

#### For Families of Children Who Are Deaf / Hard of Hearing In Tennessee

"The need and right to communicate is the most fundamental of human rights. To deny it is to harm the human spirit; to foster communication is to reveal all the possibilities of life." (National Deaf Education Project)

#### "What works for your child is what makes the choice right"

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Editor's Note: The authors of this guide do not officially endorse or certify any of the resources/service providers listed in this publication. It is the reader's responsibility to check the validity and references of anyone listed in this guide. To report edits or request additions to the Guide, please contact resourcecomittee@tnhandsandvoices. org

Electroic version is available online at www.tnhandsandvoices.org

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# INTRODUCTION

This Resource Guide may be in your hands at this moment for several reasons. Most likely, you are a parent of a child that is newly identified with a hearing loss. You may feel lost, scared, angry, and unsure of the future and many other countless emotions. This is all normal. We are here to help. Take a deep breath and join the journey with us. The road you are traveling is not easy but we promise you are not alone. Take a moment and read "Welcome to Holland".

#### WELCOME TO HOLLAND

Emily Perl Kingsley (1987)

*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.* 

This Resource Guide is for you! Whether you're a parent who has just discovered your child has a hearing loss, or you're a teacher, a school administrator, an audiologist, or someone else related to the community of deaf and hard of hearing individuals, this booklet is for you.

Please use it to:

- Connect families of children who are deaf or hard of hearing to each other for support.
- Explore choices for communication options that are presented in an unbiased way.
- Find out about services and supports available to families and professionals.
- Get information on resources for financial assistance.
- Learn about the rights of individuals who are deaf or hard of hearing and how to advocate for them.
- Discover community support systems, resources and programs.

As you look over this packet, you may come up with questions and ideas you haven't considered before as you play your role in enhancing the quality of life for a child with deafness or hearing loss.

**Remember**—the options and decisions facing any family are theirs alone to make, with information and support from professionals. There is no one "right" way when it comes to finding the program that will empower a child to succeed. His or her needs, as well as the needs of the family, will change with time. It is very important to see this all as a work in progress. Don't be afraid to remain open to new ideas, and even change your approach if necessary. And remember, research clearly shows that a communication choice should not be solely based on the degree of hearing loss. For families of babies newly identified with hearing loss, some important first steps are follow up care, under- standing communication/early intervention choices, and connecting to other families like yours for information and support. The Roadmap for Families, Loss and Found video, and Book of Choice are other great starting out resources outlining important first steps.

**Loss and Found:** a video explaining what to do if your baby didn't pass the newborn hearing screening; *http://handsandvoices.org/resources/video/index.htm* 

**The Book of Choice:** parents of children who are deaf or hard of hearing sharing stories and information; *http://handsandvoices.org/resources/products.htm#boc* 

We encourage you to contact Tennessee Hands & Voices, a non-profit, parentdriven, non-biased support system for families of deaf and hard of hearing children. You're not alone, and we can help.

#### **GETTING STARTED**

#### "YOUR CHILD HAS A HEARING LOSS"

Even though you may have suspected there was a problem, hearing a doctor or audiologist say "Your child has a hearing loss", may have come as a shock to you. Most people do not know much about hearing loss and what it means for their child and family. As the professional who delivered this news to you talked further, you may not have heard much of what he or she was saying. In your mind, questions may have started to churn:

"Can it be corrected?" "What caused it?" "Will it get better?" "Will it get worse?" "Can my child learn to talk?" "Can my child go to regular school?" "If we have more children, will they be deaf, too?" "What does the future hold for my baby?" "Will he get married?", "Will she be able to get a job?"

The answers to some of these questions may not be what you want to hear; "No, this type of hearing loss cannot be medically or surgically corrected." Or "We don't know for sure what your child's future holds - it depends on a lot of factors." You want the best for your child, but now you are not sure how to move forward.

In the days and weeks following the diagnosis of your child's hearing loss, you may feel like you are on a roller coaster. Your feelings may swing from despair to hope, from sadness to anger, from feeling incompetent to feeling confident. As you carry out your daily routines—finishing a chore or arriving at a destination - you may realize that your mind was somewhere else, thinking about your child and what you should do. You may also find within yourself unexpected sources of strength to do what has to be done in spite of feeling that you are living under a cloud.

The professionals who evaluate your child's hearing will have recommendations for you: see an ear specialist, meet with early intervention professionals, and have more testing done. As you follow these recommendations, you will meet people who can helpansweryourquestions and explain the decisions you must make. The information they give you and opinions they express may also create more confusion for you!

You will be making many decisions in the days ahead. Give yourself the time you need to make decisions that feel right for your family. Keep in mind there are very few decisions you will make that you cannot change.

#### WHO CAN HELP?

You will meet new people as a result of your child's hearing loss. Some of these people will be medical professionals, some will be parents and caregivers of other children with hearing loss, some will be educators, and some will be audiologists. Here is a brief description of ways in which each of these groups may be of help to you.

# AUDIOLOGIST

#### The audiologist can help by:

- 1. Having the appropriate equipment and the skills to test the hearing of infants and toddlers.
- 2. Obtaining complete information about your child's hearing in each ear at a range of frequencies.
- 3. Carrying out, or referring infants or difficult-to-test children for, Otoacoustic Emissions (OAE) tests and Auditory Brainstem Response (ABR) testing, when necessary.
- 4. Recommending appropriate amplification if chosen by the family.
- 5. Keeping your child equipped with well-fitting ear molds.
- 6. Testing your child while wearing amplification and questioning parents about their child's responses to sounds at home.
- 7. Giving you information about early intervention programs available to your family.
- 8. Working in partnership with you and early intervention specialists to monitor and maintain your child's amplification systems (Hearing aids,FM systems, cochlear implants).
- 9. Helping your child learn to use amplification.
- 10. Helping to make sure amplification is working properly, and teaching you how to make sure equipment is working properly
- 11. Teaching you how to trouble shoot problems.
- 12. Keeping records of your child's progress in acquisition of listening skills.

## TENNESSEE'S EARLY INTERVENTON SYSTEM (TEIS)

#### The TEIS can help by:

- 1. Initial in-home visit at which time communication options are discussed and demonstrated and programs specific to the needs of deaf and hard-ofhearing children in the community are explained.
- 2. Emotional support is offered.
- 3. Assistance in securing funding for intervention services and hearing aids.
- 4. Connections to other resources within the community.
- 5. Service Coordination.
- 6. Printed materials and video-tapes are shared with families.
- 7. Representation at IFSP meetings and IEP meetings.
- 8. Consultation with school districts around transition issues.
- 9. Connection to the state-wide parent support group, Tennessee Families for Hands & Voices.

## PEDIATRICIAN OR PRIMARY CARE PHYSICIAN (PCP)

Your child's primary care physician can help by:

- 1. Referring you to an Audiologist skilled in testing the hearing of infants, toddlers & children when you express concern about your child's hearing.
- 2. Referrals to other specialists as needed(E.N.T., Genetics Counseling etc)
- 3. Answering your questions about medical or surgical treatment of different types of hearing loss.

- 4. Confirming the need for prompt action involving amplification and early intervention once your child has been diagnosed with hearing loss.
- 5. Putting you in touch with early intervention programs.
- 6. Treating your child or referring to ear specialists -when your child has middle ear disease that increases his/her degree of hearing loss.
- Keep in mind, many Primary Care Physicians have never come into contact with children who are deaf or hard of hearing and may not issues directly related to your is recommended that you see a Pediatric ENT or Audiologist.

#### OTOLOGIST, OTOLARYNGOLOGIST (ENT)

#### *The ENT can help by:*

- 1. Confirming that there is not a medically treatable condition in your child's outer ear or middle ear that is causing the hearing loss.
- 2. Answering your questions about medical or surgicaltreatment of different types of hearing loss.
- 3. Scheduling further procedures (i.e. urinalysis, CT scan) to rule out other causes of the hearing loss.
- 4. Signing a form authorizing use of hearing aids with your child (required by law in some states before hearing aids can be fit on a child).
- 5. Placing ventilation, or PE, tubes in your child's eardrums if he has chronic middle ear disease that is not resolved by antibiotics in a timely way.

#### OTHER PARENTS OF DEAF OR HARD OF HEARING CHILDREN

\* Parents Need Parents!

#### Other parents can help by:

- 1. Sharing experiences they have had with professionals and early intervention programs.
- 2. Telling you about people and information sources they have found useful.
- 3. Listening, understanding and affirming your feelings regarding your child's hearing loss. They have been there too!
- 4. Sharing with you their feelings related to parenting a child with hearing loss and how their feelings have changed over time.
- 5. Sharing their child's achievements with you.
- 6. Early Interventionist (EI)

EI Role for the Deaf / HOH Rationale: Time is of the essence because a child's brain is programmed to learn language during the first 6 years of life—the first 3 years being the most critical. After this period, it is very difficult to acquire language and speech skills. (A.G. Bell)

#### What EI for the Deaf/HOH do:

- The early interventionist provides support for parents, and teaching parents how to stimulate speech and language in their child. (AGBELL
- Support parent-infant relationship (PAVII Paper: The Art of Home Visiting

- Listen to parental concerns and observations (PAVII)
- Respect family values (PAVII)
- Support parents in their role as advocates for their child (PAVII)
- Serve as an advocate for the infant and parent (PAVII)
- Assess the infant's development (PAVII)
- Offer specific suggestions and activities for promoting the infant's developmental well being (PAVII)
- Provide information about community resources (PAVII)
- Provide family with information about legal rights (PAVII)
- Respect the family's right to privacy & confidentiality (PAVII
- Coordinate programming with other service providers and be a supportive team member (PAVII)
- Act as a liaison with the medical community and assist with interpretation of medical information (as able) with the family (PAVII)
- Competencies Required of the EI for the Deaf/HOH (all from PAVII Paper: The Art of Home Visiting)
- Understanding of infant development and the impact of specific disability conditions on developmental rate, sequences, and allenges unique to that disability
- Knowledge of strategies which facilitate development, prevents secondary disability conditions, and supports the caregiver/family-infant relationships.
- Knowledge of counseling techniques, family systems theory, and state-of-the-art practices in working with families.
- Ability to be flexible, to be sensitive and respecting of difference of values and culture, to be a positive communicator and a good listener.

## DEAF AND HARD OF HEARING ADULTS

Most deaf and hard of hearing children are born to hearing parents who have never actually met a Deaf or Hard of Hearing adult. Many parents wonder what the future holds for their child. Meeting & getting to know successful Deaf and Hard of Hearing Adults can alleviate much of the unnecessary anxiety regarding your child's future. TN Hands & Voices can help facilitate the introduction of Deaf and Hard of Hearing Adults through its collaborations and hosting of family events.

#### Deaf and hard of hearing adults can help by:

- 1. Sharing personal experiences and information by a D/HH individual.
- 2. Sharing educational, social, and cultural experiences and perspectives.
- 3. Modeling different means of communication.
- 4. Acting as a role model for the parents and D/HH child.
- 5. Bringing hope to families about overcoming challenges and

creating success.

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#### Stages of Grief:

Accepting that your child has a hearing loss

As a parent of a deaf or hard of hearing child, the grief process is real and can recycle periodically through the child's life. There are several theories on the stages of grief. Summarized below is one accepted process that parents may experience with a child with a hearing loss.

- Denial Parent does not accept that the child truly has a hearing loss
- Anxiety Parent worries about the child's future and how their child will function in society
- **Depression** Parents ask questions. "Why did this happen? Why me? Why my child? "
- Anger Parents may say "this is not fair", "we do not deserve this"
- **Guilt** Parents may think it is all their fault that their child has a hearing loss
- Acceptance Parents education themselves about hearing loss and become an advocate for their child.
- They realize that their child can be successful in a mainly hearing world.

**Note:** While most parents will go through a grieving process, everyone's experience is different, and some may not grieve at all. Getting through the journey and arriving at the point of acceptance and then advocacy will be helpful in the success of your child. The destination is the same, but we all may travel a slightly different road to get there.

# **GET CONNECTED!**

Other Parents of Deaf and Hard of Hearing children are most beneficial in helping to work through this process.

TN Hands & Voices Parent Consultants can speak to you directly, as they are all parents of Deaf & H/H children themselves, or they can put you in contact with another parent who has gone through a similar experience with their own child. We are here for you!

Jenny Williams West TN Regional Parent Consultant 1-800-840-2410 – jenny@tnhandsandvoices.org

Tonya Bowman Middle TN Regional Parent Consultant 1-800-840-2410 – tonya@tnhandsandvoices.org

Camille Keck East Regional Parent Consultant 1-800-840-2410 – camille@tnhandsandvoices.org

#### **COMMUNICATION CHOICES**

Communicating with your child is of the utmost importance! Two-way communication, responding to your child and encouraging your child to respond to you, is the key to your child's language development. There are different ways to communicate and different philosophies about communication. As you think about how your family communicates now with your child and how you would like to communicate with him or her in the future, you are thinking about the communication methodology/mode issue. The best way to decide which approach to communication will be best for your child and family is to be open about all the modes, learn, ask questions, talk to adults who are Deaf and Hard of Hearing and other families with children who have a hearing loss, as well as professionals. Discuss, read, and obtain as much information you can about the various methods. While some parents select a spoken language approach, others will select one of the visual (sign) options. Because the various communication options differ significantly, it's essential that parents be fully informed about each of the options so that they can choose the best fit for their family.

