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Feeling the Pressure: The Forgotten Sense of Proprioception

by David Brown, CDBS Educational Specialist

That feeling inside

The way we can ‘feel’ where all our body parts are in relation to each other (and also ‘see’ them in our mind’s eye), without actually having to touch them with a hand or look at them with our eyes, is an ability that we get from our proprioceptive sense. Proprioception is a strange word, actually a combination of two Latin words that means ‘an awareness, or a feeling, of one’s own self’. Most people have never heard of this sense, and they always use the single word ‘touch’ to include several different sensory systems, including proprioception as well as perception of touch, pain, temperature, and vibration. In fact touch is a system that provides us with so many different forms of information, with so many complex and contradictory elements, that some writers have said that “it may actually be misleading to speak of a distinct ‘sense of touch’” (McLinden & McCall, 2002, p. 25). Other writers have claimed that proprioception is

actually a specialized variation of the sense of touch that encompasses the sensations of joint motion (kinesthesia) and joint position (joint position sense) (Lephart & Borsa, p. 11).

The proprioceptors

The receptors of the proprioceptive sense (the proprioceptors) are located in the muscles and joints throughout the body, and they are sensitive to stretching and to compression. A normal range of muscle tone is needed for this sensory system to work efficiently and effectively. When it is working effectively the brain, at all times, has an awareness of where the various body parts are in space, if they are moving or not, and how fast and in what direction they are moving. This constant ‘running’ awareness is conveyed to the brain depending upon which proprioceptors are being stretched or compressed, and the force applied, and the direction of the stretching or compression, and also depending upon the angle of every joint. We talk about this sense enabling us to ‘feel’ where our body parts are, but this does not mean ‘feeling’ like ‘touching’ one body part with another—it is an entirely internal sensation.

Why does it go wrong, and what happens when it does?

Injury, surgery, arthritis, cerebral palsy and other kinds of brain damage, and poorly modulated muscle tone (e.g., muscles too stiff or too floppy, or variations between these two extremes) can all result in diminished proprioceptive perception and awareness. Problems with the proprioceptive sense can be made worse when there

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are also difficulties with the vestibular sense (Brown, 2003), and with the tactile and visual senses, all of which are common for children with deaf-blindness. We have all experienced loss of proprioceptive perception when a leg 'goes to sleep' after we have been sitting for a while with it folded beneath us; for a short time we cannot 'feel' the leg or the foot at all and it is very difficult to stand and bear weight on it as the ankle and the knee refuse to lock and remain stable for us. We use a variety of behaviors like shaking the leg, rubbing it firmly with our hands, patting it hard with the hands—all strong proprioceptive stimuli—in order to restore normal sensation and function as quickly as possible. When a child has a proprioceptive sense that is not working properly some common outcomes may be:

- ❖ Inability to push up on the hands and arms when laying face down due to low muscle tone and an inability to 'feel' and lock the joints in the wrists, elbows, and shoulders.
- ❖ Inability to stand and bear weight due to low muscle tone and an inability to 'feel' and lock the joints in the ankles, knees, hips and maintain stability in the spine.
- ❖ Heavy foot stamping when learning to walk—literally 'feeling the feet' through a combination of tactile sensation and, especially, this strong proprioceptive input.
- ❖ Paradoxically, after months or years of forceful flat foot slapping on the floor while independent walking is developing, some children, once walking is mastered, develop and prefer a tip-toe barefoot style, the bare feet maximizing tactile input, and being on tip-toe maximizing the proprioceptive (pressure) input through the feet, ankles, calves, knees, thighs, and buttocks—a different way of 'feeling' the legs and the feet.
- ❖ Clumsy, poorly coordinated movements, so that sometimes the child must make several attempts to achieve the desired outcome. Also a child may use specific self-taught strategies to minimize errors, such as close visual scrutiny, or sliding the hand or arm along a wall or table in order to provide tactile information about their movements as they reach.
- ❖ Use of too little force, or of excessive force, when touching, patting, grasping, pushing and pulling, and lifting or placing things. The child may adopt

abnormally high muscle tone, use strong movements, an over-firm grip, and excessive force in making contact with people or objects, all of which may be interpreted as aggressive, rough, or clumsy by others.

