if they can't hear?

I quickly learned that the only difference between deaf people and hearing people is language. I'll never forget the feeling of my stereotypes melting away in my heart. Deaf people were normal...they share the same world as I do, and function in it often times better than many hearing people. How about seeing the music in the sunrise or the ocean waves. How about the beautiful visual culture that is filled with eye contact, body contact, warm smiles and hugs? How about the fact that babies pick up and begin using visual language faster than the oral language? For the past year, I saw my child as deaf, now I saw him as a child who laughed and took in the world with pleasure."

Acceptance



Accepting the news that your child has a hearing loss is perhaps the most difficult challenge that you will face with your child. All kinds of questions go through your mind:

- Does my child really have a hearing loss?
- Will it go away, get better?
- Will s/he need hearing aids? How will we afford this?
- Will s/he be made fun of?
- How will the hearing loss affect my child?

When you are told your child is deaf or hard of hearing, it is normal to experience a variety of emotions. These emotions may include shock, fear, denial, sadness, grief, confusion, anger, guilt, disbelief, surprise and relief.

“I can’t remember anything they said after the word “deaf.” I was devastated and shocked. I wasn’t able to get on with my daily activity.”

“I was surprised to learn she had a hearing loss, and I felt guilty about the possible causes.”

“When my daughter’s hearing loss was finally diagnosed I felt such a sense of relief. That might sound odd, but I was so relieved because despite what her doctor and my friends and family had been telling me, I knew something was wrong. Finally getting a diagnosis meant that we had a place to start, we could begin to educate ourselves and try to figure out the next step.”

The experience of learning that your child has a hearing loss often begins a journey that includes a process of grieving. Dealing with the grief, anger, and pain of such a discovery is difficult but necessary. Grieving is important so you can take actions and make decisions that need to be made for your child. You and your family members may grieve differently. It is a very individual journey and **everyone reacts differently.**

“Make time and space for grieving. Something’s been lost, your hope that your child would have “normal” hearing, so that needs to be mourned and grieved for. Find someone (friend, family, counselor) who will let you talk, cry, shout about this loss without judging you, and telling you to move on. Allowing yourself space and permission to grieve, will allow for space to think well about the adjustment you’ll need to make, and how best to help your child. Then love your baby up!”

Acceptance as a process:

Most parents describe acceptance as an ongoing process, one that comes and goes over time. When talking about acceptance you are not just talking about accepting the hearing loss itself. You are also talking about the acceptance that life as you know it has changed. Initially it feels like everything has changed. You knew how to communicate with your child and suddenly that has changed. Now you may be wondering how to communicate, educate,

Material was adapted from the Boys Town website www.babyhearing.org and High Preface.

and interact with your deaf or hard of hearing child. You may now question what options are available to you and your child and what may be in store for the future.

With time, you will realize that the hearing loss is just one part of your child. You will shift from concentrating on the part of your child that is deaf or hard of hearing to seeing the child's hearing loss as one of the wonderful qualities that makes him or her unique. You will learn to accept your child as a whole, as illustrated by the following story:

Jumbo* is a little elephant who is ridiculed by his society because his ears are different. When his mother tries to protect him from his tormentors, she is labeled uncontrollable and then separated from him. The scene which impacts most people is when the other animals and their babies were shown in warm, secure embraces while Jumbo and his mother could only touch through prison bars. All because of his ears.

While Jumbo is fictional, we believe the experience is true to life. Many deaf and hard of hearing children are viewed in terms of their ears – ears that don't work, ears that need to be fixed, ears that need testing and amplifying and maintenance. Ears that result in low language scores. This concentration on ears that need to be made "normal" can interfere with typical, warm, secure embraces, creating a sort of prison barrier within families.

Fortunately, this story has a happy ending. Intervention is provided by a mouse named Timothy who looks at Jumbo's strengths and capitalizes on them. As a result, Jumbo finds success and a sense of self-worth and pride. Jumbo is reunited with his mother and their bond is strengthened. Early intervention can assist the development of self-confident, successful children and their families if we concentrate on the strengths of the whole unit, not just focus on the ears.

* This character is known as "Dumbo", the name of the Disney movie. But his mother named him Jumbo, so we used that term.

Coping Strategies:

The great majority of children who are identified with a hearing loss are born to hearing parents. Only 10 % of people with hearing loss are born to deaf parents. In most cases there is no history of hearing loss in the family, and most know no other families in the same situation. This often leaves parents feeling very alone, and many find themselves searching out others who understand what they are going through. During this time parents find themselves being thrust into new and unfamiliar roles. They suddenly feel the need to become experts on the subject of hearing loss in order to make right decisions for their child, as well as become advocates for the services their child needs immediately, and in the years to come. Initially, this task seems overwhelming for most parents. Some helpful coping strategies may be 1) finding out all you can, 2) connecting with other parents and 3) embracing the knowledge that you and your child can be happy and successful together.

One key to coping for most parents is **finding out all you can** about your child's hearing loss and what it will mean in terms of learning to talk and/or communicate and how it will impact

Material was adapted from the Boys Town website www.babyhearing.org and High Preface.

family dynamics, education, and social development. Often, the path to finding out all you can comes through **connecting with other parents!**

“I had no idea where to begin looking for the info I needed to understand my child’s hearing loss...Getting involved with other parents was a life saver. Being able to talk to those who really understood what we were going through helped tremendously. It helped us to relax and find the comfort that we needed as we struggled to figure out what to do for our child. Even more important was being able to see deaf and hard of hearing children older than our own child. We were able to see just how normal they were, and it helped us to realize she was going to be okay.”

Having a child with a hearing loss does not need to be something awful. You and your child can be happy and successful if you can learn to embrace your child and the hearing loss and accept your ability to parent a deaf or hard of hearing child. **You will learn and grow together.**

Impact of Hearing Loss in a Family



There is no doubt about it. Having a child with special needs changes your family. It adds stresses and blessings that can't be imagined when first hearing the words, "Your child has a hearing loss."

This is a challenge your entire family is going to face for a lifetime. You and your family will experience a continuum of emotions, which may affect how you bond with your child who has a hearing loss and how you continue to bond with others.

You as a parent will be taking on roles and establishing rights that you may have never considered before learning of your child's diagnosis. You may interact differently with your spouse. One parent may take on more responsibility or change their coping and decision making behaviors. The child's grandparents, siblings, extended family and community members will be affected. They too have to adjust to the news and determine what this will mean for them. **Grandparents** have added worries. Their concern is not just for the child who is deaf or hard of hearing, but for their son or daughter and his or her spouse, and for the other grandchildren in the family. They may worry about what their responsibilities will be to the child and their family. Help grandparents to know that the best they can do for their new grandchild is to stay connected to them and keep an open mind about the child's hearing loss. Make sure that your expectations of them are clear. This way they will not needlessly feel like they are letting you down or fail to meet your expectations do to a misunderstanding. They may want to help but may or may not know how. Help them learn what they can do to help you or your child.

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

- In the course of finding answers and services, you and your family may need to share personal and private information with professionals and parents. This may feel very uncomfortable for some people.
- You may feel like you are 'on display'.
- You may feel isolated because those close to you don't understand what you are experiencing.
- You may need to alter your communication style and learn a new language. This may be frightening but also may feel exciting.
- You may find your network of friends changing because you feel like you have different opinions, interests and/or priorities now.
- You may feel overwhelmed. This is very likely because there is so much to learn and consider and so many decisions to make.

Although the effect on **brothers and sisters** will vary, there are some similarities. You as a parent need to be aware that much time and energy will be spent dealing with the hearing loss. The siblings may not get as much attention, causing feelings of 'life isn't fair' and that they are not important. Siblings may need to learn to handle cruelty, insensitivity and/or ignorance of others. They may begin to see themselves as their sibling's unofficial guardians. These experiences may be very stressful for the other children in a family but can

have rewarding results. Siblings often learn an early empathy for others and may appear more mature and independent than other children their age. Be sure to listen to each of your children and seek support on their behalf or for yourself if you feel it is necessary.

Siblings of deaf and hard of hearing children may learn to understand more about what is happening to their brother or sister by visiting places that you go with the child who is deaf or hard of hearing (i.e., audiologist, therapy room, etc.) They may be interested in participating in some of these activities. This is an acceptable practice with many professionals if you ask permission before a session.

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

On the next set of pages there is information about the feelings and possible roles that siblings with a brother or sister with special needs may have. This information was adapted from the Sibling Support Project of the Arc of the United States and is not specific only to siblings who are deaf or hard of hearing. However, it is information that may help you keep the perspective of the sibling in mind as you watch your children develop relationships and become lifelong friends.

Parenting the Child who is Deaf or Hard of Hearing



All children need three types of inner resources if they are to become self-regulating people:

- 1. Good feelings about themselves and others.*
- 2. An understanding of right and wrong.*
- 3. A fund of alternatives for solving problems.*

Twelve Strategies for Enhancing the Parent/Child Relationship and Raising Children Who Will Be Self-Regulating and Responsible Adults:

1. Express Love.

Expressions of love can head off undesirable behavior. When a child feels loved, she wants to please her parents. A warm facial expression, a kind tone, a look of admiration and enthusiasm, a hug, all express love in an unmistakable way. Older children, who may be embarrassed by physical expressions, welcome the personal attention of a one-on-one game or special time with mom or dad.

2. Be Predictable.

Children thrive in a predictable environment. Routines and schedules carried out with consistency provide stability and security. This is also true with parenting behavior -- consistent messages and consistent, reasonable consequences result in a child who trusts his parents. And it can be especially important for some deaf or hard of hearing children who have limited communication skills.

3. Communicate Clearly.

Make sure your words and actions are sending the same message. Young children need to have things spelled out for them -- to teach an abstract concept like "sharing" use examples.

If there is a communication challenge because of deafness or hearing loss, acknowledge the need to purposefully develop strategies to close the gap. With a deaf or hard of hearing child, consider creating a 'quality control' test to make sure your message was understood as intended, including consequences. Have her repeat back what she understood you to say. Role-play to teach productive, appropriate questioning techniques that will be essential at home, at school, and everywhere.

4. Understand Problem Behavior.

By being good observers, parents can gather information that will help them understand what a child's problem behavior means. Look for a pattern. What happens before the behavior starts?

*Adapted and excerpted by Leeanne Seaver from Thelma Harms Ph.D., Univ. of North Carolina, Chapel Hill

When, where, and with whom does it occur? Is there a physical cause such as hunger or fatigue? Was the communication experience unsuccessful -- resulting in frustration, anger and lashing out? Does he feel threatened, hurried or ignored? Is the child seeking attention in an unappealing way? Is he having trouble expressing himself and projecting his negative energy in a physical way? Which is needed... punishment, or a shoulder to cry on?

5. Catch Your Child Being "Good."

It's easy to take for granted what we approve of, and hard to ignore what we don't like. This makes it easy to neglect opportunities to praise good behavior and focus on bad behavior. Let your child feel and see your approval. Turn 'no' statements into 'yes' statements, i.e. "I love how careful you're being with that antique vase."

6. Set Up a Safe Environment.

Children love to explore and thrive in tactile environments where things can be pulled on, climbed over, taken apart and put back together again (maybe). This isn't being naughty -- this is their nature. Make her environment safe. The more there are appropriate things available to explore the fewer problems with inappropriate behavior she will have. Consider how this applies to adolescents and even teenagers. A safe environment is one where the rules and limits are defined and understood. Can she have the car Friday night? Yes, if we know whom she's with, where she's going, and when she'll be back.

7. Set Sensible Limits.

Neither parents nor children want to live in a police-state atmosphere in which there are so many rules it's impossible to avoid breaking them. Generally, very young children can remember only a few rules and a great deal of adult supervision is required to enforce them. Make the language simple and direct, like: "Use words, No hitting."

The limits expand as the child grows older. Going outside established limits is an exercise in trust between parent and child. If your adolescent or teenager demonstrates responsible behavior, he should be rewarded with certain privileges. If he demonstrates a lack of responsibility, the limits may need to be more tightly drawn and defined until trust is built again.

8. Defuse Explosion.

Step in while your child is still calm enough to discuss a problem. Intervene before anger gets out of control. If certain situations are recipes for disaster, talk about them ahead of time and create some plans for coping and resolving. For deaf and hard of hearing kids, not being understood because of a communication mode difference or gap is a common occurrence, and one that lends itself to frustration and anger. Anticipate these kinds of circumstances. Often parents can help children avoid a meltdown with by pointing out problem-solving alternatives that can be employed before the problem rises to a crisis state.

9. Teach Good Problem Solving Skills.

There are good solutions to problems, and not-so-good solutions to problems. How do you get your child to know the difference? Start by clearly labeling unacceptable behavior and explain why. Follow up with positive suggestions for what to do next time. For children under four, it's best to simply state what you want them to do next time. For older kids who can express themselves and think abstractly, ask them what they could do next time that would be better. Suggest additional alternatives. As kids get older and more mature, they'll be able to employ these tactics more successfully if they've been practicing them since childhood.

If the problem stems from communication gaps, which is often true for children with deafness or hearing loss, use the same strategies and exploit every opportunity to expand the child's language base around conflict resolution. Knowing how to express himself and state his position will increase your child's sense of empowerment to successfully solve problems.

10. Don't Overreact.

Giving lots of attention to problem behavior can create another whole set of problems. Telling a child to go to a time-out place or removing her from the play area where she misbehaved delivers a consequence for bad behavior without creating an attention-getting incentive to do the thing again.

11. Seek Professional Help when Needed.

Most children grow out of common behavioral problems with the patient guidance of parents and other caring adults. But for a small percentage (5 to 15%) the problem behaviors persist and can become severe. Professional help is an excellent resource that can provide support and a constructive plan of action.

12. Be Patient with Your Child and Yourself.

Misbehavior happens. It's human nature to learn from our mistakes. And a key to the healthy psychological development lies in the child's ability to do just that. If you follow all 11 steps faithfully and still experience a repeat of bad behaviors, remind yourself that your child is in a learning process called *childhood*. Your consistency, patience and love will provide him or her with the support needed to emerge into mature, autonomous adulthood.

What Siblings Would Like Parents and Service Providers to Know



In the United States, there are over six million people who have special health, developmental, and mental health concerns. Most of these people have typically developing brothers and sisters. Brothers and sisters are too important to ignore, if for only these reasons:

- These brothers and sisters will be in the lives of family members with special needs longer than anyone. Brothers and sisters will be there after parents are gone and special education services are a distant memory. If they are provided with support and information, they can help their sibs live dignified lives from childhood to their senior years.
- Throughout their lives, brothers and sisters share many of the concerns that parents of children with special needs experience, including isolation, a need for information, guilt, concerns about the future, and caregiving demands. Brothers and sisters also face issues that are uniquely theirs including resentment, peer issues, embarrassment, and pressure to achieve.

Despite the important and life-long roles they will play in the lives of their siblings who have special needs, even the most family-friendly agencies often overlook brothers and sisters. Brothers and sisters, often left in the literal and figurative waiting rooms of service delivery systems, deserve better. True “family-centered” care and services will arrive when siblings are actively included in agencies’ functional definition of “family.”

The Sibling Support Project facilitated a discussion on SibNet, its listserv for adult siblings of people with special needs, regarding the considerations that siblings want from parents, other family members, and service providers. Below is a discussion of themes discussed by SibNet members and recommendations from the Sibling Support Project:

1. The Right to One’s Own Life.

Throughout their lives, brothers and sisters may play many different roles in the lives of their siblings who have special needs. Regardless of the contributions they may make, the basic right of siblings to their *own* lives must always be remembered. Parents and service providers should not make assumptions about responsibilities typically developing siblings may assume without a frank and open discussion. “Nothing about us without us”— a phrase popular with self-advocates with special needs — applies to siblings as well. Self-determination, after all, is for everyone — including brothers and sisters.

2. Acknowledging Siblings’ Concerns.

Like parents, brothers and sisters will experience a wide array of often-ambivalent emotions regarding the impact of their siblings’ special needs. These feelings should be both expected and acknowledged by parents and other family members and service providers. Because most siblings will have the longest-lasting relationship with the family member who has a disability, these concerns will change over time. Parents and providers would be wise to learn more about siblings’ life-long and ever-changing concerns.

3. Expectations for Typically Developing Siblings.

Families need to set high expectations for all their children. However, some typically-developing brothers and sisters react to their siblings' special needs by setting unrealistically high expectations for themselves — and some feel they must somehow compensate for their siblings' special needs. Parents can help their typically-developing children by conveying clear expectations and unconditional support.

4. Expect Typical Behavior From Typically Developing Siblings.

Although difficult for parents to watch, teasing, name-calling, arguing and other forms of conflict are common among most brothers and sisters -- even when one has special needs. While parents may be appalled at siblings' harshness toward one another, much of this conflict can be a beneficial part of normal social development. A child with Down syndrome who grows up with siblings with whom he sometimes fights will likely be better prepared to face life in the community as an adult than a child with Down syndrome who grows up as an only child. Regardless of how adaptive or developmentally appropriate it might be, typical sibling conflict is more likely to result in feelings of guilt when one sibling has special health or developmental needs. When conflict arises, the message sent to many brothers and sisters is, "Leave your sibling alone. You are bigger, you are stronger, you should know better. It is your job to compromise." Typically developing siblings deserve a life where they, like other children, sometimes misbehave, get angry, and fight with their siblings.

5. Expectations for the Family Member with Special Needs.

When families have high expectations for their children who have special needs, everyone will benefit. As adults, typically developing brothers and sisters will likely play important roles in the lives of their siblings who have special needs. Parents can help siblings now by helping their children who have special needs acquire skills that will allow them to be as independent as possible as adults. To the extent possible, parents should have the same expectations for the child with special needs regarding chores and personal responsibility as they do for their typically developing children. Not only will similar expectations foster independence, it will also minimize the resentment expressed by siblings when there are two sets of rules — one for them, and another for their sibs who have special needs.

6. The Right to a Safe Environment.

Some siblings live with brothers and sisters who have challenging behaviors. Other siblings assume responsibilities for themselves and their siblings that go beyond their age level and place all parties in vulnerable situations. Siblings deserve to have their own personal safety given as much importance as the family member who has special needs.

7. Opportunities to Meet Peers.

For most parents, the thought of "going it alone," raising a child with special needs without the benefit of knowing another parent in a similar situation would be unthinkable. Yet, this routinely happens to brothers and sisters. Sibshops, listservs such as SibNet and SibKids, and similar efforts offer siblings the common-sense support and validation that parents get from Parent-to-Parent programs and similar programs. Brothers and sisters — like parents — like to know that they are not alone with their unique joys and concerns.

8. Opportunities to Obtain Information.

Throughout their lives, brothers and sisters have an ever-changing need for information about their sibling's special need, and its treatment and implications. Parents and service providers have an obligation to proactively provide siblings with helpful information. Any agency that represents a specific special need or illness and prepares materials for parents and other adults should prepare materials for siblings and young readers as well.

9. Sibs' Concerns about the Future.

Early in life, many brothers and sisters worry about what obligations they will have toward their sibling in the days to come. Ways parents can reassure their typically-developing children are to make plans for the future of their children with special needs, involve and listen to their typically-developing children as they make these plans, consider backup plans, and know that siblings' attitude toward the extent of their involvement as adults may change over time. When brothers and sisters are "brought into the loop" and given the message early that they have their parents' blessing to pursue their dreams, their future involvement with their sibling will be a choice instead of an obligation. For their own good and for the good of their siblings who have special needs, brothers and sisters should be afforded the right to their own lives. This includes having a say in whether and how they will be involved in the lives of their siblings who have special needs as adults, and the level, type, and duration of involvement.

10. Including Both Sons and Daughters.

Just as daughters are usually the family members who care for aging parents, adult sisters are usually the family members who look after the family member with special needs when parents no longer can. Serious exploration of sharing responsibilities among siblings — including brothers — should be considered.

11. Communication.

While good communication between parents and children is always important, it is especially important in families where there is a child who has special needs. An evening course in active listening can help improve communication among all family members, and books, such as *How to Talk So Kid Will Listen and Listen So Kids Will Talk* and *Siblings Without Rivalry* (both by Adele Faber and Elaine Mazlich) provide helpful tips on communicating with children.

12. One-on-One Time with Parents.

Children need to know from their parents' deeds and words that their parents care about them as individuals. When parents carve time out of a busy schedule to grab a bite at a local burger joint or window shop at the mall with their typically-developing children, it conveys a message that parents "are there" for them as well and provides an excellent opportunity to talk about a wide range of topics.

13. Celebrate Every Child's Achievements and Milestones.

Over the years, we've met siblings whose parents did not attend their high school graduation — even when their children were valedictorians — because the parents were unable to leave their child with special needs. We've also met siblings whose wedding plans were dictated by the needs of their sibling who had a special need. One child's special needs should not overshadow another's achievements and milestones. Families who seek respite resources, strive for flexibility, and seek creative solutions can help assure that the accomplishments of all family members are celebrated.

14. Parents' Perspective is More Important than the Actual Special Need.

Parents would be wise to remember that the parents' interpretation of their child's special needs will be a greater influence on the adaptation of their typically developing sibling than the actual disability itself. When parents seek support, information, and respite for themselves, they model resilience and healthy attitudes and behaviors for their typically-developing children.

15. Include Siblings in the Definition of "Family."

Many educational, health care, and social service agencies profess a desire to offer family-centered services but continue to overlook the family members who will have the longest-lasting relationship with the person who has the special needs — the sisters and brothers. When brothers and sisters receive the considerations and services they deserve, agencies can claim to offer "family-centered" instead of "parent-centered" services.

16. Actively Reach Out to Brothers and Sisters.

Parents and agency personnel should consider inviting (but not requiring) brothers and sisters to attend informational, IEP, IFSP, and transition planning meetings, and clinic visits. Siblings frequently have legitimate questions that can be answered by service providers. Brothers and sisters also have informed opinions and perspectives and can make positive contributions to the child's team.

17. Learn More about Life as a Sibling.

Anyone interested in families ought to be interested in siblings and their concerns. Parents and providers can learn more about "life as a sib" by facilitating a Sibshop, hosting a sibling panel, or reading books by and about brothers and sisters. Guidelines for conducting a sibling panel are available from the Sibling Support Project and in the Sibshop curriculum. Visit the Sibling Support Project's website for a bibliography of sibling-related books.

