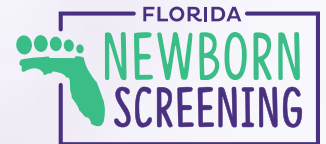


# A FLORIDA PARENT'S GUIDE TO HEARING

APRIL 2020 EDITION



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**If your child has recently been identified with a different hearing level, then this Parent Guide is for you.**

### **USE THIS GUIDE TO:**

- Learn how to understand and address your emotions, fears, and concerns,
- Learn more about the types, degrees, and causes of different hearing levels,
- Learn about hearing aids, cochlear implants, and other hearing technologies,
- Learn which professionals may be part of your child's intervention team,
- Learn about the wide variety of communication options available to your family,
- Learn the laws that support your child's education, and
- Learn how to become an advocate for your child



# START WITH A ROADMAP

■ Parenting is a wonderful, exciting, and sometimes scary journey – especially when your baby has been identified with a differing hearing level. Fortunately, you do not have to tackle the next steps alone. This guide is intended to act as a roadmap to help you work through your feelings, assemble a team of supportive professionals, and develop a communication plan that will help your baby succeed.

▶ THE ROAD SO FAR

▶ THE ROADMAP

▶ STEP-BY-STEP GUIDE

## THE ROAD SO FAR

If you have received this Parent Guide, then your child has a different hearing level. More than likely, your child completed a hearing screening in the hospital or an outpatient center, and that test produced atypical results from one or both ears. Your doctor may have suggested one or more follow-up tests; or referred you to an Otolaryngologist/Ear Nose and Throat (ENT); or Audiologist's office where they were able to identify the difference.

This may mean that your child's hearing is mildly, moderately, or severely below typical levels in both ears (bilateral) or in only one ear (unilateral). This could be caused by the shape of your child's outer or inner ear, differences in or damage to the nerves within the ears, medical conditions or medications, or a combination of these things. It is also possible that your child has been diagnosed with a genetic condition of which a hearing difference is affected.

Every person is different and therefore everyone's hearing level is different. Some people benefit from the use of hearing aids or cochlear implants to hear more clearly, just like others benefit from the use of glasses to see. Still others benefit from the use of visual/manual communication options, such as Cued Speech or American Sign Language. Remember: everyone's needs are unique. A person who uses glasses has a unique prescription, created just for them, that helps to see the world clearly. Hearing is no different. All children with differing hearing levels deserve unique early intervention and care to help reach their full potential, and here are the first steps to take to formulate a plan.

## THE ROADMAP

Any time you start a journey, it is helpful to know where you are headed. The next several sections in this Parent Guide are intended to serve as a roadmap to help navigate the next steps in the process.

There are many resources, helpful information, and tips which may feel overwhelming. While some parents prefer to see all the information up front, others prefer to digest information more slowly and take time to think about each step. Approach this guide in the way that works best for you, your family, and your child.

Also, remember that a digital copy with links is always available on the Department of Health website at [www.floridanewbornscreening.com](http://www.floridanewbornscreening.com).

## STEP-BY-STEP GUIDE

1. Adjust and adapt to your child's hearing level.
2. Understand your child's hearing level.
3. Assemble your team.
4. Develop a communication plan.
5. Learn to advocate.

Each section in this Parent Guide is designed to provide information and resources for each of these steps in your child's journey. Every child deserves a good start, and, with the help of this guide, you can be your child's best advocate.



# ADJUST AND ADAPT

■ Approximately 95% of children who have a different hearing level are born to typically hearing parents, so a diagnosis almost always comes unexpectedly. Parents may feel many emotions at once ranging from shock and denial to acceptance and peace. While it takes time to move through the feelings you may experience after your child is identified with a different hearing level, there are support networks, techniques, and systems in place to help.

## › EMOTIONAL OVERLOAD

## › UNDERSTANDING YOUR FEELINGS

## › TECHNIQUES FOR COPING AND HEALING

## › PARENT-TO-PARENT SUPPORT

## › WHAT IS “DEAF/HH PLUS?”

## › TESTIMONIALS

## EMOTIONAL OVERLOAD

The period after diagnosis can be an intensely emotional time. Learning that your child's hearing level is different is not easy, and it is common for parents to experience strong emotions. Some of these feelings are very strong and begin right away, while others develop over time.

As hearing parents become connected with the support networks and services available to them, they may begin to see this experience in a new and more positive light. Yet, in the beginning, it is vital that you, as the parent, do not neglect your needs. Remember that, while your son or daughter has never known any other reality, your reality has changed in a big way.

## UNDERSTANDING YOUR FEELINGS

While people handle situations differently, studies suggest that there are several stages of grief and some common emotions within those stages that many parents experience when their child is diagnosed with any health concern, including a different hearing level. By becoming aware of these stages and emotions, you can learn to recognize where you are, how you feel, and how to cope with the different feelings you experience.

### First Stage: Shock

The first reaction to the discovery that your child has a hearing difference can be shock. You now know you have a child who is faced with additional challenges and whose future may be different from what you would have expected. This initial shock may also be paired with feelings of:

**Denial:** It is common not to want to believe this has happened to you, your child, or your family. One danger of denial is a tendency to delay seeking advice or intervention in hope that the situation will resolve itself. You may find yourself avoiding conversations with others about your child's diagnosis because you do not yet believe it.

**Anger:** Everyone experiences strong emotions in stressful situations differently, and a parent's reaction can range from anger, to intense sadness, and even depression. You may also feel anger towards the doctor or audiologist who determined your child's diagnosis, anger towards yourself, or even some anger towards your child.

**Guilt:** An unexpected diagnosis can trigger feelings of personal blame, because you feel responsible or a feeling that you are being punished for something you did in the past. You may even feel guilt for being disappointed that parenthood has not turned out as planned. Regardless, you need to understand that your child's different hearing level is not your fault. It happened because of circumstances over which you had no control.

**Depression/Hopelessness:** Some parents may feel alone and ill-equipped to be their child's caregiver and advocate. This weight of responsibility can translate to hopelessness and despair.

**Anxiety:** Adjusting to a different hearing level requires new skills, experiences, decisions, and a new family culture as each of these are unknowns at the beginning of the journey. These changes and expectations can make life feel out of control and contribute to worry, panic, or fear of making the wrong choices.



**Isolation and Loss of Social Identity:** Parenting a child with different needs may make it difficult to relate to family members and friends who are parenting children in more typical ways. It may feel painful or sad to spend time in groups of people with whom you were once close.

These emotions can be hard to experience, but they are common, and you are not alone. If your child has recently been identified with a hearing difference and you are battling with any of these feelings, do not wait to get help. Seek out and take advantage of counseling resources, medical assistance, and the other avenues of [support](#).

## Second Stage: Recognition

Once the shock wears off, reality sets in. You recognize that your child has a difference that could affect his or her development, and that may cause a delay in the way in which he or she may function throughout his or her life.

You may experience frustration from time to time. Each time your child comes to a major life milestone, it may impact you in a new way, and you may experience the range of emotions again. Rest assured that the emotional disruptions caused by unwanted strong emotions will decrease in frequency and strength, and will be replaced with feelings of confidence as you work through the process.

## Third Stage: Recovery

Recovery begins when you accept that your child hears differently (or not at all) and that he or she will experience life differently than you do. With acceptance, you can celebrate your child's unique qualities and prepare yourself for the work ahead.

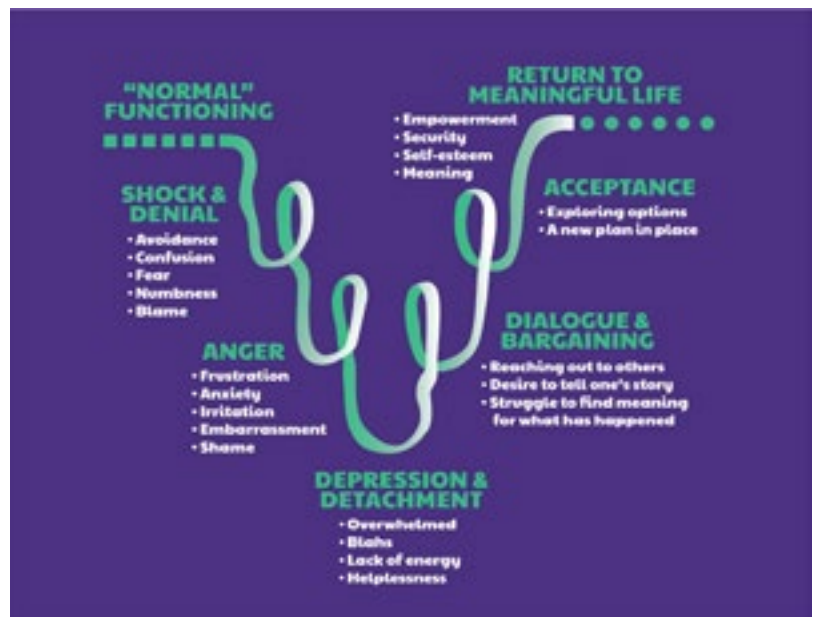
As you settle into a routine, learn to manage the doctor visits, and assemble a team of dedicated professionals to assist you. You will feel less overwhelmed and accept your new role as a parent of a child with a different hearing level. Being aware of your feelings can help you gain more control over them and will give you the strength and confidence to consistently enhance your child's development.

# TECHNIQUES FOR COPING AND HEALING

As indicated by the graphic at right, the path to acceptance is not linear and you may find yourself circling back around to feelings at different times. Here are a few suggestions that might make it easier to heal, adjust, cope, and accept your new pathway through parenthood.

## Identify Your Emotions

Rather than avoiding your feelings, ask yourself questions to identify what you feel. Once you can name your emotion, you can validate it, and find constructive ways to work through it. Here are some questions to ask when you are not sure how you feel.



**Shock:**

- Do I feel numb or frozen?
- Am I struggling to express any outward emotions?

**Denial:**

- Am I wholly focused on getting a second or third opinion that will overturn what professionals have told me about my child's diagnosis?
- Am I unable to discuss my child's diagnosis with friends or family?
- Am I focused on finding a "cure" rather than focused on acceptance?

