

## Learning to Communicate: Strategies for Developing Communication with Infants Whose Multiple Disabilities Include Visual Impairment and Hearing Loss

by Deborah Chen, Ph.D.

Professor, California State University, Northridge

All infants communicate through crying, fussing, smiling, body movements, and other nonverbal behaviors. With repeated interactions, their parents, families, and other significant caregivers interpret the meaning of these signals and respond accordingly. Through these early exchanges, infants discover that their behaviors have a powerful effect on their caregivers and develop more efficient ways to communicate - through gestures and words. However, when infants have a visual impairment and hearing loss in addition to other disabilities, the communication process does not develop naturally. Their early communicative behaviors may be subtle or unusual and therefore to identify and interpret. For example, an infant (who is totally blind and hard of hearing) may become quiet when her mother speaks to her. This passivity may be misinterpreted as disinterest rather than attentiveness. Another infant (who has cerebral palsy and is deaf) may grimace his body when his father picks him up. These behaviors may be misinterpreted as rejection rather than excitement.

At the same time, our usual responses, i.e., by talking to hearing infants or by signing to deaf infants, may not be understood or even perceived by infants with sensory impairments and multiple disabilities. Communication with these infants requires careful planning, consistent attention, and specific procedures. The purpose of this article is to discuss selected strategies that families and service providers can use for communicating with infants (birth to 36 months)

who are not yet using words and who have significant and multiple disabilities.

### Getting Started

Because the meaning of an infant's early communication behaviors is tied to context, we must first identify how and why an infant communicates during familiar activities. These observations provide information on an infant's current level of communication and ways to support interactions.

#### Make Careful Observations to Interpret Infant Behaviors

1. Observe the infant in an everyday caregiving activity (e.g., diaper change, dressing, feeding, or bathtime) and a familiar social activity (e.g., being tickled, action songs, being rocked, or other early games).
2. Identify how the infant shows interest, dislike, fatigue, or boredom through his or her behavior.
3. Identify whether the infant communicates for (a) behavior regulation (e.g., to get someone to stop or start doing something by protesting, refusing, or rejecting; requesting objects; or requesting actions); or for (b) social interaction (e.g., to get someone's attention by greeting, seeking attention; requesting social routines; or requesting comfort).

Next, we should find out about the family's typical activities and communication practices. This way, strategies will be tailored to fit the family's lifestyle and will be more useful to the family.

### Family Information

1. What is a typical day like for your infant?
2. What are your infant's favorite objects, activities, and people?
3. What are your infant's most disliked objects, activities, and people?
4. How does your infant communicate with you? What is he or she usually trying to tell you?
5. When is your infant the most communicative?
6. Have you found any special ways that help you to communicate with your infant?
7. What activities do you enjoy doing with your infant?
8. What songs or baby games do you play in your family?
9. What words do you use frequently in everyday activities with your baby?
10. What do you say when your baby does something that you like or makes you feel proud?
11. When is a good time or what is a good activity for playing with your baby?

Taking time to discuss these questions is important for all families and absolutely essential when service providers and families have different cultural and linguistic backgrounds. Otherwise, a service provider's suggestions for supporting the infant's communication may conflict with family practices. For example, an infant may be confused if an English-speaking service provider says "good boy" to praise him while his Spanish-speaking mother says "bravo." Explanations of sign hand shapes based on English letters, e.g., "S hands" for the sign SHOE, will not make sense to non-English speaking families who do not know the manual alphabet and is not immediately useful if the infant does not wear shoes. Only through careful observations of the infant and thoughtful discussions with families, can service providers suggest communication strategies that are most appropriate for a particular infant and respectful of the family's culture.

### Selected Strategies

We must differentiate between the methods for communicating with an infant (input) and the ways in which an infant is most likely to communicate (output). Input and output communication methods must be tailored to meet the individual learning needs of each infant. For example, a mother may ask an infant "want to swing?" by using an object cue (a blanket) for input, while this infant indicates "yes" by wiggling her body (output).

