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EARLY INTERVENTION: COMMUNICATION AND LANGUAGE FOR FAMILIES OF DEAF AND HARD-OF-HEARING INFANTS

"Our Child Has a Hearing Loss. What Happens Next? What Is Early Intervention?"

You are parents who have just learned that your child has a hearing loss. You have many questions. You are not alone.

"What can we do to help our child develop the skills needed to communicate with us?" "We have so many questions!"

All of these questions that you have are important. For many parents, this time can be filled with new things, many questions, and mixed feelings. It can also be confusing and even hard to deal with!

Many services and programs will be available to you soon after your child's hearing loss is found. In this discussion, the word "intervention" is used to describe any program, service, help, or information that is given to children who have a hearing loss and their families. For a family who has a child with a hearing loss, there are many interventions to consider. This discussion focuses specifically on "early intervention". The kind of early intervention we will talk about deals with *communication and language*.

This discussion will answer many of the questions that you have about the communication and language options available for you and your child.

I Didn't Know that an Infant's Hearing Could Be Tested.

Recent advances in technology have made newborn hearing screening possible. Many states, communities, and hospitals offer hearing screening for newborns. Infants can be screened while still in the birth hospital—right in the nursery or in their mother's room. Your child might have had this type of screening done. This screening has no risk and is not painful. It requires no response from the baby and, in fact, the baby can be sleeping while it is done. And it can be done in a very short time—just a few minutes.

Infants who do not pass the hearing screening are referred for more testing by an audiologist. An audiologist is a person who is trained to test hearing. There are different types of tests an audiologist can do to determine if your child has a hearing loss and what type of hearing loss it is. One type of test commonly used to test hearing in infants is the

ABR or the auditory brainstem evoked response test (also called the BAER). For this test, sounds are sent through earphones to a baby who is sleeping. Small patches called "electrodes" are taped to the baby's head. These electrodes measure specific signals from the baby's brain when it responds to these sounds. A computer then processes all of this information. The ABR is very reliable, even if an infant is only a few weeks old.

When a child's hearing loss is identified soon after birth, families and professionals can make sure the child gets intervention at an early age. This will help the child to develop the level of communication and language skills that will last a lifetime.

Hearing in Humans Is Very Complex. There Are Many Different Types of Hearing Loss.

Timing: The age when hearing loss occurs is referred to as "age of onset". The terms "pre-lingual" and "post-lingual" refer to whether the child's hearing loss occurred before or after the child began developing language. A "pre-lingual hearing loss" is one that occurs before a child begins to understand and use language. A "post-lingual hearing loss" is one that occurs after a child can understand and begins to use some language, usually when the child is around 2 years of age.

Location: The ear is divided into three parts—the outer ear, the middle ear, and the inner ear. Sound travels from the outer ear through the middle ear to the inner ear. A "conductive loss" usually involves the outer or middle ear. A "sensorineural loss" usually involves the inner ear. A "mixed hearing loss" is a combination of conductive and sensorineural hearing loss. "Auditory neuropathy" and "central hearing loss" involve either the auditory nerve (the nerve that connects the ear to the brain) or the part of the brain that helps us to understand the sounds we hear.

Degree: Depending on the degree or amount of hearing that your child has, you might hear words such as "mild", "moderate", "severe", and "profound."

Other words that you might hear are "unilateral" and "bilateral". For the purposes of this discussion, unilateral means one side. A "unilateral hearing loss" is one that involves only one ear. Bilateral means both sides. A "bilateral hearing loss" involves both ears.

This discussion does not explain hearing loss in great detail. You might want to obtain more information about hearing and hearing loss from the following website: http://www.cdc.gov/ncbddd/ehdi/links.htm

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Your Child's Hearing Loss Is Unique.

Each child is unique. Each child has his or her own special personality, talents, and preferences. And, as you have just learned, one child's hearing loss can be entirely different from another child's hearing loss.

Also, research studies suggest that approximately one-third of all children with hearing loss have one or more special needs that have nothing to do with the ear or hearing. These can include visual, physical, or other special conditions.

