



# Parent Survival Kit

## *A Resource for Parents of Children with Hearing Loss*

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## Introduction

Like you, I am the parent of a child with hearing loss. When my son was diagnosed, I was completely unprepared for the challenge of raising a deaf child. In the beginning, I had many questions, hopes, and fears. There was so much to learn. There were decisions that couldn't wait. And there was a little boy with a bright future who needed educated and empowered parents to fight for him.

I was fortunate. I found experienced professionals who offered guidance. I connected with other parents of children with hearing loss who offered a community of support. And I discovered Utah State University's program in Communicative Disorders and Deaf Education which offered me the opportunity to study best practices for hearing loss intervention and to make educated choices about how best to support my son.

A decade later, I work professionally as a hearing rehabilitation specialist, supporting children with hearing loss and their families. Reflecting on the past ten years, I am grateful for the many professionals who supported us, the friends and family members who embraced us, and the faculty of Utah State University who believed that a mother with the right education can make a difference.

This Parent Survival Kit is an effort to pass along some of what I have learned from the professionals who guided me, the University program which empowered me, and the experience of day to day life with my son who inspires me. I hope that it will help you to answer questions, access resources, and find support as you begin your journey. I aim for you to find it a source of knowledge, encouragement and – above all – hope.

Welcome. You are not alone.



# Parent Survival Kit

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# Welcome to Holland

## *Coping with the Unexpected*

Your child has been diagnosed with hearing loss and you have found yourself at the start of an unexpected journey you don't feel prepared for. Your plans have changed, the future may seem uncertain and your mind may be filled with questions about what to do and what your child's future will be. You may be faced with a steep learning curve that leaves you overwhelmed and confused by a flood of new information. There's a lot to take in. You will need time to adapt, to learn, to understand and to plan. You will do all of those things. But, the first step is to breathe, to know that you are not alone, and to believe that your child's future will be bright because you are there to support him.

For most parents, their child's hearing loss is unexpected. It's natural to feel a range of emotions including surprise, shock, anger, guilt, denial, sadness and relief. It's also normal to have a mix of feelings, feelings that seem to conflict, or feelings that are opposite from your spouse, your friends and other family members. Your feelings can ebb and flow and change unexpectedly. Sometimes, a feeling that has passed will resurface as things change and your journey continues. This grieving process is a natural response to a significant loss or change in a dream, a person, or an ideal. Go gently. Give yourself time to adapt to the new normal.

When you envisioned your child's future you had hopes, dreams and expectations. Now, the future of your child suddenly looks different. It may seem uncertain, difficult and scary right now. But, you are not alone. Thousands of parents share this journey with you. If you're feeling overwhelmed, reach out to friends, family, professionals and other parents with experience who will support you. Another parent, Emily Kingsley, wrote an essay about the experience of raising a child with disabilities called "Welcome to Holland." Her essay highlights that while there are reasons to feel disappointment, loss, and confusion, there are also many beautiful things to look forward to and many reasons to hope.

### **Strategies:**

- Give yourself and loved ones time to adapt to your child's diagnosis. Understand that it's natural to experience a range of emotions. Grieving and acceptance takes time.
- Remember you are not alone and that there are professionals and other parents of children with hearing loss who can support and guide you.
- Breathe. Take one day at a time. And remember that although your child's future maybe different from what you planned, there is much beauty and hope ahead.

### **Resources and Links:**

- Welcome to Holland, by Emily Perl Kingsley (.pdf)
- Common Parent Reactions by Boys Town: <https://youtu.be/D2Fw5eyMLRs>



## What to Do Now?

### *Remember the Day Before*

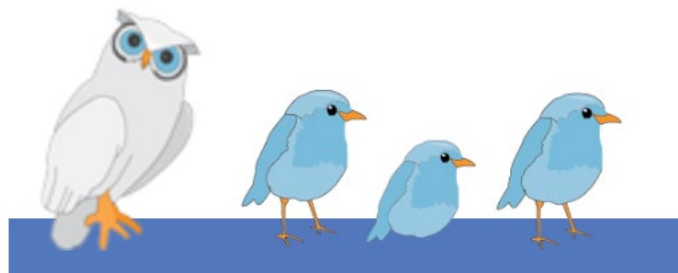
The moment your child is diagnosed with hearing loss changes your life changes forever. But, while many things change, some essential things remain the same. It's important to remember that your child is the same amazing, loveable child he was the day before the diagnosis. He needed you then, and he needs you even more now. In the years to come you will guide him, teach him, and protect him. Those things haven't changed. Try to remember the day before you knew he had hearing loss. Embrace him, play with him, encourage him, read and sing to him, and love him, enjoy him, the same way you did yesterday.

Your bond with your child is the most powerful asset you have as you go forward. Your bond allows you to know your child better than anyone else does. You will notice changes and understand his needs more readily than professionals. Your commitment to your child will motivate you to advocate for him and access the resources he needs. As parents, you will help your child to build early communication and social skills as you share songs, games, stories, and hugs. These experiences with looking, feeling, sharing, moving, responding are the foundations of your special bond with your child and they are also the basis of language.

The diagnosis of hearing loss will take your family in a direction you didn't expect to go, but hearing loss is only one part of your child. It does not define him. You and your family may have to change some expectations and life will be different that you expected. It's important to remember that your child is the same, beautiful, person he or she was before the diagnosis. The weeks and months ahead will bring some challenges and some important decisions. And, although raising a child with hearing loss is serious business, remember to have fun, to create memories and to savor these precious moments.

#### **Strategies:**

- Remember that your child is the same little boy or girl they were before the diagnosis. They love you and need you as much, if not more, than they did before.
- Be sure to build communication with your child through movement, touch, eye contact and sharing experiences.
- Enjoy these precious early years with your child. The moments you share will make memories and also nurture their development.





# The New Normal

## *Dealing with the Diagnosis*

Your child's hearing loss diagnosis may be a complete surprise or it may be the answer to a question you have had about your child's development for some time. You may be feeling a mix of emotions, including relief that you finally know what's going on; sadness at the thought that that your child might face additional challenges; guilt over the possible causes of the hearing loss; or even denial that the hearing loss exists. Every person is different, but it is important to balance your feelings so that you can move forward and help your child.

Finding balance takes time. For you and your child, this is a new journey. But, you are not alone. Thousands of parents share this path with you and can help you find your footing. Other parents of children with hearing loss can offer valuable support and information as you learn about your child's needs and plan for his future. You may also find it helpful to keep a journal or a blog or to take strength from a support group, your family, friends or congregation.

While taking care of your child, you must also remember to take care of yourself. Your days are busy, but don't forget to give yourself a break. Remember to exercise, eat well and sleep well. Parents are their own worst critics, but don't be too hard on yourself. Remember to give yourself credit for all of the work you have done so far. It's easy to let the diagnosis overwhelm you, but try not to isolate yourself from the people you love or the activities you enjoy.

Raising a child with hearing loss is a marathon, not a sprint. As parents, you are the drivers of your child's intervention and the key players on the team. If you break down, the whole system breaks down. So, be good to yourself. Remember to do the things that give you pleasure and peace of mind. Plan rewards, take time to breathe, to do something good for yourself, and to be thankful for your child. The work you are doing now will lay the foundation for the rest of his life, learning and development. Your child needs you. Stay strong!

### **Strategies:**

- Take time to find balance so that you can manage the mix of emotions and focus on helping your child. Cry, release emotions, and try to clear your head.
- Find ways to share your journey by starting a journal, a blog, talking to other parents of children with hearing loss, or confiding in friends, family or a support group.
- Give yourself credit for all of the work you have done so far. Pat yourself on the back. Your child will benefit from everything you are doing now.
- Don't forget the basics of eating well, sleeping well and exercising to stay fit, healthy and strong. This journey requires mental and physical strength and endurance.
- Don't forget to take care of yourself and to do the things that refresh and renew your energy. This is a marathon and you will need to pace yourself and reward yourself.

### **Resources and Links:**

- Where to Begin <https://www.jtc.org/where-to-begin/>
- AGB Parent Hotline for parent-to-parent support: <http://www.agbell.org/Families/Listen-Learn-Link-New-Parent-Hotline>



# How to Eat an Elephant *Taking One Bite at a Time*

When your child is diagnosed with hearing loss, you begin a lifelong journey of learning and understanding. Because more than 90 percent of children with hearing loss are born to hearing parents, most parents are caught by surprise and face a steep learning curve. From the moment of diagnosis, you confront a huge amount of information you know little about. At the same time, it's important to educate yourself, to ask questions and to understand your child's situation so that you can become the best advocate for his needs and future.

It's a lot to take on and it can feel overwhelming.

Ask questions of your child's doctor, audiologist, teachers and therapists. Each person on your child's intervention team will have different insights depending on their area of expertise and their experience.

- The fact that you are doing something to help your child is an important step

***Celebrate the small stuff! Take baby steps ...***

***Breathe. Take a walk. Reach out to other parents who have been on a similar journey.***

## **Strategies:**

Get Organized

Make a list of your questions for your child's doctors, audiologist, therapists etc.

Ask for referrals to participate on parent groups, such as Facebook groups or other virtual group opportunities.





