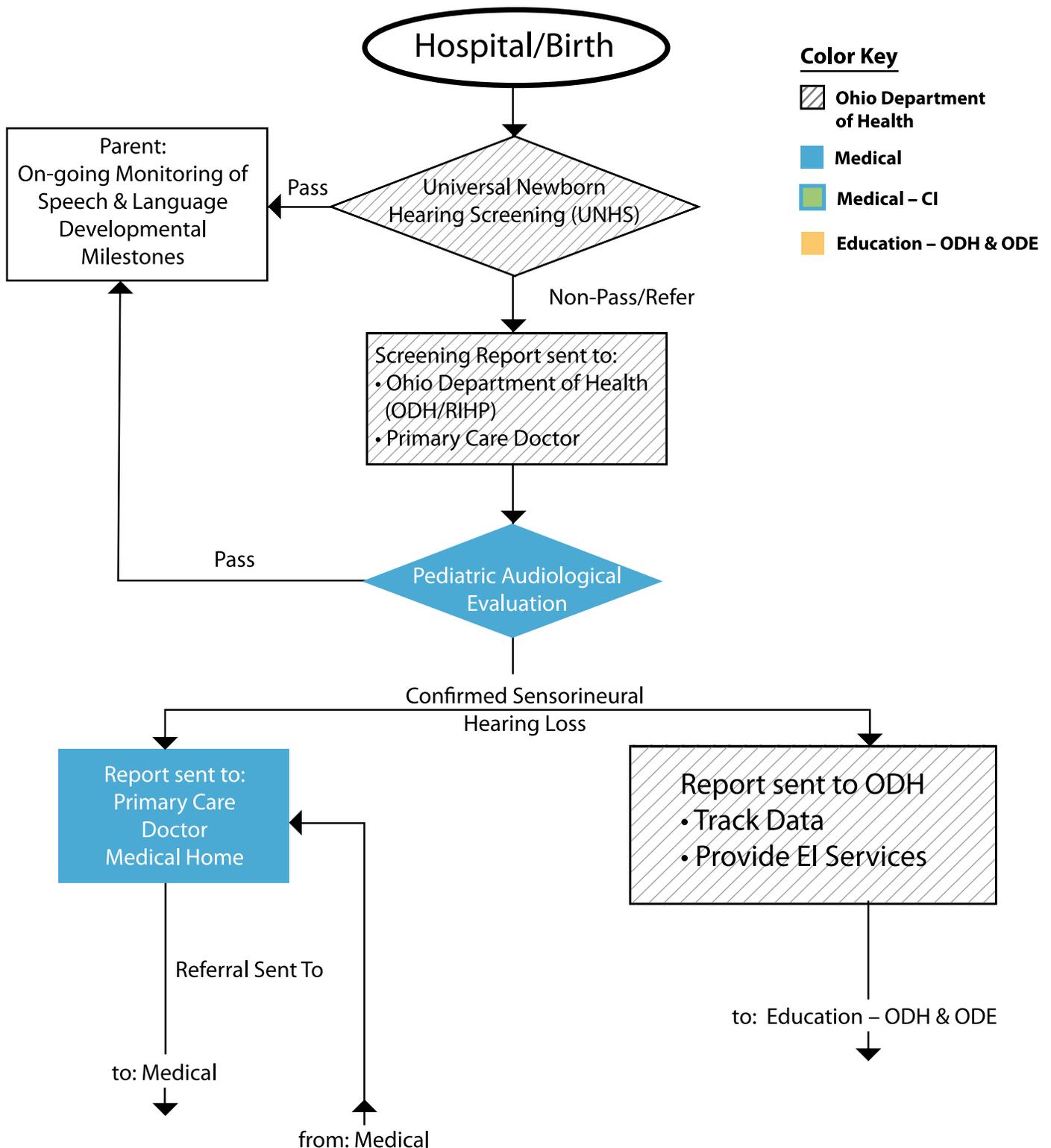




**MY CHILD HAS  
A HEARING LOSS**

# EARLY HEARING DETECTION AND INTERVENTION (EHDI) EARLY INTERVENTION SERVICES (Birth-School Years)



**Source:**

D. Richard Kang, M.D. & Kim-Jae O. Kang



# MY CHILD HAS A HEARING LOSS

“Our lives have been turned upside down”

“WHEN WE FIRST FOUND OUT OUR CHILD HAD A HEARING LOSS, WE WERE DEVASTATED.”

