

# babies & hearing loss



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

# **Babies and Hearing Loss: An Interactive Notebook for Families with a Young Child who is Deaf or Hard of Hearing**

Wisconsin Educational Services Program for the Deaf and Hard of Hearing  
(WESP-DHH) – Outreach, Dept. of Public Instruction  
and  
Wisconsin Sound Beginnings, Dept. of Health Services



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# Hello families...



I would like to welcome you to the third edition of the **Babies and Hearing Loss Interactive Notebook**. It is “interactive” because we’ve included many places where you can keep notes and maintain records. I hope this will help you as you assume your new role as parent of a child who is deaf or hard of hearing.

This notebook is a compilation of efforts by many parents and professionals in the field. As you travel your new path, please be assured that this community is here to help you. This notebook was first written approximately six years ago, after Universal Newborn Hearing Screening had been implemented in Wisconsin. Parents began finding out sooner rather than later that their child had a hearing loss. This is great news, since it allows for earlier intervention and family support.

“Hearing loss is the most common congenital condition in the US. Every day, 33 newborns are born with some degree of hearing loss. Studies have shown that early diagnosis and intervention can minimize developmental delays that arise from hearing impairment and that infants who receive intervention prior to 6 months of age maintain language development commensurate with their cognitive abilities through the age of 5 years. Therefore early screening, follow-up and treatment are critical.” —excerpt from the AAP pamphlet “UNHS”

Over the last eight years, support for families with a child who is deaf or hard of hearing has increased. In addition to this notebook, the state of Wisconsin sponsors an Annual Statewide Family Conference, the Guide By Your Side™ program, and the Deaf Mentor Project, among other services. Educational and social opportunities abound. Statewide chapters of national parent groups have sprouted. There is more information available online and through books and audio-visual materials. There has been a movement of hearing parents teaching hearing babies “baby sign language.” This has provided a great influx of materials for parents of deaf and hard of hearing babies, in addition to increased acceptance of the use of sign language. Technological and medical advances have allowed for amplification devices and cochlear implants to be used at an earlier age. Reading and math test scores of children who are deaf and hard of hearing have risen in past years. The future for our kids is brighter than ever before.

All of these advances do not negate the fact that you are a parent in an unexpected new role. But I hope it gives you the incentive to learn as much as you can and to make connections with other parents and professionals.

Sincerely,

Connie Stevens

Parent and Professional

Wisconsin Sound Beginnings Consultant, member of Wisconsin Families for Hands & Voices and AG Bell, Guide By Your Side, Family Enhancement/Shore to Shore Parent Educator

# Acknowledgements



This notebook exists only because families with young children who are deaf and hard of hearing requested it. Parent Notebook Committee members have talked with, and more importantly, listened to many families who have young children with hearing loss. Through these discussions, it became evident that what families wished for most was clear and unbiased information. We hope you will find clear and unbiased information in these pages.

Special thanks go to the dedicated parents who contributed their time, energy, wisdom and experiences to the initial creation of this important resource. These include Barb Aschenbrenner, Loraine Lucinski, Kathryn Mazack, and Connie Stevens. Thanks also to the committed group of professionals who helped write, construct and review this resource. These include Christine Kometer, Susan Felstehausen, Mary Kahler, Carol Schweitzer, Elizabeth Seeliger, Kristina Stuart, and Alice Sykora.

Thanks also to the many other parents who shared stories and photographs of their beautiful children for this notebook.

Particular acknowledgement must go to the following organizations that allowed the reproduction and adaptation of materials already created for families: Mary Pat Moeller and the Boys Town National Research Hospital, the Colorado Home Intervention Program (CHIP), Colorado Families for Hands & Voices, The Sibling Support Project, Hi-Preface, and AG Bell Association.

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# Welcome to Holland

By Emily Perl Kingsley

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this...

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very very significant loss.

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.

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# Parent's Bill Of Rights



You have the right to be mother or father, to love your child, enjoy, play, and guide your child.

You have the right to grieve, to receive emotional support, and know that all feelings are normal.

You have the right to a sense of competence/confidence about raising your child. You are the parent and know your child better than anyone.

You have the right to be an expert on your child and regarded as a professional. You are your child's best advocate/ally.

You have the right to communicate fully with your child.

You have the right to see your child as a whole child - a child first and the hearing loss second.

You have the right to share your child's progress and achievements with others with a genuine sense of pride.

You have the right to receive unbiased, thorough information about communication and education possibilities.

You have the right to meet other families who have raised a child who is deaf/hard of hearing, and adults and older children who are deaf/hard of hearing, if you so choose.

You have the right to demand the kind of services you believe would best suit your child and family.

You have the right to receive program services sensitive to your family's culture, language, faith, values, and needs.

You have the right to tell professionals and educators what you really feel about the job they are doing and to demand they respect your opinions.

You have the right to designate service providers – to have more than one choice.

You have the right to expect and receive confidentiality from all the professionals in your child's life.

You have the right to ask any question.



Celebrating  
Your Child



# 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 November 1980  
Written in Fall of 2002

# 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've shared their own personal celebrations of their children.

## Jack, born 9/97, and Tressa, born 6/03



When our first deaf child 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." 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. In June of 2003, we were pleased to welcome our first little girl into the world. Tressa is also deaf but received her implant at a much younger age. She is quickly progressing as well and is lucky to have two older brothers to keep her busy! We think of Jack and Tressa as children first, and their deafness is just part of who they are. We try to guide others into seeing them as we do.

-- 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 at [www.SADS.org](http://www.SADS.org).

-- Mike and Jean Palm, West Bend

### 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 is 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 ensure 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



Stevens, Spring Green

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.

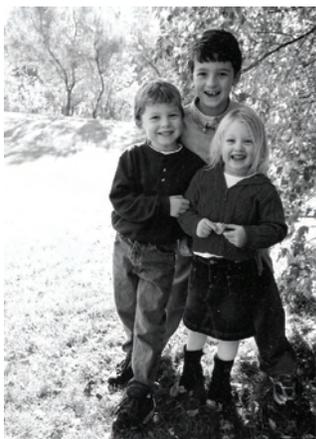
-- Dan Ruetten & Connie

# The Stories Continue...



We thought you might enjoy reading where some of the children and families are five years later.

## Jack, born 9/97, Tressa born 6/04



Our family was introduced into the world of hearing loss when our oldest son Jack was born. We were like so many families that had no known family history but had a deaf child. Jack was diagnosed with a profound loss when he was 9 months old. We had Owen who is hearing and then Tressa was born in 2004. She was diagnosed at birth as also having a profound loss. Both children have received cochlear implants. They have very different personalities and learning styles. Jack loves to read and hopes to be an author someday. Tressa is the social one of the family whose biggest goal at this point is trying to get her brothers to do what she tells them!

-- Paul & Molly Martzke, Green Bay

## Catherine & Ian, born 8/93



It's fall of 2007 and Ian and Catherine Palm are 14 years old. Early teens. Middle school students. Same parents. That's about where their similarities end. Mom wonders whether they are even related.

The twins attend middle school in West Bend. They are in separate "houses" there, with two interpreters. They cross paths in art and Spanish classes. They are learning to read and write Spanish as evidenced by the fact that they throw in fingerspelled Spanish words when communicating with the family. There's a unique challenge for mom and dad! The district invested in the Rosetta Stone language learning software and installed two computers in the classroom. This has been an effective accommodation.

They participate in a book club at the West Bend public library and are experts in anything one might wish to know about Harry Potter! Catherine volunteers at the Wisconsin Humane Society where she helps socialize cats that await adoption. Play Station 2 and Wii systems keep them occupied at home . . . maybe a little too occupied when it comes to Ian.

Both Ian and Catherine are deaf because of Long QT Syndrome. LQTS is a disturbance of the heart's electrical system, causing an abnormality of the heartbeat, or rhythm of the heart. Early symptoms in both children were episodes of syncope (fainting). Beta blocker medications help and they are further safeguarded by implanted pacemaker defibrillators. Surgeries to implant and update the devices have been and will continue to be a part of their lives. For further information about Long QT Syndrome, see [www.sads.org](http://www.sads.org).

-- Mike and Jean Palm, West Bend

### Emma, born 4/97



Well when I look back and read what I said ... "if all we have to do is learn sign language, that's no big deal" ... I am amazed at how naïve I was! There is a lot more to it than just learning sign language, but we did it and we have an amazingly intelligent girl. Emma is 10 now and is mainstreamed in a regular elementary school with an interpreter and she has so many friends! I only wish the deaf mentor program would go beyond age 6 to provide that additional support through the hormone times when we go from "I love being deaf" to "I hate being deaf." She knows that life is a little tougher for her but for the most part she takes it in stride. We recently received one of the greatest compliments a parent can receive from a teacher. The teacher said that she loved Emma's enthusiasm in the classroom and that Emma renewed her passion for teaching. She is a joy to be with and we love her very much!

-- Don & Lori Menzel, Kewaskum

### Claire, born 11/98

Claire is now 9 years old and has just started 3<sup>rd</sup> grade. It has been an amazing "ride" so far. It is much easier to look back on the early months following her diagnosis and know how unfounded many of our fears for her and her future were. Some of our most positive experiences have been in working with our school to best meet Claire's needs. Her kindergarten teacher actually put tennis balls on the bottoms of all of the chairs on her own, without us ever bringing it up. It made a huge difference. The school also purchased a mobile sound field system that has followed Claire to each grade. Her teachers love using it, and have noticed how much it helps ALL of the kids, not just Claire. Claire continues to learn, grow and succeed, as do we. There are still frequent bumps along the way, but we have a great team to help us.



-- Jack & Christine Herden, Monches

### Erik, born 2/93



Erik is finishing 8th grade this week. He plays trumpet and piano. He is editor of the school newspaper. He is in German Club and Destination Imagination. He is in Boy Scouts working toward being an Eagle Scout. He plays soccer, tennis and runs for the school track team. He is a straight A student who works hard to get good grades. He loves to write screen plays and make movies with his friends. He has a delightful personality and he has many friends. He uses a sign language interpreter and an FM system at school. Erik is becoming an amazing young man.

-- Frank & Angela Pintar, Wauwatosa

### Jennifer, born 9/98

Jennifer received a cochlear implant at 27 months of age. She has had some difficulty with speech related to the cerebral palsy but has come a long way in making strides the last couple of years. She is in 3<sup>rd</sup> grade at Lowell Elementary, which has a total communication program. This has really worked with Jennifer's needs. Her personality is really coming out, and anyone who knows Jennifer can attest to this! She loves sports and is very active with this.

-- Brian & Tammy Hogan, Mukwanago

### Jacob, born 7/01

Jacob went to an oral preschool at Lowell Elementary in Waukesha. He learned a great deal and tested above his age in verbal skills by the time he entered kindergarten. As we had hoped, Jacob was mainstreamed in kindergarten at Lowell and was taken out only 1 time per week for auditory training. The summer after Jacob completed kindergarten, he received a second cochlear implant to give him bilateral hearing. It was rough for a week after the surgery but now, 3 months later, he is doing great. He is in first grade (mainstreamed at Lowell) and still taken out one time per week for auditory training but now it is for his new cochlear implant. By second grade, Jacob probably won't have to be taken out of class for any extra help.

-- Ron & Chris Jahnke, Wauwatosa



### Tess, born 3/98



Tess is now 9 years old and in 3<sup>rd</sup> grade. She is a very happy girl who brings joy to our lives. Yes, we have had challenges along the way, but we feel more confident about her future everyday. Tess communicates mainly in sign language. We have tried to give her as many opportunities as possible to learn and use sign. We had a deaf mentor for years and exposed our household to many sign language books and videotapes. In addition, Tess got a cochlear implant over 3 years ago, mainly for safety reasons. It has taken her and the audiologists sometime to program it. She finally seems to enjoy listening and trying to talk. This fall Tess is doing very well with her adjustment to her local school district. For five years she had attended Glendale, a Madison public school one hour away from home. Glendale had a deaf and hard of hearing program. There she interacted with many adults and kids who knew sign language and deaf culture. However, we

felt it was time to bring her home to make friends with the local kids her age. We are fortunate that one of her consistent interpreters from her old school made the transition with her. This interpreter is able to manage Tess's behavior, and therefore Tess is able to concentrate on learning rather than testing the limits. I can't imagine our lives without her.

--Dan Ruetten & Connie Stevens, Spring Green

# Bonding



“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.”

-- Connie Stevens, whose daughter is deaf and has Down Syndrome

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!

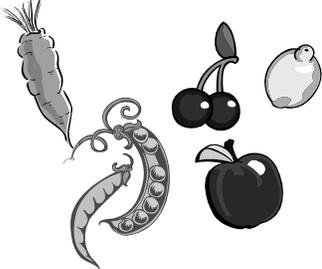
Bonding means to form a connection with another. This happens at any age but is especially important early on in your child’s life. A strong attachment during early childhood can form the foundation for trust and self-esteem later in life. Although your child may be deaf or hard of hearing, you can connect 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.

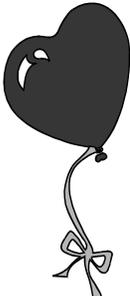
“Our first daughter was born in 1986...She was diagnosed with profound hearing impairment at 14 months of age. I remember thinking how much I loved my daughter but hated the hearing loss. I remember wondering if I still knew my child and feeling very guilty about those thoughts. ..In 1994, my third daughter 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...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 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.”

-- a mother of three daughters (two of which are hard-of-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.

To help you take note of how you have already bonded with your child, we have provided a beautiful tool on the next four pages. Take some time and jot down your answers. We hope that by doing so, you will realize that you do know your child and that you are communicating. An added benefit to making notes: you can share these with others who help care for your child. In that way, they will more easily be able to form a bond as well. If you feel you can't make any notes at this time, don't get discouraged. Perhaps the tool will give you ideas on how to relate to you child and you can revisit the chart later.

<p style="text-align: center;">Food and drink</p> 	Likes	Dislikes

<p style="text-align: center;">Toys, blankets, and other things</p> 	Likes	Dislikes

 <p>Games and activities</p>	Likes	Dislikes

 <p>Books and songs</p> 	Likes	Dislikes

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

<p>When is your child the most cooperative?</p> 	<p>When is your child the least cooperative?</p>

<p>What frightens your child?</p>	<p>What soothes your child?</p> 

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?

# Bonding Through Early Communication

The next few pages will give you some ideas on how to support your child's earliest communication efforts. They will be helpful no matter the level of your child's hearing loss.

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.
- » Stomp 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 will 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 later 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 to say or sign "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 communicates, you will respond. By being a responder, you are shaping the child's communication 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. Ideas of how to do that will now be given.

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 vocalizations, 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, frowning eyebrows, and eye gaze. Remember that there are many ways for your child to communicate his/her 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 pay more attention to your comments if you match his/her 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 reply using speech or sign, “The bear is big.”
- » Act as if the child’s sign has meaning and sign back.
- » Imitation is a good way to respond. If you can’t understand the child’s sign or vocalization, imitate it and sign “yes.” This is very affirming to the child.

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 or talk with a hard of hearing 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 say or sign “sleepy” and then yawn, laying your head on a pretend pillow. When signing or saying “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 or signing 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 or may not hear the noise, but they will feel the vibrations.

- » Balloons will pick up vibrations (offer these to your child only 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.

**Keep a written communication 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 pages. 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 that your child's actions have meaning, as well as their words. 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.

### **In 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 it 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?

# Milestones of Communication: Development of Communication Skills

Typically, parents watch their child’s development closely. Physical and communication milestones become major topics of discussion, material for comparison or boasting, and sometimes cause for concern. For example, a parent might boast, “Joey walked at nine months!” Or they may voice concern with a statement like, “Matthew still hasn’t said his first word.”

Parents of children who are deaf or hard of hearing watch those developmental milestone charts in the same way as other parents. In fact, parents with deaf or hard of hearing children may follow the milestones for communication skills even more closely since this is often the area where their children will demonstrate some delay. Typical communication milestones highlighted in traditional charts usually only recognize verbal communication skills (spoken English/speech). However, children who are deaf or hard of hearing may develop both verbal (spoken) and non-verbal (gestural and/or sign language) communication skills. This means that traditional developmental milestone charts fail to recognize all of the communication skills that your child may be developing. When we fail to recognize these emerging communication skills, we may not foster them as much as we could or would like to. And how can we celebrate emerging communicative abilities if we are unaware of them?

In order to celebrate our deaf and hard of hearing child’s communication abilities, we need to have a broader understanding of “communication.” In this notebook, both visual and oral communication milestones have been included. The notebook does not, however, contain every possible way that your child can or will communicate. It is meant to give you a sense of what and when you may see the variety of communication behaviors that may be developing in your child.

To make better use of the charts, you may need to have a better understanding of the category headings. The term **communicative intent** refers to the way in which your child uses gestures, vocalizations and/or language to let you know what they want or need from you. It is communication with a purpose. **Signed and Verbal Production** are the signs and/or spoken words that your child produces. **Listening Skill Development** may also apply to your child; this is the way in which your child develops listening skills and/or benefits from the use of hearing aids or a cochlear implant. **Literacy Development** refers to behaviors related to the written word.

Remember that every child is unique and develops at his/her own rate – this chart is meant to be a guideline only. It is also important to understand that, depending on the choices you make regarding communication method, use and type of amplification, when your child first started using amplification, etc., you may not see all of the behaviors listed or you may see them later in your child. For example, if you choose an oral-only communication approach, you may not see some of the sign behaviors develop because your child is not being exposed to sign language. If you choose not to use amplification devices on your child, you may not see the speech production or listening skills developing in your child. Finally, if your child does receive an amplification device (hearing aids, cochlear implant), it is suggested that you look at his/her “hearing age” rather than his/her “chronological age”. This is especially important to note if your child is deaf. Because he/she could not hear anything prior to amplification devices, his listening and verbal production skills may be a little later.

Please use these charts to celebrate your child and the communication milestones that he or she is developing.

## Precursory Stage: Birth to 8 Months

<b>My child can do this!</b>		<b>Communicative Intent</b>
Y	N	Uses distinctive cries to indicate different desires
Y	N	Maintains eye contact
Y	N	Attends to sign and/or gestures
Y	N	Participates in turn-taking behavior: Mother coos, then baby coos; baby drops toy and looks at mom, mom picks toy up and baby drops it again

<b>My child can do this!</b>		<b>Signed and Verbal Production</b>
Y	N	“Cooing”- Produces vowel sounds: “ahhhh,” “ohhhh”
Y	N	“Babbling”- Produces consonant-vowel sounds: “baaa,” “maaaa,” may start to produce sign babble (hand movements)
Y	N	Produces vowel-consonant sounds and plays with pitch of voice: “abba, abba”
Y	N	Produces “reduplicated babble:” “bababab,” “agabagaba”
Y	N	Imitates facial expressions and uses them to show emotion

<b>My child can do this!</b>		<b>Listening Development</b>
Y	N	Detects noises and sounds
Y	N	Looks toward the source of a sound
Y	N	Detects other peoples’ voices or name when spoken
Y	N	Responds when a sound starts and when it stops.
Y	N	Can detect the sounds “ahhhh,” “ohhhh,” “iiiiiii,” “ssssssss,” “shhhhhh,” “mmmmmm.”

<b>My child can do this!</b>		<b>Literacy Development</b>
Y	N	Mouths or chews on books

## Prelinguistic Stage: 6 to 16 Months

<b>My child can do this! Communicative Intent</b>		
Y	N	Uses different function words /signs: more, up
Y	N	Uses different pitches, stress, and duration of sounds; “No!!!”
Y	N	Uses different gestures to convey meaning: points at a toy to mean “I want that”.
Y	N	Acknowledges another person with eye contact or action
Y	N	Plays games using vocalizations/ gestures: peek-a-boo, soooo big

<b>My child can do this! Signed and Verbal Production</b>		
Y	N	Imitates non-speech oral movements: opening and closing mouth, kissing, imitates signs and sign movements
Y	N	Points to people, objects or places
Y	N	Will vocalize on request: “Say, ahhhhhhhh”.
Y	N	Will use a sign to make a request
Y	N	Imitates adult speech varying in loudness, pitch, and duration
Y	N	Can produce the vowel sounds that occur in the following words: mama, me, moo, and cat
Y	N	Can produce the consonant sounds that occur at the beginning of the following words: bat, mat, pat, nat
Y	N	Can imitate the hand shapes for the following signs: One, five, s, l, a, c, and o
Y	N	Produces speech-like utterances or sign-like movements and gestures
Y	N	Uses a combination of real words and word approximations and / or a combination of real signs and sign approximations

<b>My child can do this! Listening Development</b>		
Y	N	Can identify environmental sounds
Y	N	Can identify long and short sounds
Y	N	Can identify loud and soft sounds
Y	N	Can identify high and low pitched sounds
Y	N	Can identify speech sounds vs. environmental sounds
Y	N	Can identify voices of family members / care givers

**My child  
can do this! Literacy Development**

Y	N	Is more interested in the story than in mouthing or chewing the book
Y	N	Looks at pictures
Y	N	Vocalizes, pats pictures
Y	N	Prefers pictures of faces
Y	N	Reaches for books

### Early Linguistic Stage: 12 to 24 Months

**My child  
can do this! Communicative Intent**

Y	N	Uses names (spoken or signed) of family members to get attention or to make a request
Y	N	Uses words/signs to announce and/or greet; “bye-bye”
Y	N	Uses words/sign approximations with meaning
Y	N	Uses sign/words with facial expressions
Y	N	Uses two word/sign combinations with meaning
Y	N	Responds to routine “who” and “where” questions with a gesture: where’s your nose?
Y	N	Asks “What’s that?”

**My child  
can do this! Signed and Verbal Production**

Y	N	Produces vowel sounds like the ones that occur in the following words: bake, bet, big, bull, bun, bend, box
Y	N	Produces consonant sounds like the ones at the beginning of the following words: wet, hot
Y	N	Can say the names of family members
Y	N	Can say the names of common things: ball, cat, milk
Y	N	Can produce about ten signs that approximate adult form
Y	N	Produces 50-100 words or signs: no, me, mine are common at this stage
Y	N	Displays fingerspelling-like activity
Y	N	Uses facial expressions in the following ways: head shake to mean “no”, nod to mean “yes”, raises eyebrows when asking yes/no questions

**My child can do this! Listening Development**

Y	N	Understands common expressions: OK, Come here, sit down
Y	N	Can identify words that are similar in length but differ in vowels and consonants: toothbrush vs. mailman
Y	N	Can identify words that differ in syllable and stress patterns
Y	N	Can identify one syllable words that differ in consonant sounds and vowel sounds: ball vs. key
Y	N	Can pick the correct phrase out of a few pre-selected phrases
Y	N	Can identify voices of family members and caregivers

**My child can do this! Literacy Development**

Y	N	Gives book to an adult to read
Y	N	Turns board pages of a book
Y	N	Turns book right side up
Y	N	“Reads” to dolls or stuffed animals
Y	N	Delights in reading together with adults
Y	N	Makes the same sound for or label picture
Y	N	Fills in words in familiar stories
Y	N	Points when asked “where’s the ...?”
Y	N	Protests to changes in familiar story
Y	N	Points at pictures with one finger

## Linguistic Stage: 20 to 40 Months

**My child can do this! Communicative Intent**

Y	N	Uses variation in their vocal pitches and facial expressions to ask questions
Y	N	Can label actions in pictures using signs/words
Y	N	Engages in pretend play that involves objects and a sequence that represents a routine: hooks truck up with trailer, puts baby doll to bed.
Y	N	Can relate past experiences in 2 to 3 words/signs
Y	N	Can label a construction or a drawing
Y	N	Asks “Yes/No” and “Where” questions
Y	N	Asks simple “why” and “who” questions
Y	N	Answers “What are you doing?” “How many?” and “Whose?” questions
Y	N	Uses three word/sign combinations with the intent to communicate something to another person
Y	N	Can take turns during a game

**My child  
can do this! Signed and Verbal Production**

Y	N	Can produce consonant sounds like the ones at the beginning of the following words: cot, got, dot, tot, fox, and vote
Y	N	Imitates and spontaneously produces the hand shapes that make the letters b, f, o
Y	N	Is beginning to expand use of parts of speech such as verb endings like “-ing” or “-ed”; or repeats a sign to describe a verb: repeats sign for “WALK” to say “Took a long, long walk”
Y	N	Approximates the fingerspelling of words like “OK” and “TV”, or fingerspells commonly used fingerspelled words
Y	N	Can produce three or more word/sign combinations
Y	N	Imitates 5-7 word/sign sequences including facial expressions
Y	N	Uses negatives: words like no, can’t, don’t, not; or uses head shake to convey NO
Y	N	Moves sign to indicate action and location: SIT THERE
Y	N	Use of plurals emerging by adding ‘s’ when speaking or by signing in one of the following ways: repeating a sign, number and sign, MANY and sign

**My child  
can do this! Listening Development**

Y	N	Able to understand simple directions using listening only: e.g. “Get the ball.”
Y	N	Understands simple questions about a familiar topic or event
Y	N	Identifies single syllable words with similar consonant sounds but different vowels: ball vs. bee, cat vs. key

**My child  
can do this! Literacy Development**

Y	N	Recites familiar phrases, sometimes retells whole story
Y	N	Coordinates text with picture
Y	N	Reads familiar books to self
Y	N	Moves finger along text (emerging)
Y	N	attends to longer stories
Y	N	Moves through books to find favorite pictures
Y	N	Can turn paper pages
Y	N	Scribbles with a purpose (trying to write or draw something)

# Early Literacy



What is literacy and why are we discussing it in relation to children who are deaf and hard of hearing? Basically, being **literate** involves **knowing how to read and write**. Children who are deaf and hard of hearing will be dependent on the written word to learn much about the world. A popular saying goes, “First, children learn to read, and then they read to learn.” In addition, they will need to write in order to communicate their thoughts.