**Guilt:**

- Do I feel responsible for my child's hearing level?
- Am I lingering on something I did that I believe may have caused the difference in my child's hearing level?

**Depression:**

- Do I feel alone or isolated?
- Am I avoiding simple duties and responsibilities?
- Am I withdrawing from my support network?

**Anger:**

- Am I easily losing my temper with those who are trying to help?
- Am I often in conflict with others?
- Do I recognize problems developing in my personal relationships?

**Anxiety:**

- Am I losing sleep because of worry?
- Am I setting unreasonable goals for myself or my child?
- Am I unable to enjoy daily activities because of worry?
- Am I paralyzed when making even small decisions?

## **Practice Self-Care**

Staying healthy is an essential step towards success in high-stress situations. This may include:

- Get the sleep your body needs.
- Eat a healthy diet, exercise, and spend time outside.
- Carve out personal time to do things you have always enjoyed.

## **Seek Knowledge and Support**

It is important to know that these stages of grief are not always separated and do not have specific feelings or behaviors associated with them. Nobody can tell you how to feel, and no one way is the right way. Once you take the time to get in touch with your own feelings, find the techniques and support systems that best help you adjust and adapt to this new reality.

- Empower yourself by gathering information and educating yourself about hearing at all levels and raising children whose hearing level is different.
- Discuss your feelings and concerns with someone who will listen without judgement.
- Seek support through parent groups, individual counseling, or visits to clergy.



# PARENT-TO-PARENT SUPPORT

Talking with other parents of children with hearing at all levels can be very beneficial to a parent of a newly-identified child. In fact, some studies suggest that parent-to-parent support may be a *vital* service not otherwise provided in formal support systems. Here are a few of the benefits of parent support.

**Connectedness and Affirmation:** Connecting with fellow parents can support a feeling of social kinship with other families. Sharing experiences may help you feel understood, appreciated, and reassured about your family's and child's future. Consider reaching out to support groups or foundations that support families of children with a similar diagnosis to your child.

**Emotional Support:** Emotional well-being is key as you begin to understand your child's needs and how you will support your child. Parents of newly-identified children commonly feel distress, loneliness, vulnerability and grief. You might even feel a perceived stigma surrounding the fact that your child has "special needs." Relationships with other parents may offer you the chance to express these feelings and combat negative feelings with self-reliance, confidence, and bravery.

**Family Support:** Parent-to-parent support systems recognize that family members cope better when there is a sense of togetherness. While a hearing level may affect family members' ability to communicate with a newly-identified child, other parents can help everyone in the family better understand hearing levels and boost positive interactions between family members.

**Confidence in Decision Making:** Peer parental support offers parents the opportunity to access knowledge, information, and resources that support confident decisions. Other parents may be able to help answer questions, explain options, and even validate your and your child's choices in communication, amplification, and education.

## WHAT IS DEAF/HH PLUS?

The term "Deaf/HH Plus" is a reference to an individual with a different hearing level who identifies as Deaf or hard of hearing and who has also been diagnosed with other health concerns. This is one way that individuals with multiple health issues may choose to identify themselves.

Approximately 40% of children nationwide who have a different hearing level have one or more additional developmental or medical concerns. These can include visual impairment, developmental delays, motor issues, Attention-Deficit/Hyperactivity Disorder (ADD/ADHD), autism spectrum disorder (ASD), cranial-facial differences, genetic disorders, significant language delays, and more.

Parenting any child with a different hearing level is a challenge, but there are some extra challenges when a child has additional health concerns. There are often more questions and more decisions to make. There are often more appointments, more specialists, and more therapies to explore. In many ways, it is a community within a community—your community. Here are some things to keep in mind as you begin this journey:

### You and your child do belong

In the beginning, it is easy to feel isolated from your own family, friends, and support networks. Your child may find it difficult to meet milestones at the same pace as their typically developing siblings, cousins, or peers. Remember: you are not alone. In fact, you may now find support in multiple communities. Consider reaching out to:

- Condition-specific foundations that provide resources, events, and parent-to-parent support for families raising children much like yours.
- State and national support networks, such as Hands and Voices, that provide unbiased support to families with children at all hearing levels and with all health concerns.
- Social media pages devoted to families raising kids with your child's health concerns.

## You can set your own priorities

Professionals are often passionate advocates for their specialty, and it may be difficult to prioritize your efforts when multiple specialists or therapists believe their priority should be your priority. Remember: when your child is Deaf/HH Plus, everything cannot be on the front burner.

As you read through this Parent Guide, you will notice a heavy focus on communication and language development, hearing technology, and speech and language resources. This is primarily because the “window of opportunity” to take advantage of residual hearing is small. However, communication may not be the priority for your child—and that is ok. Depending on your child's health concerns, you may need to focus first on eating and swallowing, mobility, or self-regulation. Feel empowered to prioritize your child's needs so he or she can be successful.

## You can have high expectations

No matter what health concerns your child may have, you have a right to expect great things. All children can all reach their potential when families and intervention teams are motivated to provide whatever resources needed. You can do this—and so can your child!

# TESTIMONIALS

## FOR THE SAKE OF JOY

By **Janet DesGeorges** Executive Director at Hands & Voices, Intl.

My baby girl never heard me tell her I loved her the first two years of her life. It wasn't that I didn't love her, or that I didn't tell her every day, but rather that she had a hearing loss that went undetected for those two years, and was unable to hear any speech. There was no newborn hearing screening process in the hospital where she was born.

I remember the signs along the way. As a toddler, my daughter Sara would walk up to the TV and put her ear up to the speaker. If I entered her room, and she was looking away from me, she wouldn't turn to me, even if I had said “hello.” I did the pan banging behind her head, and when she turned her head to that, my fears would be alleviated for a while. When I thought of deafness, I understood it to be all or nothing. I didn't realize Sara could have a hearing loss and still be able to hear some noise, but not speech. I think there is an assumption by some people that if a child has a hearing loss, a parent will pick up on it right away, and seek out help for their child. It took several months for me to be able to follow through on my intuition that something was not quite right. I don't even understand why I wasn't able to seek help for my daughter the first time I questioned her ability to hear. I guess it was the hope that if I just waited, everything would turn out fine.

During that time in my daughter's life, I remember the frustration of not being able to communicate with Sara, and not understanding why. As a mother of three, and a daycare provider for fifteen years, I had a lot of confidence in my parenting skills. So, the inability for me to understand Sara when she wanted something was a mystery to me. And her inability to follow even the simplest directions was a very frustrating time in our lives.

When I think of those first two years of my daughter's life, there is a myriad of emotions that

still flood my heart to this day: Self-reproach for not having the insight to follow up on the questions that came up about Sara. Sorrow for my daughter not having a language to use during that critical time of development. Anger over the fact that the hospital where Sara was born did not do a simple test that could have changed the life of our family, and perhaps the future of my daughter's life. By having the knowledge of a difference in our daughter from the start, we could have intervened on her behalf to facilitate communication from the start. I'm sure some of the frustrations that occurred over the span of those two years, having intervened, would not have happened.

When my daughter was finally identified, the help our family received from early intervention helped to set the framework for our attitudes. We also received much unbiased information to help us set a course for our daughter's education and the tools we needed to help her succeed in life. We are very thankful for the people who could provide their professional expertise, yet also gave us the respect, as a family to make the choices we felt were appropriate.

I guess most of all, when you discover you have a child who is deaf, you come to discover that it is not an awful thing. It is just a part of who your child is. It does not change the way you love or accept your child. It does not change the hopes and dreams you have for your child, and who they will become. You just open your heart to a different way of interacting in the world around you. There is a joy in discovering your child as they grow, and I just wish that opportunity to know my child, a child with a hearing loss, had been there for me from the start. For the sake of joy, let's identify all children who are deaf or hard of hearing from birth, so families and communities can learn from the beginning how to get the message across... "I love you."

## A LIFE CHANGING TEST

By **Katie Dagenais**, a parent living in Florida

When my husband Todd and I headed into the hospital to have our first child, a girl, we naively thought we were prepared. When Jocelyn entered the world, we were so excited to meet her, and the next 24 hours were a whirlwind. But that didn't even compare to what we would go through when Jocelyn was one day old, and the nurse brought her back to our room following her newborn hearing screening. Failed was all I heard. I suddenly felt frantic. Prior to that moment, a newborn hearing screening was just a test, but now it was about my baby and there was nothing routine about it.

Two ABRs (auditory brainstem response) tests later, Jocelyn at 8 weeks old was diagnosed with moderate to severe sensorineural bilateral hearing loss – she was deaf and it was permanent. How would I communicate with her? How could I learn sign language overnight? How could I make this ok and fix her? In the weeks and months and years to come our family would go through a grieving process from shock and denial to acceptance and hope.

As I look back, it was quite the journey – an accelerated ride along the path of being a parent of a child with hearing loss. For my deaf daughter Jocelyn, the pace was life altering. Because Jocelyn had a newborn hearing screening her deafness didn't go undetected and we didn't lose any precious time. After diagnosis, Jocelyn was referred to Early Steps and to our school district. At 4-months-old she got her hearing aids and at 10-months-old she began speech therapy.

Today, Jocelyn has matured and developed much like her hearing and deaf peers. She speaks and signs and is a great big sister to her little brother, Luc, who is hearing.

Looking back now I see just how critical those first few weeks and months were to setting Jocelyn on her path for living life as a deaf person. I don't even want to think about what our reality would be if we'd gone home from the hospital totally unaware that something wasn't right with our newborn's hearing. The truth certainly wasn't easy to accept at first, but it gave us a very important head start to put our daughter on a course for success, hearing loss and all.

## CHILD WHO BENEFITED FROM A COCHLEAR IMPLANT

By **Sherra Payne**, a parent living in Florida

Nine years ago, our first child was welcomed into our family with great joy and excitement. My husband and I were thrilled with our perfect baby boy. As the days went by we marveled at what a good sleeper he was since he could sleep through anything if he was tired. Much to our dismay, when he was seven months old we found out that the reason he didn't startle to noise was because he didn't hear the noise. In March of 1993, he was diagnosed with a profound sensorineural hearing loss. As first-time parents, we didn't have many clues early on and although the news was not a total shock it set us into a tailspin of what's, why's, how's, and where do we go from here.