- ❖ Seeking strong pressure or stretching inputs (e.g., squeezing into tight spaces, crossing or twisting limbs around each other, binding body parts with cloth or string or rubber bands, pulling the teeth and lower jaw downwards, banging on the face or head, clapping or flapping the hands, swinging the legs through space while seated, hanging doubled over a bar or swinging from it by the arms, jumping up and down with the ankle and knee joints as locked as possible, hammering an object on the floor or on a table or kicking a heavy object like furniture or a door).

Excessively high or low muscle tone is usually associated with poorly modulated tactile and proprioceptive senses in these children, tactile defensiveness may be present, and awareness of touch, pain, and temperature may be fluctuating. Children often adopt specific postures (e.g., flat on the back with both legs bent and one ankle up

crossing the other knee, or legs tightly crossed, or fingers crossed or bunched together, or hands fistled, or arms folded in front of or behind the body). These postures provide essential extra tactile and proprioceptive information to the brain about where



the child's lower limbs are in space, and also confirms for them that their body is securely 'fixed' and not moving or floating around.

What can we do to help?

- ❖ Consult with the Pediatrician, Orthopedic Specialist, and Neurologist and share any observations you have made of the kinds of behaviors mentioned above that might indicate the child has poor proprioceptive perception.
- ❖ Consult with the OT (preferably Sensory Integration

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- trained) and PT, share any observations you have made of the kinds of behaviors mentioned above, and implement the therapists' suggestions. As well as specific therapy suggestions they may have ideas on environmental adaptations that will facilitate better control of movements, or ideas to make it easier for the child to succeed at a range of appropriate motor activities (e.g., simplified equipment, simplified task, extra physical supports, heavier spoon/bat/etc, clearer visual markers).
- ❖ Consult with the Adapted Physical Education specialist for older school-aged children, share any observations you have made of the kinds of behaviors mentioned above, and implement the specialist's suggestions.
 - ❖ Deep pressure massage and rhythmic joint compression. These could be part of a specific Sensory Integration program, or could be considered more as a recreational activity. Rhythmic joint compression and stretching of fingers, arms, legs, or the head and neck can be extremely motivating for children with this type of sensory difficulty and might be a useful strategy to help to build a relationship with a child who is avoiding social contact.
 - ❖ Consider the use of weighted clothing, weighted cloth across the lap when sitting, and heavy bed covers when the child is sleeping or resting.
 - ❖ Consider the binding of whole body parts or specific joints (e.g., using a blanket, tight gloves, Lycra sleeves or Lycra clothing). Bracing and wrapping have been used with adults with proprioceptive problems following illness, injury or surgery, and this is reported to serve a sensory function in addition to a mechanical function. For example, an elastic bandage has been known to enhance joint position sense in patients with osteoarthritic knees as well as in patients after significant knee surgery (Lephart & Borsa, p10).
 - ❖ "Balance and postural activities, both with and without visual input, will enhance motor function at the level of the brain stem. While consciously performed, joint positioning activities, especially at joint end ranges, will maximally stimulate the conversion of conscious to unconscious motor programming" (Lephart & Borsa, p10). Sports coaching programs and sports injury clinics use proprioceptive training ideas a lot, and it is also a major component of the Alexander Technique and other related disciplines.

- ❖ Consider introducing chewing gum or 'chewy' items that stimulate strong proprioceptive input through the jaw.
- ❖ Consider hydrotherapy/water-play, horse riding, crash mat, a whole range of acceptable 'rough & tumble' play, climbing frame to swing from, trampoline. Because diminished proprioceptive feedback enhances the risk of injury, it is always a good idea to seek professional help and guidance with any of these large movement/strong input activities, and to ensure some level of adult monitoring and supervision.

As with any sensory deficit, poor proprioceptive functioning can be difficult to identify and assess, particularly when it is only a part of a wider pattern of sensory impairments. However, like the other 'forgotten sense', the vestibular, it is crucially important to all areas of functioning so needs to be considered for any child with deaf-blindness. The pressure that they feel needs to be primarily through their proprioceptors, rather than from people in their lives who look at them and can only think in terms like 'clumsy', 'aggressive', 'mean', and 'lazy'.

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Thinking Deep Thoughts

by Liz Hartmann, Special Consultant to CDBS

What comes to mind when you read the words *cognitive development*? Do you think about the brain and intelligence? Are you thinking of a discussion you had at a recent IEP meeting? Or are you reminded of a class or workshop that discussed theorists like Piaget and Vygotsky? If you had asked me this question a couple of years ago, my answer would have been guarded. I was hesitant to discuss theories of cognitive development, partly because I knew my own understanding of this topic was limited and partly because I had experienced first hand how these theories were used to describe the limitations of children who are deafblind, rather than show their amazing abilities.