All of these factors are important for you to understand about your child because they make him or her unique. These are also the factors that will be important when you and the professionals you are working with begin the decision-making process for your child and family.

Professionals such as audiologists, early intervention specialists, speech and language pathologists (also called speech therapists), and teachers of the deaf and hard-of- hearing can work together with you to choose the kind of communication that will best meet the strengths and needs of your child and your family.

You might also want to talk with other parents of deaf or hard-of-hearing children, as well as deaf and hard-of-hearing adults.

What Are Some Things That I Can Do To Communicate With My Child Right Now?

You can communicate with your child by touch (for example, rocking and holding your child close), through vision (for example, facial expressions, eye contact, and gestures), and through sound (for example, talking and singing).

Extending your arms to your child to tell him or her that you are about to pick him or her up, smiling, laughing, hugging, kissing, or letting your child keep you in sight are all ways of communicating. The physical and visual contact with you tells your child that you are there.

Many children with hearing loss have some usable hearing and can partially hear voices (even if the words cannot be understood). Simply talk to your child the same way you would talk to a child without hearing loss. Your child might be very interested in looking at faces, so make sure that you often talk to your child when he or she is able to see your face.

Suggestions for You While You Are Exploring Intervention Options.

- Hold your child close so that he or she can focus on your face.
- Try to minimize background or distracting noises so that your child can use the hearing that he or she does have.
- Good lighting is important. Be sure that the room is not too dark or the lights too bright.
- Make eye contact often. Eye contact is very important for children. Some researchers have shown that infants as young as 2 days of age can detect eye contact.
- Be responsive to your child's communication. If he or she looks at you, smile and make eye contact. If he or she touches you, respond by touching and looking at him or her. If he or she makes vocal sounds, respond positively.
- Imitate the movements and sounds your child makes, then wait for him or her to repeat them.
- Make an effort to include natural visual and voice exchanges during activities that he or she and you enjoy.
- Take time to communicate with your child many times throughout the day.
- Position your child so that you are always or frequently within his or her sight.
- Remember to give yourself and your child some quiet time. If your child becomes fussy, he or she could be overwhelmed by all of the communication!
- Enjoy the time you and your child spend together.

Family Support Services

For many parents, their child's hearing loss is unexpected. Many parents have strong feelings after learning about the hearing loss and need time to adjust not only to having a new family member, but also to the child's hearing loss. Parents of children with recently identified hearing loss often seek different kinds of support—both formally and informally.

Family support can be anything that helps a family. This help can include advice, information, helping you understand some of the options available to you, providing you

with childcare or transportation, giving you an opportunity to have some personal relaxation time, or just being there.

Infant and Toddler Services: Part C Program

One way to coordinate early intervention services is through a program in your state called the "Part C program". This is a program for children from birth up to 3 years of age who have or are at risk for a developmental delay (that is, a lag in development). Although this program is required under federal law (*IDEA, or Individuals with Disabilities Act)*, each state has its own program qualifications. Most children with hearing loss are considered to have or be at risk for a developmental delay. It will depend on your state as to whether or not your child qualifies for this program.

The Part C program can provide a number of services to families, including a multidisciplinary assessment; an assessment of the family's concerns, resources, and priorities; and the development of an "Individualized Family Service Plan" (ISFP). All of these services help bring together the different interventions available to families.

Every family who takes part in this program is assigned a "service coordinator," or a person who works closely with the family to set up the services in the Part C program. Each child in the program is assessed by a team of experts who work with children. The team works with the child to determine the child's strengths and needs and gives this information to the family and the service coordinator.

The service coordinator then talks with the family to learn about their concerns, resources, and priorities. At this time, families will talk with the service coordinator about the interventions available for their child.

