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Early Interactions With Children Who Are Deaf-Blind

By Deborah Gleason

Are the following conditions part of your story? If yes, you are not alone.

- ◆ You may be overwhelmed with the idea that your child has vision and hearing problems.
- ◆ You may find it difficult to relax and get to know your baby.
- ◆ Medical complications may require unending appointments and interventions.
- ◆ You may have to make sense of conflicting advice or opinions from professionals.
- ◆ Your child may associate being touched with unpleasant medical procedures. He may fuss or stiffen when anyone touches him.
- ◆ Your child may appear unresponsive. He may not smile or make eye contact. It may be difficult to figure out what your child enjoys or what will make him happy.
- ◆ Interactions may be frustrating and may take a lot of effort. Your child may act passive.
- ◆ Your child may need constant help from you since he or she can't "explore" or "listen to" environmental cues.
- ◆ It may be difficult to understand what your child is trying to communicate.

All babies communicate. It is through communication that relationships are formed and sustained. All parents must learn how to interpret and respond to their baby's communications in order to form the bonds that become the foundation for development. When your child has both a visual impairment and hearing loss, however, it may be more difficult to understand what she is trying to tell you and you may not be sure how you can best communicate and interact with her. We will share some ideas to help you discover how you can make your child's world safe and understandable and how you and your young child can share many enjoyable "conversations" together.

You do not need to travel this journey of discovery alone. Professionals in many areas will help you. Many groups and many people will offer services. They will all help, but in the long run, it's you, the parents and the family, who will have the most profound effect on your child. Your child will be molded and influenced by the kinds of interactions he or she has with YOU. The caring and trusting relationship you build with your child will form the foundation for her to explore and discover an ever-expanding world.

In this fact sheet we present numerous ways you can interact with your young child. We offer practical suggestions for giving your child consistent sensory cues. We suggest ways you can recognize and then respond to your child's responses. We also include techniques that encourage exploration of the environment. Finally, we present the idea of playing simple games that are not only fun but also help develop interaction and communication.

The View From Inside the Crib

The senses of vision and hearing are often referred to as the "distance senses" – that is, they connect a child with the world that extends beyond his or her personal body space. Children who are sighted and hearing learn language and many important concepts without any specifically planned instruction. They learn simply by being surrounded by language and by having ready access to environments that are safe, interesting, and invite exploration. The senses of vision and hearing help the child organize information from the environment. The young child who is deaf-blind, however, does not have access to opportunities for this "incidental learning" and the information the child does obtain from contact with people and the environment is often fragmented or distorted.

A sighted and hearing infant comes to anticipate daily routines because of the sights and sounds associated with them and can

prepare himself or herself for the activities in advance. The infant who is deaf-blind misses these cues because of limited vision or hearing and may find the world unpredictable and confusing--possibly even scary. This child needs others to help make sense of the world. From a child's perspective, what does it mean to have both a vision and hearing loss? Many things may happen that are unpleasant "surprises." She may not understand or be able to anticipate what is happening to her. He may try to communicate, but his cues may be so subtle they are difficult for people to understand. He may also find it difficult to understand his parents' best attempts at communication. Let's look at a common routine--diaper changing--but let's do so from the perspective of the baby.

Meg has just awakened from her nap with a soiled diaper. She fusses a bit to let her dad know she's awake. She looks up as she hears footsteps and the opening of her door to see her dad walking toward her crib. She listens to her dad talk to her as he bends down over her crib, picks her up, and carries her to the changing table. Meg recognizes where she is from many previous experiences here. She knows what's coming! She watches her dad take a bag from the shelf, open it, and pull out a clean dry diaper. Then she sees him reach for a small plastic rectangular box, open it, pull out a moist disposable wipe, close the box and put it back on the shelf. After Dad removes her wet diaper, Meg watches him take the cover off a big round bucket, drop the diaper in, then replace the cover. Once she's cleaned up, she enjoys the freedom of kicking her feet without the restrictions of her bulky sleeper. Meg is beginning to learn to anticipate daily routines and to develop an understanding of many important concepts such as object permanence (something still exists even if I can't see, hear, or feel it), "containers" (in/out, open/close, size, shape), and spatial organization.