# Why is My Child Deaf?

## *Searching for Answers*

Many children are first identified with hearing loss as infants, following a newborn hearing screen. Some children pass their newborn screen and later, parents notice that their child is not responding to certain sounds. In other cases, a daycare provider or preschool teacher is the first to suggest a hearing test. Whichever way a hearing loss is discovered, many parents experience a sense of guilt following their child's diagnosis. You may be asking yourself, why did this happen? Did I do something wrong? You may be examining every moment of your pregnancy, your delivery, or your child's development, looking for clues. You may be experiencing periods of denial, anger, or sadness, even desperation, wishing it could go away or that it was a mistake. In some families, the question of why a child is deaf leads to finger-pointing and blame. Regardless of the reason, the most important thing to remember is that this is not your fault. You did not cause a hearing loss in your child.

For many parents the diagnosis of hearing loss comes as a surprise, for others, it provides an explanation for a child's behaviors or concerns about their spoken language development. But, most parents have no immediate explanation for the why their child is deaf. Finding the reason for your child's hearing loss can be helpful in coming to acceptance of the diagnosis. It can also provide information about your child's future development and guide your plans for intervention. Because more than half of all permanent hearing loss in children has a genetic cause, learning the cause can also help with family planning. Other cases can be attributed to infections, medications, physical trauma and anatomical or structural issues. And, sometimes, despite testing and detailed case histories, no cause is found. If you are looking for answers, ask your professional team to advise you or look into genetic testing. Although it can be upsetting to think about, the knowledge you gain can help your child and your family.

### **Strategies:**

- Learn about the common causes of hearing loss. Knowing the cause of your child's hearing loss can help you to reach acceptance and to plan therapy and intervention.
- Ask your professional team for information about the causes of hearing loss and how they relate to your child's specific case history. Consider genetic testing.
- Try not to get caught up in guilt and blame. Use your energy to help your child. Use your emotions to push you forward towards early and effective support for your child.
- Understand that your child's hearing loss is not the result of anything you did or didn't do. It's nobody's fault.

### **Resources and Links:**

- Common Causes of Hearing Loss: For Parents and Families, by Harvard University Center for Hereditary Deafness <https://hearing.harvard.edu/resources>
- About Hearing Loss <https://www.babyhearing.org/hearing-loss>





# Diagnosis is not Destiny

## *Imagining your Child's Future*

After diagnosis, your mind may be filled with questions about your child's future. What will he do? Will he learn to talk? Will he go to school? Will he be able to get a job? Will he have a family? Will he be happy? It's natural to have a lot of questions as you come to terms with your child's hearing loss and learn about how to support him. As you plan and learn, it's important to keep in mind that the hearing loss diagnosis is only one part of your child. It does not define him or determine his destiny. The fact that you are taking action to help your child is a critical first step in helping your child reach their full potential. Hearing loss may change the way your child learns and communicates, but it does not change who he is, or what he can become.

With early identification and early intervention, children with hearing loss can grow up with the same opportunities as children with natural hearing. They go to school, participate in sports, play instruments, dance, have active social lives, and go on to have families, jobs and children. Planning is important. Imagine the future you want for your child. Discuss your hopes and dreams with your intervention team and seek their support and guidance. Every family is different. Some families will aim for their child to speak more than one language, others may hope that their child will have a specific career, participate in sports or play a musical instrument. Consider all of the things you would like your child to do, and pursue them. Above all, do not discount your child's potential just because he has hearing loss. Have high expectations for your child, just as you would if he had normal hearing.

Many of the questions and concerns you have now will start to fade as you learn more and as you meet older children and adults with hearing loss. You will see that they are leading regular, fulfilling lives doing all of the things typical of hearing people their age. As you learn, you will grow more confident in your ability to identify progress in your child and to make choices about his education and development. All parents have fears about the future of their children and, like all children, your child may face some limitations. But, because of the steps you are taking now, your child has the potential to grown up in a world filled with potential with the same growing pains, joys, challenges and opportunities as their hearing peers.

### **Strategies:**

- Imagine your child's future. Discuss your hopes and dreams for your child with your professional team. Your goals will help to guide the intervention plan.
- Have high expectations for your child. Hearing loss is a part of your child, but it does not define who he is or what he will become.
- Take action early to ensure that your child benefits fully from intervention services and support. Your child has the best chance for success when you act early.
- Meet older children and adults with hearing loss to see first-hand that hearing loss does not hold them back from social activities, careers and educational achievement.

### **Resources and Links:**

- Parents Outlook on the Future of Their Child with hearing Loss by Boys Town:  
<https://youtu.be/RBQMjo4JB4g>



# It Takes A Village

## *Finding Community Support*

It has been said that it takes a village to raise a child. For every parent, raising children is filled with challenges. It can be stressful and exhausting, especially when your child has additional needs. To share the load, it can be helpful to have access to other people who can act as teachers, mentors and guides. Raising a child with hearing loss can feel isolating. You may feel hesitant about reaching out to your community. But, while you will receive support from early intervention services and professionals, it is also important to build your own local support system. As he grows up, your child will benefit from these adult and peer role models.

Adults in your community support system can include extended family, friends, members of your place of worship, community helpers like teachers and librarians, other parents you meet in playgroups and coaches and instructors for extracurricular activities. In the early years, your child will be with you much of the time. You can help your child make connections in the community by introducing him to the people you interact with. Each member of your child's community will contribute to their development and shape their understanding of the world.

Your child will also benefit greatly from social experience with children his own age. Take note of the things that interest your child and encourage him to participate in social activities. Some communities may offer activities that are specially organized for children who are deaf or hard of hearing. Others may offer mixed groups where a signing child can be supported by an interpreter. As your child grows up, you will want to give him social connections to other children with hearing loss, and you will also want to help him make friends with peers who are typically hearing. Your child's peer group will provide him with important age-appropriate models of social skills and language as he learns.

### **Strategies:**

- Help your child become acquainted with people in your community that you meet often through shopping, going to school, and community activities
- Join community social activities or Mommy and Me playgroups so that you can meet other parents and so that your child can meet and socialize with kids their own age
- Consider extracurricular activities like sports, dance, music, or art to help your child meet other adult mentors and peers who will support his development
- If you have a place of worship, participate in activities and engage other members to support his spiritual growth
- Connect with support groups for parents of children with hearing loss to meet other families like yours with children who learn and communicate like your child





# Voices of Experience

## *Parents as Partners*

If you are feeling confused or at a loss for what to do, you are not alone. More than 95% of children with hearing loss are born to parents who have hearing. Your child may be the first person with hearing loss you have ever met. You may be unsure of what the diagnosis means for your child's future. You may be feeling a range of emotions including shock, anger, fear, guilt, and sadness. You may be searching for answers, or deciding what steps to take. Each day will bring new emotions and new questions. While professionals offer a wealth of information, and academic learning, other parents of children with hearing loss can be empathetic, offering important emotional support and valuable insights.

It is natural to feel hesitant to reach out to other parents. But, these parents have been in your position and can relate to your journey in meaningful ways. Veteran parents will listen to you with empathy and offer ideas and information. Other new parents can share their recent experiences and provide useful insights. Meeting other families will also give your child a peer group of other children who communicate and learn the same way he does. Because these families share your journey, they are able to understand where you are coming from and support you in ways that most professionals cannot.

Parent support groups are often organized in local communities, worldwide. They can be informal meet-ups or formal local chapters of larger national organizations. Parents can connect in person or online to ask questions, share information, offer support, and exchange ideas. Many times, these introductions lead to lasting friendships and mentorships which help to demystify hearing loss and shed light on the future for your child. In the process, you will meet older children and adults with hearing loss who can speak confidently and candidly about their experiences. These encounters can help you to picture your child's future as an individual leading a rich and fulfilling life, not limited by hearing loss.

### **Strategies:**

- Connect with other parents of children with hearing loss in your community
- Ask your Audiologist or Speech and Language Therapist to help you get in touch with other parents and local support groups
- Use the internet to identify Facebook Groups or Blogs that focus on families of children with hearing loss
- Join your local chapter of national organizations like A. G. Bell and Hands & Voices
- Seek out an older child or adult who can act as a deaf mentor to support and guide you and your child

### **Resources and Links:**

- Alexander Graham Bell Association for the Deaf and Hard of Hearing Parent Hotline: <https://www.agbell.org/Families/Listen-Learn-Link-New-Parent-Hotline>
- Hands and Voices Local Chapter Directory <http://www.handsandvoices.org/chapters/starts.htm>
- MED-EL Hear Peers Forum <https://forum.hearpeers.com/>



# Taming the Paper Tiger

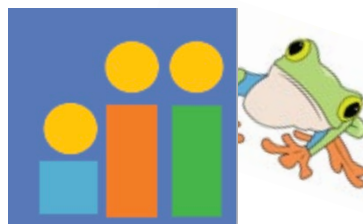
## *Getting Organized*

Every appointment your child has generates paperwork which piles up very quickly. It can be a challenge to stay on top of all the hearing loss information, assessments, audiology reports, insurance company statements, and bills that you are collecting. It's a daunting task to keep track of everything. But, each piece of paper you collect, each report and each assessment your child receives, provides needed details about your child's diagnosis and contributes to streamlining his intervention plan. Organizing all of this information is an important part of managing his care and monitoring his ongoing progress. This whole process can feel overwhelming. But, organizing this growing pile of papers will help you keep things straight, prioritize next steps and have easy access to information that you will need when interacting with professionals. Getting organized may also help you feel more in control of a complex situation and more prepared to face the decisions that lie ahead of you by being able to quickly put your finger on something you need.