Today as I reflect on these words, I have a different outlook. This past year I went back to school and through readings and discussions with others, I found myself coming to a much deeper understanding of cognitive development. And with this deeper understanding came a realization of both the positive and negative aspects concerning theories of cognitive development and how they impact children with deafblindness. The following article shares some of what I have learned by taking a brief look at the two most popular and well-established theories of cognitive development and how these theories relate to the education of children with deafblindness.

What is cognition?

Understanding cognitive development in children can be challenging, and many theorists have dedicated their lives to defining it. Their work has allowed for better understanding and, in certain cases, these theories have had a major impact on how children are assessed and educated. Furthermore, these theories have supported some of the major educational reforms of the past century.

Cognition is a difficult construct to define without restricting or oversimplifying its meaning. A comprehensive definition of cognition begins with concepts such as intelligence, thinking, reasoning and problem solving. But these words do not fully describe all aspects of cognition. Cognition is a part of every human psychological process and to understand it one must also consider communication, motor and social development. For example, if a child with deafblindness shares an object of reference with a peer in order to request a favorite activity, this child is using many different cognitive skills, such as thinking

and problem solving. These cognitive skills are closely intertwined with the social, motor and communication skills that are part of the interaction.

A tale of two theories

Jean Piaget (1973) is one of the most important and well-known theorists of child development and cognition. He is considered a **cognitive constructivist** and his theory highlights the important relationship between active learning and development. Piaget believed that cognitive development is the result of movement through stages in which cognitive change starts simply but then gets increasingly complex (Cohen & Cashon, 2003). For example, an infant in her crib learns about objects by being active and doing things with them. These interactions are so simple that the infant may not even intend to have them (e.g., the child rolls over, unknowingly hits a rattle and it makes an interesting sound). Over time, these simple interactions with objects lead to more complex and controlled ones (e.g., infant touches the rattle, picks it up and shakes it to make an interesting sound). The infant learns from these interactions and her cognitive skills develop. The child then becomes more and more active, doing more in her environment, which causes further development of her cognitive skills. These changes in cognitive skill are simplified and organized into stages. The table on page 5 identifies the four major stages of cognitive development, which have become one of the most popular aspects of Piaget's theory.

While Piaget's theory is still dominant, more recent research has found many inconsistencies in his stages, which may be due to an over-reliance on other specific skills (i.e., motor skills) to prove that the child has developed cognitive abilities. This raises the question: is the infant unable to purposely shake the rattle because she is limited by her cognitive skills or is it that she doesn't have the motor skills or coordination to pick up and shake the rattle? Other difficulties with Piaget's theory may be due to the oversimplification or incorrect interpretation of his ideas. Many current theorists agree with Piaget's idea that a child develops through active involvement, but place a smaller emphasis on Piaget's stages, which have been shown to be, at best, only roughly accurate (Flavell, Miller, & Miller 2002). Furthermore, recent research

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Stage	Characteristics	Approximate Age
Sensorimotor	Integrating senses with motor functions. Specifically goal directed behavior. Develops object permanence and other basic skills.	0–2 years
Preoperational	Cannot yet perform mental operations. Rapid increase in language ability. Engage in symbolic thought, but dominated by perception.	2–7 years
Concrete Operational	Can perform operations on objects that are immediately present or easily imagined. Cannot handle abstractions of abstractions.	7–11 years
Formal Operational	Can perform operations on abstract concepts. Capable of performing abstract and hypothetical thinking, but may still prefer concrete thinking (because it is easier).	11 years–adulthood

Piaget's Four Major Stages of Cognitive Development

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indicates that infants may have quickly emerging abilities that Piaget overlooked.

Other theorists have placed a greater emphasis on the infant's response to influences in the social and cultural environment. This theory is called **social constructivism** and is often associated with Lev Vygotsky (1978) who emphasizes the relationship between cognition and the social and cultural aspects of learning. Social constructivism shifts the focus from individual performance of skills to the understanding of relationships, interactions, and environments of the child. This theory has received attention in the field of special education, guiding research that has investigated the ongoing interaction between caregiver, environment and child. For example, a social constructivist looking at the cognitive development of a child with deafblindness may ask questions such as: How does the presence or lack of structure and routine in this environment impact the child's cognitive skill development? How does communication and social interactions with other people impact the concept development of a toddler who is deafblind?

