Our child has a hearing loss. What happens next?

What is early intervention?

What can we do to help our child learn to communicate with us?

We have so many questions!

You have just learned that your child has a hearing loss. You have many questions and you are not alone. Other parents of children with hearing loss have the same types of questions. All your questions are important. For many parents, there are new things to learn, questions to ask, and feelings to understand. It can be very confusing and stressful for many families.

Many services and programs will be available to you soon after your child’s hearing loss is found. When a child’s hearing loss is identified soon after birth, families and professionals can make sure the child gets intervention services at an early age. Here, the term intervention services include any program, service, help, or information given to families whose children have a hearing loss. Such intervention services will help children with hearing loss develop communication and language skills. There are many types of intervention services to consider. We will talk about early intervention and about communication and language. Some of the services provided to children with hearing loss and their families focus on these topics. This booklet can answer many of your questions about the early intervention services and choices in communication and languages available for you and your child.

Understanding Hearing Loss

Timing: The age when a hearing loss has occurred is known as “age of onset.” You also might come across the terms prelingual and postlingual. A prelingual hearing loss occurs before a child has learned to understand and use language. A postlingual hearing loss occurs after a child has learned some language.
Location: There are three parts to the ear—the outer ear, middle ear, and the inner ear. Sound travels from the outer ear through the middle ear to the inner ear. A conductive hearing loss involves the outer ear, the middle ear or both. A sensorineural hearing loss involves the inner ear. A mixed hearing loss is a combination of both conductive (outer or middle ear, or both) and sensorineural (inner ear) hearing losses. Auditory neuropathy and central hearing loss involve the nerve that connects the ear to the brain (hearing nerve) or the part of the brain that helps us understand the sounds we hear, or both. Other words you might encounter are unilateral or bilateral. Unilateral means “one side”; therefore, a unilateral hearing loss involves only one ear. Bilateral refers to both sides, and a bilateral hearing loss involves both ears.

Degree: You also might encounter words such as mild, moderate, severe, and profound when researching hearing loss. These terms are used to describe how much hearing loss has occurred.

For more details about hearing loss, you can visit the following websites:

http://www.nidcd.nih.gov/

http://www.ashs.org and

http://www.cdc.gov/ncbddd/hearingloss/index.html

Your Child’s Hearing Loss Is Unique

Each child is unique, with his or her own personality, talents, and preferences. And, in the same way, your child’s hearing loss is also unique. Also, research suggests that about one-third of all children with hearing loss have one or more other special needs or conditions that have nothing to do with the ear or hearing. These needs might involve visual or physical abilities, or other special conditions.

All these factors go into making your child the unique person he or she is. They are important when you and professionals work together to choose the kind of interventions that will best match the strengths and needs of your child. These professionals include audiologists, early intervention specialists, speech and language pathologists (also called speech therapists), teachers of the deaf and hard of hearing, and your child’s doctors.
Infant and Toddler Services: Part C Program

One way to help early intervention services work well together is through a state program called the “Part C program”. This is a program in each state for children from birth up to 3 years old who have a developmental delay (that is, a lag in development), or who are at risk of such a delay. Most children with hearing loss are considered to have or be at risk for a developmental delay. The Part C program is required under federal law (Individuals with Disabilities Act 2004 [IDEA 2004]). Each state program has its own rules about who may get these services based on what kind of condition the child has.. Your state’s rules will say whether or not your child qualifies for this program. Find out more about IDEA 2004 is at http://idea.ed.gov/.

Every family who takes part in the Part C program is assigned a service coordinator. The coordinator is a person who works closely with the family to set up services through the program. Each child is assessed by a team of experts who work with children. The team first learns about the child’s strengths and needs by talking to the family and doing an assessment. Then the team advises the family and the service coordinator on the best services and interventions for the child. Together the family, the service coordinator, and the team of professionals put together a plan for the child and family called an individualized family service plan.

Individualized Family Service Plan (IFSP): The IFSP outlines all of the early intervention programs and services your family and child will need. The IFSP also outlines how you will receive the services, as well as any equipment and devices you will get. The IFSP should be family focused. The strengths and needs of your child and your concerns and priorities are very important when making this plan. Each child has his or her own plan, so no two plans will be the same. It is very important that your family work closely with the service coordinator and other professionals. The goal is to learn about your child and the interventions available to you in order to get the most out of the IFSP process.