Alex just woke up with a messy diaper, too. He has a profound hearing loss, but is able to see faces and brightly colored objects when they are no more than 18 inches away. He doesn't hear his mom come into his room and is surprised to suddenly see someone moving above his crib. Because his diaper is so messy and Alex is not terribly fond of having his diaper changed, Mom decides to change his diaper quickly in his crib so they can get on to doing more playful activities. By now, Alex is beginning to recognize his mom from her touch and closeness and is hoping to be picked up to play but suddenly he's confused. "What's happening to my legs? Why am I cold? What's that cold wet thing on my bottom? I don't really like this. Maybe if I squirm away it will stop. Oops, that didn't work, how about if I stiffen up a bit.

Still no luck. I guess I'll have to resort to crying. Finally, I'm back in warm dry clothes and Mom is holding me. After all that, though, I'm not sure either of us is in the mood for playing."

Michelle is fussing because she also just woke up with a messy diaper. Michelle has no vision and a moderate hearing loss. Her mom approaches Michelle's crib and gently places her hand on Michelle's chest to greet her with their special "hello" sign, pauses, then gently brings Michelle's hand up to touch Mom's hair, which is Mom's "name sign." Michelle becomes quiet and reaches out to touch her mom's face. This has become a special greeting. (She knows it's Mom who's going to pick her up rather than Dad from the feel of Mom's soft hair rather than Dad's rough chin). Michelle feels her mom's hands gently lifting her under her arms as she says something that sounds like "up." Mom waits until Michelle starts to lift her head to indicate she is ready, then she picks her up. Michelle wonders what they'll be doing next, then feels the soft terry cloth of her changing table beneath her. She kicks her feet and feels the crumply mylar paper her sister so carefully attached to the foot of the changing table. She relaxes, knowing this is a familiar place. She feels her mom touch her diaper and then feels another clean diaper close to her hand. Michelle grabs it and enjoys crunching it together in her hands while her mom cleans her bottom. What fun it is to kick the mylar and feel it move without being restricted by all those sleepers and blankets! When she feels the clean dry diaper Mom puts on her, Michelle knows she'll be getting up from the changing table soon. As Mom gently lifts under her arms and she hears that sound, "up", again Michelle lifts her head up, letting Mom know she's ready. She relaxes into her mom's shoulder after she's picked her up and they go off to play together.

Each Child is Different

The amount of information children are able to gather depends not only on the amount and type of vision and hearing they have, but also on how they learn to use that vision and hearing. Each child learns to make use of available sensory information in his or her own way. Some children interact with their world primarily through touch, while others may rely more on vision or hearing. For many children, a combination will be most useful.

For other children, using vision, hearing, and touch all at one time is too confusing and, in different situations, they may choose to rely primarily

on one sense. Some children use their vision and hearing inconsistently. Some days they appear to use their vision well and other days they do not. Likewise, a child may seem to hear things well some days and not on other days. This can be confusing for parents and service providers alike. Although complete ophthalmological and audiological examinations are essential, they may not be able to tell you how your particular child uses his or her residual vision or hearing. This information is best gained by carefully observing your child in familiar places and at different times.

Communication May Already Be Happening

There are many ways in which your young daughter or son may already be communicating. Watch for these cues:

- ◆ Her breathing may change when she hears grandpa's voice, recognizing a familiar and beloved person in her life.
- ◆ She may open her mouth eagerly when her spoon touches her lips, clearly indicating she wants more food.
- ◆ She may keep her lips closed as the spoon approaches, and if feeding attempts continue, may turn her head away, lean back into her chair, stiffen, or become agitated, indicating she does not want to eat what is being offered.
- ◆ When Big Sister pauses in a pat-a-cake game, he may reach for her hands as an indication he wants to continue.
- ◆ When Mom stops rocking with him in the rocking chair, he may move his body in a slight rocking motion to indicate he wants to continue.
- ◆ When Dad pauses in a favorite game after saying, "I'm going to get your nose," he becomes excited, anticipating the coming kiss.
- ◆ She may actively and eagerly participate in a familiar song and movement game, such as "Row, Row, Row Your Boat," for five minutes or so; then you may feel her participation fade. She may turn her head to the side. If you persist in continuing the interaction, she may actively resist moving her hands with yours, stiffening her whole body and turning away. Clearly she has had enough

- ◆ She may crawl to the door and sit, or bang on the door, as an indication that she wants to go out. Later, she may even come take your hand and take you to the door as a request to go outside.
- ◆ During her bath, she may splash her hands in the water. When she pauses, her dad splashes his hand near hers, then pauses. She splashes again. Reciprocal interactions with this back-and-forth turn-taking help establish early "conversations."