“WE DEFINITELY REACTED DIFFERENTLY. I WANTED TO TALK ABOUT AND READ AS MUCH AS WE COULD ABOUT HEARING LOSS, WHEREAS MY HUSBAND INTERNALIZED HIS FEELINGS MUCH MORE.”

Your child has been diagnosed with a hearing loss. You may feel confused, isolated, overwhelmed, and devastated by the diagnosis. Often parents feel guilty that they may have caused their child’s hearing loss. These are common reactions that you are feeling and you are not alone!

## **Communication and Emotional Support Between Spouses/Partners**

Your spouse or partner may react differently than you about your child’s hearing loss. It is not uncommon for one partner to deal with his or her emotions by talking, while the other may cope by searching for solutions to help their child. You both love your child and you should not feel ashamed of feeling sad about your child’s hearing loss. It is helpful to talk about your feelings with each other during this time. One person may need more time to work through their feelings of sadness and depression, while the other may focus on getting information on various medical treatments and intervention options for their child.

**Individuals process their feelings differently. On an emotional level both of you do “feel” the same feelings but may respond and react differently.**

This is a time when you will need to be patient and understanding with each other. One partner may feel that the other’s reaction is uncaring or over reactive, resulting in withdrawing or judgement, instead of support and concern. Allow each other your own time to process and deal with the diagnosis in your own way. You can help each other by talking, venting, and sharing your feelings and frustrations with one another. This is an important time for couples to support each other and work together to find assistance for their child.

## **Grieving Process**

It is common for parents to go through some stages of grieving for the loss of their child’s hearing, or the “typical” child that they expected to have. You may go through some or all of these stages of grieving:

- **Denial/Shock** – “This can’t be happening to me!” You may feel you’re going to “wake-up” from this dream and feel everything is going to be alright with your child.

“WHEN I LEARNED OF MY CHILD’S HEARING LOSS, I WAS IN DENIAL BECAUSE MY CHILD ACTED LIKE A ‘NORMAL HEARING’ BABY.”

- **Anger**– You may feel angry at yourself, your spouse, and others. You may blame God that this is happening to you.
- **Guilt** – You may blame yourself and feel that you “caused” your child to be hard of hearing or deaf.
- **Depression** – You may feel helpless, alone, and hopeless about the future.
- **Acceptance** – Once you have experienced the various stages of grieving, you can learn to accept and realize that your child’s hearing loss *will not* go away and that you must find appropriate medical treatment and intervention to help your child.
- **Hope** – It is the driving force that provides you the means to make a plan of action to help your child. There is “light” at the end of the tunnel!

If either one of you feel that you are “stuck” in any of these stages, and think you are not getting enough support, it’s okay to seek help from a trained counselor to help you through this process.

### **Understanding the Diagnosis and Information Gathering**

- Learn as much as possible about your child’s diagnosis. Read and gather as much information that you can.
- Write down and ask questions for the professionals before you go to an appointment for your child.
- The professionals are there to answer your questions and to help your child. They are used to speaking to many parents about hearing loss and they understand that this is your *first* time hearing the news. Because of this, they understand that you may not have “heard” the information or explanations that they gave to you and that they may have to repeat it to you several times.
- This is a learning process. As your child grows and develops you will get to know your child better than anyone, you will become an “expert” on your child.
- The professionals are knowledgeable in their specialty area and you are the expert on your child. Work together to get appropriate medical treatment options and intervention services for your child.

### **Making a Plan of Action Through Informed Decisions**

It is important to learn all about your child’s diagnosis so that you can make *informed decisions* on what medical treatment and intervention options are best for your child and family.