Once the IFSP is completed, you and your child will receive the early intervention services and equipment that are written into the plan. As time goes on, your family, the service coordinator, and other professionals from your child’s team will look to the IFSP to ensure your child is getting the services and equipment detailed in the IFSP. You and the service coordinator can change the IFSP as your child grows or when your child’s needs change. The service coordinator will meet with you at least every 6 months to make any necessary changes in the IFSP. You can request that your child’s plan be looked at sooner if you see the need to make changes.
Programs and Services Offered Through the Part C Program: Early intervention is concerned with all of the basic skills that young children typically develop during the first 3 years of life.

Some examples are:

- Physical skills such as reaching, rolling, crawling, and walking
- Cognitive skills such as thinking, learning, and solving problems
- Communication skills such as talking, listening, and understanding
- Social and emotional skills such playing and feeling secure and happy
- Self-help skills such as being able to feed and dress one’s self

Early intervention Part C program services in each state are provided through the IFSP for children with hearing loss. They are usually focused on communication and language learning. However about one-third of all children with hearing loss have other special needs. So they may receive other services in addition to communication and language learning services. Many of these services are provided through a qualified instructor working one on one with the family and child. Services may take place in the family’s home, or at a center or clinic close to the family’s home, or a combination of both.

Family Support Services: Family support services may also be provided through the Part C program. For many parents, their child’s hearing loss is unexpected. Parents sometimes need time and support to adapt to the child’s hearing loss. Parents of children with recently identified hearing loss can seek different kinds of support. Support is anything that helps a family and may include:

- Advice
- Information
- Getting the chance to get to know other parents that have a child with hearing loss
- Locating a deaf mentor
- Finding childcare or transportation
- Giving parents time for personal relaxation
- Or just a supportive listener
Parents often find the Part C program to be an essential resource. If you have not been referred already to the Part C program in your state, please ask one of the professionals who are working with you and your child to tell you how to contact this program. You also can contact the National Early Childhood Technical Assistance Center (NECTAC) (http://www.nectac.org/default.asp). NECTAC is funded by the U.S. Department of Education, Office of Special Education Programs. It provides information about the Part C program and support to families. Once children are 3 years of age, they change from Part C to Part B services. The transition plan should begin when the child is about 2½ years of age. Please talk with your service coordinator about this.

**Communication and Language Options**

As a parent, it is never too early to begin thinking about how you can help your child build a solid language foundation. This is even more important for a child with hearing loss because children with hearing loss are more likely to have language delays. That is, they may learn language more slowly than children who do not have a hearing loss. When a child’s hearing loss is identified soon after birth, families and professionals can make sure the child gets intervention services at a very early age. This will help the child build communication and language skills using his or her best abilities.

There are many ways children with hearing loss can build communication and language skills. Many states and communities already have educational programs for infants and young children. Each program takes a different approach to communication. You might have heard about these five educational programs:

- Auditory-Oral
- Auditory-Verbal
- Bilingual American Sign Language (ASL)-English (Bi-Bi)
- Cued Speech
- Total Communication

These five programs will be discussed later in this booklet.
The difference between language and communication

Communication: Communication is about sharing ideas, facts, thoughts, and other important information. Language can be used to share this information either by speaking or signing.

Language: Languages are used to help people communicate. Languages are made up of words and rules (grammar) that tell how these words are used. Words can be spoken, signed or written and thus languages can be spoken, signed or written. Spoken languages are made up of spoken words and grammar that are unique to each spoken language. Examples of spoken languages include English, Spanish and French. Signed languages are made up of signed words and grammar that are unique to each language. Examples of signed languages include American Sign Language, British Sign Language and Italian Sign Language.

Building languages with communication strategies: Imagine language as the foundation of a house. A family can build communication strategies (the building blocks or bricks) onto the language foundation. Here is an introduction to some possible languages and communication strategies that you can use to build the languages. There are more communication strategies, but these are the most common.

American Sign Language (ASL)

Signs: Signs in ASL are created using handshapes, facial expressions, body posture and movement. Some examples are:

- **Handshape** - a spread-out hand, as in a “high-five” or a pointing handshape
- **Fist movement** – how you move your hands in space, such as from left to right or in a circling or a bouncing motion,
- **Facial expression** – raised eyebrows when asking a question and smiling when signing about something that is fun to do.