You will need to know where to find things in order to have them on hand when they are needed. You may want to consider setting up a simple filing system with folders or binders labeled or color-coded according to each doctor, therapy or intervention need. The supplies you need will be available at most office supply and big box stores. Binders and accordion files are useful for organizing large categories of paperwork (insurance statements, audiology reports, speech therapy reports and intervention plans) while dividers can be used to break these categories into smaller sections by subject or by year. Spiral notebooks or legal pads and pens can be helpful for taking notes. A weekly planner or your smartphone calendar can help you keep track of appointments. Keeping a phone log and organizing contacts will help you stay on top of professionals and service coordinators. This may be more file work than you're used to, so try a couple of strategies to see what works best. Being organized will save you time, confusion and will help you to feel confident and ready for the journey ahead.

### **Strategies:**

- Consider creating accordion files or binders to organize large volumes of information. Use dividers to organize papers by date or by subcategory. Binders could include:
  - Medical information including diagnosis, audiology, and test results
  - Technical information about your child's devices
  - Assessment reports, therapy plans, and intervention strategies
  - Insurance statements of benefit, bills, and other financial information
  - ISFP or IEP documents and communication with your service coordinator
- Purchase a weekly planner or use the calendar on your smartphone to keep track of your schedule including appointments and therapy times.
- Create a phone log to keep track of contact information for service providers and to make notes about what follow-up action is needed.





# We Hear With Our Brain

## *The Critical Window*

Many parents are surprised to learn that we hear with our brain, not our ears. Although the ears provide a path for sound to reach the brain, the brain processes sound in ways that we understand as language, music, and environmental noise. From birth, children are in a highly sensitive period for auditory brain development. During the first months and years of life, the brain changes and develops on the basis of the sensory input it receives. This sets up a critical timeline: If a child's brain does not have early and sufficient access to sound, it will not develop the auditory (listening) skills needed for listening and spoken language development. Once the brain has aged beyond this sensitive period, it's not possible to go back.

Thus, if listening and spoken language are communication goals you have for your child, there is a critical window of time in which you have to act to provide your child with auditory access to the brain through intervention. If the listening centers of the brain are not activated, the brain will begin to prune away the weaker, unused neurological connections, starting around the age of two or three. This means that unused hearing potential will be permanently lost if the brain does not receive early and sufficient access to sound.

When a hearing loss is identified, it is critical to act quickly to properly diagnose the hearing loss and to provide the intervention needed to give your child's brain the greatest opportunity to develop auditory skills. If your child is an infant, the aim is to complete diagnostic testing by 3 months of age, and to fit your child with amplification and enroll him in an early intervention program by 6 months of age. If your child is older, diagnosis and intervention should take place as soon as possible. Each day that passes has implications for your child's development. Every step you take now ensures your child can benefit from this sensitive period and take full advantage of the time that remains. Don't stop. Keep going.

### **Strategies:**

- Understand that we hear with our brain and that the brain develops according to the input it receives. If the brain doesn't receive sound input, it cannot learn to listen.
- Know that there is a critical window for brain development between birth and the age of three. After the age of three, the brain changes in permanent, irreversible ways.
- Remember that we speak what we hear and children learn to speak by listening. If your child can not hear speech, they cannot learn spoken language through listening.
- Seek proper early diagnosis to understand the nature of your child's hearing loss and to learn about what intervention approaches are available. Knowledge is power.
- Act now. Each passing day has implications for your child's development. Each step you take now will benefit your child's learning and development for the rest of his life.

### **Resources and Links:**

- Brain Development and Hearing Loss  
<https://successforkidswithhearingloss.com/for-professionals/brain-development-hearing-loss/>



# No Time for Fear

## *Early & Effective Action*

When an infant or young child is diagnosed with hearing loss, early action is extremely important. Science has shown that the first three and a half years of life are the most critical for speech and language development because the brain is most ready to learn during this early stage of development. Every day counts. Periods of hearing loss, even small ones, interrupt a child's natural interactions and development and lead to delays in language and social skills. However, when you provide your child with timely and appropriate diagnostic and intervention services, your child will have the best chance for overcoming delays and developing speech, language and social skills on a par with their hearing peers.

Young children learn to talk through listening. Hearing children start listening in the womb at 18 weeks gestation and have fully functional hearing by 24 weeks. Access to sound and hearing stimulates the brain and builds important neurological connections which allow the brain to process what it hears. This means that by the time a hearing loss is identified, a child has already lost months or even years of critical auditory experience. Therefore, if listening and spoken language are goals that you have for your child, there is a sense of urgency to accurately diagnose the hearing loss and to provide appropriate amplification and intervention as soon as possible. It becomes more difficult to overcome delays as the brain gets older.

Many parents feel overwhelmed by the amount of new information they need take in during this time. The pressure to learn and to make decisions quickly can be intimidating. Pace yourself. Take time to understand your child's hearing loss and to research intervention options. Confer with specialists, Ask questions. But, also realize that some decisions need to be made soon in order for your child to develop without further delays. The decisions you make now will impact how your child learns and communicates for the rest of his life. Educate yourself and make informed decision soon. It's demanding. But, keep going. Your child's future will be bright because of the investment of time and knowledge you are making now.

### **Strategies:**

- Understand that hearing is about the brain and that brain development is taking place every day. So, time is precious and some decisions need to be made quickly.
- Don't wait. Early intervention is critical to your child's speech, language, listening and social skill development. Decisions you make now will impact the rest of his life.
- Educate yourself so you are able to make informed decisions about what is best for you and your child. Talk to specialists. Ask questions. Get second opinions.
- Understand that it's natural to feel overwhelmed and intimidated by the decisions you have to make. It's okay to feel this way. But, keep going, don't let it paralyze you.





# Getting it Right

## Confirming the Diagnosis

Your journey with hearing loss may have started when your baby failed a newborn hearing screen. Or, maybe you noticed your child wasn't responding to certain sounds. Sometimes, hearing loss is suspected by a teacher or a caregiver or a speech therapist when a child has difficulty learning language or producing speech. However it began, your next step is to confirm your child's hearing status with a diagnostic hearing evaluation. This test cannot be done completely or accurately in your child's doctor's office. It must be done by an audiologist who has specialized equipment and who is experienced in testing children.

Confirming your child's hearing status is critical. The results of the testing will impact all of the decisions you make next. Some forms of hearing loss are temporary, other are permanent. All of them have implications for your child's learning and development. All of them require some kind of intervention. Hearing loss takes many forms. Only diagnostic hearing evaluation can determine the specific type (conductive or sensorineural) the degree (mild, moderate, severe, or profound) and the configuration (frequencies and pitches affected) of the loss. Each of these factors will help to inform your decisions about intervention and communication modes.

It is important to stress that your child is never too young to be tested for hearing loss; that hearing loss can occur at any age; and that hearing loss can fluctuate or get worse over time. Even a mild hearing loss can impact your child's development. Having a complete and correct diagnosis is the only way to know what is going on and what is needed. This can be a scary and uncertain time. But it's important to take action. Information gives you the power to make good decisions. Remember, the steps you are taking now are critical to your child's development and will help him to reach his full potential.

### Strategies:

- Don't wait! This is urgent. Your child's development depends on taking action now.
- Read and learn about the different types of hearing tests to inform yourself
- Locate a pediatric audiologist [http://ehdipals.org/SmartTool/EP\\_SmartTool.aspx](http://ehdipals.org/SmartTool/EP_SmartTool.aspx)
- Share your observations or concerns about your child with your audiologist
- Ask questions to make sure you understand the outcome of the testing
- Hearing testing and receiving a diagnosis can be emotionally difficult. It may be helpful to bring a friend along who can take notes and help you gather information.
- In many cases, it can be helpful to get a second (or third) opinion
- If your child's hearing loss is confirmed, reach out to your community to find support

### Resources and Links:

- Testing Explained: Diagnostic Audiology: <http://infantheating.org/audiology/index.html>
- Understanding your Child's Hearing Test: <https://www.jtc.org/wp-content/uploads/2017/04/2017UnderstandingHrgTest.pdf>
- Audiogram of Familiar Sounds – What Does My Child Hear: <https://www.jtc.org/audiogram-of-familiar-sounds/>
- Vocabulary List for Understanding Hearing Loss: <https://www.jtc.org/wp-content/uploads/2015/11/1stWordsForParentsLearningAboutHearingLoss.pdf>



# The Accidental Captain

## *Your Role as Team Leader*

The moment your child was diagnosed with hearing loss, you became a key member and leader of your child's intervention team. Research shows that parent involvement is a key factor in the language, communication, and academic outcomes for children with hearing loss. Although your child's intervention team will consist of many professionals with expertise in specific disciplines, you are the only one who is an expert in your child. As parent, you are the person who knows your child best. And, you are the person who can best represent the needs and priorities of your child, your family, your culture, and your community.

As the expert in your child, you will lead and guide the team in choosing an intervention approach and to help you child achieve his greatest potential. Professionals will provide important diagnostic information, clinical insights, and make suggestions for the best way to support your child's development. But, your child's needs go beyond his audiogram, his test results, and his hearing levels. They include the things that unique to your child and your family. These things are as important in the intervention process as any piece of scientific data or medical information.

As the center of your child's team, and the person who spends the most time with him, you will also have unique insights into your child's development. Professionals depend on these unique insights and observations to develop an intervention plan and to monitor your child's progress. So, take time to consider what is important to you, your family and your child. Observe your child and and be sure to communicate these observations and priorities to the members of your child's team. And remember, the best outcomes come through close parent-professional collaboration.