For the next several years we continued to search for the best opportunities for our son and our family, we chose oral communication as our method and worked endlessly to help Austin discover sounds and the spoken word. Much of our effort was to no avail and after several years of intense Auditory Verbal Therapy and using the best hearing aids available, we started to consider the Cochlear Implant, which at the time was not tried and true for children. On May 14th, 1996 at 7:00 AM we began the long road down the Cochlear Implant path.

One month later Austin received his external processor and heard his first sound. That day remains a blur in my mind but the months and years that have followed are like snapshots in time. The first time he heard a toilet flush in a public bathroom, the first time he heard his brother cry and we were at the other end of the house, the night he kissed his brother goodnight and when Tristan said, "I love you with all my heart" and Austin replied, "I love you my heart", the soft whispers goodnight after the lights are out to which he responds "goodnight, I love you." The day his teacher told me that he was the best listener in class and all the other kids wanted to sit next to him during dictation tests since he repeats the sentence quietly while he writes it out.

Today, he is thriving in a mainstream school with no support services. We no longer attend therapy sessions several times a week. He prides himself on getting 100% on his spelling pretests and being in the challenge spelling group each week. Just recently he got two A+s on Spanish dictation tests. Now he is just one of the guys on the playground and at baseball camp. He is happy, loving and carefree. People who don't know him ask why he is wearing that hearing aid and assume that he has normal hearing in one ear. When people ask, he so accurately states, "I wear my hearing on the outside!"

These are all miracles made possible for Austin using a Cochlear Implant and the support of the Implant Team. When Austin was first diagnosed with a hearing loss 9 years ago I was the parent of a "hearing impaired" child...today I am the parent of a child with impaired hearing. That may not seem like much of a difference, but as a parent I can tell you that the difference is significant. The loss of hearing, which at one time was the focus of our lives, is now just a small part of our daily routine.

We are so thankful for the opportunities available to us today that allow us to make the choices that are best for our family. Each family is different, just as each child is different but the one common factor is that the choice is ours. Once we make a decision it is very important that we follow that path and give it 100% effort. By doing that, our children will achieve their full potential and have the opportunity to reach any goals they set. For those parents who are just starting down the road, good luck and follow your heart.

## CHOICES IN DEAFNESS

By **Michele Love**, a parent living in Florida

In 1989 my husband and I had our first child, Kenneth. Named after his great grandfather he arrived to change us from a couple to a family, and we were thrilled. Ken was a wonderful baby who slept well, never cried much, was very alert and visually attune. Others would always comment how good he was, and I remember being at a restaurant with him and a business partner of my husband's commenting "Look at that, he didn't even wake up" after a server dropped an entire tray of food right next to our table. It was about that time that my husband and I began to have concerns about Ken's hearing and at 12 months of age he was officially diagnosed with a severe to profound hearing loss.

This came as a tragedy to our family. Having no knowledge of deafness and no family history of deafness, we had no idea what to expect and it felt like we had been dealt a devastating blow. I was also 2 months pregnant with our second child and had to undergo tests to make sure that I had not contracted CMV. Had CMV been the cause of Ken's deafness, it could have a serious impact on the child I was carrying, with hearing loss being one of the milder effects of the virus. Although we dealt a lot those first few months after Ken's diagnosis, we also got quite an education into the world of disabilities. As things turned out, Ken was fitted with hearing aids and our second child, Ellen, was born with normal hearing.

I never imagined that there were so many choices in modes of communication, and philosophies to do with deafness and hearing loss. In 1989 when Ken was born, there was not a standardized procedure for testing children for hearing loss at birth, and that is the most positive change that has occurred since our experience. Secondly, I have since learned that not all professionals with whom you will come into contact, are to be viewed as being all-knowing and unbiased within their field. Our road has been a long one, but I feel that we have been blessed with an opportunity that we would never have experienced had Ken been born with normal hearing. Of course, things did not seem so wonderful and fair at that time.

I was given information regarding services in our area one of which being a center that specialized in Auditory Verbal training. This is an option for parents that stresses using a child's residual hearing to train him to speak through much training and exercise both professionally and reinforced daily at home. Of course, this sounded like the perfect choice for us! I called the center, paid them a visit, and explained that through proper training, my child would be able to hear and speak using his hearing aids. This is a strict program where no visual cues are given to the child, and one's hand usually covers the mouth to avoid lip-reading dependence. We attended this program for two years, driving about 45 minutes each way two to three times a week. We also began receiving services from the county's early intervention program and several times a week a specialist would come to our home and work with our family.

At age 3 Ken was still not making much progress and only saying a few words. I learned of a program through our school system, which took an Auditory Oral approach. This mode of teaching included Auditory training, but allowed for some visual cues to be included as well. We decided to change gears and give this program a try hoping that with some visual prompts Ken's ability to speak would improve. We had a wonderful teacher who was very patient and kind with Ken, and very helpful to our family.

We stayed with the oral program until age four, when Ken was still not speaking or showing much progress. By that time, we knew that he was a very bright child, but he was not showing any inclination to speak. We were in intensive private speech therapy both privately and through the school program. The changing point for us happened when the speech therapist from the school called to talk to me. She said that day in speech; Ken wanted to play with a toy dog that was high up on a shelf. To let her know what he wanted, he got on his hands and knees to imitate a dog. It crushed me that he was unable to communicate his needs. Prior to this time, other school personnel had begun to mention that perhaps we should switch Ken to the Total Communication class at school where he would learn sign language and speech at the same time. I had held fast to the dream that he would speak, convincing myself he would be just like other children, but with hearing aids and to finally come to terms with the thought that he would never be like a “normal” child was awful. We decided to move him to the Total Communication program and looking back, I feel that this was the first time that I ever really saw Ken as “deaf.” My husband and I both had a lot of feelings to deal with that we had pushed aside in our efforts to make him a hearing child.

Ken began to blossom in the Total Communication program. All the things that never had labels or names before began to all make sense to him. He began expressing himself and his wants and desires to us. I began to take sign language classes and we worked as a family, even grandparents and aunts and uncles, taking sign classes. In less than a year Kenny was signing quite well and I could see his frustration level with communication improve dramatically. Still no speech, but slowly I was coming to grasp the idea that that would be okay.

Today, Ken is a 6th grader at the Florida School for the Deaf and the Blind and is in the top of his class. He main streams to the local public school for math, which has been a good experience for him. He swims and runs track at school, and has many friends here as well. While he is a very vocal child, he still does not have great speech, but I’ve come to decide that he’s his own person, no matter how we communicate.

I have no regrets with the road that we took to get here, nor do I have any regrets with coming to use sign language as our choice of communication. It is who he is, and he is happy, well-adjusted and would you know, a normal sixth grade boy. I would not change the way we came to this place, because it was such a growing process and an education for us. We have met a lot of wonderful people along the way, and I hope that any parent with a newly identified child will take the time to explore all your options and learn as much as you can! Communication is the key no matter what choice your family makes. It is so important that you and your child can communicate freely regardless of the method and road you choose to get there!

### **Excerpted and adapted from:**

*John W. Adams (1988) You and Your Hearing-Impaired Child: A Self-Instructional Guide for Parents, Gallaudet University Press, Washington, DC*

*Henderson, R., Johnson, A., & Moodie, S.T. (2014). A conceptual framework of parent-to-parent support for parents with children who are deaf or hard of hearing. American Journal of Audiology, 23(4), 437-448. doi:10.1044/2014\_AJA-14-0029*

*Caballero, Ana (2018). Coping with grief and emotions related to the diagnosis of hearing loss. www.hearttolearn.org*





# UNDERSTAND HEARING LEVELS

■ Before you can make informed choices about your child's hearing level and the best way to address it, you will want to understand how we hear and how hearing at all levels affects speech and development.

## › HOW WE HEAR

## › HEARING LEVELS

## › UNDERSTANDING YOUR CHILD'S HEARING LEVEL

## › WHAT IS HEARING TECHNOLOGY?

## › HEARING AID OR COCHLEAR IMPLANT - WHO DECIDES?

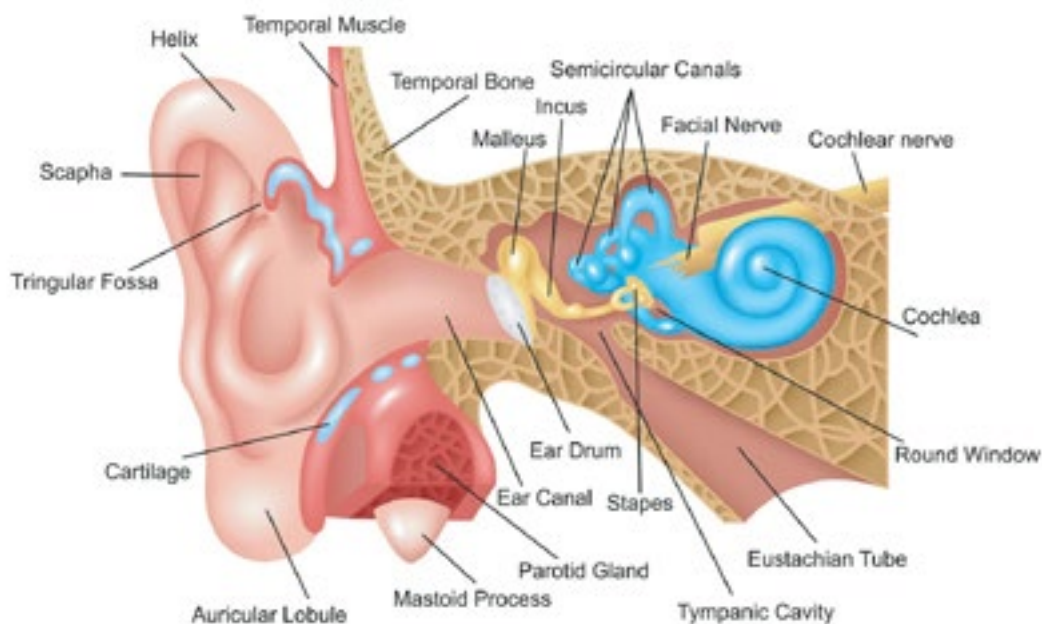
## › A NOTE ABOUT CHOICE



## HOW WE HEAR

The human ear is an incredibly complex organ and hearing sound requires several parts of the ear to work together. Humans hear sound when an object vibrates, causes movement in the air, and creates sound waves. Those sound waves then take a trip through the ear to create sound in the brain. Look at the steps below to see how we hear.