### Communication Input must be Accessible to the Infant

#### Make use of the infant's available senses

Infants with multiple disabilities must receive comprehensive audiological and ophthalmological evaluations since they are more likely to have vision and hearing problems than infants without disabilities. An infant's visual impairment is usually identified before a hearing problem because it is more obvious. If an infant is identified as having a visual impairment and hearing loss, then every effort must be made to determine whether the infant would benefit from corrective lenses and hearing aids.

#### Communication tips

- Speak naturally and close to an infant's ear. This is a natural way to help the infant discriminate speech from the environmental sounds, particularly if the infant has a slight hearing loss, middle ear infection, or other hearing problem, and does not wear a hearing aid.
- Reduce unnecessary noise. Turn off the television or radio and reduce other background sounds if you want the infant to pay attention to what is being said or other spoken information. The signal (speech) must be at least 30-40 dB louder than the background for a hearing infant to be able to attend to it; so background sounds will interfere with the ability to understand what is said.
- Hold the infant on your chest and dance or sway in time to vocalizations to help the infant make a connection between sound and movement.
- Imitate the infant's own vocalizations or actions. Infants will imitate behaviors that are within their own repertoire before they imitate new behaviors. These imitation exchanges can become enjoyable turntaking games.
- Develop other infant games, for example, by playing "peek-a-boo" and removing the scarf from the

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infant's face after saying "peek-a-boo" or bouncing the baby in time to vocalizations.

Match the infant's developmental level. Our communication should fit the infant's cognitive ability and be tied to ongoing actions and objects that the infant can perceive. Many infants whose multiple disabilities include visual impairment and hearing loss benefit from the use of caregiverese, anticipatory cues and key word signs.

### Caregiverese

How we interact with infants is very different from the ways in which we interact with children who have language. Hearing parents speak to infants using higher pitch and exaggerated intonation. Deaf parents sign to infants by making the movements bigger, making the signs on the infant's body, or making the sign on the object to which it refers. In these interactions, both hearing parents and Deaf parents use animated facial expressions, gestures, short simple phrases about what the infant is seeing or doing, and repeat words, touch the infant, wait for the infant's response, interpret the infant's behaviors as communication, and imitate and expand on the infant's utterances. These characteristics of so-called "motherese" or "fatherese" help infants to participate in early conversations.

### Communication tips

- Use short phrases with repetitive words to allow the infant time to process and understand what is said/signed, for example, "take a drink", "you're thirsty", "drink some juice", "thirsty baby."
- Add words to the infant's action to assist the infant's understanding of words and their meanings, for example, "up, up, up" when picking the infant up.
- Use facial animated expression to engage the infant's visual attention, if appropriate, and to support what is said, and to communicate in a natural way.
- Use natural gestures visually or tactually to engage the infant's attention, to communicate the meaning of words, and to model the use of gestures in communication, e.g. wave bye-bye when saying "bye-bye", gesture when saying "down."

### Anticipatory Cues

Anticipatory cues are specific sensory prompts to help prepare the infant for an upcoming activity. They include: tactile cues (e.g., "let's put your sock on" may

be communicated by touching the infant's foot which is a touch cue) or by having the infant touch the sock (object cue); auditory cues (e.g., tapping the spoon against the bowl to indicate "let's eat"); kinesthetic cues (e.g., rocking the infant in your arms before placing her in the hammock); olfactory cues (e.g., having the baby take a whiff of the soap before bathing him); or visual cues (e.g., wiggling your fingers in the infant's visual field before picking him up). Do not use cues that elicit a negative reaction or are difficult for the infant to perceive. For example, for infants who have had many pricks on their feet from blood tests, touching the foot would be an aversive tactile cue for "let's put your socks on." Other infants may be very sensitive to certain scents and react negatively to olfactory cues. Cues should be selected carefully for each infant, made in a consistent and precise manner, and have a clear connection with what they represent. This way the infant can develop an understanding of their meaning. For example, an infant will be confused if different tactile cues are used for the same message (e.g., touching the lips, or the chin, or the cheek to indicate "let's eat") or if different tactile cues on the face have different messages (e.g., touching the lips means "let's eat", touching the chin means "open up for your toothbrush.").