Tips for Developing Communication

Early communication development is based on four ideas:

- ◆ Developing a close and trusting relationship with your child
- ◆ Using consistent daily routines in which your child is fully involved
- ◆ Providing your child with cues so he or she can learn to anticipate what is going to happen
- ◆ Giving your child opportunities to have some control over his or her environment

You, as the parent, take the all-important beginning steps by developing a close and trusting relationship with your child. One of the most important things you can do to develop a sense of bonding and security is to hold your baby in your arms. Your baby will learn how you move and will feel safe and secure as he encounters events of the day with you. Rather than feeling alone and isolated in his own world, he will begin to learn about a larger world that includes caring people and a variety of interesting movements, things to touch, textures, smells, and perhaps some sounds and sights.

As you join your child in play, you demonstrate that you share your child's interests. You play simple turn-taking games together, which, through daily repetition, a child may learn to recognize. You interact in ways that encourage your child to tolerate touch and handling, and in which he or she can begin to demonstrate enjoyment during interactions. The following suggestions may be helpful as you and your child learn to communicate together:

"Hello. It's me. Let's play." Always greet your child with a special "hello" (touching her chest or shoulder, for example) to let her know someone is there. Then let her know who it is with your own special "name sign" (by helping her feel Dad's

scratchy chin or beard, or Mom's hair, or a watch or ring you always wear). Tell her what you will do together (touch her diaper to indicate diaper changing, for example, or introduce a favorite toy or movement game). Remember to say "good-bye" before you leave, perhaps by waving "bye" with your hand under her hand.

Establish predictable routines with clear beginnings and ends. What routine activities happen during the day for you and your child? Consider activities such as eating, dressing, bathing, and playing and think about how you can let your child know what will happen, when it will start, and when it will end. Perhaps you have a special blanket on which you play on the floor together. Getting this out together and sitting down on it will signal the beginning of play. Putting it away together signals the end.

Involve your child in the whole activity. Your child will learn the sequence of the activity and develop many concepts through his active participation in the whole activity. Remember that a young child who is deaf-blind must physically participate in the entire sequence of an activity in order to gather the same information that another child gathers just by watching. For example, at mealtime, you and your child go to the kitchen together, open the cabinet, take out a bowl, take out the jar of food, open the drawer to get a spoon and put the food into the bowl. Perhaps you heat it up in a microwave oven and when the bell rings, you both bring the warm food to the table. At the beginning of a meal, your child may touch his bib before you help him put it on, and when he is finished eating he can help take off his bib. You bring the dirty dishes to the sink together and turn on the warm water to rinse them. Throughout the activity, you offer your child simple signs (hungry, eat, drink, all done, wash).

Provide opportunities to make choices. Throughout the day, give your child choices: bounce or rock? cracker or juice? bells or slinky? pat your hands or kick your feet? You could show her two toys (perhaps the giggle ball and a mylar balloon) from which to choose. If she has some vision, you may hold the toys where she is best able to see them, alternately moving each one to help get her visual attention and watching to see which one she looks at longer or reaches toward. If she is not able to see the toys, you can help her touch each toy by gently bringing the toys to her hands (rather than taking her hands and putting them on the toys) and watching to see which one she touches longer, keeps her hand on, or tries to grasp. (Sometimes you may have to guess her choice.)

Remember to offer pauses. Some children take a little longer to process the information that they are receiving. It is important that they are given enough time to respond. If we don't allow the child this time, she may give up trying. Respect your child's pace and follow his or her lead. If she has chosen the giggle ball, you turn it on for her, then after a brief play time, turn it off and pause, waiting expectantly, leaving both your hand and the giggle ball very close to her hand. She can have some control over the game by telling you she wants "more." She may do this by vocalizing, or making movements such as kicking her feet, waving her arms, touching the ball, or touching your hand. When you slow down and offer plenty of pauses, you allow your child time to anticipate and respond. You also give yourself time to recognize your child's responses.

Perhaps your son has a music box with illuminated moving pictures that he enjoys, but he doesn't have the motor ability to turn the knob to activate the music and light box himself. You and your child touch the music box together, pause, and then you turn the music box on for your child. When the music and moving lights stop, however, you don't immediately turn it back on. Instead, you wait with both your hand and the toy near your son's hands for him to give a signal, such as touching the toy or your hand, or waving his arms or vocalizing that he wants more. You then immediately respond to his request by turning on the toy for him.