1. Sound waves enter the outer ear. This is the part we see on the side of our head.
2. Sound waves pass through the ear canal.
3. Sound waves reach the eardrum, which separates the outer and middle ear.
4. The movement of the sound waves causes the eardrum to vibrate and three tiny bones to move back and forth in the middle ear.
5. The vibrations of the eardrum and ear bones carry into the cochlea (the snail-shaped inner ear).
6. Nerve fibers on hair cells lining the cochlea turn vibrations into electrical signals.
7. That electrical signal stimulates the nerves and causes the brain to hear a sound.



## Human Ear Anatomy

In a normally functioning ear, these steps happen almost instantly, and the brain is then able to hear a wide range of frequencies (pitches) and intensities (loudness).

When any part of the ear does not function normally, this changes the hearing level.

# HEARING LEVELS

## What Causes Differences in Hearing Levels?

A person's distinct hearing level will determine his or her next steps. Levels of hearing that fall below typical standards can be permanent or temporary, and one person can have more than one reason why his or her hearing level is lower than typical. Learn about each cause below and how it may be treated.

TYPE	CAUSE	DURATION	POSSIBLE NEXT STEPS
<b>Conductive (1)</b>	Otitis Media or fluid in the inner ear caused by infection	Typically <b>temporary</b> with treatment, but infections can reoccur	Promptly visit the pediatrician for treatment. Untreated infections can lead to permanent lower hearing levels.
<b>Conductive (2)</b>	Physical abnormality of the outer or middle ear	Typically <b>permanent</b> until surgery	Some abnormalities can be corrected with physical reconstruction and some cannot. Surgeries of this type are typically scheduled at the age of 5-6 or later.
<b>Sensorineural</b>	Physical abnormality or damage to auditory nerve or cochlea (inner ear). This can be caused by low birth weight, exposure to drugs or a virus, or can be inherited.	<b>Permanent</b>	A child with a lower hearing level due to sensorineural damage (in one or both ears), should immediately receive: <ul style="list-style-type: none"> <li>• Auditory testing</li> <li>• Appropriate amplification (hearing aids/other)</li> <li>• Communication plan</li> <li>• Audiology follow-up</li> </ul>
<b>Mixed</b>	A combination of conductive/ sensorineural damage in the same ear	<b>Permanent</b>	See above
<b>Auditory Neuropathy</b>	Sound enters the ear normally but isn't organized in a way the brain can understand.	Can improve, stabilize, or worsen	Children should receive auditory testing and follow-up

## What Are the Different Hearing Levels?

A person's range of hearing affects speech and development in different ways, and the severity of a hearing level that falls below typical levels is just as important as the type in determining the best form of treatment. See the chart below to learn about the different levels of hearing and how each may affect speech and language.

DEGREE	POTENTIAL EFFECTS
<b>MILD</b> (26-40 decibels)	<p>A person with a hearing level that is mildly below typical levels will hear many speech sounds, but soft or breathy consonant sounds are hard to hear. These are sounds that correspond to the letters s, t, ch, sh, k, p, f, and the voiceless th. Missing these sounds can cause an individual to misunderstand what was said.</p> <p>A child with this hearing level may miss more than half of speech in a noisy environment or if a speaker is more than three feet away. An audiologist might recommend hearing aids and intervention to promote success in a school environment.</p>
<b>Moderate</b> (41-70 decibels)	<p>A person with a hearing level that is moderately below typical levels may hear the voice but not understand what is said when another person is talking at a normal level.</p> <p>Without amplification, a child may miss 50% to 100% of speech signals and speech may be unintelligible. Proper amplification may enable the child to hear and discriminate all sounds and develop language with early intervention.</p>
<b>Severe</b> (71-90 decibels)	<p>A person with hearing level that is severely below typical levels will hear no speech when a person is talking at a normal level, may hear and understand speech when the person is speaking very loudly about 1 foot from the ear and will only hear loud environmental sounds.</p> <p>If a child is born with this hearing level or develops it before learning to speak, then spoken language will be delayed without amplification. Consistent use of amplification and a strong communication plan may allow the development of normal/near normal speech.</p>
<b>Profound</b> (91 decibels or more)	<p>A person with a hearing level that is profoundly below typical levels will not hear any speech and only very loud sounds. Very often, this level prevents spoken language and speech from developing naturally. Consistent use of a cochlear implant or amplification and a strong communication plan may allow the development of normal/near normal speech.</p>

## UNDERSTANDING YOUR CHILD'S HEARING LEVEL

There are many factors that affect hearing and each of those factors may need to be addressed in a specific way. By understanding the level at which your child hears in each ear and the degree to which it affects the sounds they hear in each ear, you are arming yourself with knowledge to make wise decisions going forward.

Here are some questions you can ask your audiologist to get a clear picture of your child's hearing level.

1. Is my child's hearing level below typical levels in one ear (unilateral) or both ears (bilateral)?
2. Is my child's hearing level the same in both ears (symmetrical) or different in each ear (asymmetrical)?
3. Is my child's hearing level likely to fluctuate or remain stable over time?
4. Can my child's hearing level be corrected with medicine or surgery?
5. Can my child's hearing level be amplified with technology and/or trained through speech therapy?

Once you have a firm grasp on the answers to these questions, you may be better equipped to understand any recommendations your audiologist makes regarding amplification and other hearing technology that may help your child hear more sounds and language and develop speech.

## WHAT IS HEARING TECHNOLOGY

There are many ways to make the most of any residual hearing your child may have and there are a multitude of assistive devices on the market that may help children hear and understand sound more clearly and even develop speech more naturally or with therapeutic assistance. **The most common devices used to amplify residual hearing are hearing aids and cochlear implants.**

If your family is interested in exploring hearing aids/and or cochlear implants, remember that **early intervention is best**. Babies begin hearing in the womb before birth and within the first three months of life can tell the difference between voices and some speech sounds. A child with a lower hearing level may already be behind in developing the skills needed to understand what sounds mean, including speech. The sooner a child begins wearing an appropriate amplification device, the better opportunity he or she will have to learn to understand sounds and to develop language and speech.

## HEARING AIDS

Even children with a lower hearing level in the mild range (26 – 40 dB) require consistent amplified sound to develop to their potential. Hearing aids are a way of delivering sound to the brain that allows your child to grow the brain connections needed to learn to process and understand information from the surrounding world. A hearing aid is a small sound amplifier designed to make certain sounds louder and easier to hear. The goal is to provide enough amplification for a child to hear speech and environmental sounds at a comfortable level.

### Why are Hearing Aids so important?

Hearing aids are almost always the first step for children with a lower hearing level in one or both ears. In fact, even if your child has a hearing level profoundly below typical levels (90 – 100 dB or greater), the first step is usually hearing aids. Why? Because when babies are very young their brains are developing neural connections, or pathways that allow different stimuli to be processed.

## How Does a Hearing Aid Work?

The BTE (behind-the-ear) hearing aid is the most common hearing aid recommended for young children. This unit has all the components of the hearing aid encased in a device that fits behind the ear. The signal is delivered to the ear by a soft, custom-made earmold that is comfortable to wear and that can be replaced as the child grows.

Sounds are picked up by a microphone and carried to a programmable amplifier where select sounds are made louder in a way appropriate for the person's individual hearing level. The amplified sound is then sent through the receiver and delivered by the earmold into the ear.



## Are There Other Types of Hearing Aids?

While most children are best aided with BTEs, some children might require a different type of hearing aid. Here are three less common types used for specific reasons:

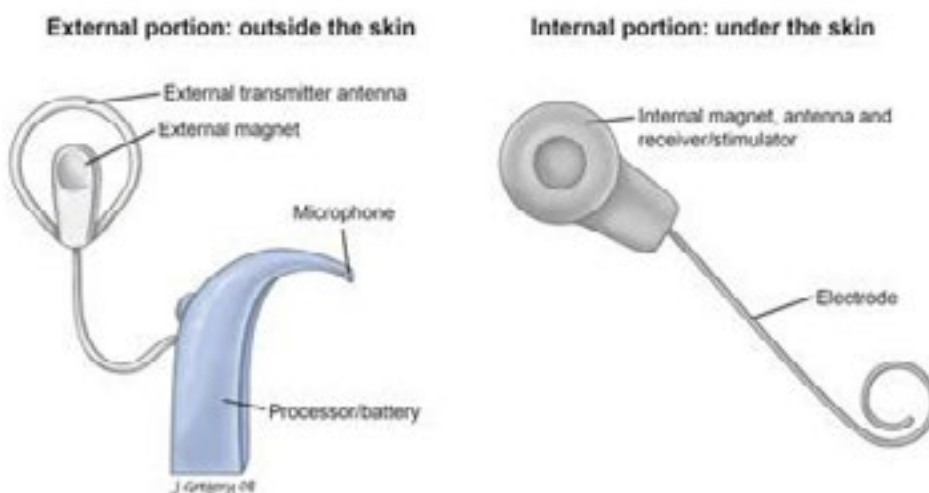
A **Bone Conduction Hearing Aid** is a specially adapted version of a BTE hearing aid. This delivers sound to the inner ear with a small vibrator attached to a headband that sits on the bony area of the skull just behind the ear. This device bypasses the outer and middle ear and delivers sounds directly to the inner ear. A bone conduction hearing aid might also be referred to as a Baha® (Bone Anchored Hearing Aid), which is a common brand name.

A **Transposition Hearing Aid** is a specialized hearing aid that takes high frequency (pitch) sounds and shifts them into the lower frequency range of hearing so that they are audible to the person with residual hearing in only the low and mid frequency range.

These are good, alternative options for a child, depending on the child's unique hearing level.

## COCHLEAR IMPLANTS

Hearing aids do not help everyone. When a hearing level is so severe that hearing aids do not provide enough amplification, a cochlear implant is another option. Cochlear implants are designed to help children with sensorineural damage become aware of sounds for the very first time.



