Your Journey With Your Baby Who Is D/deaf or Hard of Hearing

For Families with Children Who Are Deaf or Hard of Hearing

PEARS

PARENTS • EMPOWERMENT • ACCESS • RESOURCES • SUPPORT

FAMILY VOICES of Tennessee

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Dear Parent,

You have just discovered your baby has hearing loss. As parents of children with hearing loss, ourselves, we know that you are experiencing different emotions right now. When we found out that our children had hearing loss, we experienced a range of fears and emotions. Each of us had questions and concerns. All of these emotions are very natural and understandable. We want you to know that this is not the end but rather a bright beginning and rewarding future for you and your baby. There are agencies that can help you answer some of your questions and we will introduce you to a few of those agencies in this parent packet.

After you have had time to process everything, you may want to talk to another parent. Family Voices of Tennessee PEARS has specially trained Parent Guides that are located across the state who are also parents of children of varying ages who are deaf or hard of hearing. We, the Parent Guides, have experienced the same emotions, have asked the same questions and have had the same fears that other parents have. We are available to support you through this journey.

Please know that you are not alone on this journey. PEARS is here to provide support, help you navigate services for your child, and most of all - enjoy your baby!

Kind regards,
PEARS Parent Guides

FAMILY VOICES of Tennessee

Family Voices of Tennessee (FVTN) PEARS is the family based organization in Tennessee for newly identified children with hearing loss. We are contracted by the TN Department of Health Newborn Hearing Screening Program to provide family support.

PEARS Parent Guides are parents of children who are D/deaf, hard of hearing, deafblind, or deaf plus. Parent Guides are able to bring their personal experience, knowledge, and compassion to their role while making the family's needs their primary focus.

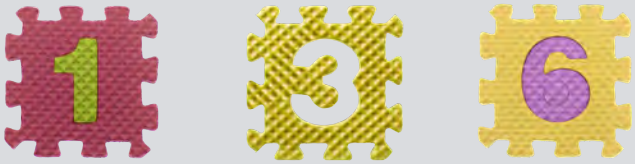
If you do not already have a Parent Guide, but would like one, please contact:

Leah Williamson, Program Coordinator
901-359-2076
leah_w@tndisability.org

How Can a Parent Guide Help Your Family?

- Provide individualized information, resources, and support, helping each family to make decisions that are right for their child.
- Bring our personal parenting experiences, knowledge, and compassion to our role while making the family's needs our primary focus.
- Provide insights on navigating healthcare and educational systems from a parent perspective.
- Give tips to help with appointments & evaluations.
- Attend doctor appointments & IEP meetings to provide moral support

You are Not Alone



What do the numbers 1-3-6 mean?

Each number stands for an age (in months). At each age, there are recommendations that have been made by the American Academy of Pediatrics' Early Hearing Detection & Intervention Guidelines.

By 1 month of age: Your baby should have a newborn hearing screen

b**y 3 months of age:** If your baby did not pass the newborn hearing screen, your baby should have another hearing test by an Audiologist.

by 6 months of age: If the results indicate that your baby has a hearing loss, your baby should be enrolled in appropriate early intervention services, and ideally have received amplification.

Where to Get

The following is a selective list & services are all free to families:

1.**Family Voices of TN PEARS;** a Parent Guide can guide you along your journey.

2. **KidCentral;** online information resource for parents www.kidcentraltn.com

3. **TN Early Intervention System (TEIS);** coordinate services such as speech & listening therapy. 800-852-7157 or www.tn.gov/education/teis

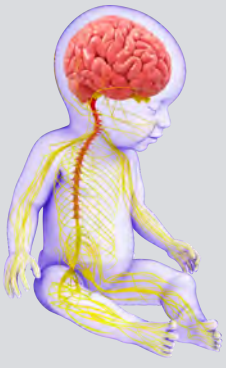
4. **TennCare Kids;** a full program of checkups & health care services for children from birth through age 20. 866-311-4287 or www.tn.gov

5. **Children's Special Services (CSS);** provides medical services & reimbursement, medical supplies, therapies, etc. 615-741-0361 or http://health.state.tn.us/MCH/special-services

Importance of Communication

Communication is a necessity in life. If your baby has difficulty communicating, how will she or he connect with people or get information? For a baby, being able to communicate with others is just as important as it is to an adult.

Neuroscientists tell us that a baby is born with millions of brain cells, all he or she will ever need. Each brain cell has branching appendages, called dendrites, that reach out to make connections with other brain cells. The places where brain cells connect are called synapses. When electrical signals pass from brain cell to brain cell, they cross the synapse between the cells. When synapses are stimulated over and over, that pattern of neural connections is “hard-wired” in the brain. It becomes an efficient, permanent pathway that allows signals to be transmitted quickly and accurately. Advances in brain-imaging technology in recent years have confirmed this process.