### **Strategies: Some things you can do to be an effective member of your child's team:**

- **Ask:** Ask questions of your professional team member and make sure that you have a clear and confident understanding of the information they provide.
- **Listen:** Listen to professional guidance and consider their suggestions in the context of the unique needs of your child and your family. Keep an open mind as you learn.
- **Talk:** Talk about your family's priorities and needs in the intervention process. Discuss what you think is best. Every family is different. There is no "one size fits all" solution.
- **Write:** Keep a notebook to write down your questions and to record observations of your child's development. A notebook helps keep track of information of track growth.
- **Be Flexible:** Be ready to make changes in professionals, approaches, and plans as you learn more about the intervention process and your child's individual needs.







# Information is Power

## *Get Smart on Hearing Loss*

One of the most important things you can do to support your child is to gather information and to educate yourself about hearing loss and communication approaches. Information is power and what you learn will help you to make important decisions about your child's future. Sources of information can include professionals, other parents of children with hearing loss, adults with hearing loss, books, videos and internet searches. Try to seek out evidence-based, balanced and objective information, and use a variety of sources to give you a broad view of the options for your child. Being well-informed puts you in the best position to make important choices about how your child will learn, communicate and interact with others.

Many countries offer early intervention services which can help to connect you with resources. Likewise, the internet provides an abundance of information and access to scientific research. When searching for information on the internet, however, you will want to keep in mind that what you find may not be well-researched or accurate. Some of what you read and much of what people will tell you will reflect individual opinions and points of view. While it can be helpful to have someone else's perspective, it's important to understand that each person's experience with hearing loss will be different. What worked well for one family or for their child might not work well for you. You will be the best person to decide if an approach or recommendation works well for your child and your family.

Learning is an ongoing process. As science uncovers more about the nature of hearing loss and how it impacts development, technology will change and intervention options will evolve. As your child grows and develops, you will learn about his individual needs your decisions will become clearer. Over time, his needs and priorities may change. As a parent, you will be responsible for following these developments and assessing whether to amend or adapt your child's intervention. Each time you make a decision, you will want to gather information and understand the scope of your options. Each stage of the journey will present different learning opportunities. Embrace it. Enjoy it. Your child will benefit from everything you learn.

### **Strategies:**

- Look for objective, evidence-based, and balanced sources of information. Hospitals, research centers, universities and government organizations are good places to start.
- Take advantage of intervention services offered by your local government or community. Ask professionals for materials and resources to help you learn.
- Make a list of your questions for your child's doctors, audiologist, therapists etc. so you remember to address any concerns or information you don't understand.
- Seek out other parents of children with hearing loss, or adults with hearing loss to compare notes on where to find resources in your community.
- Remember: learning is an ongoing process. You will continue to learn as your child develops and as scientific research reveals more about hearing loss and intervention.

### **Resources and Links:**

- Resources Links: <https://www.babyhearing.org/parenting/information-gathering>
- Glossary of Hearing Terms for Parents: <https://www.itc.org/first-words-for-parents-learning-about-hearing-loss/>



# How to Prioritize Decisions

## *Making First Decisions Fast*

It can be overwhelming to face the many decisions you must make for your child. The key to making good decisions in a timely way is to gather information and educate yourself on what your child needs. There is a lot to know in a short period of time and parents often find the learning curve is very steep. One strategy for approaching this is to prioritize and start small. Some decisions don't need to be made immediately. Triage. Focus on the things you need to know now and look for the best people and resources to help you learn.

Seek out reliable sources of information. Ask your professional team or other parents for their insights and recommendations. As you learn, you will encounter many different points of view. Bear in mind that every person's opinion is shaped by their personal experiences. Their journey may be entirely different from yours. There are many ways to deal with the diagnosis. What worked well for another family or child may or may not work well for you. If you keep the focus on your child and your family's unique needs, you'll be on the right track.

You may feel pressure to make decisions quickly. Time is short. Every day is precious in the life of a young child. But, be sure you have enough information and feel comfortable before deciding. If you have questions, ask them. Honestly consider your gut feelings, your family's priorities, and your vision of your child's future. Don't be afraid to push for what you feel is best for your family and your child. **This is an emotional period. But, try to set emotions aside and make decisions based on what you learn and what you know about your child.**

Also, remember, no decision is permanent. Sometimes the only way to discover if a decision is the right one is to make it and see how things go. Sometimes things change over time as your child grows. Allow yourself to learn through your experiences. Raising a child with hearing loss is an art, not a science. Stay informed, stay flexible and take one step at a time.

### **Strategies:**

- Prioritize your decisions and make the most immediate decisions first
- Gather information and inform yourself about the options for your child
- Seek out reliable, evidence-based, objective and balanced resources
- Reach out to professionals, other parents, older children & adults with hearing loss
- Remember that each person's experience with hearing loss is unique
- Consider what is best for your child based on his individual needs and your family
- Monitor your child's progress at regular intervals to evaluate your choices
- No decision is permanent. Stay flexible and make changes if something's not working

### **Resources and Links:**

- Decision Making Steps:  
<https://www.babyhearing.org/parenting/decision-modifications>
- Who Should be Involved:  
<https://www.babyhearing.org/parenting/levels-of-family-involvement>



# Building Your Child's Team

## *Working with Professionals*

From the moment of diagnosis, you will find yourself building and coordinating a team of medical professionals, educators and specialists to support your child. Your child's team will partner with you to support your child's learning, communication and overall development. Finding the right mix of professionals who share your vision for your child and who have the needed expertise can take time. Other parents of children with hearing loss and intervention services coordinators should be able to help you to identify prospects and connect the dots.

Your child's professional team should be focused on supporting your child and also on helping you to develop knowledge and skills as a parent. Ultimately, you spend the most time with your child and you know him better than any professional ever will. This makes you the expert in your child, the leader of the intervention team and the first and most important teacher for your child. With that in mind, every member of your child's professional team should be invested in you and your child and should add value in their area of expertise.

Professionals work both for you and with you. You have a right to get value for your money, and you should expect cooperation and coordination between service providers. They should take time to listen to you, to solicit your observations and input, and to answer your questions and support your learning. Prepare for meetings by writing down your questions and observations of your child or by making recordings of your child to share with your team. Your feedback and insights should contribute to your child's intervention plan.

Plan to attend sessions in order to ask questions and to learn the strategies and approaches you can use with your child at home. Take time to understand information and to practice techniques in your sessions so you feel confident in knowing what to do when you get home. If a professional or a therapy approach doesn't feel like a good fit for you or your child, it's okay to make a change. Remember, programs and providers vary in what they do and how they work with families. Over time, you will determine what works best for your family.

### **Strategies:**

- Attend appointments with your child in order to observe professionals and to give you opportunities to ask questions. Be confident in the answers before going home.
- Write down questions and observations, record or make videos of your child to share with your professional team. These insights can be very helpful to tracking progress.
- Ask your child's therapists to guide you on strategies and techniques you can use to build your child's learning and communication. Practice before going home.
- Check your child's progress by holding team meetings to encourage cross-disciplinary communication and coordination of your child's intervention plan.
- If something isn't working, look for ways to make constructive changes. Ensure the intervention approach and the professionals on your team are focused on your child.

### **Resources and Links:**

- Questions to ask at your appointments with your audiologist, doctor or therapist: [http://www.ehdipals.org/ParentResources/EP\\_Tips\\_Parents.aspx](http://www.ehdipals.org/ParentResources/EP_Tips_Parents.aspx)
- Partnership with your LSLS Cert. AVT <https://hearingfirst.org/lsl-services-support/parent-professional-partnerships>



# Early Communication

## *What You Can Do Right Now*

Discovering your child's hearing loss reveals a problem that was very likely hidden before the diagnosis. Before you learned of your child's hearing loss, the path towards communication seemed straightforward. But now, things might be confusing. You may be asking yourself: What do I do now? How do I talk to my child? How do I interact with a child who can't hear? The answer is: Continue to do what you did before you discovered the hearing loss. Continue to talk, to sing, to read and to play with your child. Don't stop. Each of these activities builds your bond with your child and helps to lay a strong foundation for future communication and language development.

It's important to understand that a significant portion of human communication does not rely on sound. In every stage of life, in every culture, people with and without hearing use body language, facial expressions, eye contact, touch, gestures and other forms of nonverbal communication. Long before children learn to talk or to understand language, parents and children are communicating with a variety of nonverbal cues. Children are comforted by a parent's embrace, they will respond to a silly face, they will imitate gestures and follow your gaze, or look into your eyes. Physical and visual contact tells your child that you are connected and attentive to his needs. It tells him he is safe. And, it tells him he is loved.

Many parents assume that because their child has hearing loss that speaking, singing, reading and playing in the stage before amplification doesn't matter. However, some children with moderate to severe hearing losses have sufficient residual hearing to hear portions of music or speech and will benefit from this early auditory exposure. Likewise, although children with severe to profound losses may not hear the sounds of your activities, they will enjoy the interaction and benefit from the nonverbal communication. Regardless of your child's hearing status or your stage in the intervention process, you can help you child by starting to build early communication skills now. Don't wait. Don't Stop. Keep going.

### **Strategies:**

- Understand your child's hearing diagnosis and utilize any residual hearing to access speech, music, and other sounds.
- If your child has residual hearing, reduce background noise and stay close to him when you are communicating so that he has the best chance of hearing your voice.
- If your child can't hear you, he may need to see you in order to feel secure. Try to stay within sight of your child so that he has visual confirmation that you are nearby.
- Maintain good eye contact with your child to ensure you are connecting. This also lays a good foundation for future communication and language development.
- Imitate your child's movements and gestures. Mirroring his actions builds a good habit of imitation and sets the stage for learning to copy language and to take turns.