Cochlear implants are an option for children who have a profoundly-low hearing level in both ears, lack progress in the development of auditory skills, and receive little or no benefit from hearing aids.

## How Does a Cochlear Implant Work?

A cochlear implant allows a person with a profoundly low hearing level to take in information by skipping around the hair cells in the inner ear and sending sound straight to the auditory nerve. A cochlear implant has two components: external (those worn on the outside) and internal (those that are surgically implanted in the skull).

**External components:** These include a speech processor and a transmitter. The speech processor looks much like a hearing aid and is worn behind the ear. It picks up sounds through a microphone and turns those sounds into a digital signal. That signal is sent to a transmitter worn on the head, behind the ear, that connects to the receiver with a magnet.

**Internal components:** The receiver is under the skin, behind the ear. It sends the signal from the transmitter into the inner ear, which triggers the auditory nerve and lets the brain notice the incoming sounds.

## How Does My Child Get a Cochlear Implant?

A specially trained otolaryngologist (Ear, Nose, and Throat specialist) performs cochlear implant surgery at a specially designated hospital. After the surgery and a short recovery period (one month), the implant system is activated and programmed for your child. Children with cochlear implants are evaluated and managed by pediatric audiologists trained in cochlear implant programming and management.

## WHAT OTHER DEVICES MIGHT BE AN OPTION FOR MY CHILD

### Wireless FM Systems

Children who use hearing aids will have difficulty hearing speech in a noisy environment or if a speaker is farther away (e.g., across a room, in a large classroom, or in an auditorium), so a wireless FM system may help. FM systems have two primary components: a microphone and transmitter worn by the person who is speaking and a receiver attachment (called a “boot”) that is attached to the hearing aid. When the person speaks into the microphone, their voice is transmitted directly to the hearing aid, so that speech from the speaker is always louder than any background noise that the child is hearing and distance is eliminated as an adverse listening factor.

### Telephone Amplifier

This type of assistive listening device makes the telephone signal louder and may be used with or without a hearing aid.

### Closed Captioning

This assistive device is either attached to a television or built into a television to provide written text of the spoken words.



## HEARING AID OR COCHLEAR IMPLANT - WHO DECIDES?

Children identified with a hearing level below typical levels and who are less than a year old will typically be fit with hearing aids as the first step. It's a common first choice and a great way to immediately begin stimulating the auditory nerves. Once hearing aids are fit and programmed, a child will need to wear them consistently for 3-6 months to get a clear picture of how they are helping and if they are a good choice for the child going forward. As more specific information about the hearing level is obtained, the hearing aids will be adjusted and re-programmed as necessary.

As the child reaches 6 months or so, and if there is little or no response to sound or auditory development, then the parents and the child's audiologist will come to a decision regarding amplification or cochlear implants. If parents want to pursue cochlear implants after investigating the option more fully, then a referral is made to a cochlear implant center to begin a more extensive medical and audiological evaluation process.

### A NOTE ABOUT CHOICE

At this early stage in your child's diagnosis and development, there is a lot of information to process. You will also receive much advice and hear many opinions from family, friends, and medical professionals regarding the right next step to take. It can feel overwhelming to consider making choices that could affect your child's future communication, development, and lifestyle when they are still so young.

Testing a child's hearing and fitting him or her with an amplification device is a process and not a one-time event. As you make choices, you will observe your child, see what works and what doesn't, and will adjust based on new information.

Consider this from Candace Lindow-Davies, Director of Outreach at Hands and Voices:

"I wish I knew when my son was little that the decisions I made for him were my decisions for that time. I wish I knew I could change course and that was okay. It would have taken a lot of pressure off. I wish I realized that as he grew older, he would become the decision-maker and I would become his consultant and biggest fan."

Take a breath, do your best, get good advice and remember that you can always change course if it is the right choice for your child.

Also, some families may choose not to pursue assistive devices for their child with a different hearing level. While hearing aids and/or cochlear implants are common choices (particularly in families where no other member is deaf or hard of hearing), there are communication options and lifestyle choices that allow children to learn language and function in society without hearing.





# ASSEMBLE YOUR TEAM

■ Once you understand your child's hearing level, there will be decisions to make. You will want to assemble a team of professionals who will help you manage your child's care, make good choices, and understand the ins and outs of parenting a child with a different hearing level. Early intervention by a group of dedicated professionals, family members, and other parents is a great way to get your child off on the right foot.

► **WHY DO I NEED A TEAM?**

► **WHO CAN HELP?**

► **CHOOSING YOUR TEAM MEMBERS**

## WHY DO I NEED A TEAM?

Quality intervention has a team approach with the family as the most important team member. Your family will have the biggest impact on your child's growth, development, and success because your child spends the most time with you. However, you cannot and should not do it all alone. Shortly after your child's diagnosis, you will likely have questions that need answers and may feel lost in the decision-making process when considering hearing technology, school or daycare settings, and how best to communicate with your child in the early months. It is important to remember that your role as the parent must remain that way and not assume the role of the therapist. You will learn through members of the team what to do and what not to do during your daily activities that can be of tremendous help to your child. You will want to stimulate your child with voice, music, and other sounds, but how you do this will be things that you can incorporate into your daily routine. It is equally important that any activity you do to stimulate your child is fun for both you and your child.

## WHO CAN HELP

The following list of professionals may be a part of your intervention team. One person may also fill multiple roles on the team, and you may choose these professionals in whatever order best meets your needs.

### Who Can Help

Your child's family doctor is your first line of support. He or she may:

- Act as your liaison between other doctors and therapists on your child's team.
- Provide referrals for your child to see specialists when the need arises, such as an audiologist or an Ear, Nose, and Throat (ENT) doctor.
- Answer questions about medical or surgical treatment.
- Provide a referral to the Early Steps Program or assure that a referral has been made, so support services can begin.

If you have not already chosen a pediatrician, do a little research to determine who might be the best pediatrician in your area to meet your child's specific needs. If you already have a pediatrician, openly discuss your child's needs and how he or she can meet them.

### An Otolaryngologist (or Ear, Nose, and Throat (ENT) doctor)

For a child with a different hearing level, an ENT may be as important as your child's pediatrician. This is especially true right after identification. Your ENT will:

- Confirm if there is a medically treatable condition in your child's outer ear or middle ear that is lowering the hearing level.
- Answer questions about medical or surgical treatment.
- Place ventilation, or PE tubes in your child's eardrums if he or she has chronic middle ear disease that is not cleared up by antibiotics.
- Performs any other ear, nose, and throat surgeries that may be required.

Your ENT or your pediatrician is also required to sign the form that authorizes your child to be fitted with hearing aids. This form simply affirms that there is no medical problem that would keep your child from using a hearing aid. Babies as young as 3 weeks old can be fitted with hearing aids so your pediatrician will refer you to an ENT right away.

## **A Pediatric Audiologist (or hearing doctor)**

A pediatric audiologist has specialized training in evaluating hearing and working with infants and children. If you and your ENT believe hearing aids will benefit your child, then the audiologist will do the testing and fitting to make sure the hearing aids are just right.

The audiologist will:

- Use specialized equipment to determine your child's hearing levels in both ears.
- Review hearing test results and answer any questions you may have about your child's hearing level.
- Help you choose hearing aids and arrange to fit hearing aids on your child.
- Make custom earmold impressions that fit your child's ear(s).
- Provide resources to repair or replace hearing aids and earmolds as needed.
- Provide guidance and referral as necessary for interventions such as auditory training, early language stimulation and parental guidance, and monitoring for any possible changes in your child's hearing abilities.

Once your child is fitted with hearing aids (or later, a cochlear implant), your audiologist will work with your ENT, pediatrician, and early intervention specialists to monitor and maintain your child's amplification system and maybe a resource for information on paying for hearing aids or assistive technology.

## **Early Steps Service Coordinator**

Every child with a different hearing level is referred to the Early Steps Program a few weeks after identification by Florida's Early Hearing Detection and Intervention (EHDI) program. Early Steps is Florida's early intervention system that offers services to eligible infants and toddlers (birth to thirty-six months) with significant delays or a condition likely to result in a developmental delay. Early intervention is provided to support families and caregivers in developing the competence and confidence to help their child learn and develop.

An Early Steps Service Coordinator may be one of the first team members to contact you. Your Service Coordinator will explain the program, provide you with any documents you might need to complete, and will be your key point of contact while your child is in the Early Steps Program.

## **Early Steps Primary Service Provider(s)**

Depending on your child's and family's needs, your Primary Service Provider (PSP) may be a Speech Language Pathologist (SLP), an Early Interventionist (EI), a Teacher of the Deaf (TOD) or even a combination of a few providers. Primary Service Providers offer unique services and provide ongoing support to your family by helping you to learn how to best assist your baby's communication development and overall learning.

## **Speech Language Pathologist (SLP)**

A Speech Language Pathologist (or speech therapist) will work with you and your child to develop family-centered strategies that address your child's early communication, language, and speech needs. If your family chooses to pursue speech as your child's primary form of communication, then a speech therapist is an invaluable resource.

Your child's SLP will:

- Help you teach your child to listen while wearing hearing aids.
- Help you stimulate spoken language development in your home environment.
- Work with your audiologist to help your child learn to use amplification and make sure your child's hearing aids function properly.
- Provide you with instruction and coaching in communication skill development.
- Listen to and discuss your observations and concerns about your child.
- Keep records of your child's progress in developing communication skills.

## Parent Advisor

In certain parts of the state, families are paired with a certified Parent Advisor (PA) who has received specialized training in working with families who have infants and young children with a different hearing level or who are blind/visually impaired. Through regular visits, the PA addresses family concerns and helps to determine goals and priorities. Together families, caregivers, and PAs share information, discuss ideas and monitor the child's progress.

In Florida, Parent Advisors are provided through the Parent-Infant Program with the Florida School for the Deaf and Blind. This program focuses on language development, communication options, understanding hearing aids/cochlear implants, child development, and transitioning into a school system.

## Schools for the Deaf

Schools for the Deaf have highly skilled and trained staff and teachers that focus entirely on educating children with different hearing levels from ages 0 to 22. While education may be the last thing on your mind right after diagnosis, schools for the Deaf often provide multiple services long before children are ready for school. These services might include outreach services that can provide parents with information, resources, support networks, and family events.