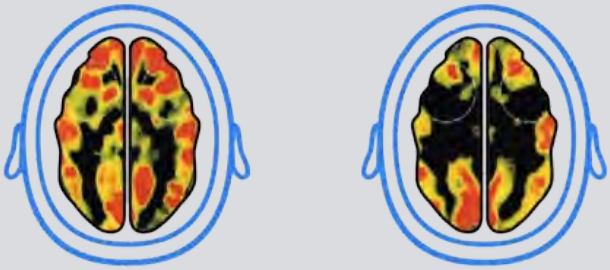


New technology has allowed us to see that there are physical differences in a child's brain that has been appropriately stimulated, versus one that has suffered lack of stimulation.

Connections that are not stimulated by repeated experiences atrophy or fade away. It is truly a "use-it-or-lose-it" situation.

We know that reorganization of the connections between brain cells after birth is highly impacted by experiences provided by the child's environment. Parents play an invaluable role in influencing the child's cognitive, language, motor, & social emotional development. It is through providing repeated, positive experiences for their child that parents have a lasting impact on his or her child's brain development.

So, no matter how you communicate with your baby, the priority is that you do communicate as much as possible every day so your baby's brain can develop healthily & to it's highest potential.



Help Your Baby Build Communication Skills

Share Close Moments

Babies love to be held. While a baby is being held, there are many opportunities for you and your baby to share experiences that will allow your baby to begin to understand how communication works.

These moments, sometimes called bonding, can take many forms. For example, the experience of rocking your child to sleep - your baby can see you smile at him and feel the comforting and rhythmic motion of rocking. Even if your baby has a hearing loss, she can certainly feel the soothing vibrations of the lullabies you sing to her. Through these things, you are communicating concepts of safety, comfort, and love.

Over time, you should begin to see your baby respond during these close moments. You should begin to see his first signals of communication.

Help Your Baby Build Communication Skills

Respond to Signals

Signals that are common in babies are crying, smiling, looking toward an object, tensing up, kicking legs, or moving arms. Really, any observable movement in your baby's body may be a signal that he or she is trying to communicate something to you. Pay attention to those signals and respond to them.

When your baby is upset, he may signal this by tensing up his whole body. You can respond to this signal by using a soothing voice or gently patting his back. Your actions will let him know that you realize he is "telling" you something, and that what he is communicating is important to you. Because your little one cannot talk or sign yet, signals are the best way for her to tell you what she is thinking about.

Help Your Baby Build Communication Skills

Play

Although it sounds too simple, playing with your baby allows you to build his understanding of the way people communicate. Many parents of newborns think it may be too early for their baby to play. Not true. The youngest of babies are best entertained by faces. Try making different faces with your baby and watch how she watches you. Even babies with hearing loss can learn a lot about the many emotions people communicate by watching faces. Older babies can learn about communication by playing fun games like peek a boo, even if they are not quite ready to respond. When your baby gets older, she can also learn by copying you or her siblings doing fun things during play like clapping, blowing, blinking, & even sticking out your tongue. Babies who begin to imitate these actions during play are showing us that they will soon be ready to imitate parts of language by using gestures, signs, or words.

How to Help Your Baby Hear & Communicate Better?

Remember: Talk to & communicate with your child often & stay up to date with all health care appointments. Your baby's health care team can help you find services & methods to overcome communication barriers. You may also be referred to a speech-language pathologist or a teacher who is experienced in working with babies with hearing loss.

Depending on your baby's hearing loss & communication needs, there are devices & tools that may help to maximize his or her communication skills.

- Hearing aids
- Cochlear implants
- Bone Anchored Hearing Aid (BAHA)

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• **Hearing aids**. Worn behind the ear, hearing aids help make sounds louder & clearer. Hearing aids can be used for different degrees of hearing loss in babies as young as 1 month. A Pediatric Audiologist who is experienced in treating infants and children can help you choose the best hearing aid and make sure that it fits securely and is properly adjusted.

• **Cochlear implants**. If your child cannot benefit from a hearing aid, your doctor or Audiologist may suggest a cochlear implant. This electronic device can provide a sense of sound to people who are profoundly deaf or hard-of-hearing. Cochlear implants can be surgically placed in children as young as 12 months, or sometimes earlier.

• **Bone Anchored Hearing Aid (BAHA).**
Primarily suited for babies who have conductive hearing loss, unilateral hearing loss, single-sided deafness & mixed hearing losses who cannot otherwise wear 'in the ear' or 'behind the ear' hearing aids.

Daily Listening Device Checks

Since your baby can't tell you whether their hearing devices are working each morning, you'll need to take action. Take five minutes at the start of each day to do a device check so your baby can hear all the sounds of speech. These checks are important because you can confirm that your baby's hearing devices are providing complete speech information to their brain & that they're noticing & actually listening to that speech information.

