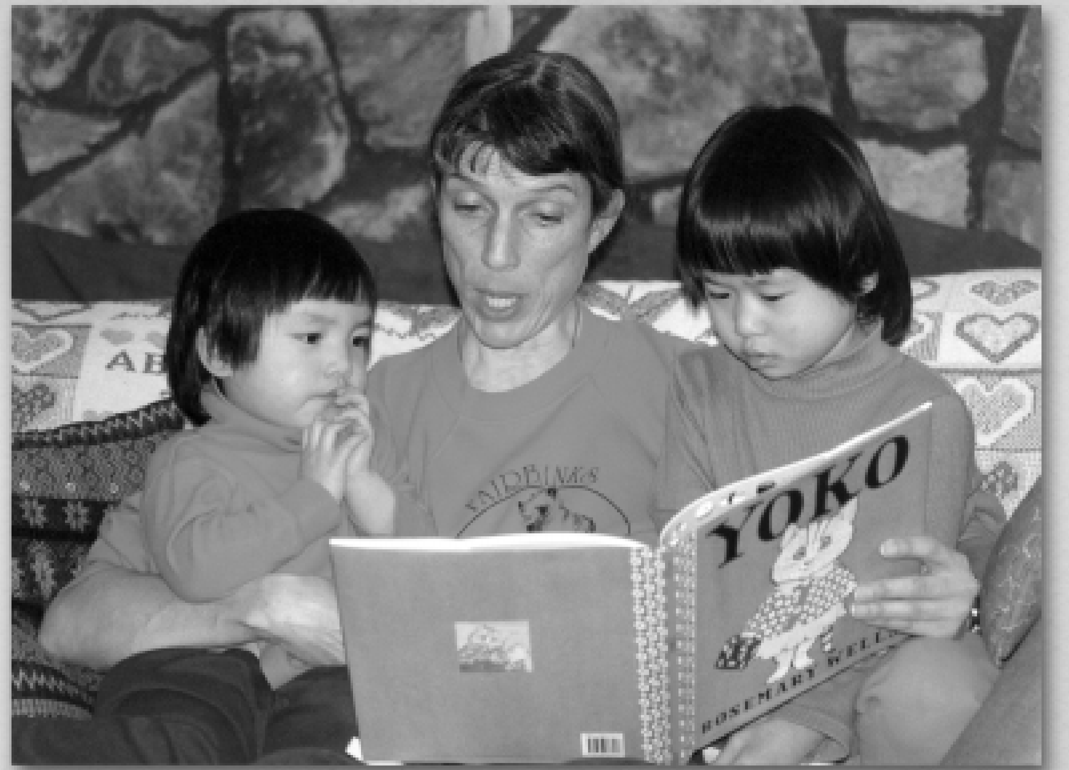
PARENTS

> *"There are only two lasting things*
> *we can leave our children;*
> *one is roots, the other is wings."*
>
> — Anonymous



Introduction

Discovering that your infant/child is deaf or has a hearing loss can result in many emotions. It is normal to experience a variety of feelings including relief, anger, shock, fear, denial, sadness, grief, confusion, guilt, disbelief, and surprise.

Most people have never had any experience with deafness or hearing loss of any kind, and therefore suddenly find themselves launched into very unfamiliar and uncomfortable territory. For many, this experience is not unlike the grief process. It is very individual and everyone reacts differently.

Some parents have little problem accepting the diagnosis and seem to move on without a hitch, while others find themselves struggling to come to terms with it, sometimes for an long period of time. Regardless of what your reaction is, be assured that it is normal. There is no right or wrong way to react.

You can learn a lot from talking to parents of children who have older children with a hearing loss. There are many different local parents groups. Find one, and go to a meeting. If there aren't any groups in your area, contact the nearest group and ask for its newsletter. These can be full of information too! (See Resource Section to find parent groups in your area.)

> *"Important advice that you should think about is having patience with your child. It will take some time to get used to some changes that you will have to sacrifice for. Remember that your child will look up to you and copy your actions. Your child will learn from you and you will learn from your child. All it takes is time and patience. Later as you get used to the changes, you will realize that learning something about your deaf child is precious. You learned that love is what brought you and your child close together. Having a deaf child might not be easy but you will be able to handle it if you have love for your child. That is most important between you both. My advice to you is to just take one day at a time and learn from your mistakes."*
>
> — Jenilee (age 14)

Advocating for Your Child

An advocate is someone who takes action on behalf of someone else. As the parent of an infant/child with a hearing loss, you are an advocate when you stand up for the needs and the rights of your child. You are an advocate when you do the following:

- Let professionals know what services you want for your infant/child and your family at your IFSP/IEP meeting
- Find the best doctors, therapists, and services for your infant/child
- Talk to other families with children with hearing loss about your experiences with the services your infant/child is receiving

It can be difficult to advocate for your infant/child without knowing what your rights are as a parent. There are organizations available to help you learn more about the laws that affect your infant/child and how to advocate.