### Frequently Asked Questions About Cues

*Is there a certain sequence for using cues with infants?*

There is no research on the use of cues with infants to guide how they should be introduced. Cues should be individualized for each infant and dependent on the specific activity. However, a helpful principle is to begin with a cue that will be easily understood by the infant, that is clearly related to the activity, and that is presented immediately before the activity begins. For example, initially, it is probably easier for an infant to understand "get ready for your bath" through a tactile cue (putting his hand in the water just before being put in the tub) than being given a whiff of bathsoap (olfactory cue). Begin with just a few cues that are very different from each other, and that represent different activities, and are therefore easy for the infant to discriminate and to discover what they mean. For example, use a tactile cue for bathtime (putting the infant's in the water), a touch cue for diaper change (tug on the infant's diaper), and an object cue for playtime (quilt for the blanket swing).

*What is the difference between a sign and a cue?*

A manual sign is a symbol, a word, or a unit of language that represents something. For example, the sign

MAMA represents mother no matter the situation. A cue is a prompt that is individualized for each child, is dependent on the specific activity or context, and is used to encourage a specific behavior. For example, tapping a child on the chin may be a prompt for “open up” if the caregiver wants to brush the child’s teeth; or for “take a bite” during meals; or “close your mouth” to prevent drooling.

### Key Word Signs

Many infants with multiple disabilities benefit from *key word signs* which are selected signs adapted for the infant’s learning needs. Using key word signs is *not* the same as using the simultaneous method (spoken English together with a sign system based on English) or using American Sign Language (ASL) which has its own grammar and visual-spatial rules and is a different language than English. Initially, a key word sign is really a prompt or cue to engage the infant’s attention and to build an understanding of the meaning of a word and what it represents. For example, the sign EAT made either by the adult touching the infant’s lips with a flat O handshape or by assisting the infant to touch his own lips is really a *touch cue* or *gesture* rather than a sign. When key word signs are used with infants who have low vision, the infant’s visual needs must be considered. Signs should be made so the infant can see them, that is, within the infant’s visual field and at an optimal viewing distance; the rate of sign production and size of hand movements should be modified to enable the infant to see the sign; and the signer’s hands should be clearly visible in contrast to his or her clothing.

### Selecting Key Word Signs for Communication Input

1. Ask the family to make a list of words that are most important for communicating with their baby.
2. Develop a list of vocabulary with family members and service providers, decide on the signs to be used for these words, identify any adaptations that are needed, and use selected signs consistently across activities.

### Selected Adaptations for Key Word Signs

- Make signs on the infant’s body.
- Physically guide the infant to produce signs (coactive signing).
- Make signs smaller and close to the infant’s face.

- Orient the infant’s attention to a signer by touching the infant’s face or body.
- Use tactile modelling by placing the baby’s hands on yours to feel the sign movements (interactive signing).
- Match the number of movements of the sign with the number of syllables in the word when providing communication input, e.g. MAMA is two movements.

Build on the infant’s interests and strengths. Infants are likely to attend to objects, activities, and people they like and are more likely to request these favorite things. For example, an infant who loves movement will be motivated to ask for “more” of a bouncing game. This favorite activity may be used in an interrupted routine strategy to elicit communication output, as shown below. Selected methods for encouraging the infant’s expressive communication should be based on the infant’s abilities. For example, infants who can control their hand movements are more likely to use some signs expressively than infants who have motor problems. An infant is more likely to make a choice between a favorite object and a disliked object than between two objects of equal appeal.