### FACTORS TO CONSIDER

Consider and answer the following questions when choosing a communication mode:

- 1. Will the communication mode enable all your family to communicate with your child?
- 2. Is a given option a good match for my child and our family?
- 3. Do you feel comfortable with the amount of information you have received about all the modes/methods of communication? Have you talked to a variety of people and heard a variety of perspectives on each choice?
- 4. Is the communication mode in the best interest of your child? Does it allow your child to have influence over his/her environment, discuss his/ her feelings and concerns, and participate in the world of imagination and abstract thought?
- 5. Does the communication enhance your relationships with each other as a family? It should promote enjoyable, meaningful communication among all family members and enable your child to feel part of your family and know the happenings of everyday life.
- 6. Has the information you have received about communication choices delivered to you in an unbiased manner?
- 7. Are you looking at your choice of communication in terms of what will be best for your child and family, and not what someone has promised you about a certain method?
- 8. Does my child have any additional disabilities that need to be considered as we choose a various communication options?
- 9. What kind of school/academic experience do I want for my child?
- 10. How important is it that my child be educated in a typical classroom or with other children who have hearing loss?
- 11. What are the long-term goals for our family and child?

#### Thoughts from parents of older children:

- 1. You may find that children may shift in communication modes as they grow and develop their own communication preferences.
- 2. Children may also shift quickly in response to changing environments
- 3. You may find you are considering and/or using a variety of choices as time goes on.

When seeking professional support, know that professionals in both the fields of medicine and education specialize in hearing and deafness. Their expertise and perspectives may vary, which can create confusion for parents trying to make the choice that is right for their child. Some professionals are willing to be interviewed by phone or e-mail prior to an appointment when parents are considering using their services. Consider the following questions:

- 1. Do you have a particular communication or educational philosophy in regard to children with hearing loss?
- 2. What experience do you have working with children with a similar background and degree of hearing loss as my child?
- 3. Which communication options have been used with the children with whom you work?

## **COMMUNICATION CHOICES - DEFINITIONS**

#### AMERICAN SIGN LANGUAGE (ASL)

American Sign Language (ASL) is a fully developed, autonomous, natural language with distinct grammar, syntax, and art forms. Sign language can perform the same range of functions as a spoken language. "Listeners" use their eyes instead of their ears to process linguistic information. "Speakers" use their hands, arms, eyes, face, head, and body. These movements and shapes function as the "word" and "intonation" of the language. If parents are not deaf, intensive ASL training is necessary in order for the family to become proficient in the language.

#### AUDITORY-ORAL (AO)

This method of teaching spoken language stresses the use of amplified residual hearing, speech and oral language development. Additionally, it allows for emphasis on speech reading and visual clues from the face or body. Tactile methods may also be used to encourage the child to feel the sounds of speech. Parents need to be highly involved with child's teacher and/or therapists to carry over training activities to the home and create an optimal "oral "learning environment.

#### AUDITORY-VERBAL (AV)

This approach to teaching spoken communication concentrates on the development of listening (auditory) and speaking (verbal) skills. It emphasizes teaching the child to use his or her amplified residual hearing and audition from amplification (hearing aids and/or cochlear implants) to the fullest extent possible. A high degree of parent involvement is necessary as parents learn methods to integrate listening and language throughout daily routines.

#### CUED SPEECH

This system is designed to clarify lip reading by using simple hand movements (cues) around the face to indicate the exact pronunciation of any spoken word. Since many spoken words look exactly alike on the mouth (e.g. pan, man), cues allow the child to see the difference between them. Cued speech can be learned through classes taught by trained teachers or therapists. A significant amount of time must be spent using and practicing cues to become proficient.

#### SIMULTANEOUS COMMUNICATION

Simultaneous communication occurs when a person uses sign language and spoken English at the same time. The signs used may be an exact match to the spoken message (Signed Exact English). Or, a person may sign some, but not all, of the words in the spoken message (Pidgin Signed English). The words that are signed and the words that are spoken occur simultaneously. Parents must consistently sign while they speak to their child. Sign language courses are routinely offered through the community, local colleges, adult education etc.

#### TOTAL COMMUNICATION (TC):

The term Total Communication was first defined as a philosophy, which included use of all modes of communication (i.e. Speech, sign language, auditory training, speech reading and finger spelling). Today the term Total Communication is commonly interpreted as Simultaneous Communication (signing while talking). This philosophy led to the formation of manual systems (e.g. Signing Exact English - Signed English) that attempt to represent spoken English.

#### Strongly recommended resources include:

#### Choices in Deafness: A Parent's Guide

A collection of family stories about their deaf child and the communication method they use. Edited by Sue Schwartz, Ph.D. Woodbine House, 2006

**The Book of Choice: Support for Parenting a Child Who Is Deaf or Hard of Hearing.** Parents of Deaf & Hard of Hearing children may request a free copy by contacting: Family Voices of TN – 615-383-9442 ext 13 In-state toll-free number for families - 1-888-643-7811 Fax: 615-383-1176 Email: familyvoices@tndisability.org

#### **Beginnings DVD:**

http://ncbegin.org http://doug.stringham.net/uvuasl/3310/ch7\_langcontinuum.pdf

# **HEARING LOSS QUESTIONS**

#### COMMON QUESTIONS TO ASK MY AUDIOLOGIST and/or ENT PHYSICIAN?

- 1. Is my child's hearing loss permanent?
- 2. How often should my child's hearing be tested?
- 3. Will my child's hearing loss get worse?
- 4. Do both ears have the same amount of hearing loss?
- 5. How will the hearing loss affect my child's speech and language development?
- 6. What could be the cause of the hearing loss?
- 7. What type of testing can we do to determine the cause of the hearing loss?
- 8. What is the best device for my child? Hearing aids, cochlear implants, Baha?
- 9. How much do hearing aids cost? Will my insurance or other agency help to cover costs?
- 10. How much will my child's hearing be improved with hearing aids?
- 11. How many years will hearing aids last?
- 12. How often do we need to replace the ear molds?
- 13. Do you have another parent of a child with hearing loss that I can talk to?
- 14. How often will we need communication therapy?

#### FACTS REGARDING HEARING LOSS

- 1. Hearing loss is the most common congenital disorder.
- 2. 3/1000 newborns having some degree of loss.
- 3. 1 in 1000 infants is born with profound hearing loss.
- 4. 2. 2-3 in 1000 infants are born with partial hearing loss.
- 5. Some will develop hearing loss after birth
- 6. 90% of infants with hearing loss are born to hearing parents.
- 7. 30 40% of children with hearing loss have at least one additional handicapping condition.

#### **TYPES OF HEARING LOSS**

#### 1. Sensorineural (SNHL):

- affects inner ear to include the cochlea and VIII nerve
- typically cannot be treated medically or surgically

#### 2. Conductive (CHL)

- affects the middle or outer ear
- can be temporary or permanent
- surgery may improve hearing in some cases
- 3. Auditory Neuropathy/Auditory Dys-synchrony (AN/AD)
  - affects the inner ear to include the cochlea and VIII nerve
- 4. Mixed
  - typically a combination of SNHL and CHL

# THE EAR

#### What is An audiogram?

- 1. The audiogram is a graph or picture that shows how the child hears.
- 2. This audiogram (Audiogram of Familiar Sounds) is typically used for counseling. It shows where various sounds are in relation to pitch and loudness. of
- 3. The audiogram can show the type and degree of hearing loss.
- 4. The child's responses are plotted based on pitch (frequency/Hz) and loudness (intensity/dB)

Bass Notes Treble Notes www.audiology.org (AAA)

- 5. The numbers across the top are from 250-8000 Hz which represents frequencies (pitch) of sound. Think of them like the keys on a piano ranging from bass notes to treble notes. The X is marked in BLUE on the audiogram and represents the LEFT EAR. The O is marked in RED and represents the RIGHT ear.
- 6. Each X and O is marked at the corresponding frequency and intensity where the child responds to create a "graph of the child's hearing".

#### DESCRIPTION OF DEGREE OF HEARING LOSS VS. POTENTIAL EFFECTS

Every child is different. The potential affects of a hearing loss depends on many factors including degree of loss, but also upon early identification and amplification, early intervention services, and parent involvement.

**MILD 20-40 dB HL** May have difficulty hearing faint or distant speech. A child with mild loss may miss up to 10% of speech signal when speaker is at a distance greater than three feet, or if the environment is noisy. Likely to experience some difficulty in communication & education settings. Consider need for hearing aid and intervention.

**MODERATE 45-50 dB HL** Understands conversational speech at a distance of 3-5 feet if the loss is in the 35dB range but may miss up to 75% of conversational speech if the loss is in the 50dB range. Amplification may enable listener to hear & discriminate all sounds. Without amplification, 50% to 100% of speech signal may be missed. Speech may be affected unless optimally amplified.

**MODERATELY/SEVERE 60-70 dB HL** Conversation must be very loud to be heard without amplification. A 55dB loss can mean 100% of the speech signal missed. May have difficulty in settings requiring verbal communication, especially in large groups. Delays in spoken language & reduced speech intelligibility expected without intervention & amplification.

**SEVERE 75-90 dB HL** If loss is pre-lingual, spoken language & speech may not develop spontaneously, or could be severely delayed unless modifications & interventions are taken. With optimal amplification, should be able to detect all the sounds of speech and identify environmental sounds. Without amplification,

is aware of loud voices about one foot from the ear and likely to rely on vision for communication.

**PROFOUND >90 dB HL or greater** Aware of vibrations more than tonal pattern. Many rely on vision rather than hearing as the primary avenue for communication and learning. Speech and oral language will not develop spontaneously without modifications and intervention. Speech intelligibility often greatly reduced and atonal voice quality likely. Residual hearing can benefit from amplification. Potential candidate for a cochlear implant. Use of a signed language or a signed system may benefit language development.

**UNILATERAL HEARING LOSS** Until recently, children with unilateral hearing loss did not have their hearing loss detected until they were in school. Now, with the advent of newborn hearing screening, we are detecting the presence of a unilateral, hearing loss during the first year of life. A review of the literature indicates that children with unilateral hearing loss may be at risk for speech and language delays and/or academic challenges. We don't know, however, which children are at risk. We also do not know at precisely what age the unilateral hearing loss has an impact.

AUDITORY NEUROPATHY SPECTRUM DISORDER (ANSD) (also sometimes known as Auditory Dys-synchrony)

Auditory neuropathy spectrum disorder 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. It can affect people of all ages, from infancy through adulthood. The number of people affected by ANSD is not known, but the condition affects a relatively small percentage of people who are deaf or hard of hearing. People with ANSD 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 ANSD 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. Taken from: http:// www.nidcd.nih.gov/health/ hearing/neuropathy. asp Hearing aids may or may not benefit these children. Cochlear implants may benefit individuals when traditional amplification fails.

For more information regarding hearing loss and listening and learning needs, see better hearing: www.betterhearing.org/hearing\_loss/children\_hearing\_loss/relationship\_hearing\_loss\_learning.pdf

# **Amplification Options**

#### WHAT IS A HEARING AID?

A hearing aid can make sounds louder for your child so your child can hear speech better. All children under the age of 18 must have medical clearance prior to being fit with hearing aids. It is recommended that all children with hearing loss be seen by an ENT physician (otolaryngologist) to complete blood work and imaging (CT and MRI) to possibly determine the cause of your child's hearing loss (etiology studies). The ENT can also provide medical clearance prior to being fit with hearing aids. In most cases, if your child has a hearing loss in both ears, then a hearing aid for each ear may be issued. The audiologist, together with the parents, will decide which type of hearing aid is best suited for the child. Hearing aids are selected based on the type, degree, configuration and etiology of the child's hearing loss.

#### WHAT ARE THE DIFFERENT TYPES OF HEARING AIDS?

Hearing aids come in several style options. Here are the most common styles for children of all ages:

#### Behind-the-Ear (BTE)

- Positioned behind the ear
- Coupled to an ear mold or slim tube
- Can be easily connected to an FM system for use at school
- Available in a variety of colors and stickers to accessorize are most often recommended for smaller children since their ears are not yet full grown

#### In the Ear (ITE)

- May be used for older children and adults when the ear is full grown
- Typically not used in young children due to ear canal growth and safety issues with the hard shell

#### In the Canal (ITC)

- May be used for older children and adults when the ear is full grown
- Typically not used in young children due to ear canal growth and safety issues with the hard shell

#### Receiver in the Ear (RITE)

- May be used for older children and adults when the ear is full grown
- This newer style aid is very popular for teens and adults as it is very cosmetically appealing

#### Slim Tube/Open Fit

- May be used for older children and adults when the ear is full grown
- This newer style aid is very popular for teens and adults as it is very cosmetically appealing.

#### Ear molds

• made of soft materials for young children

- can typically be made to swirl up to 3 colors together, add glitter or glow in the dark
- can be made of harder material for older children
- will need to be replaced as the child grows.
- may need to be replaced every 3-6 months when children are young.
- sometimes as a child's shoe size changes, new ear molds may also needed.
- will need to be remade as the child grows and could be as early as every 6-8 wks for B-3.

#### When should my child get a hearing aid?

Newborns should have a hearing test at birth. Early Hearing Detection and Intervention (EHDI) recommends that all children be screened by age 1 month, be diagnosed with hearing loss with by age 3 months and begin intervention (including hearing aids and communication therapy) by age 6 months of age.

#### How does a hearing aid work?

Acoustic sounds are picked up by a microphone and carried to a signal processor (amplifier) where they are made louder and shaped to match the hearing loss characteristics such as frequency (pitch/Hz) and intensity (loudness/dB). The sound is then sent to the receiver and delivered into the ear.