Although it may appear as if there are many differences between these two theories, it should be noted that there are also many similarities. These two theories are complementary in that both see the child as an active learner who "constructs" experiences in an active environment. They differ in that cognitive constructivism (Piaget) emphasizes the child as an individual learner while social constructivism (Vygotsky) emphasizes the child as a social and cultural learner. Are you tempted

to choose one theory over the other as your favorite? If so, you wouldn't be alone. These two theories are so often contrasted that in discussing them, many people end up showing a preference toward one theory or the other. Although tempting, taking a "one or the other approach" to cognitive development can end up hindering more than helping. When discussing theories of development it may be more important to think in terms of the strengths and weaknesses of each theory. Also, it is important that we don't fall too in love with one theory because we need to be willing to change our minds when it no longer helps us to better understand and serve children with deafblindness.

Current cognitive craze: Am I a part of it?

So you may be asking yourself, but does cognitive development theory really concern me and my friend, student, child with deafblindness? Do I really need to keep reading? The answer may surprise you.

There has been a dramatic increase in the amount of research related to cognitive development in recent years, which is largely due to the development of new ideas and methods that test these ideas. Current research and theory reflects a balanced picture of cognition, considering what the child can and cannot do. In addition, contemporary theories often incorporate cognitive development into the latest information on how the brain works and what happens when the brain interacts in everyday environments. To test these theories in more meaningful ways, cognitive theorists are collaborating with a variety

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of other professionals, including members of the medical and educational fields. In many instances, teachers and support staff are becoming an important part of the practical application of these theories, providing access to their classrooms and curriculum in order to help researchers further develop theories and study their impact within educational settings (Brown, 1992). Families are also becoming part of the cognitive craze by allowing researchers to videotape and analyze their natural routines and interactions with their children. What once used to be an activity for the few is now becoming a more inclusive endeavor. Partnerships between theorists, teachers, and families are now an important part of research that leads to new theories. This means that everyone reading this article, whether teacher, aunt, brother or principal of a child with deafblindness, may at one time play a major part in the understanding and further development of cognitive theory. We all have some experience or expertise to add.

Deafblindness and cognitive theory: Help or hinder?

In the field of deafblindness, cognitive development has been an important topic that many have addressed (e.g., Van Dijk & de Kort, 2002; Miles & McLetchie, 2004). Developing thinking skills and concepts is a crucial part of any child's education, and is especially important in addressing the unique needs of children with deafblindness. But what do we really know about cognition and deafblindness?

Literature on theories specifically related to cognitive development and deafblindness is minimal, although it is interesting to note that many of the most influential theories incorporate the example of Helen Keller to support or further explain development of cognition and communication (e.g. Werner & Kaplan 1963; Langer, 1957; Deacon, 1997). To see what influences the major theories of cognitive development have on the field of deafblindness, one must look at the practice and resources addressing deafblind education. For example, Miles & Riggio's (1999) guide *Remarkable Conversations*, highlights the critical importance of the environment in building concepts through meaningful interactions. The authors' emphasis on social, emotional, and cognitive aspects of the environment are comparable to the main ideas of social constructivism (i.e. Vygotsky's theory). In addition, the influence of social constructivism can be seen in *Home Talk: A Family Assessment in Children*

who are Deafblind, a practical tool that allows for one to better understand a child's development within a social and cultural context.

In contrast, Piaget's theory of cognitive constructivism can be connected to many of Rowland & Schweigert's (1996) assessment tools, including the *Communication Matrix*, and *Hands on Problem Solving for Children with Multiple Disabilities*. In the *Communication Matrix*, the levels of communicative competence are influenced by the stages found in Piaget's theory. The *Hands on Problem Solving Assessment* focuses on the child with multiple disabilities and how they use objects as a way to develop concepts and cognitive skills. This resource reflects Piaget's work on the use of objects and how interactions with objects lead to the unfolding of cognitive skills. The work of Jan van Dijk is representative of both these theorists. In a keynote presentation he gave in 2002 at the California Coming Together Conference on Deaf-Blindness, van Dijk noted the importance of a sensitive, responsive learning environment and the child's active participation with objects in the context of common experiences. These ideas reflect the theories of both cognitive and social constructivism.