### **Resources and Links:**

- How Can I Start Communicating With My Baby Right Now?  
<https://www.cdc.gov/ncbddd/hearingloss/parentsguide/communicating.html>



## Why Professionals Need You *You Are the Expert!*

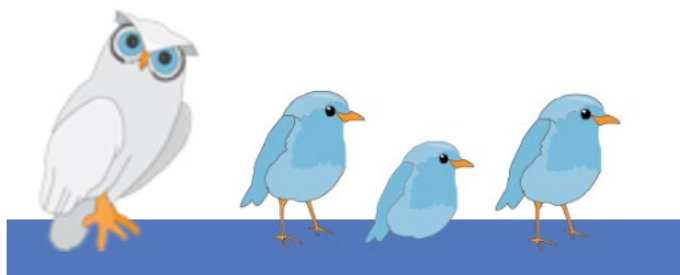
Most parents of children with hearing loss are not prepared for the demands of leading their child's intervention. You may be thinking that you aren't qualified to have a voice in your child's therapy plan or intervention because you aren't a medical professional or you feel you don't have the right expertise. In fact, you are a specialist in the most important sense. You are the expert in your child. You spend more time with your child than anyone else. You know your child better than anyone else and you can represent your child's and your family's unique priorities and needs better than any professional.

You are not alone if you are feeling intimidated, overwhelmed or underqualified to take on the responsibility of coordinating your child's care across a multi-disciplinary team of professionals. It may surprise you to know that each of these professionals is depending on you to provide critical information for a complete and accurate diagnosis and to plan the best possible intervention for your child. Although each doctor, therapist and teacher brings their professional expertise to the team, you are the only one on the team who is an expert in your child. Your insights are absolutely essential to planning effective intervention.

As a parent, and the leader of your child's intervention, it's your job to provide professionals with unique insights into your child's needs and development. It is also your right to have copies of test results, reports, and any recommendations. You should feel that your child's professionals are respectful of your views, supportive of your decisions, responsive to your concerns and ready to answer questions, provide information and make appropriate referrals. Before you leave any meeting, you should make sure you understand what you need to do for follow-up or what the next steps will be. If you don't understand something, always ask.

### Strategies:

- **Communicate:** Speak honestly and openly with your child's professionals about what you feel is important to your family and your child in the intervention process.
- **Observe:** You are with your child more than anyone else. You will notice changes more easily than anyone else. Observe, record, and report what you see.
- **Take notes:** Create a notebook to keep track of your questions, notes and observations. Share these notes with the team to help planning and track progress.
- **Advocate:** Don't be afraid to tell a professional that an idea or approach doesn't work for you or your child. Express your point of view and share your ideas.
- **Share records:** Provide professionals with copies of reports and records directly. This allows you the opportunity to ask questions and to talk about results.





# The Pointy End of the Spear

## Advocating for Your Child

Becoming an effective advocate for your child with hearing loss is one of the most important steps you will take to support your child. As parents, you are at the pointy end of the intervention spear. You will be the person to choose your child's communication approach, guide therapy plans, and direct services. At first, the thought of being the driver and lead coordinator of your child's intervention may seem daunting. But, with time, as you learn more about hearing loss and more about your child's needs, you will become confident in knowing what your child needs and empowered to fight for it. In the beginning, it's easy to feel intimidated by professionals who have lots of education and clinical experience. They will offer important information and insights based on research and years of practice. But, although they are experts in their field, they can never know your child, his preferences, personality and learning style, the way that you do. Your child is unique and you must represent his unique needs and inclinations to the team. As you work with professionals, you will monitor his progress, assess whether an intervention approach is working and make decisions about what to change.

You should have high expectations of the people who support your child. Remember that everyone on your child's team should be working in the best interest of your child at all times. If that focus shifts, you will learn to assert yourself and to push for the things that are important to your child, your family or your culture. People will have strong opinions, and some resources may be difficult to access. But, your job is to ensure your child gets what he needs. If there is something you feel a professional is missing, or something your child needs: Speak up. If you have questions or concerns, or need more information: Ask. Laws in the United States and in some other countries mandate support and education for children with hearing loss and their families. As you begin intervention and plan for the future, you will want to start learning about the rights that are afforded to your child by the laws in your country. You are the most powerful ally your child has. To effectively advocate for him, you will understand his needs, know his rights, identify resources and recruit the support he needs. By doing so, you will ensure he has every opportunity to develop and to achieve his full potential.

### Strategies:

- Ensure that you completely understand your child's diagnosis and feel confident in explaining it to others who may be helping your child
- Learn as much as you can about hearing loss, communication approaches, options for services in your community so you know what is available
- Educate yourself on the laws in your country that protect the rights of individuals with disabilities to access education and public resources. Your child has rights.
- Compare notes with other parents who have children with hearing loss and deaf and hard of hearing adults who can help you learn and access information
- Feel entitled to ask questions and to make requests that ensure your child gets the support and intervention services he needs

### Resources and Links:

- Early Intervention Advocacy Resources: <http://www.wrightslaw.com/info/ei.index.htm>
- Individuals with Disabilities Education Act: <https://sites.ed.gov/idea/about-idea/>
- Infants and toddlers, birth through age 2, with disabilities and their families receive early intervention services under IDEA Part C <https://sites.ed.gov/idea/statute-chapter-33/subchapter-IV/part-C>
- Children and youth ages 3 through 21 receive special education and related services under IDEA Part B. <https://sites.ed.gov/idea/>



# Your Child, Your Choice

## *Ensuring Informed Consent*

Choosing a communication approach for your child is one of the most important decisions you will make as a parent. How your child communicates will impact your child's early development and his interactions with everyone in your family. The decision will also have implications for the rest of his life. That's a heavy burden for that majority of parents who come to this point with no background or preparation for making this decision. It means that you will have to learn a lot very quickly and carefully consider which choice fits your family best. During this process you have a right to complete and unbiased information.

As you are learning, you will find that people have very strong opinions about communication approaches. But, as a parent, you have a right to make fully informed decisions. You have a right to professionals who offer objective information about all communication options; who provide evidenced-based resources; who respect your family's priorities, your culture, and the choices you make; and who understand that the final decisions should be yours without pressure or judgement. Every parent hopes that their child will be independent and happy. There are successful children and adults using every kind of communication. There is no one single approach that is right for every child. The right one will be the one that best fits your child and your family.

Because each child and family is different, you will make your decision based on your child's diagnosis and your family's unique cultural and linguistic needs. Communication approaches differ based on the degree to which they rely on listening, spoken language and/or visual support. The approach that is best for your child may not be the best choice for someone else. Some children do well with a single form of communication, others require a combination of approaches. The key is to choose a form of communication that everyone in the child's life can already understand or that everyone can fully commit to learning and using.

**Any communication approach you choose involves a commitment to learning new strategies, and possibly an entirely new language. Some things to consider are:**

- Does the approach fit the needs, priorities and interests of your child and your family?
- Do you understand the commitment that the communication approach requires?
- Does the approach allow your child to communicate with all members of his family? If not, consider how you will teach your family members to communicate with your child.
- Does the approach facilitate your child's communication with his peers?
- Is there a community of people who use this approach to support your family and your child as you are learning?
- Does it provide your child with the language skills needed for thinking and literacy?
- Does it provide your child with access to his extended family, his community, his peers, future education and employment?

### **Resources and Links:**

- Success for kids with hearing loss: <https://successforkidswithhearingloss.com/>
- Hands and Voices: <https://www.handsandvoices.org/>



# No One Size Fits All Solution

## *Choices in Communication*

As soon as your child is diagnosed with hearing loss you face the question of how you will communicate. Choosing a communication approach can be confusing. Audiologists, educators, doctors, other parents, adults with hearing loss, and even your own family members may have very different, even contradictory, opinions on which approach to choose. Each person's point of view will be impacted by their individual experiences with and their understanding of hearing loss. However, as parent, you have the sole right and responsibility to choose the communication style that best fits your family and your child.

A child who is deaf or hard of hearing needs to have access to communication, to education, and to society. But there are several viable communication modes, and there are successful children and adults with hearing loss using each of them. To make a decision, you will need to learn about a range of communication approaches, including their strengths and shortcomings, their education and employment outcomes, and how well each one fits with your child. Some options have a neurological time limit (spoken language) while others can be learned or added later. The right communication choice will be the one that best matches the needs of your child and your family. It's a deeply personal choice.

There is no right or wrong decision as long as your child has access to communication and the opportunity participate fully in life. Consider the opinions of professionals, other parents, adults with hearing loss, and your extended family and assess what works best for your family and your child. Make the best decision you can based on what you know now. It's okay to amend the plan later. Your child's needs may change over time as he develops and you begin to understand his strength and weaknesses. The most important step now is to learn about communication options, make a choice and start communicating.

