The Kansas Deaf-Blind Project

www.kansasdeafblind.kssdb.org

32nd Annual KDEC Conference
February 27, 2014

Presenters: Rebecca Obold-Geary & Megan Cote
Co-Directors of the Kansas Deaf-Blind Project
roboldgeary@kssdb.org
mcote@kssdb.org

The Kansas Deaf-Blind Project

* A Federally Funded 5 Year Grant (we are currently in year 1)
* Based at the Kansas State School for the Blind in KC, KS

Our Mission:
To identify & serve learners with Deaf-Blindness & their families in the state of Kansas.

Intro to Deaf-Blindness:

DEAF-BLINDNESS does NOT imply that an individual sees or hears absolutely nothing.

DEAF-BLINDNESS simply means that the individual experiences both a vision and a hearing loss, to some degree.
Key Questions:

Two key questions to ask, when assessing whether a learner has DB:

1. Does she have enough vision to compensate for her lack of hearing?
2. Does she have enough hearing to compensate for her lack of vision?

(John McInnes)

Deaf-Blindness is a disability...

- about INFORMATION GATHERING
- which LIMITS ACCESS
- which is EXPONENTIALLY MORE than a hearing loss plus a vision loss

Deaf-blindness...

- affects two of a learner’s three DISTANCE SENSES and
- necessitates that she use IMPACT SENSES (i.e., taste, touch, kinesthetic) to gather information
Types of “Information Gathering” (i.e., LEARNING)

- Direct learning
- Secondary learning
- Incidental learning

***REMEMBER***
Deaf-blindness is a disability about information gathering!

*** Remember***
Partnering with a learner with deaf-blindness involves...
INVITING THE CHILD (ADOLESCENT) “OUT,” to join you in the world, and to build levels of connections with her
Here are some stats...

In the United States, over 10,000 children and youth (birth - 22 years) experience deaf-blindness.

- Of this 10,000, approximately 5% experience total deafness and total blindness
- But approximately 91% of these 11,000 children and youth also experience additional disabilities

Etiologies of DB

In general, children might be at risk for having combined vision and hearing losses, due to a:
- hereditary syndrome or disorder
- pre-natal condition
- post-natal condition
- family history
- head injury or direct trauma to ear / eye
- prematurity

Categorizing DB

1. by time(s) of onset of sensory loss
2. by degrees / types of sensory loss
3. BOTH—by time(s) of onset and degrees of sensory loss

By far, the best predictor of an individual learner’s needs / skills is the #3 model of categorization.
Remember:
Learners who have deaf-blindness are an incredibly heterogeneous group!

LEARNER NEEDS
A learner who has deaf-blindness needs to...
- understand CONCEPTS through MORE THAN ONE sensory /communicative mode
- have the opportunity to learn and interact in an ENHANCED CONTEXT, in order to know what is going on around her

LEARNER NEEDS
Deaf-blindness requires a learner’s partners to take time to...
- plan how a learner will RECEIVE information in every activity
- plan what a learner will DO in every activity
- consider the IMMEDIATE physical, visual, and auditory ENVIRONMENTAL CONTEXTS of every activity
LEARNER NEEDS
When you meet a person who has DB...
- treat her as you would anyone else
- address her directly, not through an interpreter, intervener, or anyone else
- let her know who you are, and when you enter / leave the room
- use the words, “see,” “hear,” and so on naturally
- describe things that are happening, or are about to happen
- remember that behaviors affect attitudes!

LEARNER NEEDS
When communicating with a person who has DB...
- be in close proximity to her (yet respectful)
- alert her that a communicative interaction is about to begin or end
- use multi-modal communication
- wait for her to respond
- provide choices, in order to allow her some control

GENERAL CHARACTERISTICS
Learners with DB often demonstrate:
- inconsistent responses to sounds or visual images (i.e., use of remaining skills)
- a distorted perception of the world, due to lack of non-distorted information from the distance senses
- balance problems
- delays in motor development
- tactile sensitivity or defensiveness
- an overactive startle response
GENERAL CHARACTERISTICS (con’t.)
- difficulty interacting with things in the environment in a meaningful way
- difficulty in communicating with people in a meaningful way
- difficulty in establishing / maintaining inter-personal relationships
- difficulty in generalizing information
- light gazing
- stereotypy (fear, confusion, sensory deprivation)