The previous examples of well known and frequently used resources created by leaders in the field are representative of how theories of cognitive development have influenced supports and services for children with deafblindness. Unfortunately, there are also examples of how these theories are oversimplified or taken out of context. I had one personal experience of working with a team serving a learner with deafblindness who was labeled "functioning in the sensorimotor state", which is the lowest of Piaget's developmental stages. Without consideration to the child's abilities and based on only one assessment tool, this finding led to the child's placement in an inadequate educational setting. Instead of being placed in a motivating and contingent environment with a meaningful curriculum, the child was forced to show his ability by performing a variety of basic, meaningless and isolated tasks, like stacking blocks and using a peg board. It was believed that this child needed to master these skills before he could be ready for a "higher level" curriculum that incorporated more advanced cognitive skills. In this instance, the theory of cognitive constructivism was taken out of context and Piaget's stages were used to improperly subject the child to a poorly chosen curriculum and educational placement. As a result, he was not given the proper social, emotional and communication support

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necessary to truly develop his potential. Over time, the team realized that an approach that was child-driven, rather than theory-driven would better serve the child. Although theory could provide meaningful insights, it was only useful as one among many ways to understand the whole child.

Closing thoughts

While theoretical influences are at times subtle, it is important for those serving and supporting children with deafblindness and their families to understand how these theories can impact a child's quality of life. Theories are developed so that those studying a complex and multifaceted concept like cognition are able to organize their knowledge and beliefs into a framework that they can then test, change and further our understanding. Once these theories of cognitive development are accepted by policy makers, educators, and the general public they can have a major impact on how a child is educated and what kinds of curriculum, activities and support services they will receive. For a population as diverse and exceptional as children with deafblindness, these theories can have positive or negative results, either bringing us to a better understanding of cognitive development or obscuring important aspects of the child. Cognitive theories define complex relationships and help us to understand general development of children, but these theories will not be able to fully define the individual needs of any one child. Applying these cognitive theories to individual children with deafblindness must be done with caution, and only as one part of a very complex process. Our first concern must always be for supporting practice that focuses on the needs of children and their families.



For more information on Jean Piaget and The Piaget Society: <http://www.piaget.org>.

For more information on Lev Vygotsky: <http://www.u.arizona.edu/~sonyac/page27.html>.

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The Plastic Brain

by Gloria Rodriguez-Gil, CDBS Educational Specialist

The first time I heard about brain plasticity was when I heard Harlan Lane's presentation *Modality-Appropriate Stimulation and Deaf-Blind Children and Adults* at the 1997 National Conference on Deafblindness. He talked about how the brain adapts and compensates for sensory deprivation by increasing the brain capacity of the remaining senses. His speech gave me a lot of hope for the children who are deaf-blind—and for all of us—because it told us that we could always learn new things regardless of our situation and age. It was very important to hear that there was physical evidence that proved how this happens and why it happens.

These are exciting times. We have imaging technology that allows us to map the neural activity of the brain and technology that measures electrical brain activity that allows us to learn more about how the brain works. This definitely could verify things that we have known all along through our practice and years of research, but it could also tell us new things that will improve our work. The purpose of this article is to explain how brain plasticity works and how we can take advantage of this when we work with children who are deaf-blind.

What is brain plasticity?

Brain plasticity is the lifelong ability of the brain to modify its organization. These are some of the ways the brain modifies itself:

- ❖ The brain expands by opening new neural pathways for new knowledge and experiences. Every time the children we serve learn new things, new networks of neurons are stimulated, and that knowledge and experience is imprinted in their brains, e.g., a child who is congenitally totally deaf-blind and whose favorite activity is to eat starts at age five to sign EAT every time he wants to eat.
- ❖ When a particular sense is very diminished, the brain maximizes resources by using much more intensively the part of the brain that works with the remnant of that sense, e.g., a student with CHARGE Syndrome who has bilateral moderate to severe hearing loss and has no vision in one eye and a little bit of vision in the other eye, and who very early in life demonstrates—despite his minimal vision—that he is mainly a visual learner who finds his way around his environment, recognizes familiar people and places, explores objects and monitors his actions mainly through vision.
- ❖ Other neurons take charge when specific neurons have died because of a brain insult, e.g., a student with cortical visual impairment who is not able to see at birth, but with years of visual stimulation loves to see herself in the mirror. This “taking charge” seems to be more efficient in animals than in humans. “In studies involving rats in which one area of the brain was damaged, brain cells surrounding the damaged area underwent changes in their function and shape that allowed them to take on the functions of the damaged cells. Although this phenomenon has not been widely studied in humans, data indicate that similar (though less effective) changes occur in human brains following injury.” (Hoiland, 2004, ¶ 13)
- ❖ Areas of the brain that were in charge of a non-working sense can be taken over by another sense and the functionality of this other sense is enhanced by its larger brain representation. These are some examples given by Jude Nicholas at the DBI World Conference in 2003 that illustrates how the brain changes and compensates when there is sensory deprivation:
 1. A study using PET (Positron Emission Tomography) in congenitally blind subjects and sighted subjects during an auditory localization task revealed significantly greater activation in the occipital areas of the blind subjects compared to the sighted subjects. The occipital areas originally are in charge of processing visual input but in this example, because the subjects are blind, this area is recruited for auditory processing.
 2. PET studies have also demonstrated that Braille readers use not only somatosensory regions in the brain that traditionally perceive and interpret Braille but they also use areas of the visual cortex.
 3. ERP (Event-Related Potentials) and neuroimaging techniques have found that the brains of deaf subjects are reorganized profoundly. For example, auditory areas are activated by Sign Language.