### **Strategies:**

- Educate yourself on the various communication approaches and the implications of each one for educational and professional outcomes, and access to other users
- Understand that some communication options become less viable as your child gets older (ie: spoken language) because the brain changes and cannot be reversed
- Know that this is a deeply personal decision that should be based on the individual needs of your child and your family
- Consider which communication approach will best fit your child, your family, and your vision of your child's future
- Understand that your child's needs may change over time as he develops and as you learn more about his abilities

### **Resources and links:**

- Decision Guide to Communication Choices: <https://www.cdc.gov/ncbddd/hearingloss/freematerials/CommDecisionGUIDE3508.pdf>
- Communication Modes Comparison Chart: <http://ncbegin.org/reference-chart/>
- Considering my Child's Communication: [https://youtu.be/\\_mb5Fvof68](https://youtu.be/_mb5Fvof68)
- Choosing a Communication Mode: <https://www.babyhearing.org/parenting/communication-approach>
- Communication Options: <https://www.aqbell.org/Families/Communication-Options>





# Where the Magic Happens

## *Parents are Agents of Change*

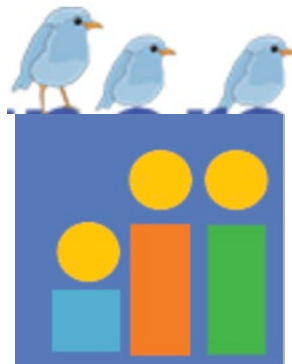
When you become a parent, you automatically become an important teacher, mentor, and role model for your child. This is even more true when you become the parent of a child with hearing loss. Over the coming months and years, you will coordinate your child's professional team, drive the intervention process, and teach your child language and communication. Many parents are surprised to learn that parent participation is the single most important factor in a deaf or hard of hearing child's communication and academic outcomes. You are the agent of change for your child. You are where the magic happens.

There are many things about your child's hearing loss over which you have no control. But, the quality and quantity of the time you spend with your child, and the role you play in his intervention are areas where you have significant power to create change. You are your child's first and most important teacher because of the special parent-child bond you share and because of the amount of time you spend with your child. No therapist, doctor, audiologist or classroom teacher will ever have the same potential to impact your child's learning.

Much of what you need to know to help your child learn you already know by natural parenting instinct. The rest you can easily learn. In fact, the most effective strategies and approaches for teaching young children, whether or not they have hearing loss, are based on your parenting intuition and a child's natural tendencies to play. To build your understanding of what to do, work with your child's therapists and teachers to learn specific approaches or seek out parent education programs to learn how to create a language-rich learning environment at home. By taking an active and meaningful role in your child's intervention, he will have the best chance of achieving his goals and reaching his full potential.

### **Strategies:**

- Spend time with your child, engaging in activities that are meaningful and language-rich.
- Sign up for training that focuses on teaching parents about hearing loss and intervention approaches
- Create a library of books, movies, websites and seminars to help extend your learning.
- Know the laws that protect your child's rights to intervention support and educational entitlements





# Remember the Stepping Stones

## *Celebrating Smaller Steps*

Parents are used to thinking about their child's development in terms of the major milestones: when their child first sits up, rolls over, takes their first steps, speaks their first words etc. While these are significant moments in your child's life, it's easy to forget that hundreds of smaller changes take place along the way. Most parents never notice these changes. But, as parents of a child with hearing loss, you will follow and appreciate these smaller stepping stones which pave the developmental path between one major milestone and the next. As your child develops, and as you monitor the efficacy of your intervention strategies, it's important to notice and celebrate these stepping stones as meaningful steps forward.

It's very normal to compare your child to other children of the same age. Try to remember that every child, whether or not they have hearing loss, will develop differently. Young children learn to listen, talk and communicate over the first few years of life. All children develop these skills in a specific developmental sequence. But, when there is a delay or disruption in hearing, that sequence will also be delayed. If your child is provided with auditory access to sounds, your child will begin to take the same developmental steps with listening and spoken language as a hearing child. But, in the beginning, those steps will take place with a delay that is at least as long as the period during which your child was deprived of sound.

At first, your child's developmental steps may be small and difficult to notice. Work with your professional team to help you track and to celebrate the intermediate steps your child is taking on the way to meeting major milestones. It can help to keep a written log or video diary of what your child is doing to capture small changes that could go unnoticed. This can provide your professional team with additional insights into your child and help you share your journey with friends and family. By being attuned, you will notice and appreciate things in your child's development that other parents overlook and you will share your child's journey in a way that most parents never do. Enjoy it. And, remember: Big successes start with smaller ones.

### **Strategies:**

- Don't compare your child's development to other children. No two children develop in the same way. Compare him only to himself and measure progress that way.
- Keep a journal or blog in which you write down the changes you notice in your child's development. Looking back through your past entries will highlight his progress.
- Use your smartphone or camera to start a video diary of your child playing and communicating. Change can often be easier to see in hindsight.
  - By making videos every month you will be better able to notice changes.
  - Videos can help professionals see what your child is doing outside of therapy
  - Sharing videos with friends and family can help them celebrate the small stuff
  - Remember to label the files or disks with the dates they were recorded

### **Resources and Links:**

- Speech and Language Milestones:  
<https://www.asha.org/public/speech/development/chart/>
- Developmental Milestones:  
<https://www.cdc.gov/ncbddd/actearly/milestones/index.html>



## When the Shoe Doesn't Fit *Making Changes in the Plan*

Intervention is an ongoing process of making choices, observing your child, and evaluating results. In hearing intervention there is no such thing as a “one size fits all” solution. Every child with hearing loss has a different hearing profile and every family has different needs and expectations. An appropriate intervention plan will be shaped by your child’s specific hearing loss diagnosis, the priorities of your family, and many other factors. It’s important to work closely with professionals and teachers to monitor your child’s development and, if you don’t see progress or feel something isn’t working, be flexible and open to making a change.

Expect things to change over time. Sometimes, your child’s development or his individual preferences will create a need for change. Sometimes an approach will look good on paper, but not work well in practice. Other times, a professional might be fully qualified, but simply doesn’t “click” with you or your child. Your child may need different things, and different professionals, at different stages of his journey. In any of these cases, it’s okay to consider changing providers, amending a therapy plan, switching to or adding a communication approach or making any other changes to refresh, revise or improve the plan.

Trust your instincts. As your child’s parent and the person who knows him best, you are also the best judge of when things are working well and when they aren’t. The decision to make a change should be guided by information, observations, and the needs of your child and your family. Each time you face a possible change, gather information, ask questions, and discuss the options with your professional team. Choose what is best for your family, and remember that it’s okay to change. There are no right or wrong decisions as long as your child has access to communication.

### **Strategies:**

- Understand that change is part of the journey and that your family and your child will need different things at different stages
- Work closely with your professional team to monitor and evaluate your child’s progress. When something isn’t working, make changes and try new things.
- Stay flexible, but stay true to the priorities and the needs that are unique to your child, your culture and your community.
- Stay informed with evidenced-based information and assessments, but also trust your instincts to guide you. Other people will have opinions. But the decisions are yours.
- Communication is the goal. You have your child’s best interests at heart and you will ensure that he fulfills his potential. There are many paths to the same destination.

### **Resources and Links:**

- Decision Modification: <https://www.babyhearing.org/parenting/decision-modifications>





# Bending in The Wind

## *Caring for the Caregiver*

You are strong and working hard to ensure your child gets everything he needs. But, the demands of the journey may be taking a toll on your energy, your relationships and your state of mind. While your child's wellbeing needs to be the focus of your attention during this early stage, it is important to pay attention to your own wellbeing too. Your child needs you to stay healthy, balanced and clear-headed so that you can be the best advocate, partner and teacher for him. This journey is a marathon, not a sprint, and you will need to pace yourself and find balance along the way.

Because you will probably be experiencing higher levels of stress and anxiety during this time, it's important to maintain your physical and mental health. Your body will need extra rest and nutrition in order to stay healthy in the midst of a crisis. Take care of yourself by getting enough sleep, eating well, and exercising to manage stress and to allow your body to recharge. It's natural to feel moments of weakness. It's cathartic to have a good cry to release some of the stress and pain you may be feeling. It can be a good idea to take a nap, go for a run, or cook a healthy meal. Managing your child's needs can be psychologically exhausting and socially isolating. Remember that your mental health is important too. Do your best to stay connected with friends and take part in events in your community. Once in a while, set aside your to-do list and have coffee with someone, volunteer, or pick up a hobby. It's also important to nurture relationships with your spouse and your family. Plan a "date night," or plan a family outing for a weekend. Spending time outside of a stressful situation doing something to help everyone relax will help ease tensions and build communication.

Remember to do something for yourself. Don't let go of the person you were before the diagnosis. Spending time doing an activity you enjoy will help you manage stress and give you much a needed outlet and social connections. Don't be afraid to plan some time away from your child. Go for a walk or have a bath. Sometimes you will need a break to clear your head and breathe without interruption so you can come back to things with a clear head. It can be difficult to do. But it's necessary. You and your child are together for the long haul. He needs you to stay fit for the journey. If you break down, everything else breaks down too.

### **Strategies:**

- Be good to yourself. Enjoy some time alone and do something nice for yourself. Take time to acknowledge everything you're doing done to help your child.
- Plan a date night to reconnect with your spouse. Enjoying some one-on-one time can help ease tensions, build communication and remind you of your partnership.
- If things are becoming difficult between yourself and your spouse or other immediate family members, consider making an appointment with a counselor.
- Find time to exercise, meet your friends for coffee, take a walk, enjoy a hobby, read a book or engage in any activity which helps you relax and feel like yourself.
- Don't forget to take a shower, get your hair cut, have dessert, or even indulge yourself a little to refresh and refuel yourself for the journey ahead. You deserve it.