Strong communication with your child can provide the foundation for literacy. Through daily contact with your child, he or she is learning words, and 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 more visually than through auditory means, 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.

In the remainder of this section, you will read examples of babies’ and young children’s early literacy behaviors and suggestions of how you can support your child’s continued interest in developing their literacy skills. Besides information presented in this notebook, we encourage you to read other materials on literacy that you will find in the library and online. This basic information will pertain to your child, no matter the level of their hearing loss.

## **Examples of early literacy behaviors:**

- » 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 events 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.

### **Strategies to promote early literacy:**

- » 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

### **Additional tips for you to use with your child when reading together:**

- » 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. They can withstand toddlers' hands and mouths and are 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:**

- » 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. Your child can then see facial expressions 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 and hard of hearing 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 and hard of hearing 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.













Supporting  
Your Family



# Supporting Your Family



## Supporting your Family



The “**Supporting your Family**” section is organized into two areas. The first area contains information to help support the family members affected by the hearing loss – mothers, fathers, siblings, grandparents and extended family. We recognize that the news may affect everyone in a different manner. We hope the information is helpful in thinking about how to go forward. The second area of this section will introduce you to national, state and local resources. It will also list mail order companies and lending services, as well as provide you with a listing of agencies that may be able to give you financial support in regards to your child’s hearing loss needs.

### Parent to Parent Matching: Guide By Your Side Program™

A good place to start is to call the Wisconsin Guide By Your Side program. This is a parent-to-parent support program for families with babies or young children with a hearing loss. Each family is matched with a regional “Parent Guide” who is an experienced parent of a child with hearing loss. The Parent Guide visits you in your home or another place that is comfortable to you and shares unbiased information and resources with your family. The program was created because Wisconsin parents of children with hearing loss repeatedly reported that in looking back at their child’s development they **wished they had known another parent of a child with hearing loss**. Seeking support from another parent who has shared some of your same experiences can have a profound impact on your family as you begin your journey. Although parents and families may process events and experiences differently, the underlying connection of wanting the best for your child remains the same. If you have not yet been connected to this free program or would like more information please call the Guide By Your Side Hotline at 1-888-656-8556.

“Our Parent Guide was outstanding in every aspect. She made us aware of programs and gave us support to pursue them. She was the boost we needed to find resources for our daughter. Thank you for offering the Guide By Your Side program!” – a Wisconsin parent

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 to wear but 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."

## The Birth to 3 Program: Early Intervention in Wisconsin

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 is a statewide program, which is administered at the county level. The Birth to 3 Program serves children ages birth to three who have developmental delays or conditions that have a high probability of resulting in developmental delay. It is a voluntary program that works with each child and family to provide individualized services and supports such as education, resources, and other supportive services.

The philosophy of the Birth to 3 program is a family-centered, community supported approach to intervention. Families play an integral part in this program, both in identifying outcomes and carrying over strategies to support their child's development throughout the day during their daily routines. Birth to 3 providers work closely with families to identify their strengths and areas of need. Through this partnership, an Individualized Family Service Plan (IFSP) is developed to address the outcomes that families have identified for their child and family. Based upon these outcomes, types and frequencies services are determined. Guiding paperwork in the development of an IFSP and a sample of a blank IFSP form are located in the "Keeping Track" section of the Parent Notebook. Please note, these are only samples, and your specific county IFSP may look slightly different. You may want to review them to better understand the components of the IFSP.

A key resource for families within their Birth to 3 Program is their Service Coordinator. The role of the service coordinator is to guide families through the Birth to 3 process, help to identify and locate resources for families, and, to provide ongoing coordination to the early intervention team while the child is in Birth to 3. The service coordinator is responsible for the completion and revisions on the IFSP (with team input), locating and accessing services determined on the IFSP and supporting families as they transition within and out of the Birth to 3 program. In addition, the service coordinator can be supportive in locating community resources for families even if they are not listed on the IFSP. Service coordinators are automatically a part of every early intervention team and do not need to be linked to a specific outcome on the IFSP.

A child with a unilateral or bilateral permanent hearing loss of any decibel level is eligible for the Birth to 3 Program and does not need to demonstrate a developmental delay. Eligibility is based on

a child's need and not family income. A copy of the Birth to 3 Eligibility Guidance document can be found at: <http://www.waisman.wisc.edu/birthto3/EligibilityGuidelines.pdf>

Following the determination of eligibility, the Individualized Family Service Plan team (IFSP team) meets to develop the IFSP. Resources, services and supports are individually established for each child based on the outcomes determined by the IFSP team.

Your audiologist should make the referral to your county Birth to 3 Program upon diagnosis of your child's hearing loss. However, anyone can make a referral to the Birth to 3 Program. To locate the program in your county, you can call **The FirstStep Hotline** at 1-800-642-7837, or locate your county contact on the WI Birth to 3 Program website at: <http://www.dhs.wisconsin.gov/bdds/birthto3/index.htm>

An additional resource providing an overview of the Birth to 3 system and philosophy also found on this website is "Families are the Foundation of Wisconsin's Birth to 3 Program": <http://www.dhs.wisconsin.gov/bdds/b3fdn/index.htm>

# Acceptance



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

- » Does my child really have a hearing loss?
- » Will it go away or get better?
- » Will she need hearing aids? How will we afford them?
- » Will he be made fun of?
- » How will the hearing loss affect my child? My marriage? My family?

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.”

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.

**Everyone reacts differently, and that is okay.**

“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.”

“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, 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 good 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 of children who are deaf or hard of hearing , 3) meeting adults who are deaf or hard of hearing, and 4) 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 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.”

**... or with adults who are deaf or hard of hearing.**

“Already, we can tell how much better communication is at home... [our deaf mentor] instills in all of [our children] that it is okay to be just the way you are... We owe so much to her, not only for bringing us a new language, but also for teaching us life's lessons.

--a Wisconsin parent

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 Within the 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 due to a misunderstanding. They may want to help but 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.

Later in this section, 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 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.

## Myths About Deafness

Like all minority groups, deaf and hard of hearing people suffer from stereotyping by many who don't know and understand them. A number of myths about deaf and hard of hearing people circulate widely in our society and get in the way of understanding between hearing and deaf/hard of hearing people.

*MYTH:* All hearing losses are the same.

*FACT:* The single term, deafness, covers a wide range of hearing losses that have very different effects on a person's ability to process sound and thus to understand speech.

*MYTH:* All deaf people use sign language.

*FACT:* Many deaf people, especially pre-lingually deaf people, use sign language. Many others do not. In addition, there are several kinds of sign language systems.

*MYTH:* All deaf people use hearing aids.

*FACT:* Many deaf people benefit considerably from hearing aids. Many others do not; indeed, they find hearing aids to be annoying, and they choose not to use them.

*MYTH:* Deaf people are alike in abilities, tastes, ideas, and outlooks.

*FACT:* Deaf people are as diverse in their abilities, tastes, ideas, habits and outlooks as any other large group of people.

*MYTH:* People with a hearing loss are 'deaf and dumb'.

*FACT:* The inability to hear affects neither native intelligence nor the physical ability to produce sounds. Deafness doesn't make people dumb in the sense of being unintelligent or mute. Deaf people, understandably, find this stereotype particularly offensive. The appropriate term, when referencing this particular group, is either Deaf or Hard of Hearing.

*MYTH:* All Deaf people can read lips.

*FACT:* Some deaf people are very skilled lip readers, but many are not. This is because many speech sounds have identical mouth movements. For example, P and B look exactly alike on the lips as do the phrases 'olive juice' and 'I love you'. Only about 26-30% of speech is visible on the lips. Even the best speech readers cannot read everything.

*MYTH:* All deaf people are mute.

*FACT:* Some deaf people speak very well and clearly; others do not because their hearing loss prevents them from learning spoken language or they choose not to use their voices. Deafness usually has little effect on the vocal chords, and very few deaf people are truly mute.

*MYTH:* Deaf people are not sensitive to noise.

*FACT:* Some types of hearing loss actually accentuate sensitivity to noise. Loud sounds become garbled and uncomfortable. Hearing aid users often find loud sounds, which are greatly magnified by their aids, very unpleasant.

*MYTH:* Hearing aids restore hearing.

*FACT:* Hearing aids amplify sound. They have no effect on a person's ability to process that sound. In cases where a hearing loss distorts sounds, a hearing aid may only amplify the distortion-making things worse.

# 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:

- » Good feelings about themselves and others.
- » An understanding of right and wrong.
- » 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?

When, where, and with who 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, e.g. "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.

# Parenting the Child Who is "DeafPlus"



We acknowledge that "DeafPlus" may not be the term agreed upon by everyone when discussing this section. Some other terms that are commonly used are: special needs, multi-involved, multi-handicapped, deaf-blind, deaf-blind with severe disabilities, etc.

For simplicity's sake, we will use DeafPlus to include those children who are deaf or hard of hearing **and** have any of the following conditions: complicating medical conditions, cerebral palsy, blindness or other visual conditions, Down Syndrome, developmental delays, autism, sensory integration issues, etc.

We hope that by adding this section it helps you understand that each child has a unique combination of challenges and strengths. Because DeafPlus incorporates a broad range of other conditions, we will not be adding specific resources for those conditions. However, we have listed some resources that may be of help to anyone in the DeafPlus category.

The following was written by Laura Di Julius - the mother of a deaf child with severe cerebral palsy:

For some families, the hearing loss diagnosis may be only one of many diagnoses. Depending on the severity of these other issues, the hearing loss may not seem to be the priority. There may be immediate health concerns, feeding challenges, seizures, progressive conditions, or any number of other situations. It may seem that communication would be less important than many of these needs, but communication is such a basic and foundational part of life, that confronting this fact is essential to the well being of any individual and can only help whatever other condition one may be faced with. In fact it can be **the key**.

When my son Jeremy was born, hearing loss was not the first thing that we as parents became aware of. He cried all night and most of the day! When he was eventually evaluated by a neurologist at 4 months, the list of referrals was long and included an eye exam, EEG, CAT scan, MRI, evaluations by an audiologist, physical therapist, occupational therapist, and more. It was all foreign to me and of course, overwhelming. What was this all about? And none of this was helping our immediate situation. We still had to deal with an infant who cried constantly, never slept, was difficult to feed, and had to be carefully handled and positioned. As you may imagine, his hearing loss was the least of our concerns, if not seemingly irrelevant to our dilemma as we navigated the new and daunting world of exams, evaluations, diagnoses, medical jargon, therapies, approaches to treatment, financial worries, and choices.

But this was the missing element! All human beings have the need to communicate, and once we started down this path, the world opened up. I now see it as being one of the keys in Jeremy's

progress, self-esteem, and sense of self. Through a blend of communication methods, Jeremy began to develop his ability to understand the world around him and to be understood. He cried less, slept better, learned to make choices, and could express himself. He became happier and healthier.

Of course, this is my personal story. You may have a child with less severe or more severe conditions, or be unsure whether or not he/she has other developmental delays. Whatever the case, it can be challenging to figure out priorities and what exactly needs to be done for your own unique child and family. Some of the communication methods presented as options for typically developing deaf or hard of hearing children may not be possible or ideal for your child, due to other limitations such as physical ability, stamina, cognitive development, vision impairment, or health conditions. As is true for all families, you will have to investigate what works for you, experiment with existing methods, adapt them for your child, and look to others for support and information that can help you to make sense of it all and create as much harmony and success in your family as possible.

Please use this section as a resource to help you with this process. Undoubtedly, you will also find your own resources...a friend, therapist, doctor, teacher, minister, your local library, a community member, good old Google, or whatever else you may stumble upon in your quest for that needed piece of the puzzle. Or maybe you will become the expert in your own unique area, as many of us as parents are required to do, and become a resource for others. We are all experts on our own children and families. But even experts need mentors, guides, peers, and ongoing learning and support.

Good luck on your journey!

Laura Di Julius

As Laura mentioned, she began to communicate with her son “through a blend of communication methods”. Jeremy most likely used what is called **purposeful responses**. Those include, but are not limited to the following:

- » Change in affect, mood, or facial expressions
- » Change in vocalization
- » Change in oral-motor pattern
- » Change in breathing pattern
- » Shift in eye gaze toward adult or object when an activity is initiated or interrupted
- » Visual search for object or adult when object is presented
- » Motor attempt to stop or continue activity
- » Motor movement of extremity

Children of all abilities will use these responses, with or without a formal mode of communication. However, it is very important for DeafPlus children to have their caregivers understand that they are

communicating through purposeful responses and it will require both parties to work through what those responses mean. For instance, the adult will need to decide whether the change in the child's behavior means that the child likes or dislikes something. This takes patience, on both parts. Adults will need to be patient with the child, and the child also practices patience with the adult.

The following was written by Connie Stevens, mother of a deaf daughter with Down Syndrome:

“When I get frustrated trying to communicate with my daughter, I try to put myself in her shoes and I realize that she is probably just as frustrated... Over time, one thing I have learned is that Tess will not move on to a new piece of the conversation until I acknowledge what she is communicating. For instance, if she is using a sign I am not familiar with, she will not go onto another sign until I copy her and nod my head. By doing this, I am affirming that what she has to ‘say/sign’ is valid and important, even though at the time I may not know what she is telling me. I guess it is like adults saying to each other, “I understand”, even though they may not. But it helps move the conversation and relationship onward.”

The following was written by Linda and Jack Kemper, parents of DeafPlus son, Alex:

Being the parents of a deaf multiply involved child has its challenges and its rewards. Alex is the sweetest, most good natured kid you'd ever want to know. Even though every day he struggles with no hearing in one ear, auditory neuropathy in the other ear, he is visually impaired, cognitively delayed, autistic, has an insufficient immune system, and has to take daily blood thinner shots because for reasons they don't know his blood forms clots if he doesn't.

We sign with Alex, we talk to him, and we've used PECs (Picture Exchange Communication). We bombard him from every direction with communication. He does also use a talking device called a Dynamyte. He does great with it. He's also a whiz with the computer, which sometimes has its drawbacks. (Sometimes he's too good with it, like being able to bypass the password to get on it to use it. We had to buy him his own computer so our information didn't disappear from ours.)

Alex has even developed quite a sense of humor and can even be a bit mischievous at times, which we are always glad to see because for a long time Alex was always very compliant. It's also said that deaf children don't develop a sense of humor or imagination. Well, that is not true in Alex's case—he has both. Maybe not to the degree of his peers, but it's still there.

We went through a lot of hospitalizations with Alex when he was younger before they found out about his immune system and the clotting disorder. One of the most frustrating things in the hospital was staff doing things to him without explaining or giving us a chance to explain to him what was going to happen, because they just assumed he wouldn't understand.

But Alex is now 14 and doing quite well even with all the strikes against him. He only weighs 50 pounds (and it has been an uphill battle to even get him to 50 pounds). Its part of the syndrome he has.

There are so many things the doctors told us he would never do that he is now doing that sometimes we just sit back with awe and amazement for all he's been able to accomplish and all that we know he will continue to accomplish. He has to work so hard to accomplish the littlest thing sometimes that it makes us ashamed of all the things we all take for granted.

We have learned so much from Alex about unconditional love. He has taught us patience. Because of him we have met so many wonderful people and had so many wonderful experiences that we would have never had. We are forever grateful that he is in our lives.

Managing the health care of a DeafPlus child can be addressed with the concept of medical home. This concept involves the idea that everyone involved in your child's care be included in a medical home where primary care is accessible, continuous, comprehensive, family-centered, coordinated, compassionate and culturally effective. You can access information about this idea at: [www.medicalhomeinfo.org](http://www.medicalhomeinfo.org).

You may find a primary care physician who is familiar with this concept or you may find that you are providing new information to them. Either way, you will most likely be the "Lead Coordinator" (Case Manager) for your child. Stay strong and organized and seek support from others. You are not alone.

# Resources



This section is divided into four areas: Resources for Individuals who are Deafblind; Resources for Individuals who are Deaf/Hard of Hearing with additional disabilities (Deafplus); Sibling Perspectives and Resources; and Resources for Individuals who are Deaf or Hard of Hearing.

## Deafblind

**A wonderful and highly suggested book is “Remarkable Conversations: A guide to developing meaningful communication with children and young adults who are deafblind” by Barbara Miles and Marianne Riggio**

**WESPDHH Outreach** [www.wesp-dhh.wi.gov](http://www.wesp-dhh.wi.gov) (262) 787-9540

The Outreach Program supports children who are deaf, hard of hearing and deafblind by providing a broad array of services to families and educational programs. Services are determined based on the needs of the child. The Outreach program provides information, support, and training to school districts and educational programs in serving deaf, and hard of hearing and deafblind children and their families. Services and support are determined based on the child's needs.

**Wisconsin Deafblind Technical Assistant Project (WDBTAP)**

[www.wdbtap.wi.gov](http://www.wdbtap.wi.gov) (608) 356-2023

Wisconsin's Federal Deafblind Project providing technical assistance, trainings, and resources to parents, professionals and individuals who are deafblind.

There is a wonderful “**Parent Roadmap**” to help families navigate, much like this “Babies and Hearing Loss” binder. The above website provides a direct link to this publication, in addition to links to many other sites.

**Website partly available in Spanish.**

**Deafblind Resources** [www.deafblindresources.org](http://www.deafblindresources.org)

Deafblind Resources is a project created to provide a network for exchanging information about congenital deafblindness and intervention strategies.

**National Consortium on Deaf-Blindness (NCDB)** [www.nationaldb.org](http://www.nationaldb.org)

Information to nurture, empower, and instruct children who are deafblind. NCDB brings together the resources of three agencies with long histories of expertise in the field of db, The Teaching Research Institute (TRI) at Western Oregon University, the Helen Keller National Center (HKNC), and the Hilton/Perkins Program at Perkins School for the Blind. NCDB works collaboratively with families, federal, state and local agencies to provide technical assistance, information and personnel training. **Website partly available in Spanish.**

**Center for Deaf-Blind Persons** [www.deaf-blind.org](http://www.deaf-blind.org)

Provides support to adult individuals who are deafblind and/or those people working with them.

# Resources for Individuals Who are DeafPlus



The resources on this page are specifically for those who are DeafPlus. Additional resources for people who are Deaf and Hard of Hearing follow this page and for those who are Deafblind, that section is right before this page.

## **Every Move Counts** [www.everymovecounts.net](http://www.everymovecounts.net)

Jane Korsten, Lisa Berry, Terry Foss. Sensory-based communication techniques.

“Empowerment and participation come with the ability to experience the world and communicate. Only when communication is recognized and consistently reinforced will those with severe physical, sensory-motor, communicative and developmental differences find the effort to communicate worthwhile.”

Every Move Counts represents the completion of a 33-month Innovative Research Grant awarded by the National Institutes of Health and funded through the National Institutes for the Neurologically and Communicatively Disordered.

## **Design to Learn Materials** [www.designtolearn.com](http://www.designtolearn.com)

### **Website partly available in Spanish.**

For people who live or work with individuals who have severe disabilities. Strategies and materials address the educational needs of children and adults who have severe disabilities, including multiple and “low incidence” disabilities such as deafblindness and autism.

Design to Learn materials are especially useful for individuals who do not have conventional means of communication—in other words, for nonverbal or non-speaking.

- » First Things First: Practical strategies for encouraging early communication in children who have no or minimal intentional communication.
- » Tangible Symbol Systems: Teach individuals to communicate using objects or pictures that represent items, people, and events in their daily lives.
- » Home Talk: An assessment tool for parents and care providers of children who are deafblind and who have other disabilities. Its purpose is to help you participate in the planning of your child’s educational program.
- » Communication Matrix: A communication skills assessment instrument designed for professionals for individuals functioning at the earliest stages of communication and individuals who use any form of communication, including pre-symbolic and augmentative or alternative forms.

**Enabling Devices** [www.enablingdevices.com](http://www.enablingdevices.com) (800) 832-8697

A catalog with a wide-range of adaptive toys/tools to help children learn, communicate, and live. Includes videos of some products in use.

**Family Voices of Wisconsin** [www.fvofwi.org](http://www.fvofwi.org)

**National Office of Family Voices** [www.familyvoices.org](http://www.familyvoices.org)

**Circles of Life Conference** [www.colwisconsin.org](http://www.colwisconsin.org)

# 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 Kids 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 care for them. 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**

Don Meyer, Director

6512 23rd Ave NW #213

Seattle, WA 98117

(206) 297-6368

[donmeyer@siblingsupport.org](mailto:donmeyer@siblingsupport.org)

[www.siblingsupport.org](http://www.siblingsupport.org)

From this project a wonderful new book has been published: “The Sibling SLAM Book: What it’s really like to have a brother or sister with special needs.” Edited by Don Meyer. 2005.

# 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! To help you not feel overwhelmed, we have indicated those that are particularly family-friendly and specific to children with hearing loss, with a smiley face – ☺. We have compiled a listing in alphabetical order of major national and then statewide organizations. 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.

Resources have been updated as of May 2011. Please refer to the WESP-DHH Outreach webpage for information on changes after that date. **In addition, you can get an online copy of the notebook by visiting [http://www.wesp-dhh.wi.gov/wesp/out\\_parentnotebook.cfm](http://www.wesp-dhh.wi.gov/wesp/out_parentnotebook.cfm).**

## National Resources

### ☺ **Alexander Graham Bell Association for the Deaf and Hard of Hearing (A.G.**

**Bell)\*\*** 3417 Volta Place NW  
Washington, D.C. 20007  
(866) 337-5220 Voice Toll Free  
(202) 337-5221 TTY  
(202) 337-8314 Fax

[www.nc.agbell.org](http://www.nc.agbell.org)

\*\*statewide chapter listed in next section

“Advocating Independence through Listening and Talking” A membership organization focusing on the auditory approach. Provides an annual conference, newsletters, journals (Volta Voices and the Volta Review), on-line bookstore and information relating to oral education and the use of technology. Financial aid programs available for children with hearing loss. **Website available in various languages.**

### **American Academy of Audiology (AAA)**

(800) AAA-2336 Toll Free  
[www.audiology.org](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**

800 Florida Ave NE  
Washington, DC  
20002-3695  
(800) 942-ASDC Parent Hotline Toll Free  
(410) 795-0965 Fax  
[www.deafchildren.org](http://www.deafchildren.org)

“Helping families raise children who are deaf or hard of hearing since 1967”

A non-profit, parent organization that provides a positive attitude toward signing and deaf culture. It also provides current information, support and encouragement. Publishes “Endeavor,” a publication free to families for one year.