#### WHAT ARE THE PARTS OF A HEARING AID?

The hearing aid has 3 basic parts:

- 1. Microphone
- 2. Amplifier
- 3. Receiver

The BTE is pictured here as it is the most often prescribed hearing aid for young children.



#### HEARING AID BATTERIES

- 1. The hearing aid works using a small battery.
- 2. Size 13 (orange) & 675 (blue) are most commonly used for children.
- 3. Battery life varies based on program settings and use of device.
- 4. Batteries can be dangerous if swallowed.
- 5. Keep batteries away from pets and small children
- 6. For small children, it is recommended that you obtain safety / tamper resistant battery doors. (You may have to ask for this)

#### ADDITIONAL PARTS

**<u>Ear mold</u>**: Custom made to seal the ear to hold BTE hearing aid in place, deliver sound to the ear and prevent feedback (whistling).

Tubing: Soft, flexible, connects the ear mold to the BTE hearing aid; securely

attaches to the ear mold. Tubing must be replaced periodically as it hardens

<u>Ear hook:</u> Curved, hard plastic that supports the hearing aid on top of the ear; protects the receiver and carries the sound to the ear mold and then to the ear canal. Filters (in different colors) can be in ear hooks to further shape the sound for hearing loss.

<u>Slim Tube</u>: A thin tube that connects to the BTE hearing aid and then attached to a dome or slip tip. This newer option is for older children and adults and is very cosmetically appealing.

**<u>Receiver:</u>** The speaker inside the hearing aid that opens to the ear hook.

<u>Microphone</u>: Collects sound for amplification through a small opening in the hearing aid case.

**<u>Program Button</u>**: Typically a pushbutton, which allows for easy access to various programs and features for older children and adults.

<u>Volume Control</u>: A wheel, button or toggle switch where the child can increase and decrease the volume. This feature is typically disabled for young children. Some newer instrument may have one button to serve as a program and/or and volume control.

<u>**Battery Door:</u>** Holds the battery in place; opening the door will turn the hearing aid off. Tamper resistant battery doors are available and should be used for all young children or children with younger siblings</u>

#### HOW WILL I GET MY CHILD TO WEAR THE HEARING AID?

- 1. The goal is the wear the hearing aid during all waking hours.
- 2. Begin allowing the child to wear the aids for short periods of time (15-30 minutes 3-4 times a day at a minimum).
- 3. Increase the wearing time by 15-30 minutes for each of the 3-4 sessions.
- 4. Have several of the child's favorite toys, games, activities and videos available for these short periods of time.
- 5. We want the child to associate listening with "fun" time and enjoy the listening experience.
- 6. Keep a diary and note the amount of time the child is wearing his/her aid(s) daily. Make note of observations. Share the diary with the audiologist.
- 7. Hats with drawstrings under chin are useful in keeping aids on infants. Hannah Andersson has a great pilot cap in many colors available for purchase. http://www.hannaandersson.com
- 8. Taupe tape can also be used to assist in keeping hearing aids on the child.
- 9. With infants who are just getting used to wearing hearing aids, who remove them on their own, it may be best to remove aids while riding in the car.

#### WHICH HEARING AID MANUFACTURER SHOULD I CHOOSE?

Your audiologist will guide you in this decision. Most pediatric audiologist will have a few manufacturers which they prefer to use for children. Ask you

audiologist why he or she uses a certain manufacturer or device. You may also visit the websites to familiarize yourself with the options.

Here are a few pediatric hearing aid manufacturers

www.oticonusa.com www.phonak.com www.siemens-hearing.com www.starkey.com www.unitron.com www.widex.com

#### DAILY HEARING AID CHECK

- 1. Use stethoset to listen to hearing aid
- 2. Turn hearing aid "on" and attach ear mold to stethoset.
- 3. Use the Ling Sounds (eee, ooo, ahhh, s, sh, m).
- 4. The aid should sound clear.
- 5. You should NOT hear noise, static, "motor boating", intermittency or distortion.

If not clear, remove ear mold and tone hook and listen again. The problem could be the ear mold and/or tone hook and not the aid.

An FM system is an assistive listening device (ALD) which can be used with or with out the child's personal hearing aids. The FM system will improve the signal to noise ratio in noisy environments such as a restaurant, car, party or classroom. There are 3 issues where hearing aids alone are limited: noise, distance and reverberation (echo). The FM system directly solves the issue of distance by utilizing a transmitter (microphone) for the speaker (teacher), which is typically worn at the mouth (boom microphone) or 6 inches from the mouth (lapel microphone). Your child's audiologist can test to see if your child may potentially benefit from an FM system. Additional information about FM systems can be found at: www.phonak.com, www.oticonusa.com as well as other manufacturers.

# **COCHLEAR IMPLANTS**



#### **COCHLEAR IMPLANTS**

- 1. The cochlear implant has 3 basic external parts:
- 2. Processor
- 3. Controller/battery rack OR battery module
- 4. Coil Cable/ headpiece.
- 5.

#### The cochlear implant works using small disposable batteries or rechargeable batteries

- 1. Disposable batteries are size 675 specific for CI use (2 or 3)
- 2. Rechargeable batteries are available for most CIs
- 3. Battery life varies based on program settings and use of device
- 4. Batteries can be dangerous is swallowed
- 5. Keep batteries away from pets and small children
- 6.

#### How does a Cochlear Implant work?

- 1. Sound waves enter through the microphone.
- 2. The sound processor converts the sound into a distinctive digital code.
- 3. The electrically coded signal is transmitted across the skin through the headpiece/coil to the internal portion of the device.
- 4. The internal device delivers the sound to the electrodes positioned in the cochlea.
- 5. The electrodes stimulate the hearing nerve.
- 6. The hearing nerve sends the signal to the brain for processing.

#### Steps to Determine Pediatric Cochlear Implant Candidacy

- 1. Audiologic Evaluation
- 2. Medical Evaluation
- 3. Speech Language Evaluation
- 4. Psychological Evaluation
- 5. Educational Evaluation

#### Is my child a candidate for a cochlear implant?

Children (12 - 24 months)

- Profound, bilateral sensorineural deafness (> 90 dB HL)
- Little or no benefit from hearing aids

Children (2 -17 years)

- Severe to Profound, bilateral sensorineural deafness (> 70 dB HL)
- Little or no benefit from hearing aids

The decision to have a cochlear implant is an individual decision if the child meets the candidacy criteria. The cochlear implant team, together with the parents, will make the decision.

There are 3 manufacturers in the United States that are FDA approved. Additional helpful resources are available at these websites.

- Advanced Bionics www.advancedbionics.com
- Cochlear Americas www.cochlearamericas.com
- MED EL www.medel.com

#### How do I get my child to wear the cochlear implant?

- 1. Since the child is most likely acclimated to wearing hearing aids, the initial CI wearing schedule is different from the initial hearing aid schedule.
- 2. The child should wear the CI device during all hours in which they are awake. Use a schedule that the child has already become accustomed to with the hearing aids.
- 3. The CI may have 2-4 "progressive maps or programs".
- 4. Begin on P1 and gradually increase overtime to P3/4
- 5. Each time the child device is reprogrammed (remapped), these settings may change.
- 6. The child may still need time to gradually increase wearing time to all waking hours.

#### Listening Check for CIs

- Use monitor earphones to listen to CI microphone.
- Attach monitor earphones to accessory port and turn on processor.
- Use the Ling Sounds (eee, ooo, ahhh, s, sh, m).
- The device should sound clear.
- You should NOT hear noise, static or distortion.
- Remember you are ONLY listening to the microphone. You cannot hear what the child hears.

Useful website regarding cochlear implant education: <u>http://www.gallaudet.</u> <u>edu/Clerc Center/Information and Resources/Cochlear Implant Education</u> <u>Center/CI Navigating a Forest.html</u>

#### OTHER TYPES OF AMPLIFICATION

Bone Conduction Hearing Aids

- Used for conductive type hearing loss
- Used in the absence of outer ear and ear canal
- Used for excessively draining ears
- Microphone collects sound
- Signal is transmitted to an oscillator
- Oscillator vibrates against the skull
- Inner ear picks up the vibrations and interprets as sound.
- You may listen to this aid simply by placing the oscillator on your forehead

or on the mastoid bone behind the ear.

Baha

- Surgically implantable hearing device
- Must be 5 years of age or older
- Must have conductive, mixed or single sided deafness
- Baha soft band may be worn until age 5
- Soft band looks like the BC hearing aid but is digital and programmed on the computer by the
- Audiologist
- Used to be referred to as a bone anchored hearing aid but this term is no longer used since the Baha is an implantable medical device and not a traditional hearing aid.

#### **Transition to Preschool**

The transitions between early intervention and preschool services, and later preschool and kindergarten, are emotional for all parents as they watch their children grow. When a child demonstrates a hearing loss, these emotions are magnified. Issues associated with hearing loss coupled with the responsibility of making the right choices for their children often results in a time of uncertainty. The education process can be overwhelming for any parent.

The first and perhaps MOST IMPORTANT step in making the transition easier for your child is educating yourself about services or programs available to meet his/her unique needs. Learning about your child's schooling options can help significantly with the IFSP/IEP transition meeting.

The following resources can provide valuable information about education options, hearing technologies, legal rights, and support groups:

1. Alexander Graham Bell Association for the Deaf and Hard of Hearing (AG Bell)

www.agbell.org Voice: 202-337-5220 TTY: 202-337-5221 Fax: 202-337-8314

- 2. Auditory-Verbal International, Inc. www.auditory-verbal.org Voice: 703-739-1049 Fax: 703-739-0395
- 3. Hands & Voices Headquarters www.handsandvoices.org Voice: 303-492-6283 Toll Free Voice: 866-422-0422
- 4. Center for Hearing and Communication (Formerly known as - League for the Hard of Hearing) www.chchearing.org Voice: 917-305-7700

TTY: 917-305-7999 Fax: 917-305-7888

- 5. National Association for the Deaf www.nad.org Voice: 301-587-1788 TTY: 301-587-1789 Fax: 301-587-1791
- National Institute on Deafness and Other Communication Disorders Voice: 301-496-7243 TTY: 301-402-0252
- Oral Deaf Education/OPTION Schools www.oraldeafed.org Phone: 877-672-5332 Fax/TTY: 877-672-5889
- Zero to Three: National Center for Infants, Toddlers, and Families www.zerotothree.org Phone: 202-638-1144

Visit local preschool settings and envision your child participating in the program. Try to envision your child in the environment. How would your child interact? What, if any, accommodations need to be made? Is there access to other children or adults using the same communication mode? A checklist can help in this area:

- Parent Checklist: Preschool/Kindergarten Placement for Children Who are Deaf/Hard of Hearing
- Preschool/Kindergarten Placement for Children <u>http://www.</u> handsandvoices.org/pdf/parent\_checklist.pdf
- Find parent support and collaboration. Parents who are entering this transition period can benefit immensely from knowledge gained by parents who've already experienced the process. There is an article on preschool from a parent's perspective at the link listed below:
- Surviving Preschool: Experiences of the Reluctant Parent
- Surviving Preschool: <u>http://www.handsandvoices.org/articles/fam\_perspectives/preschool.html</u>
- Parent involvement is CRUCIAL to the success of any program.

Once your child enters into an educational setting, visit with the teachers frequently. Remaining involved will assure that the program is meeting your child's needs. Consultation with your child's teacher, speech-language pathologist, and audiologist is vital to monitor your child's progress.

The following assessment is available to assure the program is meeting your child's individual needs:

• Functional Auditory Performance Indicator http://www.cde.state.co.us/cdesped/download/pdf/FAPI\_3-1-04g.pdf For more on transitions, see "Bridge to Preschool" at: <u>http://www.handsandvoices.</u> <u>org/pdf/TransRevised0107.pdf.</u> This page Adapted from Supporting Families in Transition between Early Intervention and School Age Programs by Cheryl Johnson, at <u>www.handsandvoices.org</u>

#### Communication Considerations at the Time of Transition from Part C to Part B Services by Janet DesGeorges What are the Communication Considerations for Transitions from Part C to Part B? (Early Intervention B-3 services to School Age services)

When a child turns three, Intervention services they were receiving under Part C, now moves to the educational arena of Part B of the IDEA. Transition planning from an IFSP to an IEP includes moving from a "family- centered" model to a "student-centered" model of services. The impact of communication choices, availability of services, and student needs in a classroom setting begins to emerge in a way that parents must be prepared for.

# What issues are at the forefront of Transition from Early Intervention to School Based Services?

The issues that are at the forefront of the transition process usually center on the following areas:

#### Eligibility of the child for Part B services:

"Disability" alone does not qualify a child for special education. Eligibility depends on a qualifying condition and the need for specialized instruction and related services. Particularly for children who have been early identified and well served in early intervention, this may be an issue. Eligibility teams often mistakenly look at only one component of a child's progress (academic) and fail to address the communication needs, the social/emotional needs, as well as the academic needs of the student. For example, even if a child is doing 'well', does the child need access to an FM system, access skills (i.e. the ability to be understood), or sign language support?

# Parents Role as part of an IEP 'team' rather than primary decision makers.

Parents must be prepared to negotiate school services as part of a 'team' through honing advocacy skills and being able to articulate a child's communication needs. Parents should know the difference between their right to choose their child's 'language' vs. an IEP team determination of services or methods.

#### Availability of a continuum of services/school settings/ communication modes offered at the school level.

The beauty of special education is that the student's unique needs should be addressed based on their individual needs, not just what a school 'has to offer'. When a school offers support for only one communication mode, it is the right of parents to advocate that their child's communication needs be supported.