18. Create Local Programs Specifically for Brothers and Sisters.

If your community has a Parent-to-Parent Program or similar parent support effort, a fair question to ask is: why isn't there a similar effort for the brothers and sisters? Like their parents, brothers and sisters benefit from talking with others who "get it." Sibshops and other programs for preschool, school-age, teen, and adult siblings are growing in number. The Sibling Support Project, which maintains a database of over 200 Sibshops and other sibling programs, provides training and technical assistance on how to create local programs for siblings.

19. Include Brothers and Sisters on Advisory Boards and in Policies Regarding Families.

Reserving board seats for siblings will give the board a unique, important perspective and reflect the agency's concern for the well-being of brothers and sisters. Developing policies based on the important roles played by brothers and sisters will help assure that their concerns and contributions are a part of the agency's commitment to families.

20. Fund Services for Brothers and Sisters.

No classmate in an inclusive classroom will have a greater impact on the social development of a child with a disability than brothers and sisters will. They will be their siblings' life-long "typically developing role models." As noted earlier, brothers and sisters will likely be in the lives of their siblings longer than anyone — longer than their parents and certainly longer

than any service provider. For most brothers and sisters, their future and the future of their siblings with special needs are inexorably entwined. Despite this, there is no federal funding to support projects that will help brothers and sisters get the information, skills and support they will need throughout their lives. Governmental agencies would be wise to invest in the family members who will take a personal interest in the wellbeing of people with disabilities and advocate for them when their parents no longer can. As one sister wrote: "We will become caregivers for our siblings when our parents no longer can. Anyone interested in the welfare of people with disabilities ought to be interested in us."

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About the Sibling Support Project

The Sibling Support Project, believing that disabilities, illness, and mental health issues affect the lives of *all* family members, seeks to increase the peer support and information opportunities for brothers and sisters of people with special needs and to increase parents' and providers' understanding of sibling issues.

Our mission is accomplished by training local service providers on how to create Sibshops (lively community-based for school-age brothers and sisters); hosting workshops, listservs, and websites for young and adult siblings; and increasing parents' and providers' awareness of siblings' unique, life-long, and ever-changing concerns through workshops, websites, and written materials.

Based in Seattle since 1990, the Sibling Support Project is the only national effort dedicated to the interests of over six million brothers and sisters of people with special health, mental health and developmental needs.

For more information about Sibshops, sibling issues, and our workshops, listservs and publications, contact:

Sibling Support Project of the Arc of the United States

Don Meyer, Director

6512 23rd Ave NW #213

Seattle, WA 98117

(206) 297-6368

donmeyer@siblingsupport.org

www.thearc.org/siblingsupport/

Bonding Through Early Communication



“When I discovered that Tess was indeed deaf, it impacted how I interacted with her. I stopped talking and singing to her. I was very sad for a few months. I love music. I thought that was an area she could never appreciate and share with me. But after becoming more educated about deafness, I realized that Tess could still benefit from these things. She may not be able to hear it, but she could see my facial expressions that come with talking and singing. She could see my lips move and feel my chest rise and fall with my songs and laughter. She could still enjoy music by dancing with me and feeling the vibrations on the floor and on balloons and drums. I have learned to enjoy her more than I ever thought possible.” --Quote from a mother of a daughter who is deaf.

One question you may be asking yourself is “How am I going to bond with my child when they can’t even hear my voice?” It is not only possible but it is essential!

Bonding means to form a connection with another. This happens at any age but is especially important early on in your child’s life. A strong attachment during early childhood can form the foundation for trust and self-esteem later in life. Although your child may be deaf or hard of hearing, you can connect in many different ways using all of the senses that are available to your child. Communication is an important part of bonding but communication does not need to rely solely on speaking and hearing.

Communication means sending a message and having the other person receive it. For instance, when your baby cries, you will be able to decipher if this is a hunger cry or one associated with pain. Besides crying your baby is attempting all forms of communication with you by using his/her eyes, smiles, kicks, etc. You will instinctively learn to use touch, sight and movement to communicate, thus building their language and the bond between you. You can do all the things you normally do with a child; you will just need to do them a little differently.

“Our first daughter was born in 1986. My husband began to suspect that she couldn’t hear around the time she was six months old. She was finally diagnosed with profound hearing impairment at 14 months of age. I remember thinking how much I loved my daughter but hated the hearing loss. I remember wondering if I still knew my child and feeling very guilty about those thoughts. By the time she was diagnosed, I was pregnant with my second daughter. Because of her sister’s hearing loss, she was screened for hearing loss at birth and had normal hearing. In 1994, my third daughter was born. The hospital had much more sophisticated equipment to do the hearing screening. I was devastated by the news of yet another child with hearing loss. I just hated that news and I was worried. Knowing what I had gone through with my first daughter, I was very worried about bonding with her. With this baby, I knew that I had to do something greater. I knew that she couldn’t hear my voice, so what was I going to do to let her know that I was her mother? I started to sign to her right away but I knew that a newborn’s visual acuity was not very good. I knew that I had to use all of her other senses. So every time I went to pick her up I would blow gently on her cheek so she would always know it was me picking her up.”

-- Quote from a mother of three daughters, two are hard of hearing

The following are some suggestions on how you can gain your child's attention without using cues that require them to use their hearing.

- Get on the same eye level as your child. If they are lying on the bed or floor get down there with them.
- Tap your child gently on the arm.
- Wave your hand within his/her field of vision.
- Lightly shake his/her bed or chair.
- Stamp on the floor.
- Turn the lights on and off quickly.
- If your child is able to perceive sound, make a noise. If they can perceive speech, teach the child to recognize his/her name.

The following are some ways that you can keep your child's attention.

- Face your child and maintain eye contact.
- Create a visual world - use gestures, facial expressions (to convey happiness, sadness, sleepiness, questions, etc.), body movements, and sign language to explain the world to your child.
- Make a scrapbook of your child's favorite people and things and talk about them.
- Point things of interest out to your child.
- Talk to your child - although your child may or may not be able to hear you, he/she learn to read your facial expressions and learn to recognize words on your lips when you talk. It may seem odd to talk to your deaf child but it will get easier as you realize they are so much like other children.
- Move the child's legs and engage in a variety of touching behaviors such as tapping, stroking and tickling. Keep the hands free for possible communication efforts.
- Play, play, play. Anything that engages the child. Copy facial expressions, teach him or her to blow raspberries, play peek-a-boo.
- Offer them books (more about this will be discussed in a section titled, "literacy").

The following are some ways you can make the interaction easier on your child.

- Clear the visual path between you and the child - keep your hands away from your face so the child can see your eyes and lips
- Be aware of light sources and the impact of shade - do not stand in front of an un-shaded window or in front of a lamp that is on. The light from these sources makes it difficult for the child to see you.
- Be aware of competing background noise. When you are talking to your child you may want to turn off the radio or television.

Building conversations builds the child's language base.

Conversation is a lot like a game of volleyball. The rules are simple -- you pass the ball back and forth, taking turns. Everybody gets a chance to serve the ball, and players try to keep the ball in the air. When a child cries or points, she is serving the ball to you. You respond by turning to her and maybe raising your eyebrows as if to say "What do you want?" She then

communicates again. Turn taking is an important part of communication. You want the child to learn that when she gestures, you will respond. By being a responder, you are shaping the child's gestures into true language. When you respond to the child's signals, it is important that you use effective communication, not simply giving the child what he or she wants.

Use the following tools in developing turn taking and conversation.

- Be a good observer. Watch the child and become aware of the ways she is trying to communicate. Look for gestures, reaching, tugging, pointing or other body movements which can communicate meaning. Pay close attention to your child's facial expressions, smiling, fussing or crying, furrowing eyebrows, and eye gaze. Remember that there are many ways for your child to communicate his needs. It is up to you to watch, listen and respond to his/her cues.

Also, tune into situational or contextual clues to figure out what the child is trying to communicate. Does the child go to the kitchen? Maybe she is hungry. Follow the child's lead and comment on your child's world. It is much easier to communicate with someone if they are interested in what is taking place. As your child explores and plays, comment on what is taking place or attach labels for objects that are being played with. For instance, sign or say 'sticky' if your child is exploring something sticky or 'cat, black' if your family pet walks by. You will probably find that your child will be interested in looking at what you have to say and your signs will make more sense if you match his interests. And be patient. You and your child will continue to strengthen your bond as you learn to communicate together.

Encourage your child to keep the conversation going.

- Smile, clap, nod your head up and down.
- Use encouraging words, signs and/or gestures: yes, right, good, thank you.
- Rephrase what your child is communicating; for instance, if they point at the bear, you could sign 'The bear is big.'
- Act as if the child's signal has meaning and sign back.
- Imitation is a good way to respond. If you can't understand the child's sign or gesture, imitate it and sign 'yes.'

Keep interactions fun and simple.

This is what we normally do when interacting with young children who are not deaf or hard of hearing. The same happens when you sign with a deaf child. This makes the child's job of language learning easier because we use words and signs appropriate for a child. Remember, children love repetition. If you are teaching your child a new word or sign use it as often as possible.

Be expressive; use your face and body to support your words. For instance, if you are sleepy you could sign "sleepy" or you could yawn and lay your head on your pretend pillow. When signing "no," you should not be smiling. This might confuse your child.

Draw your child's attention up to your face when you are talking to him/her. If your child is looking at an interesting toy that is lying in front of him, pick it up and put it close to your face before you begin talking about it.

Sometimes, exaggerated facial expressions help make meaning clearer for your child. It may feel very awkward, silly or unnatural to exaggerate your facial expressions for your child. The exercises listed below may help you feel more comfortable.

- During a meal or some other time when family members are together, do all of your communication with facial expression and gestures (no voice or sign).
- Play charades. Act out people or events that have particular emotions attached like a surprise birthday party or Eeyore the mopey donkey from Winnie the Pooh.
- Play follow the leader – everyone must copy the leader's expression. A large mirror makes it more fun so you can see each other and yourself all at once.
- Produce the facial expression that shows each emotion: fear, sadness, surprise, delight, anger, terror, shock, smelling something awful, doubt, excitement.

Remember that your child has four other senses that may be more acute because of their hearing loss. Take advantage of these other senses.

- Offer toys that light up and vibrate.
- Provide different fabrics and textures - let your child develop the sense of touch by allowing them to explore all types of fabric, foods, paint, play-dough, water, etc.
- Make drums out of empty oatmeal containers, coffee cans, pots and pans. They may not hear the noise but they will feel the vibrations.
- Balloons will pick up vibrations - offer these to your child under close supervision since broken balloon pieces can be swallowed.
- Place mirrors around the house at your child's eye level. There are some on the market that are not breakable.

Are we communicating? - Keep a written log.

You may find it helpful to keep a written log of your child's efforts to communicate with you or the other members of your family. You can use the "Are We Communicating?" chart on the following page. Remember to include your child's use of facial expressions, gestures, mime and pointing as well as vocalizations. Next, add your interpretation of what these acts mean and finally how you responded. For instance, your child leads you by the hand to the kitchen. Your translation would be "I'm hungry". The response would be to offer food. In completing this activity you may grow to recognize your child's actions as well as their words as communication. You will also be able to keep track of how your child's communication skills are growing and developing over time. Keeping track of how you and your child communicate may also be helpful as an example to others that will be caring for your child. It will give babysitters, therapists and teachers a better understanding of the ways your child communicates.

You are communicating with your child in many different ways and teaching them important lessons about themselves, your family and about the world.

SUMMARY

Communication is an important way to the bond with your child. It allows your child to express ideas and feelings. It allows you to teach your child about the environment and world he/she lives in. Communication attaches meaning to things. By communicating with your child you are helping him/her build a foundation for language and is the beginning of the road to reading.

Any place can be a good place for you and your child to communicate. Talk, smile, sign, sing, play, and love your child as much as possible. Most all of, have fun discovering together.



Are We Communicating?

Date	What is your child telling you and how?	What does this mean to you?	How did you respond?



Are We Communicating?

Date	What is your child telling you and how?	What does this mean to you?	How did you respond?



Are We Communicating?

Date	What is your child telling you and how?	What does this mean to you?	How did you respond?

Early Literacy



What is literacy and why are we discussing it in relation to children who are deaf and hard of hearing? Being literate involves knowing how to read and write. Children who are deaf and hard of hearing may be dependent on the written word to learn much about the world. First children learn to read and then they read to learn. In addition, like all people, they will need to write in order to communicate their thoughts.

Strong communication with your child can provide the foundation for literacy. Through your daily contact with your child he or she is learning words, thus language. Attaching words and descriptions of activities during your everyday routines (eating, diaper changing, baths, play, shopping) gives your child the building blocks they will need to become literate. Language, whether it is spoken or signed, whether it is English, French or American Sign Language, is learned through interaction with other people. Deaf and hard of hearing children have the same aptitude for language development as hearing children do. However they may interact with their world visually instead of auditorally, depending on their level of hearing loss and the choices you and your family make. In addition to listening and speaking, they watch and often gesture to make their intentions known. So language, reading and writing skills develop at the same time and are closely linked. Early literacy development is a continuous process that begins in the first years of life. The skills develop in real life settings through positive interactions with written materials, language and other people.

Examples of early literacy behaviors follow.

- Book handling – letting children physically manipulate and handle books are some of the earliest stages. They will learn how the pages feel and how to turn them. They will learn to hold the book right side up.
- Looking and recognizing – behaviors related to how children pay attention to and interact with pictures in books such as gazing at pictures or laughing at a favorite picture. Behaviors that show recognition of and a beginning understanding of pictures in books, such as pointing to pictures of familiar objects.
- Picture and story comprehension – behaviors that show a child's understanding of pictures and event in a book, such as imitating an action seen in a picture or talking about the events in a story.
- Story reading behaviors – behaviors that include children's verbal and signed interactions with books and their increasing understanding of print in books, such as babbling in imitation of reading, page turning, or running their finger along printed words.

A summary of strategies to use to promote early literacy follows.

- Emphasize real world activities with associated language
- Talk with your child and let him/her see conversations with others
- Provide positive encounters with reading and reading material

- Expose your child to a variety of print formats
- Turn on the close captioning on your TV
- Read to yourself – if your child sees you reading they will want to model it
- Give access to books and writing utensils

Reading to Deaf and Hard of Hearing Children - Developing Literacy Skills

Additional tips for you to use with your child when reading together follows.

- Let the child choose what book they want to read. If they are still too young to choose themselves, pick age appropriate books. For infants and toddlers, board books are wonderful. They contain bright, simple pictures, are sturdy and easy to hold so they can withstand toddlers' hands and stiff enough to prop up.
- Prop a book up anywhere the infant is located: crib, floor, bouncy seat.
- For infants and toddlers, stick to the main idea. Do not sign or read every word. The child's attention span will only allow you to focus on the main concept.
- Let the child decide how they want to read the book. Let them turn the pages, skip pages, go back and forth. As they get older, they will grow to understand that there is a story in between the covers. The important thing initially is to foster their love of reading. Use big books and flannel boards. Flannel boards use their tactile skills too.
- Don't be limited by the words. Expand on the book's ideas. Talk about what you see in the book and apply it to the child's life. "See that doggie? We have a doggie. Your doggie's name is Max."
- Be dramatic. Make reading fun and interesting. You may even want to act out the story after you have read it. If your child is old enough, involve him/her in the story. Give them a part to play.
- Read it again and again and again. Babies and toddlers love repetition. They may begin to memorize the words to the story and eventually associate their memorized words to the ones written on the page.

Tips for you to use when signing the story with your child follows.

- If you are signing the book to your child, you may want to use a mirror. Some children prefer to sit in an adult's lap, therefore signing can be difficult. Using a mirror allows the child to see your facial expressions, a very important element in sign language.
- Sign on the baby's body and in their space and on the book. They will be focused on the book and may not want to look at the reader/adult.
- Bring the book up to your face to see expression in relation to the story. This helps keep your young child's attention.
- Sign even if the child is not looking at you. Most deaf/hh children are visual and have good peripheral vision. They will catch some of the signing even when not looking at you.

- Use props when reading a book. For instance, let them see that the bear they see in the book and the stuffed bear they play with use the same basic sign.
- If you don't know some signs, don't panic. Use gestures, point to pictures, and act out that part of the story.
- You may want to keep a sign language dictionary close by when reading to look up signs you don't yet know. It may be a good way for you and your child to expand your sign vocabulary. But be careful. If it takes too long to find the word you may lose your child's interest in the book.
- Fingerspell - deaf/hh kids need to know the alphabet and see the connection between letters and words/signs. They are also interested in forming the letters on their little hands.

Resources for Families of Children who are Deaf and Hard of Hearing



There are thousands of resources for parents of children who are deaf and hard of hearing. It's easy to feel overwhelmed by it all! We have tried to help sort through them to compile a listing of major national and statewide organizations for deaf and hard of hearing topics. These organizations provide information about books to read, materials to try, parents to meet, information to learn, and much more. We have not listed any specific materials in this section, as we strongly feel that the age of your child, the mode of communication chosen, the level of your child's hearing loss, and the child's other siblings are all factors that will affect which materials are helpful and relevant to you.

National Resources

Alexander Graham Bell Association for the Deaf and Hard of Hearing (A.G. Bell)

3417 Volta Place NW
Washington, D.C. 20007
(202) 337-5220 Voice
(202) 337-5221 TTY
(202) 337-8314 Fax
<http://www.agbell.org>

A membership organization and information center focusing specifically on children with hearing loss and the auditory approach. Provides newsletters, journals, and information relating to oral education and the use of technology. Financial aid programs available for children with hearing loss.

American Academy of Audiology (AAA)

8300 Greensboro Dr. Suite 750
McLean, VA 22102
(800) AAA-2336 Toll-Free
(703) 790-8466 Voice
(703) 790-8631 Fax
<http://www.audiology.org>

A professional organization dedicated to providing quality-hearing care to the public. Offers professional development, education, research, and increased public awareness of hearing disorders and audiologic services.

American Society for Deaf Children

P.O. Box 3355
Gettysburg, PA 17325
(717) 334-7922 Business V/TTY
(717) 334-8808 Fax
(800) 942-ASDC Parent Hotline
<http://www.deafchildren.org>
E-mail: asdc@deafchildren.org

A nonprofit, parent organization that provides a positive attitude toward signing and deaf culture. It also provides current information, support and encouragement to parents and families with children who are deaf or hard of hearing. Publishes "Endeavor", a publication free to families for one year.

American Speech-Language-Hearing Association (ASHA)

10801 Rockville Pike
Rockville, MD 20852
Helpline: (800) 638-8255 V/TTY
(301) 897-5700 TTY
(240) 333-4705 Fax
<http://www.asha.org>
E-mail: actioncenter@asha.org

ASHA is a national professional association for speech-language pathologists and audiologists. Provides information for professionals and consumers on topics of current interest.

Boys Town

Boystown National Research Hosp
Center for Childhood Deafness
555 North 30th Street
Omaha, NE 68131
(402) 498-6521
<http://www.babyhearing.org>

Boys Town is a research center on hearing loss and related disorders. Provides educational materials for hard of hearing kids and their parents in an easy to access way.

Cochlear Implant Association, Inc.

5335 Wisconsin Ave. NW, Ste
440
Washington, D.C. 20015-2052
(202) 895-2781
(202) 895-2782 Fax
<http://www.cici.org>

Provides information and support to cochlear implant users and their families, and professionals.

Families for Hands and Voices

P.O. Box 371926
Denver, CO 80237
(303) 300-9763
(866) 422-0422 Toll Free
<http://www.handsandvoices.org>

Hands & Voices is a parent driven, non-profit organization dedicated to providing unbiased support to families with children who are deaf or hard of hearing. We provide support activities and information concerning deaf and hard of hearing issues to parents and professionals that may include outreach events, educational seminars, advocacy, lobbying efforts, parent to parent networking, and a newsletter. We strive to connect families with resources and information to make informed decisions around the issues of deafness or hearing loss.

Family Support Connection at Lifetrack Resources.

Lifetrack Resources
709 University Avenue West
St. Paul, MN 55104-4804
(866) DHOHKID (ie, 1-866-346-4543) Toll-free
(651) 265-2379 TTY

Contact Persons:

Candace Lindow-Davies (651) 265-2435
CandaceD@lifetrackresources.org
Laura Iversen (651) 265-2372
LauraI@lifetrackresources.org

The Family Support Connection provides unbiased information, referral, and support to families of deaf or hard of hearing children living in Minnesota. Parents contacting the Family Support Connection can obtain information about a wide variety of topics such as American Sign Language, educational options, cued speech, parent deaf and hard of hearing children, cochlear implants, auditory training and assistive listening devices. Parents can obtain much information about these topics as well as an online copy of our resource directory by visiting <http://www.familysupportconnection.com>

Family Village

Deaf and Hard of Hearing Resources
UW-Madison Waisman Center
1500 Highland Avenue
Madison, WI 53705-2280
http://www.familyvillage.wisc.edu/lib_deaf.htm
E-mail: familyvillage@waisman.wisc.edu

A global community for disability related issues with a section on deaf and hard of hearing information.

Gallaudet University –Laurent Clerc National Deaf Education Center

National Deaf Education Network and Clearinghouse
800 Florida Avenue, NE
Washington, D.C. 20002-3695
<http://clerccenter.gallaudet.edu/InfoToGo/501.html>

Call for a free Odessey newsletter: 1-800-526-9105. Galludet is the only four-year liberal arts university for students who are deaf or hard of hearing. Centralized source of information on topics dealing with deafness and hearing loss. Has helpful books and resources for parents of children who are deaf or hard of hearing.

John Tracy Clinic

806 West Adams Blvd.
Los Angeles, CA 90007
(213) 748-5481 Voice
(213) 749-1651 Fax
(213) 747-2924 TTY
(800) 522-4582 Toll Free
<http://www.jtc.org/index.htm>

Provides parent-centered services to families of children birth through five years who have diagnosed hearing losses. Offers free correspondence course helping you relate to your child who is deaf or hard of hearing.

National Association of the Deaf (NAD)

814 Thayer Avenue #302
Silver Spring, MD 20910-4500
(301) 587-1788 Voice
(301) 587-1789 TTY
(301) 587-1791 Fax
<http://www.nad.org>
E-mail: NADinfo@nad.org

Provides consumer advocacy information and support for the Deaf. Public information center, research library and bookstore are available.

National Information Center for Children and Youth with Disabilities (NICHCY)

P.O. Box 1492
Washington, D.C. 20013
(800) 695-0285 V/TTY
(202) 884-8200 V/TTY
(202) 884-8441 Fax
<http://www.nichcy.org>
Email: nichcy@aed.org

NICHCY is the national information and referral center that provides information on disabilities and disability-related issues for families, educators and other professionals. Special focus is on children and youth up to age 22.