It is important to remember to take care of yourself while caring for your infant/child. Taking time for yourself will make both you and your family happier and more effective.

Five Steps to Becoming Your Infant/Child's Best Advocate

1. Begin by assuming that you are an equal partner in your infant/child's education.
2. Deal with your perceptions or feelings about yourself as a parent of an infant/child with special needs.
3. Gather information. You don't have to memorize everything, but rather be aware and ask questions.
    - Know your rights regarding IDEA (Individuals with Disabilities Education Act).
    - Other rights are protected by ADA (Americans with Disabilities Act), which ensures that all people with handicaps have access to public events, spaces, and opportunities.
    - Know that now all issues are controlled by the local school system.
    - Know how the system operates.
    - Know the people.
4. Improve your skills in:
    - Communication
    - Documentation/letter writing
    - Record keeping
5. Participation is the most important thing you can do for your infant/child.
    - Participate in Individualized Education Plans (IEPs) and share your ideas
    - Teacher conferences
    - Parent group meetings
    - School functions

Don't ever forget, that you are an equal partner and deserved to be treated like one. And remember, you and your infant/child have other rights in addition to your legal rights. You have the right to decide what is best for your infant/child.

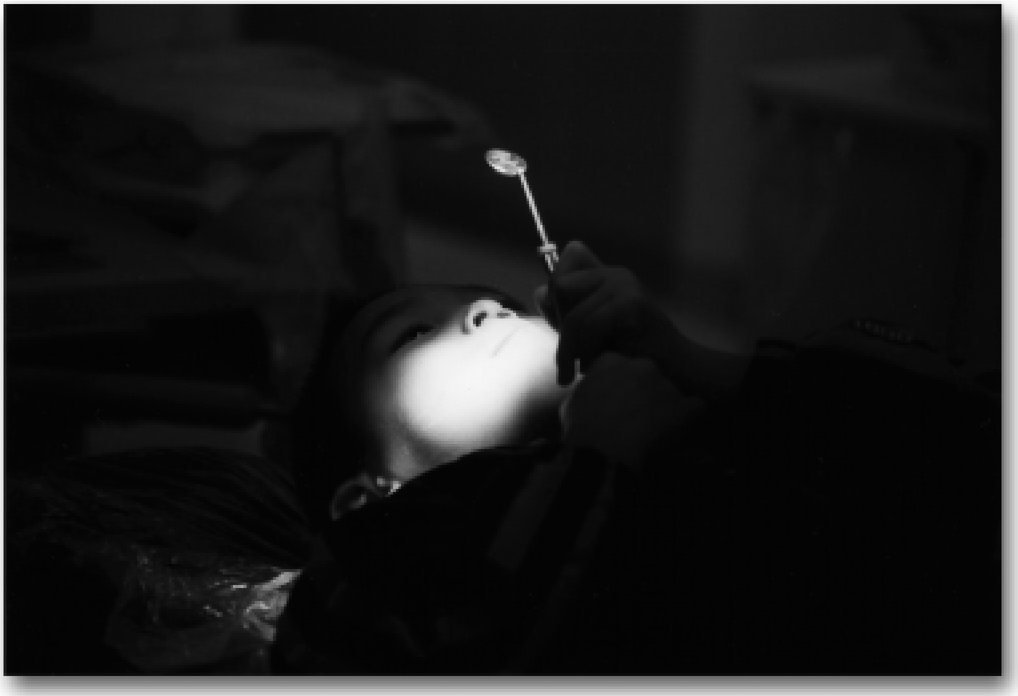
Dealing with Professionals

The audiologist (hearing loss specialist) is an important part of your infant/child's team of caregivers. Make sure that he/she is willing to listen to you and take time to answer your questions. Following are some questions that you may want to ask your audiologist:

- How much experience do you have testing infants and young children? How about fitting infants and young children with hearing aids?
- How much of your time do you spend working with young children (practicing pediatric audiology)?
- Do you know what FM systems are? Do you recommend them for infant/young children?
- How soon do you suggest fitting hearing aids for a deaf or a hard-of-hearing infant/child? (The audiologist should be ready to fit your infant/child with hearing aids as soon as the loss is confirmed.)
- Will you be able to direct me to the speech and language pathologists? How about early intervention programs? (If not, the audiologist probably does not have many pediatric (infant/children) patients.)
- What do you know about cochlear implants? Where can I get more information about them?