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- ❖ There is increased activity in areas of the brain devoted to a particular sense. “Sustained sensory experiences lead to the elaboration of brain tissue allocated to that sense, and this is true in maturity as well as in early development” (Harlan Lane, *Modality-Appropriate Stimulation and Deaf-Blind Children and Adults*, June 7, 1997, p.1). Dr. Lane gives the example of Braille readers and string players having increased cortical representation of the fingers.

Taking advantage of brain plasticity

How can we take advantage of the brain plasticity of children who are deaf-blind, who are sensory deprived, who might have an insult to the brain and additional disabilities? How can we overcome these obvious obstacles and provide a rich and balanced environment where the brains of these children can develop and reach their fullest potential? Here are some ideas:

New knowledge and experience

First of all, children who are deaf-blind need to be exposed to experiences and instruction in order to learn. There is no way children who are deaf-blind can learn while passively sitting or lying down in environments where nothing is happening for them. Learning on their own is difficult because of their vision and hearing loss, and is compounded in many cases by additional disabilities such as motor impairments. In these cases, adults or peers around children who are deaf-blind need to provide them with opportunities and support throughout the learning experience. Concrete experiences, in which children learn by “doing” (what we refer to as “hands-on”) are probably the best. I see this support as a dance between the child and the adult or peer. The adult or peer observes the child very carefully in order to learn when to provide physical support and verbal prompts, comments, times to be quiet so that the child can process and experience at his own pace, times to wait for the child’s response, times to follow the child’s lead when he has taken over the activity, and times to stop when the child has had enough.

Frequent stimulation and consistency

Instructional activities and experiences have to happen many, many times in order for the child to learn. It is hard to say how many times—it will vary from child to child and may be over the course of months or years. If possible, at the beginning the experience needs to happen with the same person, the same materials, the same place, and

with the same sequence of events in the routine. Later, the child might be able to generalize this example to other environments, materials, people, etc.

Let’s go back to the example of the child who is congenitally deaf-blind and who started signing EAT at age 5 after at least 3 years of consistent signing at home and at school. At the beginning, he signed EAT only at school and at home during mealtime. One day he was on a field trip with his Orientation and Mobility Instructor when he suddenly signed EAT to his teacher because he wanted to eat. It was a happy moment for all because the child signed EAT appropriately, and in a different place and with a person he had never eaten with before.

Motivation and attention

In order to learn, a child needs to attend. Attention at the beginning is often very limited. It grows over a long period of time. Initially the child might not know what he needs to pay attention to, but routine and clear cues used over time will help the child attend to the meaningful parts of his daily activities. Attention comes and goes depending greatly on the child’s interest and biobehavioral state (see next section). The child is more likely to attend to a motivating activity or to a motivating person even if the activity itself isn’t particularly motivating.

Often children who are deaf-blind are more focused on themselves than on the world around them. I always make a point to say hello to children and be as upbeat as possible even when children are primarily at a stage of being self-absorbed. For example, imagine a child who is mainly interested in playing with his tongue. I am sure that over a period of time, he will be more interested in me than in his tongue because we will have developed a trusting relationship. He will find that he can do more interesting things with me than with his tongue.

If possible, do not finish or change the activity if the child is still attending to the activity. The idea is to increase the child’s attention span and if the child is still attending we want to take advantage of this situation. Sometimes attention increases when activities that involve movement are embedded in between sedentary activities. These movement activities can provide the calmness the child needs to be able to attend during sedentary activities, or raise the child’s level of arousal and bring it up to an alert state.