Individualized Family Service Plan (IFSP)

The family and the service coordinator, together with the professionals who were involved in the child's assessment, design a plan for the child called an "Individualized Family Service Plan" (IFSP). This plan outlines all of the services, programs, and equipment that a family and child will need for the child and his or her hearing loss. This plan will also outline how the family will receive these services and equipment.
This plan is family focused―the strengths and needs of the child and the concerns, resources, and priorities of the family are very important when making this plan.
Because each child has his or her own plan, no two plans will be the same. It is very important that the family work closely with the service coordinator and others to learn as much about their child and the interventions available to them in order to get the most out of the IFSP process.

Once the IFSP is completed, the services and equipment that are written into the plan will be available. As time goes on, the family, the service coordinator, and other professionals (such as an early intervention specialist, audiologist, and speech-language pathologist) will look to the IFSP to be sure that the child is getting what was outlined in the IFSP. The IFSP will change as the child grows and his or her needs change. The service coordinator will meet with the family at least every 6 months to look at the IFSP and make necessary changes. In addition, a family can ask that the plan be looked at again any time they see the need to make changes.

Early Intervention and Part C

Early intervention services through the Part C program usually start with the IFSP, but they do not end there! Besides the IFSP, there are other services that the Part C program in each state provides to families of children with hearing loss. Through the Part C program, a child will receive the early intervention and educational services that are appropriate. For instance, if the family and the service coordinator decide that the child should receive instruction in learning to communicate with either sign language or speech (or a combination of both); the schedule and location for this instruction will be set up with a qualified instructor. This type of training can be done right in the child's home with an educator working one on one with the family and child, it can be offered at a center or clinic in the family's community or it can be provided in both types of locations.

Parents often find the Part C program to be an essential resource. If you have not already been referred to the Part C program in your state, please ask one of the professionals (for example, a health care provider, an audiologist, or a speech-language pathologist) whom you are currently working with to tell you how to contact this program. You can also contact a "Parent Training and Information Center". A Parent Training and Information Center is a federally funded center that provides information about Part C and support to families. Once children are 3 years of age they change from Part C to Part B services. The transition should begin when the child is about 2½ years of age. Please talk with your service coordinator about this.

Your Child and Family Might Be Offered Several Different Approaches to Communication and Language.

As a parent, it is never too early to begin thinking about how you will help your child build a solid language foundation. This is even more important to a parent of a child with hearing loss because children with hearing loss are more likely to have language delays. That is, they 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 at a very early age. This will help the child to have communication and language skills that will make the most of his or her abilities.

There are many ways that children with hearing loss can learn and develop language and communication skills. In many states and communities, educational programs have already been established for infants and young children. Such programs take different approaches to communication. You might be asked if you would like to have your child and family take part in one of these educational programs.

There are five of educational programs that will be discussed later in this text. They are *Auditory-Oral, Auditory-Verbal, Bilingual American Sign Language (ASL)-English (Bi-Bi), Cued Speech,* and *Total Communication*. Each one of these educational programs takes a different approach to communication.

Educational Programs Use Different Approaches to Communication and Language.
Educational programs that are established for infants and young children are often very complex. They can involve parent support, education and information, support and activities for siblings, and other services, in addition to teaching the family how to help the child with hearing loss learn language and communication.

For this discussion, the focus will be on the different approaches these different types of programs take to communication. If you would like further information on any of these educational programs, you might want to refer to the following website: http://www.cdc.gov/ncbddd/ehdi/links.htm

The five programs emphasize different languages and different ways to communicate (for example, listening with hearing aids, using sign language, and lipreading). These ways of communicating are explained in this discussion. Some educational programs use more ways to communicate than others. That does not mean that one program is better or worse than the others. It just means that different ways to communicate are emphasized.

Communication, Language, Speech, and Signing—What's the Difference?
What are the differences between *communication, language, speech,* and *signing?*

Communication: Communication is sharing ideas. These ideas can be shared using language. The language can be spoken language or sign language.

Language: Language uses symbols such as words and grammar rules. The symbols can be in sign language or spoken language.

Spoken language: Spoken language uses the voice and mouth to express language. There are many spoken languages. Some examples are English, French, and Spanish.

Sign language: Sign language uses the hands, face, and body to express language. There are many sign languages. Some examples are American Sign Language (ASL), Italian Sign Language, and French Sign Language.

