TSBVI TETN #35064: The Importance of Early Identification of Deafblindness in Babies

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Presented by

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Developed by

Texas School for the Blind & Visually Impaired Outreach Programs
DEFINITION OF DEAFBLINDNESS

Texas Deafblind Census

(A) meets the eligibility criteria for auditory impairment and visual impairment;

(B) student with a visual impairment and has a suspected hearing loss that cannot be demonstrated conclusively, but speech/language professional indicates there is no speech at an age when speech would normally be expected;

(C) has documented hearing and visual losses that, if considered individually, may not meet the requirements for auditory impairment or visual impairment, but the combination of such losses adversely affects the student's educational performance; or

(D) has a documented medical diagnosis of a progressive medical condition that will result in concomitant hearing and visual losses that, without special education intervention, will adversely affect the student's educational performance.
NATIONALLY BABIES ARE UNDER IDENTIFIED

Nationally almost twice as many children age 3- to 6-year-old category than 0- to 3-year-old category.

Graph 1 - National demographics for deafblind children birth to 6

IN TEXAS BABIES ARE UNDER IDENTIFIED

2008 Deafblind Census

2008 birthday (0-1 yr) = 6  
2007 birthday (1-2 yr) = 15  
2006 birthday (2-3 yr) = 25

2005 birthday (3-4 yr) = 41  
2004 birthday (4-5 yr) = 29  
2003 birthday (5-6 yr) = 42

Graph 2 - Texas demographics for deafblind children birth to 6
WHY IS EARLY IDENTIFICATION IMPORTANT?

To Help the Child

- Bond with parents/caregivers so they feel safe and secure
- Improve overall development: growth and learning are impaired if the child is stressed
- Improve language/communication outcomes: the loving interactions between the baby and parents is the basis for communication

To Help the Parents

- Bonding and attachment may not occur easily without support due to combined vision and hearing loss and/or the presence of additional disabilities
- Parents play a critical role in their child’s overall development if they know what to do. Understanding all of the child’s challenges helps parents feel competent as they care for their baby
- Parents need support to address the desperation and loss they may feel when they learn their child has both vision and hearing impairments

It is the Law

“A national child count, commonly referred to as the "Census", is conducted on December 1st of each year to supplement OSEP's federal Child Count . . .”
RISK FACTORS FOR SENSORY IMPAIRMENTS

High risk factors for hearing loss
Family history of hearing loss
Prematurity
Facial malformations
Anoxia
Birth trauma/head trauma
Meningitis
Encephalitis
Hypothyroidism
Microcephaly
Congenital viral or bacterial infections (Rubella, CMV)
Ototoxic drugs were used (aminoglycosides, diuretics-lasix, kanamycin, gentamycin)
Jaundice
Rh factor
Recurring Otitis media
Syndromes/hereditary conditions

High risk factors for vision loss
Family history of vision loss
Prematurity
Facial malformations
Anoxia
Birth trauma/head trauma
Meningitis
Encephalitis
Microcephaly
Congenital viral or bacterial infections (Rubella, CMV)
Retinoblastoma
Syndromes/hereditary conditions

RISK FACTORS FOR DUAL SENSORY IMPAIRMENTS

PRE/POST NATAL CONDITIONS

PREMATURITY

Associated Vision Loss
- 4.3% of the premature infants have serious visual defects
- Optic atrophy, refractive errors and cataracts
- Optic atrophy associated with severe cerebral palsy

Associated Hearing Loss
- Sensorineural deafness from hypoxia and hyperbilirubinemia
ACQUIRED CONDITIONS

DIRECT TRAUMA TO THE EYE AND EAR

Associated Vision Loss
- Retinal detachment from an accident
- Cataracts and glaucoma
- Scotomas (blind spots in the field of vision)

Associated Hearing Loss
- Displaced ossicular chain
- Perforation of the eardrum
- Temporal bone fracture from a severe blow to the ear or head

SEVERE HEAD INJURY

Associated Vision Loss
- Visual perceptual deficits; Field cuts; Nystagmus
- Blindness; Decreased acuity; Scotoma
- Optic nerve atrophy
- Retinal detachment