# TN Hands & Voices is available to assist parents with the IEP and transition period. Contact info@tnhandsandvoices.org or 901-235-2021

# What should every parent or professional know about their rights regarding communication options as they enter the school years?

For the first time in IDEA history, the reauthorization of 1997 included language regarding the communication needs of students who are deaf and hard of hearing that still exists today. At its very essence, "Communication Considerations" is now REQUIRED to be considered at every student's IEP Planning meeting.

#### Where else can I find information about this subject?

- Bridge to Preschool: Navigating a Successful Transition <u>http://www.handsandvoices.org/pdf/TransRevised0107.pdf</u>
- Supporting Families in Transition between Early Intervention and School Age Programs. By Cheryl Johnson, Special Education Unit, Colorado Department of Education. <u>http://www.handsandvoices.org/pdf/trans\_cheryl.pdf</u>
- Advocacy and Special Education Law Support: <u>www.wrightslaw.com</u>

"<u>Communication Considerations A to Z</u>"<sup>TM</sup> is a series from Hands & Voices that's designed to help families and the professionals working with them access information and further resources to assist them in raising and educating children who are deaf or hard of hearing. We've recruited some of the best in the business to share their insights on the many diverse considerations that play into communication modes & methods, and so many other variables that are part of informed decision making. We hope you find the time to read them all!

PARENTING A CHILD WHO IS DEAF OR HARD OF HEARING All children need three types of inner resources if they are to become selfdisciplining 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-Disciplined 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. Learning occurs through repetition. Routines and schedules carried out with consistency provide stability and security. This is also true with parenting behavior—consistent messages delivered by repeating the same words 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 purpose- fully 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, i.e. "I love how careful you're being with that antique vase."

#### 6. Set Up a Safe Environment.

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

#### 7. Set Sensible Limits.

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

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

#### 8. Defuse Explosion.

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

#### 9. Teach Good Problem Solving Skills.

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

#### 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 re- peat 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

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

#### IFSP and IEP

# How can a parent of a child with hearing loss prepare for transition to preschool or elementary school?

Parents of children with hearing loss and deafness often face educational battles. Transitioning a child to a preschool or elementary program is a critical time for families. The key to a successful transition is knowledge about the laws and regulations that help ensure accessibility, accommodations, modifications, and a free, appropriate public education. Parents and educational professionals must also consider various factors, such as support services, the learning environment, and the team of professionals serving the child with hearing loss.

#### What is the IDEA?

The Individuals with Disabilities Education Act (IDEA) guarantees that all children with disabilities are entitled to a free and appropriate public education. IDEA helps to protect the rights of children with disabilities and their parents or guardians. Visit www.ed.gov/index.jhtml for more information on IDEA regulations and amendments.

#### What is an IEP?

Children with hearing loss have unique educational needs and require technical and educational support in the classroom. The Individualized Education Plan (IEP) is a legal, written plan that specifies special education and related services necessary to ensure an appropriate public education for children with hearing loss.

#### What is included in an IEP?

IDEA requires that the following information be included in the IEP:

- Current levels of the student's educational performance, including how the student's hearing loss may affect his or her progress in a mainstream environment.
- Measurable annual goals and objectives that allow the student to participate in the general curriculum and meet other educational needs specific to the student's hearing loss.
- How the student's progress will be measured relative to those goals and how parents will stay informed of their child's progress.
- Reasons the student is not able to participate in regular education classes or extracurricular activities.
- Specific details regarding special education and related services, including supplementary aids and audiological services that will be provided to the student.
- Specific details regarding program modifications (i.e. changing the level of the material being presented in the classroom) or supports, such as the use of an instructional aid or modifications made to enable the student's participation.
- The dates that services will begin as well as frequency, location, and duration of the services outlined in the IEP.

Formal evaluations should include:

•Receptive and expressive vocabulary

- Speech perception
- Speech production
- •Audiological information
- •Syntax
- •Language usage
- •Figurative language (for older students)
- •Written language

Based on these evaluations, the IEP team will develop educational goals and objectives, outline necessary special education and related services, accommodations and assistive technology, and make recommendations for placement.

#### What is an IEP meeting?

An IEP meeting is collaboration between the school personnel and parents of a child with hearing loss. When a school district learns that a child in its district has a hearing loss and requires special education services, the school district must conduct a meeting within 30 days to develop an educational program for the child. This is known as the IEP meeting. The purpose of the IEP meeting is for the school district and the parents to jointly determine the needs of the particular child, and to develop and educational plan for the child that is appropriate to meet the child's needs.

#### Who attends the IEP meeting?

- •The child's parents or guardians (unless the give up their right to attend)
- •Regular education teacher (if the child is participating in regular education)
- •Special education teacher or representative

•The LEA (a representative of the education department who is qualified to supervise an education program for the child with hearing loss, and who is knowledgeable about the general curriculum and the school district's resources to assist children who are deaf or hearing impaired)

•Person who can interpret the instructional implications of evaluation results of the child (this person may also be one of the teachers or the LEA representative mentioned above).

# What if the parents cannot attend the meeting at the scheduled time? Can parents request an IEP meeting at other times?

The IEP meeting must be scheduled at a time and place that is mutually agreeable to the parents and the school district. If parents are unable to attend the IEP meeting scheduled by the school district, another meeting time must be arranged. The meeting must be held within a reasonable time from the request.

#### What is the Parent's role?

Parents are equal participants in the IEP team meeting under the birth-to-three family-centered approach and can prepare for transition by putting together a report on their child that outlines the history of hearing loss identification, present service delivery, a vision statement, strengths and the mode of communication their child uses. Including a photo of the child helps personalize the information. Parents should also observe the continuum of programs offered and present a rationale for the "best fit" for their child. If an alternative is suggested by the school,

inquire about the experience, background and training of the service personnel and how team members can meet the student's individual needs.

Come prepared to the IEP meeting with your own written parent report that includes:

1)A description of your child's hearing loss, skills, and areas of need.

2)Your goals, concerns, and vision statement for your child.

3)A specific outline of the services based on the student's needs and evaluations for the upcoming school year and past service delivery.

*For more information on IEPs in the state of Tennessee, please refer to the following websites:* 

http://www.tn.gov/education/speced/doc/80608SEMManualfinal.pdf http://www.state.tn.us/education/speced/assessment.shtml

http://www.mnps.org/Page57088.aspx

http://hope.cochlearamericas.com/hope-for-next-year-iep-goals-reports

http://hope.cochlearamericas.com/sites/default/files/TeachersGuide.Chpt3\_.pdf

http://hope.cochlearamericas.com/where-do-we-go-here-transition-topreschool-for-children-cochlear-implants

http://hope.cochlearamericas.com/online-courses/serving-children-school

## IFSP/ IEP RESOURCES

Information is organized by:

- 1. Individual Family Service Plan (IFSP)
- 2. Individual Educational Program (IEP)

#### Individual Family Service Plan - IFSP Resources Clerc Center – Info to Go

http://www.gallaudet.edu/Clerc Center/Information and Resources/Info to Go/Help for Babies (0 to 3).html http://www.gallaudet.edu/Clerc Center/Information and Resources/Info to Go/Laws.html

## Wright's Law

http://www.wrightslaw.com/

http://www.wrightslaw.com/info/ei.index.htm

http://www.wrightslaw.com/info/safgd.index.htm

My Baby's Hearing (Boys Town National Research Hospital)

http://www.babyhearing.org/LanguageLearning/EarlyIntervention/index.asp http://www.babyhearing.org/LanguageLearning/SupportTeam/school.asp http://www.babyhearing.org/LanguageLearning/Decisions/index.asp

## Support and Training for Exceptional Parents (S.T.E.P.)

http://www.tnstep.org

## State of Tennessee

<u>www.tn.gov/education/speced/doc/seifsp.doc</u> <u>http://www.tn.gov/sos/rules/0520/0520-01/0520-01-10.pdf</u> (official rules)

#### Individual Education Plan - IEP Resources Clerc Center - Info to Go

http://www.gallaudet.edu/Clerc\_Center/Information\_and\_Resources/Info\_to\_ Go/Educate\_Children (3 to 21).html http://www.gallaudet.edu/Clerc\_Center/Information\_and\_Resources/Info\_to\_ Go/Laws.html

#### Wright's Law

http://www.wrightslaw.com/info/iep.index.htm http://www.wrightslaw.com/info/safgd.index.htm

#### My Baby's Hearing (Boys Town National Research Hospital)

http://www.babyhearing.org/LanguageLearning/GettingReady/index.asp

#### Support and Training for Exceptional Parents (S.T.E.P.)

http://www.tnstep.org

#### State of Tennessee

http://www.tn.gov/education/speced/doc/seiep.doc http://www.tn.gov/sos/rules/0520/0520-01/0520-01-10.pdf (official rules)

#### STATE AND NATIONAL RESOURCES

Information is organized by:

- State of Tennessee
- United States of America

#### **Tennessee Resources**

Information for Families about Hearing Loss in Children, Parenting, and Communication Options.

> TN Hands & Voices www.tnhandsandvoices.org info@tnhandsandvoices.org

Family Voices (English / Spanish) 1 (888) 643-7811 familyvoices@tndisability.org http//www.tndisability.org/familyvoices

Tennessee School for the Deaf (TSD) Knoxville (865) 579-2500 Carol Robbins (865) 579-2507 / robbinc@tsd.k12.tn.us Jackson (731) 423-5705 www.tsdeaf.org

> University of TN – Center on Deafness 1 - 800 – 342 - 3262 www.centerondeafness.utk.edu/newborn

Nashville Library Services www.tndeaflibrary.nashville.gov

Sibshops 1 – 865 – 579 - 2429 http://www.siblingsupport.org/

National Cued Speech Association http://www.cuedspeech.org/

Memphis City Schools Free Sign Language Classes Contact Sonia Howley, 901-416-5221 howleysd@mcsk12.net

Deaf Family Literacy Memphis - DFLM In-Home Sign Language Training for Families info@deaffamilyliteracymemphis.org

Deaf Connect of the Mid-South ASL classes half price (\$50) for Parents of Deaf/HOH plus the cost of the book (\$75) Voice - (901) 278-9307 tty - (901) 278-9308 email - dc@deafconnectmidsouth.org

> Hearing Bridges Sign Language Classes web: http://hearingbridges.org/ Address: 415 4th Avenue South Nashville, TN 37201 Phone: 615 248-8828 Video Phone: 615 290-5147 \$110

Brentwood Baptist Deaf Church 7777 Concord Road, Brentwood, Tennessee 37027 Phone: (615) 290-5156 vp Fax: (615) 324-6194 Voice: (615) 324-6101 http://brentwooddeaf.org/ Gateway Communications http://www.gatecommunications.org/gatecomm/signlanguage\_classes.htm Address: 330 Mallory Station Road Suite 10 Franklin, TN 37067 Video Phone: 877 399-4049 Office email: gateoffice@gatecommunications.org Price: contact Gateway for pricing information

> Online ASL Instruction -ASLUniversity.com ASLPro.com

National Resources Information for Families about Hearing Impairment in Children, parenting, and communication options.

> Boys Town National Research Hospital (English / Spanish) www.babyhearing.org

Beginnings: For parents of children who are deaf or hard of hearing, Inc. (English / Spanish) www.ncbegin.org

> The Children's Hospital of Philadelphia (English / Spanish) www.raisingdeafkids.org

A. G. Bell Association for the Deaf and Hard of Hearing http://www.listeningandspokenlanguage.org/Landing.aspx?id=549 www.agbell.org

> American Society for Deaf Children www.deafchildren.org

> > Hands & Voices www.handsandvoices.org

National Institute on Deafness and Other Communication Disorders www.nidcd.nih.gov/health/hearing

National Center for Hearing Assessment and Management (NCHAM) / Early Hearing Detection and Intervention (EHDI) <u>http://www.infanthearing.org/</u>

Laurent Clerc Center

http://www.gallaudet.edu/Clerc\_Center/Information\_and\_Resources/Info\_to\_ Go/Hearing\_Loss\_Information.html

Communicate with Your Child (brochure) http://www.communicatewithyourchild.org/brochures/cwyc\_english.pdf Centers for Disease Control and Prevention: Early Hearing Detection and Intervention (CDC/EHDI) – Hearing Loss in Children: What Should You Know? http://www.cdc.gov/ncbddd/hearingloss/index.html

#### Tennessee Resources Information about Hearing Impairment - All Ages

Library Services for the Deaf and Hard of Hearing 1 - 800 - 3423262 www.tndeaflibrary.nashville.gov

Tennessee Disability Pathfinder (English / Spanish) 1-800-640-4636 tnpathfinder@vanderbilt.edu www.familypathfinder.org

> Tennessee School for the Deaf 1 - 865 - 594-6022 <u>http://tsdeaf.org/</u>

Vocational Rehabilitation Telephone: (615) 313-4891 <u>http://tennessee.gov/humanserv/rehab/vrs.html</u>

Jackson Center for Independent Living (JCIL) Description Of Services: Provides interpreter services, technical assistance, referral service, workshops, and sign language classes. Emergency interpreting services available 24 hours a day, 7 days a week, 365 days a year by calling 1-888-877-8830 pager # 2858 (voice only). Serves 22 counties in West Tennessee. Web Address: <u>http://www.jdhhs.org</u>

Tennessee Department of Education <u>http://www.tn.gov/education</u> <u>http://www.tn.gov/education/speced/doc/71309DandHI.pdf</u> (official guidelines / definitions) <u>http://www.tn.gov/education/parents.shtml</u>

#### National Resources Information about Hearing Impairment – All Ages

U.S. Department of Education: Opening Doors publication (available in multiple formats / languages-scroll to the bottom of the page for language options) www.edpubs.org Laurent Clerc National Deaf Education Center 1 - 202 - 651-5051 <u>http://www.clerccenter.gallaudet.edu/infotogo</u> <u>http://www.gallaudet.edu/clerc\_center/information\_and\_resources/info\_to\_go.html</u>

> A.G. Bell 1 – 866 – 337 - 5220 www.agbell.org

#### Hands & Voices 1 - 866 - 422-0422 www.handsandvoices.org

Let Them Hear Foundation Advocacy Program 1 - 877 - 432-7435 – 1-877-HEAR-HELP www.deafspecialeducation.com

Tennessee Resources Information about and educational services for 0 – 3 children with hearing impairment.