**American Speech-Language-Hearing Association (ASHA)**

2200 Research Boulevard  
Rockville, MD 20850  
Helplines V/TTY: Toll Free  
(800) 638-8255 non-  
members (800) 498-2071  
members  
[www.asha.org](http://www.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 National Research Hospital**

[www.babyhearing.org](http://www.babyhearing.org)

Boys Town has focused research on hearing loss and related disorders since 1977. This website provides information to parents in an easy to access way. Includes simulations of hearing loss. They also publish materials for parents and children. **Website available in Spanish.**

### **Center for Disease Control and Prevention**

[www.cdc.gov/ncbddd/hearingloss/freematerials.html](http://www.cdc.gov/ncbddd/hearingloss/freematerials.html)

The CDC has published various brochures/questionnaires for new parents. Contact them for a free copy or you can print them off on-line from a .pdf format.

**Materials available in Spanish.**

[www.cdc.gov/ncbddd/ehdi/CDROM](http://www.cdc.gov/ncbddd/ehdi/CDROM)

This website offers clear, concise information.

### **Cochlear Implant Awareness Foundation**

[www.ciafonline.org](http://www.ciafonline.org)

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

### **Deafness Research Foundation**

[www.drf.org](http://www.drf.org)

“Dedicated to Healthy Hearing” DRF funds research in hearing and balance science. They publish “Hearing Health Magazine” which provides information on technology, treatment and issues affecting people with hearing loss.

### ☺ **Hands & Voices\*\***

P.O. Box 371926

Boulder, CO

80237 (303) 492-

6283

(866) 422-0422 Toll Free

[www.handsandvoices.org](http://www.handsandvoices.org)

\*\*statewide chapter listed in next section

“What Works for your Child is what makes the Choice right”

A national parent driven, non-profit organization dedicated to providing unbiased support to families with children who are deaf or hard of hearing. Provides support activities and information to parents and professionals that may include outreach events, educational seminars, advocacy, lobbying efforts, parent to parent networking, and a newsletter. They 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**

709 University Avenue West  
St. Paul, MN 55104-4804  
(866) DHOHKID (1-866-346-4543) Toll-free  
(866) 261-0857 Videophone

[www.familysupportconnection.org](http://www.familysupportconnection.org)

The Family Support Connection provides unbiased information, referral, and support to families of deaf or hard of hearing children living in or on the border of Minnesota, through the Minnesota Chapter of Hands & Voices. Information includes: American Sign Language, educational options, cued speech, parenting deaf and hard of hearing children, cochlear implants, auditory training and assistive listening devices.

**Family Village**

Deaf and Hard of Hearing Resources  
UW-Madison Waisman Center  
1500 Highland Avenue  
Madison, WI 53705-2280  
[www.familyvillage.wisc.edu/lib\\_deaf.htm](http://www.familyvillage.wisc.edu/lib_deaf.htm)

A global community for disability related issues with a section on deaf and hard of hearing information. There are resources here that are not found elsewhere.

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

National Deaf Education Network and  
Clearinghouse 800 Florida Avenue, NE  
Washington, D.C. 20002-3695 1-800-526-  
9105  
[www.gallaudet.edu/clerc\\_center.html](http://www.gallaudet.edu/clerc_center.html)  
\*\*\*Call for free “Odyssey” magazine.

Gallaudet 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. It has helpful books and resources for parents of children who are deaf or hard of hearing. One of these is the Shared Reading Project.

**Hearing Loss Association of America - formerly called Self Help for Hard of Hearing People, Inc. (SHHH)\*\***

National Chapter  
7910 Woodmont Ave. Suite  
1200 Bethesda, MD 20814  
(301) 657-2248 Voice/TTY  
[www.shhh.org](http://www.shhh.org)  
\*\*state chapters can be found online

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

☺ **John Tracy Clinic**

806 West Adams Blvd.  
Los Angeles, CA 90007  
(213) 747-2924 TTY  
(800) 522-4582 Toll \_  
[www.jtc.org](http://www.jtc.org)

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. **Website available in Spanish.**

**National Association of the Deaf (NAD)**

8630 Fenton Street, Suite 820  
Silver Spring, MD 20910-4500  
(301) 587-1788 Voice  
(301) 587-1789 TTY  
[www.nad.org](http://www.nad.org)

“The nation’s premier civil rights organization of, by and for deaf and hard of hearing individuals in the U.S. Established in 1880.

☺ **National Center for Hearing Assessment and Management**

Utah State University  
2615 Old Main Hill  
Logan, Utah 84322  
Tel: 435-797-3584 \_  
[www.infanthearing.org](http://www.infanthearing.org)

The goal of the **National Center for Hearing Assessment and Management (NCHAM** - pronounced "en-cham") is to ensure that all infants and toddlers with hearing loss are identified as early as possible and provided with timely and appropriate audiological, educational, and medical intervention. There is a wealth of information at this website so it can be a little overwhelming, however they have current short videos and online access to a great sign language resource: “Sign with Me: A Family Sign Language Curriculum. Volumes 1, 2 and 3”.

**National Dissemination Center for Children with Disabilities (NICHCY)**

1825 Connecticut Ave  
NW  
Suite 700  
Washington, D.C.  
20013 (800) 695-0285  
V/TTY (202) 884-8441  
Fax [www.nichcy.org](http://www.nichcy.org)

Information on: disabilities in children birth to 22; IDEA (law authorizing special education); research-based information on effective educational practices. **Website available in Spanish.**

## **National Institute on Deafness and Other Communication Disorders**

National Institutes of Health  
31 Center Drive, MSC 2320  
Bethesda, MD 20892-  
2320 [www.nidcd.nih.gov](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. They offer great resources to help prevent “Noise Induced Hearing Loss”.

# Additional Online Resources

## **Clerc's Children**

[clercschildren.com](http://clercschildren.com)

“Web-based dual language curriculum filled with auditory and visual stimulation which plays an important role in developing age appropriate reading, writing and communication skills.”

## **Oral Deaf Education \_**

[www.oraldeafed.org](http://www.oraldeafed.org)

“Even children with profound hearing loss can learn to talk and listen.” Includes many free resources.

## **Phonak**

[www.phonak.com](http://www.phonak.com)

This website gives consumers a demonstration of various levels of hearing loss. Click on “hearing and hearing loss” tab, then “understanding hearing loss”, then “how hearing loss sounds”.

## **Raising Deaf Kids: A world of information about children with hearing loss \_**

[www.raisingdeafkids.org](http://www.raisingdeafkids.org)

The Deafness and Family Communication Center (DFCC) is at the Children's Hospital of Philadelphia. They offer clinical services for deaf and hard-of-hearing children and teenagers and do research on how hearing loss affects children, teenagers and their families. **Website is also available in Spanish.**

## **Sign Language Dictionaries**

[www.aslpro.com](http://www.aslpro.com)

[www.handspeak.com](http://www.handspeak.com)

[www.lifeprint.com](http://www.lifeprint.com)

## **Wrightslaw \_**

[www.wrightslaw.com](http://www.wrightslaw.com)

This website gives accurate, reliable information about special education law and advocacy for children with disabilities.

# 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 1900 South Avenue  
LaCrosse, WI 54601-  
9980 1-800-642-7837  
(STEP)  
[www.mch-hotlines.org](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 and Youth with Special Health Care Needs**

- » Northern Regional Center – Wausau  
Phone: (715) 261-1900 or (866) 640-4106  
[www.co.marathon.wi.us/cyshcn.asp](http://www.co.marathon.wi.us/cyshcn.asp)
- » Northeast Regional Center - Neenah  
Phone: (877) 568-5205  
[www.northeastregionalcenter.org](http://www.northeastregionalcenter.org)
- » Southern Regional Center - Madison  
Phone: (608) 265-8610 or (800) 532-3321  
[www.waisman.wisc.edu/cshcn\\_](http://www.waisman.wisc.edu/cshcn_)
- » Southeast Regional Center - Milwaukee  
Phone: (414) 266-6333 or (800) 234-5437  
[www.specialneedsfamilycenter.org](http://www.specialneedsfamilycenter.org)
- » Western Regional Center - Chippewa Falls  
Phone: (715) 726-7900 or (800) 400-3678  
[www.co.chippewa.wi.us/ccdph/cyshcn](http://www.co.chippewa.wi.us/ccdph/cyshcn)
- » Great Lakes Inter-Tribal Council (GLITC)  
Lac du Flambeau (800) 472-7207

## Statewide Government Agencies

### **Wisconsin Birth to 3 Program**

Department of Health  
Services 1 West Wilson  
Street Madison, WI 53702  
(608) 266-8276  
[www.dhs.wisconsin.gov/bdds/birthto3](http://www.dhs.wisconsin.gov/bdds/birthto3)

### **Wisconsin Office for the Deaf and Hard of Hearing**

Department of Health  
Services 1 West Wilson  
Street Madison, WI 53702  
(608) 261-7823  
[www.dhs.wisconsin.gov/sensory/](http://www.dhs.wisconsin.gov/sensory/)

The Office for the Deaf and Hard of Hearing (ODHH) “exists to ensure that the variety of life’s choices and equal opportunities are available to all deaf, deafblind and hard of hearing people”. It provides free technical assistance and training in communication assistive technology, Deaf Culture, and hard of hearing issues. It has an Interpreter Service Fund as well as online information on locating interpreters. It provides information on and can assist with application to the Telecommunications Equipment Purchase Program (TEPP) and Telecommunications Assistance Program (TAP).

The state is broken into five regions. Refer online for email addresses and more current information if you find that the following information is out of date.

#### » **Northeastern Region**

(Counties covered: Brown, Calumet, Dodge, Door, Fond du Lac, Green Lake, Kewaunee, Manitowoc, Marinette, Menomonie, Oconto, Outagamie, Ozaukee, Shawano, Sheboygan, Washington, Waupaca, Winnebago)

#### » **Northern Region**

(Counties covered: Adams, Ashland, Florence, Forest, Iron, Juneau, Langlade, Lincoln, Marathon, Marquette, Oneida, Portage, Price, Taylor, Vilas, Washara, Wood)

#### » **Southern Region**

1 W. Wilson St, Rm 451 Madison, WI  
53707-7851 (608 437-5828) Voice  
attn: Bette Mentz  
(Counties covered: Columbia, Dane, Grant, Green, Iowa, Jefferson, LaFayette, Richland, Rock, Sauk, and Walworth)

» **Southeastern Region**

141 NW Barstow Street Room 157

Waukesha, WI 53188

(attn: Jennifer Koehn

(Counties covered: Kenosha, Milwaukee, Racine, and Waukesha)

» **Western Region**

610 Gibson Street Suite

1 Eau Claire, WI 54701

(715) 836-2107 Voice

attn: Carolyn Small

(Counties covered: Bayfield, Barron, Buffalo, Burnett, Chippewa, Clark, Crawford, Douglas, Dunn, Eau Claire, Jackson, LaCrosse, Monroe, Pepin, Pierce, Polk, Rusk, Sawyer, St. Croix, Trempeleau, Vernon, and Washburn)

**Wisconsin Council on Deaf and Hard of Hearing**

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

The Council for the Deaf and Hard of Hearing is a group of nine members appointed by the Governor to advise him/her about issues related to hearing loss. The Council must have three Deaf members; three hard of hearing members; one member who is deafblind or has a dual sensory loss; two members-at-large.

**Wisconsin Department of Public Instruction**

125 South Webster

Street P.O. Box 7841

Madison, WI 53707-7841

USA (800) 441-4563 toll-free

(608) 266-3390 \_

[www.dpi.state.wi.us](http://www.dpi.state.wi.us)

This website has a vast amount of information related to education and special education. It can be overwhelming. Search for deafness/hearing impairment first.

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

» **WESPDHH Outreach**

Marcy Dicker, Director

N25 W23131 Paul Road Suite 100

Pewaukee, WI 53072

(262) 787-9540 voice

(262) 649-9633 vp

(888) 656-8559 Toll Free \_

[www.wesp-dhh.wi.gov](http://www.wesp-dhh.wi.gov)

Outreach provides a variety of programs and services to students who are deaf, hard of hearing, and deafblind, their families and the educational teams and school districts

that serve them, regardless of the student's educational placement or communication modality. Services through WESPDHH include consultation to school districts and Birth to 3 Programs; conferences and workshops for families and professionals; and specialized programs. (see brochure at the beginning of this notebook.) A statewide calendar of events is also maintained at this website.

» **Wisconsin School for the Deaf**

309 West Walworth  
Avenue Delavan, WI  
53115 877-973-3323 voice  
877-973-3324 tty \_  
[www.wsd.k12.wi.us](http://www.wsd.k12.wi.us)

A residential school program (located in Delavan, WI) which provides a bi-lingual, bi-cultural educational option. Summer camp opportunities.

**Wisconsin Genetics**

[www.slh.wisc.edu/genetics](http://www.slh.wisc.edu/genetics)

This website features a Google map to locate medical genetics providers in WI, frequently asked questions like who would benefit from a genetics evaluation, family stories showing how genetic services benefited them, and information about family history. Also features a “For Healthcare Providers” section.

**Wisconsin Sound Beginnings** - State Early Hearing Detection and Intervention Program

(EHDI) Elizabeth Seeliger, Director

1 West Wilson St.

Madison, WI 53701

(608) 267-9191 Voice \_

[elizabeth.seeliger@dhs.wisconsin.gov](mailto:elizabeth.seeliger@dhs.wisconsin.gov)

Wisconsin Sound Beginnings promotes and supports universal newborn hearing screening statewide, and seeks to assure timely and appropriate follow-up services are available to all families of children who are deaf or hard of hearing. The program’s goals are:

- » Screen 100% of Wisconsin newborns for hearing loss.
- » Diagnose all infants with hearing loss by 3 months of age.
- » Provide appropriate medical evaluation and intervention services to all infants with confirmed significant hearing loss by 6 months of age.
- » Establish a comprehensive data collection and surveillance system.

The program supports initiatives such as the Guide By Your Side Program, as well as provider education, training, and technical assistance opportunities.

## **Wisconsin Statewide Parent-Educator Initiative (WSPEI)**

(within WI Department of Public Instruction) (877-844-4925) toll-free \_  
[dpi.wi.gov/sped/parent.html](http://dpi.wi.gov/sped/parent.html)

“Parent Involvement in Education for Children with Disabilities”

WSPEI is a service for parents, educators, and others interested in parent-educator partnerships for children with disabilities. Its goal is to help parents and school districts find or create the resources that will help them build positive working relationships that lead to shared decision making and children’s learning. WSPEI sponsors Parents in Partnership (PIP).

## **Other Wisconsin Resources**

### **Center for Communication, Hearing and Deafness (historically known as Center for the Deaf and Hard of Hearing)**

10243 W. National Ave.  
West Allis, WI 53227  
(414) 604-2200 Voice  
(414) 604-7217 TTY  
[www.cdhh.org](http://www.cdhh.org)

Services provided: birth to three services; hearing evaluations and hearing aid fittings; aural rehabilitation; speechreading and communication strategies classes; sign language classes; pre- and post-cochlear implant training; toddler communication groups; parent seminars and workshops; speech-language therapy; auditory-verbal therapy; CommunicationLink, interpreter coordination service; education and counseling; UniversaLink, assistive communication technology program; music and drum program; coordinates the Family Learning Vacation at Wisconsin Lion’s Camp.

### **University of Wisconsin’s Speech and Hearing Clinics (Communicative Disorders Clinics)**

» **Madison**

(608) 262-3951 \_  
[www.comdis.wisc.edu](http://www.comdis.wisc.edu)

» **Stevens Point**

(715) 346-3667 \_  
[www.uwsp.edu/commd/](http://www.uwsp.edu/commd/)

» **Eau Claire**

(715) 836-4186

» **Milwaukee** [www.graduateschool.uwm.edu/students/prospective/areas-of-study/communication-sciences-disorders/](http://www.graduateschool.uwm.edu/students/prospective/areas-of-study/communication-sciences-disorders/)

» **Whitewater**

262-472-1301

Depending on each location, there may be auditory and speech therapy available through these clinics. This therapy may be given by a graduate student who is supervised by clinical staff or clinical staff may do therapy themselves. This may take place individually or in a playgroup setting.

### **Waisman Center**

1500 Highland Avenue  
Madison, WI 53705  
[www.waisman.wisc.edu](http://www.waisman.wisc.edu)

This center offers many programs, services and information, some of which includes: auditory/speech therapy, birth to three information, childcare program, Children's Theatre, professional and parent advocacy training.

### **Parents as Leaders Parent Training Program**

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 ext 255)  
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 [www.wisdeaf.org/](http://www.wisdeaf.org/)**

Established in 1876, 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. Go online to subscribe to WADnet. This is a listserv noting activities across the state. There are many local chapters. Go online for the area closest to you.

### **Wisconsin FACETS Statewide Center**

2714 N. Dr. Martin Luther King  
Drive Milwaukee, WI 53212  
(414) 374-4645  
(877) 374-0511 Toll Free  
(414) 374-4635 tty \_  
[www.wifacets.org](http://www.wifacets.org)

Wisconsin Family Assistance Center for Education, Training & Support, Inc. (WI FACETS) is a nonprofit organization serving Wisconsin children and adults with disabilities, their families and those who support them. Founded in 1995 by parents who believed that parents are the best advocates for their children, WI FACETS operates programs to help parents support and enrich their children's lives. There are regional offices. Call or check online for the one nearest you.

## Wisconsin Camps

In addition to the following information, check with your regional Office of Deaf and Hard of Hearing to ask if any local church, program or school is offering special camps. Sometimes universities and interpreter training programs will develop a program. This changes year to year.

**Family Learning Vacation** – Organized through the Center for Communication, Hearing and Deafness. 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! This weekend is usually held during the third weekend in August.

### **Lion’s Camp and Retreat and Conference Center**

3834 County Road A  
Rosholt, WI 54473  
(715) 677-4969 Voice  
(715) 677-6999 TTY  
(715) 677-3297 Fax  
[www.wisconsinlionscamp.com](http://www.wisconsinlionscamp.com)  
[info@wisconsinlionscamp.com](mailto:info@wisconsinlionscamp.com)

The Lion’s Camp sponsors different camp sessions for DHH children and/or their families, as well as other special needs children. 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 or other special needs. They are also eligible if they require special aids, instruction, or services even if not taking advantage of them at present.

### **Wisconsin School for the Deaf**

[www.wsd.k12.wi.us](http://www.wsd.k12.wi.us)

During the summer, the Wisconsin School for the Deaf provides a variety of summer camp experiences for any student in the state of Wisconsin who is deaf or hard of hearing.



# 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. First we have placed statewide chapters of national parent organizations. Then resources are listed by region for your convenience. In addition to what is listed, you may be inclined to contact local churches. Some of them have added sign language interpreters for masses or offer mass given directly by someone in sign language.

## Statewide

### **Wisconsin Alexander Graham Bell Chapter**

Ron Janke  
1509 Mary Ann Drive  
Waukesha, WI 53188  
262-524-0402  
[cjahnke6@wi.rr.com](mailto:cjahnke6@wi.rr.com)

### **Wisconsin Hands & Voices Chapter**

PO Box 9644  
Green Bay, WI 54308  
(920) 544-1047  
[handsandvoiceswi@yahoo.com](mailto:handsandvoiceswi@yahoo.com)  
[www.handsandvoiceswi.org](http://www.handsandvoiceswi.org)

### **Wisconsin Guide By Your Side™ Program**

Laurie Nelson, Program Coordinator  
1-888-656-8556  
608-822-3756  
[http://www.wesp-dhh.wi.gov/wesp/out\\_gbys.cfm](http://www.wesp-dhh.wi.gov/wesp/out_gbys.cfm)

# Regional

## Southeast Region

### **Deaf and Hard of Hearing Alliance (DHHA)**

9431 West Beloit Avenue, Suite 109  
South Milwaukee, WI 53227

The mission of DHHA is to provide opportunities for leadership and growth within the Signing (Deaf) community while respecting culture, language and a visual environment. DHHA sponsors sign language classes throughout the year; Youth Activities (DHHA-YA), a Lady Bug Tea every June, comedy nights, a holiday party, and other community events.

### **Communication Connections, Inc.**

P.O.Box 505, Pewaukee, WI 53072-0505  
Allison Schley, (262) 853-2922 (262) 853-2922  
[allison@communicationconnections.org](mailto:allison@communicationconnections.org)

Communication Connections provides education and social opportunities to families with hearing loss for children 0-6.

## Northeast Region

### **DEAF – Deaf Education and Families**

Kennedy Elementary  
School 1754 9<sup>th</sup> Street  
Green Bay, WI 54304  
School number (920) 492-2640

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

### **Hand-N-Hand of Northeastern Wisconsin, Inc.**

411 St. John's St.  
Green Bay, WI 54301 Coordinator: Jenny Geiken (920) 737-0477 v/tty \_  
[jlgeiken@hnhnew.org](mailto:jlgeiken@hnhnew.org): [www.hnhnew.org](http://www.hnhnew.org)

Provides support and facilitates resources for families with children experiencing hearing loss. Hand-N-Hand offers a playgroup for children who are deaf and hard of hearing ages birth to five and their families. The goals of Hand-N-Hand are to have children and their families interact while promoting language, early literacy, and social and emotional development. Parents are children area encouraged to participate in play, arts and crafts and stories. Activities are presenting using sign language and speech. Sponsors parent education classes, which may include sign language classes.

## Notthern Region

Contact the Northern CYSHCN Regional Center to find a listing of local parent support opportunities in your region. They can be reached at (866) 640-4106.

## Western Region

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

### **Touching Families Support Group**

Carol Thompson  
715-838-9158

A support group for parents of children who are deaf and hard of hearing. This is a group which meets in Eau Claire, Chippewa County. For further details, contact Carol Thompson.

### **Potluck Dinners and Family Picnics**

Dawn Koplitz  
E4521 Walnut Rd.  
Eau Claire, WI 54701  
715-878-9488  
[Koplitz5@hotmail.com](mailto:Koplitz5@hotmail.com)

Area families with deaf and hard of hearing kids of all ages and various communication modes gather twice a year for a winter potluck and a summer family picnic. For more information, contact Dawn Koplitz.

# Listservs and Online Newsletters

This list is not exhaustive. Those listed here were either not listed elsewhere, are pertinent to Wisconsin families or post topics specifically on children. You can subscribe to more newsletters by looking through the larger national resource section.

## **About.com: Deafness**

Visit [DEAFNESS.about.com/gi/pages/mmail.htm](http://DEAFNESS.about.com/gi/pages/mmail.htm) and click subscribe on preferred topics.

## **DAWN (Disability Advocates: Wisconsin Network)**

DAWN is a grassroots, statewide network of people who care about disability related issues and want to advocate for change through public policy. Sign up at [www.dawninfo.org](http://www.dawninfo.org).

## **Hands & Voices**

Go to the bulletin board at [www.handsandvoices.org](http://www.handsandvoices.org).

## **DeafHHChildParentNetworkWI**

This is a group of parents who have deaf or hard of hearing children in Wisconsin. This group was created to bring families together in a supportive forum. The goal is to provide an environment that allows for exchange between parents; to provide opportunities for networking by community, by region and throughout the state of Wisconsin. Become a member by going to: [groups.yahoo.com/group/DeafHHChildParentNetworkWI](http://groups.yahoo.com/group/DeafHHChildParentNetworkWI)

## **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, go to [www.wisdeaf.org](http://www.wisdeaf.org) and follow the instructions.