Visual Attention: People with hearing can hear voices even when they cannot see who is talking. People who communicate in ASL need to look at the person who is signing to them. It is important to make sure your child is looking and paying attention when you are signing.
Eye contact: Eye contact is very important when you are signing in ASL. If you have eye contact with your child, then you can be sure that you are paying attention to each other.

Fingerspelling: Fingerspelling began as a part of ASL. Fingerspelling spells words by forming each letter using the hands and fingers. Very young children do not need to know how a word is spelled to understand fingerspelling. Instead they learn fingerspelled words by the shape and movement of the hand.

**Spoken English**

Spoken words: Spoken words are formed using the vocal cords (voice) and mouth and are made of speech sounds such as vowel and consonant sounds.

Auditory training and listening: Auditory training teaches a child or an adult to rely on listening to communicate. It takes advantage of a person’s residual hearing. That is the amount of hearing that a person with a hearing loss still has, even if it is very minimal. Many children who are deaf have some residual hearing.

Speech: Speech uses the mouth, lips, tongue, and vocal cords to produce sounds for communication. Speech and auditory training (or listening) are often used together. Different speech sounds can make a difference in the meaning between two words. For example, the only difference between the two words “big” and “pig” is in the first speech sound (“bū” rather than “pū”).

Speech reading: In speech reading (also known as “lip reading”) a person who is deaf or hard of hearing watches a speaker’s mouth and facial expressions to understand what is being said. Speech reading is also used along with other building blocks, such as listening, to communicate.

**English Coding Systems**

Note: English coding systems use visual methods to express the spoken English language. Coding systems are not a language of their own. Instead of using speech and hearing, coding uses signs borrowed from ASL to represent the English language. English grammar and word order are used.
Manually Coded English (MCE): Manually Coded English, or MCE, is made up of signs (hand shapes and hand motions) that represent English words. You might have heard of Morse code. Morse code is a system of dots and dashes that can be tapped out to form English words and phrases. MCE is a code for the English language. Many of the signs in MCE are borrowed from ASL. However, the grammar, word order, and sentence structure used in MCE are those of the English language. MCE does not use the grammar, word order, and sentence structure of ASL.

Finger spelling: Finger spelling began as part of ASL. Finger spelling is the spelling of words by forming each letter using the hands and fingers. It is used with English coding systems, as well as in ASL.

Other communication tools: The remaining three building blocks can be used for communication and language. These three building blocks are cued speech, simultaneous communication, and natural gestures.

Cued Speech: Cued speech, or cueing, can help people who are deaf or hard of hearing understand speech. Cued speech is not a language or a representation of a language. Instead, it is a system of hand signals used by the speaker to help the listener tell the difference between certain speech sounds. Some speech sounds are hard to tell apart using speech reading alone. (One example is the difference between the sound of “b” and the sound of “p”). Cued speech consists of eight hand shapes representing consonant sounds. These are placed at four locations near the mouth to represent vowel sounds. Cued speech must be used in combination with speech reading.

Conceptually Accurate Signed English (CASE): Conceptually Accurate Signed English, or CASE, is sometimes used by people who are deaf or hard of hearing to communicate with one another. Sometimes it is called PSE, or Pidgin Sign English. CASE is a mix of English and ASL. CASE is not a language. It is a form of communication that varies depending on the experience and preferences of the people using it.

Simultaneous Communication: Simultaneous communication is a technique that can be used with MCE. The person signing speaks and signs at the same time. The person listening and watching uses speech reading, hearing, and MCE or CASE to understand what is being said.
Natural gestures: Natural gestures are body movements and facial expressions that you often use to help others understand your message. For instance, if you want to hold a child, you can simply stretch your arms towards the child. Or, when you put your index finger over your mouth and nose you are telling someone to be quiet. These are examples of natural gestures.

The critical period for language development

It is extremely important to remember that children have a “critical period” for learning language. This is true no matter which communication strategies and communication tools you choose to help your child learn language. Children learn language best during early childhood. It is more difficult to learn a language later in life. This is true for sign languages, like ASL, and for spoken languages, like English.

The Five Educational Programs

There are many ways children with hearing loss can build communication and language skills. Many states and communities already have educational programs for infants and young children. Each program takes a different approach to communication. The five educational programs (Auditory-Oral, Auditory-Verbal, Bilingual Bicultural (Bi-Bi), Cued Speech, and Total Communication) emphasize different languages, communication strategies and other communication tools that we have just talked about. Some educational programs use more ways to communicate than others. This does not mean one program is better than the others. It just means different programs emphasize different ways to communicate. Here is a short description of each program.