> Tennessee Newborn Hearing Screening Program (615) 262-6160 <u>http://health.state.tn.us/NBS/hearing.htm</u>

TN Department of Early Learning: TN Early Intervention System (TEIS) 1-800-852-7157 <u>http://www.tn.gov/education/teis/parent\_info.shtml</u>

http://www.tn.gov/education/teis/index.shtml

Tennessee School for the Deaf 1 - 865 - 594-6022 http://tsdeaf.org/

Support and Training for Exceptional Parents (S.T.E.P.) http://www.tnstep.org

Vanderbilt Bill Wilkerson Center, National Center for Childhood Deafness and Family Communication (NCCDFC) <u>http://www.mc.vanderbilt.edu/nccdfc</u>

> Tennessee Hands & Voices www.tnhandsandvoices.org 1-800-840-2410

Memphis Oral School for the Deaf-Sound Beginnings (birth-3)
Phone: (901) 758-2228 http://www.mosdkids.org

Deaf Family Literacy Memphis - DFLM In-Home Sign Language Training for Families info@deaffamilyliteracymemphis.org

National Resources Information about and educational services for 0 – 3 children with hearing impairment.

National Early Childhood Technical Assistance Center (NECTAC) <u>http://www.nectac.org/partc/statepolicies.asp?text=1</u> 1 - 919 - 962 - 2001

Laurent Clerc National Deaf Education Center 1 - 202 - 651-5051 <u>http://www.gallaudet.edu/Clerc Center/Information and Resources/Info to</u> <u>Go/Help for Babies (0\_to\_3).html</u>

National Dissemination Center for Children with Disabilities (NICHCY) <u>http://www.nichcy.org/babies</u> 1 – 800 – 695 - 0285

The Children's Hospital of Philadelphia (English / Spanish) www.raisingdeafkids.org/communicating/choices John Tracy Clinic www.itc.org

> National Cued Speech Association <u>www.cuedspeech.org</u> 1 - 800 - 459 - 3529

Let Them Hear Foundation Advocacy Program 1 – 877 – 432 – 7435 <u>http://www.deafspecialeducation.com</u>

Boys Town National Research Hospital (English / Spanish) www.babyhearing.org

Beginnings: For parents of children who are deaf or hard of hearing, Inc. (English / Spanish) www.ncbegin.org

> The Children's Hospital of Philadelphia (English / Spanish) www.raisingdeafkids.org

A. G. Bell Association for the Deaf and Hard of Hearing

http://www.listeningandspokenlanguage.org/Landing.aspx?id=549 www.agbell.org

American Society for Deaf Children www.deafchildren.org

> Hands & Voices www.handsandvoices.org

National Institute on Deafness and Other Communication Disorders www.nidcd.nih.gov/health/hearing

National Center for Hearing Assessment and Management (NCHAM) / Early Hearing Detection and Intervention (EHDI) <u>http://www.infanthearing.org</u>/

Laurent Clerc Center <u>http://www.gallaudet.edu/Clerc Center/Information and</u> <u>Resources/Info to Go/Hearing Loss Information.html</u>

Communicate with Your Child (brochure) http://www.communicatewithyourchild.org/brochures/cwyc\_english.pdf

Centers for Disease Control and Prevention: Early Hearing Detection and Intervention (CDC/EHDI) – Hearing Loss in Children: What Should You Know? <u>www.cdc.gov/ncbddd/ehdi/CDROM</u> <u>http://www.cdc.gov/ncbddd/hearingloss/index.html</u>

Tennessee Resources Information about and educational services for 3 - 5 children with hearing impairment.

> Tennessee Hands & Voices www.tnhandsandvoices.org

Tennessee Department of Education <u>http://www.tn.gov/education</u> <u>http://www.tn.gov/education/speced/doc/71309DandHI.pdf</u> (official guidelines / definitions) <u>http://www.tn.gov/education/parents.shtml</u>

> Tennessee School for the Deaf 1 - 865 - 594-6022 http://tsdeaf.org/

Support and Training for Exceptional Parents (S.T.E.P.) <u>http://www.tnstep.org</u>

Memphis Oral School for the Deaf – Preschool Program (2 – 6yrs) Phone: (901) 758-2228 http://www.mosdkids.org/

Memphis City Schools Hearing Intervention PK Program (3 - 5yrs) Contact: Colonial Hearing, Speech, & Vision Center Deborah Harris, Coordinator (901) 416-5203 Thomas Stanton, Program Supervisor (901) 416-5203

National Resources Information about and educational services for 3 - 5 children with hearing impairment.

Laurent Clerc National Deaf Education Center 1 - 202 - 651-5051 <u>http://www.gallaudet.edu/Clerc Center/Information and Resources/Info\_to\_Go/Educate Children (3\_to\_21).html</u>

> Kendall Demonstration School for the Deaf (Pre-K – 8th) Gallaudet College 1 – 866 – 782 - 1556 <u>http://www.gallaudet.edu/KDES/About\_.html</u>

The National Agenda: Core Curriculum for the Deaf <u>http://www.ndepnow.org/pdfs/national\_agenda.pdf</u> Boys Town National Research Hospital (English / Spanish) <u>www.babyhearing.org</u>

Beginnings: For parents of children who are deaf or hard of hearing, Inc. (English / Spanish) www.ncbegin.org

> The Children's Hospital of Philadelphia (English / Spanish) www.raisingdeafkids.org

A. G. Bell Association for the Deaf and Hard of Hearing <u>http://www.listeningandspokenlanguage.org/Landing.aspx?id=549</u> <u>www.agbell.org</u>

> American Society for Deaf Children www.deafchildren.org

> > Hands & Voices www.handsandvoices.org

National Institute on Deafness and Other Communication Disorders www.nidcd.nih.gov/health/hearing

National Center for Hearing Assessment and Management (NCHAM) / Early Hearing Detection and Intervention (EHDI) <u>http://www.infanthearing.org</u>/ Laurent Clerc Center

http://www.gallaudet.edu/Clerc Center/Information and Resources/Info to Go/Hearing Loss Information.html

Communicate with Your Child (brochure)

http://www.communicatewithyourchild.org/brochures/cwyc\_english.pdf

Centers for Disease Control and Prevention: Early Hearing Detection and Intervention (CDC/EHDI) – Hearing Loss in Children: What Should You Know? www.cdc.gov/ncbddd/ehdi/CDROM http://www.cdc.gov/ncbddd/hearingloss/index.html

Tennessee Resources Information about and educational services for school ages K – 12 with hearing impairment.

> Tennessee School for the Deaf 1 - 865 - 594-6022 http://tsdeaf.org/

**Tennessee Department of Education** 

http://www.tn.gov/education http://www.tn.gov/education/speced/doc/71309DandHI.pdf (official guidelines / definitions) http://www.tn.gov/education/parents.shtml http://www.tn.gov/education/speced/ http://www.tn.gov/education/speced/tools.shtml (IEP)

Support and Training for Exceptional Parents (S.T.E.P.)

http://www.tnstep.org

Vanderbilt Mama Lere Hearing School Nashville, TN 615-936-5262 http://www.vanderbilthealth.com/mamalere/

Memphis City Schools Hearing Intervention Program K-12 Contact: Colonial Hearing, Speech & Vision Center Deborah Harris, Coordinator (901) 416-8940 Thomas Stanton, Program Supervisor (901) 416-5203

STARS: Services for Students Who Are Deaf and Hard of Hearing <u>http://starsnashville.org/programs/deaf</u>-hard-of-hearing-prevention/

National Resources

Information about and educational services for school ages K – 12 with hearing impairment.

The National Agenda: Core Curriculum for the Deaf <u>http://www.ndepnow.org/pdfs/national\_agenda.pdf</u> Laurent Clerc National Deaf Education Center 1 - 202 - 651-5051 <u>http://www.gallaudet.edu/Clerc\_Center/Information\_and\_Resources/Info\_to\_Go</u>

> Model Secondary School for the Deaf (9th – 12th) Gallaudet College 1 – 866 – 782 - 1556 <u>http://www.gallaudet.edu/mssd.html</u>

Kendall Demonstration School for the Deaf (Pre-K – 8th) Gallaudet College 1 – 866 – 782 – 1556 <u>http://www.gallaudet.edu/KDES/About\_.html</u>

Lexington School for the Deaf <u>http://www.lexnyc.com/</u>

Clarke School for the Deaf http://www.clarkeschools.org/

Tennessee Resources Information About and Educational Services for Post-Secondary Ages

> Postsecondary Education Consortium – UT-K 1 - 865 - 974-0607 <u>http://www.sunsite.utk.edu/cod/staff.html</u>

STARS: Services for Students Who Are Deaf and Hard of Hearing <u>http://starsnashville.org/programs/deaf</u>-hard-of-hearing-prevention/

TN Council for the Deaf and Hard of Hearing <u>http://tennessee.gov/humanserv/rehab/cc6.html</u> 1 - 800 - 270 - 1349

Rehabilitation Services 1 - 800 - 270 - 1349 http://www.tn.gov/humanserv/rehab/dhhs.html

Secondary Transition Project, The Arc Tennessee 1 - 800 - 835-7077 www.thearctn.org/Transitions.php

TN Rehabilitation Center http://www.tennessee.gov/humanserv/rehab/rehab\_main.html TN Regulatory Authority (TDAP) 1 - 800-342-8359 ext. 179 http://www.state.tn.us/tra/consumerfiles/tdapform.pdf

National Resources Information About and Educational Services for Post-Secondary Ages

> National Center on Deafness 1 – 818 – 677 - 2054 <u>ncod@csun.edu</u> <u>http://www.csun.edu/ncod</u>/

Gallaudet University http://www.gallaudet.edu/

Laurent Clerc National Deaf Education Center 1 - 202 - 651-5051 <u>http://www.gallaudet.edu/clerc\_center.html</u>

> PEPNet2 http://www.pepnet.org/

Tennessee Resources Information About and Services for Young Adults

TN Council for the Deaf and Hard of Hearing <u>http://tennessee.gov/humanserv/rehab/cc6.html</u> 1 - 800 - 270 - 1349

Rehabilitation Services 1 – 800 – 270 - 1349 <u>http://www.tn.gov/humanserv/rehab/dhhs.html</u> Secondary Transition Project, The Arc Tennessee 1 - 800 - 835-7077 <u>www.thearctn.org/Transitions.php</u>

TN Rehabilitation Center http://www.tennessee.gov/humanserv/rehab/rehab\_main.html

TN Regulatory Authority (TDAP) 1 - 800-342-8359 ext. 179 http://www.state.tn.us/tra/consumerfiles/tdapform.pdf

National Resources Information About and Services for Young Adults

Laurent Clerc National Deaf Education Center 1 - 202 - 651-5051 http://www.gallaudet.edu/Clerc Center/Information and Resources/Info to

## Go/Transition to Adulthood.html

<u>Disability.gov</u>: Connecting People to Resources Nation Wide <u>https://www.disability.gov</u>/

Telecommunications Equipment Distribution Program Association <u>http://www.tedpa.org/about.aspx</u>

Tennessee Resources Information About Educational Services for Individuals with Deafness

Tennessee Technology Access Center (TAC) <u>http://tac.ataccess.org</u>

Tennessee Technical Assistance and Resources for Enhancing Deaf-Blind Supports (Project TREDS) \* Resource Packet 1 – 800 – 288 – 2266 <u>http://www.vanderbilt.edu/kennedy/treds/</u>

ARC of Middle TN <u>http://www.thearctn.org/</u> TN Disability Coalition 1 – 615 – 383 – 9442 <u>http://www.tndisability.org/</u> TN Department of Human Services - Disability 1 – 615 – 313 - 4700 <u>http://www.state.tn.us/humanserv/Disability.html</u>

National Resources Information About and Educational Services for Individuals with Deafness Plus United Cerebral Palsy <u>http://www.ucp.org</u> Disabled Children's Relief Fund (DCRF) <u>http://www.dcrf.com</u> Disability Resources Monthly Guide to Disabilities on the Internet <u>http://www.disabilityresources.org/index.html</u> National Family Association for DeafBlind <u>http://www.nfadb.org/</u> Deaf-Blindness Resource, Technology Assistance, Training <u>http://nationaldb.org/</u> Helen Keller National Center for DeafBlind Youths and Adults <u>http://www.hknc.org/</u>

Tennessee Resources Funding and Other Services TennCare <u>http://www.tn.gov/tenncare/tenndercare/index.shtml</u> Child Care Resource and Referral <u>http://www.tnccrr.org/</u> Children's Special Services (CSS) TN Dept. of Health <u>http://health.state.tn.us/mch/css.htm</u>

Graceful Sounds http://www.gracefulsounds.org Friends of Tennessee's Babies with Special Needs 1 – 856 – 789 – 2409 http://www.fotbabies.org

TEIS – Tennessee's Early Intervention Services 1-800-852-7157 http://tennessee.gov/education/teis/index.shtml