Associated Hearing Loss
- Tears in the eardrum/displacement of the bones in the middle ear
- Damage to the inner ear
- Damage to the auditory nerve or portion of the brain which receives/interprets messages

INTRAVENTRICULAR HEMORRHAGE (IVH)

Associated Vision Loss
- Cortical Visual Impairment

Associated Hearing Loss
- Central Auditory Processing Disorder

ASPHYXIA

Associated Vision Loss
- Cortical Visual Impairment

Associated Hearing Loss
- Central Auditory Processing Disorder
PERIVENTRICULAR LEUKOMALACIA (PVL)

Associated Vision Loss
- Cortical Visual Impairment

Associated Hearing Loss
- Central Auditory Processing Disorder

TUMORS

Associated Vision Loss
- Retinoblastoma is a cancerous (malignant) tumor which develops from an immature retina

Associated Hearing Loss
- Tumors may also result in conductive or sensorineural hearing losses

POST HEMORRHAGIC HYDROCEPHALUS (PHH)

Associated Vision Loss
- Cortical Visual Impairment
- 50% moderate or severe impairment by age 5

Associated Hearing Loss
- Central Auditory Processing Disorder
- 50% moderate or severe impairment by age 5

INFECTIONS

MENINGITIS

Associated Vision Loss
- Cortical Visual Impairment

Associated Hearing Loss
- Hearing loss occurs in approximately 10% of bacterial meningitis
- Hearing loss may be present in one or both ears
- Damage to the eighth cranial nerve
- Deafness may occur
**ENCEPHALITIS**

Associated Vision Loss
- Blindness and visual impairments

Associated Hearing Loss
- Sensorineural loss may result

**CONGENITAL INFECTIONS**

**SYPHILIS**

Associated Vision Loss
- Astigmatism
- Chorioretinitis (an inflammation of the retina and choroids area)
- Iridocyclitis (inflammation of the iris and ciliary body)
- Glaucoma
- Optic atrophy may be present

Associated Hearing Loss
- Sensorineural

**TOXOPLASMOSIS**

Associated Vision Loss
- Mild vision loss to blindness
- Chorioretinitis (an inflammation of the retina and choroids area)
- Retinal detachment
- Cataracts
- Retinal necrosis

Associated Hearing Loss
- Sensorineural present at birth or develop later
- Degrees of hearing loss varies including profound hearing loss

**RUBELLA**

Associated Vision Loss
- Cataracts
- Abnormalities to the cornea, iris, ciliary body and retina
- Glaucoma
- Microphthalmus (small eyes)
• Ocular motor disorders
• Severe refraction errors, especially myopia
• Common to have acuity worse than 20/200

Associated Hearing Loss
• Sensorineural loss is the most common long term problem
• May involve only one ear
• Degree of hearing impairment varies
• Hearing loss may develop over time and be progressive

**HERPES**

Associated Vision Loss
• Optic nerve atrophy (wasting away of the optic nerve)
• Retinitis (inflammation of the retina)
• Inflammation, lesions, and cloudiness of the cornea (keratitis)
• Retinal detachment
• Cataracts
• Strabismus
• Visual Field Deficits

Associated Hearing Loss
• High risk for hearing loss

**CYTOMEGALOVIRUS (CMV)**

Associated Vision Loss
• Retinitis (inflammation of the retina)
• Optic atrophy
• Anophthalmia (absence of the eyeball)
• Coloboma
• Iridocyclitis
• Photophobia (intolerance of light)

Associated Hearing Loss
• Sensorineural
• Hearing loss ranges from mild to profound
• Occurs in both ears and may be progressive
HEREDITARY SYNDROMES

DOWN SYNDROME
Associated Vision Loss
- Problems in visual acuity (nearsightedness and farsightedness)
- Strabismus (crossed eyes)
- Keratoconus (cone shaped cornea)
Associated Hearing Loss
- Moderate hearing loss
- Conductive hearing losses from recurrent middle ear infections