National Institute on Deafness and Other Communication Disorders

National Institutes of Health
31 Center Drive, MSC 2320
Bethesda, MD 20892-2320
<http://www.nidcd.nih.gov>

NIDCD is mandated to conduct and support biomedical and behavioral research and research training in the normal and disordered processes of hearing, balance, smell, taste, voice, speech, and language. The Institute also conducts and supports research and research training related to disease prevention and health promotion; addresses special biomedical and behavioral problems associated with people who have communication impairments or disorders; and supports efforts to create devices which substitute for lost and impaired sensory and communication function.

Self Help for Hard of Hearing People, Inc. (SHHH)

National Chapter
7910 Woodmont Ave. Suite 1200
Bethesda, MD 20814
(301) 657-2248 Voice
(301) 657-2249 TTY
(301) 913-9413 Fax
<http://www.shhh.org>
E-mail: National@shhh.org

Links to education/ children with hearing loss, organizations and other resources on the web. Listserv for parents of heard of hearing kids

Listen Up Web Page

There are a number of different pieces of information, including a parent listserv, materials and programs to purchase about children exercising residual and speech skills, information resources, a special collection of books related to hearing impairment and fun places for kids. It can be found at <http://www.listen-up.org/>

Internet Guide on Deaf and Hard of Hearing and Related Topics

Links to education/children with hearing loss, organizations and other resources on the web maintained by Mississippi State University. It can be found at <http://www2.msstate.edu/~jat/ig.html>

State of Wisconsin Resources

Statewide Information and Referral Services

The organizations listed below may be helpful in identifying and locating appropriate resources, programs, supports or services in Wisconsin.

Wisconsin First Step – First Call for Help

c/o Gunderson Lutheran Medical Center
1910 South Avenue
LaCrosse, WI 54601-9980
1-800-642-7837
<http://www.mch-hotlines.org>

A 24-hour information and referral service to assist families who have children with special needs available seven days a week.

Regional Centers for Children with Special Health Care Needs

- ◆ Northern Regional Center - Rhinelander
Center Name: "Family Resource Connection"
Phone: (715) 365-8030 or (888) 266-0028
- ◆ Northeastern Regional Center - Green Bay
Center Name: "Children with Special Health Care Needs"
Phone: (800) 236-3030 Ext. 8296
Web site: www.northeasternCSHCN.org
- ◆ Western Regional Center - Chippewa Falls
Center Name: "We'Re FOR U"
Phone: (715) 726-7900 or (800) 400-3678
- ◆ Southern Regional Center - Madison
Center Name: "Waisman Resource Center"
Phone: (800) 532-3321 or (608) 263-5890
- ◆ Southeastern Regional Center - Milwaukee
Center Name: "The Special Needs Family Center"
Phone: (414) 266-6333 or (800) 234-5437
Web site: www.specialneedsfamilycenter.org

Statewide Government Agencies

Wisconsin Birth to 3 Program

Department of Health and Family Services
1 West Wilson Street
Madison, WI 53702
(608) 266-8276
<http://www.dhfs.state.wi.us/bdds/b3.htm>

Wisconsin Bureau for the Deaf and Hard of Hearing

The Bureau for the Deaf and Hard of Hearing (BDHH) provides community and informational resources in regions, and technical assistance and training in communication assistive technology, Deaf Culture, and hard of hearing issues. BDHH provides information on and can assist with application to the Telecommunications Equipment Purchase Program (TEPP) and Telecommunications Assistance Program (TAP).

Department of Health & Family Services
1 West Wilson Street
Madison, WI 53702
(608) 266-3118
(608) 266-3118 TTY
<http://www.dhfs.state.wi.us/sensory/>

Northeastern Region

200 North Jefferson Street Suite 311
Green Bay, WI 54301-5191
(920) 448-5295 Voice Interpreted/TTY
(Counties covered: Brown, Calumet, Door, Fond du Lac, Green Lake, Kewaunee, Manitowoc, Marinette, Marquette, Menomonie, Oconto, Outagamie, Shawano, Sheboygan, Waupaca, Waushara, and Winnebago)

Southeastern Region I

141 NW Barstow Street Room 157
Waukesha, WI 53188-3789
(262) 521-5128 Voice/TTY
(Counties covered: Jefferson, Kenosha, Ozaukee, Racine, Walworth, Washington, and Waukesha)

Southern Region

2917 International Lane Suite 230
Madison, WI 53704-3135
(608) 243-5730 Voice/TTY
(Counties covered: Adams, Columbia, Crawford, Dane, Dodge, Grant, Green, Iowa, Juneau, LaFayette, Richland, Rock, and Sauk)

Northern Region

2801 North 7th Street Suite 300
Wausau, WI 54403-3281
(715) 842-7693 Voice/TTY
(Counties covered: Ashland, Bayfield, Florence, Forest, Iron, Langlade, Lincoln, Marathon, Oneida, Portage, Price, Sawyer, Taylor, Vilas, and Wood)

Southeastern Region II

912 North Hawley Road Room 215
Milwaukee, WI 53218
(414) 302-2765 Voice/TTY
(County covered: Milwaukee)

Western Region

610 Gibson Street Suite 1
Eau Claire, WI 54701
(715) 836-2107 Voice/TTY
(Counties covered: Barron, Buffalo, Burnett, Chippewa, Clark, Douglas, Dunn, Eau Claire, Jackson, LaCrosse, Monroe, Pepin, Pierce, Polk, Rusk, St. Croix, Tempeleau, Vernon, and Washburn)

Wisconsin Council on Deaf and Hard of Hearing

(608) 266-3154

<http://www.dhhcouncil.state.wi.us>

E-mail: sykoram@dhfs.state.wi.us

Wisconsin Department of Public Instruction

125 South Webster Street

P.O. Box 7841

Madison, WI 53707-7841 USA

(800) 441-4563 (U.S. Only) / (608) 266-3390

<http://www.dpi.state.wi.us>

**Wisconsin Educational Services Program for the Deaf & Hard of Hearing
(Formerly the Wisconsin School for the Deaf)**

309 West Walworth Avenue

Delavan, WI 53115

(877) 973-3323 Voice

(877) 973-3324 TTY

<http://www.wsd.k12.wi.us/wsdcontact.html>

Statewide General Resources**Deaf Wisconsin Directory**

<http://www.deafworldweb.org/int/us/wi/org.html>

HI-PREFACE Manual

CESA 6

P.O. Box 2568

Oshkosh, WI 54903

(800) 596-7690

Wisconsin developed manuals that serve as a resource guide for parents and providers on comprehensive deaf and hard of hearing topics by section with content information and additional resource information. A small cost is involved.

Parents as Leaders Parent Training Program

UW-Madison Waisman Center

1500 Highland Avenue

Madison, WI 53705

For parents of children under 6:

(800) 532-3321/(608) 263-6745 (Beth)

For parents of children ages 6-14:

(800) 862-3725/(608) 742-8811 (Martha ex 255)

<http://www.waisman.wisc.edu>

This initiative brings together parents of children with special needs to learn about their parental rights and gain advocacy skills.

Wisconsin Association for the Deaf

P.O. Box 397
Darien, WI 53114
(262) 724-4244 Voice
<http://www.wi-deaf.org/>
E-mail:
WADPresidentWIS@aol.com

The mission of WAD is to ensure that a comprehensive and coordinated system of resources is accessible to Wisconsin people who are Deaf and hard of hearing, enabling them to achieve their maximum potential, through independence, productivity, and integration into the community.

Wisconsin Center for the Deaf and Hard of Hearing

3505 North 124 Street
Brookfield, WI 53005
(800) 542-9838 Voice/TTY

Provides early intervention services for children who are deaf and hard of hearing and their families with the goals of building children's communication skills, enhancing their families' ability to communicate with them, and providing complete information about communication options so that parents can make informed decisions. Additional services include: adult services, pre- and post-cochlear implant therapy, audiological services, interpreter referral services, communication technology equipment and much more.

Wisconsin Deaf Citizens Task Force

2782 North 71st Street
Milwaukee, WI 53210
(414) 607-3297 Phone
TTY Relay: 711
<http://www.geocities.com/wdctf2002/>

An advocacy group dedicated to ensure equality and fairness for deaf and hard of hearing citizens of Wisconsin.

Wisconsin Deaf Mentor Project

Deaf Mentor Project
19601 West Bluemound Road Suite 200
Brookfield, WI 53045
Marika Kovacs-Houlihan
Deaf Mentor Project Coordinator
deafmentor@juno.com (first choice contact)
(262) 787-9541 TTY via relay #711
Marcy Dropkin
Project Director, Deaf Mentor Project
(262) 787-9540 Voice/TTY
mdropkin@cesa1.k12.wi.us

Wisconsin Deaf Sports Club

Wisconsin Deaf Sports Club
P.O. Box 55296
Madison, WI 53705-9096
<http://www.wi-deafsports.org/>

Wisconsin Deaf Sports Club (WDSC) is a 501(c)3 non-profit state-wide organization of over 300 members. WDSC offers various recreational activities and competitive sports throughout the year. The recreational activities consist of Door Count Campout, Winterfest, Angles (fishing), picnics and social events. The competitive sports include basketball, flag football, racquetball, softball and volleyball. WDSC is affiliated with Central Athletic Association of the Deaf (CAAD) and USA Deaf Sports Federation (USADSF).

Wisconsin Hispanic Association of the Deaf

<http://www.geocities.com/Heartland/Ranch/6142/whad.html>
E-mail: Barrazaa@milwaukee.tec.wi.us

Wisconsin Self Help for Hard of Hearing People, Inc.

(800) 947-6644 to contact TTY users
<http://www.wi-shhh.org/>

Promotes awareness, education and self help for those with hearing loss through outreach, advocacy, education, legislative and equal access issues that affect those with hearing loss.

Wisconsin Camps

Family Learning Vacation – Organized through the Center for the Deaf and Hard of Hearing. A weekend of fun, learning, communication and more fun for children of all ages who are deaf or hard of hearing and their families! Parents attend workshops while the children participate in a fun-filled Children's Program. Plenty of family time provided as well!

Camp Whitcomb/Mason- Happy Campers Summer Deaf Camp

Contact Mrs. Patricia Dyreson
Director of Religious Education
St. Joseph Church
1905 West Beltline Hwy
Madison, WI 53713
(608) 278-1981 (TTY-Church)
(608) 271-1984 (TTY/Fax-Home)

Deaf children are welcome (ages 6-13) to a five day and five-night summer camp with a Christian emphasis. Sponsored by Catholic Deaf and Hard of Hearing Society of Madison, St. Joseph Archdiocese of Milwaukee and Knights of Columbus of Madison. The camp is a 300-acre, year-round educational facility located on Lake Keesus in Hartland, Wisconsin.

Lion's Camp and Retreat and Conference Center

3834 County Road A
Rosholt, WI 54473
(715) 677-4761 Voice
(715) 677-6999 TTY
(715) 677-4527 Fax
<http://www.wisconsinlionscamp.com>
E-mail: lionscamp@wi-net.com

The Lion's Camp sponsors different camp sessions for DHH children and/or their families. For the families, they usually offer a winter and fall weekend for a reasonable fee. They will provide program activities, lodging and meals. Parents or guardians assume total responsibility for their children while at camp. During the summer, children ages 6-17 are eligible for camp if they require attendance in a special class or school for the deaf or hard of hearing. They are also eligible if they require special aids, instruction, or services even if not taking advantage of them at present.

Resources for Parent to Parent Support Opportunities



The resources listed below are opportunities for you to meet and connect with other parents with deaf and hard of hearing children, either in person or on the internet. It may also be a way for you to support and introduce your child to other kids with hearing loss. The resources are listed by region for your convenience.

Southeast Region

Dreams Come True – Language group for children birth to 5 who are deaf and hard of hearing. Activities are presented using sign and speech.

Scheutze Recreation Center

1120 Baxter Street

Waukesha, WI

Allison Schley

(262) 970-9967

itacr27@worldnet.att.net

Southern Region

Children at the Crossroads Theatre

Madison Civic Center

211 State Street

Madison, WI

They have children's shows on occasional Saturdays and the 1:00 show has a sign interpreter. For more information, call 608- 266-6550 or visit

www.ci.madison.wi.us/cvcenter/series/kitc.html

Shore to Shore – Parent Network based in Madison & Spring Green with statewide connections. Shore to Shore offers children who are deaf & hard of hearing and their families the opportunity to connect in a friendly environment that promotes language, early literacy, and social & emotional development. Activities are presented using sign language and speech. Shore to Shore also sponsors parent education, and ASL classes.

PO Box 374

Spring Green, WI 53588

(608) 588-9101

csteve@merr.com

or

2202 South Park Street

Madison, WI 53713

(608) 256-7799 voice/TTY

(608) 241-5150

shoretoshore1997@hotmail.com

Waisman Center Children's Theatre

1500 Highland Avenue
Madison, WI 53705

Sign interpreters are present at all of their shows. Tickets are \$2.00 for Adults \$1.00 for children. Call (608) 263-5837 for a schedule and directions.

Northeast Region

DEAF – Deaf Education and Families

Support and networking group for parents of deaf and hard of hearing children of all ages that gathers regularly.

Kennedy Elementary School
1754 9th Street

Green Bay, WI 54304

School number (920) 492-2640

Hand-N-Hand Playgroup

The playgroup is for children who are deaf and hard of hearing ages birth to five. Parents and children are encouraged to participate in play, arts & crafts and stories. Activities are presented using sign language and speech. Hand-N-Hand also sponsors parent education classes, which currently include presentations related to hearing loss and sign language classes.

Howe Neighborhood Family Resource Center

526 South Monroe Avenue

Green Bay, WI 54301

Coordinator: Jenny Geiken

(920) 435-0831

jlgeiken@mail.com

St. Elizabeth Ann Seton Parish, Green Bay

Offers interpreted religious services

Michele Stein

(920) 437-7531

Northern Region

Contact the Northern CSHCN Regional Center to find a listing of local parent support opportunities in your region. They can be reached at (888) 266-0028.

Western Region

Contact the Western CSHCN Regional Center to find a listing of local parent support opportunities in your region. They can be reached at (800) 400-3678.

Listservs

DAWN (Disability Advocates: Wisconsin Network) – DAWN is a new grassroots, statewide network of people who care about disability related issues and want to advocate for change through public policy. Sign up at www.wcdd.org then click on DAWN and follow the instructions.

Deaf Education -A practical discussion list regarding deaf education. You can get many emails a day because people are posing questions and others responding (you get all of them). Send an e-mail to this address and in the subject simply type ‘subscribe edudeaf your name’:

Deafdigest – send e-mail to deafdigest@athena.grapevine2.net. This service usually has a long listing of different things. But it is another way to keep in touch with the deaf community.

ParentDeaf-HH: A Parent Support and information list. To subscribe send a message to: listproc@list.educ.kent.edu. The body of the message must say: subscribe PARENTDEAF-HH <yourname without brackets>

Silent Web – Visit DEAFNESS.about.com/gi/pages/mmail.htm and click subscribe

WADnet Posts - This service lets you know what is taking place in the Deaf Community throughout Wisconsin. IT lists play dates of closed-captioned movies, job announcements, social hours, etc. To subscribe write jpowell@mailbag.com (put WADnet in the subject of your e-mail).

PARENTDEAF-HH An internet discussion group for parents founded by the American Society for Deaf Children. To subscribe send a message to listserv@listserv.kent.edu with nothing in the body of the message except: subscribe PARENTDEAF-HH, your name and email address.

Resource Materials



Adco

800-726-0851

<http://www.adcohearing.com>

“From TTYs to closed caption decoders, books, videos and sign language gifts, we are the largest distributor in the Rocky Mountain region of products for the Deaf and Hard-of-Hearing.”

Butte

800-330-9791

<http://www.buttepublications.com>

“At Butte you'll find time tested as well as exciting new titles covering language skill building (English or sign), professional resources, recreation and other interesting and informative publications.”

Dawn Sign Press

800-549-5350

<http://www.dawnsign.com>

“Our books and videos use creative approaches to teaching American Sign Language (ASL) — "a natural and visual language." Many of our publications focus on the education of deaf children, at home and in the classroom. You'll also discover materials on the world of culturally Deaf people-known as the Deaf-World-that will enrich your appreciation of its diversity and its contributions to society.”

Garlic Press

541-345-0063

Features a wide range of books that include sign language.

Gallaudet University Press

<http://gupress.gallaudet.edu>

Gallaudet University Press publishes scholarly and general interest books, children's books under its Kendall Green publications imprint, and sign language and textbooks under the imprint Clerc Books.

Many of these publications are available through the Gallaudet University Bookstore available at 800-621-2736 or <http://bookstore.gallaudet.edu>

Harris

800-825-6758

<http://www.harriscomm.com>

Since 1982, Harris Communications has been the one-stop shop of products for the Deaf community and people with a hearing loss. The product line includes a wide variety of assistive products including text telephones (TTYs), wireless email pagers, amplified phones, assistive listening devices (ALDs), as well as books, videos, and novelties related to hearing loss and sign language.

Kaplan

800-334-2014

Kaplan Products include adaptive toys for children with special needs like Sign language puzzles and computer software.

The Clerc Center Catalog 800-526-9105

<http://clerccenter.gallaudet.edu> click on products

Clerc Center products include books, manuals, curricula, occasional papers, video tapes 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.

Features *Shared Reading Project* book bags.

Penton Overseas 800-748-5804

Features sign language videos for children.

Potomac 800-433-2838

We have a wide range of products for people who are deaf and hard of hearing, including TTYs, signaling and alerting systems, and assistive listening devices. We also have related books, videos, and computer software.

Sign Enhancers 800-767-4461

www.signenhancers.com/home.lasso

Since 1989, Sign Enhancers has won the trust and respect of customers worldwide. This trust has made us one of the largest sign language-related companies in the world. Our products are the best on the market! Go ahead, try them for yourself.

Lending Services

The Catalogs listed above will provide a good feeling for the different materials and items available to support your child. Before purchasing you may want to try them out through the lending service listed below or your local libraries!

Wisconsin Assistive Technology Initiative (WATI)

Polk Library
800 Algoma Blvd
Oshkosh, WI 54901
1-800-991-5576 or 1-920-424-2247
1-920-424-1396 Fax
<http://www.wati.org>

Wisconsin School for the Deaf

309 West Walworth Avenue
Delavan, WI 53115
877-973-3323 Voice: press 0 and ask for library or captioned media
877-973-3324 TTY
<http://www.wsd.k12.wi.us/wsdcontact.html>

To request a list of books and videos which are available through the WSD Library Media Center, call (877) wsd-deaf or email Shelly McDowell at mcdowsr@wsd.k12.wi.us. Ask for the library rate at your post office when you need to return the materials to the WSD library.

Captioned Media Program

800-237-6213

<http://www.cfv.org>

The CMP loans closed captioned videos. These may not be needed until after your child can read but you can find some that use sign language. It is free and they deliver through the US mail. Call (800) 237-6213 for a catalog or visit www.cfv.org.

Funding Sources



Supporting the needs of a child who is deaf or hard of hearing can be very expensive. The following resources have been provided to help you look into funding opportunities. A key has been provided to help you identify which items the resources will or will not fund.

This key will help you know what each source funds...

(H) = Hearing Aids (O) = Other Assistive Technology
(T) = Therapies (I) = Individually Determined Support

National Resources (in alphabetical order)

A.G. Bell (H), (O), (T), (I)

3417 Volta Place, N.W.
Washington, D.C. 20007-2778
(202) 337-5220
(202) 337-5221 TTY

Disabled Children's Relief Fund (T), (O)

P.O. Box 7420
Freeport, NY 11520
(516) 377-1605

Geoffrey Foundation (H), (O), (T)

P.O. Box 1112
Kennebunkport, ME 04046
(207) 967-5798

Hear Now (H), (O)

9745 East Hampden Ave. Suite 300
Denver, CO 80231-4923
(800) 648-HEAR

or

Hear Now (H), (O)

4248 Park Glen Road
Minneapolis, MN 55416
(800) 648-4327

The Hearing Impaired Kids Endowment (Hike) Fund (H), (O)

International Center for Job's Daughters

233 West 6th Street
Papillion, NE 68046
(402) 592-7987

The Hike Fund also has a State contact: (H), (O)

Helen Wheeler
P.O. Box 24
Mauston, WI 53948-9318
(608) 847-4194

Miracle Ear Children's Foundation (H)

(800) 234-5422

Sertoma Club

1912 East Meyer Blvd
Kansas City, MO 64132-1174
(608) 221-3029

Illinois/Wisconsin Regional Director

Mark Sweeney
(217) 529-5692

Sertoma Speech and Hearing Center, Palos Hills, IL

David Rompola
(708) 599-9500

Regional Contact: Starkey Hearing Foundation (H)

P.O. Box 9457
Minneapolis, MN 55440-9457
(952) 941-6401

Travelers Protective Association Scholarship Trust for the Deaf and Near-Deaf

3755 Lindell Blvd
St. Louis, MO 63108
(314) 371-0533

Wisconsin Resources

ABC for Health

152 West Johnson Street Suite 206
Madison, WI 53703-2213
(608) 261-6939
(800) 585-4222 Toll Free
www.safetyweb.org

Advocacy & health benefits counseling
available to all Wisconsin residents with
private or public insurance questions and
concerns.