CHARACTERISTICS RELEVANT TO LEARNING
It is important to remember that learners who have DB often:
- lack the ability to anticipate events
- are deprived of many of the most basic extrinsic motivations (i.e., curiosity); sensory info is so distorted it is ineffective as a source of motivation to explore and interact with people and the environment
- will not benefit from being left alone, for long periods of time, with toys / materials

CHARACTERISTICS RELEVANT TO LEARNING (con’t.)
- cannot benefit from incidental or secondary learning, but must be taught through direct instruction
- cannot independently learn from mistakes, because she is unable to correctly understand the results of her actions
- may not benefit from group instruction, alone, because she cannot learn from watching and listening to others
- The best way to informally gauge cognitive skills is by observing the way she “remembers”
LEARNERS WITH DB

Almost always experience...
- feelings of vulnerability
- more security / safety in a seated position
- lengthier periods of time, learning to trust others / the world
- challenges counteracting boredom

And...
- perceive time very differently
- respond positively to enhanced textures
- find it difficult to interpret movement
- fatigue more rapidly than same-aged peers
- demonstrate increased tactile sensitivity, particularly around the face

SUMMARY

A child with deaf-blindness is NOT
- a “deaf child” who cannot see or
- a “blind child” who cannot hear

Deaf-blindness is a unique and complex disability!
SUMMARY

Learners who have deaf-blindness are an incredibly heterogeneous group!

The Kansas Deaf-Blind Project
www.kansasdeafblind.kssdb.org

KS DB Family Specialist:
Dinell Smith breeesmother@gmail.com

KS DB Project Directors:
Rebecca Obold-Geary- roboldgeary@kssdb.org
Megan Cote- mcote@kssdb.org

How does the Kansas Deaf-Blind Project provide support?
• Provide free TA in the school & in the home.
• Provide parent scholarships for training- to attend conference(s). Project SPARKLE.
• Provide state-wide trainings & district trainings
• Intervener training scholarships @ USU.
• Family weekends.
• Partner with Families Together to offer trainings.
• Facebook page.
• Parent-to-Parent Mentorship.
• Distance Mentorship.
• Access to free on-line training modules related to Deaf-Blindness.
Kansas Deaf-Blind PROJECT

vs.

Deaf-Blind FUND

**Project:**
Federally Funded
Based at Kansas State School for the Blind

**Fund:**
State Funded
Based at KSDE under Joan Houghton
One of only 2 states in the country to have such an allocation.

Kansas Deaf-Blind FUND

If a child is on the Deaf-Blind Registry, the educational team can apply for materials to support the learner—up to $3,000 annually.

This is done through Joan Houghton at KSDE or her assistant, Cynthia Penrod.

Applications are submitted in the Spring.

If I suspect that I have a learner with Deaf-Blindness, what do I do?

- Go to www.kansasdeafblind.kssdb.org
- Download the application and instructions.
- Mail the application and supporting documents to:
  Kansas Deaf-Blind Project
  Rebecca Obold-Geary
  1100 State Ave.
  Kansas City, KS 66102
- Questions: contact Rebecca Obold-Geary
  roboldgeary@kssdb.org or 913-305-3087
RESOURCES

- National Center on Deaf-Blindness
- Washington Sensory Disabilities Services: Deaf-Blind
- Perkins School for the Blind: Webcasts
- KS DB Library all items free for the asking
- Intervener website: www.intervener.org
- Kansas Deaf-Blind Project Modules.

RESOURCES

East Carolina University has created a number of excellent, web-based modules regarding deaf-blindness.

These are available, *free of charge*, for self-paced learning.
RESOURCES

East Carolina University’s deaf-blind modules can be located at:

mast.ecu.edu/picker.php

Pertinent to this topic, check out:

Students with Deafblindness (left column):
- Introduction
- Developmental Impact
- Educational Implications