TRISOMY 13
Associated Vision Loss
- Micophthalmia (abnormally small eyes)
- Colobomas (fissures) of the iris
- Retinal dysplasia (abnormal development of retinal tissue)
- Cataracts
Associated Hearing Loss
- Varying degree of loss

USHER SYNDROME
Associated Vision Loss
- Retinitis Pigmentosa
- Night blindness
- Visual loss in the peripheral fields
- Blindness may not occur until middle or late adult life
Associated Hearing Loss
- Congenital hearing loss
- Severe to moderate loss in both ears
- High frequency loss is typical
ALSTROM SYNDROME

Associated Vision Loss
- Nystagmus with sensitivity to light
- Blindness from retinitis pigmentosa
- Progressive vision loss by age seven nearing total blindness
- Mild to moderate cataracts in the teen years
- Glaucoma and dislocated lens

Associated Hearing Loss
- Mild sensorineural hearing loss occurs in both ears around seven to ten years
- Progressive loss occurs later in life

CHARGE SYNDROME

Associated Vision Loss
- Coloboma
- Visual field and acuity losses (often occurring in the upper field of vision)
- Total loss of vision will be present if anophthalmos (absence of the eyeball) occurs
- Microphthalmus (small eyes)
- Optic nerve hypoplasia (defective development of optic nerve)
- Cataract, retinal detachment, nystagmus
- Disorders of refraction and ocular movement

Associated Hearing Loss
- Sensorineural loss and structural deformities in the outer ear
- External ear abnormalities
- Chronic otitis media (middle ear infection)
- Varying degree of loss

GOLDENHAR SYNDROME

Associated Vision Loss
- Stigmatism
- Coloboma of the eyelid, iris or choroids
- Cataracts, nystagmus, strabismus, and retinal detachment
- Central visual pathway abnormalities
Associated Hearing Loss

- Physical malformation of the ear
- External ear canal absent or narrowed
- Abnormalities in the middle ear
- Abnormalities in the inner ear
- A mixed loss may be present as well
- Hearing loss in one ear

Compiled by Gigi Newton Winter 2008
For those most important people: PARENTS

Suggestions and Activities to Try With Infants and Toddlers with Dual Sensory Losses

Compiled by Gigi Newton, Early Childhood Consultant
Texas Deafblind Project, Fall 2008

As a parent of a child with dual sensory losses, please always remember you are a parent first. Your first and foremost responsibility is to lovingly hold and touch your baby. No matter what you and your baby have been through medically and emotionally, you must convey love and trust to your child. This is a must for all mammals to develop and be emotionally secured so they can learn new information. The power of loving touch is underestimated by our culture in the United States. Research has proven that bonding and attachment must be in place for overall development to occur. If trust and attachment does not happen, it can break down all areas of development. I’m referring to the development of physical growth, emotional well-being, and communication.

INFORMATION COMPiled TO SUPPORT MY BELIEF:

Development Through Relationships: Entering the Social World
Speech held at the World Conference on Deafblindness. Lisbon 1999 by Jan van Dijk (Prof Dr. The Netherlands.) In co-operation with Barbara McLetchie, Cathy Nelson & Isabel Amaral

“Through the technique of the Strange Situation, it has become clear that 35% of children all over the world have already built up such a negative model of insecure attachment. It can be assumed that this percentage is far higher when it comes to children with impairments. Broesterhuizen estimates that no more than 25% of deafblind children have a secure bond with their mother. There is hope that in the future, increasing numbers of deafblind children will have a more favourable
start in their lives as educators are becoming aware of the uniqueness of the world of the deafblind.”

You may read this entire article by linking to http://nationaldb.org/ISSelectedTopics.php?topicID=69&topicCatID=7

Sense of Touch
Author unknown, quoted from the following web site: http://www.iloveindia.com/parenting/senses/touch.html

Babies and even newborns have keen sense of touch and they recognize emotions through touch. While hugs and kisses can soothe a baby or make him happy, any hurtful experience can shake him thoroughly. Here are some ways where importance of ‘touch’ can be clearly seen in infants:

Babies love to feel with their hands and fingers and may use their mouths too for further exploration. So, at about 4 months of age, they put almost everything they can get their hands on, in their mouths. Babies love to touch and feel books, toys and other things with variety of textures. New textures can be challenging and exciting to them. Older babies can also differentiate between rough and smooth textures and contrast of textures.