Watch for cues. Stay alert for signals your child may give you that he or she is "ready" to communicate and participate in turn-taking games. Your child may signal that she wants to continue the game or, perhaps, she is "all done" or needs a break from the communication/interaction. She may kick her feet, wave her arms, make sounds, reach to touch your hand or the giggle ball, or use another signal. When she no longer indicates she wants "more," you may offer her another choice of play activities. Look for the following: quiet alertness, orienting toward the person or activity, reaching toward the person or activity, or vocalizing. Children have many ways of letting you know they would like to continue the interaction. Watch for small hand or body movements that reach toward the person or object. Watch for searching hand or foot movements, a smile, an open mouth. Stay in physical contact (allow him to lean on you or keep his hand on you or sit close enough so your leg is touching his leg). The following cues will tell you when your child has had enough and needs a break: turning away the face or body, leaning back, stiffening, fussing or crying, withdrawing, engaging in self-stimulatory behavior such as

head waving or eye poking, closing eyes or mouth, or shifting attention to another object or activity (pulling on a blanket, sucking on fingers, etc.). Reading these cues and responding appropriately is a very important part of early interactions.

Invent your own games. Perhaps now she'd rather play one of her favorite games that you and she invented together. You begin at her toes and slowly move your hands up her legs, up her chest, pause at her chin, then continue to her cheeks, ending by rubbing your nose and face against hers. Because this is a game you often play together, and always in the same way, she has learned to anticipate what will happen. You may notice her excitement build as she begins to anticipate the fun. Perhaps she starts to move her face back and forth too, or reach up for your face. When you put your hands back on her toes, she might kick her feet indicating she wants to play again.

Explore the world together ("hand under hand"). It is very important for family members to remember that if a child has limited vision and hearing that they are not aware that you are both "looking" at the same object or engaging in the same activity (for example, the child may not be aware that other people eat!). Helping your child understand that others are sharing in the same experiences with him is an important factor in building relationships and self-esteem.

The hands of a child who is deaf-blind become his ears, eyes and voice. If he is exploring a toy, join him by gently placing one of your fingers under part of his hands. Likewise, if you want to show something to a child, encourage him to place his hands over your hands as you move toward the object. This way you can explore together. Then you may gently remove your hand so he can play on his own.

These strategies will send a message to the child that you are joining him and not simply manipulating him. When a child's hands are being manipulated hand over hand through a task often his reaction will be to pull away. If, however, a child learns to seek out your hands to share and explore, you will naturally be fostering a stronger desire to reach out to you for information and again, building a stronger sense of self-esteem.

Join your child in her play. What is interesting or fun for your child? Perhaps she has one of your shiny metal mixing bowls filled with brightly colored mylar paper and she likes to move her hands over the crinkly reflective paper in the bowl. You could sit across from her with your hands partly under hers in the bowl. After she moves her hands in the mylar, you can take a turn crinkling the paper. She will feel the movement of both your hands

and the paper beneath her hands and will know that you share her interest. Pause so she may take another turn. As you take turns back and forth, you are having an early "conversation" about something that is of interest to your child. Initially, your son may accidentally bang his arm down on his sound/light piano toy, not realizing he has caused the sound and the keys to light up. With repeated experiences, however, his movements will become more purposeful as he realizes he made something happen. You can join him in play as you invent a turn-taking game: First, he bangs on the piano, then you take a turn and pause and wait for him to repeat his turn. By joining your child in a movement or activity he likes, by following your child's lead, and by imitating your child's movements and/or sounds, you and your child can share many enjoyable "conversations."

Encourage use of all sensory information. Help your child who is deaf-blind learn to use vision and hearing for functional activities and to interpret the limited sights and sounds that are available. Approach your child gently to let him know you're available for interaction; do not "surprise" him with unexpected or abrupt touches or sounds. Attend to and imitate any actions and sounds; invite him to take another turn; let him know you share his interests. Offer consistent touch and object cues to signal the beginning of an activity and use movement and body contact during your interactions.