## Your Family

A child with a different hearing level needs everything a child with typical hearing needs. Your child needs your smile, gestures, talking, playing, and responding to his or her moods, actions, signs, and noises. All children need to be surrounded by additional language and sound, in order to learn how to process the sounds.

You are the most important member of your child's team. You will help your child by modeling natural language and helping him or her develop communication and social skills through natural everyday routines.

Having other family members on your team may offer another layer of support and understanding and may even allow you to take a needed break from caregiving.

Have open and honest conversations with members of your immediate and extended family regarding your child's needs, abilities, strengths, and areas in which he or she struggles. Also, keep your family informed about changes in your child's communication plan or plan of care to know how best to interact with your child.

## Parent-to-Parent Support

Mothers and fathers of children who hear at all different levels share a special bond, because no one understands what you are going through like another parent who has already experienced it. In fact, studies show that parent-to-parent support can be one of the most important, influential, and empowering factors in a child's success.

Another parent who is further along in their journey with hearing will have experiences to share, advice to give, and possibly even incredibly helpful resources that may be difficult to find on your own.

Supporting parents can:

- Connect you with other professionals who understand different hearing levels (like dentists, optometrists, or childcare services)
- Share experiences they have had with professionals and early intervention programs.
- Tell you about people and information sources they have found useful.
- Listen to you and share their feelings related to parenting a child who hears differently and how their feelings have changed over time.
- Tell you about their child's achievements and provide encouragement.
- Offer an opportunity for your child to spend time with other children who hear differently or who do not hear at all.

## The Deaf Community

According to the American Journal of Audiology, 23 studies indicate that parents of children who hear differently say that their child's participation in both hearing and the Deaf community is a priority (1). Just as you need other experienced parents for support, answers to questions, and resources, children with different hearing levels need time with other children and adults who hear differently and who may serve as role models.

Deaf adult role models:

- Can be language models for children with different hearing levels.
- Can help explain the importance of visual environments, room designs, lighting, and visual technology that create accessibility in the home and at school.
- Can provide networks to events and activities within the Deaf community.
- Can be examples of success as people with different hearing levels.

1. "American Journal of Audiology - ASHAWire." <https://pubs.asha.org/journal/aja>. Accessed 24 Apr. 2020.

## ANOTHER NOTE FOR DEAF/HH PLUS FAMILIES

You may choose to add extra professionals to your intervention team, depending on your child's specific needs.

If your child both hears and sees differently, then you may regularly see an ophthalmologist (eye doctor). You might also consider adding a vision specialist to your team. Depending on the severity of the visual problem, you may need the services of a consultant who specializes in dual sensory impairments. These professionals can help make decisions about glasses or other visual aids and help you create a home environment that best suits your child's visual needs.

If your child has challenges with mobility or motor skills, then you may consider adding a physical therapist or occupational therapist to your team. PTs and OTs can help children develop skills like walking, coordination, balance, and fine motor skills.

If the difference in your child's hearing level is the result of a genetic condition, then you may include a geneticist or genetic counselor on your team. A genetics team can confirm a condition through testing and can sometimes offer predicted outcomes and resources.

## CHOOSING YOUR TEAM MEMBERS

It is important that you are comfortable working with the professionals you choose. It is all right to ask them questions and expect the answers to be understandable. It is all right to expect kindness, understanding, and a listening ear.

It is also important to consider choosing a different professional if you do not feel comfortable or confident with your child's care. After all, you are the most important member of your child's team and your instincts as a parent and caregiver will help you make the best possible choices when choosing doctors, specialists, therapists, and educators.





## DEVELOP A PLAN

■ The development of a rich and vibrant language is a key component to ensuring social, emotional, and cognitive growth. Fortunately, your child has an abundance of options. These include a variety of methods known as “communication opportunities” to build language. If you remain flexible, stay open-minded, and do your homework, then it will be easier to use the variety of language opportunities that are available for your child.

› **HOW DO WE  
COMMUNICATE?**

› **WHAT IS LANGUAGE**

› **HOW DO I ENCOURAGE  
COMMUNICATION  
AND LANGUAGE  
DEVELOPMENT?**

› **COMMUNICATION  
OPPORTUNITIES**

› **DEVELOPING A PLAN**



## HOW DO PEOPLE COMMUNICATE

There are different ways to communicate and different ideas about communication. We communicate verbally, non-verbally, and in writing. A smile, a cry, a gesture, a look, a sign – these communicate thoughts or ideas.

Once you understand that communication takes many forms, you will begin to see the value of each type and how a communication plan that combines one or more communication strategies will help your child to develop language.

Technology has also expanded communication options for young children who hear differently. The choice to use amplification (hearing aids, cochlear implants, FM systems, and more) may allow your child to utilize more communication opportunities.

Remember: your plan is not all about hearing levels. It is not all about speech. It is about communication of any kind that helps you and your child express feelings, understand ideas, and get a message across.

## WHAT IS LANGUAGE

If communication is all about the message, then language is about understanding, using, and responding to words.

*Receptive language* refers to the words or symbols a person understands and associates with that object or action.

*Expressive language* refers to how a person formulates thoughts that he/she wants to share in the form of ideas, descriptions, or feelings.

*Syntax* is the arrangement of how words are put together to make sentences.

*Speech* is oral communication. Pitch, rate, and loudness all vary as we speak and can change depending upon the words preceding and following. These variations may be difficult to perceive for the person with a different hearing level.

Language development is often a challenge for children with a lower hearing level because of all the noise in the world that competes with speech communication. Although your child appears to “hear,” it will be difficult to understand what is being said. Even a hearing level that is mildly below typical levels or a hearing difference in just one ear will affect how well a person can understand speech in a noisy car, loud classroom, or when someone is speaking from across the room.

Hearing aids and other amplification technology can help but is not a perfect solution to a child’s difficulties hearing and understanding soft or distant speech, or speech in a loud, noisy environment. It can take intensive work and time to learn to discriminate these tiny speech differences through hearing alone or in combination with speech reading. It can also take many repetitions of a sign, gesture, look, word, phrase, or sound before your child begins to understand. Two-way communication, responding to your child, and encouraging your child to respond to you, is the key to your child’s language development. It is through the consistent daily practice of language in all activities that children become effective communicators.

# HOW DO WE ENCOURAGE COMMUNICATION AND LANGUAGE DEVELOPMENT?

All children develop language skills over time. Your child may learn to communicate and acquire language through listening, speaking, observing, lip-reading, using sign language or cued speech, reading, or even using an augmentative and alternative communication device (AAC). The first step toward developing a plan that includes one or more of these communication opportunities is to consider how your family communicates now and how you would like to communicate with your child in the future.

Here are some great questions to ask yourself when getting started:

1. Do I understand all the different ways my child may acquire language?
2. Do I understand which communication opportunities may be best for my child, based on his or her hearing level and any other developmental or health challenges he or she may be facing (such as visual impairment)?
3. Is our family willing and able to be flexible and open-minded to different communication opportunities?
4. Am I able to find and receive training on one or more communication opportunities that are new to me and my family?
5. Is our family committed to extending the extra effort to learn new ways to communicate?

You may not know the answer to these questions now. In the beginning, it is most important to ask yourself these questions and take some time to consider the answers while you learn.

## COMMUNICATION OPPORTUNITIES

Choosing one manner of communication or several over another is a personal decision you and your family will make. It is not only dependent on the level of your child's hearing, but also depends on your family's values, available time, and commitment to learning new skills, and vision of your child's future. Yet, no matter what, you need to adapt your communication style to meet the needs of your child.

The variety of methods and options available to encourage communication and language development are known as communication opportunities. Communication opportunities are all about building a solid language to be a successful communicator.

*Here are five common communication opportunities.*

## **American Sign Language (ASL)**

**Definition:** American Sign Language, or ASL, is the language of the American Deaf Community. This complete visual language does not require the use of spoken words or sounds. ASL has its own vocabulary and all the language components of a true language, including grammar and sentence structure. It is a completely distinct language from any spoken language, including English.

**An Opportunity For:** Any person with any level of hearing. If your child has significant visual impairment in addition to a hearing difference, then ASL may not be the best choice or accommodations for the visual impairment may be required.

As a visual language, very young infants can develop the basics of ASL, just as hearing children pick up the basics of a spoken language. Emotions, philosophical ideas, and other abstract concepts can be fully conveyed in American Sign Language.

Just as hearing people communicate effortlessly in their native spoken language, deaf people who use ASL can easily and effortlessly communicate with other fluent users.

ASL users may be bilingual, or fluent in other languages in addition to ASL. Bilingual education is designed to give children with a different hearing level fluency in two languages – American Sign Language (ASL) and English and/or the family’s native language. Bilingualism also seeks to provide children with knowledge about and acceptance of two cultures – Deaf and hearing.

**Family Responsibility:** Parental motivation and involvement in the process makes language development easier for their child with a different hearing level. Most hearing parents are not fluent in ASL but can learn it alongside their child with assistance from deaf mentors, classes in ASL, web applications, visual dictionaries, and involvement in social activities with others who use ASL.

ASL training and education about Deaf culture is important for the family and caregivers to become fluent and sensitive to the visual needs of their child.

**Required Training:** To become fluent in ASL, your child will need to have access to individuals who use ASL. Schools for the Deaf and deaf education programs offer unique opportunities for hearing parents to learn ASL while, at the same time, providing their child with full exposure to the language in an accessible environment.

## **Auditory-Oral Training**

**Definition:** Auditory-Oral training encourages your child to maximize use of residual hearing to learn spoken English or another spoken language. This is accomplished through constant use of spoken language in the home with special attention given to providing language and listening experiences.

An Auditory-Oral training program teaches babies and young children to use their hearing, and consists of four main communication features: speech, hearing, speech reading (lip reading), and gestures or body language. It relies on residual amplified hearing to allow the child to monitor his or her voice in speech production.

The greater the amount of residual hearing an individual has, the better the chance that individual will learn to listen and speak. Therefore, Auditory-Oral training emphasizes maximum use of residual hearing through hearing aids, FM systems, cochlear implants, and auditory training to develop speech and communication skills.