Check the Batteries

Use a battery tester to see that the battery is fully charged & always replace low batteries.

Listen to Each Hearing Device

Your Audiologist can provide you with a listening tube, a handy tool to let you listen to the sound from the devices.

Do a Listening Check

Learn how to perform the Ling Six-Sound Test. You'll produce specific speech sounds to see how your baby reacts without being able to see your mouth. These six sounds represent all the frequencies or pitches of speech. This quick at-home check will confirm your baby is hearing, responding, & identifying these sounds. Turn your baby's devices on & then use a normal conversational voice to say these speech sounds:

/m/ as in me
/ah/ as in hot
/oo/ as in boot
/ee/ as in feet
/sh/ as in shoe
/s/ as in sun

You'll become the expert on how your baby responds to sounds. Take note of sounds your baby doesn't respond to & share with your professional team.

How to Keep Hearing Aids On Little Ears

Keeping baby hearing aids on little ears can be tricky but you can try:

Distract: call their name or use a toy to draw their attention away from the device

Adhesive: medical or wig tape may help keep the device on when used appropriately

Hats: a hat or cap can discourage touching; there are a number of little hats made especially for hearing device retention

Headbands: secures over the hearing aids, but make sure the microphone isn't covered.

Special Clips: keep the hearing aids attached to your child's clothes. Even if the hearing aids are pulled off, you won't lose the expensive devices.

Keeping Hearing Aids on Little Ears

It's a good idea to develop a routine each day for putting your infant or child's hearing aids on. Spend time cuddling & holding your child when you put their hearing aids in to develop a positive association with them. When your curious child pulls the hearing aids off, be consistent but gentle in replacing them each time so he or she knows that's where they belong.

Most babies go through a phase of pulling their hearing aids off. But if your baby insists on pulling their devices off frequently, there could be an underlying problem, like earmolds that don't fit anymore, hearing devices that aren't working properly, or ear infections causing discomfort. Share all of your concerns about hearing device wear time with your Audiologist to make sure there isn't an underlying problem.

Children's Books with D/HH Characters 0-8 yrs

Ada & the Helpers
by Travis D. Peterson
This little deaf fox will dance her way into your child's heart. On her way to dance in a talent show, Ada meets three new creatures, each with a disability of their own.

Lucy
by Sally O. Lee
Lucy discovers she can't hear in one ear after a play session with friends. After her parents take her to the doctor, who confirms her hearing loss, Lucy is sad until she begins to notice others with different disabilities.

Ranvir Cannot Hear
by Genevieve Yusuf
This beautifully illustrated story is about a young elephant who goes on a long journey in search of his hearing & learns about inclusion & empowerment in the process. British & American Sign Language alphabets are included in the back.

Children's Books with D/HH Characters 0-8 yrs

Super Kena: A Girl Made Fierce with Hearing Aids
by Becky Cymbaluk
Kena, a girl with hearing aids, works through issues with classmates who don't understand her hearing loss. With the help of her mom, Kena realizes her hearing aids give her ears "superpowers" and makes plans to form a team of her other differently abled friends in an effort to explain their superpowers to the class during Show & Tell.

Freddie & the Fairy
by Julia Donaldson
Fairy Besse Belle has hearing loss, but that doesn't stop her from trying to grant Freddie's wishes. Unfortunately, Freddie mumbles, so the Fairy Queen steps in to help.

Mighty Mila
by Katie Petruzziello
Petruzziello is mom to three kids, including a daughter who is deaf and uses cochlear implants to hear. Her daughter's observation that few books included deaf/hard of hearing characters like her prompted Petruzziello to write one.

Children's Books with D/HH Characters 0-8 yrs

Dad & Me in the Morning
by Patricia Lakin
Parents & children will enjoy this sweet read, describing the very special relationship a dad has with his deaf son & how they find ways to communicate with each other. A great introduction to American Sign Language (ASL) and Deaf culture.

Cosmo Gets an Ear
Gary Clemente
This interactive book, written from a young child's perspective, describes the journey from hearing loss to hearing aid. Readers and/or listeners can interact by answering multiple-choice questions, as well as learning about benefits to wearing hearing aids and how to take care of them.