# Resource Materials



The catalogs listed below 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 services listed below or your local libraries!

## **Adco**

800-726-0851 \_

[www.adcohearing.com](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**

866-312-8883 \_

[www.buttepublications.com](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, and other interesting and informative publications.”

## **Dawn Sign Press**

800-549-5350 \_

[www.dawnsign.com](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.”

## **Dragonfly Toys**

[www.dragonflytoys.com](http://www.dragonflytoys.com)

Search for products based on your indication of your child’s strengths or needs in 6 different developmental areas. From toys to technology, for children with special needs.

## **Garlic Press**

541-345-0063 \_

[www.garlicpress.com](http://www.garlicpress.com)

Features a wide range of educational books for all subjects that include sign language.

## **Gallaudet University Press**

202-651-5488 (v/tty) \_

[gupress.gallaudet.edu](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.

### **The Clerc Center Catalog**

[clerccenter.gallaudet.edu](http://clerccenter.gallaudet.edu) click on “Information and Resources”

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.

### **Harris Communications**

800-825-6758 \_

[www.harriscomm.com](http://www.harriscomm.com)

“Since 1982, Harris Communications has been the one-stop source of products for Deaf and Hard of Hearing people.” 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 \_

[www.kaplanco.com](http://www.kaplanco.com)

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

### **Sign Enhancers**

800-767-4461 \_

[www.signenhancers.com](http://www.signenhancers.com)

Sign Enhancers produces many ASL videos.

### **Sign Media**

800-475-4756

[www.signmedia.com](http://www.signmedia.com)

Sign Media produces many ASL videos, including Rainbow’s End, similar to Sesame Street with characters who all sign.

# Lending Services

## **Wisconsin Libraries** (through the Department of Public Instruction)

Your local library is a wonderful place to borrow books and audio-visual materials. In addition to what is presently in your library, you may be able to order materials from other libraries within your library system.

If you find it hard to get out of the house, you can order materials online. All you need is your library card with the barcode number. Your PIN is the two digit month and date of your birthday.

To find out which library is near you, go to: \_

[www.dpi.wi.gov/pld/lib\\_dir.html](http://www.dpi.wi.gov/pld/lib_dir.html)

\_OR\_ [www.dpi.wi.gov/pld/ttb.html](http://www.dpi.wi.gov/pld/ttb.html)

## **Wisconsin Assistive Technology Initiative (WATI)**

1-800-758-6232

x 340\_

[www.wati.org](http://www.wati.org)

A lending library of assistive technology, software and early literacy videos available during the traditional school year. Families need to contact their B-3 or school team if they are interested in loaning materials.

## **Described and Captioned Media Program**

1-800-237-6213

[www.dcmp.org](http://www.dcmp.org)

The DCMP loans sign language and closed captioned videos. It is free and they deliver through the US mail. You will need to login and get approval first, but that can be done online. **Sign language videos that are spoken in Spanish, called “Signing Fiesta,” are available.**



# 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:

HH) = 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  
[www.agbell.org](http://www.agbell.org)

### **CareCredit (H)**

P.O.Box 1710  
Costa Mesa, CA 92628-1710  
(800) 300-3046 Corporate  
(800) 677-0718 Enrollment  
[www.carecredit.com](http://www.carecredit.com)

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

P.O. Box 89  
Freeport, NY 11520  
(516) 377-1605  
[www.dcrf.com](http://www.dcrf.com)

**ESCO Financial / HELPCard (H)**

3215 Fernbrook Lane, N  
Plymouth, MN 55447  
800-992-3726  
[www.earserv.com](http://www.earserv.com)

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

P.O. Box 1112  
Kennebunkport, ME 04046  
(207) 967-5798  
Website: N/A

**The HIKE Fund, Inc. (H), (O)**

c/o HIKE Board Executive Secretary  
10115 Cherryhill Pl  
Spring Hill, FL 34608-7116  
[www.thehikefund.org](http://www.thehikefund.org)

**Miracle Ear Children's Foundation (H)**

P.O. Box 59261  
Minneapolis, MN 55429-0261  
[www.miracle-ear.com/childrenrequest.aspx](http://www.miracle-ear.com/childrenrequest.aspx)  
(800) 234-5422

**Sertoma Club**

1912 East Meyer Blvd  
Kansas City, MO 64132-1174  
(816) 333-8300  
[www.sertoma.org](http://www.sertoma.org)

**Starkey Hearing Foundation / Hear Now (H), (O)**

6700 Washington Avenue South  
Eden Prairie, MN 55344  
1-800-328-8602  
[www.starkeyhearingfoundation.org/hear-now.php](http://www.starkeyhearingfoundation.org/hear-now.php)

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

3755 Lindell Blvd  
St. Louis, MO 63108  
(314) 371-0533  
[www.tpahq.org/scholarshiptrust.html](http://www.tpahq.org/scholarshiptrust.html)

**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](http://www.safetyweb.org)

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

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

Department of Health Services (DHS)  
1 West Wilson Street Room 418  
P.O. Box 7851  
Madison, WI 53707-7851  
(608) 266-3236  
[www.dhs.wisconsin.gov/bdds/kbp](http://www.dhs.wisconsin.gov/bdds/kbp)

**Wisconsin Knights Templar Hearing Foundation (H)**

Sharilyn Gronitz  
36275 Sunset Drive  
Dousman, WI 53118  
(414) 965-2200  
(800) 242-2307  
Website: N/A

**Wisconsin Lions Foundation (H)**

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

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

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

[www.dhs.wisconsin.gov/medicaid/](http://www.dhs.wisconsin.gov/medicaid/)

### **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

[www.dhs.wisconsin.gov/aboutdhs/DLTC/teppbroc.pdf](http://www.dhs.wisconsin.gov/aboutdhs/DLTC/teppbroc.pdf)

### **Wisconsin Telecommunications Assistance Program (O)**

WI Department of Health Services  
Office for the Deaf and Hard of Hearing (ODHH)

P.O. Box 7851  
Madison, WI 53707-7851  
(608) 266-3118  
(608) 266-3118 TTY

<http://www.dhs.wisconsin.gov/sensory/TAP/TAP.htm>

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.

### **WisLoan**

[www.dhs.wisconsin.gov/disabilities/wistech/wisloan.htm](http://www.dhs.wisconsin.gov/disabilities/wistech/wisloan.htm)

1-877-463-3778

WisLoan provides low interest loans for hearing aids and assistive technology.

## **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 de Paul chapters

- » Goodwill Industries
- » Kiwanis Club chapters
- » Rotary Club chapters
- » Birth to Three Programs
- » Family Support Programs
- » Quota Clubs

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, or find them online at: [www.mch-hotlines.org](http://www.mch-hotlines.org).



Getting the Facts



# 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. Don't feel bad. Remember, 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 don't understand something. Please ask the professional you are working with to explain it another way. For instance, it is okay to ask if they can draw you a picture or if they have any other visual materials to show you. 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 “**Getting the Facts**” you'll find information that will help you better understand the ear, the types and degrees of hearing loss, and the types of tests used to diagnose hearing loss. You will be introduced to new terminology that is often used during these discussions. The terminology in bold text 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:

- » the outer ear
- » the middle ear
- » the 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**).

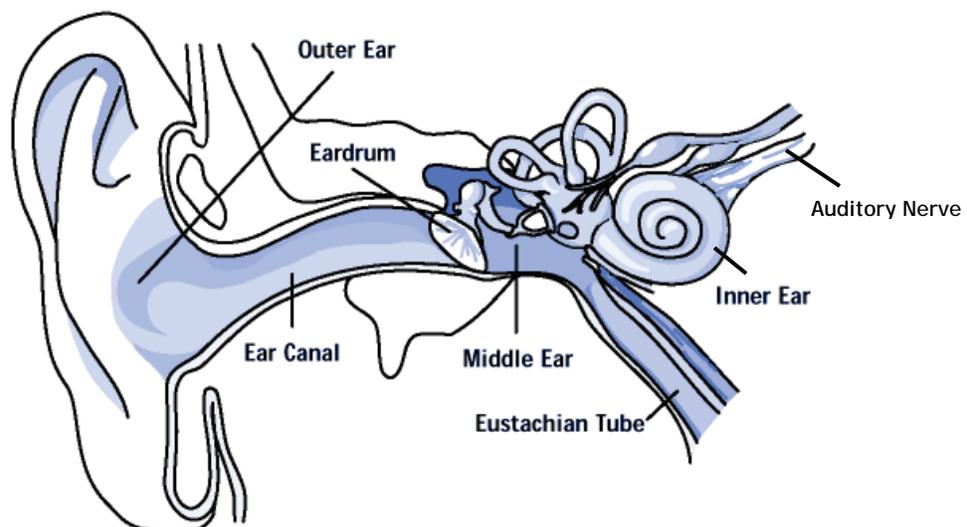
## Middle Ear

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, or 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** (8<sup>th</sup> 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.

For an animated simulation of the ear and hearing loss, visit:  
[www.audibel.com/understanding/simulator\\_flash.html](http://www.audibel.com/understanding/simulator_flash.html)



# 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."

**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 in large doses such as streptomycin, kanamycin, garamycin, ethacrynic acid
- » Premature birth with NICU admission
- » Head injuries
- » High fever
- » Rh factors
- » Measles

### **Auditory Neuropathy**

**Auditory neuropathy (AN)** is a hearing disorder in which sound enters the inner ear normally but the transmission of signals from the inner ear to the brain is impaired. People with auditory neuropathy may have normal hearing, or hearing loss ranging from mild to severe; they always have poor speech-perception abilities, meaning they have trouble understanding speech clearly. Often, speech perception is worse than would be predicted by the degree of hearing loss. For example, a person with auditory neuropathy may be able to hear sounds, but would still have difficulty recognizing spoken words. Sounds may fade in and out for these individuals and seem out of sync. This is a permanent type of hearing loss and cannot be treated with medications or surgery.

Common causes of auditory neuropathy may be:

- » Jaundice
- » Premature birth
- » Low birth weight
- » Inadequate supply of oxygen to an unborn baby
- » Genetic factors
- » Neurological disorders such as Charcot-Marie-Tooth syndrome and Friedreich's ataxia

Auditory neuropathy is not yet fully understood, however the ability to diagnosis this type of hearing loss as greatly improved in the past five years. Additional information regarding auditory neuropathy can be found following the Types of Hearing Loss section.

### **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 not 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:

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

# Auditory Neuropathy



The identification of **Auditory Neuropathy (AN)** in the past few years has increased due to better diagnostic processes, however information for families and professionals about AN remains fairly limited, thus this page will provide a more in-depth understanding of this newly diagnosed condition.

The number of people affected by Auditory Neuropathy is not known, but the condition affects a relatively small percentage of people who are deaf or hearing-impaired. It can affect people of all ages, from infancy through adulthood.

Although scientists believe the condition probably has more than one cause. In some cases, it may involve damage to the inner hair cells--specialized sensory cells in the inner ear that transmit information about sounds through the nervous system to the brain. Other causes may include faulty connections between the inner hair cells and the nerve leading from the inner ear to the brain, or damage to the nerve itself. A combination of these problems may occur in some cases. Although outer hair cells--hair cells adjacent to and more numerous than the inner hair cells--are generally more prone to damage than inner hair cells, outer hair cells seem to function normally in people with auditory neuropathy.

Several factors have been linked to auditory neuropathy in children. However, a clear cause and effect relationship has not been proven. Some children who have been diagnosed with auditory neuropathy experienced certain health problems as newborns, or during or shortly before birth. These problems include jaundice, premature birth, low birth weight, and an inadequate supply of oxygen to the unborn baby. In addition, some drugs that have been used to treat medical complications in pregnant women or newborns may damage the inner hair cells in the baby's ears, causing auditory neuropathy.

Auditory neuropathy runs in some families, which suggests that genetic factors may be involved in some cases. Some people with auditory neuropathy have neurological disorders that also cause problems outside of the hearing system. Examples of such disorders are.

Health professionals, including otolaryngologists (ear, nose, and throat doctors), pediatricians, and audiologists, use a combination of methods to diagnose auditory neuropathy. These include tests of auditory brainstem response (ABR) and otoacoustic emissions (OAE). The hallmark of auditory neuropathy is a negligible or very abnormal ABR reading together with a normal OAE reading. A normal OAE reading is a sign that the outer hair cells are working normally. Other tests may also be used as part of a more comprehensive evaluation of an individual's hearing and speech-perception abilities.

Researchers are still seeking effective treatments for people with auditory neuropathy. Meanwhile, professionals in the hearing field differ in their opinions about the potential benefits of hearing aids, cochlear implants, and other technologies for people with auditory neuropathy. Some professionals report that hearing aids and personal listening devices such as FM systems are helpful for some children and adults with auditory neuropathy. Cochlear implants (electronic devices that compensate for damaged or nonworking parts of the inner ear) may also help some people with auditory

neuropathy. However, no tests are currently available to determine whether an individual with auditory neuropathy might benefit from a hearing aid or cochlear implant.

Debate also continues about the best ways to educate and provide communication skills for children who have hearing impairments such as auditory neuropathy. However, most hearing health experts agree that parents should work with a team of professionals who considers the situation and options for each child as well as the child's family members and caregivers. Most also agree that parents and caregivers should interact often with infants who have auditory neuropathy by holding, facing, smiling at, and responding to the child.

There are two main philosophies of how to teach infants and children with auditory neuropathy how to communicate. One philosophy favors using sign language as the child's first language. The second philosophy encourages the use of listening skills and skills in spoken English together with technologies such as hearing aids and cochlear implants. A combination of these two approaches can also be used. Some health professionals believe it may be especially difficult for children with auditory neuropathy to learn to communicate only through spoken language because their ability to understand speech is often greatly impaired. Adults with auditory neuropathy and older children who have already developed spoken language may benefit from learning how to speechread (also known as lip reading).

NIDCD maintains a directory of organizations that can answer questions and provide printed or electronic information on auditory neuropathy. Please see the list of organizations at: <http://www.nidcd.nih.gov/health/hearing/neuropathy.asp>.

# 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 is (called “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 working normally.

**What it will show:** Along with other diagnostic tests, the OAE can find a hearing loss that is greater than a mild loss that occurs in the inner ear. However, wax in the ear, a noisy test environment or fluid in the middle ear can cause an absent response to this test.

**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:** An audiologist familiar with how a baby responds to sounds will look for changes in behavior. Sounds of different pitches and loudness will be presented. Babies may start or stop sucking, open their eyes wide.

**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. This test is usually done to determine the need for more testing or to verify other test results.

**Who it is for:** This test is usually done with babies under 6 months old, especially when no other tests are available.

## Visual Reinforcement 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 48 months.

## Tympanometry

**Also known as:** Impedance testing, immittance 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. 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.

# 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.

For a simulation of what speech may sound like to children with different degrees of hearing loss, visit: [www.phonak.com/consumer/hearinglossdemo.htm](http://www.phonak.com/consumer/hearinglossdemo.htm).

<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. Cochlear implants may offer the most access to auditory awareness and development of speech. Unless implanted, children will likely use vision in addition to or in place of hearing.
Profound Hearing Loss	91 dB or more	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. Cochlear implants may offer the most access to auditory awareness and development of speech.
Unilateral Hearing Loss (one side)		May have difficulty hearing faint or distant spoken conversations, especially in the presence of competing noise. 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.

# What is an Audiogram?

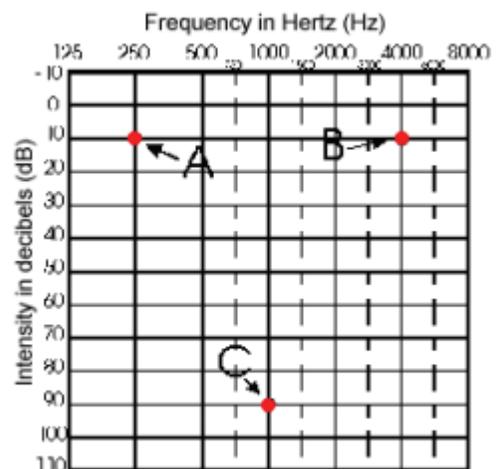


An **audiogram** is a graph of the softest levels at which your child can hear sound. It is a picture of the results of a test that is done by an audiologist. Your child's audiogram will often be used to describe his or her hearing loss.

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.



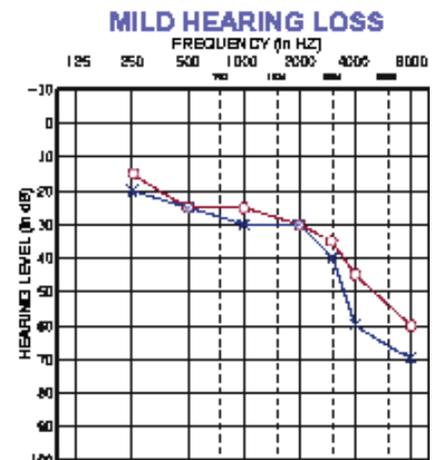
As the audiologist tests your child's hearing, they will make marks using different symbols on the audiogram that represent the softest levels at which your child is aware of sound. This softest level of sound awareness is called the **threshold**. By looking at the point where the pitch and loudness 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 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.

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.



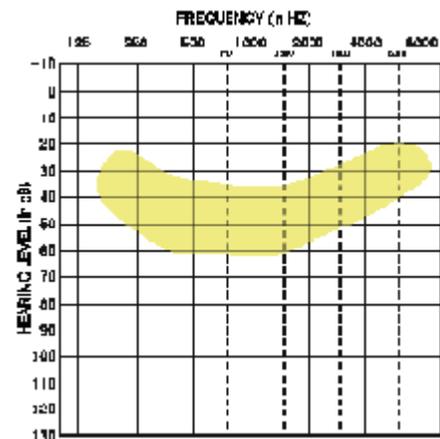
After the audiologist has information about various pitches, they will connect the symbols to make a line on the graph for each ear. This line is the **configuration** of the audiogram. Configurations vary due to each child's individual hearing loss. Some configurations go somewhat straight across. These 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. An audiogram showing where the speech sounds fall within the speech banana can be found at [www.babyhearing.org](http://www.babyhearing.org).

### 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



# Exploring the Possibilities



# 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 you choose 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.

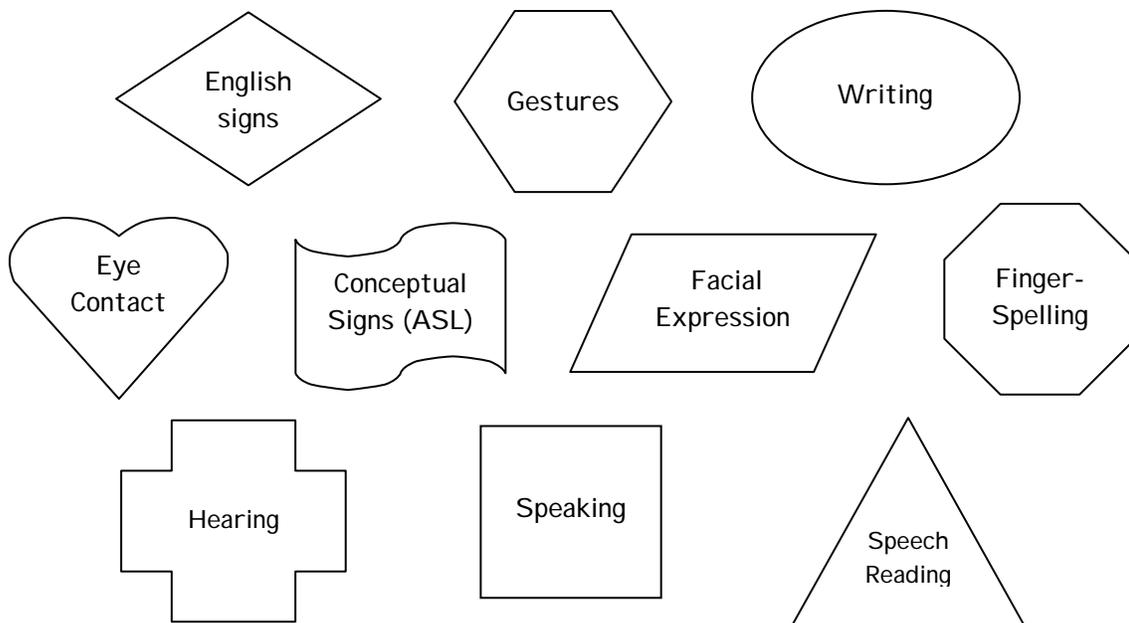
# Building Blocks for Communication



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. 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 five 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.



## Explanation 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.

Speech-reading – Your child watches 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)

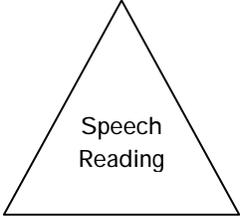
**Description:** ASL is the visual language of many deaf persons in the US and Canada—particularly those who are part of the Deaf community. It is a distinct language with its own grammar and word order. Fluency in ASL will allow your child full access to the Deaf community. English is often learned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

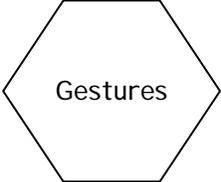
**Parent Involvement:** You will also need to learn ASL in order to fully communicate with your child. Opportunities to learn ASL are available through books, videos, interactive ASL classes, the statewide Deaf Mentor Program, and through meeting other deaf people. See the “Resources” section in this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



Conceptual Signs (ASL)



Speech Reading



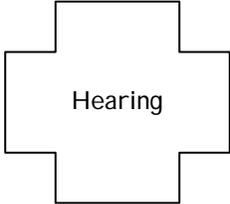
Gestures

## 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.

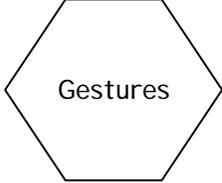
**Parent Involvement:** You will need to work closely with the child’s therapist or early Interventionist to apply training activities in the home and to enhance your child’s oral learning environment.



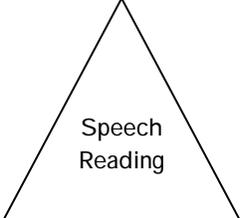
Hearing



Speaking



Gestures



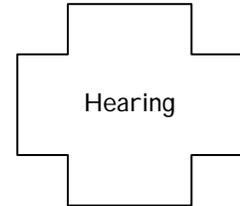
Speech Reading

## Auditory - Verbal

**Description:** Your child and family 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 one-on-one therapy sessions, including parents, which focus on the development of auditory skills with a specially trained Auditory Verbal Integration (AVI) therapist. Visual cues are typically not used during this therapy and sign language is discouraged.