Little accidents such as banging their head against the legs of the table may be hurtful but it teaches the baby, the importance of limits and to keep away from things that are sharp or hot or may hurt them. Newborns, just out of their mother’s womb, feel secure and snug in the warm and soft baby blankets or tucked in wraps and swaddling can soothe them almost immediately.

The Sense of Smell
By Emily Grantner
http://whalonlab.msu.edu/Student_Webpages/Babies/Emily
An hour after birth, a newborn can locate his mother's nipple by smell. Within two weeks, a baby can recognize the scent of its mother’s milk and distinguish it between stranger's milk. This scent can also provide reassurance to infants. To soothe your crying infant, you can try placing a cloth diaper that you have put on your shoulder to burp him with next to his head in the crib. This is a reminder to the infant of you and can put your baby asleep fast.

For the infant or toddler who doesn’t like being touched or doesn’t enjoy having the body in different positions here are some of Gigi’s favorite topics for you to review:

**Assessment of Biobehavioral States and Analysis of Related Influences**
This is a super article written by Stacy Shafer and Millie Smith. For children with profound disabilities, it is important to assess their biobehavioral state before planning intervention. [http://www.tsbvi.edu/Outreach/seehear/archive/biobehav.htm](http://www.tsbvi.edu/Outreach/seehear/archive/biobehav.htm)

**The Happiest Baby on the Block**
Written by Dr. Harvey Karp.
Dr. Harvey Karp is a nationally renowned pediatrician and child development specialist. He is an Assistant Professor of Pediatrics at the UCLA School of Medicine. Over the past 30 years, he has taught thousands of parents the techniques he describes in his books and videos.

Try to get a copy of Dr. Harvey Karp’s video or DVD “The Happiest Baby on the Block.”

If you visit his website you can see clips of “The Happiest Baby on the Block” and read reviews of his book by following this link. [http://www.thehappiestbaby.com/](http://www.thehappiestbaby.com/)

**Bonding and Relaxation Techniques (BART)**
This is a modified touch or massage technique develop for parents and uses an individualized care plan. The founder of BART, Evelyn Guyer,
RN, BSN, CE, took specific massage techniques and modified them for the parents of children with sensory losses.

Evelyn retired in 2006, but remains as a special consultant to the Foundation. Please direct any inquiries about BART to the new Director, Lisa Davis, at http://www.infantmassagefoundation.com/bart.html.

BART can have benefits for both the parent and the child. It is something the parent does with their child and not to their child.

**Possible benefits for the child who receives daily massage**

- Creates bonding/attachment between the child and parent
- Stimulation of the respiratory systems
- Stimulation of the circulatory systems
- Stimulation of the gastrointestinal systems
- Speeds myelination of the brain / nervous system
- Provides psychological benefits
- Provides relaxation for the child and parent
- Enhances interaction and communication

**Possible Benefits for the Parent Who Gives Their Child Daily Massages**

- Helps the parent to read the child’s signals and cues
- Helps the parent relax
- Builds the parent's confidence (this is extremely important to empower parents)
- Parents know that this becomes a positive/constructive time
- It is fun for the parent (this gives parents fun time and during our world's hectic schedule we need all this we can get!!!!!!!!)

**For BART training in Texas, contact:**

Stacy Shafer, Vision Consultant for Outreach, Early Childhood
stacyshafer@tsbvi.edu
512-206-9140

or

Gigi Newton, Texas Deafblind Project, Early Childhood
Active Learning Theory

For the infant or toddler with little physical movement or who does not explore their environment, I recommend reading “Active Learning and the Use of the Little Room” by Lilli Nielsen.