Communication Options

There are many ways to communicate. Whichever method or methods you choose, communication is key! Some of the options include:

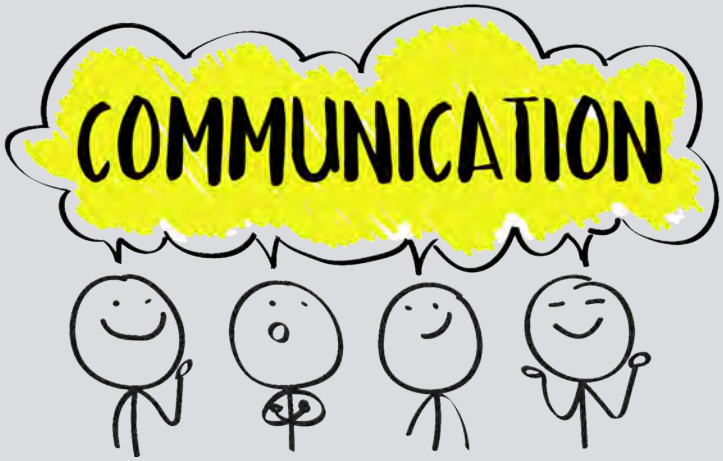
Auditory-Verbal / Listening & Spoken Language; approach that teaches & encourages the child to make maximum use of any residual hearing through amplification. This approach stresses spoken language development & strives to make the most of the child's ability to learn through listening.

Cued Speech; a system of hand cues with the natural mouth movements of speech, specifying each sound of spoken language clearly. A hand shape at a location cues a syllable. This integration provides clear access to all the sounds as parents coo, babble and talk.

Communication Options

American Sign Language: A fully developed, autonomous, natural language with a unique grammar, syntax, vocabulary, & cultural heritage; gestures, visual components, & structures are not derived from English, nor are they a simplified version of English. It is not used simultaneously with voiced English. The acquisition of English is addressed through these of teaching strategies for English as a Second Language.

Simultaneous Communication; Combines spoken & signed communication. Parents are encouraged to both speak & sign when communicating with their child. The child uses amplification, is encouraged to use their residual hearing as well as sign & speak. An English based manual system is used for the signs.



Common Facts About Hearing Loss

A. Hearing loss ranges from mild to very profound, including complete deafness

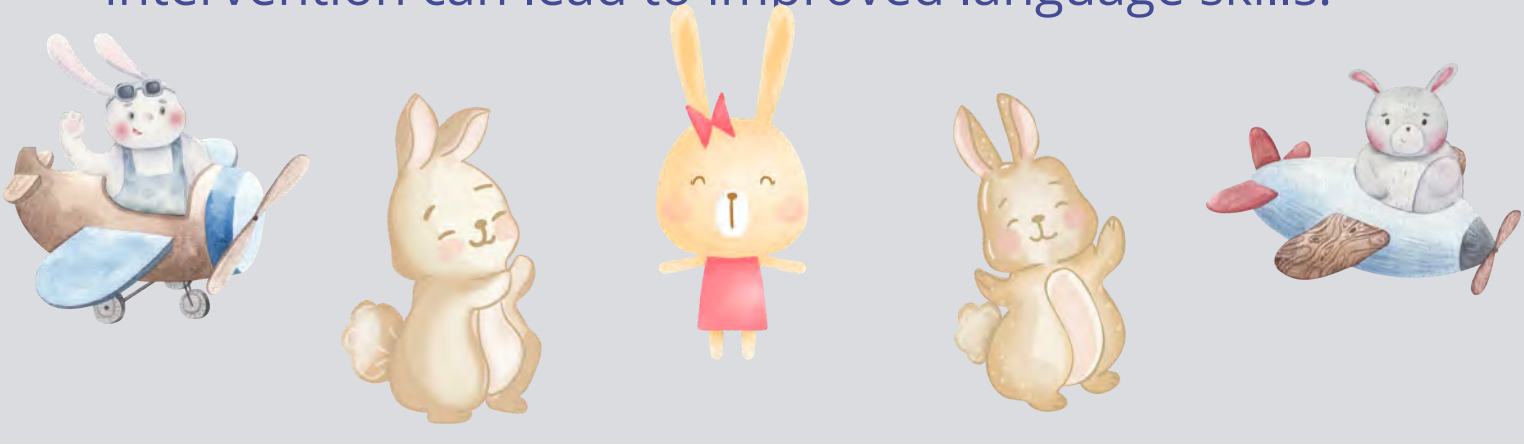
B. 33 babies are born with hearing loss every day in the United States

C. 95% of babies born with hearing loss are born to hearing parents.

D. Hearing loss is the number one most common birth defect in the United States.

E. There are different types of hearing loss; sensorineural, conductive, mixed, auditory neuropathy, & unspecified.

F. Early identification of hearing loss with early intervention can lead to improved language skills.



Common Facts About Hearing Loss

G. Infants identified with hearing loss can be fit with amplification as early as four weeks of age.

H. Not all hearing loss is present at birth. Causes for hearing loss later in childhood could include genetic factors, illness, and trauma.

I. Most states require that hospitals screen babies at birth for possible hearing loss. This screening is painless and only takes a few minutes.

J. With advances in infant hearing screening, hearing technology, family education & appropriate educational intervention, infants & toddlers with hearing loss now have the opportunity to develop language at the same rate as children with typical hearing.

Important Contacts:

Notes:

Contact Us

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