Questions for parents to begin asking about their infant/child's hearing tests?

- What does this test measure? What will this test tell me about my infant/child's hearing loss?
- How does this test work?
- Why do we do this test at this time?
- What are you looking for with this test? What do you expect to find with this test?
- How do we read the results or findings of this test?



Check List

for Effective Parent-Professional Collaboration

☐ Do I believe that I am an equal partner with professionals, accepting my share of the responsibility for solving problems and making plans on behalf of my infant/child?

☐ Am I able to see the professional as a person who is working with me for the well being of my infant/child?

☐ Do I see as my goal for communications with professionals the mutual understanding of a problem so that we can take action as a team to reduce the problem?

☐ Do I clearly express my own needs and the needs of my family to professionals in an assertive manner?

☐ Do I state my desire to be an active participant in the decision-making process concerning services for my infant/child and do I seek agreement on how to make sure I am involved?

☐ Do I take an active, assertive role in planning and implementing the Individual Education Program for my child?

☐ Do I come to appointments having thought through the information I want to give and the questions I want answered?

☐ Do I accept the fact that a professional often has responsibility for service coordination and communication with many families, including my own?

☐ Do I treat each professional as an individual and avoid letting past negative experiences or negative attitudes get in the way of establishing a good working relationship?

☐ Do I communicate quickly with professionals who are serving the needs of my infant/child when there are significant changes or when notable situations occur?

☐ Do I communicate with other parents, thereby reducing my isolation and theirs, and sharing my expertise?

☐ Do I encourage the professionals involved with my infant/child to communicate with each other and to keep me informed as well?

Literacy Skills

Always remember, your deaf or hard of hearing infant/child:

- Needs to see you more than a hearing infant/child. Deaf infants/children may not know you are there without seeing you.
- Responds well to movements. For example, he/she will watch the movements and changing expressions of your eyes.
- Uses your face to understand what you say. For example, hearing infants/children learn the difference between a question and an order by listening to their parent's voices go up or down in pitch. Deaf or hard of hearing infants/children watch their parent's faces for a questioning facial expression or a firm, ordering expression.
- Keep it simple. Show pictures of simple objects and pictures to your infant/child. Infants/children become confused when there is too much to look at. For example, your infant/child will be more interested in one toy than in a chest full of toys.
- Keep a diary of your infant/child's progress. Write down the many things you and your infant/child do together such as:
  - facial expressions I used and my infant/child watched…
  - my infant/child watched with interest when I …
  - my infant/child watched my face and signed when I said these words….
  - words I want to use with my infant/child in the future are…
  - pictures and things I want to show my infant/child in the future are…
  - facial expressions I want to show my infant/child in the future are….

As your infant/child starts new activities and responds to you, expand his/her language by adding new words and new ideas such as:

- A good way to stimulate your infant/child's thinking is to offer choices
- Many pre-reading activities do not require books
- Many toys and activities encourage reading, writing, and speaking
- Before you start any activity, get rid of distractions

Tips

for Reading to your Deaf or Hard of Hearing Child

- Choose books both you and your infant/child like.
- Make sure your infant/child can see your face, your signs, and the print at the same time.
- Don't be limited by the words. Expand on the book's ideas.
- Talk about the story with your infant/child as you read. Ask your infant/child questions. Connect ideas in the story with your experiences. Have your infant/child guess what will happen next.
- Be dramatic. Play with the signs and exaggerate your facial expressions and movements to show different characters.
- Vary where you make the signs. Sometimes sign on the page; sometimes sign on your child; sometimes sign in the usual place.
- If you don't know some signs, don't panic. Use gestures, point to pictures, and act out that part of the story. Later you can ask your infant/child's teacher for the sign.
- Keep attention by tapping lightly on your infant/child's shoulder, or giving him/her a gentle nudge.
- Let your infant/child guide you through the story. For very young children, this may mean letting him/her turn the pages as you briefly describe the pictures. When your child is older, you can actually read the story.
- Act out the story after you have read it.
- Read the story over and over if your infant/child asks. This is an important part of his/her language development (learning).
- Have fun! Make your time together a positive experience!

Record Keeping

Creating a Home File – How Do I Keep Track of All of This?