Hans and Anna Spartvedt Trust

Marshall and Ilsley Trust Company
P.O. Box 8988
Madison, WI 53708-8988
(608) 232-2004

Katie Beckett Medicaid Eligibility Option (H), (O), (T), (I)

Department of Health and Family Services (DHFS)
1 West Wilson Street Room 418
P.O. Box 7851
Madison, WI 53707-7851
(608) 266-0805

Wisconsin Knights Templar Hearing Foundation (H)

Sharilyn Gronitz

36275 Sunset Drive
Dousman, WI 53118
(414) 965-2200
(800) 242-2307

Wisconsin Lions Foundation (H)

Evert Hartvig, Hearing Program Coordinator
3834 County Road A
Rosholt, WI 54473
(877) 463-6953
(715) 677-4969
(715) 677-4527 Fax
<http://www.wlf.info>

Wisconsin Medicaid – General Eligibility (H), (O), (T), (I)

Department of Health and Family Services
1 West Wilson Street
Madison, WI 53702
(800) 362-3002

Wisconsin Telecommunications Equipment Purchase Program (O)

Public Service Commission
P.O. Box 7854
Madison, WI 53707-7854
(608) 231-3305 Voice
(608) 267-1479 TTY
(608) 266-3957 Fax
<http://psc.wi.gov/consumer/telecom/tepp/teppbroc.htm>
E-mail: pscsecs@psc.state.wi.us

Wisconsin Telecommunications Assistance Program (O)

TAP provides funds to people who meet income and hearing loss eligibility criteria to enable them to purchase special telecommunication devices, such as a TTY. For an application, contact:

Wisconsin Department of Health and Family Services
Bureau for the Deaf and Hard of Hearing
1 West Wilson Street
Madison, WI 53702
(608) 266-3118
(608) 266-3118 TTY
<http://www.dhfs.state.wi.us/sensory/TAP/TAP.htm>

Local Resources

Local funding sources known to have provided assistance in covering hearing aids and/or therapeutic services include local chapters of:

- The Lions Club
- The Jaycees
- St. Vincent dePaul chapters
- Goodwill Industries
- Kiwanis Club chapters
- Rotary Club chapters
- Birth to Three Programs
- Family Support Programs

Many service organizations have local chapters that look for beneficiaries each year. If they do not have a fund already set up, many will help organize a local fund drive to cover hearing aids, therapeutic services, medical supplies, or education costs. Contact the president of the chapter to determine if they have programs for children with special needs. The First Step Hotline is a good place to get phone numbers for local organizations that assist children with special needs. Call them at 1-800-642-7837. They are staffed by parents from 8-5 and are incredibly friendly. You can call 24 hours a day as well. They also have a website: www.mch-hotlines.org

Wisconsin Sound Beginnings Birth to 3 Consultant Program



What is the Wisconsin Sound Beginnings (WSB) Birth to 3 Consultant Program?

The mission of the *Wisconsin Sound Beginnings Consultant Program* is to advise and assist local Birth to 3 Programs in providing “best practices” services and supports to families with infants and toddlers who are deaf or hard of hearing.

How Can the WSB Birth to 3 Consultants Help Your County's Birth to 3 Program?

When your county receives a referral for a child who is who is deaf or hard of hearing, we suggest you contact a WSB Birth to 3 Consultant to help your county respond to the child and family's needs. Following are ways a WSB Birth to 3 Consultant can help your county and the families your serve.

- Provide support and assistance to your program when serving a family with a child who is deaf or hard of hearing. In collaboration with your program and staff, our consultants can:
 - Identify the resources, needs and goals of your program through interviews with program administrative and other staff as well as observations of current programming practices and resources.
 - Assist service providers in determining the general strengths and needs of a child through observation of and interaction with the child in his or her natural environment.
- Provide support to service providers in working with the child and family by assisting in determining family strengths, needs, resources and priorities. Our consultants can:
 - Meet with a service provider and family for a face-to-face interview.
 - Utilize telephone contact and e-mail correspondence.
 - Assist in assessment planning.
 - Participate in the development of the IFSP.
- Assist the program administrative staff and/or service providers in exploring the range of services and programming options appropriate to meet the individual child and family situations. Consultants can:
 - Locate available resources that support a specific service or program option.
 - Discuss and provide information on a specific intervention strategy.
- Identify available local, state and national resources available to the child and family, service providers and the Birth to 3 Program. Consultants can:
 - Facilitate and support collaborative partnerships that will support your program.

- Provide assistance, support and resources to families and Birth to 3 Programs as a child and family prepares for transition into the public school and/or other settings that a family may choose at age three. Consultants can:
 - Provide support and information regarding transition and programming available to school-age children.
 - Participate in transition meetings and IEP team meetings.

What Will it Cost Your County to Access the WSB Birth to 3 Consultants?

Wisconsin Sound Beginnings has a limited amount of funding to seed the work of the WSB Birth to 3 consultants. Once you make contact with a WSB Birth to 3 Consultant, you will negotiate this with the consultant. Typically, WSB has funds to support the provision of 2-3 activities per county from a WSB Birth to 3 Consultant. This may include any of the activities describes on the other side of this page, including onsite visits, follow up and other ongoing communication. (See *How Can WSB Birth to 3 Consultants Help Your County?*)

There will be no cost to county Birth to 3 programs for these initial consultation activities. If the consultant agrees to more extensive consultation or is available to fulfill other roles beyond those of the Wisconsin Sound Beginnings Birth to 3 Consultant Program, your county can negotiate directly with that person or her agency for ongoing work. This may include additional consultation or direct service provision.

How Can Your County Contact a WSB Birth to 3 Consultant?

Attached please find a contact list for the Wisconsin Sound Beginnings Birth to 3 Consultants. The list is organized by the five DHFS regions and also includes the statewide training and consultation team. *Please do not hesitate to contact one of the people designated for your region, especially when you receive a referral for a child with a newly confirmed hearing loss.* They are committed, prepared and available to help you. Additionally, the statewide team is available to provide support and assistance to the regional team.

I am excited to have met so many people in the state who are committed to caring for and teaching the children with hearing loss. I am excited to find that there are birth to three teachers and speech language paths that are committed to learning rather than just “getting by” (Wisconsin Sound Beginning Consultant).

The Wisconsin Sound Beginnings Birth to 3 Consultant Program is supported by a grant from the U.S. Department of Health and Human Services, Maternal and Child Health Bureau which has resulted in contracts to the Wisconsin Personnel Development Project (WPDP) of the Waisman Center and the Wisconsin Association of Perinatal Care (WAPC). Other *Birth to 3 Sound Beginnings* supporters include the Wisconsin Department of Public Instruction, and The Wisconsin Department of Health and Family Services, Division of Public Health, Birth to 3 Program, and Bureau for the Deaf and Hard of Hearing.

WISCONSIN SOUND BEGINNINGS
BIRTH TO 3 STATEWIDE TRAINING AND CONSULTATION TEAM

Marcy Dicker Dropkin
Outreach Coordinator
WI Educational Services Program/DHH
Department of Public Instruction
19601 W. Blue Mound Rd.
Brookfield, WI 53045
Phone: 262-787-9540 voice/tty
Fax: 262-787-9501
E-mail: mdropkin@cesa1.k12.wi.us

Anne Heintzelman
Waisman Center-DD Clinic
1500 Highland Ave., Room 155
Madison, WI 53705
Phone: 608-263-9915, Dept. 608-262-3951
Fax: 608-263-0529
E-mail: heintzelman@waisman.wisc.edu

Mary Kahler
Beaver Dam Unified School District
705 McKinley St.
Beaver Dam, WI 53916
Phone: 920-885-7470 X174
Fax: 920-885-7536
E-mail: kahlerm@beaverdam.k12.wi.us

Sherry Kimball
Waisman Center-Bridges B-3
1500 Highland Ave., Room A126
Madison, WI 53705
Phone: 608-263-5984
Fax: 608-265-3441
E-mail: kimball@waisman.wisc.edu

Marika Kovacs-Houlihan
Deaf Mentor Project
19601 W. Bluemound Rd
Milwaukee, WI 53045
Phone: 262-787-9541 (TTY)
Phone: 262-787-9500 (Voice – Front Desk)
E-mail: deafmentor@juno.com

Donna Miller
B-3 Program, DHFS
1 W. Wilson St., Room 418
Madison, WI 53707

Phone: 608-267-5150
Fax: 608-261-6752
E-mail: milledm@dhfs.state.wi.us

Jean Nothnagel
Health Policy Coordinator Birth to 3 Program
DHFS/DSL/BDDS
1 W. Wilson St. PO Box 7851
Madison, WI 53707-7851
Ph: 608.266.5442
Fax: 608.261.6752
E-mail: nothnjl@dhfs.state.wi.us

Carol Schweitzer
Department of Public Instruction
125 S. Webster St
PO Box 7841
Madison, WI 53707
Phone: 608-266-7097
Fax: 608-267-3746
E-mail: carol.schweitzer@dpi.state.wi.us

Elizabeth Seeliger
Dept. of Health & Family Services
1 W. Wilson St., Room 351
Madison, WI 53707
Phone: 608-267-9191
Fax: 608-267-3824
E-mail: seeliel@dhfs.state.wi.us

Alice Sykora
Dept. of Health & Family Services
1 W. Wilson St., Room 451
Madison, WI 53707
Phone: 608-266-3168
Fax: 608-266-3256
E-mail: sykoram@dhfs.state.wi.us

Linda Tuchman
Waisman Center Early Intervention
1500 Highland Ave., Rm S101D
Madison, WI 53705
Phone: 608-263-6467
Fax: 608-265-3441
E-mail: tuchman@waisman.wisc.edu

WISCONSIN SOUND BEGINNINGS BIRTH TO 3 REGIONAL CONSULTANTS

Northern Region

Pamela Brayton
Speech/Language Pathologist
Achievement Center
1640 W. River Drive
Stevens Point, WI 54481
715-342-0393
715-342-0391 (F)
aceip@coredcs.com

Stacie Heckendorf
Educational Audiologist
WESP-DHH
Phone: 608-267-3720
Fax: 608-267-3746
anastasia.heckendorf@dpi.state.wi.us

Mary Jennings
Teacher of Deaf/Hard of Hearing
CESA 12
618 Beaser Avenue
Ashland, WI 54806
715-682-2363
715-682-7244 (F)
maryjenn@cheqnet.net

Kim Nevers
Teacher
Marathon Co. B-3 Program
1100 N. Lake View Drive
Wausau, WI 54403
715-848-4547
715-845-5398 (F)
knevers@norcen.org

Northeastern Region

Bonnie Eldred
Deaf Mentor/Parent
P. O. Box 2372
Fond du Lac, WI 54936
eldredb@charter.net

Jessica Jenkins-Werner
Audiologist/SLP
ENT Surgical Associates/Rehab
Resources
1520 N. Meade St
Appleton, WI 54911
920-734-7181 (W)
920-734-0621 (F)
920-996-0289 (H)
jjenkins@hbs.net

Jennifer Geiken
Teacher of Deaf/Hard of Hearing
1145 Lawe St.
Green Bay, WI 54301
920-435-0831
jlgeiken@mail.com

Angie Zarate
Teacher of Deaf/Hard of Hearing
Appleton Area School District-
Edison School
412 N. Meade Street
Appleton, WI 54911
920-757-1325 (H)
920-832-6235 (W)
920-993-7033 (F)
zarateangela@aasd.k12.wi.us
angjohnz@execpc.com

Southern Region

Connie Stevens
Parent Volunteer/Shore to Shore/
Family Enhancement
P.O. Box 374
Spring Green, WI 53588
608-588-9101
csteve@merr.com

Angela Van Ooyen
Pediatric Speech-Language
Pathologist
Rehab Resources, Inc.
1223 Madison St.
Beaver Dam, WI 53916
920-885-4750
920-885-3839 (F)
vanooyen@charter.net

Southeastern Region

Tracey Irene
Audiologist
Professional Hearing Services
1111 Delafield Street, Suite 102
Waukesha, WI 53188
262-549-5150
262-549-1337 (F)
ti1001@aol.com

Laura Knoke
Child & Family Specialist

Center for DHH
3505 N. 124th St
Brookfield, WI 53005
262-790-1040
262-790-0584 (TTY)
262-790-0580 (F)
LKnoke@cdhh.org

Marika Kovacs
Deaf Mentor Project
19601 W. Bluemound Rd.
Brookfield, WI 53045
Direct TTY: 262-787-9541 (via
relay 711)
Front desk voice: 262-787-9500
deafmentor@juno.com

Allison Schley
Child/Family Specialist
Waukesha, WI
262-970-9967 (H)
itacr27@att.worldnet.net

Western Region

Joyce Klein
B-3 Teacher & Service Coord
Barron County DHHS
330 E. LaSalle, 3rd floor
Barron, WI 54812
715-538-5014
715-537-6848 (F)
jklein@co.barron.wi.us

Cheri Messick
Speech/Language Pathologist
Lakeview Medical Center
1100 N. Main
Rice Lake, WI 54868
715-236-6433
715-236-6588 (F)
messick@chibardun.net

Christy Pletz
Teacher of Deaf/Hard of Hearing
Eau Claire Area School District
875 Kari Drive
Eau Claire, WI 54701
715-833-5350
cpletz@ecasd.k12.wi.us

Getting the Facts

(Insert Tabbed Divider Here)

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. And you may still not understand it. Do not feel bad. Remember that the professionals have had many, many years of schooling to understand the things they are trying to explain to you now. It is OK 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. Be patient with the new information.

In the ***Getting the Facts*** section of this notebook you will find information that will help you better understand the ear, the types of tests used to diagnose hearing loss, the types of hearing loss, and the terminology that is often used when describing each. The terminology that is underlined in this section is also located in the ***Glossary*** found at the back of the notebook.

“When our son was diagnosed with a hearing loss we had to learn two new languages. Sign language and the medical jargon that the professionals used to describe the daily events happening in his life. OAE, ABR, amplification, audiogram, sensorineural, bilateral, visual communication. The list goes on and on. I felt like we needed a translator with us at every appointment.”

Description of the Ear



The ear is made up of three parts:

- Outer ear
- Middle ear
- Inner ear

Outer Ear

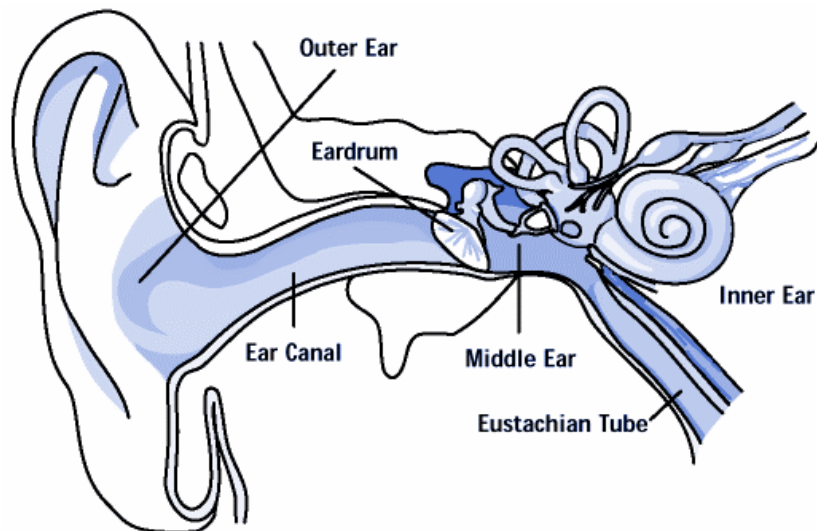
This part of the ear includes the auricle or pinna (ear on the outside of the head) and the ear canal. It is also called the external ear. Sound travels through the ear canal and moves or vibrates the eardrum (tympanic membrane).

Middle Ear

This part of the ear is between the eardrum and the inner ear. The middle ear contains three tiny bones (the ossicles). The eardrum vibrates causing the middle ear bones (ossicles) to move and send the sound through the middle ear to the inner ear. There is also a tube that runs from the middle ear space to the back of the throat called the Eustachian tube.

Inner Ear

The inner ear includes the cochlea (snail shaped organ), the semi-circular canal (balance mechanism), and the auditory nerve (8th cranial nerve leading from the ear to the brain). When the sound vibrations enter the inner ear from the middle ear, the cochlea sends nerve impulses to the brain through the auditory nerve. Once the brain receives the nerve impulses, there is a sensation of hearing.



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 has different possible treatments or therapeutic strategies.

Conductive Hearing Loss:

This type of hearing loss occurs in the outer ear and/or in the middle ear. Something is preventing sound waves from reaching the inner ear. This blockage can be partial or complete. Conductive hearing losses don't cause total hearing loss but do cause a loss of loudness. When the sound is made louder, the sound is heard clearly.

Most conductive hearing losses can be treated with medication, surgery, or environmental change. Sometimes hearing aids or other amplification devices can help by making sound louder.

Common causes of conductive hearing loss are:

- Faulty development of the outer ear and/or middle ear
- Blockage of the ear canal (wax or foreign object)
- Damage to the ear drum
- Damage to the three bones in the middle ear
- Failure of the Eustachian tube to let air into the middle ear space
- Infection in the middle ear
- Fluid in the middle ear
- Growth of extra bony material around the three bones in the middle ear
- Cysts

Sensorineural Hearing Loss:

This type of hearing loss occurs in the inner ear, the auditory nerve or the parts of the brain that receives the nerve impulses from the auditory nerve. This type of hearing loss is sometimes called “nerve deafness.” Hearing loss due to trouble with the auditory nerve is called “auditory neuropathy” or auditory dyssynchrony syndrome.

Sensorineural hearing loss can range from mild to profound. Not only is there a loss of loudness but there is also a loss of clarity. Almost all children with this type of loss will have some degree of loudness and/or clarity left. What hearing is left is called residual hearing. This residual hearing can be amplified and the child may be able to be taught to pick up sounds and/or speech. This type of hearing loss cannot be treated by medication or surgery. It is considered permanent because nerve cells cannot grow back or be replaced.

Common causes of sensorineural hearing loss are:

- Faulty development of the inner ear
- Family history of hearing loss
- Damage to the inner ear and/or hearing nerve from illness before birth
- Rubella

- Toxoplasmosis
- Cytomegalovirus (CMV)
- Meningitis
- Lack of oxygen at birth
- Treatment with certain drugs such as streptomycin, kanamycin, garamycin, ethacrynic acid
- Quinine that reaches toxic levels
- Premature birth with NICU admission
- Damage to ear from loud noises
- Head injuries
- High fever
- Rh factors
- Measles

Mixed Hearing Loss:

A mixed hearing loss occurs in both the outer/middle ear and in the inner ear. It is a combination of conductive and sensorineural hearing loss.

Unilateral Hearing Loss:

A unilateral hearing loss occurs in only one ear. It can be conductive, sensorineural or mixed. Although a child with this loss has good hearing in one ear, he/she will have difficulty knowing where sound is coming from, hearing in noisy environments, and hearing on the affected side.

Progressive Hearing Loss:

A progressive hearing loss occurs when a child loses their hearing over time. A baby may be able to hear at birth and gradually lose their hearing. It is important to note that because a baby passes their newborn hearing screening does ensure that they will always have normal hearing. This loss can be conductive, sensorineural or mixed.

Fluctuating Hearing Loss:

This type of loss is one that changes frequently by improving or worsening. Some conductive hearing losses are fluctuating.

An example of this is hearing that worsens when a child has fluid in the middle ear, caused by an ear infection, and the hearing improves when the infection is resolved.

Syndromic Hearing Loss:

Sometimes an infant or young child who is deaf or hard of hearing may have other signs or symptoms as well. When multiple congenital malformations appear together, they may be described as a syndrome. This is important because if hearing loss is detected early, then specialists, such as genetic professionals, may be able to test for certain syndromes that may not be physically identifiable by appearance alone. Two examples of such syndromes are:

- 1) Usher's Syndrome which is associated with progressive loss of vision
- 2) Jervell and Lange-Nielsen Syndrome, which is associated with heart defects.



Degrees of Hearing Loss and Potential Effects

The following chart was created to help explain what sounds your child may and may not hear without 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 your child's 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/her hearing potential and how they may or may not benefit from use of amplification.

<u>Degree of Loss</u>	<u>Decibels</u>	<u>Potential Effects</u>
Minimal 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 she/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. 50-100% of spoken conversations may be missed. Proper amplification and intervention should enable the child to hear and recognize all sounds.
Moderate to Severe	56-70 dB	Conversation must be very loud to be heard without amplification. Proper amplification will help the child to develop awareness of spoken language. Age of amplification, consist use of hearing aids, and intervention are important to help the child learn to use his/her hearing.

<u>Degree of Loss</u>	<u>Decibels</u>	<u>Potential Effects</u>
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, many children will be able to detect sounds such as speech. Most children will use vision in addition to or in place of hearing.
Profound Hearing Loss	91 dB or	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. Amplification may or may not be useful in hearing spoken conversation.
Unilateral Hearing Loss (one side)		May have difficulty hearing faint or distant spoken conversations. Usually have difficulty knowing where sounds are coming from. May have difficulty understanding spoken conversations coming from the side of the head that has the hearing loss.



Types of Hearing Tests

Hearing testing is done to find out how well a child can hear. Usually an audiologist will do the testing. If a child does have a hearing loss the audiologist may do other tests to find out more specific information about:

- what kind of hearing loss it is
- how severe the hearing loss or the “degree” of hearing loss
- what the reason for the loss is

The audiologist and the family will discuss different ways to help the child and family to communicate. When looking for an audiologist, it is important to find one who has experience with infants and children. If you are looking for an audiologist, contact Wisconsin First Step (800-642-STEP/7837). When first contacting the audiologist, ask what experience they have had with young children.

Different hearing tests may be done depending on the age of the child and the information the audiologist is looking for. The following is a description of different tests and the ages of children they work best with.

Otoacoustic Emissions Testing

Also known as: OAE, DPOAE, TEOAE

How it is done: A small earphone is placed in the ear canal and sound is sent to the eardrum. When the inner ear hears the sound, an echo is sent back. A microphone in the earphone listens for the echo. A strong echo means the ear is hearing normally.

What it will show: It can find a hearing loss that occurs in the inner ear.

Who is it for: This test is used for infants up to 6 months of age, for children who cannot respond to other types of hearing tests, and for children with severe handicaps. It is also used for people of all ages.

Auditory Brainstem Response

Also known as: Brainstem Audiometry Evoked Response, BSER, BAER, ABR.

How it is done: This is a more thorough test than the OAE described above because it tests both the ear and the brain’s response to sound. This test can only be done if the child is either asleep or sedated. Electrodes are attached to the child’s head and tiny earphones are placed over or in the child’s ears. Sounds are given through the ear piece and the electrodes measure how the child’s brain responds. The audiologist will compare your child’s hearing response to information gathered on infants and children with normal hearing. This test gathers specific information about the child’s hearing at different pitches and loudness levels.

What it will show: This test gives an approximation of the amount of hearing. If there is a loss, the type of hearing loss can be found.

Who it is for: This test is used for infants up to 6 months of age, for children who cannot respond to other types of hearing tests, and for children with severe handicaps.

Behavioral Observation Audiometry

How it is done: A trained person in behavioral responses observes the child's reactions to different frequency and loudness that are introduced. Reactions may include a sucking reflex or a head turn.

What it will show: The test relies heavily on parent and provider interpretation. Therefore, this test will only give an approximation of the degree of hearing loss. Earphones are not used which means that information about each ear is not available.

Who it is for: This test is usually done with very young babies, especially when no other test are available.