### Interrupted Routine Strategy

1. Select a movement activity that the infant enjoys and do about three movements.
2. Create a need for the infant to communicate by stopping the movement.
3. Wait quietly (count silently to 10 or 15 depending on the infant’s response time) and observe what the infant does.
4. If the infant responds, interpret the infant’s behavior as communicative. Add words to the infant’s behaviors. Respond to the infant’s communication by continuing the activity.
5. If the infant does not demonstrate an observable response, prompt the desired response (e.g., wiggle the infant’s arms or legs), and immediately continue the activity.

Repeat this prompting procedure two more times so that the infant has three direct instruction experiences. Then repeat from Step 3: interrupt the activity and wait quietly for the infant’s response.

### Criteria for Selecting First Signs For Promoting Communication Output

1. Identify the infant's favorite activities, objects, and people based on observations and the family interview described previously.
2. To represent these preferences, select signs that are easy to produce, touch the body (e.g., EAT, MAMA), have symmetrical movements (e.g., MORE), and look like or feel like what they represent (e.g., EAT, WASH, DOWN).
3. Provide frequent opportunities for the infant to use these signs.

### Considerations for Selecting Key Word Signs as Communication Output for Infants with Motor Problems

- Identify key words that have been selected by the infant's family and service providers and determine their usefulness for the infant's expressive communication.
- Determine whether a manual sign is the most effective way for this infant to express a desire or need. What type of physical assistance does the infant need to produce the selected sign? Is there an easier way for the infant to communicate (e.g., using an object, picture, or other signal system).

*Provide time and repetition.* Very young children without disabilities need to hear a word used in context about 200 times before they use it. Infants with multiple disabilities will need even more repeated experiences to understand the meaning of a cue or word used in everyday activities. This significant need for consistency and repetition highlights the importance of making communication an essential part of every learning activity and daily routine. Not only the infants, but everyone involved with them—family members and service providers—should all be learning how to communicate.

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# Communicating with Bruno

by Gretchen Hester

**M**y three-old son, Bruno loves to be active. I try to involve him in many activities with his cousins – swimming, carving pumpkins at Halloween, visiting the Discovery Museum, and the petting zoo. Swimming is a favorite activity for Bruno because he enjoys more freedom of movement in the water. He enjoys touching objects, toys, and pets. He loves his English bull dogs! We use books that have scents, shiny objects, and different textures to “read” to him. He will attend to a light box to play with his toys. He loves to rocked back and forth, and to swing in his swing. For his birthday, I had pony rides and he enjoyed being on a pony although he was very medicated because of a big seizure the previous day.

When Bruno was born, the doctors told me that he would not live and I should just take him home from the hospital and let him die. He just celebrated his third birthday! Bruno has multiple disabilities which include severe epilepsy, developmental delays, cerebral palsy, a temperature regulation problem, and is cortically deaf and blind because of global brain malformations. He has agenesis (absence) of the corpus callosum (band of white matter that connects both hemispheres of the brain). He also has optic nerve hypoplasia in both eyes (it is much more severe in the right eye as compared to the left) and suffers from nystagmus as well. Bruno’s medical needs have always been extensive so he has nursing care. He has been on many drugs to control his seizures, but they haven’t worked. Last year, he started the ketogenic diet and that worked for a few months. Last October, he had a vagal nerve implant and that had helped him healthwise- but he still has seizures. Recently, he was in a study with Dr. Bill Good at the University of California, San Francisco. Dr. Good found that Bruno’s myoclonic seizures affected his vision for several minutes after the seizure.

I’ve learned how to interpret Bruno’s communication by watching him carefully. When I was working at the University of California, San Francisco, I noticed that

when we went outside, he would stop breathing, throw his arms back, and turn blue. I didn’t know if this was a seizure. This happened several times and then after a hospitalization (attempting to determine the cause of the episodes) I figured out that wind was frightening him so much that he would stop breathing. There was a sort of a “wind tunnel” as we went out of the hospital building. Bruno is still afraid of the wind but is able to continue to breath. When we last went ice-skating, he was terribly scared when the wind hit his face while he was in his wheelchair on the ice. He much preferred attempting to skate with me holding him. This way, we were going at a slower speed and there was no wind, as well as he was more involved and could tell what was going on with sensory input of the ice skates on the ice. He is scared when he is not sure what is going on since he can’t see or hear things that approach him, even wind.