The Critical Period for Language Development

It is extremely important to remember that children have a "critical period" for learning speech and language. They learn speech and language best in early childhood. It is more difficult to learn speech and language later in life. This is true for both signed languages, like ASL, and spoken languages, like English.

Speak with your child's professionals (for example, an early intervention specialist, a speech-language pathologist, or an audiologist) often about whether your child's communication and language skills are progressing to the best of his or her ability.

Communication Strategies

Next, imagine language as a "platform". A family can build communication strategies or "building blocks" on the language platform.

Here is an introduction to some possible building blocks for language that can be used. There are more, but these are the most common.

American Sign Language

The following building blocks are stacked on the language platform called American Sign Language (ASL).

<u>Fingerspelling:</u> Fingerspelling began as part of ASL. Fingerspelling is the spelling of words by using the hands and fingers to form each letter.

<u>Parts of Signs:</u> Words in spoken language are made of speech sounds. For example, "cat" is made up of the sounds "k", "a", and "t". Signs in ASL are composed of parts, too. Examples of these parts are *handshape* (for example, a spread-out hand when you do a "high-five," a pointing handshape, and a fist) and *movement* (how you move your hands in space, such as bouncing or moving in a straight line).

<u>Visual Attention:</u> Hearing babies can hear voices even when they cannot see who is talking. Babies who communicate in ASL need to be looking at the person who is signing to them. It is important to make sure your baby is looking directly at you when you are signing.

<u>Eye Contact:</u> Eye contact is very important when you are signing ASL. If you have eye contact with your baby, then you will be sure that you are paying attention to each other.

Facial Expression: Facial expression in ASL helps you to form questions and other kinds of sentences. For example, if your eyebrows are raised, you are probably asking a question that can be answered with a "yes" or a "no".

Spoken English
The following building blocks are stacked on the language platform called spoken English. These building blocks all use speech and hearing to express the English language.

Auditory Training or Listening: Auditory training is a strategy by which a child or adult relies on listening for communication and language. It takes advantage of *"residual hearing"*. The amount of hearing that a person with a hearing loss still has is called residual hearing**,** even if it is very minimal. Many deaf children have some residual hearing.

Speech: As we talked about before, speech is the process of using the mouth, lips, tongue, and vocal cords to produce sounds that are used to communicate. Speech and auditory training or listening are building blocks that 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.

Speechreading: Speechreading (also known as lipreading) is a technique by which a deaf or hard-of-hearing person watches a speaker's mouth and facial expressions in order to understand what is being said. Children and adults can use speechreading in combination with other building blocks such as auditory training or listening, but not alone.

English Coding Systems
The following building blocks are also stacked on the language platform called English. However, they use signing instead of speech to express the English language.

Fingerspelling: Fingerspelling began as part of ASL. Fingerspelling is the spelling of words by using the hands and fingers. It is also used with English coding systems.

Manually Coded English: Manually Coded English, or MCE, is made up of signs (handshapes and hand motions) that stand for the words of English. You 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 a language–the English language. Many of the signs in MCE are borrowed from American Sign Language (ASL). But unlike ASL, the grammar, word order, and sentence structure that are used with MCE are those of the English language.

Conceptually Accurate Signed English: Conceptually Accurate Signed English (CASE) is a way to communicate that deaf and hearing people sometimes use together. Sometimes it is called PSE or Pidgin Sign English. CASE is a mix of English and ASL. CASE is not a language but a form of communication that varies depending on the experience and preferences of the people using it.

Other Communication Tools

The remaining three building blocks can be used for communication and language. These three building blocks include "cued speech", "simultaneous communication" and "natural gestures".

Cued Speech: Cued Speech can help people who are deaf or hard-of-hearing to 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 speechreading alone. Thus, it must be used in combination with speechreading. Cued Speech consists of eight handshapes (representing consonant sounds) placed at four locations near the mouth (representing vowel sounds).

Simultaneous Communication: Simultaneous Communication is a technique that can be used with MCE or CASE. The person signing speaks and signs at the same time. The person listening and watching the message uses speechreading, sound, and MCE or CASE to understand what is being said.