National Resources Funding, Hearing Aid Donors & Other Services ARCH National Resource Center for Respite and Crisis Care Services 1-888-671-2594 http://archrespite.org/

A.G. Bell Association: Financial Aid & Scholarship Awards www.agbell.org 1 - 866-337 – 5220

United Healthcare Children's Foundation (UHCCF) <u>http://www.uhccf.org</u>

Disabled Children's Relief Fund <u>http://www.dcrf.com</u>

Lions Clubs http://www.lionsclubs.org

Sertoma Club http://www.sertoma.org

Hear Now (Starkey) http://www.sotheworldmayhear.org

HIKE Fund http://www.thehikefund.org

Colorado Neurological Institute http://www.thecni.org/hearing/assistance

Oticon Pediatrics Hearing Aid Loaner Bank (Starkey)

1 - 888 - 684 - 7331

http://www.oticonusa.com/Oticon/Professionals/Pediatrics/National\_Loaner\_ Bank.html

American Speech and Hearing Association (ASHA) <u>http://www.asha.org/familyfunding</u>

Audient www.audientalliance.org

Travelers Protective Association www.travelersprotectiveasn.com/deaf\_scholarships.htm

Vocational Rehabilitation www.state.tn.us/humanserv/rehab/vrs.htm

Graceful Sounds www.gracefulsounds.org

Deaf Connect www.deafconnectmidsouth.org

Tennessee Summer Camps Camp Rise & Sign – Bridges

http://hearingbridges.org/event/register\_for\_camp\_rise\_and\_sign Voice/TTY 615-248-8828 · Video Phone 615-290-5147

Camp Summer Sign – Brentwood Baptist Deaf Church http://www.brentwooddeaf.org campsummersign@brentwoodbaptist.com (615) 324-6101

Deaf Camps at Bill Rice Ranch <u>http://www.billriceranch.org/</u> 627 Bill Rice Ranch Road · Murfreesboro, TN 37128-4555 Phone: 800-253-RICE info@billriceranch.org

TN School for the Deaf <u>http://tsdeaf.org/summercamp/index.html</u> Dr. Steve Farmer, Camp Director Email: <u>sfarmer@tsd.k12.tn.us</u> Phone:(865) 978-6022 VP or (865) 579-2425 (Voice)

#### LIBRARY RESOURCES BOOKS

American Sign Language Dictionary: Sternberg M.L.A. New York: Harper and Row.

A Child Sacrificed to the Deaf Culture: By Tom Bertling. Wilsonville, OR: Kodiak Media Group, (1994)

Balancing Act: By Virginia M Scott. Butte Publications, Inc., (1997)

The Book of Choice: Support for Parenting a Child Who Is Deaf or Hard of Hearing Edited by Leeanne Seaver (2010) http://handsandvoices.org/resources/ products.htm

Choices in Deafness: A Parent's Guide. A collection of family stories about their deaf child and the communication method they use. Edited by Sue Schwartz, Ph.D. Woodbine House, 2006

Come Sign with Us: Sigh Language Activities for Children. By Jan C. Hafer and Robert M. Wilson. Illustrated by Paul Setzer. 1998)

Cochlear Implants in Children: Ethics and Choices. John B. Christianson and Irene W. Geigh Washington, D.C.: Gallaudet University Press, 2002. Covers the ongoing controversy about implanting cochlear hearing devices in children. Describes findings from a survey and follow up interviews with parents of children who have implants.

Cochlear Implantation for Infants and Children: advances/senior editor, Graeme M. Clark: editors, Robert S.C. Cowan, Richard C. Dowell. Published by San Diego: Singular Pub. Group, (1997)

The Comprehensive Signed English Dictionary: Harry Bornstein, Karen L. Saulnier, and Lillian B. Hamilton, Editors

Deaf History Unveiled: Sixteen essays offer the current results of Harlan Lane, Renate Fischer, Margret Winzer, William McCagg, and 12 other noted historians in this field. John Vickrey Van Cleve, Editor

Deaf Plus: A Multicultural Perspective K.M. Christensen, Ed. Berkeley, CA: DawnSignPress, 2000 Eleven essays with information for teachers, administrators, psychologists, social workers, and families with deaf children about the multilingual and multicultural dimensions of the Deaf Community, including education/social needs of deaf children with Spanish-speaking heritage.

Deaf President Now: The 1988 Revolution at Gallaudet University. John B. Christiansen and Sharon N. Barnartt

Facilitating Hearing and Listening in Young Children Carol Flexer, 2nd edition, San Diego, A:: Singular Publishing Group, 1999; Emphasizes the need to create an "auditory world" Information on many facets of hearing loss, amplification technology, cochlear implants, federal laws and listening strategies.

The Feel of Silence: A compelling memoir about a lawyer and professor with a profound hearing loss surviving the trials of accommodating the hearing world, by Bonnie Poitras Tucker, J.D. Temple University Press, (1996)

From Emotions to Advocacy: The Special Education Survival Guide Pam Wright and Pete Wright Harbor House Law Press, Inc. Hartfield, VA 23071 www. wrightslaw.com

Foundations of Bilingual Education and Bilingualism: Baker, C. (1996) Clevedon: Multilingual Matters

Good Morning Me! Eberlein, L., Stelford Publishing, Denver, (2006) Introduces your child to initial vowel/consonant combinations through entertaining repetition; www.soundsgreatseries.com

How the Student with Hearing Loss Can Succeed in College: A handbook for Students, Families and Professionals. Edited by Carol Flexer, Ph.D., Denise Wray, Ph.D., and Ron Leavitt, M.S. Foreword by Mark Ross, Ph.D. Alexander Graham Bell Association for the Deaf, Inc., (1990)

Handtalk School: Words and sign Language depict a group of students involved in putting on a Thanksgiving play at a school for deaf children. By Mary Beth. New York: Toronto: New York: Four Winds Press; Collier Macmillan Canada; Maxwell Macmillan International, (1991)

How to Communicate with Infants before They Can Speak Garcia, Joseph (1999) www.harriscomm.com

IDEA Advocacy for Children who are Deaf or Hard of hearing: A guide for parents of children who are deaf or hard of hearing and the professional involved in their education. By Bonnie Poitras Tucker, J.D. Singular Publishing Group, (1997)

DEA as Amended in 2004 by Rud Rutherford Turnbull, Nancy Huerta, Matthew Stowe, Publication date June,2005

Kid-friendly Parenting with Deaf and Hard of Hearing Children: By Daria J. Medwid, Denise Chapman Weston. Washington, D.C.: Clerc books, (1995) The Mask of Benevolence: disabling the deaf community, by Harlan Lane. New York: Knopf, (1992)

My Sense of Silence: memoirs of a childhood with deafness, by Lennard J. Davis. Urbana: University of Illinois Press, (2000)

Never the Twain Shall Meet: Bell, Gallaudet, and the Communications Debate. Richard Winefield Not Deaf Enough: Raising a Child who is Hard of Hearing with Hugs, Humor and Imagination. Patricia Ann Morgan Candlish. Washington, D.C.: Alexander Graham Bell Association for the Deaf, 1996. A parent's perspective provides an overview of services for hard of hearing children.

Our Forgotten Children: Hard of Hearing Pupils in the Schools. Edited by Julia Davis, Ph.D., SHHH Publications, (2001) 3rd edition Raising and Educating a Deaf child: by Marc Marschart. New York: Oxford University Press, (1997)

The Signing Family: what every parent should know about sign communication, by David A. Stewart. Washington, D.C.: Gallaudet University Press, (1998)

Signs for Me: Basic sign vocabulary for children, by Bahan, B., & Dannis, J. (1990) Berkeley, CA Dawn Sign Press

The Silent Garden: Ogden, P.W., & Lipsett, 5. (1982) Understanding the hearingimpaired child. New York: St. Martin Press

So your child has a hearing loss: next steps for parents. Washington, DC: AG Bell, (2000)

Sounds Like Home: Growing Up Black and Deaf in the South, by Mary Hering Wright

Special Children, Challenged Parents: the struggles and rewards of raising a child with a disability, by Robert A Naseef. Secucus, N.J.: Carol Pub. Group, (1997)

What's That Pig Outdoors? An inspiring autobiography of Henry Kisor, oral deaf book editor and columnist for the Chicago Sun Times. Henry Kisor, (1990)

When Bad Things Happen to Good People: Kushner, H. (1981) New York: Avon Books

When the Mind Hears: by Harlan Lane. A history of the Deaf, presenting the fundamental issues and controversies confronting deaf people

When your Child is Deaf: David M. Luterman with audiologist Mark Ross, who is hard of hearing from New York Press

Wrightslaw: Special Education Law Peter W.D. Wright and Pamela Darr Wright Harbor Law Press, 1st edition 1999 www.wrightslaw.com

The Parent Journey – Raising Deaf and Hard of Hearing Children: Karen Griffard Putz, BOD Hands & Voices

### VIDEO RESOURCES

Described and Captioned Media Program National Association of the Deaf 1447 E. Main Street Spartanburg, SC 29307 800-237-6213 (VOICE); 800-237-6819 (TTY); 800-538-5636 (FAX) Email: info@dcmp.org www.dcmp.org

What Is the Captioned Media Program?

Free-loan Media (no rental fees); Open-captioned (no need for a decoder); Funded by the U.S. Department of Education; Includes prepaid return labels; Deaf and hard of hearing persons, teachers, parents, and other may borrow materials; other services include provision of free captioning information.

#### What Media Is Available?

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

A is for Access: Creating Full & Effective Communication Access for Students who are Deaf or Hard of Hearing

To order, call Hands & Voices Toll-Free: (866) 422-0422 V/TTY in Colorado: (303) 492-6283 or download an order form at www.handsandvoices.org

American Culture: The Deaf Perspective.

(4 tapes) Available from the San Francisco Public Library, (415) 557-4400; (415) 557-4433 (TTY) http://sfpl.org/

Building conversations

A family sign language curriculum, produced by Boys Town National Research Hospital. (2 tapes) www.boystownpress.org

Computer-Assisted Note taking (CAN)

You see it-visual technologies for Deaf and Hard of Hearing People. Gallaudet University http://research.gallaudet.edu/Publications/#PUB16

Come Sign with Us

Children can learn sign language from the popular activities featured in the bestselling book: Come sign with us" on videotape. Gallaudet University Press http://gupress.gallaudet.edu/2794.html

Dreams Spoken Here Available at www.oraldeafed.org Early Intervention Illustrated Series: "The Home Team" and "The Art & Science of Home Visits."

To view these tapes, contact your Colorado Hearing Resource (CO-Hear) Coordinator. To purchase a copy, contact Boys Town Press or go to www. handsandvoices.org/resources/products.htm

Families with Deaf Children

(VHS) Parents and professionals talk about having a hard-of-hearing child. Available through your Co-Hear coordinator

Families with Hard of Hearing Children What if your child has a hearing loss? (VHS) Parents and professionals talk about having a hard-of-hearing child. Available through your Co-Hear coordinator

Home Total Communication Video Tapes Shows over 1000 signs, available from Hope, Inc.1856 N.1200 East, North Logan, Utah 84341, 435-245-2888 http://hopepubl.com/

Loss and Found

A video from Hands & Voices that tells what to do if your baby did not pass the newborn hearing screen; http://handsandvoices.org/resources/video/index.htm

One Mother's Story Available by Modern Signs Press. www.modernsignspress.com

Pathways to Language and Communication A film that examines all communication choices without bias; from Beginnings, 919.715.4092

Read With Me Series Brenda Schick and Mary Pat Moeller; Boystown Press www.boystownpress.org

Sign Enhancers Showing ASL use, (800) 767-4461 www.signenhancers.com

Sign With Me Sign With Me Series – A family Sign Language Curriculum Boystown Press

Brenda Schick and Mary Pat Moeller www.boystownpress.org

Teaching the Kids with High Tech Ears Considerations for kids with cochlear implants in the classroom Seaver Creative Services, Email: parentadvocate@handsandvoices.org; available at www.buttepublications. com or www.handsandvoices.org/resources/products.htm

The Time is Now We think THE TIME IS NOW for Hands & Voices families and professionals every one of them linked in the community of the deaf and hard of hearing-sharing the same thought: to move beyond the methodology wars and join our Hands & Voices mission of non-biased support to families with children with hearing loss; http://handsandvoices.org/resources/products.htm

We are Hands & Voices

A short video describing parent involvement and the Hands & Voices philosophy and organization.

Order through http://handsandvoices.org/resources/ products.htm

## Tennessee Deaf Library

Tennessee's lending library of books, media programs, and assistive communication devices is one of the largest, if not THE largest in a public library in the country, with over 12,750 items in the collection. It includes materials to educate the hearing public about hearing loss and deafness as well as accessible informational and entertaining materials for people who are deaf or hard of hearing. Materials about deaf-blindness are also available. So, if you are experiencing a hearing a loss or want to learn more about any aspect relating to hearing loss "check out" our collection!

http://tndeaflibrary.nashville.gov/library

To help you select the appropriate book or media program you may...

- search the collection online (through the Nashville Public Library) or
- contact us for suggestions

All materials available for loan (books, media programs, and equipment) may be borrowed for 3-weeks. Regardless of where you live in Tennessee you may borrow materials from the Library Services for the Deaf & Hard of Hearing collection. However, your hometown will determine the type of library card you will need. Click on LSDHH Application in the Help Center for more information about applications.

# GLOSSARY

**ACOUSTICS**: Pertaining to sound, the sense of hearing or the science of sound. Often used to refer to the quality of the sound environment.