For more information about Lilli Nielsen and the official site for her materials visit the following link:
www.lilliworks.com

Articles on Active Learning on the TSBVI website

- An Introduction to Dr. Lilli Nielsen's Active Learning  
  http://www.tsbvi.edu/Education/vmi/nielsen.htm
- Active Learning and the Exploration of Real Objects 
  http://www.tsbvi.edu/Outreach/seehear/winter04/active.htm
- Incorporating Active Learning Theory into Activity Routines 
  http://www.tsbvi.edu/Outreach/seehear/winter06/learning.htm
- What my Daughter Taught me About Active Learning— or, Whose Goal is it Anyway? 
  http://www.tsbvi.edu/Outreach/seehear/fall06/active.htm
- Five Phases of Educational Treatment Used in Active Learning Based on Excerpts from Are You Blind? By Dr. Lilli Nielsen 
  http://www.tsbvi.edu/Outreach/seehear/spring04/phases.htm
- Taking a Look at the FIELA Curriculum: 730 Learning Environments by Dr. Lilli Nielsen 
  http://www.tsbvi.edu/Outreach/seehear/fall05/fiela.htm

Suggestions for Resonance Board Activities

- Allow the child to play alone on the resonance board with favorite objects. Don’t interrupt his/her actions with chatter or comments, unless the child takes a break.
- Play with your child on the resonance board offering and exploring objects and mimicking his/her actions.
- Place your child’s Little Room on Resonance Board and let him/her quietly explore while you observe his/her exploration patterns. Remember, don’t interrupt the exploration by talking.

How to make a Resonance Board

The Resonance Board
Developed by Lilli Nielsen

The resonance board is made from 4 mm plywood, 150 cm x 150 cm. Along the edge of the underside attach a wooden strip 2 cm x 2 cm. IT IS VERY IMPORTANT TO APPLY THE STRIP ALONG THE EDGE AND THAT THE STRIP IS NOT WIDER THAN 2 CM. Using American lumber products by a 4 ft. x 8 ft. sheet of ¼ inch plywood (paneling) and cut it to 4 ft. x 4 ft. or 4 ft. x 6 ft. Cabinet quality Birch plywood is recommended. For the lip under the plywood buy a 1 x 2 and have it custom cut to 2 cm (approximately ¾ in.). Please note that only one piece of plywood is used. The bottom of the resonance board is open. The scraps of plywood can be used to make a small resonance board or low tables.

If the board is correctly made the sounds which the child produces on the sounding board will be transmitted through the wood to all parts of the child’s body which are in contact with the board. The sounds will have a prolonged and reinforced effect which is important to motivate increased activity by the child. The weight of the child will cause the board to bend downwards slightly. This will make beads and balls roll back toward the center when the child’s body movements move them towards the edge of the board. This is an example of the prolonged reaction to the child’s activities.

The air space under the resonance board has an insulating effect on a cold floor. Because of its flexibility, children and adults do not become tired from sitting on the board.

The child will have an opportunity to develop an understanding of space by learning about the limited space which the resonance board
represents. When the child starts to move about on the board he/she will develop a good basis for motivation to use the space beyond the resonance board. This will allow him/her to start moving from place to place.

When using the resonance board for the first time, an adult should sit on the board with the child between her legs. The adult plays with objects to make small sounds on the board. When the child initiates communication with the adult (by looking at the adult, changing body position, etc.) the adult responds by talking softly about their play. The adult limits talking to the child to times when the child is not actively engaged in learning. The adult continues to make sounds which are a little louder and by and by moves the child’s body directly on to the board. Not until then, when you have made sure the child feels secure and is made to feel at home in the situation, do you start putting objects around the child, under his hands, feet and head. By observing the child’s reactions you will be able to decide how long the session should last, when the child is able to lie on the board alone and for how long.

Check these websites out!!!
http://www.nationaldb.org/ISModules.php
Developed by Washington Services for Disabilities Services and Washington State Services for Children with Deaf-Blindness
The movies on the DVD are designed to introduce or review specific techniques or concepts ("effective practices").