Visual Reinforced Audiometry

How it is done: The child will sit either in a chair or on the lap of an adult in the sound booth. A toy that is of interest to the child is near the speaker where the sound will come from. When sound is introduced the toy will light up. Children will learn to look at the toy in response to the sound. Children naturally turn to the sound source and this process uses that tendency. Earphones may or may not be used for this test.

What it will show: This test will give information about how your child hears different pitches at different loudness levels. Earphones are used to collect individual ear information. If earphones are not used, the information will reflect the better ear.

Who it is for: This test is used for children of about 6 months to about 2 years of age.

Play Audiometry

How it is done: Children learn to drop a block or perform some other task when they hear a sound. The child is rewarded for a correct response. Some listening activities may include stringing beads, building block towers, putting pegs in a peg board, putting pennies in a bank, or doing a puzzle. Earphones may or may not be used with this test.

What it will show: This test will give information about how your child hears different pitches at different loudness levels. Earphones are used to collect individual ear information. If earphones are not used, the information will reflect the better ear.

Who it is for: This test is used with children older than 17 months.

Pure Tone Audiometry

How it is done: Tones of different pitch and loudness levels are introduced to your child. Your child will indicate if they have heard the tone, usually by raising their hand. The tones are presented either through earphones or through a vibrator placed behind the ear.

What it will show: This test will give information about how your child hears different pitches at different loudness levels. Earphones are used to collect individual ear information. If earphones are not used, the information will reflect the better ear.

Who it is for: This test is used with children older than 30 months.

Tympanometry

Also known as: Impedance testing, immitance testing, compliance and acoustic reflexes.

How it is done: A probe is placed in your child's ear and a signal presented. The signal can be a sound or change in pressure depending on what information the audiologist is trying to gather. The signal bounces off the eardrum and back to the probe. It only takes between 3-30 seconds per ear.

What it will show: Tympanometry will chart the way the eardrum is moving which shows how the middle ear is functioning. It determines if there is fluid in the middle ear or if the middle ear bones are working properly. Compliance testing will measure the point at which the eardrum moves best. It can determine if there is a hole in the eardrum or if the child's tubes are open. Acoustic reflex measure how loud the sound must be to cause the middle ear muscles to contract. Individuals with severe to profound hearing losses do not have these reflexes.

Who it is for: This test is used for any child where a middle ear problem is suspected.

What is an Audiogram?

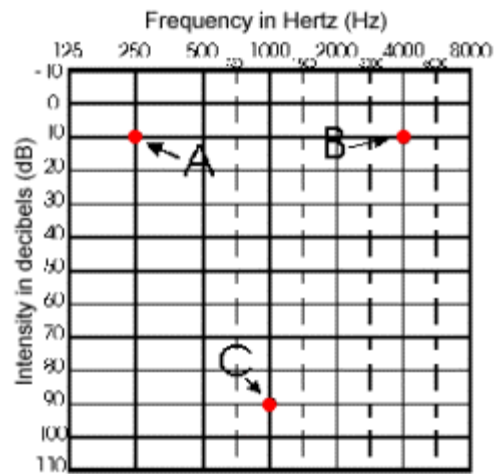


An audiogram is a graph of the softest levels at which your child can hear sound. It is a picture of the results of a test that is done by an audiologist. Your child's audiogram will often be used to describe his/her hearing loss.

The audiogram shows two things: intensity and frequency. Intensity (loudness) is measured in decibels (dB). Loudness levels are located along the lines on the audiogram that are drawn up and down. Intensities usually go from 0 dB to 110 dB; with 0 dB being very quiet and 110 dB being very loud. Frequency, which is another word for pitch, is measured in Hertz (Hz). The different pitches are found along the lines drawn left to right on the audiogram. Pitches range from 125 Hz to 8000 Hz. 125 Hz is a very low sound and 8000 Hz is a very high sound.

What does an audiogram look like?

Every point on an audiogram represents a different sound. For example, point A on the audiogram to the right represents a soft low-pitch sound and point B represents a soft high-pitch sound. Point C represents a loud mid-pitch sound.



As the audiologist tests your child's hearing, they will make marks using different symbols on the audiogram that represent the softest levels at which your child is aware of sound. This softest level of sound awareness is called the threshold. By looking at the point where the pitch and loudness lines cross (where the mark is made), you can see what loudness levels the child can detect at various pitches.

What do the symbols and drawn lines mean on the audiogram?

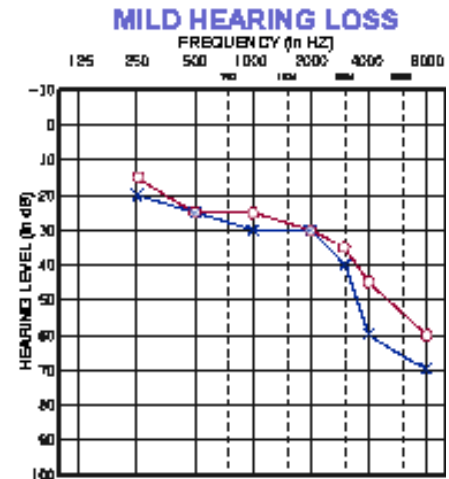
If your child is tested with earphones, it is called Air Conduction testing. Because sound is presented to each individual ear, information can be gathered about the hearing in each ear, separately. The symbols used to represent Air Conduction testing are an X for the left ear and an O for the right ear. Sometimes colors are used for all of the different symbols: red for the right and blue for the left.

If the child does not hear the sound at the loudest level of the audiometer (the machine used to test hearing), it may be indicated several different ways, with a NR (no response), a squiggly downward line, or an arrow downward from the X or O.

Graphs were included with permission from Boys Town National Research Hospital www.babyhearing.org

If your child is tested using a bone conduction vibrator, (a vibrating piece of plastic that is placed behind their ear rather than in it) different symbols will be used. A > is used to show the left ear results and < for the right ear.

After the audiologist has information about various pitches, they will connect the symbols to make a line on the graph for each ear. This line is the configuration of the audiogram. Configurations vary due to 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.

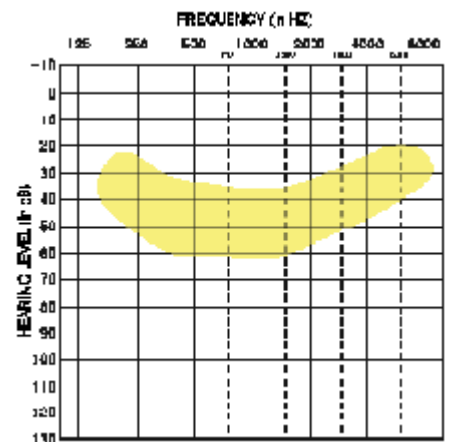


Due to the relationship of hearing and speech, an audiologist may try to get some additional information. The audiologist may try to find out the softest level at which your child can *perceive* speech. This is called the speech detection threshold (SDT).

The audiologist may also try to find out the softest level at which your child *understands* speech. The speech reception threshold (SRT) is typically used with children older than 30 months. The audiologist may read a list of two syllable spondee words (such as baseball, ice cream, and bathtub) to the child and have the child repeat the words or point to a picture. This is usually recorded in decibels.

Word recognition or speech discrimination testing may also be done using hearing alone or using hearing and looking at the audiologist's face. A variety of stimuli are used with this type of test and it is usually recorded in percentages (how many words were repeated correctly).

Many of the speech sounds are made in the pitches between 250 and 5000 Hz and are spoken at a loudness level of 20 dB to 60 dB. Sometimes an audiogram will have shading on it that resembles the outline of a banana and falls in between the pitch and loudness levels mentioned above. This is put on the audiogram to show where speech sounds typically occur. If the audiologist fits a hearing aid on your child, they will try to make sure that your child can hear sounds in this area.



The audiologist may also use the audiogram to chart what sounds your child can hear with hearing aids on. The softest sounds your child can hear with hearing instruments on is called aided thresholds. Many times the letter A will be the symbol used to represent aided thresholds. Ideally, these A's will be within the "banana" lines.

What can you find out from an audiogram?

Although your child's audiogram will be referred to often through the years and may even be used to describe your child's hearing loss; it is **not** a predictive measure. An audiogram can be compared to a growth chart. A growth chart will give you some indication as to how big the child may become as an adult; but it is not a precise indicator of who that child will become. An audiogram can give you an idea of what that child's usable hearing (residual hearing) is, but it is not a precise indicator of how your child will use their hearing to learn speech or how your child will process sound. Remember that every child is unique.

Exploring the Possibilities

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Exploring the Possibilities



Decisions. Selections. Choices. Options.... When you discover that your child is deaf or hard of hearing, you are almost instantly faced with all of these. Decisions about evaluation procedures, selections of hearing instruments, choices about therapies or providers, communication options. All of this can feel utterly overwhelming.

In this section we have chosen to call them *possibilities*. That is what they are. Possibilities are achievable. The ***Exploring the Possibilities*** section, was created to help you better understand the possibilities that exist so that you can feel comfortable about the decisions ahead of you. You will find information about the many different parts of communication. After you have a better sense of the building blocks that make up communication it will be possible to combine them in just about any way to build a communication system that works for your child and family.

You will also find information about the possibilities that exist within amplification systems such as hearing instruments, cochlear implants, and assistive listening devices. Information is knowledge and knowledge is power. Once you learn what possibilities are out there you will have the ability to make decisions for your child and the power to alter those decisions if they are not resulting in positive outcomes.

The Exploring the Possibilities section is a place to discover ways to foster a supportive, predictable and responsive world for your child who is deaf or hard of hearing. You will foster your baby's understanding of the world around him and be his guide in finding the best ways for him to tell others his needs and thoughts. Your child will develop new and creative ways to interact with others and the world around him. The information provided in this section will help you to gather information about and understand many of the ways you and your child can be successful.

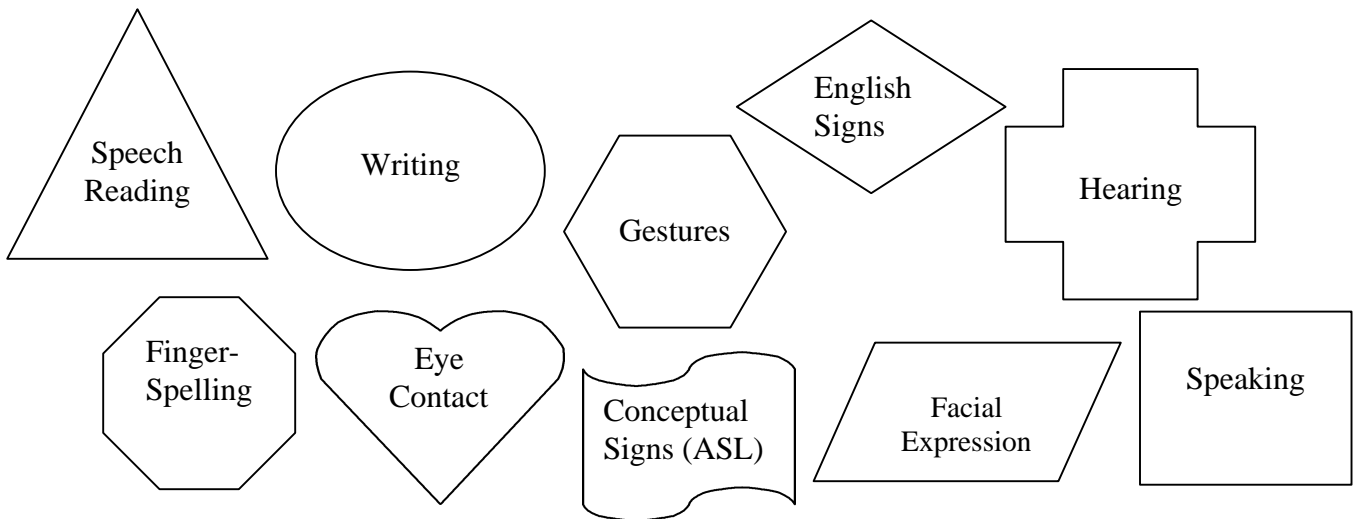
Building Blocks for Communication







Most people think of communication as people talking to one another. However, communication is much more than just talking. It is made up of many different parts, working together. The “verbal part” of communication is talking, or speech, and language. Yet communication never occurs without the “non-verbal parts.” Those non-verbal parts include eye contact, gestures, head and body movement and facial expression. The non-verbal part can also include language in the form of sign language. You simply cannot have one without the other. If you don’t believe it, try to tell someone a story while sitting on your hands, and looking away from them, and using no facial expressions. I bet you will find it nearly impossible.

When you are the parent of a deaf or hard of hearing child, you are almost immediately asked to make decisions about communication. This usually means trying to learn about the variety of options that are available. There are many different communication possibilities. In this section of the notebook we will explore the six most common communication methods; American Sign Language, Auditory-Oral, Auditory-Verbal, Cued Speech and Manually Coded English Systems.

However, before the methods are defined, it is important for you to understand the different components, or building blocks, that make up communication. The building blocks are pictured below. As you look at the pictures, you may want to think about which building blocks are especially important to you and your family. This may help you think about the communication method that will best suite the needs of your family.



KEY

-  Hearing – Use of hearing aids or cochlear implants to maximize your child’s ability to hear.
-  Speaking – Use of your child’s voice to express thoughts, ideas, and opinions.
-  Lip-reading – Your child will watch the speaker’s face and lips for cues about what is being said.
-  Gestures – Movements made by the speaker or listener such as pointing, nodding, etc.

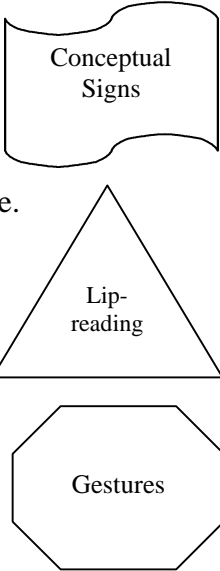
The following boxes include a description of each communication method, the building blocks that are emphasized, the focus or goal of each method and a bit about parent involvement.

American Sign Language (ASL)

Description
ASL is the visual language of many deaf persons in the United States and Canada, those who are part of the Deaf community. It is a distinct language with its own grammar and word order. Fluency in ASL will allow your child full access to the Deaf community. English is often learned as a second language.

Goal
To teach your child to learn a language that utilizes their visual abilities. Your child will learn to communicate fully through the use of their eyes, hands, facial expressions and body movements.

Parent Involvement
You will also need to learn ASL in order to fully communicate with your child. Opportunities to learn ASL are available through books, videos and interactive ASL classes, the statewide Deaf Mentor Program, and through meeting other deaf people. See the resources section in this notebook to locate learning opportunities in your area. Through these experiences, parents may learn more about deaf culture and deaf community resources.



Conceptual Signs

Lip-reading

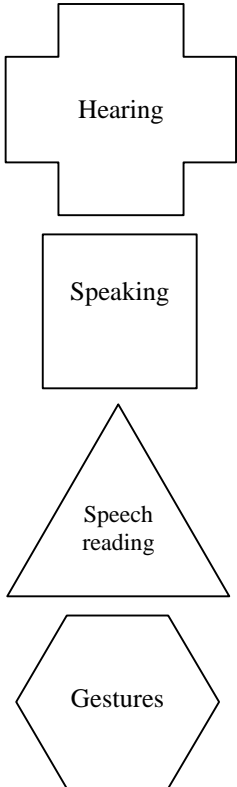
Gestures

Auditory - Oral

Description
Your child will be taught to make the most of what hearing they have through the use of amplification (hearing aids, cochlear implants, FM system). The child's listening skills are encouraged through auditory training with a therapist or early interventionist. Lip-reading is used to aid the child's communication, and while sign language is not encouraged, natural gestures such as facial expressions, hand gestures and body language may be used to support the child's communication.

Goal
To teach your child to develop speech and oral communication, through early, consistent and successful use of an amplification system.

Parent Involvement
You will need to work closely with the child's therapist or early Interventionist to apply training activities in the home and to enhance your child's oral learning environment.



Hearing

Speaking

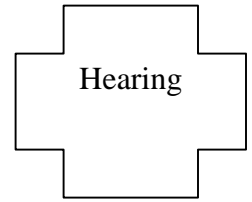
Speech reading

Gestures

Auditory - Verbal

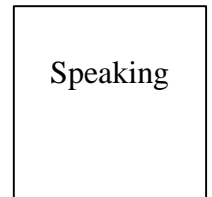
Description

Your child will be taught to make the most of their hearing through the use of amplification (hearing aids, cochlear implants, FM system). The child's listening skills are encouraged through intense, one-on-one auditory training, sometimes with a specially trained Auditory Verbal Integration (AVI) therapist. Sign language is not used and visual cues are strongly discouraged.



Goal

To teach your child to develop speech and oral communication, through early, consistent and successful use of an amplification system.



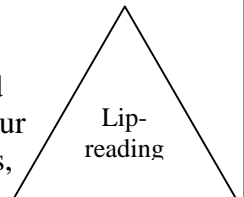
Parent Involvement

With the help of therapists, you will need to incorporate auditory-verbal training activities into your child's daily routine and play activities. It is important to provide a language rich environment and to make hearing a meaningful part of the child's experiences. You will also need to ensure full-time use of amplification.

Cued Speech

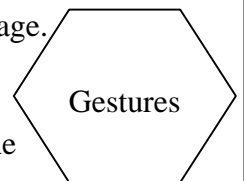
Description

This is a sound-based visual communication system that is made up of eight hand shapes in different positions, which represent groups of consonant sounds, and four positions about the face to represent vowel sounds. Combinations of hand shapes, positions, and locations give cues to the exact pronunciation of words that are mouthed. This system makes it possible for your child to "see" the spoken language.



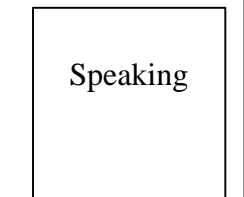
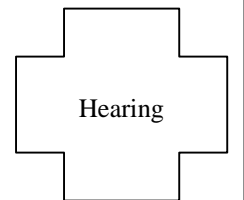
Goal

Your child will learn to speak through the use of amplification, lip-reading and the cues from the hand shape system.



Parent Involvement

You will use hand shape cues when you communicate with your child. Cued speech can be learned through intensive classes taught by trained teachers or therapists. Just like any manual communication system, it takes time and dedication to learn the cues and become proficient in their use.



Manually Coded English Systems

Description

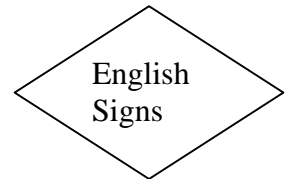
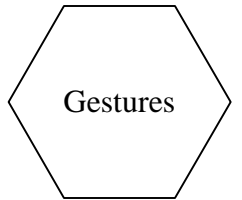
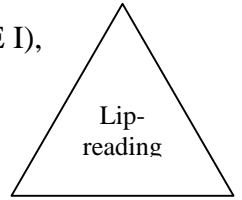
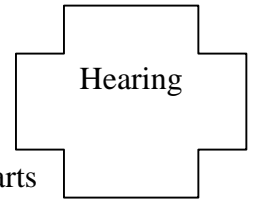
There are several signed systems, which modify the signs used in ASL with to represent English grammar and word order. These sign systems are not languages but are visual representations of English. The signs are used to support spoken English or to convey tenses, plurals, possessives, and other parts of the English language. Examples of manually coded sign systems are Signed English (a.k.a. Manually Coded English), Seeing Essential English (SEE I), and Signing Exact English (SEE II).

Goal

Your child will learn to use signs as words and learn to sign using the word order and grammar of English. Your child will learn to sign the little words used in English such as “a” and “the” and grammatical endings such as “-ing” and “-ed”.

Parent Involvement

You will also need to learn the signed system that you choose for your child and just like any manual communication system, it takes time and dedication to learn the system and become proficient at using it.



When you are “deciding on” a communication method, it is important to remember that no choice is permanent. If you choose an approach that focuses on one building block and it does not seem to be working for your child after several months of consistent effort, there is no reason that you cannot try a different approach. The important thing is to communicate in one way or another with your child.

About Fitting Hearing Aids for Infants and Young Children



Hearing loss can affect communication. Understanding hearing loss and the role hearing instruments play is helpful in making informed decisions. Fitting and selecting hearing instruments for your child can be an important, costly and confusing process. The following information may be helpful as you enter this phase with your child.

The Importance of Hearing Instruments

Children who have normal hearing begin using single words at about one year of age. In reality, a great deal of language is learned before children utter their first word. Hearing loss can disrupt language development because learning spoken language depends on the ability to hear speech.

The earlier that finding and addressing any hearing loss begins, the greater the possibility of developing listening abilities and using spoken language. The use of hearing instruments is an integral part of this process.

Audiologists usually recommend hearing instruments as soon as possible after a loss is identified. Ideally, an audiology facility that specializes in serving young children will have a cost-saving loaner hearing instrument program where a loaner hearing instrument can be selected immediately after a hearing loss is determined. As more complete information about a child's loss is obtained, a hearing instrument evaluation can be completed to recommend hearing instruments for purchase.

Tests necessary before Receiving Hearing Instruments

Before hearing instruments can be purchased, an audiologist must determine the degree of your child's hearing loss. This can be done using special test methods for infants, toddlers, and young children. These tests are described earlier in the *Getting the Facts* section of this notebook.

Selection and Evaluation of Hearing Instruments

After determining the degree of hearing loss and receiving medical clearance to use hearing instruments, the audiologist will begin the hearing instrument evaluation process. Audiologists may use one of several assessment methods when evaluating hearing instruments for children. Regardless of the technique used, the goal is to enable conversational speech to be heard at a comfortable level. These assessment methods may include:

Info. adapted and included with permission from Boys Town National Research Hospital
http://www.boystownhospital.org/parents/hearing_aids/selecting.asp

- **Probe-Tube Microphone Testing** – during probe-tube microphone testing, a tiny, soft microphone is placed in your baby’s ear next to the earmold. The amplification provided by the hearing instrument is then measured while in the ear. The measured response is evaluated to estimate the instrumented benefit and adjustments are made to the hearing instrument as needed.
- **Real-Ear-to-Coupler-Difference (RECD) Measures** – in RECD testing a tiny, soft microphone is also placed in your baby’s ear next to the earmold. The effect of your child’s ear and earmold are measured without the hearing instrument. The hearing instrument is evaluated separately and its response added to the RECD measurement. This allows different hearing instruments and settings to be compared without having to test each one on the child.
- **Behavioral Testing** – When probe-tube measures cannot be completed, behavioral testing methods can be used to assess a child’s performance with hearing instruments. The softest level at which a child responds to sound while wearing the hearing instrument is compared to the softest level of response without the hearing instrument to estimate instrumented benefit. This type of evaluation does not require the placement of measuring equipment on the child, but provides less comprehensive information.