Unlike Auditory-Verbal training, Auditory-Oral training includes the use of speech reading, natural gestures, and body language. Manual forms of communication, such as American Sign Language, are not encouraged. Natural gestures and body language are accepted.

**An Opportunity For:** Individuals with residual hearing using hearing aids or a cochlear implant.

**Family Responsibility:** Consistent meaningful listening and language is essential for your child to develop speech and language skills through Auditory-Oral training. Since the family is primarily responsible for the child's language development, parents are expected to incorporate learning techniques acquired from therapists into the child's daily routine and play activities. The family must also encourage consistent use of hearing aids, an FM system, and/or cochlear implant.

Parents need to be highly involved with their child's early interventionist, audiologist, therapists, and teachers to bring learning techniques into the home and create an "oral" learning environment.

**Required Training:** Auditory-Oral training requires consistent and on-going speech and listening therapy administered by a Speech Language Therapist specially trained in auditory-oral methods. The primary caregiver will have the responsibility of incorporating these techniques into the child's daily routine and keeping a regular schedule of therapy appointments.

## **Auditory-Verbal Training (AVT)**

**Definition:** Auditory-Verbal consists mainly of two communication features: hearing and speech. AVT uses the child's residual hearing to encourage the development of listening skills so he or she can understand spoken language and communicate through speech. Since the focus is on development of speech and language through hearing, speech reading, American Sign Language, natural gestures, and body language are discouraged.

In therapy, the child is expected to rely on hearing alone during specific teaching times with parents and a trained Speech Language Therapist. While signing and gesturing is discouraged, the therapist may use hand cues during formal teaching times. For example, therapists may cover their mouth with their hand or a screen when speaking to discourage lip reading. The therapist may also move a hand toward the child's mouth as a prompt for vocal imitation or as a signal for turn taking; and the adult "talking through" a screen placed in front of the speaker's mouth. These hand cues only further encourage the need to carefully listen and use speech to communicate.

**An Opportunity For:** Individuals with residual hearing using hearing aids or a cochlear implant.

**Family Responsibility:** Auditory-Verbal training requires your child to listen carefully to spoken language (such as English or the family's native language) and then fill in missing language information from experience and familiarity with the language. Therefore, children using auditory-verbal techniques need constant exposure to language.

This may include reading aloud to the child, inclusion in family discussions at the dinner table, conversation in the car, and more. The consistent use of hearing aids or cochlear implants is also necessary for your child to learn to listen and develop speech and language through Auditory-Verbal techniques.

Parents need to be highly involved with the child's Speech Language Therapist to learn training methods, incorporate these techniques into the child's daily routine, and keep a regular schedule of therapy appointments.

**Required Training:** Auditory-Verbal training requires consistent and on-going speech and listening therapy administered by a Speech Language Therapist specially trained in auditory-verbal methods. The primary caregiver will have the responsibility of incorporating these techniques into the child's daily routine and keeping a regular schedule of therapy appointments.

## Cued Speech

**Definition:** Cued Speech is a system of eight hand shapes that represent groups of consonant sounds, and four hand placements that represent groups of vowel sounds, used with the natural lip movements of the speaker. The hand shapes and placements are grouped in sets that do not look alike on the lips to make speech visible and clear to the cue-reader.

Cued speech consists of four main communication features: Cued speech handshapes, speech reading, speech, and the use of residual hearing. Use of personal amplification such as hearing aids, FM systems, or cochlear implants is also important with this approach.

Cued Speech is not a language unto itself and must always accompany speech. It is used as a tool for speech reading spoken languages. This system is believed to encourage the development of reading by encouraging a child to learn spoken language as a first language.

In learning to read and write, the goal in using cued speech is increasing the ability to phonetically sound out words. The rhyme and rhythm of English, idiomatic expressions and tongue twisters can all be appreciated by individuals who use this technique.

**An Opportunity For:** Individuals with residual hearing using hearing aids or a cochlear implant. If your child has significant visual impairment in addition to hearing difference, then cued speech may not be the best choice or accommodations for the visual impairment may be required.

**Family Responsibility:** Parents are the primary teachers of cued speech to their child and are expected to cue always while speaking. Consequently, at least one parent (and the primary caregiver if there is not an at-home parent), and preferably all caregivers must learn to cue fluently for the child to develop age-appropriate speech and language.

**Required Training:** Cued speech can be learned through classes taught by trained teachers or therapists. Although the hand shapes can be learned during a long weekend training session, a significant amount of time must be spent using and practicing cues to become proficient.

Many parents find it easy to learn cued speech in a short time. Intensive 3 to 7 day workshops equip a person with enough knowledge to begin to use cued speech. Practice over several months to a year will often be enough to become proficient with cued speech.

## Total Communication

**Definition:** The use of multiple modes of communication, such as signing, oral communication, hearing and listening, writing, and visual aids to encourage language development. Techniques in a total communication approach may include formal signs, natural gestures, fingerspelling, body language, listening, lipreading and speech.

The intention of this philosophy is to provide a child with all strategies necessary to support his or her development of communication and language.

In addition to the communication opportunities already mentioned, here are more methods of communication that can be a part of a total communication plan:

- **Manually Coded English (MCE):** Manually Coded English (MCE) is a system of signs (most of which are borrowed from ASL) presented in English grammatical word order. MCE is a signed representation of spoken English. There are several manually coded English systems including:
  - Seeing Essential English (SEE 1)
  - Signing Exact English (SEE 2)
  - Signed English
  - Pidgin Signed English (PSE)
- **Gestures:** Natural gestures and body language are things that you would normally do to help your child understand your message. For instance, if you ask a toddler if he wants to be picked up, you might stretch your arms toward him and ask “Up?” If you express unhappiness about a teenager’s messy room, you might place your hands on your hips, and show a concerned facial expression.
- **Simultaneous Communication (Sim-Comm):** Simultaneous Communication is signing and talking at the same time. It is often used between a hearing person and a deaf person, or in conjunction with Manually Coded English systems.
- **Speech reading (lip reading):** Speech reading, or lip-reading, is a technique by which a person attempts to understand speech by watching the speaker’s mouth and facial expressions.
- **Vibro-Tactile:** Vibro-Tactile uses a person’s sense of touch to convey meaning. A child without hearing or who has very little residual hearing will turn to the source of vibration or even air movements in his or her environment. Vibro-tactile senses can be increased using Vibro-Tactile aids that convert sound into vibration patterns.

Adapted from:

[http://www.gallaudet.edu/clerc\\_center/information\\_and\\_resources/info\\_to\\_go/educate\\_children\\_%283\\_to\\_21%29/resources\\_for\\_mainstream\\_programs/language\\_and\\_communication/total\\_communication.html](http://www.gallaudet.edu/clerc_center/information_and_resources/info_to_go/educate_children_%283_to_21%29/resources_for_mainstream_programs/language_and_communication/total_communication.html)

## DEVELOPING A COMMUNICATIONS PLAN

Every child is beautifully unique—and your child’s personality, learning style, persistence, and motivation all play an important part in communication growth. You will discover these qualities in your child, along with his or her strengths and non-strengths, as you interact. Also, every family has different communication dynamics and your decisions involve the whole family. Know your options, learn all you can about those options, and resist pressure to decide until you feel ready.

Additional ideas to consider when developing a communication plan:

### **You are not alone.**

If you have assembled a team of professionals you trust, then you have access to a wealth of help and information when it comes time to discuss your communication plan.

Your child’s audiologist and early intervention service provider can help you understand your child’s hearing ability, monitor any changes in hearing, and help you clarify what communication opportunities may be most beneficial.

A Speech Language Pathologist, American Sign Language instructor, or Cued Speech instructor will help you learn and implement strategies once you decide and can help you determine whether those strategies need to be adjusted.

You may also choose to talk to adults in the Deaf community or other families with children who hear differently to better understand what these options may be like.

### **You can change your mind.**

The communication opportunities you select when your child is very young may need to change once your child’s personality and preferences develop and as more information about your child’s hearing level becomes apparent.

If there is a bump in the road and your family or child is not moving forward in using language at the expected rate, you can consider another path or a combination. If your child’s hearing level changes, the level and type of amplification may need to change as well, and your team of professionals is available to help you assess and make these decisions.

### **You are your child’s best chance for success.**

Your child will benefit the most when you and other caregivers are willing and able to consistently commit to meeting his or her communication and developmental needs. It is through the daily exposure and practice of language in all activities that children become effective communicators. If your family is committed to learn and grow along with your child and provide access to role models and other language development professionals, then your child will be more likely to succeed.





# BECOME AN ADVOCATE

■ You are not only the parent of a child who hears differently. You are also your child's main advocate for services, support, healthcare, and education. Learning what it takes to be an effective parent advocate takes work in the beginning, but it is always worth it once you and your child experience success together.

› **A PARENT'S ROLE AS  
ADVOCATE**

› **UNDERSTAND THE LAW**

› **UNDERSTAND YOUR  
RIGHTS**

› **ASK THE RIGHT  
QUESTIONS**

## A PARENT'S ROLE AS ADVOCATE

Parents are advocates for their children with different hearing levels. It is a role that takes energy and dedication but is also highly rewarding. Advocacy looks different for every child who hears differently, but it is an essential part of parenting your child. After all, you know your child best and are the person that will navigate challenges with insurance coverage, educational needs, and healthcare requirements. You are your child's supporter, defender, and champion.

While advocacy is often something you learn as you go, here are some tips for learning how to wisely use your influence as a parent to secure the support and services your child needs to be successful.

### Plan and be prepared

Whether you advocate for your child in an educational setting or working to settle an insurance claim, be prepared up front with all the information.

- Keep written records of your child's medical, therapeutic, and educational history.
- Prepare any questions you may have before arriving at a physician or therapy appointment.
- When you leave a physician's or therapist's office, write down any questions that come to mind for the next visit.
- Do your research in each situation before jumping into action.
- Ask lots of questions, and listen carefully to the answers, before you decide.

### Be passionate, not demanding

When learning to be an advocate, adopt the old saying "You get more with honey than with vinegar." In most cases, a calm, kind, and well-prepared parent is going to get a lot more accomplished than a parent who approaches complex situations with anger and frustration. Try not to take things personally, and always consider both sides of the story.