- Actions Speak Louder Than Words
- Little Room Adaptations
- Materials for Active Learning

[http://www.dblink.org/lib/topics/modules.htm](http://www.dblink.org/lib/topics/modules.htm)

These videos are also available from Teaching Research Publications on a single DVD that can be played on a computer or home DVD player. Cost: $5.00 per DVD (includes shipping).

To order by mail, phone, or email:
Teaching Research Publications
Attn: Lisa Wilson
345 N. Monmouth Ave.
Monmouth, OR 97361
503-838-8786
wilsonl@wou.edu


Hold Everything! Twenty Stay-Put Play Spaces for Infants, Preschoolers, and Developmentally Young Children with Sensory Impairments and Other Special Needs  Kay L. Clarke  Cost: $18.00

A booklet based on a workshop by the same name sponsored by The Ohio Center for Deafblind Education. The goal of this booklet is to provide parents and early childhood educators with 20 initial ideas for developing "stay-put" play spaces for infants and young children with sensory impairments and other special needs.

Remember to make use of all senses as your child can tolerate them. This includes: Touch, Smell, Taste, Hearing and Vision. Your child may have trouble using multiple senses at one time. You may want to talk to your occupational therapist and/or physical therapist to get ideas how to help. Your teacher of the visually impaired and/or teacher of the deaf and hard of hearing may also have good suggestions.
HELP YOUR CHILD USE RESIDUAL VISION AND HEARING

Parents must be observers and read their child’s body, as this is their communication to you. Parents need to work closely with their teacher of the visually impaired and teacher of the hearing impaired. Teaming will ensure the child is using their visual and hearing sense to their fullest functional ability.

The following link from Vision Associates has a great video clip. The Power of Vision Testing shows the difference for a little one when they put glasses on the child.
http://www.visionkits.com/
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 whenever 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 crumple 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 "Good" Communication**

Early communication development is based on four ideas:

1. Developing a close and trusting relationship with your child
2. Using consistent daily routines in which your child is fully involved
3. Providing your child with cues so he or she can learn to anticipate what is going to happen

4. 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.

Deborah Gleason is the Regional Coordinator for Asia/Pacific Programs for the Hilton/Perkins International Program at Perkins School for the Blind. She has many years experience as a Vision and Deafblind Teacher/Consultant with young children, and served as a national trainer for the VIISA Project at Utah State University. She teaches regional, national and international seminars on assessment and family-centered intervention for young children with visual impairment, deafblindness, and multiple disabilities.

Special thanks to Marianne Riggio for her suggestions and input. Marianne is an Educational Consultant with the Hilton/Perkins Program and has many years experience teaching infants and children who are deaf-blind.

ADDITIONAL RESOURCES

Orientation and mobility activities for parents to use with their infants and toddlers who are visually impaired.

Developmentally supportive care is a method of caring for fragile infants who are not yet able to regulate their physiological, motor
or state systems. The strategies include supportive environments, pacing and timing, transition support for new environments and situations, supportive movement, handling and positioning, and supporting sleep wake cycles.


Presents information about assessment and intervention strategies for infants and young children (birth to 36 months) who have visual impairment in addition to other disabilities, including deaf-blindness. Includes: a description of early intervention services, recent research about brain development, early developmental needs, the importance of caregiver interactions, early identification including a discussion of conditions associated with multiple disabilities, functional vision assessment, hearing loss assessment including functional hearing assessment, and interventions that focus on early communication. AFB Press, Customer Service, P.O. Box 1020, Sewickley, PA 15143, (800) 232-3044, (412) 741-0609 (fax).


Describes the work of interveners in early intervention and educational settings for children and youth who are deaf-blind. A discussion of issues, concepts, and terminology associated with interveners and the role they play is provided. Available from DB-LINK.

This article provides an overview of the following topics: the effects of deaf-blindness on development, causes of deaf-blindness, and early screening and assessment strategies. It addresses hearing and vision evaluation, developmental and cognitive assessment, educational and communication assessment, and genetic evaluation.


Young children with major auditory and visual impairments are identified as “deaf-blind.” They have unique communication, developmental, emotional, and educational needs that require special knowledge, expertise, technology, and assistance. This article is intended to introduce professionals from a variety of disciplines to current practices and important considerations in intervention with infants and young children who are deaf-blind.