Natural Gestures: Natural gestures are body movements and facial expressions that you would use with anyone to help him or her understand your message. For instance, if you wanted to ask a child if he or she wanted to be picked up, you might stretch your arms towards him or her and ask "Up?" Or, you might put your index finger over your mouth and nose to indicate that you want your child to be quiet. These are examples of natural gestures.

The Five Educational Programs.

As mentioned before, here are the five educational programs that we initially talked about: *Auditory-Oral, Auditory-Verbal, Bilingual American Sign Language-English (Bi-Bi), Cued Speech, and Total Communication.*

Each educational program is made up of a combination of the building blocks and languages that were just talked about. An important point to remember is that some of these programs have more languages and building blocks and some have fewer. The

number of building blocks offered by a program DOES NOT have anything to do with whether or not it is a good program.

Here is a short description of each of these educational programs. It is important to remember that each family best understands its own child. Each family should make an individualized decision about language and communication strategies and educational programs.

This discussion does not explain the different approaches in a lot of detail. If you would like more information on any of these educational programs, you might want to refer to the following website: http://www.cdc.gov/ncbddd/ehdi/links.htm

Auditory-Oral: The Auditory-Oral approach stresses maximum use of residual hearing through technology (for example, hearing aids or cochlear implants) for development of spoken language. This approach includes the use of speechreading and natural gestures.

Auditory-Verbal: The Auditory-Verbal approach stresses maximum use of residual hearing through technology (for example, hearing aids or cochlear implants) for development of spoken language. This approach uses a child's residual hearing to encourage him or her to communicate through spoken language. The focus is on listening and therefore does not include visual cues such as speechreading or natural gestures.

Bilingual ASL-English (Bi-Bi): The Bilingual ASL-English (Bi-Bi) approach stresses development of two languages–American Sign Language (ASL) and the native language of the family (for example, English or Spanish). ASL is usually taught as the child's first language and English (or the family's native language) is taught as the child's second language through reading, writing, speech, and use of residual hearing. Respect for Deaf and hearing cultures is also taught.

Cued Speech: Cued Speech can help people who are deaf or hard-of-hearing to understand speech. It is a system of hand signals used by the speaker to help the listener tell the difference between certain speech sounds. Cued Speech can be used with all the different educational approaches explained in this discussion.

Total Communication: This approach uses a combination of sign language, speech, and use of residual hearing through technology (for example, hearing aids or cochlear implants) to help each individual child make the most of his or her strengths for learning speech and language. Speech, speechreading, residual hearing, sign language, reading and 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).

Communication Starts Early.
For a child with hearing, communication and introduction to language start right at birth. For a child with a hearing loss, communication and introduction to language can also start right at birth.

A child sees his or her mother smile just before he or she falls asleep and, by the age of 2 to 4 weeks, the child is smiling back. A baby feels his or her father's soft touch during bath time and wiggles in delight. As the baby grows and develops, he or she becomes more and more skillful at communication and language.

Language is an important part of the interaction between parent and child. Early communication is the beginning of the development of language and other skills. This early groundwork of language, then, helps with the ability to read and write, social skills development, and later growth in school. The gift of language will open doors for you and your child and will help him or her build communication skills that will last a lifetime.

Families as Decision Makers
Experience shows that there is no one best intervention choice for all children. Earlier, this discussion talked about how each child is different and unique. Just because a method of communication works well for one child and family does not mean it will be the best choice for every child and family.

Finding the best choice for each child is often a complex process. It can involve getting information over time about the different educational programs, as well as watching the child closely to see how he or she is doing. Trying out a communication approach might be necessary in order to decide if it is a good choice for an individual child. Some children start and continue with just one educational program or set of communication strategies. Other children will have to change programs to have the best opportunity to develop communication and language. Each family best understands its own child. Therefore, with the guidance of professionals and others, each family should make its own decisions about language and communication.

Remember, decision making is a process, just as the development of your child is a process.