Probe-tube microphone or RECD measurements are usually the methods of choice for fitting hearing instruments for children for several reasons. First they allow hearing instrument performance to be measured at typical speech levels so that performance in conversational situations can be predicted. Second, they allow direct measurement of the maximum level of sound provided by the hearing instrument to the child’s ear. The hearing instrument can then be adjusted to a safe and comfortable level. Third, they provide more complete information and can be done quickly.

How are Hearing Aids Selected?

Just as hearing losses come in all shapes and sizes, there are many different types of hearing aids. Your audiologist will consider the following when selecting a hearing instrument for your child.

- **Gain-** The amount of amplification the hearing instrument provides. For example, a powerful hearing instrument would have high gain. Gain is usually expressed in decibels (dB).
- **Frequency Response-** The amount of gain a hearing instrument provides across a range of pitches. Gain is usually provided only pitches where hearing loss is present.
- **Saturation Sound Pressure Level (SSPL)-** The loudest sound the hearing instrument can produce, regardless of the volume of the incoming sound or the amount of gain. The hearing instrument should be set so that it never becomes uncomfortably loud or potentially damaging to the ear.

The audiologist will also discuss other important characteristics, including flexibility in adjusting frequency response, gain and saturation response. This flexibility is useful as additional information about the hearing loss is obtained or in cases where hearing changes.

The compatibility of a hearing instrument with assistive devices is also considered, because many children with hearing loss use additional amplification devices, such as Frequency Modulated (FM) Systems (to learn more about FM Systems go to the *Looking Ahead* section of this notebook).

Characteristics You will Considered when Choosing Hearing Instruments

The audiologist will look at the specific characteristics of the hearing instruments to determine what specifications will work the best to help your child hear. However, there are many decisions that you will have to make as well. You will want to consider the following when selecting a hearing instrument for your child;

- **Style** – Hearing aids come in many different styles, which differ mostly in size. This is not a major consideration for very young children as they are almost always fit with the Behind-the-ear (BTE) style hearing aids.
- **Electronic Circuitry** – Circuitry refers to the technology of the electrical components inside the hearing instrument. Hearing instruments may contain one of three kinds of circuitry; nonprogrammable analog hearing aids, programmable analog hearing aids, or programmable digital hearing aids.
- **Additional Features** – Hearing instruments may or may not include features such as Telecoils, directional or multiple microphones, multi-memory ability.
- **Cost** – Hearing instruments vary greatly in price. The price of the instrument will be determined primarily by which of the above characteristics you decide on. Some insurance plans cover some types of hearing instruments or a portion of the cost. Check with your insurance provider before selecting a hearing instrument for your child. Financial assistance may also be available. See *the Supporting your Family* section for more details.

Why are BTE hearing instruments the primary choice for young children?

Safety is the overriding reason for fitting the BTE style-hearing instrument on young children. They are larger than many other styles and therefore do not pose as great of a choking risk. They also come equipped with many safety features that are often not readily available on other types of hearing instruments such as volume-control covers and tamper-resistant battery compartments. BTE's also tend to require fewer repairs, and are more compatible with assistive listening devices than other styles of hearing instruments.

What is the Difference Between the Types of Circuitry?

When choosing the hearing aid that you will purchase for your child, circuitry can become an important part of the decision. This consideration may have the greatest effect on the quality of sound, the flexibility of the instrument and the cost of the hearing instrument. It can also be the most difficult to understand. Be sure to talk with your child's audiologist if you need additional explanation.

- Non-programmable analog hearing aids- are also known as conventional hearing aids. This circuitry is “hard-wired” which means that they are set up to amplify certain sounds a certain amount. If the user is unhappy with the amount or quality of the sound, there is very little that the audiologist can do to adjust it. They typically add the same amount of amplification to all levels of sound intensity. Therefore, low bass sounds will be amplified with the same amount of volume as high treble sounds. Some people find that conventional hearing aids provide either too little sound or too much sound to comfortably reach a listening level for the particular hearing loss, especially if they have a loss in the high pitches. Non-programmable analog hearing instruments represent the most basic type of amplification and are a good choice when finances are the major concern.
- Programmable analog hearing aids - contain a computer chip, which can be programmed by the hearing specialist using a computer. This offers a better way to accommodate a given patient's listening needs because it allows the greatest flexibility and most fine-tuning capability. Programmable hearing instruments often contain options that are not available in conventional hearing aids. The major advantage of this type of hearing aid is flexibility. The sounds that are amplified and the levels at which they are amplified can be easily adjusted. This can be very helpful for young children as more information is discovered about their hearing loss or if they have fluctuating hearing.
- Programmable digital hearing aids - These hearing aids convert the sound to a digital (numeric) signal. The numbers are then adjusted based on the individual needs of the user's hearing loss, listening needs and characteristics of the incoming sound. Advancements in hearing aids that process sound digitally offer the potential for dramatic improvements in sound quality and ease of use. Many individuals compare the difference in sound quality to that of audiotape vs. a Compact Disc (CD). Some users of digital hearing aids report a more natural and comfortable sound. They often offer automatic adjustment for loud or soft sounds without having to use a volume control. This is especially nice for young children, as they cannot adjust their own aids. As with programmable analog hearing aids, a range of features are available, such as directional or multiple microphones, and single or multiple programs.

What is a Cochlear Implant?



A cochlear implant is an electronic device designed to provide enhanced sound detection and the potential for greater speech understanding to children with severe to profound hearing loss who obtain negligible benefit from hearing aids. Unlike hearing aids that deliver amplified sounds to the ear cochlear implants bypass the damaged parts of the ear and send electrical 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 have been approved for use in children since June 1990. Currently, approximately 7,000 children in the United States have been implanted.

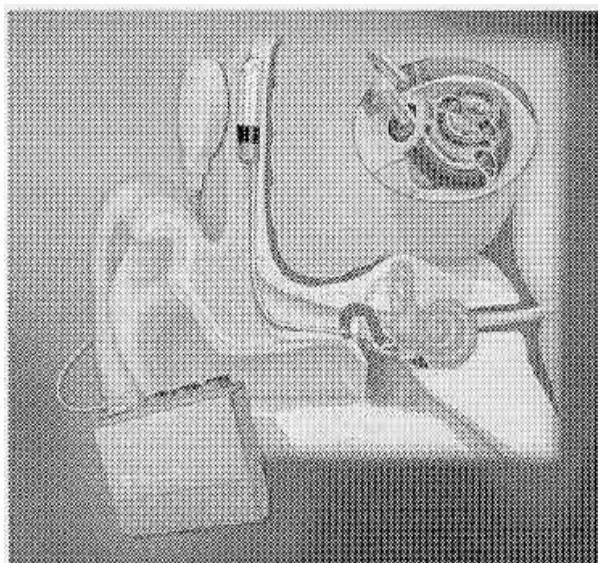
HOW DO COCHLEAR IMPLANTS WORK?

A cochlear implant converts speech, music, and environmental sounds into electrical signals and sends these signals to the hearing nerve, where the signals are interpreted as sound by the brain. A cochlear implant works in this way:

1. Sound (signals) are received by the microphone.
2. Electrical pulses that represent the energy contained in sound signals are sent from the microphone to the speech processor.
3. The speech processor selects and codes the most useful portions of the sound signals.
4. Code is sent to the transmitter.
5. Transmitter sends code across skin to receiver/stimulator
6. Receiver/stimulator converts code to electrical signals.
7. Electrical signals are sent to electrode array in the cochlea to stimulate hearing nerve fibers.
8. Signals are recognized as sounds by the brain.

Three cochlear implant systems are currently approved for sale by the Food and Drug Administration (FDA) in the United States. All cochlear Implant systems consist of internal and external components. The external components consist of:

- a microphone (to pick up the sound and transmit it to the speech processor),
- a speech processor (which selects and codes useful sound) and
- a transmitter with a magnet (which sends the code to the receiver).



Information on Cochlear Implants adapted and included with permission from AGBell
For more information about Cochlear Implants go to www.agbell.org.

The transmitter is placed on top of the skin behind the ear. A cord connects the transmitter to the speech processor, which is worn in a pocket or clipped to a belt. Alternatively, users may select cochlear Implant systems in ear-level styles that look like behind-the-ear hearing aids.

The internal components consist of a receiver coil and electrode array. A small receiver coil with an enclosed magnet is surgically placed under the skin behind the ear and serves to convert the coded sound into electronic signals. Electrical contacts, in the form of an electrode array, are inserted into the Inner ear and stimulate the hearing nerve fibers to send these signals to the brain where they are recognized as sound.

Although implant systems differ in the number of channels, electrodes, and speech coding strategies, they have common features that allow electrical stimulation of the hearing nerve. Of these devices, research has consistently shown that multi-channel systems offer better speech recognition for the patient than do the earlier single-channel devices.

HOW DO I KNOW IF MY CHILD IS A CANDIDATE FOR A COCHLEAR IMPLANT?

Children who are candidates for a cochlear implant must:

- Have a profound sensorineural hearing loss in both ears.
- Receive little or no benefit from hearing aids (usually determined through a trial period of using two hearing aids) as indicated by whether age-appropriate communication skills are developing.

Be of an age that will allow the clinical team from an implant center to determine if preverbal behaviors or speech recognition abilities are developing through the use of using hearing aids.

- Have an intact auditory nerve as indicated by CT- or MRI-scans.
- Be healthy enough to tolerate surgery (typically an outpatient procedure).
- Have had active middle-ear disease (otitis) brought under control (if applicable).

Additionally, their families must possess a clear understanding of the benefits and limitations of a cochlear implant, and have the time to accommodate pre-implant evaluations and postoperative follow-up services. Children undergo audiological, medical, and psychological procedures to determine implant candidacy, and the time involved in completing these procedures varies with the age and abilities of the child.

Some centers require assurance from the family that the child's home and educational environment will rely on spoken language (an oral approach) to ensure the best possible outcomes from the implant.

Most cochlear implant centers take a team approach to determining implant candidacy. In addition to the family, the following professionals are typically involved in the decision:

- Audiologist
- Surgeon
- Speech-language pathologist and/or therapist—to assess child’s overall communication abilities
- Educator—to review child’s abilities in the school setting
- Psychologist—to evaluate child’s cognitive, social, and emotional development before, during, and after the procedure

A team approach enables the candidacy process to move forward more efficiently because it considers the whole child, and screens for any potential issues that might affect the child’s ability to learn language with an implant.

HOW DO SELECT A COCHLEAR IMPLANT CENTER?

Cochlear implant manufacturers maintain a list of implant centers worldwide. To select the right center for you and your child, consider the following factors:

1. Is the center located close enough to your home so that you can accommodate frequent visits?
2. Who is on the implant team? Do they have experience with children?
3. How many cochlear implant surgeries has the center done? How many have been performed on children?
4. If you have used sign language with your child, is there someone at the implant center who can communicate with him or her?
5. What are the center’s facilities for cochlear implant (re)habilitation? What is the team audiologist’s experience with (re)habilitation?
6. Is the implant team sensitive and responsive to your questions? To your child’s questions?

It is also recommended that parents talk with other parents of children who have been implanted at the center. Obtain parent referrals from the center so that you can hear others’ experiences and ideas. Take advantage, also, of the center’s in-house library. The team should be able to provide you with information, books, brochures, and videotapes about cochlear implants. Read, watch, and ask all you can.

WHAT DOES THE SURGERY INVOLVE?

Surgery

Cochlear implant surgery is typically performed under general anesthesia and lasts for approximately 2 1/2 hours. The procedure can be performed in either an inpatient or outpatient setting and carries the normal risks of major ear surgery requiring general

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For more information about Cochlear Implants go to www.agbell.org.

anesthesia. The surgeon exposes the mastoid bone behind the ear canal and drills open a channel to the inner ear. The electrodes are threaded into the Inner ear and the receiver coil is placed in the bone behind the ear. The skin is closed over the receiver-stimulator. A pressure bandage is placed to reduce swelling around the incision. Most children go home the same day or spend no more than one night in the hospital.

Device Fitting

After four to six weeks to allow for healing around the surgical site, the process of “fitting” the external parts takes place. During the fitting session, the headpiece and microphone are placed over the implant. The speech processor is connected to the headpiece and the audiologists’ computer. Measurements are used to program the speech processor for the individual child. The speech processor is disconnected from the audiologist’s computer and rechargeable or disposable batteries are then inserted. The child can then take the implant system home. Device programming is performed more often during the first months of implant use with visits required on a less frequent basis thereafter.

Follow-Up Services

Once the speech processor is set, the child requires intensive auditory and speech training. Implanted children require this communication training to help them jumpstart their language and listening skills, which they were not able to fully develop prior to the implant. Long-term postoperative (re)habilitation should include training the focuses on communication behaviors, listening skills, speech production, and expanding a child’s language repertoire. These services can be provided by staff at an implant center or at the child’s school if that setting has qualified personnel. In addition, children should return to the implant center at least every six to twelve months for monitoring and program adjustments of the speech processor.

WHAT ARE THE POTENTIAL BENEFITS ASSOCIATED WITH COCHLEAR IMPLANTS?

Although there is a wide range of performance in children using cochlear implants, the benefits for most users include sound awareness, environmental sound recognition, enhanced lip-reading abilities, speech recognition (understanding the speech of others without lip-reading), and improved speech production. Today, advances in implant technology enable more children to maximize these benefits and develop spoken language skills.

Even though thousands of children have received cochlear implants, surgeons and audiologists are currently unable to predict before surgery the degree of benefit an individual child will receive from an implant. Factors affecting implant performance include:

- Age at implantation and whether the child has had some experience with effective hearing previously
- Postoperative (re)habilitation
- Primary mode of communication
- Educational setting

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- Length of implant use

Research suggests that implantation works best for children who are prelingually deaf and are implanted at the earliest possible age after performance limitations with hearing aids are determined. Of special importance when considering implantation is the critical period for speech and language development (0-6 years old). Before becoming a candidate for an implant, children must complete a six-month trial period with hearing aids to see whether or not this technology can provide them with satisfactory sound. Children may be considered candidates for an implant if the hearing aid trial period has failed to promote more age-appropriate listening and speaking.

Currently, the minimum age for implantation is eighteen months. However, the promising results demonstrated by children implanted at an early age has promoted the trend to lower the age of implantation, with some centers implanting under the age of twelve months. With a renewed focus on early identification of hearing loss, and the passing of early identification legislation at the federal level (the “Walsh Bill”), many more children will be identified with hearing loss soon after birth. It is likely, as a result, that as the age of identification decreases, so too will the age of implantation in an effort to tap natural language learning abilities that are maximal during a child’s first six-year “critical period”.

HOW MUCH DO COCHLEAR IMPLANTS COST?

Cochlear implants are covered benefits in most medical insurance policies and in most states’ Medicaid plans. Currently, the cost for evaluation, implantation, and follow-up programs and (re)habilitation is approximately \$40,000. Included in these costs are audiological testing, medical examinations, surgical fees, anesthesiologist, operating room and hospital charges, and follow-up programs. Auditory and speech training is sometimes not covered by medical insurance.

Follow-up care after the first year includes testing and monitoring and occasional reprogramming of the device. Like any child with a hearing loss, children with cochlear implants will need ongoing therapy to ensure maximum listening and speech skills.

WHAT TYPE OF SCHOOL IS BEST FOR MY CHILD WITH A COCHLEAR IMPLANT?

Making the decision regarding educational placement for a child with hearing loss is often confusing. For a child with a cochlear implant, the decision can impact his or her progress with the technology. Research has shown that for children to make significant progress learning to listen and speak with a cochlear implant, their homes and schools must be primarily auditory environments that provide lots of opportunities for children to listen and use their own voices.

In theory, children’s special education services are supposed to be tailored to their needs. In practice, children are apt to receive a generic set of services based on their disability, rather
Information on Cochlear Implants adapted and included with permission from AGBell
For more information about Cochlear Implants go to www.agbell.org.

than on their individual strengths and weaknesses. As a result, parents must be aggressive in requesting accommodation for their child. However, unlike general education, special education allows parents to have some say in their child's educational programming and supplementary services. The foundation of your child's education is the Individualized Education Plan, known as the IEP. An IEP is a legal, written plan that specifies special education and related services necessary to meet the individualized needs of a student with a disability.

After your child receives a cochlear implant, parents should revisit their children's IEP goals and determine whether these goals are still relevant, or should be modified to better address their children's needs. Questions to consider include:

- What are realistic language development goals for my child post-implant?
- What are realistic speech production and speech perception goals for my child post-implant?
- How does the school district plan to reach those goals? How will these goals be integrated with academic objectives?
- What responsibility does the school district take for cochlear implant (re)habilitation? What experience does the school have in this area?
- Will the school district provide auditory support or technology to assist my child in the classroom, such as personal FM system or FM sound-field system, if not already in use? If the school district pledges to provide support in this area, be sure to get its commitment in writing.

Supporting Environmental Awareness in a Deaf or Hard of Hearing Child



For a young child who is deaf or hard of hearing it is very important to make sure that the environment in which they spend their time is friendly, accessible and predictable. Fostering a supportive and accessible environment will help even young babies become aware of their environment, connect visual or auditory signals with routines or important events and feel safe and secure in the place they live. Once a baby begins to understand their environment, they begin to understand how to interact with it. The following items will help your baby better understand the world around him. Many of the items are inexpensive. The state waiver that is included in this section can help with the expense of establishing a visually friendly home. See the Catalog section of the *Supporting your Family* section for places to purchase the equipment discussed below.

Doorbell Flashers and Telephone Visual Alert System

Picture this scenario: A young hard of hearing toddler is playing on the floor with his mother. They are playing with his cars and running them up and down a ramp and the child is very engaged. The doorbell rings and his mother gets up and goes into the other room to answer the door. The child looks up to find his mother gone. He is scared because he has no idea of where she went or why she left so suddenly. The young child with hearing loss does not have access to all of the clues in the environment around him that signal a hearing child that his mother just went to answer the door. He did not hear the doorbell or knock, the sound of his mother getting up off of the floor, of her footsteps, of the door unlocking, or of his mother talking to the neighbor.

A doorbell flasher can be a great way to help even a very young deaf or hard of hearing child gain the assurance that comes with knowing what will happen next. They may connect the flashing light to their mother going to answer the door or to the exciting anticipation of a new visitor.

Similar to the visual signal for the doorbell, the visual alert system for the telephone will help a child come to associate the visual stimulus with an action or response from the family. Families can also use the visual cues to call attention to sounds that the child may be able to hear with or without the use of other technology. This will help the child develop some awareness of the auditory signals as well.

Lighting

A child who is deaf or hard of hearing tends to be more visually aware of the surroundings and tends to depend much on visual information even if they have access to sound through the use of hearing aids or a cochlear implant. Therefore, it is important to be aware of the lighting in your baby's environment. A few examples of things to consider follow:

- Make sure that the child can see you when you are talking.
- Make sure that there is enough light on your face but not so much that there is a glare or that it is uncomfortable for you or the child.

- It is also good to be aware of backlighting which may cause a shadow on your face.
- You can also use lights to get you child's attention by flicking them on and off.

Alarm Systems

Visual Signals that accompany smoke and fire alarms are very important. Even with hearing aids, some children may not be able to hear these important sounds. In addition it may be important to alert children to certain events when they are not typically wearing their hearing aids (e.g., while asleep). You may purchase a smoke alarm that has a strobe light that flashes throughout your home and all hotels will have them for your room upon request. Older children need an awareness of these events as they start to stay home on their own and increase their independence. Devices are available to provide either visual or vibratory signals to the child who is deaf or hard of hearing.

Other examples of assistive technology and devices that many deaf and hard of hearing people use in their homes are listed below. You may want to include some of these in your home now or as your child grows.

- **Assistive Listening Devices (ALDs):** Enhanced audio quality and volume for listening to the TV, radio or at equipped movie theaters. These devices allow the volume to remain low for other family members.
- **Close Captioning:** Most TVs now have built-in captioning chips that display visual text known as captioning to show up on the TV screen. You may want to make this available to your child as early as possible.
- **Personal FM Systems:** Traditionally, FM systems have been used in educational settings to overcome the difficulties of listening in a noisy classroom setting. The teacher wears a small microphone and transmitter and the child wears a hearing aid and receiver. Sound is sent directly to the child via wireless FM transmission. These systems have been shown to improve communication in difficult listening environments.
- **Telephone Flasher:** A visual flashing system that signals that the phone is ringing throughout the home.
- **Telephone Ringers and/or Amplifiers:** Telephone amplifier devices may work with a person's hearing aid or independently from it. The amplifier may increase the volume of the person's voice on the other end by 20 to 50dB. Some telephones have adjustable controls that increase the volume of the ring or adjust the tone of a ringing telephone so that it can be heard more easily.
- **TTY:** A telecommunications device with a keyboard and display screen (also called a TDD).
- **Wake Up Alarm:** A clock that flashes a light, has an adjustable loud buzzer with tone control, or vibrates.

Two Wisconsin programs provide funding for the purchase of telecommunications devices. The **Telecommunications Equipment Purchase Program**, known as TEPP, gets its funding from all Wisconsin telephone service providers. There is a required \$100 co-payment. Families and individuals that meet certain financial eligibility requirements can apply for a waiver of the \$100 co-payment through the **Telecommunications Assistance Program**, or TAP, a state-funded program. Information about the TEPP Program and an application are included on the following pages.

Would some special equipment help you make better personal use of the telephone?

TEPPP

The Telecommunications Equipment Purchase Program

is the way to get what you need for a reasonable price!

What is the Telecommunications Equipment Purchase Program (TEPPP)?

The TEPPP is to help people with disabilities buy equipment they need in order to use basic telephone services. The TEPPP is one of several different programs paid for by the Wisconsin Universal Service Fund (USF) established by the Public Service Commission. Money collected from Wisconsin telephone service providers goes into the USF.

This sounds too good to be true!

What's the catch?

There is NO CATCH, all you do is request the simple application form, fill it out and mail it in.

The few rules are that an applicant:

- Be a Wisconsin resident.
- Be a person who is deaf, hard of hearing, speech impaired, or mobility or motion impaired.
- Need special equipment to use the telephone in your home or when traveling (like a TTY, volume control, visual alert system, etc.).