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Biobehavioral states

This term refers to the level of arousal of the central nervous system. According to the Carolina Record of Individual Behavior (CRIB) the human biobehavioral states range from “deep sleep” to “uncontrollable agitation”. When working with children who are deaf-blind, we need to take into consideration their biobehavioral states because they will indicate the level of stress or availability of the child for interaction and learning. The optimum time for learning is when we are at the “awake” states (quiet awake and active awake); many children who are deaf-blind and who have additional disabilities have problems being in these alert states due to internal and external factors. Some of the internal factors include children’s health and medication, their central nervous status, nutrition, their sensory and cognitive abilities and their sleeping patterns. The external factors have to do with children’s physical environments (e.g., light, background noise, consistency, predictability) and social interactions (e.g., bonding, communication, clear cues and expectations).

These are the biobehavioral states defined by CRIB:

Biobehavioral States	Description
Deep sleep	Lack of body movement and responsiveness
Quiet sleep	Smooth regular respirations and a general lack of movement
Active sleep	Irregular respirations, movements of eyes and face and increased responsiveness
Drowsy	Delayed responsiveness and glazed eyes
Quiet awake	Attentiveness to stimuli and minimal body activity
Active awake	Much body activity and sensitivity to stimuli
Fussy awake	Very heightened sensitivity to stimuli and irregular respiration and general fussiness
Mild agitation	Uncomfortable, complaining or moaning, restless, irritated
Uncontrollable agitation	Crying, changes in color and very irregular respirations

Source: Nelson, C., & van Dijk, J. (2001). *Child-guided strategies for understanding children who are deafblind or have severe multiple disabilities: The van Dijk approach to assessment*. The Netherlands: Instituut Voor Doven.

A Multi-sensory approach

When working with children who are deaf-blind we always recommend the multi-sensory approach in which all senses (residual hearing and vision, touch, smell, proprioceptive, vestibular, taste) are used, as they are needed to provide these children with the clearest

picture possible of the world around them. Under the premise of brain plasticity, this makes complete sense. It stimulates the residual vision and hearing the child has and enhances the other senses so they can compensate for the lack of vision and hearing. This increases the child’s sensory capacity and provides more avenues for learning and communication.

Within this approach we need to find a balance between too much stimuli and too little. We don’t want to overwhelm the child with more information than he or she can process, and we don’t want to give so much information at once that the child has difficulty knowing what to focus on. A common situation that describes this last point is when we are telling the child what is going to happen next in his schedule. We may show him an object cue visually and also present it tactually, while also signing, telling him orally and maybe even showing him a picture and a written word because we want him to start understanding pictures and written words. In this situation, we want to cover all the possible avenues, but be careful—this may be too much information for this child. On the other hand, too little sensory information will keep the child in the “dark” and will not develop the child’s brain.

Children who are deaf-blind develop a unique learning style mainly because the two main senses that we use for learning are precisely the ones affected. It is important to learn how the senses work in general so that you can take advantage of available senses when working with these children. It is also important to know how these senses work in a particular child so you learn how he or she uses and process information with his remaining senses.

When appropriate, augment the child’s sensory capabilities as early as possible by using devices like glasses, hearing aids, FM systems, and CCTVs. Find ways to physically support the child so he can be “anchored” and free to reach out and learn.

Time to process

Children who are deaf-blind need more time to process information. This happens for many reasons, some more obvious than others (e.g., lack of vision and hearing, cognitive disabilities, brain insult, underdeveloped areas of the brain, processing disorders similar to those in children who have learning disabilities). The description that Mary Morse (2001) gives us when she compares a main neural pathway with a highway comes to mind. A

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brain insult would be an event that makes a section of this highway totally impassable. She gives the following story:

“Compare this situation with traveling on a highway. A driver comes to a section of highway that is totally unpassable because of some event. Luckily, there is a lot of undeveloped land where secondary roads may be built. The secondary roads may not always have the same scenery as the destroyed highway; they may not be as efficient as the highway would have been, and using these secondary roads may take the driver longer to reach his destination; however, the entire journey need not be canceled, even though the destination may change while the driver is traveling.” (Understanding Deaf-Blindness, p. 324).

In this description you can visualize what could be happening to a child who is deaf-blind: a message sent to the brain may take much longer and may lose some of the information before arriving to where it is supposed to go.