Getting Started

Decide what type of storage you will use.
Examples include:

- Binders
- An accordion file
- A tote bag
- A computer
- A filing cabinet
- A box
- A drawer

Organizing Your File

Use folders or dividers to separate different sections, and subsections. Examples of the sections include:

- ***"Get to Know Me"***
  - Pictures
  - Likes/Dislikes (food, activities, toys, friends, pets, etc.)
  - Strengths/Weaknesses
  - Daily routine

- ***Important Documents*** (originals in a safe place and copies in the file)
  - Birth certificate
  - Immunization record
  - Social Security Number
  - Insurance card
  - Legal documents (guardianship, consents for emergencies, etc.)

- ***Directory of Names/Phone Numbers***
  - District administration (School Board, superintendent, special education director)
  - School administration
  - Teacher
  - Related services (therapists, psychologists, etc.)
  - Case manager
  - Respite/day care providers
  - Doctors
  - Pharmacy/medical supply company
  - Hospital
  - Support groups/counselor
  - Transportation

- ***Communication***
  - Keep a log of incoming and outgoing calls. Include date, name, title agency, what was discussed, highlight items on which action is expected and date on which action is expected. It may be a good idea to follow-up your call with a letter.

- ***Calendar of Appointments and Meetings***

- ***Current and Past Individualized Education Plans/Individualized Family Service Plans***
  - Report card
  - Samples of work
  - Evaluations and assessments
  - Correspondence from the school
  - Record of parent observations and participation

- ***Medical Records/Reports***
  - Diagnostic reports/lab results
  - Primary care and consultants
  - Medical records
  - Medical care/medication schedule
  - Family medical history
  - Log of treatments and reactions
  - Log of hospitalizations

- ***Developmental Records/Reports***
  - Evaluations by doctors, therapists, psychologists
  - Log of services and responses (what works and what doesn't)

- ***Adaptive & Medical Equipment***
  - Instruction and service manuals
  - Catalogs

- ***Resources***
  - Education rights and responsibilities
  - Local, regional & national organizations
  - Articles, fact sheets, brochures, etc.
  - Copies of laws and regulations
  - Glossary and acronyms

Your Rights

It is very important to remember that legal rights are not the only right that you and your infant/child are entitled to receive. You have the right to voice your concerns and be taken seriously. It is your right to decide what is best for your infant/child. There are many professionals and educators who are experts in the field of hearing loss available to assist you in the decision making process. You may not agree with the expert's suggestions regarding how to care for your infant/child.

Remember, you do not have to accept what the professionals advise. If you and your family feel you know of better alternatives for your infant/child, you have the right to choose those. However, if you want something else, you may have to make calls, write letters, get audiologists or physicians involved, and/or go to meetings to get what you want. Advocacy is an ongoing and very challenging process. Always pursue what you feel is in your infant/child's best interests.

There are a number of procedural safeguards in place to ensure that infants/children and their families receive appropriate services. These include:

- A means to resolve complaints by parents, including through legal means
- The right to confidentiality
- The right to accept or decline services
- The right to examine records
- Written prior notice (in the parent's native language) regarding the infant/child's identification, evaluation, and placement
- The right to use mediation (legal support) to resolve disputes

There are also important federal laws that protect the rights of the deaf and hard of hearing. These include:

IDEA

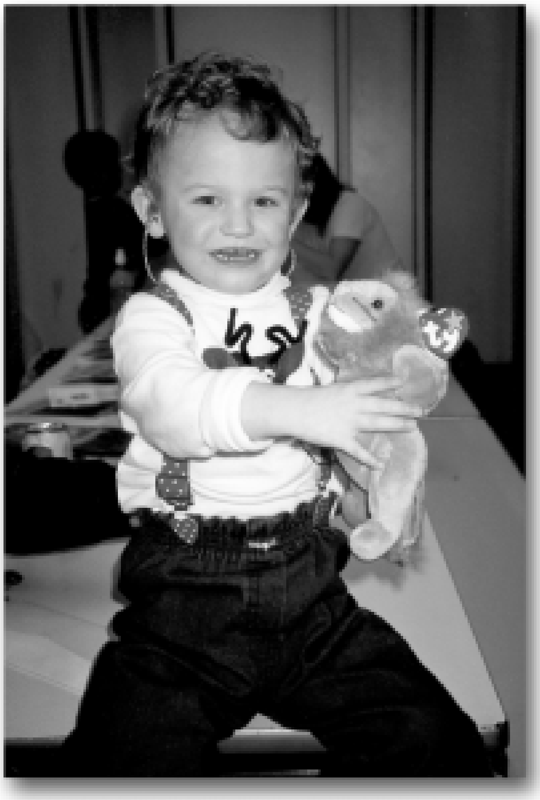
Individuals with Disabilities Education Act of 1997 (IDEA '97: PL 105-107), is the federal law that requires that all children be given a free, appropriate public education, with meaningful access to the general curriculum, and high expectations and standards.