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

**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.

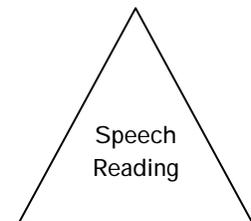
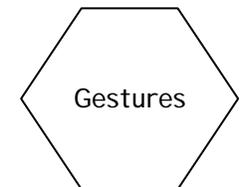
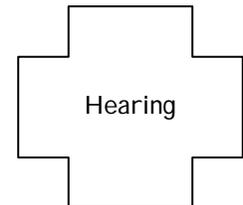


## Cued Speech

**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.

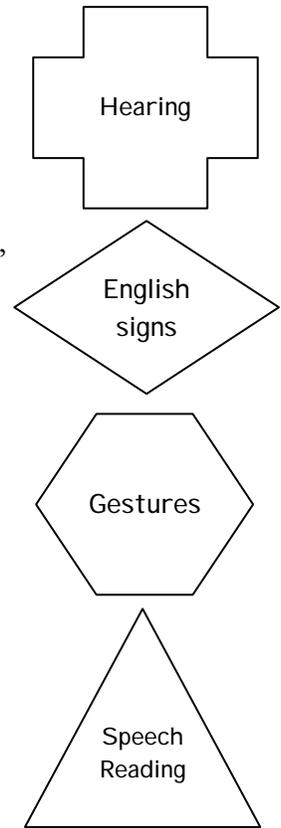


## Manually Coded English Systems

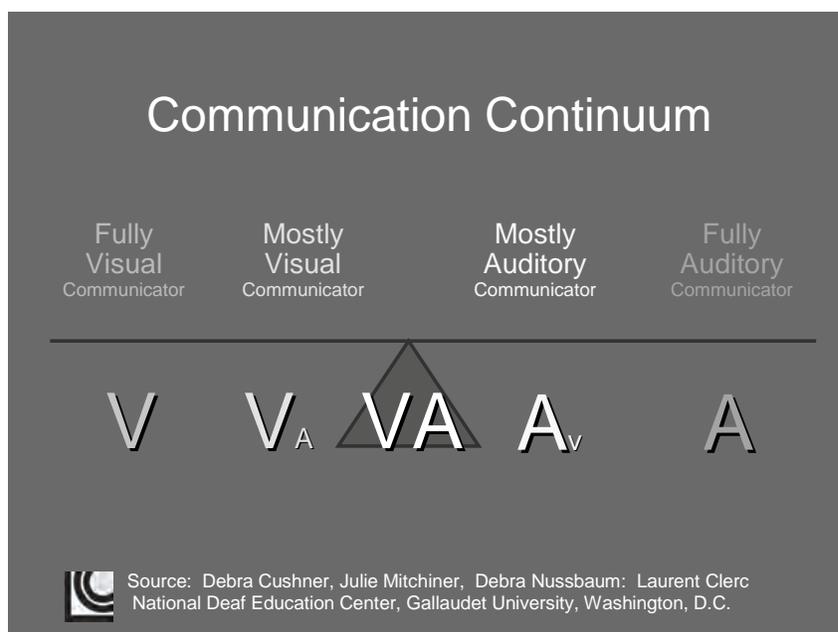
**Description:** There are several signed systems, which modify the signs used in ASL with to represent English grammar and word order. These sign systems are not languages but are visual representations of English. The signs are used to support spoken English or to convey tenses, plurals, possessives, 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 choosing a communication method, it is important to remember that no choice is permanent. If you decide on an approach that focuses on one building block that 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:

- » **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 Need to Consider 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 10,000 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).



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 I 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 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
- » 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 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 for a Deaf/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 Resources 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 boy 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. If his mother did not tell/sign that someone is at the door, he may be scared, because he doesn't know where she went or why she left so suddenly. This is partly due to the fact that the young child with hearing loss may not have access to all of the clues in the environment around him that signal to a hearing child that his mother just went to answer the door. For instance, he may not have heard 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 their 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.
- » **Closed 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. These may also be helpful in the home or during extracurricular activities in which your child is involved.
- » **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).
- » **Video Relay:** A telecommunications device that allows the user to see another person on a television or computer screen. This may allow person-to-person sign language conversations or with the use of a communication assistant who is interpreting using sign language and/or voice.
- » **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. Additional information can be found online at: [psc.wi.gov/consumerinfo/assistancepgms/tepp/tepp-ind.htm](http://psc.wi.gov/consumerinfo/assistancepgms/tepp/tepp-ind.htm).

---

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

Some common examples are:

- ☎ TTY
- ☎ Amplified handset or phone
- ☎ TTY with Braille or large visual display
- ☎ Special modem
- ☎ VCO or HCO<sup>1</sup> phone
- ☎ Hands-free speaker phone
- ☎ Puff activator
- ☎ Phone signaling system, and
- ☎ Other specialized equipment may be approved on an individual basis

## How do I apply or get answers to my questions?

Fill out an application on-line or print an application at:

<http://psc.wi.gov/>

Get an application, or answers to your questions by calling or writing:

**Public Service Commission**  
**P.O. Box 7854**  
**Madison, WI 53707-7854**

- ☎ (608) 267-1479 TTY
- ☎ (800) 251-8345 TTY
- ☎ (608) 231-3305 Voice
- ☎ (608) 266-3957 Fax

[pscsecs@psc.state.wi.us](mailto:pscsecs@psc.state.wi.us) E-Mail

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Information on voice carry-over (VCO) and hearing carry-over (HCO) services can be obtained from the Wisconsin TRS by calling 1-800-283-9877 (TTY) or 1-800-395-9877 (voice).

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## Where do I send my TEPP form

**USF Administrator**  
**Wipfli LLP**  
**P.O. Box 8700**  
**Madison, WI 53708-8700**

- ☎ (608) 274-1980 Voice
  - ☎ (608) 274-4448 TTY
  - ☎ (608) 274-8085 Fax
- [TEPP@Wipfli.com](mailto:TEPP@Wipfli.com) E-Mail

## When will I receive the voucher?

It can take several weeks from the time you mail an application to when you receive your voucher in the mail. It also takes longer if you apply for TAP.

## 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 (unless TAP qualified or using an HH voucher), 2) for any purchase amount over the total of the voucher plus your \$100, and 3) for any non-qualifying items purchased. Vouchers must be used within 120 days (4 months) of the date issued or they expire.



PSC of Wisconsin 5/2005

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**PUBLIC SERVICE**  
**COMMISSION OF WISCONSIN**

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

# TEPP

## **Telecommunications Equipment Purchase Program**

*....is the way to get  
telephone equipment  
you need at a reasonable  
cost.*

---

## What is the Telecommunications Equipment Purchase Program (TEPP)?

The TEPP is to help people with disabilities buy equipment they need in order to use basic telephone services. The TEPP is 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 fill out an application on-line or send in the simple application form.

#### **TEPP requires 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 the home or when traveling (like a TTY, amplification, visual alert system, etc.).

There's no age or income limit, but an individual can only get TEPP money once every three years for the same type of disability.

## How much will TEPP pay?

The amount depends on your disability. On the application form, you identify 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 voucher amounts for each category of disability:**

<u>Type of disability</u>	<u>Amount</u>
Hard of Hearing (HH) (No co-payment required for HH vouchers)	\$ 125
Deaf/Severely HH	800
Speech Impaired	1,600
Mobility/Motion Impaired	1,600
Deaf with Low Vision	2,500
Deaf and Blind	7,200



## How much do I have to pay?

You pay the first \$100 (except for HH vouchers). The voucher pays the rest, up to the maximum voucher amount. If you buy equipment that costs more than the voucher plus your \$100, you also pay the extra charges. For example, if you are deaf or severely hard-of-hearing, you can get a voucher for \$800. If you buy equipment with a total cost of \$918, you will pay \$118.

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

The Telecommunication Assistance Program (TAP) may be able to pay the \$100. TAP is a program of the Office for the Deaf and Hard of Hearing (Department of Health & Family Services). TAP is only for persons who are deaf or severely hard of hearing in a low-income household. TAP funds pay 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 also fill out the household income lines and 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. **For questions on TAP, contact:** Office for the Deaf and Hard of Hearing at (608) 266-3118 Voice/TTY.

## Telecommunications Equipment Purchase Program (TEPP) APPLICATION FOR VOUCHER

**Mailing address and Fax number are below.** For questions about the application or the Telecommunications Equipment Purchase Program (TEPP), you may call: (608) 274-1980 Voice, (608) 274-4448 TTY, or email [TEPP@Wipfli.com](mailto:TEPP@Wipfli.com). You may fill out and file your application from our website at: <http://psc.wi.gov/>

**PERSONAL INFORMATION (Please print your responses.)**

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

Applicant's Street Address or Rural Home Address (no P.O. Boxes)

Apt. No.

City

State

ZIP Code

Telephone Number: ( ) - -  TTY  Voice

Email Address:

Social Security No.: - -

Date of Birth:

**DISABILITY CATEGORY (CHECK ONE)**

- Hard of Hearing (Voucher Maximum \$125 with no co-payment required)
- Severely Hard of Hearing **or** Deaf (Voucher Maximum \$800)
- Speech Impaired (Voucher Maximum \$1,600)
- Mobility Impaired or Motion Impaired (Voucher Maximum \$1,600)
- Severely Hard of Hearing **or** Deaf **and** Low Vision (Voucher Maximum \$2,500)
- Severely Hard of Hearing **or** Deaf **and** Blind (Voucher Maximum \$7,200)

**HOUSEHOLD INFORMATION**

Number of people in your household: \_\_\_\_\_

\*Annual household income: \$ \_\_\_\_\_ (according to most recent tax return filed and including income of spouse or parent/guardian, if applicable)

*\*There is no income limit for TEPP. Income information will be used to determine if Severely Hard of Hearing or Deaf applicants are eligible for assistance which can pay the \$100 co-payment.*

**Have you previously received assistance from:**  
**TEPP? TAP?**

- |                                       |                                       |
|---------------------------------------|---------------------------------------|
| <input type="checkbox"/> Yes          | <input type="checkbox"/> Yes          |
| <input type="checkbox"/> No           | <input type="checkbox"/> No           |
| <input type="checkbox"/> Don't recall | <input type="checkbox"/> Don't recall |

**SELF-CERTIFICATION AND SIGNATURE**

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 understand that I need to make a \$100 co-payment when I purchase the equipment unless I qualify for TAP assistance or checked the Hard of Hearing category.

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

Applicant Signature or Guardian Signature (check box)

Guardian

Date

**MAIL APPLICATION TO:**

USF Fund Administrator, c/o Wipfli LLP  
P.O. Box 8700, Madison, WI 53708-8700

**OR FAX APPLICATION TO:**

USF Fund Administrator, (608) 274-8085

*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.*

*Applications 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. Voucher recipients are responsible for the first \$100 of the equipment purchased, unless they qualify for TAP assistance or applied in the Hard of Hearing Category. Voucher recipients are also responsible for any additional amount exceeding the maximum value of the voucher plus the co-payment.*

**THIS SECTION FOR OFFICE USE ONLY**

**TEPP**

Date received: \_\_\_\_\_

Eligible

Ineligible: Reason: \_\_\_\_\_

USF Administer and date: \_\_\_\_\_

**TAP**

Eligible

Ineligible: Reason: \_\_\_\_\_



# Keeping Track



# 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>

\*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.



# 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

\*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!

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



# Information that 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 (Who the 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











\_\_\_\_\_ County Birth to 3 Services

# Individualized Family Service Plan

CHILD: \_\_\_\_\_

BIRTHDATE: \_\_\_\_\_



Service Coordinator: \_\_\_\_\_

Phone Number: \_\_\_\_\_

Referral Date: \_\_\_\_\_

Initial IFSP Date: \_\_\_\_\_ Next IFSP Review Due: \_\_\_\_\_

IFSP Review Date(s)\*: 1) \_\_\_\_\_ 2) \_\_\_\_\_ 3) \_\_\_\_\_

4) \_\_\_\_\_ 5) \_\_\_\_\_ 6) \_\_\_\_\_

7) \_\_\_\_\_ 8) \_\_\_\_\_ 9) \_\_\_\_\_



ALL ABOUT \_\_\_\_\_ Date: \_\_\_\_\_

Child lives with: Relationship:	Other parent/guardian name: (if applicable)
Address:	Address:
Home phone:	Home phone:
Alternate phone:	Alternate phone:
Email:	
Other parent/guardian: (if different from above)	
Address:	Phone:
Primary Language of Parents:	Primary Language of Child:
Spends day with:	
<input type="checkbox"/> Mom	<input type="checkbox"/> Childcare Provider: _____
<input type="checkbox"/> Dad	<input type="checkbox"/> Other (Specify): _____
Siblings:	
Other important people or information:	
Primary Medical Care Provider/Medical Home:	

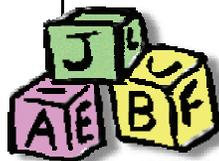
Services and programs my child/family currently use:

- |  |   |   |
|--|---|---|
| <input type="checkbox"/> Badger Care             | <input type="checkbox"/> Health Dept.       | <input type="checkbox"/> SSI            |
| <input type="checkbox"/> CYSHCN                  | <input type="checkbox"/> Healthy Start      | <input type="checkbox"/> Support Groups |
| <input type="checkbox"/> Dept. of Human Services | <input type="checkbox"/> Katie Beckett      | <input type="checkbox"/> W2             |
| <input type="checkbox"/> Family Resource Center  | <input type="checkbox"/> Library            | <input type="checkbox"/> WIC            |
| <input type="checkbox"/> Family Support          | <input type="checkbox"/> Medical Assistance | <input type="checkbox"/> YMCA           |
| <input type="checkbox"/> Head Start              | <input type="checkbox"/> MUMS               | <input type="checkbox"/> Other _____    |

We want more information about the following programs: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**TELL US ABOUT YOUR FAMILY** \*Date: \_\_\_\_\_

<p>What is going well for your child and family right now? (e.g., activities, routines, times of day, relationships)</p>	<p>What is your family concerned or interested in learning more about?</p>
<p>People or supports that are helpful to your family:</p>	<p>What are some activities you enjoy doing with your child and family?</p>
<p>What would you like to see happen for your child and family in the next six months?</p>	<p>What activities or times of day are difficult or stressful for your child and family?</p>



\*HFS 90.09 (2)



## SUMMARY OF ALL DEVELOPMENTAL AREAS\*

(For use with the Early Intervention Team Report and IFSP. Include tools, strategies, and locations.)

Name \_\_\_\_\_

Date: \_\_\_\_\_

Birth date \_\_\_\_\_

Age at evaluation \_\_\_\_\_

Adjusted Age \_\_\_\_\_

### PHYSICAL DEVELOPMENT

**HEALTH** (Includes Medical, Dental, Nutrition):

**VISION/HEARING** (Screening, Glasses, Hearing Aids, History of Ear Infections):

**FINE MOTOR** (Use of Hands and Upper Body, Sensory):

**GROSS MOTOR** (Quality and Function of Movement, Equipment/Devices):

\* HFS 90.08(7)(h); HFS 90.08(7)(c); HFS 90.08(7)(h)(1); HFS 90.10(5)(a)

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## SUMMARY OF ALL DEVELOPMENTAL AREAS\*

---

(For use with the Early Intervention Team Report and IFSP. Include tools, strategies, and locations.)

### COMMUNICATION (Understanding, Expression, Intelligibility, Use of Language)

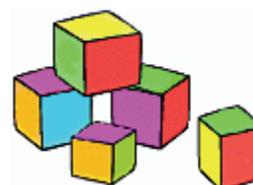
### COGNITION (Thinking, Play Skills, Sensory)

### SOCIAL EMOTIONAL (Engagement, Response to Caregivers, Coping, Sensory)

### SELF-HELP (Feeding, Dressing, Toileting, Sleeping)

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\* HFS 90.08(7)(h); HFS 90.08(7)(c); HFS 90.08(7)(h)(1); HFS 90.10(5)(a)





# EARLY INTERVENTION TEAM REPORT\*

## WISCONSIN EARLY INTERVENTION ELIGIBILITY DETERMINATION

Child's Name: \_\_\_\_\_ Date: \_\_\_\_\_

(Check A or B)

A This child meets the eligibility criteria for early intervention services (Check 1 or 2)\*:

1 a) A developmental delay of 25% or greater or -1.3 standard deviation in the following area(s):

b) Atypical development based on:

2 A diagnosed physical or mental condition exists which has a high probability of resulting in a developmental delay. Specify condition(s) and source of diagnosis: \_\_\_\_\_

Comments: \_\_\_\_\_

B This child does not meet eligibility criteria for Birth to 3 services:

Offer to re-screen the child within 6 months.

Notes: \_\_\_\_\_

The following community resources might benefit the family:

The following information was given to the family: \_\_\_\_\_

## PARTICIPANTS IN EARLY INTERVENTION TEAM MEETING

<i>Signature</i>	<i>Title</i>
	<i>Parent/Guardian</i>
	<i>Parent/Guardian</i>
	<i>Service Coordinator</i>

\* HFS 90.08(5); HFS 90.08(6); HFS 90.08(7); HFS 90.08(4)



**CHILD AND FAMILY OUTCOME\*** Date: \_\_\_\_\_

<i>We want: (What will happen or change?)</i>
<i>So that: (Why is this important?)</i>
<i>What is already happening? (What is the child doing now? What has been tried? What is working?)</i>
<i>We will know we are successful when: (What can we measure?)</i>

<i>What will happen within the child and family's everyday routines and activities and places?</i>	<i>Notes</i>

Date(s) Reviewed: \_\_\_\_\_

Describe progress toward outcome:

Check one:  Accomplished  Continue  Other: \_\_\_\_\_

\* HFS 90.10(5)(c)

**EARLY INTERVENTION SERVICES TO HELP  
'S DEVELOPMENT**

**BIRTH TO 3 SERVICES**      **Date:** \_\_\_\_\_



Services	Start/End Dates	Location	Frequency*	Intensity	Funding Sources
Service Coordination					

If a service will not be provided in a natural environment, please attach a plan with steps to be taken to get back to a natural environment.

**NEEDED MEDICAL AND OTHER SERVICES**

(These are resources, supports or services that assist the family but are not funded by Birth to 3.)

SUPPORTS NEEDED	WHO WILL HELP	STEPS TAKEN	FUNDING SOURCE

IFSP Team discussion found that no medical or other services were identified at this time.

**Comments:**

\_\_\_\_\_

\* HFS 90.10(5)(d)

## TEAM SIGNATURE PAGE\*

- ▶ I /We have received a copy of and understand the parent and child rights.
- ▶ This plan reflects the outcomes that are important to my child and family.
- ▶ I /We give consent for the services described in this IFSP for my child and family.
- ▶ I understand that this plan will be shared with all team members listed below so we can work in partnership on behalf of my family.

\_\_\_\_\_  
Parent/Guardian Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Parent/Guardian Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Parent/Guardian Signature

\_\_\_\_\_  
Date Reviewed

We have worked together with the family to create this Individualized Family Service Plan and agree that this plan will guide our work.

OTHER IFSP TEAM MEMBERS NAMES & SIGNATURES

Date

Service Coordinator:	
Team Member:	



\* HFS90.12(2)(b)

**TRANSITION PLAN FOR \_\_\_\_\_ Date: \_\_\_\_\_**

A transition is any major event that impacts a child and family, such as moving out of county or state, moving into or between programs, coming home from the NICU, changing a child care situation, or turning 3. \* For children turning 3, this page is to be filled out by 2 years 3 months.

What kind of transition is this? \_\_\_\_\_

What does your family want and hope for your child for this transition?

\_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

Date(s) of transition planning discussions: \_\_\_\_\_

Who participated in these discussions and what options were discussed?

\_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

**NEXT STEPS**

Who will do what?	When?

**If referring to public school system:**

Family given "Step Ahead at Age 3".

Non-identifying, confidential information forwarded to school district. Date: \_\_\_\_\_

Transition Planning Conference held and Preschool Options discussed. Date: \_\_\_\_\_

Comments: \_\_\_\_\_

Referral made at least 90 days before 3<sup>rd</sup> birthday. Date: \_\_\_\_\_

Comments: \_\_\_\_\_

\* HFS 90.10(5)(f)

**JUSTIFICATION FOR SERVICES PROVIDED IN  
LOCATIONS OTHER THAN NATURAL ENVIRONMENTS\***

Child's Name: \_\_\_\_\_ Date: \_\_\_\_\_

---

List services and activities provided in a setting other than the child's natural environment:

Team recommendation, explaining why this outcome cannot be met in the child's natural environment:

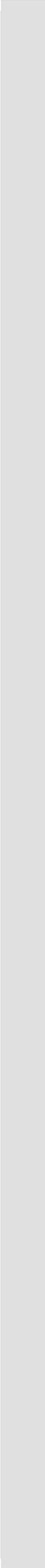
How will the outcome be met in this setting?

What activities will be provided to include this outcome in the child's home and community environment?

When will services be provided in the child's home and community environment (time frame)?



\* HFS 90.11(5)(a)



# Guidelines for Completing Wisconsin's Individualized Family Service Plan

“The IFSP is a promise to children and families—a promise that their strengths will be built on, that their needs will be met in a way that is respectful of their beliefs and values, and that their hopes and aspirations will be encouraged and enabled.”  
(McGonigel & Johnson, 1991, p.1)



2006

## Background and Acknowledgements

**The Wisconsin Birth to 3 Program IFSP Document and Guidelines** have been developed as part of a comprehensive statewide effort to provide consistent guidance and materials to County Birth to 3 Programs. This is a key aspect of our State's accountability to families served by the Birth to 3 Program. A statewide document provides consistency to families no matter where they live in Wisconsin and helps to facilitate transitions out of the Birth to 3 Program. In addition, the document responds to requests from County Birth to 3 Programs for a document and process that clearly outlines the elements of the IFSP process required by HFS90 (Wisconsin Administrative Code for the Birth to 3 Program), reflects Wisconsin's mission and Guiding Principles for implementing early intervention, and includes strategies for effectively engaging teams, including families, in the IFSP process. While County Birth to 3 Programs are not required to use this document, programs are encouraged to adopt the IFSP form and use it as it is to maintain the integrity and consistency of the document.

### THANK YOU

Wisconsin's Birth to 3 Program would like to express sincere appreciation to the members of the IFSP Workgroup for their dedication to developing these IFSP materials. This group dedicated hours to sharing ideas about their program practices to create this document and guidance for Wisconsin's Birth to 3 Program. Throughout their work, they strove to keep children and families in the center of their discussions while also including all of the required HFS90 elements. They continually asked each other these types of questions: "Why do we need this? Are we asking the right questions? Are we asking for more information than we need? Are we gathering this information for families or for our convenience?"

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**The following counties piloted the IFSP Form and provided feedback to the Workgroup:** Calumet, Chippewa, Columbia, Dane (Bridges), Dodge, Green Lake, Headwaters (Forest, Oneida, Vilas), Milwaukee (Milwaukee Center for Independence), Pierce, Price, Racine, Rock, and Waukesha

***"Thank You" to all of the members of the Workgroup and Pilot Counties who contributed to the Wisconsin IFSP Document and Guidelines.  
A special "thanks" to Amy Wilson for her steadfast facilitation of the workgroup. Thanks to Arianna Keil for finalizing this work.***

## The Cover Page

**PURPOSE:** To identify whom this Individualized Family Service Plan belongs to, and record the name of the service coordinator. This page identifies when the original IFSP was developed and how often updates have occurred [HFS 90.10(5)(e)]

### **PROCESS:**

**Referral Date:** This date documents the date a call was received by the Birth to 3 Program for a referral. If the referral is for an evaluation or for a referral of a child with a diagnosed condition likely to lead to a developmental delay, this date marks the beginning of the 45-day timeline for determining eligibility and developing the initial IFSP. If the referring person does not specify that the referral is for an evaluation, then the program needs an intake process to determine whether a screening will be conducted or if an evaluation will be planned and conducted. For example, during an initial intake visit, the family and service coordinator could determine that an evaluation is necessary. If the caller specifies the referral is for a screening, the date of referral is documented when an evaluation is deemed necessary. For further guidance, refer to the *Birth to 3 Flow Chart* listed in the Appendix of these guidelines or at this website <http://www.waisman.wisc.edu/birthto3/BIRTHTO3FLOWCHART-COLORDDMM.PDF>.

**Initial IFSP Date:** This is the date the first IFSP is written with the family. If an interim IFSP is written with a family, enter the date of the interim IFSP also. For additional guidance about an interim IFSP, visit this website: <http://www.waisman.wisc.edu/birthto3/INTERIMIFSPGUIDE.HTML>. [90.10(2)(b)2]

**Number of Days between Referral and Initial IFSP Dates:** Calculate and record the number of calendar days between these two dates to demonstrate timeliness in meeting the required 45 day interval.

**IFSP Review Due Date:** This date lists the projected date of the next IFSP review date, as determined by the IFSP team. The projected date for the first review helps the family anticipate the timeline for future reviews.