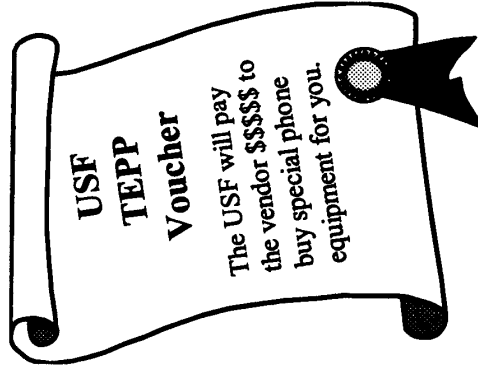
There's no age or income limit, but the same household can only get TEPPP money once every three years for the same type of disability. (For example, just one voucher even if two or more deaf people is in the same household.)

How much will TEPPP pay?

The amount depends on your disability. On the form, you check off which disability affects your telephone use. You will be mailed a voucher (like a check) for the amount you are qualified to get. These amounts were set based on the usual cost of the equipment needed.

Below are the maximum voucher amounts allowed for each type of disability:

Type of disability	Amount
Hard of Hearing (HH)	\$200
Deaf/Severely HH	500
Speech Impaired	1,500
Mobility Impaired	1,500
Deaf with low vision	2,500
Deaf and Blind	6,700



How much do I have to pay?

You pay the first \$100. The voucher pays the rest, up to the maximum voucher amount. If you buy equipment that is more expensive than the voucher plus your \$100, you must also pay the extra charges. For example, if you mark "Deaf/Severely HH" as your disability, you will get a voucher for \$500. If you buy equipment with a total cost of \$618, you will pay \$118.

What if I can't afford the \$100?

The Wisconsin Office for the Deaf and Hard of Hearing (WDHH) has a special program -- the Telecommunication Assistance Program (TAP). This is only for qualified persons who are deaf, deaf blind, or hard of hearing.

Unlike TEPP, TAP does have income requirements. But, this separate, state funded program pays the \$100 TEPP co-payment if you qualify.

How do I get TAP to pay the \$100?

The TEPP and TAP application form are combined. For TAP, you must fill out the household income lines and you also need to send a hearing loss certificate. You must add up all income for everyone living in your house. If your total household income meets the TAP income limits your application will automatically be processed for a TEPP and TAP voucher so your voucher may include the \$100 co-payment.

What kind of phone equipment will TEPP allow me to buy?

- ☛ TTY
- ☛ Amplified handset or phone
- ☛ Telebraille/TTY unit
- ☛ TTY with large visual display
- ☛ Special modem
- ☛ Hands-free speaker phone
- ☛ Puff activator
- ☛ Phone signaling system using flashing lights, a vibrator or a loud bell, and
- ☛ Other specialized equipment may be approved on an individual basis

How do I get an application?

To get a TEPP application form, or answers to your questions, call or write:

Public Service Commission
P.O. Box 7854
Madison, WI 53707-7854
☛ (608) 267-1479 TTY
☛ (608) 231-3305 Voice
☛ (608) 266-3957 Fax
pscrecs@psc.state.wi.us E-Mail

OR, contact:

- ☛ The Wisconsin Office for the Deaf and Hard of Hearing at:
(608) 243-5626 Voice/TTY
- ☛ The Office for Persons with Physical Disabilities or an Independent Living Center at: (608) 267-9582 Voice
(608) 267-9880 TTY
- ☛ Your local telephone company
- ☛ Vendors of specialized equipment.

Where do I mail my TEPP form?

Send completed applications to:

USF Administrator
Williams, Young and Assocs., LLC
P.O. Box 8700
Madison, WI 53708-8700
(608) 274-1980 Voice
(608) 274-4448 TTY
(608) 274-8085 Fax

When will I receive the voucher?

It takes three weeks from the time you mail an application to process it and mail a voucher to you. It takes two or more weeks longer if you apply for TAP also. **If you have questions about the status of your application you may call or write the USF administrator.**

If money is not available when your application arrives, TEPP will hold your application in the order it is received until money is available.

How do I use a TEPP voucher?

Choose your equipment and where you want to buy it. Use the voucher (like a check) to pay the vendor for your qualifying special equipment. You pay: 1) \$100, if not TAP qualified, 2) for any purchase amount over the total of the voucher plus your \$100, and 3) for any non-qualifying items purchased.



Telecommunications Equipment Purchase Program (TEPP)

"Meeting Needs for Specialized Telephone Equipment"

APPLICATION FOR VOUCHER

Please **print** your responses. You may direct any questions about the application or the Telecommunications Equipment Purchase Program (TEPP) by calling: (608) 274-4448 TTY, (608) 274-1980 Voice, or email TEPP@williamsyoung.com.

Mail the application to: **USF Fund Administrator, c/o Williams Young, LLC, P.O. Box 8700, Madison, WI 53708-8700** or

Fax the application to: **USF Fund Administrator, (608) 274-8085**

PERSONAL INFORMATION

Applicant's Name (Last, First, Middle) (Maiden, if applicable)

Applicant's Postal Address

City State ZIP Code

Telephone Number: () TTY Voice

Email Address:

Social Security Number: Date of Birth:

DISABILITY (CHECK ONE):

- Hard of Hearing (Voucher Maximum \$200 and no co-payment required)
- Deaf/Severely Hard of Hearing (Voucher Maximum \$800)
- Speech Impaired (Voucher Maximum \$1,600)
- Mobility Impaired or Motion Impaired (Voucher Maximum \$1,600)
- Deaf-Low Vision (Voucher Maximum \$2,500)
- Deaf-Blind (Voucher Maximum \$7,200)

Have you received assistance from the following:

HOUSEHOLD INFORMATION

Number of people in your household: _____
*Annual household income according to most recent tax return filed: \$ _____
*(include income of spouse or parent/guardian, if applicable)

There is no income limit for TEPP assistance. Income information will be used to determine if you may be eligible for the Department of Health and Family Services/TAP (Telecommunications Assistance Program) assistance which can pay the \$100 co-payment for equipment purchases.

TEPP

Yes

When: _____

No

TAP

Yes

When: _____

No

I certify that I have a disability in the category checked above that limits or curtails my access to or use of telecommunications services. Equipment to be purchased with this voucher is necessary for me to effectively access telecommunications services.

I understand that any deliberate fraud or misuse of this program will result in legal action taken by the State of Wisconsin. I also understand that I need to make a \$100 co-payment at the time the equipment is purchased unless I qualify as a TAP applicant or in the Hard of Hearing Category.

THESE STATEMENTS ARE TRUE AND CORRECT TO THE BEST OF MY KNOWLEDGE.

Applicant or Guardian Signature

Date

The information requested on this form is authorized for collection to administer the Universal Service Fund pursuant to s. 196.218, Stats., and PSC 160.71, Wis. Adm. Code. The information collected is used to determine eligibility for the Universal Service Fund programs of the Public Service Commission of Wisconsin. Completion of this form is voluntary; however, failure to furnish the requested information may result in denial of eligibility for support under these programs. Personally identifiable information collected on this form is not likely to be used for purposes unrelated to the Universal Service Fund programs.

Applicants are processed in the order they are received. Vouchers will be issued on a first come, first served basis in compliance with rules governing the Universal Service Fund. Specific limitations will apply as identified in PSC §160.07 and 160.071, relating to funding, definition of disability and voucher amount. If the applicant receives a voucher, he/she is responsible for the first \$100 of the equipment purchased, unless he/she is qualified as a TAP recipient or in the Hard of Hearing Category, and any additional amount exceeding the maximum value of the voucher plus the co-payment.

THIS SECTION FOR OFFICE USE ONLY

PP

Date received: _____

Eligible

Ineligible: Reason: _____

USF Administer and date: _____

TAP

Eligible

Ineligible: Reason: _____

Keeping Track

(Insert Tabbed Divider Here)

Keeping Track



The Keeping Track section is intended to provide you with a place to keep all of the information you are gathering about your child. In this section, you will find:

- ☺ A plastic business card holder - to keep the cards of professionals that are becoming part of your child's life. Many times the business cards also have appointment dates and times on them.
- ☺ Annual and Monthly Calendars - to write down and manage the many appointments you will have, medical, social, and other.
- ☺ At-a-Glance Appointment Record - designed by other parents to record information about upcoming appointments as well as develop a written history of key items from past appointments all in one place.
- ☺ Forms to Request from Providers - to help you get a sense of the medical records that you may want or need in the future. Collecting them as you go along may save you the time and effort of tracking them down later.
- ☺ Information Providers May Request From You - organizes the information regularly needed by medical providers, child care providers, family members and so on. Perhaps you will be able to give out copies of this form rather than re-writing this information over and over again.
- ☺ Plastic Sheet Protectors – provided for you to store your child's most recent hearing tests and IFSP's. A sheet protector is also available for health insurance information to be stored and easily located when needed.
- ☺ Note Pages – sometimes professionals may ask you to carry a message to another professional. Other times professionals may wish to keep a running dialog with one another. For example, the audiologist and the birth to three providers may want to communicate about how your child is using their hearing instrument. Blank pages are provided for you or the professionals you work with to record notes.

You may find that all of the organizational tools provided are useful just the way they are or you may wish to change them to better fit your style. In any case, they are meant to make life a little simpler. Don't forget to make photocopies of pages you find particularly useful!

**Insert Your Business Cards
into the Plastic Business Card Holder**

Annual Calendar



<u>January</u>	<u>February</u>
<u>March</u>	<u>April</u>
<u>May</u>	<u>June</u>
<u>July</u>	<u>August</u>
<u>September</u>	<u>October</u>
<u>November</u>	<u>December</u>

Annual Calendar



<u>January</u>	<u>February</u>
<u>March</u>	<u>April</u>
<u>May</u>	<u>June</u>
<u>July</u>	<u>August</u>
<u>September</u>	<u>October</u>
<u>November</u>	<u>December</u>

Annual Calendar



<u>January</u>	<u>February</u>
<u>March</u>	<u>April</u>
<u>May</u>	<u>June</u>
<u>July</u>	<u>August</u>
<u>September</u>	<u>October</u>
<u>November</u>	<u>December</u>



Monthly Calendar



Notes	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday



Monthly Calendar



Notes	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday



Monthly Calendar



Notes	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday

***Note: This is the last copy of this document.
If you wish to have additional copies, please photocopy this page before you write on it.**



Appointment Record

_____ *Child's Name*

Appointment Date / Time	Provider's Name and Address	Provider's Phone #	Reason for Appointment	Notes/Follow-up Instructions



Appointment Record

_____ *Child's Name*

Appointment Date / Time	Provider's Name and Address	Provider's Phone #	Reason for Appointment	Notes/Follow-up Instructions



Appointment Record

_____ *Child's Name*

Appointment Date / Time	Provider's Name and Address	Provider's Phone #	Reason for Appointment	Notes/Follow-up Instructions

Keeping Track - 11

***Note: This is the last copy of this document.
If you wish to have additional copies, please photocopy this page before you write on it.**



Checklist of Information to Request from Providers

The following is a list of documents pertaining to your child's hearing healthcare. You may wish to request copies of some or all of these from your child's healthcare providers. You may receive some of them only once, while others you will receive regularly. As a parent, you have the right to any medical records that pertain to your child. All you need to do is ask!

Type of Report	Provided by...
<input type="checkbox"/> Hearing Screening Results	Birthing Hospital/ Primary Care Provider
<input type="checkbox"/> Hearing Evaluations	Audiologist
<input type="checkbox"/> Confirmation of Hearing Loss Report Form	Audiologist
<input type="checkbox"/> Hearing Instrument Recommendations	Audiologist
<input type="checkbox"/> Brochures: <i>Babies and Hearing Loss and Birth - 3</i>	Audiologist/Primary Care Provider
<input type="checkbox"/> Medical Records	Primary Care Provider
<input type="checkbox"/> Speech and Language Evaluations	Birth - 3/ Speech Language Pathologist
<input type="checkbox"/> Individualized Family Service Plan	Birth - 3
<input type="checkbox"/> Transition Plan	Birth - 3
<input type="checkbox"/> Other Evaluations: <i>(OT, PT, vision, genetics, etc.)</i>	



Information Providers May Request From You

Child's Information:

First Name: _____ Middle Name: _____ Last Name: _____

Date of Birth: _____ Place of Birth (Hosp, City, State): _____

Siblings: Yes No Names/Ages: _____

Primary Family Language: _____

Parent/Guardian Information (Person(s) child lives with):

Father: _____ Phone: () _____

Address: _____ Apt/Lot Number: _____

Mother: _____ Phone: () _____

Address: _____ Apt/Lot Number: _____

Step-Parent: _____ Phone: () _____

Address: _____ Apt/Lot Number: _____

Father place of employment: _____

Hours: From _____ to _____ Work Phone: () _____

Mother place of employment: _____

Hours: From _____ to _____ Work Phone: () _____

Child's Emergency Information:

(Please list 2 additional persons that can be notified in case of an accident or illness in the event a parent cannot be contacted):

First Contact Name & Address: _____

Relationship: _____ Phone: () _____

Second Contact Name & Address: _____

Relationship: _____ Phone: () _____

If emergency treatment is required, and we are unable to reach either you or your emergency contacts, I authorize school personnel to call:

Physician: _____ Phone: () _____

Child's Insurance Information

Name of Insurance	Group/Policy #	Child's Social Security Number	Phone Number
			()
			()

Child's Medical Information

Title	Name	Address	Phone Number
Primary Care Provider			()
Audiologist			()
ENT			()
Other			()
Other			()
Other			()

Child's Early Intervention Information

Title	Name	Address	Phone Number
Service Coordinator			()
Therapist			()
Other			()
Other			()

Child's Amplification Information

Type of Amplification (Hearing Aids, Cochlear Implant, FM System)	Right Side	Left Side
Make and Model		
Serial Number		
Date of Purchase		
Date Warranty or Guarantee Expires		

Child's Amplification Information (continued)

Date Service Plan (if any) Expires		
Earmold Material and Style	/	/
Date the earmold was fit		
Type of Cord (if applicable)		
Accessories (if applicable)		

Amplification Contacts...	Name	Address	Phone Number
for repair			()
for programming			()
for batteries			()
for insurance			()

Special Concerns or Additional Information

Parent/Guardian Signature

Date

**Insert Your
Child's Most Recent Hearing Tests
into the Plastic Sheet Protector**

**Insert Your
Individualized Family Service Plan (IFSP)
into the Plastic Sheet Protector**

**Insert Your
Health Insurance Information and Records
into the Plastic Sheet Protector**

Notes:

Between Providers and You

To be used by parents and providers for questions, treatment suggestions, progress notes, etc.





Notes:

Between Providers and You

To be used by parents and providers for questions, treatment suggestions, progress notes, etc.



Notes:

Between Providers and You

To be used by parents and providers for questions,
treatment suggestions, progress notes, etc.

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Between Providers and You

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treatment suggestions, progress notes, etc.

Notes:



Between Providers and You

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Looking Ahead

(Insert Tabbed Divider Here)

Looking Ahead



The purpose of the looking ahead section is to prepare your family for the rewards and challenges of transitioning out of the birth to three period and entering a new phase of your child's life which may include transitioning out of county services and into school services. Resources have been compiled in this section to help you understand what is to come, what actions you may need to take, and when to begin considering the up-coming changes. All families are different. If your baby is very young, this might seem like the farthest thing from your mind or you might already be considering plans for this child's college career. Whatever, your case may be, this information is here for you when you are ready.

“Preparing for our daughter's transition out of Birth to Three was an all-consuming, anxiety inducing task for several weeks, for a variety of reasons. We had a tremendously high level of respect, maybe even adoration, for all the professionals/therapists working with us to help ensure our daughter could achieve her full potential in life. We also had a very emotional bond with the professionals and we were terrified to lose them. We couldn't imagine going out into the "big, bad world" without them.

Many parents had also told us about the gray area that hard hearing kids often fall into from the school's perspective, and the annual struggles we might be involved in for the next 15 years. With the guidance of the professionals that had come to know us so well, by observing our daughter carefully, and by visiting a variety of programs and asking numerous questions, we made it through the process. Since we are both working parents, we also relied on things we had learned in our careers and applied them to the IEP meeting. Fortunately, although the road was bumpy and curvy, the end result exceeded our expectations.

Now, just over a year later, we not only have the resources/people from our previous Birth to Three providers, we have a whole new circle of resources that are learning with us, and developing wonderful, positive relationships with our daughter. We have found the professionals in the school system to be true advocates for our child, always trying to consider what is in her best interest. As parents, when we look ahead to Claire's future, we are confident in the school system, the IEP process, and the growing abilities of our daughter.”

--Christy Herden, mother of Claire

Exploring School Placement Options



If the child meets the eligibility criteria for special education services, an Individual Education Plan (IEP) is created which contains goals and objectives as well as a listing of supplementary aids and services for the child and supports for school staff. Based on these, an appropriate placement is chosen.

Before this is done, however, families may want to consider what types of appropriate placements or school options are available. Some options within the state that have been used are:

- Placement in a regular preschool with services provided there.
- Placement in a self-contained classroom for deaf and hard of hearing students and taught by a teacher for the deaf and hard of hearing with additional services provided as recommended by the IEP team.
- Placement in an Early Childhood room with additional services provided as recommended by the IEP team.
- Placement in an Early Childhood room which is team taught by a teacher for the deaf and hard of hearing and an Early Childhood teacher.
- Placement at home and/or daycare setting with services provided there.

These are just some of the placement options. Some placements are combined and/or altered slightly to reflect the needs and strengths of the child, the preference of the family and resources of the local school district. The modifications or adaptations that are made to a program are only limited by the team's creativity and flexibility. Furthermore, different programs and related services can be added and utilized in different ways.

Speech and language therapy is often added. A speech and language pathologist has a good understanding of how to promote communication and develop language. It is advantageous if this person has had some experience working with children who have a hearing loss and has some knowledge of non-verbal communication. In addition, it is also helpful if this person has some background in whatever the child's unique communication needs are; be they cochlear implants, American Sign Language, signed system, Cued Speech.

Educational audiology is a related service. An educational audiologist can ensure that the correct amplification is in place and oversee the child's auditory skill development. In addition they can assess the acoustic environment and determine the child's hearing with and without assistive listening devices.

Educational interpreting may be involved in the child's programming. Although most young children who are deaf or hard of hearing and rely on a signed language to communicate are not developmentally ready to use an interpreter, there are a variety of ways that such a person could be used:

- To develop the child's use of an interpreter. Eventually the child, who is using signed language, will need an interpreter. There are activities that can be used to develop skills in using an interpreter.

- To provide information about signed languages and deafness to those who are unfamiliar with it. In doing this, the interpreter could relate his/her experiences and suggest resources on general topics relating to hearing loss.
- To foster the child's participation in group activities.
- To promote an expanded communication environment for the child.
- To be a member of the child's team, including development and implementation of the IEP.

However, interpreters should not be used to teach the child. Although interpreters are trained in the use of signed language, they are not trained to teach language to young children. They are usually not trained to work with young children or families. A child needs interaction, language modeling and experiences paired with language before benefiting from interpreting services.

In addition, interpreters should not become the child's constant companion. It is not appropriate to expect the interpreter to function as the child's only language resource.

And interpreters should not be expected to resolve all communication needs within the classroom. Interaction with peers can become frustrating and incomplete to young children who are deaf or hard of hearing, if they are continually through the use of the interpreter.

A deaf or hard of hearing person functioning in some capacity with the school environment is a valuable resource to the child and the staff. This person could provide first hand experiences to the staff on hearing loss as well as promote a near optimal communication environment for the child.

Providing non-disabled hearing peers for young deaf and hard of hearing children whether in a self-contained classroom for the deaf and hard of hearing or in an Early Childhood classroom setting is particularly worthwhile. This is essential if speaking options are being promoted for the child.

While considering a placement, families may want to answer these questions about different options:

- If the child is using a signed language, what is the signing ability of the staff?
- Does the staff have training in working with young children? Are they aware of developmentally appropriate practices?
- What is done in the setting to promote communication?
- Does this particular setting 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?
- Does the staff have knowledge on auditory skill development and the technology used to develop auditory skills?
- What will the transportation be for my child? How will my child get to and from the school? Will the drivers have some knowledge of how to communicate with a deaf or hard of hearing child?
- What is the acoustic environment like?

Making a decision of where the child will attend school or what kinds of placements the child may be very difficult. When making such a decision it is important for families to keep the goals they have for the child in mind foremost. In addition they many want to:

- Gain background information on what is best practice in educating children who are deaf or hard of hearing.
- Visit different programs that serve young children who are deaf or hard of hearing.
- List what the available options are (be creative and inclusive).
- Talk with other families who have children who are deaf or hard of hearing. Ask them about their decisions and how they made them.
- List advantages and disadvantages of each available option listed.
- Consider what transportation might be involved.

No decision about placement is final.

Eligibility Criteria for Children who are Deaf or Hard of Hearing when Entering School



Below is the criterion for children who are deaf or hard of hearing in order to receive special education services in public schools.

Criteria for Hearing Impairment

PI 11.36(4) HEARING IMPAIRMENT. Hearing impairment, including deafness, means a significant impairment in hearing, with or without amplification, whether permanent or chronically fluctuating, that significantly adversely affects a child's educational performance including academic performance, speech perception and production, or language and communication skills. A current evaluation by an audiologist licensed under Chapter 459, Stats., shall be one of the components for an initial evaluation of a child with a suspected hearing impairment.

For ease of discussion, let's look at the criteria in two sections; first, the AUDIOLOGICAL EVALUATION.

"A current evaluation by an audiologist licensed under Chapter 459 shall be one of the components for an initial evaluation of a child with a suspected hearing impairment. Hearing impairment, including deafness, means a significant impairment in hearing, with or without amplification, whether permanent or chronically fluctuating..."

For a child transitioning from Birth to 3 to school, the transition and then IEP team must first review existing information on the child. If there is an audiological evaluation that the parents, Birth to 3 staff and school staff believe to be a 'current' and accurate representation of the child's hearing, then this document may be used as part of the school evaluation. There is no requirement for a new audiological evaluation to be done at the time of the IEP evaluation unless someone on the IEP team determines a need for something more current or comprehensive. It is likely that an IEP team will request a new audiological evaluation for children who have a progressive hearing loss and for those with documentation of chronically fluctuating hearing loss and how it impacts the child's varied hearing ability. There is no requirement for a child to have a specific decibel loss, nor that the child have a hearing impairment bilaterally.