# Thicker than Water

## *How to Support Siblings*

In every family with a child with hearing loss, each family member will have their own unique reaction to the diagnosis and the resulting changes in the family's activities and stress levels. It will take time for everyone to adjust to these new priorities and to feel comfortable in their new role. As you devote yourself to supporting your child with hearing loss, his siblings may be confused, they may feel jealous, and they may feel isolated. Although your time and energy are focused on helping your child with hearing loss during this critical early stage, it is important to remember that his siblings also need your time and attention. You will want to be available to your other children and to embrace them with a positive attitude, reassurance, and love as you begin this journey together.

Understanding that your other children are affected by the diagnosis is important to finding your family's balance. You can help reduce feelings of isolation and jealousy by spending private time one-on-one with your other children. When your attention is focused on your child with hearing loss, try to include them in the process and make them feel like valued members of the team. Siblings are a valuable source of support for children with hearing loss. Like all siblings, they are natural playmates and companions. Importantly, they provide excellent peer models of behavior and language. They are great communication partners and will help challenge, motivate, and encourage language and social development.

Be sure to acknowledge the contributions of your other children to reinforce their importance in the family and their place on the team. Highlight the sibling's contribution and comment on how the child with hearing loss is benefitting from his sibling's support or guidance.

### **Strategies:**

- Encourage hearing siblings to communicate with their brother or sister with hearing loss. Siblings can participate in teaching language and communication by playing games, pretend play, singing songs, and reading.
- Try to set aside time each day to be one-on-one with each child. Make the time you spend together meaningful by planning a special meal, reading a favorite book, going to the park or by letting your child choose the activity and following his lead.
- Give siblings a role to play in the intervention process. For example, older siblings can be excellent language models while playing games or reading a book. Encourage them to take part in therapy sessions and to feel included in the family's learning.
- Help your other children become knowledgeable hearing loss, technology or communication modes. Encourage them to learn and to take pride in their expertise. This approach helps them to become confident, accepting and supportive.

### **Resources and Links:**

- Encouraging Siblings to Communicate:  
<https://www.babyhearing.org/parenting/encouraging-siblings-to-communicate>
- *I have a Sister, My Sister is Deaf*, by Jeanne Whitehouse Peterson
- *It Isn't Fair! Siblings of Children with Disabilities*, by Stanley D. Klein and Maxwell J. Schliefer



# The Butterfly Effect

## *How This Affects Everyone*

In families of children with hearing loss, all family members are affected. Although service providers typically focus on the child, each person will have their own individual reaction to the diagnosis. Some may feel shock, anger, confusion, guilt or surprise. Others may have strong feelings of denial. It's normal to have different feelings as everyone adjusts to your child's hearing loss and as you find your way forward. Your own reaction may be different from everyone else and your opinions and attitudes may clash. Often, with time, tensions ease and families develop positive and healthy attitudes. A diagnosis can bring families closer together as you learn to communicate, support one another, and to work together as a team.

Everyone in the family will be part of the community in which your child grows up. They are bonded to your little one, but they may also feel the emotional impact of the diagnosis. It can be helpful to build family cohesion by sharing information and including siblings and close relatives in activities. Extended family members will naturally want to be involved in supporting you and your child. They can be a great source of support but it can be difficult for them to know what to do if they don't know what your child needs. Where appropriate, give them a role to play or make them part of your decision-making process.

Sometimes, the situation pushes families apart. Your child's diagnosis can put additional strain on relationships that were already weak or fragile. Financial, social and emotional pressures increase. People can be tired, brittle, and communication can break down. Spouses can feel disconnected from each other and siblings can feel jealous of the time and attention spent on their brother or sister with hearing loss. Some families feel isolated socially as they find their place in the hearing and/or deaf community. If you find that things are difficult, you may wish to talk to someone. Reach out to counselors, clergy, service providers or other trained professionals to guide and support your family. Finding balance takes time.

### **Strategies:**

- Be patient with one another. Give each other space to think, to grieve and to come to terms with your child's hearing loss. In most families, this is a big adjustment.
- Understand that it's okay to have different, even contradictory feelings and opinions.
- Communicate information and talk to one another to avoid misunderstandings.
- Take advantage of an extra pair of hands and recruit extended family members where appropriate, to help with childcare or attending appointments. Give them a role to play.
- Extended family members may be able to be more objective. They can act as a sounding board when gathering information and discussing the options.
- Reach out for professional support and guidance from a trained counselor or confidant if things become difficult. Sometimes an outsider can help see things clearly.





## When Others Don't Agree

### *Dealing with Dissent*

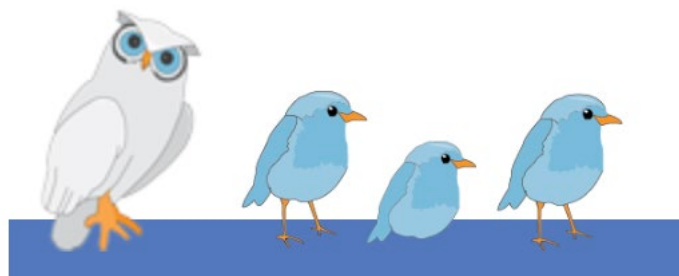
As the parent of a child with hearing loss, you will make many important decisions about your child's communication approach, educational placement, and amplification choice. As you interact with family, friends and professionals, you are likely to find that everyone you talk to has an opinion about the "right" or "best" way to support your child. However, because every diagnosis of hearing loss is different and every child's needs are unique, there are many "right" ways to provide communication and education to children with hearing loss. In your case, the "right" way will be the one that best fits with your family's priorities, and your child's unique needs. It's up to you to learn about the options and determine which ones to choose.

When someone disagrees with your decision, remember that as a parent, it is not only your right, but your responsibility to make decisions for your child. You make decisions every day for your child, about the food they eat, the clothes they wear etc. You will make these decision for them until they are old enough to make them on their own. In the same way, you must make decisions about your child's communication and education. The decision you are making are important and time-sensitive. They cannot wait until your child is old enough to make them on his own. You must do what is best for him now, based on what you know about your family, your child, his diagnosis and the information available.

Other people are entitled to their opinion and it's fair to listen and to acknowledge their point of view. But, every child and family is unique and what worked well for someone else may not fit your family at all. Do not let the opinions of others sway you or discourage you. You do not need to apologize for or make excuses for your decisions. Simply explain that you have chosen what is most appropriate for your child. You are the one that knows your child best. You have immersed yourself in learning about his diagnosis and his needs. Be confident in the decisions you make and remain open to change as your child learns and develops. Remember, there's not one "right" or "best" way to provide intervention for your child.

#### **Strategies:**

- Don't get caught up in debates about the "right" or "wrong" way to support your child. The "right" way is the way that is best for your family and your child.
- Be open to the input and advice of others, but make the decision that is best for your child and for your family. It's your job to do what is best for your child.
- Be confident in the choices you make and do not feel as though you need to defend or to explain them.
- Understand that each child is unique and what may have worked well for another child or family may not work well for yours.
- Be flexible and prepared to make changes if your initial decision does not turn out to be a good fit for you or your child.





# The Paternal Giving Tree

## *The Important Role of Dads*

A note for Dads: When a child is diagnosed with hearing loss, the intervention process commonly focuses on the mother as the primary caregiver and intervention coordinator. Dads are often a step removed from the day-to-day appointments and therapy sessions because of social conventions including work and responsibilities outside of the home. However, it's important to recognize that you, dad, play a critical role as a source of support for the family as well as a primary role model, teacher and playmate for your child. Every child with hearing loss needs one essential thing: You.

Because men are often called upon to be the “rock” for their families, society commonly expects men to compartmentalize their emotions. It may be difficult for you to deal with your feelings or to share your questions and concerns. But, families need to work together and communicate well in order to make important decisions together. Dads want to be strong. But, this time, being strong means working as a team and being open about how you feel. It may feel uncomfortable at first, but to be in sync with one another, you need to share thoughts and feelings. You are entitled to sadness, anger, and fear. You also need time to grieve.

The traditional role of fathers as bread-winners makes you important to the financial stability of the family, but it also can lead to feeling removed from the details of the diagnosis and the decisions about intervention. Although work may take up much of your time, try to get involved and stay involved, as much as you can. It might be difficult to attend appointments and therapy sessions, but service providers can offer written reports or even videos to help you stay informed. Communicate, ask questions, and learn as much as you can. If you're struggling, reach out to other fathers of children with hearing loss who can understand.

Along the way, don't forget to have fun and enjoy time with your child. It's critically important to form strong bonds and to have fun. In addition to the financial stability you give your family, you are giving your child an essential sense of emotional security, protection, and love. Don't let the diagnosis stand in the way of savoring these precious early years. The pass quickly.

### **Strategies:**

- Give yourself time and space to grieve. It's important to acknowledge these emotions and come to a point of acceptance so that you can start working for your child.
- It can be difficult to balance your role as provider for your family with the pressures of your child's diagnosis and intervention. Reach out to other dads if you are struggling.
- Do your best to attend appointments and therapy sessions with your child; if you can't attend, ask your provider for written doctor's reports, or videos from therapy sessions.
- Understand that each parent has a role and that one parent may be better suited to certain tasks than the other. “Playing to your strengths” can be a good strategy.
- Have fun! Play with your child. Get down on the floor and follow their lead. Sing, read, pretend. Having a child is a good excuse to behave like a child yourself. Enjoy!