**IFSP Review Dates:** These dates are the actual dates for reviews. The IFSP must be reviewed at least every 6 months and evaluated annually, or more frequently as requested by the family or other team members. [HFS 90.10(5)(h)]

**Optional Additions:** County Birth to 3 Programs may decide to add a county logo or the logo of a contracted provider to the cover page. Counties may also choose to add the child's photo on this page or a graphic that reflects the program. The teddy bear graphic is a placeholder for a photograph of a child and family, if programs choose to ask families for a picture. Programs may add the child's name to each page as well as page numbers, if they choose.

## All About the Child Page

**PURPOSE:** To share demographic and other information about the child and family that will introduce the family and begin to identify the supports and programs a family currently uses or may be interested in learning more about. [HFS 90.09(2)]

**PROCESS:** This information is gathered starting with the initial contacts, continues throughout the IFSP development process, and is added to and changed as needed. It is also the time to discuss with a family their preferences for ongoing communication (e.g., phone, e-mail, face-to-face).

**Child Lives With and Parent/Guardian Section:** You will notice three sections for parent/guardian information. In some cases, only the first part (child lives with) will be filled out and might contain both parents' names if they live at the same address. In other cases, a child might live with a parent but also have involvement with a second parent. There might also be circumstances that warrant filling out multiple parent/guardian sections, such as:

- The child lives with grandparents or extended family but the biological mother and/or father are still the guardians
- The child lives with foster parents but the biological parent(s) is/are still involved.

**Address:** Includes street address, city, state and zip code (include PO Box information if necessary for mailing)

**Home Phone:** Note the family's home phone number or document if the family does not have a phone. **Alternate Phone:** Consider work phone or cell phone.

**Email:** If a family chooses to share their email address, document that information on this line. Ask if the family uses their e-mail or would prefer another means of communication. If using email to communicate with a family, be sure to follow confidentiality guidelines from your agency and Health Insurance Portability and Accountability Act (HIPAA).

**Primary Language of Parent(s)/Child:** List language preferences of the family and their preferences for their child and family. If the preferred language of the parent is not English, make sure you use an interpreter. [HFS 90.08(7)(d)1; HFS 90.12(1)(c)]

**Spends Days With:** Check the appropriate box and add the name of the childcare provider, or, if "other" was checked, add information about that person.

**Siblings:** This space is to record the name(s) of other children who are in the home, as the siblings play important roles in the child's life.

**Other Important People or Information:** Families may want to list friends or other people who are supports in their lives (e.g., significant others) or pets who are special to them. Programs could also record other helpful information (e.g., school district, emergency contacts; best times of day to visit).

**Primary Medical Care Provider/Medical Home:** Add the name of the doctor, clinic, or other health care provider from whom the child receives his/her primary medical care. You may also list the child's specialists here and link to the Other Services/Needed Community and Medical Supports page.

**Services and Programs Families Currently Use:** This section highlights the supports families currently use by checking the appropriate boxes. This section is currently alphabetized but your program may choose to categorize these into groupings such as Financial, Health and Community Resources. County Birth to 3 Programs have the latitude to add supports that are specific to their communities. In reviewing these supports with families, the service coordinator or other team member may identify a program or resource a family is interested in finding more information about. These supports are to be listed under the "We Want More Information About" section. Be sure to list this information on the Needed Medical and Other Services section also.

## Tell Us About Your Family Page

**PURPOSE:** To record information gathered from the family (i.e., family directed assessment), which provides valuable insights into the family's strengths, concerns, routines, supports and interests. This information is vital in helping team members understand family dynamics, routines and activities in order to assist the family throughout the Birth to 3 process. Whether and how much information a family chooses to share is voluntary. However, it will have more meaning to families and the team if the service coordinator explains to the family how this information will guide the team's early intervention work. The more insight the team has about the family along the way, the better the team will be able to link strategies to support outcomes if the child is found eligible for Birth to 3. Gathering this information supports an ongoing relationship between the family and the Birth to 3 team during the early stages of learning about the family. This information will also lead to a more meaningful IFSP, if gathered with care. [HFS 90.09(2)]

**PROCESS:** The family and service coordinator discuss various strategies for gathering this information and have conversations about why the information on this page will be useful both to the evaluation and IFSP development. Information captured during this part of the IFSP process will be invaluable for learning about family routines and activities around which intervention may be planned. This information will also be helpful in addressing or identifying any unmet medical needs or community services and supports. The information can be recorded at multiple times and in a variety of ways.

Remind the parent(s) that the IFSP will be shared only with people for whom they have given consent (e.g., physicians, health insurance companies, schools at transition time).

This page might be filled out:

- During conversations between the family and service coordinator in which there is discussion about how the information shared by the family will be valuable in assisting the team to develop meaningful outcomes for the family. The service coordinator can offer to share the written information with other team members to help them prepare for their evaluations and reduce the number of times the family is asked to share the same information.
- By the family alone and reviewed with the service coordinator (you may choose to leave it with the family at an initial visit or send it by mail or e-mail along with the confirmation of the evaluation);
- During conversations between the family and other members of the evaluation and IFSP teams;
- By the family and service coordinator, with information gathered through the use of other family directed assessment tools found on the Birth to 3 Training and Technical Assistance website [http://www.waisman.wisc.edu/birthto3/WPDP/Unit\\_Three.html](http://www.waisman.wisc.edu/birthto3/WPDP/Unit_Three.html) (under Interactive Learning: Fundamentals of Service Coordination for Wisconsin Birth to 3; Unit 3(IFSP Document); Application Station: Tools for Completing the IFSP; or through use of materials and resources available through TaCTICS or Robin McWilliam's materials, family mapping, or materials your program already uses and finds helpful.

<http://www.fpg.unc.edu/~inclusion/RBI.pdf>

## Prompts for families when filling out this page:

- What is going well for your child and family right now?

Tell us about your child and family. Tell us what is really great about your child. Describe what currently feels positive for your family. Describe activities or routines your child is doing well with and what he/she is learning. Tell us what times of the day are best for your child and family. Tell us about whom your child or family connects with (e.g., friends, family members).

- What is your family concerned or interested in learning more about?

Describe what worries you about your child or family. Are there things you want your child to do that he/she is unable to do? Are there things that you want for your family that aren't currently happening? What keeps you awake at night? Are there things you would like to better understand or learn about?

- People or supports that are helpful to your family.

Describe or name other people in your life that support you, that you appreciate or that you find helpful. Consider using a mapping tool found in the Appendix to assist with this area.

- What are some activities you enjoy or would like to do as a family?

Think about your typical day from beginning to end. How does your family spend its time? What do you do at home or when you go out? Describe some of your favorite activities/places to go as a family. Are you involved with any community groups, church or library events? Are there activities you would like to do but feel you can't participate in? What are the barriers/challenges?

- What would you like to see happen for your child and family in the next 6 months?

Are there activities you would like to participate in as a family? Are there things you would like to do or learn more about?

What would you like to see your child/family do next?

- What activities or times of the day are difficult or stressful for your child and family?

Is there anything about your routine that is challenging for your child? Are you having difficulties accessing resources to help in difficult situations or are there any barriers you are experiencing? Are there any activities you would like to do but have had to change (due to the child's behavior)?

Be considerate of families' feelings. You can gather this information over time during conversations with families and by using a variety of family directed assessment tools. **Remember this may be the most valuable information you gather!** It can begin to shape the outcomes written later in the IFSP. A family identifying that they would like more information about their child's diagnosis could be a potential outcome on the Child/Family Outcomes page. Or, if they identified the need for child care assistance, the service coordinator may identify this on the *Other Services/Needed Community and Medical Supports* page later in the IFSP, along with steps taken to link the family to the identified program or support. This information also highlights strengths and supports that the family already has in place that will be helpful later in developing outcomes. Keep in mind that you can have families fill out a new page for each IFSP review or you can date any new information added to the original page.

## Summary of All Developmental Areas/EI Team Report Pages

**PURPOSE:** To fulfill the HFS90 requirement for an Early Intervention Team Report that summarizes the completed evaluations and findings and documents a child's eligibility or non-eligibility for the Wisconsin Birth to 3 Program. By integrating the EI Team Report into the IFSP, the IFSP requirement to include a summary of all developmental areas is addressed. Note: the inclusion of eligibility information fulfills this requirement for the Early Intervention Team Report, not an IFSP requirement. [HFS 90.08(7)(h); HFS 90.10(5)(a)]

**PROCESS:** This page can be added to the IFSP document or can be used as a stand-alone document. If a child is found not eligible or a family does not wish to pursue Birth to 3 Services even after being found eligible, the service coordinator can pull this portion out of the IFSP and send the summary to the family and other team members.

The members of the Early Intervention Team discuss their findings and conclusions and determine if there is documentation, data or other evidence that the child meets the eligibility requirements of HFS 90. Please refer to the recently distributed eligibility guidelines for more information about this area- <http://www.waisman.wisc.edu/birthto3/elig.html> (PDF and accessible html version). The *Early Intervention Team Report* includes the results of the evaluations, a summary of all areas of development, a determination of eligibility or non-eligibility and signatures of all team members present. If the child is not eligible for Birth to 3, the team needs to discuss recommendations for follow-up as well as referrals to other community resources.

If a team member cannot be present, that member shall be involved through other means, such as participating in a conference call, or be represented by someone who is knowledgeable about the child and about the team members' findings and conclusions [HFS 90.08(7)g].

**TO BEGIN:** Fill out the top information about the child including the date of the report, as the *Early Intervention Team Report* can be a stand alone document.

The first two pages of the *Summary of All Developmental Areas* have two functions. First, these pages assist early intervention team members in summarizing their findings as well as the child's present levels of development. Based on HFS 90, the areas of development include: Physical Development, which encompasses Health, Vision/Hearing, Fine Motor and Gross Motor; Communication; Cognition; Social/Emotional; and Self Help/language in HFS 90 is Adaptive. For use during the Early Intervention Team Meeting, be sure to include strategies and tools used to determine the status in each area, as well as the locations(s) of the assessments and observations. Individual discipline reports may be shared with the family as an additional information piece for families; however, these reports do not take the place of the requirement of the Early Intervention Team Report. We have included key words to assist in focusing your discussions about summarizing the child's development in each of the five areas, highlighting strengths and needs.

The second use of the first two pages of the *Summary of All Developmental Areas* is to fulfill the HFS 90 requirement that the IFSP will include information about the child's developmental status. This information can be updated during periodic and annual IFSP reviews.

Remember, the summary statements about a child's development are to be based on a variety of strategies and tools including review of previous records, parent reports and interviews, evaluation and assessment tools, and observations of the child in natural environments. Programs can write the name of the assessment tool once and reference it again if the tool is used to assess other areas of development. In addition, if programs choose to write a combined Early Intervention Team Report, be sure to include a space to document the discussions that take place with the family, as well as documenting any additional information mentioned by the family. Be sure to add the Eligibility Determination page if your program has the procedure of a combined EI Team Report.

## Summary of All Developmental Areas/EI Team Report Pages

**Eligibility Determination:** This page documents whether the child meets the eligibility criteria for Birth to 3. The service coordinator checks the appropriate box indicating if the child is or is not found eligible for the Birth to 3 Program. The service coordinator will write the area(s) of development as well as the percentage of delay or degree of standard deviation below the mean in each area to document eligibility for Wisconsin's Birth to 3 Program. If a child is found eligible based on Atypical Development, the service coordinator should describe the concerns. Examples of Atypical Development can be found in HFS 90, page 428, as well as in the eligibility guidelines. When a child has a diagnosed condition with a high probability of resulting in a developmental delay, then the service coordinator will document the diagnosis and the source of the diagnosis. You will notice a comments section, which is included after the first eligibility section. The purpose of this section is to give programs the opportunity to document any further comments, including an explanation when a child is found eligible but a family declines the development of an IFSP.

If a child is found not eligible for the Birth to 3 Program, then the team must offer to re-screen the child within a maximum of 6 months, while recognizing there may be circumstances in which the team decides to contact the family sooner. There is a section for notes next to this option for the team to document whether the service coordinator will call the family within 6 months, whether the family will call the service coordinator if concerns arise, or if the family declined the re-screen opportunity. Another team discussion is that of options for community resources or information that might benefit the child and family. All participants who are active members in the early intervention team discussions must sign the EI Team Report. If a team member participated through a conference call, the signature may be by proxy. [HFS 90.08(7)h]

## Child and Family Outcomes Page

**PURPOSE:** To document the ideas that are important to the family about what they want to see happen for their child and family. These ideas are transferred from the "Tell Us About Your Family" page or are gathered throughout the process as a result of conversations with the family. [HFS 90.10(5)(c)]

**PROCESS:** The ideas gathered throughout the evaluation and assessment processes should be brought forward to the outcomes page. These outcomes link back to conversations with the family and reflect both child and family outcomes. For more information and examples on writing outcomes, go to the Birth to 3 Training and Technical Assistance Website and access Birth to 3 Basics IFSP section. ([www.waisman.wisc.edu/birthto3/](http://www.waisman.wisc.edu/birthto3/)) Remember that outcomes cross developmental domains and can often be incorporated into multiple routines. This is the opportunity for the team to address how an outcome might address engagement, independence, and social relationships.

**To Begin:** Reflect back on discussions with the family. Ask the family if the ideas they brought forward earlier in the process (on the "Tell Us About Your Family" page or from another assessment tool) are still important to them, and, if so, these ideas may become the outcomes. Remember that the information written on this page can reflect both child and family outcomes. You may fill out one or more outcomes pages, depending on team discussions.

**We want:** A Statement of what the family wants to see happen for their child and family. Note: Many of the child outcomes will cross developmental domains.

- Child Outcome: We want Johnny to move around the house on his own.
- Family Outcome: We want information about Down syndrome.
- Child/Family Outcome: We want Ben to handle transitions without having tantrums.

**So that:** Why is this important to the family? What will be different for the family? The answer is more than "so that the child will have age appropriate skills." It is the "why this will help the family" answer.

- Child: So that we don't have to carry him all the time, as Johnny's mom is expecting another baby soon."
- Family: So that the family can read and understand information about Down syndrome and be able to talk to her team about her questions and concerns.
- Child/Family: So that we can go to the store or to a restaurant as a family.

**What is already happening?:** List activities that the child and family are already doing to support this outcome. This can include things that are happening at child care or at Grandma's house also. This is a good place to emphasize strengths and to highlight what the family is already doing.

- Child: Johnny is able to walk along the furniture. He has a push toy but it seems to get away from him as his feet can't keep up with the toy.
- Family: Mom is conducting Internet searches and received some written information from her physician.
- Child/Family: Family is going to the store in shifts. Family gives Ben a toy or food to distract him in stores. They don't go to restaurants together.

**We will know we are successful when:** Identify what can be observed and is meaningful to the family to show that change has occurred. Family criteria of success may or may not be from a developmental perspective and can include parent report or perception of observed change. It is important to set the criteria based on what's important and meaningful to the family.

Child: Johnny can get himself from the dining room to the kitchen for meals without being carried by his mom.  
Family: Family reports they are have received information they wanted and know how to access additional information and resources.  
Child/Family: When we can eat out as a family once per month.

**What will happen within the child and family's everyday routines and activities considering the various places where the child and family spend their time.** This section is not intended to be limited to just strategies that the professionals will be doing, but should consider other strategies that will support the family in achieving this outcome throughout their family's routines and activities. This section should open the door to any opportunity that the child and family can do within their day, within their routines.

- Child: This section may include ideas from the team about how the push toy can be weighted so that Johnny's push toy will work better for him as well as ideas about how the family can carry this into their routines and activities. At lunchtime Johnny's family will hold his hand to help him walk to his high chair  
Family: Mom will call the doctor to ask questions about her daughter. The team will look into local support groups. The Service Coordinator will assist mom with parent matches.
- Child/Family: Use pictures to show Ben what is happening next. Introduce the brushing protocol as well as other "heavy work" activities. Initially, go to stores at a time that won't be so busy and noisy. Develop a plan of what will happen if Ben gets upset when you are at a store. Try having Ben push the cart in the store or have him sit on a sit fit in a restaurant.

The notes section on the right can be used to update what is happening with the activities listed, such as updating whether the activities have changed but the outcome remains the same but an activity will be changed at an IFSP review meeting.

**Progress toward outcome or date accomplished:** This is filled out at IFSP review meetings or anytime the plan is reviewed. The Service Coordinator should discuss with the family and team the progress made toward the outcome listed above. The service coordinator can check the appropriate box, which will show if the outcome is accomplished, continued or no longer an outcome.

**Revisions of outcomes for IFSP reviews and evaluations:** At each review meeting, additional Outcomes pages can be added for new outcomes. If work is continuing on previous outcomes, indicate this on the initial outcome page and continue to use this page. You may want to re-order the pages so that only current, active outcomes are viewed first. (See the Appendix for team requirements related to major and minor changes to IFSPs.)

## Early Intervention Services Page

**PURPOSE:** To document the early intervention services, defined in HFS 90.11(2) that the team decides to pursue following discussion and completion of the child and family outcomes. This page documents and details other supports or services the child or family identifies as needed, but that aren't required to be funded by the Birth to 3 Program. This section also includes the steps that will be taken to secure those services from public or private sources (HFS 90.10(5)(d)5).

**PROCESS:** The top portion of this page will be completed upon conclusion of the outcomes discussion, as services are identified to support the outcomes written with the family. Teams can continue discussions from the development of the outcomes by asking the question, "Who can help with these outcomes" as well as "what team member(s) is most appropriate to assist the family in supporting the IFSP outcomes." Consider the supports already in place as you are determining Early Intervention Services. The Birth to 3 Program offers 15 Early Intervention Services, as described in HFS 90.10(4)(a-o), as well as service coordination, which is a Core Early Intervention Service for all families.

**Birth to 3 Services:** List the Early Intervention Service(s) as determined by the IFSP team. Service coordination is a Core Service; therefore it is to be listed on the IFSP for all families. You are not required to include the intensity of service coordination. That section has been blocked off on the form.

**Start/End Date:** The start date is the projected month, date, year for initiating the services. The end date is the expected duration of the services. The start date for service coordination is the same date as the IFSP meeting. For other services, the projected date should be as accurate as possible. The actual dates will need to be reported to the State Birth to 3 Program. It is important to record the start date for each service as accurately as possible for potential verification of the reported dates.

**Location:** The location(s) where the early intervention services will occur. To the maximum extent appropriate to the needs of the child, early intervention services shall be provided in the child's natural environments, including home and community settings where children without disabilities participate. A setting other than a natural environment may be used only when early intervention outcomes cannot be satisfactorily achieved for the child in a natural environment. If reasons exist for providing services in settings other than the child's natural environments, those reasons shall be documented in the child's IFSP [HFS 90.11(5)a]. If a service will not be provided in a natural environment, the team will need to complete an additional page which documents the reason why the service is not being provided in a natural environment and the steps to be taken to transition the service back into natural environments. The last page of the IFSP document is titled Justification for Services Provided in Locations other than Natural Environments. Use this form when a service is not provided in a natural environment. This form has been included solely for the purpose of documenting services not provided in natural environments, as well as plans for transitioning the provision of such services into a child's home and community environment.

**Frequency:** The number of days or sessions the service will be provided (e.g., once per month, once per week, eight times during duration defined with start and end date). Be specific and refrain from using ranges (e.g., 1 time per week, not 1 to 3 times per month).

**Intensity:** The length of time the service will be provided during a session. Be specific and refrain from using ranges of time. (30 minutes, not 30-60 minutes).

**Funding Source(s):** List payment arrangements (e.g., Private Insurance, Medical Assistance, County Birth to 3 Program, Parental Cost Share). Programs may choose to cost out the plan.

### **Needed Medical and Other Services:**

This section describes supports needed that are not required to be funded by the Birth to 3 Program. Identifying other services not required by HFS90 and assisting families in making links to desired services contributes to the support of families in their efforts to achieve child and family outcomes. While Birth to 3 staff can make these links, families should know that access to these services cannot be guaranteed.

Draw information gathered throughout the assessment process and link those ideas identified by the family or the rest of the team to this section. Look at the "All About" page and relate the supports identified by the family (as ones they need more information about) to this section of the IFSP. You may also discuss ideas reflected on the "Tell Us About Your Family" page and, as a team, consider supports available to the family. This does not apply to routine medical services such as immunizations and well baby care unless a child needs those services and they are not otherwise available or being provided (HFS 90.10(5)(d)5).

This section documents Needed Medical and Other Services as appropriate and describes who will help, as well as the steps planned/taken to link families to those services. The funding source may also be filled in if known, such as Medical Assistance. Common examples of other services include, but aren't limited to: housing assistance, WIC referrals and child care resources. Examples of medical services are immunization and well baby services for families who have no confirmed medical provider or referral to medical resources for concerns not met by existing providers.

If no other services have been identified through team discussions, please document this by checking the small box on the bottom of the page and add any comments for a description.

## Team Signature Page

**PURPOSE:** To obtain parental consent for the services described in the IFSP and to ensure that the family has read and understands their rights and procedural safeguards. [HFS 90.12(2)(b)]

**PROCESS:** In addition to getting signatures, take this opportunity to review and discuss parent and child rights and ensure that the parents understand the information. Make sure the family knows that services are voluntary and can be changed or modified at parent request. The family should be informed that they can revoke their consent at any time. It's also a good time to remind families that team members will have access to the IFSP to guide their involvement with the family. The IFSP will also become a part of the child's early intervention record that the Birth to 3 Program would share with others not listed on the IFSP, only when the family signs consent to share the record.

**Signature Line:** Review the four items listed above the signature line, making sure parents understand what each item means. Encourage parents to read the items and ask questions for clarification. At least one parent should sign and date this page. Both parents can sign if they are at the meeting. The purpose of the third signature line is for a parent's signature when a major or minor change has occurred or the IFSP has been reviewed.

**Names of Other Team Members:** The name of anyone who has been involved with the development of the plan (through presence at meeting, phone presence, or report) may be listed here to show the family who has worked together to develop the plan. Some programs find it useful to add phone numbers or email addresses behind the listed name or signature. Signatures are not required, but we encourage any team member present to sign the page, indicating that this IFSP will guide their work. The service coordinator can print the names of others who were involved in the evaluation and assessment processes but weren't present at the IFSP meeting, such as a child care provider, public health nurse, physician, Early Head Start staff or anyone else the family would like added.

## Transition Planning Page

**PURPOSE:** To prepare a written plan with the steps to be taken to support the child and family through transitions from the Birth to 3 Program. [HFS 90.10(5)(f)]

**PROCESS:** A transition is any major event that impacts a child and family, such as moving out of the county or state, moving into or between programs, coming home from the NICU, changing a childcare situation, or turning 3. This page is not limited to transitions upon age 3, but could include any transitional time in the child and family's life. Discussion of transitions is encouraged throughout a child's involvement with the Birth to 3 Program. It is possible that a child and family may have multiple transitions throughout their involvement in the Birth to 3 Program and therefore would have more than one transition planning page--one for each individual transitional event. The planning page itself is also a fluid document that represents a process and may be added to over time. The Transition Planning page should be filled out in the IFSP no later than when the child is 2 years, 3 months of age. This will ensure prompt coordination and ongoing discussions about the transition process.[IDEA 2004]

**What kind of transition is this?** State the type of transition (examples are on the Transition page of the IFSP)

What does your family want and hope for your child during this transition?

- Consider key questions to ask the family about the transition, such as:
  - What are your concerns, fears, excitements, and goals for this transition?
  - What would you like to see happen through this transition? Who would you like to see support you through this transition?
  - What additional information do you want to help you through this process?
- Use this information (what the family wants and hopes for their child) to develop your next steps.

**Transition Discussions held on:** You may list multiple dates in this section. Transition discussions may happen over several months and during multiple meetings.

**Who participated in these discussions & what options were discussed?** List participants in meetings and list options discussed even if they are not pursued.