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**Time is critical when you as parents, need to make a plan of action through informed decisions.**

**Critical developments in the brain's ability to hear and speak occur especially during the first year of life. The longer the infant is deprived of hearing speech sounds, the more difficult it is for the child to catch up in language when he or she finally gets some sound input.**

**If a child born with severe to profound hearing loss does not receive any sound input into his or her brain by age 3, research has shown that his or her chance of optimal hearing and speaking decreases considerably.**

- **Medical Treatment Options** – What amplification and hearing technology treatment options: hearing aids or implantable hearing aids, and/or the possibility of cochlear implant(s) or other surgical procedures will benefit your child to optimize their hearing? More information can be found under *Section VII. Medical Treatment, under Amplification and Hearing Technology.*
- **Communication Options** – What are the primary communication goals for your child; spoken language, simultaneous communication (total communication), or American Sign Language? More information can be found under *Section VIII. Early Intervention, under Communication Options.*

**The communication option you choose for your child will dictate the intervention required to accomplish your child's goals.**

You will be learning and collecting a lot of information, and at times it may feel overwhelming. It's okay to take some time to relax and process the information.

Remember, *you have a child that needs its parents to do all the things they normally would do. Cuddle, talk, sing, and play with your child!*

It is important to bond with your child in a natural and loving manner. Your child needs to feel your love! Even though your child may be deaf or hard of hearing, your voice may be seen and felt. Talk to your child so that they can watch your facial expressions as you naturally communicate to them.





### **Taking Care of Myself and My Family**

Being parents of a child with hearing loss has many challenges. You will be making important decisions for the future of your child and your family so it is important to *take care of yourself, first*.

- Take time for yourself. Maintain your health, eat well and get plenty of rest. Continue to do the things that you enjoy; read a book for pleasure, listen to your favorite music, cook, if that's something you enjoy, or take a walk.
- Keep an open line of communication with your partner. Talk to each other openly and discuss your concerns. Remember you are both different individuals that may react and handle situations in different ways. Allow for those differences.
- Laugh and enjoy some time together with your partner and family without always thinking about your child's hearing loss.
- Be sensitive to the needs and actions/reactions of sibling(s) of your child with hearing loss. *Just as parents need support, siblings of children with hearing loss need your support.*
- Continue to connect with good friends. These times will allow you to re-energize so that you can focus better on your child.

### **Siblings (Brothers and Sisters) of Children with Hearing Loss**

Having a child with a hearing loss affects the *whole* family. Just as parents process their feelings differently and need support, siblings of children with hearing loss need their parents' support. Some siblings are able to express their feelings through words and others may react through their behaviors. You may find that your child is more needy or clingy, or may have mood swings. Your child most likely does not understand the changes in their parents' behaviors and family routines and may feel confused.

Changes in parents' behaviors and family routines are noticed and felt by all the children in the family. Seeing a parent tearful at times, as well as, parents spending more time with the child with hearing loss in numerous medical and therapy appointments, may make them feel uncomfortable. Changes in your child's behaviors or moods are signs that they are reacting to the changes in the family. They are seeking your attention and your support.

The following is important to consider for siblings:

- **Communication** – Allow your child to talk and ask questions about their concerns regarding their brother or sister who has a hearing loss. Your discussions should be at their level of understanding.

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- **Support** – Your child needs your support and understanding. They also need to be able to talk to other siblings about what it is like to have a brother or sister that has a hearing loss. A sibling support group may be helpful for an older child. See below for information on the Sibling Support Project. Ask your professionals for sibling support groups in your community.
  - **Individual Time** – Parents spend more time with the child with hearing loss due to appointments, maintenance on amplification technology devices, and therapy at home. Your child may feel “left out” due to all the attention their sibling is getting. They may feel “jealous” of their brother or sister. Schedule a regular “me and mommy or daddy time” with your child. They need to feel that the special time is just for them with their parent.
  - **Respect for Uniqueness** – Other people may ask questions or react in different ways to your child with hearing loss. Your child will understand that their sibling is “different” than other children. As parents it is an opportunity to talk to your child that everyone is “unique” and “special” in their own way. Learning about differences and tolerance in others is an important life lesson for all.
  - **Typical Behaviors** – Your child with hearing loss may need more guidance, but siblings may think parents give “special” treatment to their brother or sister. Do not expect your typically hearing children to “know better or understand”. Remember, they are children also.
  - **Family Life** – Siblings need to feel that they are not limited by their brother or sister who has a hearing loss. They need to feel that they live a life that is as “typical” as any other family.



The *Sibling Support Project* is dedicated to the life-long concerns of brothers and sisters of people who have special health, developmental, or mental health concerns.