Adapt the environment. Create clearly defined spaces for your child to play and explore; provide optimal visual contrast and auditory feedback; include toys and materials with sensory characteristics she will appreciate (e.g., shiny reflective toys such as a mylar balloon, toys with vibration, and easily activated sound toys that provide auditory feedback within his or her range of usable hearing). Objects may be placed where your child can find them--attached to the crib, high chair, or car seat, or in a hanging mobile or some special play space. In this way he or she will not "lose" them. They may also be placed so any movement the child makes produces a result. You need to provide opportunities that not only encourage your child to interact with the environment and the people and objects in it, but also give results of that interaction, so he can make the connection of "I did something"/"I made that happen." The little boy who kicks his feet while lying on a water-filled mat may not initially realize that he caused the movement he feels. However, with repeated experiences-- "The mat only moves beneath me when I move"--the child will learn that he can make something happen. This child will become a more active player in the world.

Monitor levels of stimulation. Be sensitive to the type and amount of sensory stimulation your child can handle at any given time and adjust activities and materials accordingly. Be sure to monitor or eliminate background noise and confusing visual effects.

Use appropriate cues. Use simple, consistent, and respectful cues that will be understandable to your child. Cues should be clearly related to the activity from your child's perspective and presented just before the activity starts. To let your child know it is bath time, for example, you might dip his foot in the water, sign "bath," pause to observe his response, then lower him into the tub. In this way your child will learn to anticipate familiar activities; his world will be predictable and interesting; and he will develop a trusting relationship with the people who care for him.

Expose your child to language. Children hear a great deal of verbal language long before they learn to talk themselves. Likewise, a young child with deaf-blindness needs to be involved in an environment that is rich in all forms of communication. This may include words, signs, gestures, touch cues, object cues, movement cues, contextual cues, visual and/or auditory cues. Provide your child with language in any form he can understand. It is important to expose the youngest infant to sign language. When you use object cues, pair them with simple signs. As you respond to your child's communications, offer him simple signs. As a parent, you instinctively can discriminate between a cry of hunger and a cry of pain. Just as a mother would respond to a baby's cry by saying, "Oh, you're hungry", we must provide the same response using signs so the child will gradually learn that "every time I'm hungry and I cry, mom does this; maybe if I do the same thing I won't need to cry."

Help your child interact with others. As she begins to interact with other children, you can be a facilitator. Help other children learn effective ways to understand and respond. Help them learn how to use their hands to provide cues and how to use their hands to play together in a respectful way that encourages active participation and exploration by both children.

Playing games is much more than mere play. Through play, your child can learn a great deal:

- ◆ Trust and anticipation that certain things will always occur
- ◆ How to make things happen
- ◆ Ways to ask for help, ask for more, ask to be done

- ◆ The power of making choices
- ◆ Better understanding of the world
- ◆ Communication in its many different forms

Summary

The term "deaf-blind" can be confusing. We know that very few children are totally deaf and totally blind, and when the term is used, it refers to a child who has a combination of vision loss and hearing loss. Most young children who are deaf-blind have some usable vision and/or some usable hearing. The combined effects of both losses, however, are far greater than either loss would be by itself. Your child will require special methods of communication and special educational services that will surpass what may be required for a child who experiences either vision loss or hearing loss alone.

It is you, however, the parents and family members, who will have the greatest influence on your child's development. Seek out help from others, but be assured that your loving responses to your child, coupled with ideas gleaned from professionals and those who have "been there," will make the biggest difference. Just as other parents do, you will discover your child's unique personality and celebrate your child's achievements.

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Programs

State-Deaf-Blind Projects

State deaf-blind projects are funded by the U.S. Department of Education to help early intervention agencies, schools, and families address the developmental, educational, and transition needs of children who are deaf-blind. Visit nationaldb.org to find the state project in your state.

National Center on Deaf-Blindness

NCDB, also funded by the U.S. Department of Education, works closely with state deaf-blind projects to positively impact the lives of children who are deaf-blind and their families. NCDB's focus is on strengthening systems of support related to key initiatives, including early identification and referral, qualified personnel, literacy, transition, and family engagement. NCDB has an extensive website with information for both families and service providers.

National Family Association for Deaf-Blind

NFADB is a nonprofit, volunteer-based family organization that seeks to empower the voices of families of individuals who are deaf-blind and to advocate for their unique needs. The organization's philosophy is that individuals who are deaf-blind are valued members of society and are entitled to the same opportunities and choices as other members of the community.

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