**ACOUSTIC REFLEX:** A protective mechanism in which the muscles in the middle ear contract in response to loud sounds.

**ACQUIRED HEARING LOSS:** Hearing loss, which is not present at birth. This type of hearing loss appears after birth, at any time in one's life, perhaps as a result of a disease, a condition, or an injury. The following are examples of conditions that can cause acquired hearing loss in children are: ear infections (otitis media), ototoxic drugs, meningitis, measles, encephalitis, chicken pox, influenza, mumps, head injury, noise exposure.

**ADVOCACY:** The role parents or guardians play in developing and monitoring their child's educational program. Advocating for your child means knowing what rights are assured you by the law and actively participating in the decision-making process to ensure that the services are delivered in line with your goals for your child's development and education.

**AIR BONE GAP:** A difference between hearing responses by the earphone or speaker (air conduction) and bone vibrator (bone conduction). A gap or difference between air-conduction and bone-conduction responses indicates a conductive hearing loss due to problems in the middle ear. If not gap is present, this typically shows a sensorineural hearing loss.

**AMBIENT NOISE:** Background noise which competes with the main speech signal.

**AMERICANS WITH DISABILITIES ACT (ADA):** Public law 101-336 passed in 1990 that prohibits discrimination on the basis of disability in employment, transportation, public accommodation, state and local government and telecommunications. This is a "civil rights act" for persons with disabilities.

**AMPLIFICATION:** The use of hearing aids and other electronic devices to increase the loudness of a sound so that it may be more easily received and understood.

**ANVIL:** The second of the three bones in the middle ear. Technically called the Incus.

**AIR CONDUCTION:** The transmission of sound to the inner ear through the ear canal and the middle ear. Air-conduction testing is performed by sending sounds to the ear though an earphone or speaker.

**ASSISTIVE COMMUNICATION DEVICES:** Devices and systems which are available to help deaf and hard of hearing people improve communication, adapt to their environment, and function in society more effectively.

**ASSITIVE LISTENING DEVICE:** A category of devices that are designed to help hard of hearing people function better in particular situations. Many ALDs are used in conjunction with the person's hearing aids and/or cochlear implants to improve their performance. These include amplified telephones, FM systems, infrared systems and induction loop systems.

ATRESIA: congenital absence of the ear canal opening.

**AUDITORY BRAINSTEM IMPLANT (ABI):** An ABI is similar to a cochlear implant, except the electrodes are implanted in the brainstem. The ABIs are used when a person has neurofibromatosis type 2 (NF2) and is at least 12 years of age. People with ABIs typically only perceive environmental sounds and do not hear speech clearly.

**AUDITORY BRAINSTEM RESPONSE (ABR):** A non-invasive, objective test that measures activity in the brainstem in response to an auditory stimulus. This test can indicate whether or not sound is being detected, even in an infant. The ABR is typically administered while the child is sleeping and is completely painless. This test may also be referred to as BAER. The ALGO 2 automated ABR screening device is used in many hospitals for universal newborn hearing screening.

**AUDITORY NERVE:** The eighth cranial nerve (VIII) that carries impulses (information) between the cochlea and the auditory pathway to the auditory cortex in the brain.

**AUDITORY STEADY STATE RESPONSES (ASSR):** Like the ABR, the ASSR is a measure of the brainstem's responses to particular auditory stimuli. This noninvasive, objective and painless test is also administered while the child is sleeping. The ASSR technology offers the audiologist an additional way to determine your child's hearing across different frequencies. The equipment has higher upper limits than traditional ABR equipment, thus allowing the audiologist to more accurately differentiate between severe and profound hearing loss in infants.

**AUDIOGRAM:** A graph on which a person's ability to hear different pitches (frequencies) at different volumes (intensities) of sound is documented. The audiogram gives a visual picture of the child's hearing loss.

**AUDIOLOGICAL ASSESSMENT:** A hearing test comprised of identifying audiometric thresholds, otoscopy, impedance testing, otoacoustic emissions, speech recognition, and speech discrimination measurements, which show the type, degree and configuration of hearing loss.

**AUDIOLOGIST:** A professional who evaluates hearing function, and treats/ supports persons with hearing loss or balance disorders. New graduates are required to have their Doctorate in Audiology (Au.D.). Audiologists may be certified by American Speech Language Hearing Association (ASHA), American Academy of Audiology (AAA), or American Board of Audiology. Most states require licensure.

**AUDITORY NEUROPATHY/DYS-SYNCHRONY (AN/AD):** An auditory disorder that disrupts the synchronous activity of the hearing system. This type of sensorineural hearing loss ranges from normal to profound can fluctuate and the effects vary widely. Typically the ABR test will be abnormal while the OAE test may be normal or show some presence of normal function in the cochlea (organ of hearing).

**AUDITORY PROCESSING DISORDER (APD):** a condition in which peripheral hearing is normal; however, the ability to process and understand what is heard is affected. There is significant variability of symptoms. Testing to accurately diagnose APD should be completed by an audiologist and the child should be at

least 7 years of age.

**AUDITORY TRAINING:** The process of training auditory skills with the use of amplification (hearing aids and/or cochlear implants) in the awareness, discrimination, identification, and comprehension of sound. This service should be provided by a speech language pathologist with expertise in hearing loss.

**AURAL/ORAL COMMUNICATION:** A communication approach which uses spoken language skills using residual hearing, amplification and the use of lipreading (speech reading).

**AURAL HABILITATION:** Treatment designed in order to understand and use spoken language. The focus is to provide speech, language and listening therapy using amplification and the individual's residual hearing.

**AUDITORY VERBAL THERAPIST (AVT):** A therapist who specializes in development of speech and verbal language through the maximized use of the auditory channel.

**BAHA:** A surgically implantable medical device for the treatment of hearing loss that works directly through bone conduction. The device can be used for bilateral conductive and mixed hearing loss as well as unilateral sensorineural hearing loss and is typically for those who do not benefit from conventional hearing aids. Two companies currently have FDA approval to surgically implant the Baha: Oticon Medical and Cochlear Americas. The device is FDA approved for children age 5 and older.

**BEHIND-THE-EAR HEARING AID (BTE):** A hearing aid that rests behind the ear. Sound from the aid is carried through a small tube to an ear mold that fits into the ear. The BTE style aid is used often in young children as it is more cost effective to remake the ear mold as the child grows rather than the actual hearing aid.

**BEHAVIORAL OBSERVATION AUDIOMETRY (BOA):** The testing of infants and young children is accomplished without reinforcement and the patient's responses are based on the subjective observation under a structured testing environment. This method must be accompanied by physiological measures in order to accurately diagnose hearing loss. Typically used with young children at a developmental age of birth to six months.

**BILINGUAL / BICULTURAL:** Belonging to both a hearing/English language culture and Deaf Community/ASL culture

**BILATERAL HEARING LOSS:** Hearing loss that is present in both ears. It can present with various types, degrees and configurations.

BINAURAL HEARING AIDS: Hearing aids worn on both ears.

**BODY AIDS:** An amplification unit that is worn on the body provides increased gain (power) and less feedback for individuals with a severe to profound hearing loss. Primarily used only in special situations where ear-level hearing aids cannot be used.

**BONE CONDUCTION HEARING:** Sound is delivered through the bones in the skull to directly stimulate the organ of hearing (cochlea).

**BONE CONDUCTION TESTING:** Testing conducted using a bone oscillator to determine the type of hearing loss. The bone oscillator is typically placed on the

mastoid bone behind the ear and directly stimulates the cochlea (organ of hearing) through the bones in the skull and bypasses the middle ear.

**BONE CONDUCTION HEARING AID:** This type of hearing aid is reserved for conductive or mixed bilateral hearing loss in situations where traditional amplification cannot be used due to a small (stenosis), absent ear canal (atresia) or chronic middle ear pathology with excessive drainage. A hearing aid microphone is wired directly to a bone oscillator (receiver) and placed on the mastoid bone to directly stimulate the organ of hearing (cochlea).

**CERUMEN:** The medical term for earwax. It secreted from the glands in the ear canal and protects it from infection.

**CHOLESTEATOMA:** A non-cancerous tumor where skin cells grow uncontrolled (usually through a hole in the eardrum) and accumulates in the middle ear. It may also be the result of chronic otitis media and have a strong distinct odor. A cholesteatoma damages the middle ear and surrounding structures and needs to be surgically removed.

**CHRONOLOGICAL AGE/ADJUSTED AGE:** Chronological age refers to the age of an individual as measured from birth to a given date. It is used when comparing to other children born at that same time. If a baby was born prematurely, however, his/her development may be measured at his/her adjusted age. Adjusted age is the age of the baby based on his due date. Healthcare providers may use this age when they evaluate the baby's growth and development. So, if a baby is 6 months old, but was born two months early, his adjusted age is 4 months

**COCHLEA**: The auditory portion of the inner ear consisting of fluid-filled channels containing the hair cells. The cochlea is shaped like a small snail shell and normally consists of two and a half turns. The cochlea converts incoming sound waves from the middle ear into electrical signals and transmits these signals to the auditory nerve.

**COCHLEAR IMPLANT:** A cochlear implant is an electronic device that is surgically implanted in the cochlea of the inner ear. It transmits auditory information directly to the brain, by-passing damaged or absent auditory nerves. Typically, cochlear implant users have severe to profound hearing losses and do not get much benefit from hearing aids. Successful CI users gain useful hearing and improved communication abilities with consistent use of the device and therapy. The FDA has approved CIs for children who are profoundly deaf at age 12 months and for those with severe hearing loss at age 24 months. Adults with a moderate to profound hearing loss can receive a cochlear implant as well. Presently, there are 3 manufacturers that are FDA approved to implant this device: Advanced Bionics, Cochlear Americas, and Med El.

COGNITION: The ability to think, learn and remember.

**CONDITIONED PLAY AUDIOMETRY (CPA):** The testing of young children is accomplished by conditioning the child to respond to sound using with small toys. Blocks, rings, pegs and puzzles can be used to obtain a reliable audiogram. Typically used with young children at a developmental age of 2 to 5 years.

**CONDUCTIVE HEARING LOSS:** Conductive hearing loss occurs when sound is not conducted efficiently through the outer ear canal to the eardrum and the tiny







**GENETIC COUNSELING:** counseling and diagnosis of genetic conditions for individuals with birth defect/genetic disorders, which may involve hearing loss and genetic counseling including recurrence risk information for individuals with hearing loss and their families.

**HARD OF HEARING:** A hearing loss, whether permanent or fluctuating, which adversely affects an individual's ability to detect and decipher some sounds. The term preferred over "hearing impaired" by the Deaf and hard of hearing community to refer to individuals who have hearing loss, but also have and use residual hearing.

**HEARING SCREENING:** Audiometric testing of the ability to hear selected frequencies at intensities above normal hearing. The purpose is to identify individuals with hearing loss, with minimal time expenditure, and to refer them for further testing.

**HEARING AID:** An electronic device that delivers and amplifies sound to the ear.

HEARING IMPAIRMENT: A partial or total inability to hear

**HEARING LOSS:** The following hearing levels are typically characterized as follows:

(need to list the source of the levels listed here, ASHA?- J. Cundall, 9/12)

Normal Hearing	0 dB to 15 dB
Slight Loss	16 dB to 25 dB
Mild Loss	26 dB to 40 dB
Moderate	41 dB to 55 dB
Moderate/Severe	56 dB to 70 dB
Severe Loss	71 dB to 90 dB
Profound	91 dB or more

HUGGIES: The brand name of a plastic-ringed device designed to "hug" the hearing aid to the ear. One of many options for retention for infants and toddlers.

**I.D.E.I.A.:** The Individuals with Disabilities Education Improvement Act, Public Law 108-446; formerly known as Public Law PL 105-17;101-476, PL 94-142 and PL 99- 457. Part C (See "Part C") provides services to children birth to three years of age with disabilities. Part B of IDEA covers educational mandates for students age three through high school graduation or age-out of the system.

**INCLUSION:** Often used synonymously with the term "mainstreaming," this term refers to the concept that students with disabilities should be integrated and included to the maximum extent possible with their (typically developing) peers in the educational setting.

**INDIVIDUAL FAMILY SERVICE PLAN (IFSP):** The IFSP addresses 1) The family's strengths, needs, concerns and priorities; 2) identifies support services available to meet those needs; and 3) empowers the family to meet the developmental needs of their infant or toddler with a disability. The IFSP is a written

plan developed by parents or guardians with input from a multi disciplinary

team. (Reference part C.)

**INDIVIDUALIZED EDUCATION PROGRAM (IEP):** A team-developed, written program, which identifies therapeutic and educational goals and objectives, needed to appropriately address the educational needs of a school-aged student with a disability. An IEP for a child who is

deaf or hard of hearing must be accompanied by that child's Communication Plan, and must take into account such factors as 1) communication needs and the child's and family's preferred mode of communication 2) linguistic needs; 3) severity of hearing loss; 4) academic progress; 5) social/ emotional needs, including opportunities for peer interactions and communication; and 6) appropriate accommodations and assistive communication devices to facilitate learning; 7) opportunities for interaction with peers and adults using the child's same communication mode; 8) the proficiency of the staff delivering identified services on the IEP and opportunities for direct instruction in the child's communication mode: 9) all educational placement options, and 10) how the extra-curricular activities will be made communication-accessible.

**INTENSITY:** The loudness of a sound, measured in decibels (dB).

**INTERPRETER:** A person who facilitates communication between hearing and deaf or hard of hearing persons through interpretation into a signed language, or transliteration of a language into a visual and/or phonemic code by an oral interpreter, a signed language interpreter or cued speech interpreter.