### **Resources and Links:**

- Listening to Dads, Hands & Voices:  
[http://handsandvoices.org/articles/early\\_intervention/V16-1\\_dads.htm](http://handsandvoices.org/articles/early_intervention/V16-1_dads.htm)





# A Family Affair

## *The Role of Grandparents*

How grandparents respond to your child's diagnosis will depend greatly on family dynamics. A diagnosis of hearing loss will place strain on everyone in the family in different ways. Just as you are going through a process of grieving and acceptance, grandparents can also have difficulty accepting that their long-awaited grandchild has hearing loss. Grandparents may be feeling sad for your child, but they will also be feeling sad for you. They will want to be supportive, but may be feeling helpless at the same time. Like you, they may be experiencing shock, or disbelief, or grieving. Acceptance takes time. In the same way that you need time to learn and adapt to your child's diagnosis, grandparents will need time to learn and adapt too.

Grandparents will naturally have questions. They will have opinions and they may offer unwanted advice. They may have very different, possibly outdated, ideas of what it means to have hearing loss. Grandparents are often living far away, which can make them feel disconnected and isolated from the day-to-day realities and the decisions you are making. Still, it will be important for them to talk to you about their feelings and for you to share your own point of view. They may not completely agree with what is best for your child but, the decisions are yours, and communication will pave the way for understanding.

Whether grandparents live nearby or at a distance, try to include them in your learning. Share information. When possible, invite them to attend meetings or communicate with your intervention team. When grandparents are in the loop, they have an opportunity to support you, to learn what your child needs and how to support him. As grandparents learn about your child's hearing-related needs, they can become more involved and offer meaningful support. Their support could range from emotional, to financial, to providing an extra pair of hands at appointments, to babysitting when you need a break. By including grandparents, you are creating opportunities for them to nurture and encourage your child, while supporting you too.

### **Strategies:**

- Give grandparents time and space to come to terms with their grandchild's diagnosis. It may help to connect them with other grandparents of children with hearing loss.
- Understand that grandparents will have grown up at a time when hearing loss had very different implications for social, academic and professional outcomes.
- Include grandparents in your family's learning process. Where possible, invite grandparents to attend appointments with your child's intervention team.
- Provide grandparents with information that is specific to your child and helps them to learn what to expect and what to do to support you and their grandchild.
- Listen to grandparents' opinions and suggestions and, where you disagree, try to communicate and work together in the best interests of your child.

### **Resources and Links:**

- *Grandparenting a Child with Special Needs*. By Thompson, C. (2009).
- A Family Affair: Grandparenting a Child who is Deaf or Hard of Hearing, By Krystyann Krywko, Ed.D (Source: Volta Voices, November/December 2013)  
<https://www.agbell.org/Portals/26/family-archives/Family%20Resources/A%20Family%20Affair.pdf?ver=2018-04-09-153900-340>
- Tips for getting Extended Family Involved:  
<https://www.babyhearing.org/parenting/getting-extended-family-members-involved>



# Success Has Many Colors

## *Managing Expectations*

While the key to successful outcomes for children with hearing loss depend heavily on early intervention, outcomes will also vary widely depending on many intrinsic and extrinsic factors. Because each hearing loss diagnosis is, like a fingerprint, unique, each child with hearing loss will have a unique hearing history and access to sound. Every child with hearing loss will also have natural talents and aptitudes, just as children with hearing do. Success for children with hearing loss, therefore, looks very different for different children. In the early stages of planning intervention for your child, you and your professional team will evaluate your child's unique medical history and environment and discuss appropriate goals and expectations for your child's specific case.

The long-term speech, language, literacy and academic outcomes for your child will depend on several factors including factors which you cannot control (like the type and configuration of your child's hearing loss, your child's natural abilities, and other developmental concerns) as well as factors which you can control like the age of your child's amplification, the choice of intervention and access to services, the degree and quality of parent involvement. Because these criteria are different for every child, it's important that you don't directly compare your child any other child with hearing loss. Your professional team may use developmental scales to track your child's progress against developmental norms, but his progress will be measured against his own performance.

Due to advances in technology and to early identification and intervention, language, literacy and academic outcomes for children with hearing loss are better today than they have ever been. You should be encouraged to have high expectations of your child and to push those working with you to share your belief. However, it can take time for children with hearing loss to overcome delays in speech and language and to meet the hallmark milestones of first words and word-combinations. For this reason, it's helpful to work with a professional who can highlight the many interim, but important steps your child is taking on the way to using first words. The journey is long, but success can be measured in baby steps. Be sure to acknowledge and celebrate the baby steps along the way.

### **Strategies:**

- Providing your child with early and appropriate intervention gives them the best opportunity to achieve to their full potential. Don't wait to get services and support.
- Become an active participant in your child's rehabilitation. Parents are the key to effective intervention and to maximizing outcomes for their children with hearing loss.
- Understand that your child's hearing loss and his natural abilities are unique. Therefore, how he progresses and the measure of his success will also be unique.
- Do not compare your child's progress to that of any other child, with or without hearing loss. Your child's progress should be measured only against himself.
- Small successes lead to bigger ones. Your professional team will track these small steps. Be sure to appreciate the small successes along the way and celebrate them!

### **Resources and Links:**

- Expectations Now and Then – My Baby's Hearing: <https://youtu.be/7Nndfq1Ox9I>
- Parents Views of Success: <https://www.babyhearing.org/parenting/definition-of-success>



# Genetic Testing: *What Does it Offer You?*

Genetic testing can provide useful information as you begin to understand the nature of your child's hearing loss, choose a communication mode, and plan for intervention. Parents opt for genetic testing for various reasons. For some parents, knowing the cause of their child's hearing loss provides peace of mind and helps them to better accept the diagnosis. For other parents, genetic testing helps them to understand the origin of their child's hearing loss and to make decisions about family planning. The choice to undertake genetic testing is personal, and it won't be right for everyone.

One important reason to consider genetic testing is that it can provide important medical information and help plan intervention for your child. If genetic hearing loss is identified, knowing whether it is nonsyndromic or syndromic has implications for your child's development and can impact choices for intervention and communication mode.

Approximately 70% of hearing loss is nonsyndromic, in which the only medical issue is the loss of hearing. In about 30% of genetic hearing loss cases, the genetic deafness is syndromic, which can involve additional medical diagnoses, other therapies and support.

It's important to note that although a child born with hearing loss can sometimes have a family history of hearing loss, most people with inherited hearing loss do not have a family history of deafness. Genetic testing can diagnose these cases. To date, science has identified hundreds of different types of genetic hearing loss and, as the study and understanding of the human genome improves, new types are constantly discovered. Currently, genetic forms of hearing loss account for more than half of hearing loss in infants. Genetic testing is one way to learn more about your child's hearing loss. Whether and when to pursue it is up to you.

## **Strategies:**

- Discuss the possible benefits of genetic testing with your spouse and medical team to determine whether it can provide benefit to you and your family
- Contact a genetic counselor, a clinical geneticist, or a genetic testing lab to get the most current information about genetic testing for hearing loss
- If your team is unfamiliar with genetic testing for hearing loss, they can visit the website GeneTests ([www.genetests.org](http://www.genetests.org)) to search for a laboratory to assist you

## **Resources and Links:**

- *Genetics of Hearing Loss* <https://www.cdc.gov/ncbddd/hearingloss/genetics.html>
- *Understanding the Genetics of Deafness*, Harvard University Medical School <https://hearing.harvard.edu/resources>
- *A Parent's Guide to Genetics and Hearing Loss*, Centers for Disease Control and Prevention <https://www.cdc.gov/ncbddd/hearingloss/freematerials/parentsguide508.pdf>
- *Questions You May Want to Ask Your Child's Genetics Team*, Centers for Disease Control and Prevention [https://www.cdc.gov/ncbddd/hearingloss/freematerials/genetics-questions\\_eng.pdf](https://www.cdc.gov/ncbddd/hearingloss/freematerials/genetics-questions_eng.pdf)



# Attitude is Everything

## *The Power of Positive Thinking*

Despite what you may be feeling right now, the fact that you have identified your child's hearing loss and that you are seeking intervention is a positive step forward. You are now in a strong position to understand your child's needs and to provide support for his development. Your child will have the opportunity to achieve his full potential because of the steps you are taking now. Although it seems counterintuitive to put a positive spin on a complicated and emotionally difficult time, you should be proud of how far you've come. Although the road ahead is curved and bumpy, it is also filled with unexpected beauty and surprises. There is a lot to look forward to, and many reasons to hope.

Having a positive attitude towards your child's hearing loss and having confidence in the intervention choices you are making now sets the example for your child's own emerging self-esteem and confidence. All children look to their parents for cues and guidance about the world around them. Their attitudes are shaped by the things you say and by the feelings you express. There is no doubt that learning of your child's hearing loss is an emotional and stressful event for you, as a parent. But for your child, hearing loss is his "normal." He is unaware that there is anything amiss. He is unaware that you may feel a crisis. He looks to you for the same things that hearing children need: love and a sense of security.

While it is natural to feel sadness, anger, guilt and many other complex emotions as you come to terms with the diagnosis, it is also useful to appreciate the value of early identification and intervention. Your child has years of rich social, exploratory and learning experiences ahead of him. During this time, you are the most important teacher and guide for your child in his most impressionable years. Your comfort level and attitude will shape how he feels about hearing loss and about himself. If you adopt an attitude of confidence and positivity towards your child, and express a level of comfort with hearing loss, you instill in your child the feeling that although hearing loss is part of who he is, it does not define him.