Often people who don’t know him have a difficult time understanding him. They are not sure why he does not look at or listen to them. It is difficult for them to comprehend the idea of him as a deaf-blind child. Sometimes people will touch him on his face. He doesn’t like this, and I believe it is because of all the tubes he had as a baby in the hospital. California Deaf-Blind Services and Jeri Hart from the Blind Babies Foundation have helped me learn how to communicate with Bruno. I use specific touch cues in particular situations. When he is in the hospital, I tap his toes before an injection or blood test. This warns him that

something unpleasant is about to happen. At the swimming pool, I touch his lips to signal that he is going underwater. Before eating, I tap his hand that is holding the spoon.

When he was a baby, I started with scents during everyday activities to help him understand what was coming up. I put rosemary in his bath to signal bath time, lavender on his pillow so that he would know it was time to sleep, and he felt and smelled bananas and pears at meals when he was going to eat them. Once he

## Communicating with Bruno (cont. from page 7)

got the idea that certain scents were tied to these particular activities, I paired them with objects (a rubber ducky was used with the rosemary scent before going into the bath). I used other object cues like a leash to mean that we are going to walk his dogs. Because of his cerebral palsy it is difficult for Bruno to make signs but I have added a few signs to his object cues. I speak to him at the same time that I make a sign on his hand or help him make a sign. I'm learning signs and how to adapt them for him. By his behavior, I know that he understands the signs for STAND, SIT, WALK, EAT, DRINK, and MORE.

I use "identification cues" to help Bruno identify familiar people. He touches their ring, watch, or they touch him in a special way. For example, his grandmother kisses him on both cheeks to greet him. His aunt sings to him by placing her lips on his face. Because he can't see or hear me, he likes being physically close; so if he is alone, he yells to get my attention. Bruno has a little piano that he likes to play; he'll push on the same button over and over again to get me to come over to him and reset it.

I was told that he would never drink or hold a bottle by himself, but now he does. I was told that he would never eat by himself. He doesn't as yet, but he holds his spoon and he loves eating, so eventually he will.

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**California Deaf-Blind Services Staff and Offices  
1-800-822-7884 Voice/TTY**

**Northern California Office**

Lori Goetz, Ph.D. .... Project Director  
Barbara Franklin, Ph.D. .... Principal Investigator  
Maurice Belote ..... Project Coordinator  
Sam Morgan ..... Educational Specialist  
Cindi Avanzino ..... Family Specialist  
Jackie Kenley ..... Project Assistant  
Rebecca Randall ..... Project Assistant  
**SFSU 1600 Holloway, HSS 322 • San Francisco, CA 94132  
(415) 405-3567 VOICE/TTY • (415) 405-0413 FAX**

**Southern California Office**

Deborah Chen, Ph.D. .... Site Co-Director  
June Downing, Ph.D. .... Site Co-Director  
Melinda Shipman ..... Family Specialist  
Sandy Staples ..... Educational Specialist  
JoAnne DeJaco ..... Family Specialist  
Nancy Cornelius ..... Family Specialist  
Gloria Rodriguez ..... Educational Specialist  
Sylvia Freiberg ..... Project Assistant  
**18111 Nordhoff – EDUC • Northridge, CA 91330-8265  
(818) 677-2577 VOICE/TTY • (818) 677-3982 FAX**

**California Department of Education**

Patrick McMenamin ..... Contract Monitor  
**(916) 327-3535**

San Francisco State University  
Special Education Department  
1600 Holloway Avenue  
San Francisco, CA 94132

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