For more information on Sibling Support Project, see website:

<http://www.siblingsupport.org/>

*Ohio SIBS Special Initiatives by Brothers and Sisters*

The Ohio State University Nisonger Center Columbus, Ohio

Website: <http://www.ohiosibs.com/>

### **Your Support System**

A support system includes and provides everything from emotional comfort, helpful information, and professional services. Your support system will be of great value to you while you are going through this process. The professionals that are helping your child and family, your relatives, and friends are part of your *support team* and your support system. Allow family and friends the opportunity to learn about hearing loss, share websites, and resources so they can engage in conversations with you and be part of your support team.

The *support team* members in your support system include:

- **Professionals** – that are helping you and your family. They include: your child’s primary care doctor, ENT doctor, audiologist, speech-language therapist, psychologist, nurse, occupational and/or physical therapist, social worker, early intervention specialists, and educators.
- **Family and Relatives** – spouse/partner, parents, siblings, aunts, uncles, and grandparents can be a great source of support.
- **Good Friends** – that you can share what you are going through.
- **Religious Organizations** – can help provide spiritual support.
- **Parent Support Groups** – meeting with other parents of children with hearing loss can be supportive because they’ve “been there” and can truly empathize with you.  
*Parent-to-parent* support can provide information on everyday practical issues that are specific to raising a child with hearing loss, such as how to keep hearing aids on your child or the care of a cochlear implant, etc. It provides an opportunity for families to socialize and have their children be with other children like themselves. Exchanging information and resources about services in the community can be very helpful. Ask your professionals for a list of parent support groups in the community.
- **Internet** – can provide you with much information. Make sure that you are looking at sources that have accurate and up-to-date information. Many parents chat on-line and have blogs that can be helpful to you. Helpful websites on specific topics are provided throughout this parent’s guide
- **Community/Local, State, & National Organizations** – can provide more information, resources, parent support, and educational workshops/conferences in the area or nationally. See below for a list of resources in central Ohio and for a directory of organizations.

“THE GREATEST SUPPORT WE FOUND IS OTHER PARENTS. THEY KNOW WHAT YOU ARE GOING THROUGH.”

“FINDING A FAMILY WITH A CHILD 2 TO 3 YEARS OLDER THAN YOURS WILL GIVE YOU VALUABLE INSIGHT WITH CURRENT INFORMATION.”

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Keep a list of your “support team”, including professionals and others on the forms provided in *APPENDIX F – “My Support Team – List of Professional”, and “My Support Team List”* adapted from BEGINNINGS for Parents of Children Who Are Deaf or Hard of Hearing, Inc.

For other resource information, see the following under *Section RESOURCES – Central Ohio Service Providers for Children with Hearing Loss and Resource Directory of Organizations*.

### **Working Together as a Team**

In order to provide the best care for your child, both parents and professionals must work together as a team. Parents know their child best and are a vital member of the professional team. Your input regarding your child is very important and helpful to the professionals.

Parents and professionals should:

- Be open-minded to each other’s expertise; parents know their child best and professionals know their specialty area.
- Maintain an open line of communication; trust and mutual respect for each other will help you develop a working relationship.
- Work together as a team; share any concerns that may affect the care of the child; both parents and professionals should be open to suggestions.



The Parent Advisory Board at Nationwide Children’s Hospital for parents of children with hearing loss meets to discuss how best to serve the needs of children with hearing loss.

If you have concerns regarding the care of your child, it is important to *speak directly* with the professional working with your child. If your concerns are not resolved, then you may want to speak with that professional’s supervisor. You are your child’s advocate and you need to do what you feel is right for your child.

### **Advocacy**

Advocating for your child is:

- researching hearing loss and how it will effect your child’s development
- learning about appropriate medical treatment options
- accessing resources available within and outside your community
- working with professionals to make informed decisions on appropriate medical treatment options

- carrying out the plan of actions the you and your professionals have chosen
- obtaining information and emotional support through parent-to-parent support groups
- joining organizations that provide information through educational workshops and conferences
- learning the process of developing your child's IFSP and IEP
- being a role model for your child so that they can learn how to advocate for them self

Some of the above have been discussed and others will be provided in more detail later in this parent's guide.



# NOTES

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