**INTONATION:** The aspect of speech made up of changes in stress and pitch in the voice.

**LISTENING AND SPOKEN LANGUAGE SPECALIST (LSLS)**: Listening and Spoken Language Specialists (LSLS<sup>TM</sup>) work with infants and children who are deaf or hard of hearing and their families seeking a listening and spoken language outcome in a variety of settings: home-based intervention, public schools, independent schools, private therapy, clinical centers for the deaf and hard of hearing, audiological and cochlear implant centers.

**LARGE VESTIBULAR AQUEDUCT SYNDROME (LVAS):** A genetic condition where the vestibular aqueduct is larger than normal. The result is that many people with enlarged vestibular aqueducts suffer from hearing loss from head trauma or from rapid changes in pressure.

**LEAST RESTRICTIVE ENVIRONMENT:** A basic principle of Public Law 101-476 (IDEIA) which requires public agencies to establish procedures to ensure that to the maximum extent appropriate, children with disabilities, including children in public or private institutions or other care facilities, are educated with children who are not disabled, and that special classes, separate schooling, or other removal of children with disabilities from the regular educational environment occurs only when the nature or severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily.

**MAINSTREAMING:** Educational placement of students with disabilities into typical, general education classrooms, for some or all parts of the school day, based on the student's IEP. This placement decision may be rooted in the philosophy that

all children with "disabilities" should be integrated with their non-disabled peers to the maximum extent possible, when appropriate to the needs of the child with a disability. Mainstreaming is one point on a continuum of educational options. The term is sometimes used synonymously with "inclusion."

**MAP:** The program stored in the speech processor of a cochlear implant that tells the system how to process sound on each channel so that it is most audible and comfortable for the individual user. Each implant user's map varies considerably from every other user. Maps also change over time.

**MAPPING:** The process of programming a cochlear implant speech processor with various speech strategies, programming and features.

**MENIERE'S DISEASE (SYNDROME):** A syndrome that consists of vertigo, tinnitus, a feeling of fullness in the affected ear and a fluctuating hearing loss. It is thought to be caused by fluid imbalance in the inner ear.

**MENINGITIS:** A bacterial or viral inflammation that can cause auditory disorders due to infection or inflammation of the inner ear or auditory nerve.

**MIDDLE EAR:** An air-filled cavity, about the size of a pea, between the eardrum and inner ear containing three tiny bones (called ossicles)—malleus (hammer), incus (anvil) and stapes (stirrup)—that conduct sound from the eardrum to the inner ear via the oval window.

**MIXED HEARING LOSS:** A combination of both sensorineural (inner ear) and conductive (middle ear or outer ear) hearing loss. The audiogram show an airbone gap of 15 dB or more.

MONAURAL AMPLIFICATION: The use of one hearing aid.

**MORPHEME:** A linguistic unit that cannot be divided into smaller meaningful parts.

**MOST COMFORTABLE LOUDENSS LEVEL (MCL):** The volume at which sounds are most comfortable for an individual with hearing loss.

**MULTI-DISCIPLINARY ASSESSMENT AND EVALUATION:** Qualified persons representing two or more disciplines or professions, i.e.; a speech therapist and an audiologist make this assessment and evaluation of the child. The child's development is evaluated to determine if there are any

delays or conditions that would indicate the need for special services.

**MYRINGOTOMY:** A small incision made in the eardrum by a physician to equalize air pressure and/or to drain infection or fluid from the middle ear.

**NATIVE LANGUAGE:** The language of the home, i.e. the native language of children who are deaf with deaf parents is often American Sign Language.

**NEUROLOGIST:** A medical doctor whose specialty is problems of the peripheral and central nervous systems, and their connection to the senses.

**NEUROTOLOGIST:** An otologist who specializes in the nervous system related to the auditory and vestibular systems.

**NEWBORN HEARING SCREENING:** A program in place in many hospitals across the country that allows a child's hearing to be evaluated immediately

after the baby is born. Tennessee passed "Claire's Law" in April 2008 to require newborn hearing screening; effective July 1, 2008. The law states that a child shall be screened for hearing loss prior to discharge from the birth facility or prior to one month of age."

**NOISE INDUCED HEARING LOSS:** A permanent hearing loss caused by exposure to loud noise. It can be caused by a single incident or exposure to noise over time.

**NOTETAKER**: A person who takes notes for an individual with hearing loss.

NYSTAGMUS: Involuntary movement of the eyes that may accompany vertigo.

**OPEN FIT HEARING AID:** An ear piece that fits more open in the ear canal and thus permit natural sounds to enter and the louder low frequency sounds from the hearing aid to escape thus preventing the distorted and muffled occlusion effect. The open fitting is reserved for older children and adults.

**ORAL**: An unspecific term that is sometimes used when referring to individuals with hearing loss and deafness who talk but don't necessarily use sign language. Emphasis is placed on use of residual hearing, lip reading and contextual cues to communicate using spoken language.

**OTITIS**: An inflammation involving some portion of the outer, middle or inner ear.

**OTITIS MEDIA:** A middle ear infection. Children with recurring episodes may experience fluctuating hearing loss and may be at risk for speech/ language delays. Fluid can be present with or without infection and may cause temporary hearing loss, which can evolve into permanent loss.

**OTO-ACOUSTIC EMISSIONS (OAE):** An objective audiological test that verifies cochlear (organ of hearing) activity, often is used in testing infants suspected of hearing loss. OAE cannot determine the type or degree of hearing loss and must be used in conjunction with other audiological tests.

OTOLOGIST: A physician who specializes in medical problems of the ear.

**OTOLARYNGOLOGIST:** A doctor trained to specialize in diseases of the ear, sinuses, mouth, throat, larynx and other structures of the head and neck. Commonly called an ENT (ears, nose and throat doctor).

**OTORRHEA:** A purulent discharge (puss) draining from the ear canal.

OTORRHAGIA: Bleeding from the ear canal. Ear hemorrhage.

**OTOSCLEROSIS:** A genetic condition where abnormal spongy bone grows on the tiny bones in the middle ear causing a progressive hearing loss,

**OTOSCOPE:** A special instrument that contains a flashlight and magnifying glass used for examining the ear.

**OTOTOXIC:** A chemical or drug that could potentially be harmful to the function of the auditory system.

**OUTER EAR:** The external ear and the ear canal. This part of the ear that collects sounds waves and directs them into the ear.

**OUTPUT:** Refers to how much amplification is being put out by a hearing aid

**PARENT-INFANT PROGRAM**: A program of family-centered education and infant intervention which stresses early exposure to language and attention to developmental processes which enhance the learning language.

**PART C:** Part C is the section of Public Law PL 105-17 (I.D.E.A.) that refers to early intervention services available to eligible children from birth through two years of age and their families.

**PART B:** Part B is the section of Public Law PL 105-17 (I.D.E.A.) that refers to early intervention services available to eligible children aged three through twenty-one in the public schools.

**PERI-LINGUAL DEAFNESS:** Refers to hearing loss acquired while learning a first language.

**PERILYMPHATIC FISTUA:** A tear in the oval or round windows separating the middle ear from the inner ear allowing perilymph to drain into the middle ear. This can cause hearing and balance problems sometimes similar to Meniere's disease.

**PERI-LINGUAL:** During the period of language acquisition.

**PHONEME:** The smallest unit in a language that is capable of conveying a change in meaning. For example, the "m" in "mall" and the "b" in "ball." There are 41 phonemes in the English language. A phoneme may also be referred to as speech sounds.

**PINNA:** The external or outer ear (auricle).

**PIDGIN SIGNED ENGLISH (PSE):** When an individual uses American Sign Language signs for the most part, but in English word order.

**POST-LINGUAL DEAFNESS:** Refers to hearing loss acquired after learning a first language.

**PRE-LINGUAL DEAFNESS:** Refers to hearing loss, which is congenital or acquired before acquisition of language

**REAL-EAR MEASUREMENT**: A verification measure of the actual gain and output of the hearing aid in the ear canal. This test uses a "probe-microphone" that is placed into the ear canal along with the hearing aid and ear mold fitted in place. It assesses how effectively sound is actually being amplified by the hearing aids in the ear. It is considered a very important measurement because everyone's ear canals are shaped differently and this will effect how a hearing aid functions.

**REAL EAR TO COUPLER DIFFERENCE (RECD):** A measurement typically made in young children during the verification process. This measurement allows the audiologist to accurately account for the child's individual ear size when fitting hearing aids.

**RECEPTIVE LANGAUGE:** A child's ability to understand the language that is spoken or signed to him.

**RELAY TELEPHONE SERVICES:** Relay Telephone Service/Relay Network. A service which involves an operator "relaying" conversation between a TDD/TTY user (generally a person with a hearing loss and/or speech impairment) and a hearing/speaking individual using an ordinary, non-adapted phone.

**RESIDUAL HEARING:** The amount of hearing that remains usable when a hearing loss is present without the use of amplification.

SEMANTICS: The meaning of words and how they relate to one another.

**SENSORINEURAL:** A type of hearing impairment caused by damage that occurs to the inner ear (cochlea) and/ or nerve of hearing. Sensorineural damage is usually irreversible.

**SIGN LANGUAGE:** A manual form of communication using hand movements, gestures and facial expressions rather than spoken words. Forms of sign language are American Sign Language (ASL), signed English and Pidgin.

SIMULATED REAL EAR MEASURE (SREM): A verification measure of the actual gain and output of the hearing aid without the hearing aid in the child's ear. It assesses how effectively sound is actually being amplified by the hearing aids. An average or measured RECD is applied to this measure for the most accurate fitting.

**SPEECH RECOGNITION THRESHOLD (SRT):** This is the softest level at which an individual identifies 50% of the simple spoken words presented and repeats them correctly. A two-syllable word that has equal stress on both syllables is used to obtain an SRT. Some examples of spondee words include baseball, cowboy, hotdog, ice cream and railroad.

**SPEECH LANGUAGE PATHOLOGIST**: A trained health care professional that has a Masters degree in Speech-language pathology whose professional practice includes the evaluation, rehabilitation and prevention of speech and language disorders. Speech and language delays are frequently seen in children with hearing loss. Speech Language Pathologists are typically certified by the American Speech Language Hearing Association (ASHA). Most states require licensure.

**SPEECH AWARENESS THRESHOLD (SAT):** This is the softest level at which an individual demonstrates the ability to detect speech with 50% accuracy.

**SPEECH INTELLIGIBILITY:** The degree to which an individual can to understood when speaking.

**SPEECH BANANA:** On an audiological graph measured in decibels and frequencies, the area wherein most conversational sounds of spoken language occur. Sometimes called the "speech banana" because of the shape this area depicts on the graph. The purpose of wearing hearing aids is to amplify sound into this zone.

**SPEECHREADING:** The interpretation of lip and mouth movements, facial expressions, gestures, prosodic and melodic aspects of speech, structural characteristics of language, and topical and contextual cues.

SYNTAX: The ways that words are combined to form sentence structure.

**TACTILE AIDS:** A type of assistive listening device that emits a vibration or "tactile" signal to indicate the presence of sound(s). It is worn on the body and triggers the sense of touch or feeling to draw attention to information that cannot be heard by the individual with hearing loss.

**TEACHER OF THE DEAF:** A teacher who has a master's degree in deaf education and can communicate fluently with deaf students. These qualifications are needed in order to educate the deaf student.

**TELECOIL:** A small coil of wire in most hearing aids and cochlear implants that allows the device to pick up the magnetic fields emitted by telephones, various assistive listening devices, or induction room loops. Sometimes referred to as "t-switch" or "t-coil".

**TELECOMMUNICATION DEVICES FOR THE DEAF (TDD'S):** Originally and often still called TTY's, these electronic devices allow the deaf and hard of hearing to communicate via a text telephone system. This term appears in ADA regulations and legislation.

**TELECAPTION (CLOSED CAPTION DECODER)**: An electronic device or computer chip that can display closed captions encoded in television programs or videos. Also called a telecaption adapter and designed for use by individuals who are deaf or hard of hearing. These remote captioning systems allow closed captioning to be displayed outside of the normal on-screen viewing area.

**THRESHOLD**: The softest sounds (speech or tones) a person can detect 50% of the time.

**TINNITUS:** (TIN-ih-tus or tih-NIGH-tus) A sensation of various noises in the ears. It is not a disease, but a symptom of an underlying auditory condition. It is often associated with hearing loss and exposure to loud noise.

**TOTAL COMMUNICATION:** A communication methodology that utilizes spoken language, sign language and the use of facial expressions/gestures.

**TYMPANOGRAM:** A pressure or "impedance" test that tells how the ear canal, eardrum, Eustachian tube, and middle ear bones are working. It is not a hearing test.

**TYMPANIC MEMBRANE**: The eardrum. It separates the outer ear from the middle ear as it vibrates in response to incoming sounds, which are then transmitted to the middle and inner ear.

UNILATERAL HEARING LOSS: A hearing loss that is present in one ear.

**UNCOMFORTABLE LOUDNESS LEVEL (UCL):** The intensity at which sounds become uncomfortably loud.

**VIDEO RELAY/VIDEO PHONE:** Video Relay Service (VRS) is a communication technology where an individual who is deaf can communicate with a hearing person and vice versa. This service utilizes sign language interpreters to convey messages. Special equipment is needed.

**VIDEO/VISUAL REINFORCEMENT AUDIOMETRY (VRA):** The testing of young children is accomplished by conditioning the child to look at a toy or video each time he or she hears a sound; typically used with young children at a developmental of age 6 months to 2 years.