**Next Steps:**

**Who will do what?** This should not be limited to what providers will do, but can also include the things the family will do (e.g., attend meetings, go on tours, give pertinent information as needed.) This should directly correlate with what the family indicated were their wants and hopes for their child and family during this transition.

Be mindful of additional resources that may be available to families during this transition. These could include: Children and Youth with Special Health Care Needs Regional Centers, Public Health Departments, preschools, private/clinical therapy services, community programs, Family Resource Centers, Family Support Program or Long Term Supports, or other services available in your community during this transition.

**When:** Give a general indication in this section of the timeline for transition steps.

**If referring to the public school system:** You will notice a number of statements with check boxes which are designed to encourage discussions throughout a transition to a local school district. Please check and date when these steps are completed. Comment sections have been included in the last two check box sections to allow programs to document situations where a family might decline a transition planning meeting. The comment sections can also be used to document other discussions held with the family about these particular transition steps.

**Notes:** If this is a transition out of this program and into another one, seek parent consent to send a copy of the current IFSP to the receiving agency. This could happen by getting a signed release of information from the parents to send the IFSP to the receiving agency or by giving a copy to the parent(s).

See the *Wisconsin Early Childhood Collaborating Partners* website transition section: for current and ongoing information and resources about early childhood transitions: <http://www.collaboratingpartners.com/transition/index.htm>.

## Justification for Services Provided in Locations Other than Natural Environments Page

**PURPOSE:** To document services not provided in natural environments, and as well as plans for transitioning the provision of such services into a child's home and community environment. [HFS 90.11(5)(a)]

**PROCESS:** The last page of the IFSP document is titled Justification for Services Provided in Locations other than Natural Environments. Use this form when a service is not provided in a natural environment. This form has been included solely for the purpose of documenting services not provided in natural environments, as well as plans for transitioning the provision of such services into a child's home and community environment.

To fill out this form, list the services provided in settings other than natural environments, and explain why the team recommended this setting. Outline how outcomes will be met in this setting, as well as activities provided to include this outcome in the child's home and community environment. Please also identify the time frame for moving such services into the child's natural environment.

## How to Use the IFSP for Reviews

**Annual IFSP review meeting:** This is the time to evaluate and revise the entire IFSP. Written notice should be sent to all participants before the meeting date to ensure attendance. Participants at an annual IFSP review meeting should include, to the extent possible, those persons who were involved with the development of the IFSP or reviews, a person directly involved with the evaluation and assessment, and as appropriate, those providing services to the child or family. If a professional who was directly involved with the evaluation and assessment cannot be present, the service coordinator shall ensure their involvement through a conference call, having another knowledgeable representative attend the meeting, or making pertinent records available for the meeting. [HFS 90.10(7)]

**Periodic IFSP Review:** HFS 90 states that an IFSP review shall take place every 6 months or more frequently if warranted or if a parent requests it. The purpose of the review is to determine the progress being made towards achieving the planned outcomes and whether changes to outcomes or services are necessary. The review should be held with parents and the service coordinator and other family members or an advocate if requested by the parent. Service providers may be invited as well.

## Appendices

The following documents, available on the *Wisconsin Birth to 3 Training and Technical Assistance* website of the Waisman Center, includes additional information and resources referenced throughout this document ([www.waisman.wisc.edu/birthto3/](http://www.waisman.wisc.edu/birthto3/)). You are encouraged you to watch this site for new information and updates about the Wisconsin Birth to 3 Program, including the IFSP process.

**Wisconsin Birth to 3 Guiding Principles:** <http://b3icc.state.wi.us/GuidPrinc.pdf>

**Wisconsin Birth to 3 Program Flow Chart:**

<http://www.waisman.wisc.edu/birthto3/BIRTHTO3FLOWCHART-COLORDMM.PDF> or

<http://www.waisman.wisc.edu/birthto3/TXT/FLOWSTART.HTML> (accessible html version)

**Wisconsin Birth to 3 Program Eligibility Guidelines:**

<http://www.waisman.wisc.edu/birthto3/elig.html> (PDF and accessible html version)

**Identifying Family Strengths, Concerns, Priorities, and Resources:**

[http://www.waisman.wisc.edu/birthto3/FAMILY\\_CONCERNS.PDF](http://www.waisman.wisc.edu/birthto3/FAMILY_CONCERNS.PDF) or

[http://www.waisman.wisc.edu/birthto3/TXT/FAMILY\\_CONCERNS.HTML](http://www.waisman.wisc.edu/birthto3/TXT/FAMILY_CONCERNS.HTML) (accessible html version)

**Functional Intervention Planning - The Routines-Based Interview:** <http://www.fpg.unc.edu/~inclusion/RBI.pdf>

**Wisconsin Birth to 3 Program Interim IFSP Guidelines:**

<http://www.waisman.wisc.edu/birthto3/INTERIMIFSPGUIDE.HTML>

**Memo on Needed Medical and Other Services in the IFSP:** <http://www.waisman.wisc.edu/birthto3/0105memo.html>

**Guidelines for Major and Minor Changes at IFSP Team Meetings and Periodic Reviews**

<http://www.waisman.wisc.edu/birthto3/GUIDELINESFORCHANGE.HTML>



# Looking Ahead



# 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 upcoming 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 Options After Your Child Turns Three



In Wisconsin, Birth to 3 early intervention services end on a child's third birthday. This often means a move from one educational and support system to another. It is a new system in which you may encounter new people, new guidelines, and new philosophies of educational focus. These supports may or may not be associated with the public school system. Or they may be a combination of public school and community resources. However, before you get to a point of deciding upon an "option (s)" of support, there are important steps that can be taken to support your choice. This is called the **Transition Planning Process**. Transition planning is a process that allows you to look ahead and plan for your child's future, while embracing your family's and child's current strengths.

This section will discuss components of the Transition Planning Process and the main service options offered to support your child. There may be additional options within your community or outside of your community that are not mentioned here. It may also happen that your options of choice may not be discovered until the end of the transition planning process. Remember, each deaf or hard of hearing child and their family are unique. This individual focus should be your guiding focus as you determine the next steps in your family's and child's journey

## Transition Planning Process

Planning for your child's transition is a process. It is something that happens over time. It is important for you to learn about your child's natural learning style and what does and does not support their learning. Doing this will take you time, and that is OK. As your child develops, you will see different strengths arise as well as identify different challenges. The timing of when to start this process will vary from family to family. Some families will want to visit and learn about options well before their child turns 3, some may wish to wait until closer to their child's third birthday. The key point to remember is to provide yourself with enough time to learn about your child's development and to gain a strong understanding of various options that may be supportive to them. Your goal is to feel that, at the end of the process, you will be able to make an informed and educated decision regarding your child's transition.

The term "Transition Planning Process" will most often be related to a component of the Birth to 3 system and the IFSP. Yet, even if you are not involved with the Birth to 3 program, you will still want to follow some general guidelines to assist you with this process.

These include:

- » Starting Early: This will result in feeling like you have more control over the transition, as well as allow time to address unexpected situations that may arise.
- » Learning the Rules: It is helpful to learn the rules of the systems you may be entering; this will make it easier to navigate the system.
- » Being Open: Flexibility is important, especially as new information is learned.

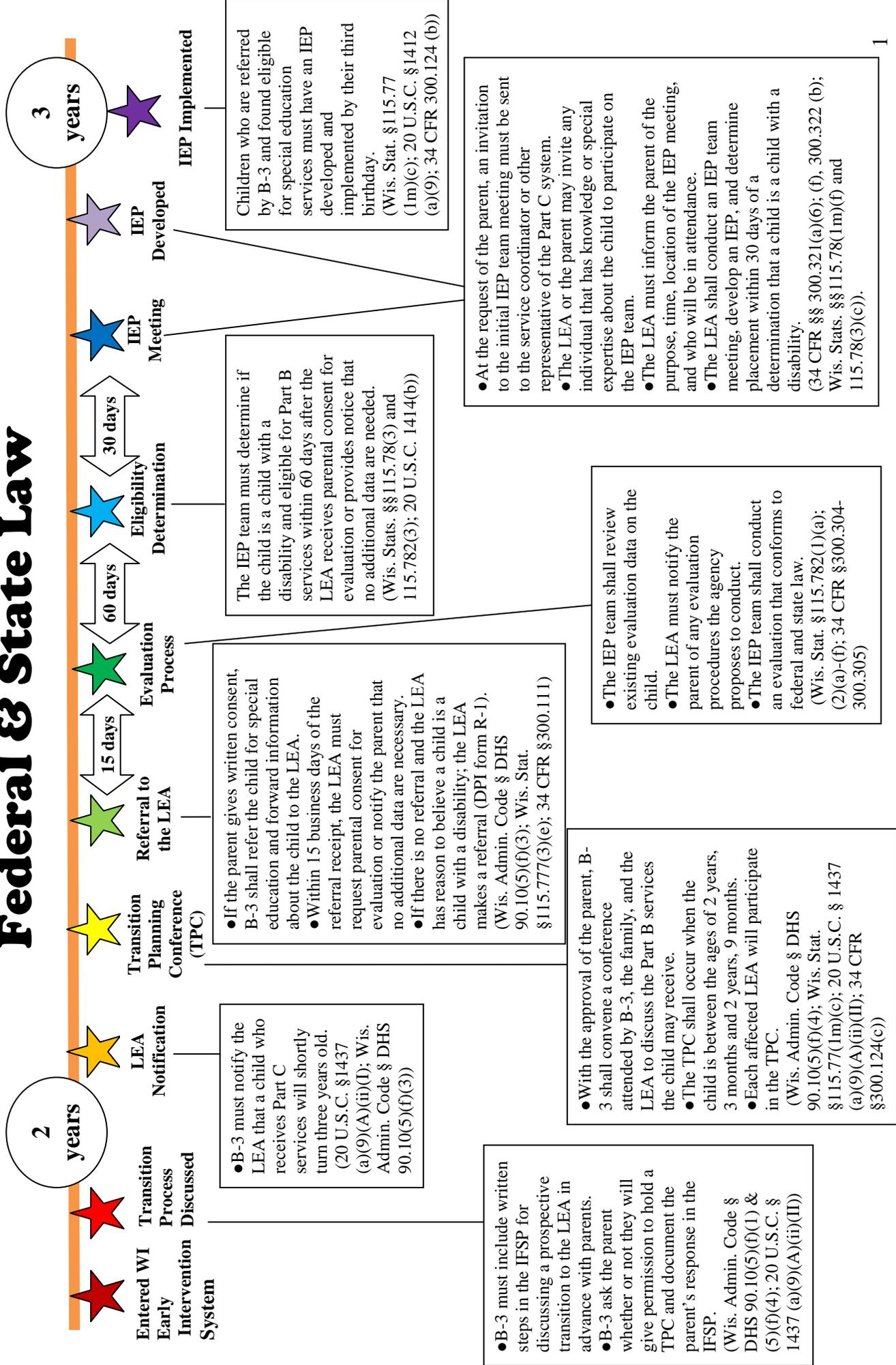
- » Establishing Priorities: Think about which points are negotiable and which are not. Reflect upon what is most important to you.
- » Communicating: Everyone has different priorities and values, do not assume that yours are known to others. This will allow others to understand what is best for your child.
- » Remembering No Transition is Permanent: You can and will make changes as you move forward. Evaluating your choices after they are made is important for your child's ongoing development. (Source: Making Transitions Work for You, Birth through 5 News, University of Connecticut Cooperative Extension System, Spring 2001, Volume 2., Number3)

If you are involved with the Birth to 3 program, a transition plan is part of your IFSP. This plan is reviewed at each IFSP update and can be discussed at anytime. The facilitation of the transition plan is guided by your service coordinator and is developed based on information you would like regarding any component of transition. It outlines the steps that will be taken to ensure a smooth and pleasant transition. This plan could include, but is not limited to:

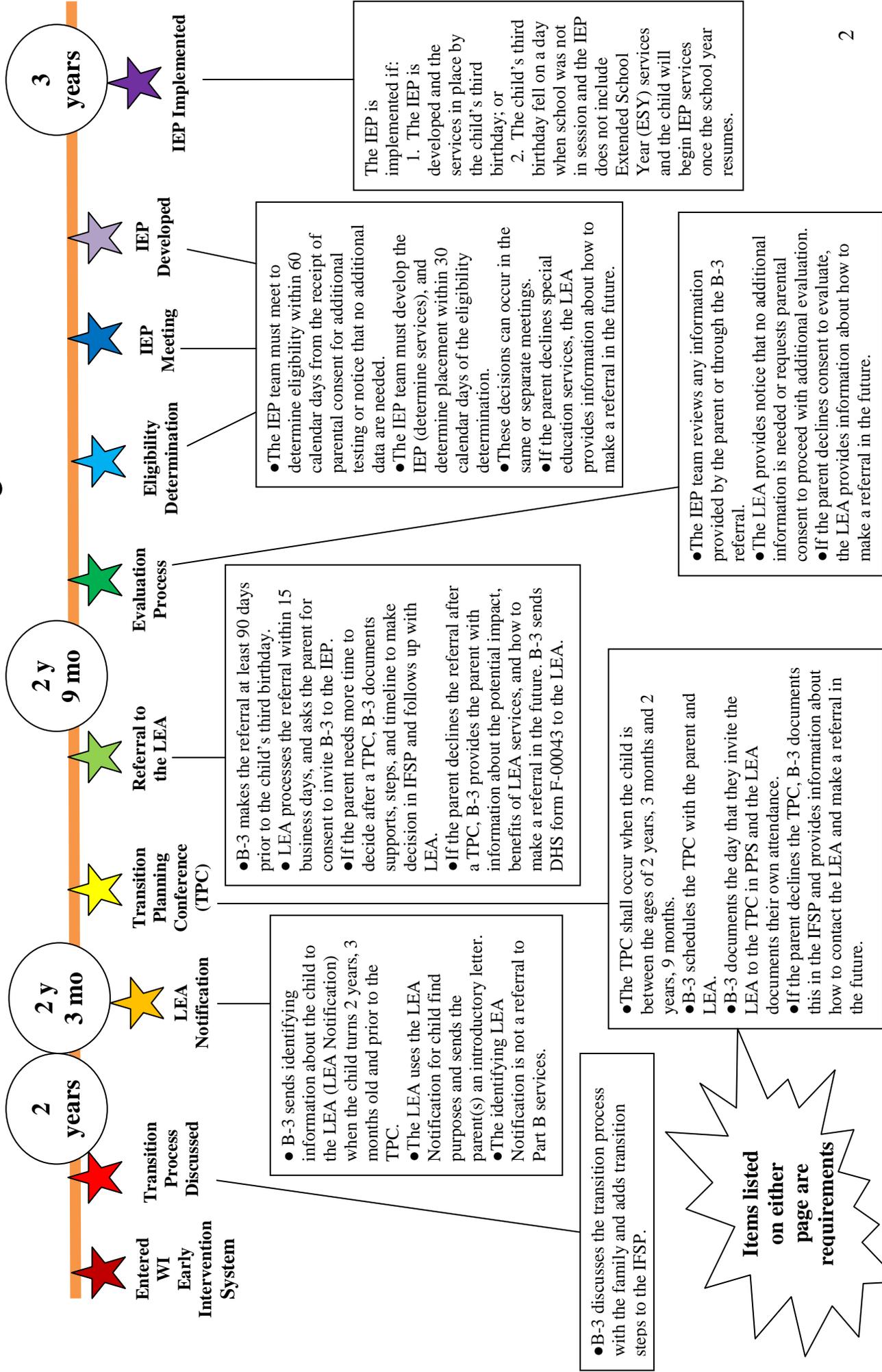
- » Learning about and locating different options for your child within your community, regionally, and state or nation wide.
- » Organizing informational meetings or visits to different programs or with service providers
- » Educating you on the transition process from Early Intervention to Early Childhood services
- » Sharing timelines regarding when specific components of transition should be completed to ensure a smooth transition from services
- » Connecting you with other families that have gone through transition and have explored different options.
- » Hosting a Transition Planning Conference: A time when you and your Birth to 3 team meet the receiving program(s) together to develop your child's transition plan.

Additional information about preparing for transitions, responsibilities of Birth to 3 and school programs, and transition timelines can be found in the enclosed booklet, "Step Ahead at Age 3," on pages 1-6. \*\*Note that IDEA 2004 has changed the 90 day timeline for the school to complete the referral process. Refer to the timeline chart on the following page.\*\*

# IDEA Part C to Part B Transition: Federal & State Law



# IDEA Part C to Part B Transition: Wisconsin Policy



## Service/Support Options

OK, so now you know the framework of transition planning, but what you really want to know is “What ARE my options?” Well, before that is answered, it is very important for you to remember that you do have options, not just an option, but options that can be supported to match your families and child’s needs.

### **Community Resources (Non-Public School Associated)**

Some families choose options of support that do not involve the public school system. When choosing these, families follow the guidelines of the chosen service provider when determining goals for their child. Examples of these options may include but are not limited to:

- » Continuing with or beginning to receive services through a family or public insurance plan.
- » Accessing private therapy through personal financial means.
- » Having your child attend a variety of community events (library, playgroups, children’s theaters, etc.).
- » Having your child attend a local preschool.
- » Having your child attend a private school.
- » A combination of the above options

### **Public School Options/ Special Education**

If choosing options that are connected with the Public School System, specific guidelines need to be followed based on the Individual with Disabilities Education Act, 2004 (IDEA part B) law. This is the same law that governs Birth to 3 (IDEA part C), however there are differences between parts B and C. In summary, when a child turns age three, they move from part C of IDEA (Birth to 3) in to part B of IDEA, 3- 21 years. Part C places the focus of support on a child’s family to help them embed intervention strategies into their daily family routines. Part B shifts the focus from the family to the child, exploring strategies to support a child’s ability to develop their academic and functional skills. The family is still considered a core component in identifying the goals for the child; however supports become more child focused.

Additional Information about transitions to special education services can be found in the enclosed booklet, *Step Ahead at Age 3*, pages 7-11.

## Special Education: The Individualized Education Plan (IEP) Process

The IEP process consists of several different steps: Referral, Screening/Evaluation; Determining Eligibility; IEP Development; Services Begin. A summary of what happens within these steps can be found in *Step Ahead at Age 3*, pages 11-15.

### **Eligibility Determination for Special Education Services for a Deaf/ Hard of Hearing Child:**

For a deaf or hard of hearing child to receive special education services from a public school, they need to meet the eligibility criteria for Hearing Impairment **and** show a need for special education services. There are three main areas that need to be discussed and reviewed to determine the eligibility and need for special education:

- » A current audiological evaluation by a licensed audiologist demonstrating a “significant impairment in hearing:” an impairment that impedes the student’s ability to listen with comprehension in a variety of quiet and noisy environments; with or without amplification.
- » Does the hearing loss “adversely affect a child’s educational performance”?
  - ✗ Academic performance: how does the hearing loss impact the child’s access to language compared to normal hearing peers?
  - ✗ Speech perception and/or production: how is the child perceiving speech used by adults and peers, how is the child using their speech in these environments?
  - ✗ Language and communication skills: How is the child accessing and using language and communication skills for educational, social and functional purposes?
- » Is there a need for special education?
  - ✗ Are there needs that cannot be met in a regular education classroom?
  - ✗ Are the modifications that can be made in the regular education classroom to the child to access the general education curriculum to meet the educational standards that apply to all students?
  - ✗ Are there additions or modifications that the child needs which are not provided through the general education curriculum?

It is important to remember that the above components need to be discussed among the IEP team. It is possible for a child to have a documented hearing loss and **NOT** show a need for special education services. A full copy of the Eligibility Criteria Guidelines can be found on the WI Department of Public Instruction’s website: [www.dpi.wi.gov/sped/pdf/dhhguide.pdf](http://www.dpi.wi.gov/sped/pdf/dhhguide.pdf)

If a child meets the eligibility criteria for special education services, an Individual Education Plan (IEP) is created with the family. This plan will be what guides the supports and services you receive from your local education agency (LEA). It will contain educational and functional goals for your child. It will identify possible supplementary aids, services, and supports for school staff that will be needed for your child to meet the goals of the plan. It is from this plan that service providers and preschool environmental options are discussed and decided.



# Eligibility Criteria for Children Who Are Deaf/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 team 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 an 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 three-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 three. 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 three 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 three-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 three 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.

## Preschool Options

In Wisconsin, Best Practices for Early Childhood focuses on a continuum of alternative placements, including integrated placement options, such as community-based settings with typically developing age peers. Settings may include but are not limited to:

- » Home
- » General Educational settings such as 4 or 5 year old Kindergarten, Preschools and Child Care Centers, and Head Start
- » Special Education Classroom
- » Part time General Education/ Part time Special Education
- » Residential Facility
- » Schools with specific programs/expertise
- » Any combination of the above

Although the concept of Preschool Options to educate a child with “non-disabled” peers is proactive in nature, it often creates confusion around options that are best for children who are deaf and hard of hearing. For some deaf and hard of hearing children, their best option is to be with peers who also are deaf or hard of hearing. What guides the decision of placement options is not that children will be with “non-disabled” peers, but what options will best support an individual child’s development as it relates to their educational plan. Thus it’s important to remember that one option does not fit all children who are deaf or hard of hearing. Nor should placement be limited to what the school district already has in place.

However, before arriving at the point of placement, families should consider several factors to support this decision-making process. Core to these factors are your child's strengths, learning and communication style, and specific goals you have for your child and how these can be met in specific environments. 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 preschool setting with services provided there.
- » Placement at Wisconsin School for the Deaf if a child needs a Bilingual-Bicultural approach to education.

These are just some of the placement options. Some placements may be 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. Thus it is important for you to begin the transition process early. This will allow time for your team to partner and explore options and combinations of services to meet your child's unique needs. Specific tools to help identify what your child's needs are in this section of the notebook.

## Possible Services and Providers

**Speech and Language Therapy:** 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:** 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. They can also support others in learning about basic care and maintenance of hearing technology.

**Educational Interpreting (sign or oral):** Although most young children who are deaf or hard of hearing that rely on a sign language or oral interpreting are not developmentally ready to use an interpreter in the true context of interpreting, they should be considered on a child's team. Interpreters can be viewed as a person who can facilitate the language development of a child and can support the progression of a child's future use of an interpreter in academic and social settings. These individuals can be used in a variety of ways to support children:

A sign language interpreter can:

- » 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.
- » Promote an expanded communication environment for the child by supporting other children and adults in using sign language to communicate with the child, fostering participation in group activities.
- » Be a member and resource on the child's educational team, including development and implementation of the IEP.
- » Provide information about how a child visually access information and how to ensure that information in a variety of environments is accessible to a child.

The use of an oral interpreter is not as common as a sign language interpreter. This person may be the sign language interpreter; however they will be using their skills in a different manner.

- » An oral interpreter usually helps to support a child's auditory and speech development by repeating key words or phrases that are spoken by others in the classroom. This person does not usually repeat everything that is being said, rather supports the child by filling in "gaps" of spoken information that the child may have missed.
- » They may use a combination of signs as well as spoken language to help a child understand concepts and ideas within their environments.
- » They can be a member on a child's educational team supporting the development and implementation of a child's IEP.
- » An oral interpreter may fade out of the child's team over time. Typical use of this service is to support a child's auditory development to the level of when a child can successfully use their auditory skills in an educational environment to access academic and social language.

It is important to remember that interpreters are not teachers. Although interpreters are trained in the use of signed language, they are not trained to teach language or academic concepts to young children. They are usually not trained to work with young children or families. If a child does not have a foundation in sign language, an interpreter can help support the development of sign language modeling and supporting experiences paired with sign language. This foundation is needed before a child can benefit from straight interpreting (continual signing of what a person is saying).

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. 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 communication continually happens through the use of the interpreter. Direct communication with peers and adults is an important component of a child's academic and social emotional development.