Part C of IDEA refers to the services all states are required to provide to infants/children and their families, ages birth to three.

Part B of IDEA refers to the services all states are required to provide to children aged three through age 21, including access to public education.

ADA

Americans with Disabilities Act (PL 101-336), ensures that all people with handicaps have access to public events, spaces, and opportunities.



Hearing Check List

Here are some things a child with normal hearing should be able to do. Use the hearing milestone chart to check your child's hearing at home.

0-3 months

- ☐ Jumps at a sudden, loud noise
- ☐ Calms down when you speak

3-6 months

- ☐ Turns head or moves eyes to find your voice
- ☐ Plays at making noises and sounds

6-10 months

- ☐ Reacts to hearing his/her name
- ☐ Begins to understand easy words like "no" and "bye-bye"

10-15 months

- ☐ Repeats simple words and sounds you make
- ☐ Uses two to three words other than "ma-ma" and "da-da"

18 months

- ☐ Follows simple spoken directions
- ☐ Uses seven or more true words

24 months

- ☐ Understands when you call from another room
- ☐ Points to body parts when asked

Parent Stories

From Lisa Coleman's testimony

On behalf of The National Campaign for Hearing Health

Before the House Committee on Appropriations Subcommittee on Labor, Health and Human Services and Education

April 23, 2002

"Now, I would like to share with you my experience with my daughters Corrine, age 9, who was diagnosed late at age 2 and Emily, age 7, who was diagnosed at birth.

If there were ever parents that should have self-diagnosed a hearing loss on their own, it should have been my husband Lance and I. Lance is an Ear Nose and Throat physician and when Corinne was born I had just completed my Master's Degree in Child and Family Development. When Corinne was born she looked and responded very normally, but as months progressed, she didn't seem to be talking. We counseled with our pediatrician who encouraged us to watch and wait 3 months, 6 months, and then 12 months. We watched and waited, but Corrine showed no improvement. Finally, without the approval of pediatrician, we scheduled a hearing test when she was 22 months. Corinne failed the hearing test and at age 2, the average age of diagnosis without a newborn screen, Corinne was fitted with hearing aids.

Developmentally, just think about what two-year-olds are notorious for. Corinne tried to do all of those things with her hearing aids. She sucked them, threw them, and tried to hide them. We had a solution - hearing aids to assist her hearing, — but no means to keep them on. Finally a few months later by a stroke of luck, we found a hat that we cinched on and she couldn't get her hearing aids off. So Corrine wore that hat from sun up to sun down.

Soon after diagnosis, we tried to enroll Corinne in an early intervention program, but because of the school calendar, it was late spring and no one could take us on their case until early fall because of summer break. She was eventually admitted to early intervention at age 2-1/2, but was soon forced to exit the program because early intervention stops at age three.

Corinne started preschool at age 3 with essentially no expressive and very little receptive speech. To improve her communication skills we started speech therapy, which resulted in hundreds of hours and thousands of dollars over the course of four years. With such significant language delays, our family has learned to use a communication tool, which also has taken hundreds of hours of practice and study.

Our Emily was born when Corinne was age 2-1/2. She was tested at birth with the appropriate equipment and had a hearing aid at 5 months. Emily did not reject her aids. She left them in and just soaked up the sound. Emily was enrolled in an Early Intervention Program at 6 months where her speech was monitored regularly. She developed speech normally right along with her hearing peers. Emily has never had to have regular speech therapy. Her vocabulary has been very expressive, confident and dramatic from a young age.

The contrast in our experiences dealing with every aspect of essentially the same hearing loss in both girls has been dramatic. From testing, to aiding, to early intervention, speech therapy, language development, socialization and ongoing voicing and speaking confidence issues— our younger daughter Emily has had a tremendous advantage because of her earlier identification."

Emily: "I'm Emily and I'm so glad I got tested when I was born, I haven't had to work as hard as Corinne. Thank you."

Corinne: "I am Corinne and because there was no newborn hearing screening when I was born I had lots and lots of speech therapy. My little sister Emily didn't have to do all that work. I wish that all kids with a hearing loss could be identified early like she was. I really hope you will put the money for hearing testing back in the budgets to help other kids. Thank you."