Auditory-Oral: The Auditory-Oral approach stresses technology to make the most of residual hearing) to develop spoken language. Examples include the use of hearing aids or cochlear implants. This approach also includes the use of speech reading and natural gestures.

Auditory-Verbal: The Auditory-Verbal approach also stresses technology to make the most of residual hearing to develop spoken language. However, this approach focuses on listening and, therefore, does not encourage the use of speech reading.

Bilingual-Bicultural (Bi-Bi): The Bi-Bi approach focuses on the use of two languages: ASL and the native language of the family (for example, English or Spanish). ASL usually is taught as the child’s first language. English (or the family’s native language) is taught as the child’s second language through reading, writing, and speech. Respect for Deaf culture also is taught.
**Cued Speech:** The Cued Speech educational program focuses on the use of cued speech and speech reading. It is a system of hand signals used by the speaker to help the listener tell the difference between certain speech sounds.

**Total Communication:** This approach uses a combination of sign language, speech, and best use of residual hearing through technology to help children learn speech and language. The technology might include hearing aids or cochlear implants. Sign language can be either ASL or signs from English Coding Systems. Signing, speaking, speech reading, listening, signing, cued speech, reading, writing, and natural gestures can all be used in this approach. Which ones are stressed depends on the child’s strengths and weaknesses. Most total communication programs use some form of simultaneous communication (speaking and signing at the same time).

**Families as Decision Makers**

Experience shows that there is no one best intervention choice for all children. Earlier, we talked about how each child’s strengths and needs are unique. Just because a method of communication works well for one child and his or her family does not mean it will be the best choice for every other child and family.

Finding the best choice for your child often is a complex process. It can involve getting information about the different educational programs over time, as well as watching your child closely to see how he or she is doing. You may need to try out a communication approach to decide if it is a good fit for your child. Some children start and continue with just one educational program or a set of communication strategies. Other children might change programs to have the best opportunity to develop language and communication skills. You understand your own child the best. Therefore, with the guidance of professionals and others, you should make your own decisions about language and communication choices.

**Communication With Your Child Can Begin Now**

Parents of young children are experts at communicating with their children long before those children learn to talk or to understand what their parents are saying to them. All of us have seen parents making funny faces for their babies. When a father makes a silly face for his baby, at first the baby might look surprised. But then the baby will break into a wide smile, or giggle and wiggle arms or legs. In the same way, communication also happens when a mother rocks her baby after a feeding, holds the baby close and gazes into her little one’s eyes. Communication can include:
• Touch (such as rocking and holding your child)
• Vision (facial expressions, eye contact)
• Gestures, and
• Sound

Extending your arms to your child shows that you are about to pick him or her up. Other ways of communicating include smiling, laughing, hugging and letting your child keep you in sight. Your physical and visual contact with your child tells him or her that you are there and everything is safe.

Many children with hearing loss have some hearing and can partially hear voices, especially if the person talking is very close. So try speaking to your child while he or she is close to you and talk in a voice that you would use with a child who has full hearing. Your child might be very interested in looking at faces and will begin to understand that your face and mouth are sending important messages. So make sure that you often talk to your child when he or she is able to see your face.

Some things to remember when communicating with your child:

• Set your child close to you so that he or she can see your face.
• Try to minimize background noises so that your child can use the hearing he or she has to the best of his or her ability.
• Use good lighting. Be sure that the room is not too dark or the lights too bright. And don’t sit or stand in front of a bright light such as a window. If you are in front of a bright light, your face will be in a shadow and your child will not be able to see your mouth.
• Make eye contact often.
• Imitate the movements and sounds your child makes, then wait for him or her to repeat them.
• Work on communicating with your child during activities that you both enjoy.
• Take time to communicate with your child many times throughout the day.
• Make some quiet time for both you and your child. If your child becomes restless, he or she may be overwhelmed by all of the communication.
• And most importantly, enjoy the time you and your child spend together.
These are some things you can do now while you are exploring and beginning to build communication and language for your child. Please, talk with your child’s health care professionals for more communication ideas.

Remember, communication and language are important in the interaction between parent and child. The development of language and other skills begins with communication. This early groundwork of language then helps the child learn reading and writing in school, as well as social skills. The gift of language will open doors for you and your child and will help your child build communication skills that will last a lifetime.