**Deaf or Hard of Hearing Individuals:** A 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.

## Peers

As children transition, it is important to explore environments that will provide age appropriate peers to be language and social emotional models. For children who are deaf or hard of hearing, there is not a “one-size” fits all. As noted throughout this section, gaining information about your child is important to help you know the kind of peers that will be good models for your child. For some children, the peers may be hearing and good spoken language models. For other children, peers may be deaf using only ASL to communicate. Still for others, it may be a combination of the two. A few things to consider when thinking about appropriate peers are:

- » Does my child have easy and direct communication with peers?
- » What are the language and academic level of the peers? Are they on par or a bit above my child's?
- » How are peers communicating in a non-verbal manner? Is there appropriate behaviors for communication (ex. Do they use aggressive means to communicate)?
- » What is the group size of peers? Does it allow for peers to learn from others while continuing learning from the “teacher”? Do peers engage in natural social activities to share ideas with each other?
- » Are the peers interactive with your child or new children? Would your child feel welcome in the group?

## Guiding Questions and Transition Tools: Deaf and Hard of Hearing

The following information will help provide you with an idea of some of the things specific to deaf or hard of hearing. These questions and tools can be used consistently across different environments. These will help you to “record” what you are learning throughout the transition process. These are only a few tools, there may be others that you and your team use or find that you like better. That's OK. The important thing is that you feel that you are gaining the information that you need as a parent to make future educational decisions for your child. Guiding questions include:

- » 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?
- » Are the staff members fluent in the child's first language (spoken or ASL)?

- » 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.

The following pages are reproduced with permission from the Colorado School for the Deaf and Blind (CSDB) and the Colorado Chapter of Hands & Voices. They are tools to help guide you as you begin to explore different options and environments for your child. They provide ideas of questions to ask teachers, supports within different environments (personnel and equipment), and considerations for peers. It is important to note that these forms are from **Colorado, not from Wisconsin**. Thus, some of the guidelines and components of these forms do not apply in Wisconsin. This is especially true of the Communication Plan. Wisconsin **does not** have a Communication Plan as part of their IEP paperwork, yet there are some guiding questions that you may find helpful when having discussions with your IEP team.

## Preschool/Kindergarten Placement Checklist for Children who are Deaf and Hard of Hearing

This checklist is intended to assist parents when considering preschool or kindergarten placement options for their deaf or hard of hearing child. The information should be obtained through observation and discussion with the current early intervention provider and the prospective teacher(s) and IEP team. Placement decisions should consider the child's communication, pre-academic, and social needs in the context of the proposed learning environment.

### Teacher Interview

Name of School: \_\_\_\_\_ Date of Observation: \_\_\_\_\_

Individual Interviewed: \_\_\_\_\_

Title: \_\_\_ Deaf Education Teacher check type: classroom itinerant consultative  
 \_\_\_ Preschool or Kindergarten Teacher \_\_\_ Special Education Teacher \_\_\_ Other

If not a deaf education teacher/specialist, describe previous experience with children who are deaf or hard of hearing: \_\_\_\_\_

Days program offered: \_\_\_\_\_ Hours per day: \_\_\_\_\_

Child's communication mode(s): \_\_\_\_\_ Mode(s) observed in classroom: \_\_\_\_\_

Total number of children in classroom: \_\_\_\_\_ Number of children with hearing loss: \_\_\_\_\_

Age span of children: \_\_\_ to \_\_\_ Child: adult ratio: \_\_\_\_\_

Average speaking/signing distance between teacher and child: \_\_\_\_\_ft

Number of children who are typical language models: \_\_\_\_\_

Amplification used or available: \_\_\_Personal FM \_\_\_Classroom FM/Infrared Other\_\_\_\_\_

Related and Support Services:

<u>Area</u>	<u>Available?</u>		<u>Has had training with D/HH?</u>		<u># of hours in classroom/week</u>
Speech-language therapy	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> No	_____
Educational audiology	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> No	_____
Occupational therapy/physical therapy	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> No	_____
Psychology	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> No	_____
Counseling by psychologist or social worker	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> No	_____
Other support services available:	___Deaf/Hard of Hearing Role Models				
___Parent counseling and training	___Parent Support Groups/Activities				
___Transportation	___After school programs				

Comments \_\_\_\_\_

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## Classroom Observation

<b>I. Classroom- Physical Environment</b>	YES	NO
1. Is the room size conducive to learning? (A large room/high ceiling can distort sound; a small room may be noisier.)	_____	_____
2. Is the room adequately lit? (Lighting and shadows may affect speechreading and signing abilities.)	_____	_____
3. Is the ambient noise level for the classroom within recommended standards (noise $\leq 35$ dbA and reverberation $\leq 6$ msec, ANSI S12.60.2002)?	_____	_____
4. Is the room treated to reduce noise (carpet on floor, acoustical ceiling tiles, window coverings, cork or other wall coverings)?	_____	_____
5. Are noise sources in the classroom minimized (e.g., fish tanks, ventilation/heater fans, computers)?	_____	_____
6. Does noise from adjacent spaces (hallways, outside the building) spill over into classroom?	_____	_____
Comments _____		

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<b>II. General Learning Environment</b>	YES	NO
7. Does teacher(s)/adult(s) use a variety of techniques to elicit positive behavior from children?	_____	_____
8. Are there a variety of centers (fine motor, art, manipulatives, science, music, dramatic play, sensory, literacy)?	_____	_____
9. Is there a schedule identifying daily routines?	_____	_____
10. Is there a behavior management system that provides clear structure for the class and consistent rules?	_____	_____
11. Does the curriculum standards-based including a variety of themes, topics, and children's literature?	_____	_____
12. Does the teacher use lesson plans to guide daily activities?	_____	_____
13. Are activities modified to meet a variety of children's needs?	_____	_____
Comments _____		

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<b>III. Instructional Style</b>	YES	NO
14. Classroom Discourse and Language		
a. Are the teacher(s) and other adults good language models for the children?	_____	_____
b. Is language consistently accessible to the child? (If sign is used, do all adults in the classroom consistently sign, including their communications with other adults?)	_____	_____
c. Are peer responses repeated?	_____	_____
d. Is vocabulary and language expanded by an adult?	_____	_____
15. Teacher's Speaking Skills		

- |  |                   |       |
|--|-------------------|-------|
| a. Is enunciation clear?   | _____             | _____ |
| b. Is rate appropriate?  | _____             | _____ |
| c. Is loudness appropriate?  | _____             | _____ |
| d. Is facial expression used to clarify the message?   | _____             | _____ |
| e. Are gestures used appropriately?  | _____             | _____ |
| f. Are teacher's (or other speaker's) lips available for speechreading?  | _____             | _____ |
| g. Is teacher's style animated?  | _____             | _____ |
| h. Is a buddy system available to provide additional assistance or clarification?  | _____             | _____ |
| <b>16. Use of Visual Information</b>   |                   |       |
| a. Are props or other visual materials used for stories and activities?  | _____             | _____ |
| b. Are appropriate attention-getting strategies utilized?  | _____             | _____ |
| c. Are fingerplays, action songs, and dramatic play used in circle time, story time, centers, etc.                             | _____             | _____ |
| <b>17. Small Group/Circle Time</b>   |                   |       |
| a. Are all children encouraged to share and participate?   | _____             | _____ |
| b. Does the teacher face children when speaking?   | _____             | _____ |
| c. Do the children face one another when speaking?   | _____             | _____ |
| d. Does the teacher lead group activities in an organized, but child-friendly manner?  | _____             | _____ |
| e. Is appropriate wait time utilized to encourage children to think and participate?   | _____             | _____ |
| f. Are children seated within the teacher's "arc of arms"?   | _____             | _____ |
| g. Does teacher obtain eye contact prior to and while speaking?  | _____             | _____ |
| h. Is the FM microphone passed around to all speakers?   | _____             | _____ |
| <b>18. Use of Sign</b>   | ___Not Applicable |       |
| a. Is sign consistently used by all adults in the class?   | _____             | _____ |
| b. Is sign consistently used by all children in the class?   | _____             | _____ |
| c. Does the type of sign used in the classroom match the signs used by this child?   | _____             | _____ |
| d. Is fingerspelling used?   | _____             | _____ |
| e. Are gestures used appropriately?  | _____             | _____ |
| f. Are there opportunities for parents and peers to learn to sign?   | _____             | _____ |
| <b>19. Opportunities for Hands-on Experience</b>   |                   |       |
| a. Are a variety of materials available?   | _____             | _____ |
| Check those used: ___books ___visual props ___audio tapes ___video tapes<br>___objects for dramatic play ___manipulatives      |                   |       |
| b. Are stories experienced in a variety of ways?   | _____             | _____ |
| c. Are there field trips?  | _____             | _____ |
| d. Are cooking experiences available?  | _____             | _____ |
| e. Are art and sensory activities activities conducted?  | _____             | _____ |
| <b>20. Amplification/Equipment</b>   | ___Not Applicable |       |
| a. Are personal amplification (hearing aids/cochlear implant) and assistive devices (FM, infrared) checked at school each day? | _____             | _____ |
| b. Is amplification used consistently in all learning environments?  | _____             | _____ |

Comments \_\_\_\_\_

## Reflection

<b>IV. Individual Child Considerations</b>	<b>YES</b>	<b>NO</b>
21. Language Considerations/Abilities Think about how your child communicates thoughts, ideas, and needs. Think about how your child communicates and interacts with other children. Will your child's communication needs be nurtured in this classroom environment? Does the child have sufficient language abilities to benefit from instruction in the classroom? Will this child develop English language competency in this environment	_____	_____
22. Social Interactions Think about how your child plays alone and in groups. Think about how your child interacts with other children. Will your child's social needs be nurtured in this classroom environment? Will this child be encouraged to develop self-advocacy skills?	_____	_____
23. Auditory Skills Does your child attend well? Is your child able to listen in noise? Think about what your child does when he/she cannot hear? Does your child take responsibility for his/her hearing aids? Will your child's auditory needs be supported in this classroom environment? In the lunchroom and other school environments? Is the staff qualified and able to support the child's auditory needs?	_____	_____
Comments _____ _____ _____ _____		

<b>V. School Culture</b>	<b>YES</b>	<b>NO</b>
24. Is there evidence that the school administration supports students with disabilities?	_____	_____
25. Is the school/district administrator knowledgeable about hearing loss?	_____	_____
26. Is the school committed to making the necessary accommodations for children with hearing loss?	_____	_____
27. Is the teacher open to consultation with other professionals or specialists?	_____	_____
28. Does the teacher provide opportunities for individualized attention?	_____	_____
29. Is the teacher welcoming of children with special needs?	_____	_____
30. Is the teacher willing to use amplification technology (hearing aids, FMs, cochlear implants)?	_____	_____
Comments _____ _____		



# THE IEP CHECKLIST:

## RECOMMENDED ACCOMMODATIONS AND MODIFICATIONS FOR STUDENTS WITH HEARING LOSS

Name: \_\_\_\_\_

Date: \_\_\_\_\_

### Amplification Options

- Personal hearing device (hearing aid, cochlear implant, tactile device).
- Personal FM system (hearing aid + FM).
- FM system/auditory trainer (without personal hearing aid).
- Walkman-style FM system.
- Sound-field FM system.

### Assistive Devices

- TDD.
- TV captioned.
- Other.

### Communication Accommodations

- Specialized seating arrangements:  
\_\_\_\_\_
- Obtain student's attention prior to speaking.
- Reduce auditory distractions (background noise).
- Reduce visual distractions.
- Enhance speechreading conditions (avoid hands in front of face, mustaches well-trimmed, no gum chewing).
- Present information in simple structured, sequential manner.
- Clearly enunciate speech. Allow extra time for processing information.
- Repeat or rephrase information when necessary.
- Frequently check for understanding.
- Educational interpreter (ASL, signed English, cued speech, oral).

### Physical Environment Accommodations

- Noise reduction (carpet & other sound absorption materials).
- Specialized lighting.
- Room design modifications.
- Flashing fire alarm.

### Instructional Accommodations

- Use of visual supplements (overheads, chalkboard, charts, vocabulary lists, lecture outlines).
- Captioning or scripts for television, videos, movies, filmstrips.
- Buddy system for notes, extra explanations/directions.
- Check for understanding of information.
- Down time / break from listening.
- Extra time to complete assignments.
- Step-by-step directions.
- Tutor.
- Note taker.

### Curricular Modifications

- Modify reading assignments (shorten length, adapt or eliminate phonics assignments).
- Modify written assignments (shorten length, adjust evaluation criteria).
- Pre-tutor vocabulary.
- Provide supplemental materials to reinforce concepts.
- Provide extra practice .
- Alternative curriculum.

### Evaluation Modifications

- Reduce quantity of tests.
- Use alternative tests.
- Provide reading assistance with tests.
- Allow extra time.
- Other modifications: \_\_\_\_\_

### Other Needs? Considerations.

- Supplemental instruction (speech, language, pragmatic skills, auditory, speechreading skills).
- Counseling.
- Sign language instruction.
- Vocational services.
- Family supports.
- Deaf/Hard of Hearing role models.
- Recreational/Social opportunities.
- Financial assistance.
- Transition services.

Source: Johnson, Benson, & Seaton. (1997). *Educational Audiology Handbook*. Appendix 11-A, p.448. Singular publishing Group, Inc.

Administrative Unit Name

Date

_____	_____	_____
Legal Name of Child/Student	Child/Student ID	DOB

## Communication Plan for Child/Student who is Deaf/Hard of Hearing

The IEP team has considered each area listed below, and has not denied instructional opportunity based on the amount of the child's/student's residual hearing, the ability of the parent(s) to communicate, nor the child's/student's experience with other communication modes.

1. The child's/student's primary communication mode is one or more of the following:  
*(check those that apply)*

Aural, oral, speech-based

English based manual or sign system

American Sign Language

Issues considered:

Action plan, if any:

2. The IEP team has considered the availability of deaf/hard of hearing adult role models and peer group of the child's/student's communication mode or language.

Issues considered:

Action plan, if any:

3. An explanation of all educational options provided by the administrative unit and available for the child/student has been provided.

Issues considered:

Action plan, if any:

4. Teachers, interpreters, and other specialists delivering the communication plan to the child/student must have demonstrated proficiency in, and be able to accommodate for, the child's/student's primary communication mode or language.

Issues considered:

Action plan, if any:

5. The communication-accessible academic instruction, school services, and extracurricular activities the child/student will receive have been identified.

Issues considered:

Action plan, if any:

**Must be reviewed at all IEP meetings for children/students with a hearing disability.**

## **COMMUNICATION PLAN for CHILD/STUDENT WHO IS DEAF/HARD OF HEARING (Form 7b, Page 1 of 1)**

1. The Plan must include a statement identifying the child's primary communication mode as one or more of the following: Aural, Oral, Speech-based, English Based Manual or Sign System, American Sign Language. The IEP team cannot deny instructional opportunity based on the amount of the child's residual hearing, the ability of the parent(s) to communicate, nor the child's experience with other communication modes [ECEA Section 4.02(4)(k)(I)].

When discussing these issues, the following questions may be helpful to clarify the child's needs: When considering the child's primary communication mode, is there just one? Does the child use a combination of modes? What mode do the parents use with their child? What mode does the child use to communicate with his/her friends?

2. The Plan must include a statement documenting that an explanation was given of all educational options provided by the school district and available to the child [ECEA Section 4.02(4)(k)(ii)].

When considering all educational options, are the options available in your school district? What about statewide options including the Colorado School for the Deaf & the Blind, the Magnet School for the Deaf in Denver and open enrollment in other schools or districts? Encourage the family to check out the **Colorado Program Directory for Students who are Deaf or Hard of Hearing** and the **Resource Guide** if they are interested in pursuing those kinds of options for their child. These resources will also prove helpful in locating peers and adult role models.

3. The Plan must include a statement documenting that the IEP team, in addressing the child's needs, considered the availability of Deaf and Hard of Hearing role models and a Deaf/Hard of Hearing peer group of the child's communication mode or language [ECEA 4.01 (4)(k)(iii)].

Because of the low incidence of a hearing disability, many students who are Deaf or Hard of Hearing find themselves without contact with other Deaf/Hard of Hearing children. Combine that with the fact that 95% of these children are born into families with normal hearing, and you have the potential for serious isolation. How about some time during the week to "chat" on-line with other Deaf/Hard of Hearing kids? Does the family know about the various regional activities, which occur during the year for Deaf/Hard of Hearing children? Explore all known opportunities.

4. The Plan must include a statement that the teachers, interpreters, and other specialists delivering the Communication Plan to the student must have demonstrated proficiency in, and be able to accommodate for, the child's primary communication mode or language [ECEA 4.02 (4)(k)(iv)].

Discuss the communication proficiency of the child/student's service providers and write a statement of the needs of the staff. Is training/in-service/mentoring a possibility? Is there an accommodation not being utilized? Review the IEP Checklist: Recommended Accommodations and Modifications that is available through CDE and addresses frequent accommodations used with children with a hearing loss.

5. The Plan must include a statement of the communication-accessible academic instruction, school services, and extracurricular activities that the student will receive [ECEA 4.02(4)(k)(v)].

These questions may help to clarify the student's needs: Is the student enjoying full access to academic instruction and services? To extra-curricular activities? The IEP checklist for Recommended Accommodations and Modifications (for students with a hearing loss) may be a useful resource for this discussion. Are TTY's, captioned television, interpreters for field trips, etc. being utilized?

# Final Thoughts



As noted in the beginning of this section, transition is a process. As with anything that is a process, there will be changes and modifications along the way. It is important for you to remember that these will happen. They are inevitable. One main change that often times is forgotten as that, while you as the parent are planning for transition, your child is continually growing and changing. Thus, what you may have thought is as a wonderful “match” for your child, may no longer be the best fit. That’s OK. Just because you choose one path for your family and child, does not mean that you must continue along that path. You can re-explore options that may be a better match. Remember, no decision about options or placement is ever final.

## **Additional Resources:**

### **Birth to 3**

- » Wisconsin Birth to 3 Program: Birth to 3 Publications [dhs.wisconsin.gov/bdds/birthto3/index.htm](https://dhs.wisconsin.gov/bdds/birthto3/index.htm)
- » Wisconsin Birth to 3 Training and Technical Assistance: Family Resources: Transitions [www.waisman.wisc.edu:8000/birthto3/](http://www.waisman.wisc.edu:8000/birthto3/)

### **Early Childhood: Department of Public Instruction**

- » Wisconsin Statewide Parent-Educator Initiative: Information Especially for Parents [www.dpi.wi.gov/sped/hmparents.html](http://www.dpi.wi.gov/sped/hmparents.html)
- » Services for the Deaf and Hard of Hearing [www.dpi.wi.gov/sped/hi\\_deaf.html](http://www.dpi.wi.gov/sped/hi_deaf.html)
- » Early Childhood Special Education [www.dpi.wi.gov/ec/ecspedhm.html](http://www.dpi.wi.gov/ec/ecspedhm.html)
- » Wisconsin Model Early Learning Standards [www.collaboratingpartners.com/EarlyLS\\_docs.htm](http://www.collaboratingpartners.com/EarlyLS_docs.htm)

### **Transitions: Collaborating Partners**

- » Early Education Transitions [www.collaboratingpartners.com/transition/index.htm](http://www.collaboratingpartners.com/transition/index.htm)

# 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 literature. Much of this terminology is also used in this notebook. This glossary contains many of the unfamiliar words that you may encounter.

**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 culturally 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 (e.g. 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/Dyssynchrony:**

A type of hearing loss in which the hair cells function normally, but the sound becomes unorganized as it is carried to the brain by the auditory nerve. Persons with AN/AD frequently have an absent ABR, but present OAEs.

**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.

**BAHA (Bone-Anchored Hearing Aid):**

A surgically implantable system for treatment of hearing loss that works through direct bone conduction. The system works by enhancing natural bone transmission as a pathway for sound to travel to the inner ear, bypassing the external auditory canal and middle ear.

**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 and 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. BOA is typically part of a set of tests done when hearing loss is suspected (see Auditory Brainstem Response, Visual Reinforcement Audiometry). BOA is an important part of the diagnostic test battery, especially if there are concerns about AN/AD. Since AN/AD kids do not all have the same responses to sound, BOA is very important to verify ABR results.

**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. Hearing loss alone may qualify as an eligible condition.

**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.

**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. It is a visual representation of English.

**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 (Otolaryngologist):**

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.

**Hereditary Hearing Loss:**

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. Others who have knowledge or expertise about the child or the 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: 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. Using the visual components of communication to aid understanding. Visual cues may include lip movements, facial expressions, and postures.

**Localization:**

The ability to determine the location 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 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 ear canal or outer parts of the ear.

**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 in response to sound 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:**

Hearing loss that happens 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. Typically for children who have frequent ear infections or middle ear fluid.

**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 who are deaf or hard of hearing. 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 persons who are deaf or hard of hearing 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 responsible for maintaining balance, posture, and the body's orientation in space. 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.



Dear Parents,

Every expectant parent plans on a healthy, typically-developing child and begins building hopes, expectations, and dreams for their new baby. These dreams can be altered when a child is diagnosed with a hearing loss. 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 to his or her fullest potential.

We understand the dedication, time commitments, and variety of feelings that may come with this responsibility. The **Babies and Hearing Loss Interactive 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. The Wisconsin Sound Beginnings organization initiated and produced the first copy of the **Babies and Hearing Loss Notebook**, and now the Wisconsin Educational Services Program for the Deaf and Hard of Hearing (WESP-DHH) has taken this important project under their wing. We hope 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. New dreams are possible!

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 Educational Services Program for the Deaf and Hard of Hearing (WESP-DHH) Outreach.

Best Wishes,

Marcy Dicker  
Program Director  
WESP-DHH Outreach

Elizabeth Seeliger  
Program Director  
Wisconsin Sound Beginnings

# 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:

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» 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:

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» 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:

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» 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:

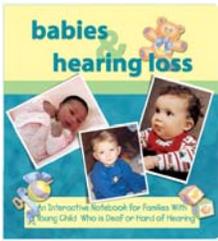
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» Please rate the sections of this notebook for their usefulness.  
(1 = most useful. 6 = least useful.)

- |                              |                                   |
|------------------------------|-----------------------------------|
| _____ 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 Interactive Notebook** please include them on a separate sheet of paper. We are very interested in your feedback!



# PARENT NOTEBOOK ORDER FORM

Available in a binder or saved on a CD

\* The Parent Notebook is available in Electronic Format on the WESP-DHH Outreach website: [http://www.wesp-dhh.wi.gov/cms\\_files/resources/Babies\\_and\\_Hearing\\_Loss\\_10-11.pdf](http://www.wesp-dhh.wi.gov/cms_files/resources/Babies_and_Hearing_Loss_10-11.pdf)

Name: \_\_\_\_\_

Shipping Address: \_\_\_\_\_  
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Number of Notebooks requesting: \_\_\_\_\_  
 Number of CD's you are requesting: \_\_\_\_\_



How did you learn about us?

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Would you like to join our mailing list?  Yes  No  
If so (please check one)

- Please send me WESP-DHH Outreach mailings through the mail.
- Please send me WESP-DHH Outreach mailings via email.

Email Address: \_\_\_\_\_

Role (check all that apply)

- |  |  |
|--|--|
| <input type="checkbox"/> Teacher of the Deaf/Hard of Hearing | <input type="checkbox"/> Educational Interpreter     |
| <input type="checkbox"/> Educational Audiologist             | <input type="checkbox"/> Speech/Language Pathologist |
| <input type="checkbox"/> Administrator                       | <input type="checkbox"/> Parent                      |
| <input type="checkbox"/> Other                               |  |

Comments:

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Please send form to:

Karen Waite  
WESP-DHH  
N25 W23131 Paul Road, Suite 100  
Pewaukee, WI 53072  
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**babies  
&  
hearing loss**