Conclusion: Keeping the system learning

The brain is always adjusting, adapting, changing, compensating, and creating new pathways, so that it can respond to the person's needs internally and externally. This brain capacity gives children who are deaf-blind, as well as family members and service providers, great opportunities to find alternative ways to access the parts of the brain that are available in each situation.

The pathways for learning will be unique for each child and so should be our approach.

There are no recipes, but there are things we can do: create opportunities for experiencing and learning that are motivating to the child; provide environments conducive to learning and communication; support and participate with the child during the learning process; understand and respond to internal and external factors that affect the child's biobehavioral state; and take advantage of the child's sensory learning style.

As Mary Morse says, “make the situation predictable, interesting, and challenging but not overly stressful” (Understanding Deaf-Blindness, p.331). When you think about it, life should be like that for all of us.

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Can Hearing Be Restored?

by Teresa Becerra, mother of a teenage son with a cochlear implant

While a human sense cannot be physically implanted, today's advances in hearing science have made it possible for the human sense of hearing to somehow be restored for the first time. For the last twenty-five years, scientists in this field have worked on technology that has evolved from a primitive device with limited benefits to today's powerful technology that can provide deaf individuals with the means for functional hearing. This sophisticated technology called cochlear implant has been surgically implanted in qualifying candidates of all ages who have either congenital or post-linguistic deafness.

Regardless of the wonders of this medical science, the cochlear implant alone is not a magic fix to restore the natural hearing sense. It is a combination of the cochlear implant and a multidisciplinary rehabilitation program that allows the deaf individual to access the hearing world. The cochlear implant is a way for deaf individuals to have better opportunity to access spoken information through auditory input, improving speech perception, speech production and language development.

Cochlear implants can benefit deaf individuals with oral communication expanding the boundaries between the deaf and hearing worlds. Opportunities for socialization and academic success are also impacted by the cochlear implant, but are not necessarily of better quality because of it.

The success of cochlear implants differ from person to person and is influenced by many factors such as the individual's age, type and degree of hearing loss, cognitive level, physical condition of the cochlea and auditory structures, as well as their age at implantation, the post surgery approach, the individual's personality characteristics, family background, and many other important factors.

The cochlear implant does not change a deaf person's identity. It is a better hearing device that can provide them with a unique and personal functional hearing system in order to achieve the best outcomes. There are important aspects to consider, however, such as respecting the deaf individual's rights as a deaf person, providing all options and communication methods available, providing opportunities to be part of the deaf culture, and allowing

the deaf individual to decide how to communicate with others. These and other considerations are necessary for a better perspective and more realistic expectations, as well as allowing the deaf individual to find his/her own identity and be part of a world of his/her personal choice.

Cochlear implantation is a difficult decision to make. It requires many changes in the individual's life after surgery and might not be suitable for everyone. Life with a cochlear implant can be a mixed miracle, full of challenges as well as rewards.



A complete article from the parent's point of view will be available in the near future to address issues related to cochlear implants and what parents need to know, before and after, when considering the cochlear implant option for a deaf child.



Save the Date:

December 10

COPE-DB

Holiday Party 2005

Los Angeles Area

Place TBA

COPE-DB Family Picnic Update

Upcoming!

Northern California Family Picnic
Saturday, June 11, 2005
Benicia City Park
Benicia, California



Los Angeles Family Picnic
Saturday, August 27, 2005
Foundation for the Junior Blind
5300 Angeles Vista Blvd.
Los Angeles, California

Once again, families had a great time at this year's L.A. picnic. There were lawn games, swimming, dancing, and lots of great food. Many kids particularly enjoyed the Mattel playground and its multi-sensory experience.

We want to say a HUGE THANKS to Judith Harris and everyone at Junior Blind of America (formerly Foundation for the Junior Blind) for hosting another fabulous picnic event!

Bakersfield Family Picnic
Saturday, October 22, 2005
10 a.m. – 3 p.m.
Hart Park, Group Picnic Area #8
Bakersfield, California

Join us for the annual Bakersfield picnic at a new location this year: beautiful Hart Park, which is famous for its wild peacocks. Bring the whole family for games, prizes, lunch, and quality time with other COPE-DB families.

To R.S.V.P. for the Bakersfield picnic, or for more information about the event, contact Jackie Kenley at CDBS (800-822-7884, extension 3).



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California Deaf-Blind Services *reSources*

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