The eligibility criterion does not eliminate a child's eligibility for special education based on whether the child uses or does not use amplification.

Secondly, the criteria requires the IEP team to evaluate how the child's hearing loss **ADVERSELY AFFECTS A CHILD'S EDUCATIONAL PERFORMANCE** including developmental progress typical of 3 year olds.

"... significantly adversely affects a child's educational performance including academic performance, speech perception and production, or language and communication skills."

EDUCATIONAL PERFORMANCE

The transition and IEP team is to evaluate the child's ability to participate in activities typical of children age 3. The team is also asked to state how the child's disability impacts his or her participation in age appropriate activities.

Speech perception and / or production is one way that a child's hearing disability may impact their ability to participate in the activities typical of children who are 3 years old. Listening and speaking including verbal play with sound are the initial stages of language development. The many activities of preschool programs revolve around sound with verbal games and letter-sound association leading to early literacy. These activities may be very difficult for a young child with a hearing loss.

Language development and communication skills are central to learning. Young children with a loss in hearing often demonstrate delays in language development and challenges in their communication skills. Challenges with communication often lead to delays in social development through understanding rules and skills of interaction needed for successful play.

After the IEP team has reviewed the information about the child related to:

- 1) the audiological evaluation including documentation of hearing loss and the child's use of their hearing, and
- 2) the adverse effects of the hearing loss on the child's developmental progress typical of 3-year olds,

then the IEP team determines if the child has an *impairment in hearing*. See the attached eligibility criteria worksheet for a student with an impairment in hearing.

The next step for the IEP team is to determine if the child, due to his or her impairment in hearing, is in need of special education.

NEED FOR SPECIAL EDUCATION

When determining if a child needs special education, the IEP team responds to 3 questions. The questions below are modified to address the educational focus of 3-year olds.

1. Does the child have needs that cannot be met with typical age appropriate activities for 3-year olds in preschool settings as structured?

If yes,

2. Are there modifications that can be made in the preschool setting or in placement options considered by the IEP team to allow the child to participate in activities and make developmental progress that is typical of all 3-year old children?

If yes,

3. Are there additional services or modifications needed in the preschool settings or in placement options considered by the IEP team that the child needs in order to make developmental progress that is typical for 3-year olds?

If the answer to question 1 and 2 or 3 is “yes”, then the child is a child with a disability in need of special education.

The IEP team will then continue to discuss the present level of performance of the child, his or her needs and services. Based on the child’s needs and services, the IEP team determines the appropriate placement for the child to receive the services stated within her or his IEP.

Glossary



Learning about your child's hearing loss can be a struggle because of all of the new terminology that is used by various professionals and in the literature. Much of this terminology is also used in this notebook. This glossary contains many of the unfamiliar words that you have or will encounter throughout this notebook. The terms with a smiley face in front of them indicate a professional or other type of person that may be able to help you or your child along this journey.

Acoustic Feedback:

A whistling sound produced by a hearing aid. The amplified signal generated by the receiver of the hearing aid leaks outside, is picked up by the microphone, and is then re-amplified.

Acquired Deafness:

A loss of hearing that occurs or develops some time during a person's life but is not present at birth.

Aided Thresholds

The softest level that a given sound can be heard with the hearing aids on and the gain set at a pre-selected level.

Air Conduction (AC):

The process by which sound is sent (conducted) to the inner ear through the external ear canal, middle ear and into the inner ear. Air-conduction testing is performed by sending sounds to the ear through an earphone or loudspeaker.

Air-Bone Gap:

A difference between hearing responses for earphone or loudspeaker (air conduction) versus bone vibrator (bone-conduction) stimulation. A gap or difference between air-conduction and bone-conduction responses indicates conductive hearing loss due to problems in the middle ear.

Americans with Disabilities Act (ADA):

Signed into law in 1990, this is a "civil rights act" for persons with disabilities. The ADA requires public services and buildings to make reasonable accommodations to allow access to persons with disabilities, including hearing loss.

American Sign Language (ASL):

A manual language with its own word order and grammar, used primarily by people who are deaf.

Amplifier:

An electronic device for increasing the strength or gain of an electrical signal.

Amplification:

Used as a general term to refer to whatever device is being used to amplify sound (i.e., hearing aids, cochlear implants, FM systems).

Assistive Listening Device (ALD):

Devices, other than hearing aids, that improve listening for individuals with hearing loss. Some systems improve hearing in noisy situations by positioning the microphone closer to the sound source, or improve the quality of amplified speech or music. Includes FM systems and infrared systems.

Atresia (aural):

An ear malformation in which there is an absence of the external ear canal, usually with abnormalities of the outer ear, and/or middle ear space.

Audiogram:

A graphic representation of hearing loss, showing the amount of hearing loss (in decibels or dB) at different frequencies (250 - 8000 Hertz or Hz).

Audiologist:

A health care professional who is trained to evaluate hearing loss and related disorders, including balance (vestibular) disorders and tinnitus, and to rehabilitate individuals with hearing loss and related disorders. An audiologist uses a variety of tests and procedures to assess hearing and balance function and to fit and dispense hearing aids and other assistive devices. The minimum academic degree is a Master's. State licensure is required to practice audiology in most states.

Audiology:

The study of hearing; the profession is concerned with measurement and rehabilitation of auditory and communication problems.

Audiometer:

A device for presenting precisely measured tones of specific frequencies (or speech and recorded signals) and intensity levels in order to obtain an audiogram.

Auditory Brainstem Response (ABR) test:

A test that can be used to assess auditory function in infants and young children using electrodes on the head to record electrical activity from the hearing nerve. Other terms are: Brainstem Evoked Response (BSER), Brainstem Auditory Evoked Potential (BAEP), and Brainstem Auditory Evoked Response (BAER).

Auditory Neuropathy/Dysynchrony:

A term that describes a pattern of abnormal findings for a number of audiometric measures, e.g., auditory brain stem response (ABR), pure-tone and speech audiometry, and/or acoustic reflexes, yet normal findings for otoacoustic emissions (OAE). The most common pattern is the absence of an ABR with normal OAE.

Auditory Nerve:

The cranial nerve (VIII) that carries nerve impulses from the inner ear to the brain.

Auditory Training:

The process of training a person to use their hearing abilities by listening to environmental sounds, music and speech and then practicing recognizing and understanding what has been heard.

Aural (re)habilitation:

Specialized training for people with hearing loss to help them learn spoken communication skills through speech reading and auditory training.

Balance:

The biological system that enables individuals to know where their bodies are in the environment and to maintain a desired position. Normal balance depends on information from the labyrinth or vestibular system in the inner ear and from other senses such as sight and touch.

Balance Disorder:

A disruption in the labyrinth, the inner ear organ that controls the balance system, which allows individuals to know where their bodies are in the environment. The labyrinth works with other systems in the body, such as the visual and skeletal systems, to maintain posture.

Behavioral Observation Audiometry (BOA):

A pediatric audiometric procedure in which behavioral responses to sounds (e.g., eye opening, head turning) are detected by an observer. This procedure has been shown to be unreliable and affected by observer bias. It has been replaced by newer test methods (see Auditory Brainstem Response, Visual Reinforcement Audiometry).

Behind-the-Ear (BTE) Hearing Instrument:

A style of hearing instrument that has the electronic components in a case that sits behind the top of the ear. It is then held in place by a custom made earmold.

Bicultural:

To be a part of two cultures, such as deaf culture and hearing culture.

Bilateral Hearing Loss:

A hearing loss in both ears.

Bilingual:

To be fluent in two languages. When talking about children who are deaf or hard of hearing it generally means the proficient use of both English and ASL.

Bilingual-Bicultural:

Bilingual-Bicultural education of deaf and hard-of-hearing children encourages children to use American Sign Language as their first language and English as their second.

Binaural:

Refers to both ears.

Birth to 3 Program:

This early intervention program serves children ages birth to three years of age in Wisconsin who have developmental delays or conditions known to result in a developmental delay.

Bone Conduction:

The transmission of sound (mechanical vibrations) through the bones of the skull to the inner ear. Bone conduction testing is completed using a bone oscillator (vibrator) that is placed on the mastoid bone behind the ear or on the forehead.

Bone-conduction Hearing Aid:

A hearing aid in which the amplified signal directly stimulates the inner ear via a bone vibrator placed on the mastoid bone behind the ear. This type of hearing aid typically is used for individuals with atresia or chronic ear drainage.

Captioning:

A text display of spoken words, presented on a television or a movie screen that allows a deaf or hard-of-hearing viewer to follow the dialogue and the action of a program simultaneously.

Central Auditory Processing Disorder (CAPD):

A language disorder that involves the perception and processing of information that has been heard. Children with CAPD have problems following spoken instructions and usually show other language-learning problems, even though the inner ear is functioning normally.

Cerumen:

Ear wax.

Chloral Hydrate:

A common medication used to induce sleep, sometimes used during ABR testing with children.

Cochlea:

Also called the “inner ear.” A snail-shaped structure that contains the sensory organ of hearing and changes sound vibrations to nerve impulses. The impulses are carried to the brain along the VIII nerve, or auditory nerve.

Cochlear Implant:

A medical device that is surgically implanted and bypasses damaged inner ear structures and directly stimulates the auditory nerve, helping individuals who have severe to profound hearing loss to interpret sounds and speech.

Conditioned Play Audiometry (CPA):

A type of hearing test in which the audiologist teaches the child to respond when a sound is heard by playing some type of game. For example, the child puts a peg in a hole or a block in a bucket every time a sound is heard.

Conductive Hearing Loss:

A loss of sensitivity to sound, resulting from an abnormality or blockage of the outer ear or the middle ear. The most common cause of conductive hearing loss is middle ear fluid or infection. Other causes include wax buildup in the ear canal, a hole in the eardrum, or damage to the tiny bones of the middle ear.

Configuration

The term used to describe the severity of the hearing loss and the shape of the audiogram.

Congenital Hearing Loss:

A hearing loss that is present from birth and which may or may not be hereditary.

Congenital Malformation

Any deformity of the face, body, or organs that is present at birth

Cued Speech:

Cued Speech is a communication method, which uses hand shapes and positions to represent the essential sounds of spoken language.

Cytomegalovirus (CMV):

One group of herpes viruses that infects humans and can cause a variety of symptoms, including deafness or hearing impairment. A child may be infected with the virus before, at or after birth.

Deaf:

A term used to describe persons who have a hearing loss greater than 90 dB HL. It also may be used to refer to those who consider themselves part of the Deaf community or culture and choose to communicate using American Sign Language instead of spoken communication.

Decibel (dB):

The unit that measures the intensity or volume of sound.

Direct Audio Input:

The capability of connecting a sound source, such as a TV or tape recorder, directly into a hearing aid. Also refers to the connection of an FM auditory trainer directly into a Behind-the-ear hearing aid.

Dizziness:

A physical unsteadiness, imbalance, and lightheadedness associated with balance disorders. See vertigo.

Dynamic Range:

The difference between the softest sounds a person can hear and the loudest sounds they can tolerate.

Ear Canal:

The passageway from the outer ear to the eardrum.

Eardrum:

Also called the tympanic membrane; the eardrum separates the outer ear from the middle ear and is important in conducting sound to the middle ear and inner ear.

Ear Infection:

Also called Otitis Media; the presence and growth of bacteria or viruses in the ear.

Earmold:

A custom-made earmold used with a behind-the-ear hearing aids and delivers amplified sounds into the ear. The earmold helps to hold the hearing aid in the ear and directs sound from the hearing aid into the ear canal. Earmolds are made from soft materials after an impression is taken of the ear. They are made individually for each person.

Earphone:

A device for presenting sounds to the ear. Earphones may fit over the external ear or fit into the ear canal.

Ear Wax (cerumen):

A normal secretion from glands in the outer ear that keeps the skin of the ear dry and protected from infection.

Educational Audiologist:

An audiologist with special training and experience to provide auditory rehabilitation services to children in school settings.

ENT physician:

A doctor that concentrates on problems with the ear, nose, and throat.

Eustachian Tube:

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

External Ear:

The outer portion of the ear that is normally visible. Components of the external or outer ear include the pinna and the external ear canal.

Feedback:

The shrill whistling sound made when amplified sound from the 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.

Fluctuating Hearing Loss

A hearing loss that changes unpredictably in severity. Sometimes conductive losses associated with the onset of middle ear infections are called fluctuating hearing losses.

FM System:

An assistive listening device that improves listening in noise. Signals are transmitted from a talker through a microphone to the listener by FM radio waves that are directly imputed into the child's hearing instrument.

Frequency:

The unit of measurement related to the pitch of a sound. Frequency is expressed in Hz (Hertz) or cps (cycles per second). The more cycles per second, the higher the pitch.

Functional Gain:

The difference in a person's responses between aided and unaided threshold measures. Functional gain is less reliable and valid than other methods of testing aided benefit.

Gain:

An increase in the amplitude or energy of an electrical signal with amplification. Gain is the difference between the input signal and the output signal. It is a characteristic that hearing specialists look at when choosing a hearing instrument.

Genetic Professionals:

Consists of Clinical Geneticists (physicians) and Genetic Counselors who will work together to provide a genetic evaluation.

Genetic Testing:

May be able to provide information about the cause of hearing loss, possible associated medical conditions, and the risk of hearing loss for other family members through methods, which may include a review of family and medical history, a physical examination, discussion about laboratory tests such as DNA or chromosome testing, and discussion about ongoing care.

Hair Cells:

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

Hard of Hearing:

The term to describe those with mild to severe hearing loss.

Hearing Aid:

Also known as hearing instrument; an electronic device that brings amplified sound to the ear. A hearing aid usually consists of a microphone, amplifier, and receiver.

Hearing Aid Dispenser (Dealer):

Is a professional who is licensed to test hearing in adults for the purpose of fitting hearing aids. In Wisconsin, a hearing aid dispenser is not licensed to test children's hearing but may dispense a hearing aid prescribed by an audiologist.

Hearing Aid Evaluation (HAE):

The process of selecting an appropriate hearing aid. The audiologist will evaluate different types of hearing aids to determine which is best suited to a particular hearing loss.

Hearing Disorder:

A disruption in the normal hearing process that may occur in the outer, middle, inner ear or the nerves to the brain.

Hearing Loss (or impairment):

A problem with hearing that is characterized by decreased sensitivity to sound in comparison to normal hearing. See conductive, sensorineural, and mixed hearing loss.

Hearing Threshold Level (HTL):

The softest intensity level (volume) measured in dB hearing level that a person can hear a sound of a particular test pitch. A completely normal HTL is 0 dB. Also known as HL.

Hereditary Hearing Impairment:

Hearing loss passed down through generations of a family.

Hertz (Hz):

Cycles per second. Frequency is denoted in Hz.

Individualized Education Program (IEP):

A written statement for a child with a disability (between the ages of 3 and 21) that 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 be invited to be part of the team.

Individualized Family Services Plan (IFSP):

A team-developed, written plan for infants and toddlers birth to 36 months and their families, which addresses: 1) assessment of strengths and needs and identification of services to meet such needs; 2) assessment of family resources and priorities, and the identification of supports and services necessary to enhance the capacity of the family to meet the developmental needs of the child. In Wisconsin this is the responsibility of the county that the child resides in.

Inner Ear:

The part of the ear that contains both the organ of hearing (the cochlea) and the organ of balance (the labyrinth).

Jervell and Lange-Nielsen Syndrome

A disorder made up of the following symptoms: endogenous, sensorineural hearing loss present at birth accompanied by a congenital heritable defect of the heart. Clinical feature includes fainting episodes.

Lip-reading:

Also known as speech-reading; a communication strategy that understands spoken language by interpreting lip movements, facial expressions, and postures.

Localization:

The ability to determine the direction of a sound source.

Mastoid Bone:

A portion of the temporal bone located behind the external ear. Bone-conduction stimulation often is applied to the mastoid bone.

Microtia:

Abnormal growth of the outer ear. Severity varies from minor skin tags or differences in ear shape to complete absence of the outer ear.

Middle Ear:

The part of the ear that includes the eardrum and three tiny bones (ossicles) of the middle ear, ending at the round window that leads to the inner ear.

Mixed Hearing Loss:

A hearing loss with both conductive (middle ear pathology) and sensory (cochlear or VIIIth-nerve pathology) components. The audiogram shows a bone-conduction hearing deficit plus a gap between earphone and bone-conduction responses.

Multimemory:

Hearing aids that have the ability to store different listening programs or settings that amplify sound according to particular listening environments and may be accessed by the user.

Nonsyndromic Hereditary Hearing Impairment:

A hearing loss or deafness that is inherited and is not associated with other inherited physical characteristics.

Ossicles:

The chain of three tiny bones in the middle ear (malleus, incus, stapes). Sometimes these bones are called the hammer, anvil and stirrup in common terms.

Otitis Externa:

An inflammation of the outer part of the ear and sometimes in the auditory canal.

Otitis Media:

An inflammation of the middle ear caused by infection.

Otitis Media with Effusion (OME):

Otitis media with abnormal fluid in the middle ear.

Otoacoustic Emissions (OAE):

Low-intensity sounds produced by the inner ear that can be measured with a sensitive microphone placed in the ear canal. It is also a test used to detect hearing loss.

Otolaryngologist:

Also known as an ENT; a physician/surgeon who specializes in diseases of the ear, nose, throat, head and neck.

Otologist:

A physician/surgeon who specializes in the treatment of ear problems.

Otology:

The branch of medicine that specializes on 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.

Postlingually Deafened:

The process of becoming deaf after a person has acquired language.

Pressure-Equalizing (PE) Tube:

Also called a tympanostomy tube; a tube that is inserted in the eardrum to equalize the pressure between the middle ear and the ear canal and to permit drainage.

Prelingually Deafened:

An individual who is either born deaf or who lost his or her hearing early in childhood, before acquiring language.

Probe Microphone:

A tiny microphone attached to a soft, small tube. The probe microphone is placed in the ear canal and is used to measure a variety of sounds during a hearing aid evaluation.

Real-Ear-to-Coupler Difference (RECD):

The difference, in decibels and across frequencies, between the response of a hearing aid measured in a real ear versus a standard coupler. The RECD is a measure that allows the audiologist to accurately specify the sound levels delivered to the ears of infants and young children.

Real Ear Measurement:

A test technique used to measure the sound levels in the ear canal produced by a hearing aid. A probe microphone is placed in the ear canal alongside the hearing aid.

Residual Hearing:

The amount of measurable, usable hearing.

Sensorineural Loss:

A hearing loss caused by damage to the inner ear (cochlea) and/or the hearing nerve.

Sign Language:

A method of communication used primarily by people who are deaf or hard of hearing in which hand movements, gestures, and facial expressions convey grammatical structure and meaning.

Speech Awareness Threshold (SAT):

The lowest hearing level in dB at which a person can detect the presence of a speech signal, also known as the speech detection threshold (SDT)

Speech Frequencies:

The frequencies within the 500 to 4000 Hz region, which are most important for hearing and understanding of speech.

Speech Detection Threshold

The softest level a person can perceive the presence of a speech signal.

Speech Reception Threshold (SRT):

The lowest hearing level in dB at which 50 percent of two-syllable (spondee) words can be identified correctly. Also known as the ST (speech threshold or spondee threshold).

Speech-Language Pathologist:

A professional who evaluates and provides treatment for speech, language, cognitive-communication, and swallowing problems of children and adults. Speech and language delays are frequently seen in children with hearing impairments. Minimum academic degree is a Master's degree. State licensure is required to practice speech-language pathology in many states.

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.

Syndromic Hearing Impairment:

A hearing loss that is accompanied by additional physical characteristics (e.g., blindness, mental retardation or involvement of other organs).

Telecoil:

A wire coil contained within a hearing aid that picks up magnetic energy available from telephones or other assistive listening devices.

Threshold:

See also Hearing Threshold Level; the softest level at which a sound can be heard 50 percent of the time. The term is used for both speech and pure tone testing.

Tinnitus:

A sensation of ringing, roaring, or buzzing sound in the ears or head. It is often associated with hearing impairment and/or noise exposure.

Toxoplasmosis

A common disease found in birds, cats, and mammals across North America. The infection is caused by a parasite called toxoplasma gondi and affects 10 to 20 out of every 100 people in North America by the time they are adults. If a mother is infected while she is pregnant, her baby could be born with hearing loss.

TTY/TTD:

A device for severely or profoundly hearing-impaired persons to send or receive written messages transmitted via telephone lines.

Tympanogram:

A measure of tympanic membrane (eardrum) mobility.

Tympanostomy Tube:

See Pressure-Equalizing tube.

Unilateral Hearing Loss:

A hearing loss in one ear only.

Usher's Syndrome

Hereditary disease that affects hearing and vision and sometimes balance.

Vertigo:

A spinning sensation, sometimes occurring with nausea and/or vomiting.

Vestibular System:

The system in the body that is responsible for maintaining balance, posture, and the body's orientation in space. This system also regulates body movement and keeps objects in visual focus as the body moves.

Volume Control:

A device for increasing or decreasing the gain or volume of a hearing instrument.

Visual Reinforcement Audiometry (VRA):

A pediatric hearing test procedure in which the child's responses to sound are reinforced with a visual event (e.g., a moving toy). This procedure is most appropriate for children in the 6-month to 3-year age range.

Wide Dynamic Range Compression:

A special type of hearing aid or amplification device that compresses a wide range of sounds into a narrower range. This makes soft sounds easier to hear and makes loud sounds more comfortable for listening.

Feedback Form



❖ Was the Babies and Hearing Loss Notebook useful to you and your family?

- Not Useful •Somewhat Useful •Very Useful

Please comment on what was or was not useful about the notebook:

❖ Has the information in this notebook helped you to understand the impact of hearing loss on your child and family?

- Not Useful •Somewhat Useful •Very Useful

Please comment on how this was helpful or not:

❖ Did you find this notebook helpful in making decisions about your child's hearing healthcare?

- Not Useful •Somewhat Useful •Very Useful

Please comment on how this was helpful or not:

❖ Did you find the Keeping Track Section of this notebook useful?

- Not Useful •Somewhat Useful •Very Useful

Please comment on which keeping track pages were most useful for you:

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

(1 = most useful. 6 = least useful.)

- | | |
|------------------------------|-----------------------------------|
| _____ Celebrating your Child | _____ Exploring the Possibilities |
| _____ Supporting you Family | _____ Keeping Track |
| _____ Getting the Facts | _____ Looking Ahead |

❖ If you have additional comments about the Babies and Hearing Loss Notebook please include them on a separate sheet of paper. We are very interested in your feedback!