Discusses 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. Includes information on cueing, and selecting and using first key word signs for the infants’ expressive communication.

Position Paper on Services to Young Children with Visual Impairments and Deafblindness in Natural Environments: Executive Summary. Miller, Tom; Bernas-Pierce, Julie. (2005). The purpose of this paper is to promote specialized groups as a service option within Natural Environments law and implementation in order to enhance the development and support the families of
children with visual impairments, birth to three. A longer version of this paper is also available: http://www.perkins.org/downloads/NatEnvirMonograph.pdf.

Promoting Learning Through Active Interaction: A Guide to Early Communication with Young Children Who Have Multiple Disabilities. Klein, M. Diane, Ph.D.; Chen, Deborah, Ph.D.; Haney, Michele, Ph.D. Baltimore: Paul H. Brookes Publishing Co., 2000. The Promoting Learning through Active Interaction (PLAI) curriculum is designed primarily for infants, preschoolers, and young children with severe or multiple disabilities (including deaf-blindness) who are not yet initiating symbolic communication and who have a limited repertoire of communicative behavior. It can also be used with older children who have not yet developed intentional communication.

Tactile Strategies for Children Who Have Visual Impairments and Multiple Disabilities: Promoting Communication and Learning Skills. Chen, Deborah; Downing, June E. New York: AFB Press, 2006. This book is designed to help service providers and family members learn to interact through touch with children who need tactile information to support their learning. Topics include: the sense of touch, supporting interactions though touch, assessing tactile skills and planning interventions, focusing on tactile strategies, considering multiple communication options, adapting manual signs to meet a child’s needs, selecting appropriate tactile strategies, and encouraging emergent literacy. Cost: $39.95. Available from AFB Press. Phone: 800-232-3044. Publisher’s web site: http://www.afb.org

PROGRAMS

State Deaf-Blind Projects, Services for Children with Deaf-Blindness Programs. U.S. Department of Education, Office of Special Education Programs - Projects assist states in assuring the provision of technical assistance to agencies and education
personnel serving children and youth who are deaf-blind. They support research, development, replication, pre-service and in-service training, parental involvement activities, and other activities to improve services to children who are deaf-blind. For information concerning particular state projects and contacts. Contact DB-LINK, (800) 438-9376, TTY: (800) 854-7013, Fax: (503) 838-8150, info@nationaldb.org http://nationaldb.org/peoplePrograms.php

Hilton/Perkins Program, Perkins School for the Blind - Hilton/Perkins program provides consultation, training and technical assistance to programs throughout the nation and in developing countries. Emphasis is on program development for multi-handicapped blind and deaf-blind infants, toddlers and school-aged children.

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National Early Childhood Technical Assistance System [NEC*TAS] - NEC*TAS is a consortium project intended to design and provide technical assistance for four primary target populations—Part C Staff, Interagency Coordinating Council members and staff, Part B-Section 619 staff, and Early Childhood project staff. Assists target populations in developing and providing comprehensive, culturally sensitive, and coordinated services for young children with special needs and their families.

Frank Porter Graham Child Development Center
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137 E. Franklin Street
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(919) 962-2001 E-mail: nectas@unc.edu
National Family Association for Deaf-Blind [NFADB] - NFADB is a national network of families focused on issues surrounding deaf-blindness. As a national organization, NFADB advocates for all persons who are deaf-blind, supports national policy to benefit people who are deaf-blind, encourages the founding and strengthening of family organizations in each state, provides information and publishes a newsletter.

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National Consortium on Deaf-Blindness [NCDB] NCDB is a national technical assistance and dissemination center for children and youth who are deaf-blind.

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http://nationaldb.org/
http://www.tsbvi.edu/Outreach/seehear/fall04/deafblind.htm


Newton, Gigi, 2008. For those most important people; PARENTS Suggestions and Activities to Try with Infants and Toddlers with Dual Sensory Losses, handout.


Texas Deafblind Census, 2009.

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