### Focus on the big picture

Simply put, don't sweat the small stuff. Before approaching any situation in which you need to advocate, ask yourself "What is my goal?" It can be easy to lose sight of what you and your child are really working toward when you are faced with obstacles or if you feel you are not being heard. Setting clear short and long-term goals will help you see more clearly when to push and when to let things go.

## UNDERSTAND THE LAW

To be a successful parent advocate, you need to know and understand the laws that protect your child and provide services. There have been many forms of legislation passed that specify services and rights for individuals with hearing differences. While some protections in these laws will not apply to your child until he or she enrolls in school, it is still valuable to have and understand the information as early as possible.

### Individuals with Disabilities Education Act (IDEA)

This federal law ensures that all states provide children, including those with disabilities, a free, appropriate public education. This means that all children, regardless of ability, have the right to a free school curriculum that will meet their individual needs. There are two sections within IDEA that are especially important for young children with hearing differences:

- **IDEA: Part C**

Part C regulates services for infants and toddlers from birth to 36 months. This is the section of the law that refers to early intervention services for young children with disabilities, including children identified with a different hearing level.

The purpose of this section of law is to “expand opportunities for children under three years of age who would be at risk of having substantial developmental delay if they did not receive early intervention services.” (34 CFR § 303.1(e).)

IDEA: Part C also puts a heavy focus on families and their right to make decisions regarding what is best for their child. The Florida Early Steps Program uses Family Support Coordinators which will help guide families through this decision-making process, and parents are encouraged to choose services that they feel are the best match for their family.

- **IDEA: Part B**

Part B regulates special education services for children ages 3 through 21. When your child reaches the age of 3, he or she may be eligible for your school district’s Prekindergarten Program for Children with Disabilities.

IDEA: Part B ensures that your child will receive an Individualized Education Plan (IEP) that outlines whatever therapy, resources, services, and accommodations are required to provide quality education. An IEP for a child with a different hearing level might include the need for a quiet classroom, access to special equipment like an FM system, special training for staff and teachers, or weekly speech therapy. IDEA: Part B was put in place to ensure that schools provide whatever resources are required to provide your child with appropriate education.

## **Section 504 of the Rehabilitation Act of 1973**

This ensures that eligible children with disabilities receive special accommodations or services in the classroom to provide equal access to classroom instruction. Even if your child is not eligible under Part B, schools may need to provide accommodations under Section 504 of the Rehabilitation Act of 1973.

## **Americans with Disabilities Act of 1990 (ADA)**

This ensures that all people with disabilities have access to public events, spaces and opportunities. Families often find the ADA law supportive in determining accommodations for involvement in community resources such as childcare or recreational activities.

If you have private insurance, check the coverage for your child’s needs including audiology testing, hearing aids, follow-up services, and speech/language/auditory therapy. It may be necessary for you to educate insurance companies and/or your employer to obtain coverage for your child’s needs.

## UNDERSTAND YOUR RIGHTS

Parents are the best advocates in working collaboratively with partners to plan for their children's needs, and you do have certain rights when interacting with these partners.

- It is your right to expect professionals to treat your concerns seriously and respectfully.
- It is your right to decide what is best for your child.
- It is your right to participate in decisions regarding your child.
- It is your right to accept or decline services offered to you by professionals or the school district.
- It is your right to change physicians, therapists, or any other service provider if you do not feel they are providing quality care or meeting your child's specific needs.

Remember, you are your child's best chance for success. Advocating for your child may involve writing letters, making phone calls, enlisting professional support, and attending meetings. It may involve repeated efforts to secure hard-to-find services. It can be discouraging when things do not seem to be going well, but it is equally thrilling when you finally achieve what you set out to do.

## ASK THE RIGHT QUESTIONS

Learning your child has a hearing difference can be overwhelming. There is so much information to process, decisions to make, and appointments to keep. Here are some sample questionnaires that might ease your mind if you just aren't sure how to start gathering the information you need.

These questions are not meant to be comprehensive, but rather are intended to open a dialogue between professionals and parents. You may also find that some of these questions overlap between professionals. This is intentional since everyone sees different types of professionals at different points in the journey.

The more information you have, the more assistance you can offer your child.

### QUESTIONS TO ASK AN AUDIOLOGIST

1. What kind of hearing difference does my child have? Type: sensorineural, conductive, or mixed? Degree: mild, moderate, severe, profound?
2. Do both ears hear at the same level?
3. Will the hearing level(s) change (permanent or temporary)?
4. Does my child have any usable hearing? What will she/he be able to hear?
5. How will the hearing level affect my child's speech? Understanding of language?
6. What are the possible reasons for my child's different hearing level?
7. If I plan to have other children, should I seek genetic counseling?
8. How often do I need to have my child's hearing tested?
9. How do I get a copy of these results?
10. Will my child's hearing level continue to go down? Is it progressive?

#### Early Intervention:

1. What is the referral process to obtain early intervention services?
2. Is my child eligible for early intervention?
3. What can I do at home with my child to help?

**Hearing Aids/Cochlear Implants:**

1. Does my child need a hearing aid? What are my options? Should she/he have an aid in both ears?
2. What is the cost of hearing aid?
3. Can you connect me with a loaner program for hearing aids?
4. What will my child hear with the hearing aids?
5. Where can I go for a cochlear implant evaluation? Why do you think a cochlear implant might help even more than hearing aids? At what point in time could or should we consider a cochlear implant for my child?
6. What financial assistance is available?
7. How often will my child need new earmolds? New hearing aids?
8. What should I do if my child rejects the hearing aid? How can I keep the hearing aids on my child's ears?
9. How can I keep the hearing aids from damaging my child's remaining hearing?
10. What do I need to know about caring for hearing aids?

**Communication Options/Education:**

1. How will my child's hearing level affect their educational experience?
2. What are my child's communication options (sign language, oral, total communication, cued speech)?
3. When should I begin school, therapy, or classes for my child? What is available in this area?

**Support:**

1. Is there a parent group in my area? Where? Whom should I contact?
2. How can you help me meet another parent who is parenting a child with a similar hearing level?
3. What other resources are available for me to learn about hearing differences—books, DVDs, websites, webinars, web applications, social media groups, etc.?

**QUESTIONS TO ASK AN EAR, NOSE AND THROAT DOCTOR (ENT)**

1. Do you have the most recent report from my child's audiologist?
2. What is your role in my child's ongoing health care (a one-time consultation or an on-going relationship)?
3. How do I describe these results to family members?
4. Does my child need additional testing (i.e. urinalysis, CT scan, MRI, EKG, blood tests, or vision screening) or a consult with another health professional to rule out other problems that could be associated with my child's hearing level?
5. Will you confer with my child's other professionals (i.e. audiologist, primary care provider, early interventionists)?
6. Would you suggest genetic counseling for our family?
7. Can you tell if my child's hearing level will get worse or change?
8. Is there some medically treatable cause for my child's different hearing level?
9. What treatments are available (i.e. ventilation or pressure equalization tubes, other surgery, antibiotics, and cochlear implants)?
10. Do I need to restrict my child's activities in any way?
11. Would my child benefit from a hearing aid? If so, how?
12. Do I need your signature to allow my child to be fit with hearing aids?
13. If hearing aids and other more conservative measures do not work, will my child be a candidate for a cochlear implant?

## QUESTIONS TO ASK THE SPEECH-LANGUAGE PATHOLOGIST

1. What kind of specific training have you had for working with children who hear differently?
2. What experience have you had with children who hear differently?
3. What communication philosophy or method do you have experience with? (Total Communication, Oral, Auditory Verbal, Cued Speech, American Sign Language, etc.)
4. How do you decide what child needs which method?
5. If you sign, which sign language system do you prefer? (Signing Exact English, American Sign Language, Signed English)
6. If you use the Oral approach what strategies do you use? (Auditory-Verbal, Auditory-Oral, etc.)
7. What kinds of things do you do to evaluate communication skills?
8. How do you monitor the speech and language progress of a child and what tools do you use?
9. Do you encourage parent involvement? If so, what kind?
10. How do you coordinate your efforts with other professionals such as the audiologist, Teacher of the Deaf, educational interpreter and other school personnel?
11. Do you have experience with children with cochlear implants?
12. How do you determine an amount of time to work on speech, language auditory training?
13. How can I get financial assistance to help cover costs?





# CONCLUSION

■ Your child can succeed—in school, in work, and in life! Keep this as your focus, whatever your child’s age, hearing level, or health concern.

► **FROM CHALLENGES TO ADVANTAGES**

► **WE WANT TO HELP**

While you will have the support of many professionals, ultimately you as parents will make many decisions about what is in the best interest of your child. As with all children, there is no magic formula for raising a child who hears differently. It helps to:

- Maintain a positive attitude
- Educate yourself about hearing levels and what they mean.
- Seek out the best resources
- Take an active role in your child's therapy and education

The fact that your child has a different hearing level is only one part of your parenting journey. Your child is a child first, and a child identified with hearing difference second.

## FROM CHALLENGES TO ADVANTAGES

Your child's life will have its challenges. However, sometimes these challenges can turn into advantages.

For example, the ability to work hard and concentrate more, coupled with the routines of audiologic and language therapy, frequently produces children who are self-disciplined and focused.

Moreover, the outcomes for children with different hearing levels have greatly improved in the last two decades due to major advances in technology and an emphasis on early detection and early intervention programs.

## WE WANT TO HELP

You can do this—and we want to help. For even more information and resources, contact the Florida EHDI program.

**Address:**

**Florida Newborn Hearing Screening Program/Early Hearing Detection and Intervention (EHDI)**

Division of Children's Medical Services

Florida Department of Health

4052 Bald Cypress Way, Bin A-06

Tallahassee, Florida 32399-1707

**Phone:** (850) 245-4673 or Toll-Free 866-289-2037

**Email:** CMS.NewbornHearingScreening@FLHealth.gov

**Website:** <http://www.floridanewbornscreening.com>

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**CHILDREN'S MEDICAL SERVICES**  
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**FLORIDANEWBORNSCREENING.COM**  
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**WWW.CMS-KIDS.COM**

