2017 Texas Symposium on DeafBlindness
The Forgotten Senses
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The Forgotten Senses: DeafBlindness and Posture

David Brown, DeafBlind Educational Specialist

We are them and they are us
Aren't we all on the very broad spectrum of DeafBlindness???

Slide 3
“Even though it is not totally possible, we must try to step into the experience of our students and how they perceive the world. By doing so, we will find the best ways to communicate together and to create meaningful learning opportunities that will open up the world to them.”
Marianne Riggio DeafBlind International Review #56 January 2016

Slide 4
We must always remember that everything joins up!
Self determination + Sensory perception + Self image + Emotional competence + The attitude & behavior of others + Self regulation + Executive function + Availability for learning + Previous experience + Expectations & Motivators + Communication & language

Slide 5
Most people focus on the child’s disabilities, but close attention to their abilities can reveal more about the difficulties they face as well as the strategies they use to function effectively.

Assessment Questions
D Brown, “Follow the Child” (2001)
- How do you feel?
- What do you like?
- What do you want?
- What do you do?

Slide 7
Everything that children with DeafBlindness do has meaning, and the first obligation on the teacher is to ascertain that meaning (or at least to come up with a really good guess).

Slide 8
Working with children with DeafBlindness teaches you that everything is much more complicated than it seems.

Slide 9
Remember the uniqueness, low incidence, and complexity of DeafBlindness

Slide 10
The changing nature of the population of children with DeafBlindness
Slide 11
DeafBlindness involves many more senses than just vision & hearing, and it is not enough only to consider the tactile sense as a compensatory channel.

Slide 12
DeafBlindness increasingly involves problems with the perception of:
- Vision
- Hearing
- Touch
- Proprioception
- Temperature
- Pain
- Vestibular
- Smell
- Taste

Slide 13

Figure 1 Graphic showing Pyramid of Learning (Williams & Shellenberger, 104): a pyramid shape representing the central nervous system. The levels of the pyramid from bottom to top include: Sensory - Systems, Sensory Motor - Development, Perceptual Motor - Development, Cognitive - Intellectual
“The Forgotten Senses”

**PROPRIOCEPTION**

- The receptors are in the muscles and joints throughout the body
- Tells us about the position of our body and all of our limbs, and if anything is moving

**VESTIBULAR**

- The receptors are in the Inner Ears
- Tells us about head position & the pull of gravity, detects head movement, and has very close links with the eyes and vision

**The Proprioceptive Sense**

- Helps us to plan, position, and grade our movements without looking to see what we are doing.
- “An awareness, or a feeling, of one’s own self”.
- One specialized aspect of the complex sense of touch, like a kind of ‘internal touch’.
- Receptors of this sense respond to the stretching or compression or twisting of joints and muscles.
- Keeps our brains constantly aware of the position of all our body parts, and also tells us if they are moving or not.

![Figure 2 Two photos of David: on the left David is raising his left hand over his head while touching his nose with his right hand. In the second photo David holds both hands over his head and touches his right index finger to his left thumb.](image-url)
Causes of Pediatric Vestibular Disorders

- Head/neck trauma
- Chronic ear infections
- Maternal drug/alcohol abuse
- Cytomegalovirus infection
- Meningitis
- Migraine
- Metabolic disorders (e.g., diabetes)
- Ototoxic drugs
- Posterior brain tumor
- Neurological disorders (cerebral palsy, Hydrocephalus)
- Genetic syndromes (e.g., Wallenberg, Usher, CHARGE)
- Family history of vestibular issues
- Cochlear implants
- Lack of use - movement issues, fear, ill health

Dr. George Williams “Balance in CHARGE” CHARGE Syndrome Foundation Manual

Vestibular function has a role in…

- Detecting motion
- Detecting & responding to gravity
- Providing stability during body movement
- Locating body parts & developing body schema
- Influencing muscle tone and posture

Dr. George Williams “Balance in CHARGE” CHARGE Syndrome Foundation Manual - continued

- Facilitating the crossing of the midline
- Motor control, coordination & sequencing
- Assisting with auditory & visual perception
- Modulating arousal & alertness for attention and calming

Vision and the Vestibular Sense

The Vestibulo-ocular Reflex

In normal head movement the eyes move in the opposite direction of the head, and at the same speed, to stabilize the retinal image (VOR)
Self-stimulation (1)
- The senses connect the brain to the body
- Sensory inputs have a significant & direct impact on arousal levels
- Many children with DeafBlindness are not in touch with/ do not feel their bodies very well
- We all self-stimulate (all the time?) to maintain alertness, to wake up, to calm down, to maintain postural control, to keep/ get comfortable, to occupy our minds, to self-regulate, to fight boredom, to maintain attention, to keep sane, and generally to improve our functioning to achieve our goals

Self-stimulation (2)
- Sensory deficits and poor sensory perception make children with DeafBlindness self-stimulate in mostly normal ways – but often with more intensity, more persistence, and for a longer period of their lives than “normal”
- For various reasons children with DeafBlindness may have poor social awareness, so self-stimulation behaviors may be more obvious
- Attempts to stifle and stop self-stimulation behaviors may result in worse self-regulation and generally less good functioning
- Observing how and when a child self-stimulates will offer invaluable insights into who they are and how they work, for assessment, teaching, behavior management, and relationship building

Slide 23
I believe that posture should be included as a “self-stimulation” and a “self-regulation” behavior

Slide 24
[Self-regulation]… “is defined as the capacity to manage one’s thoughts, feelings and actions in adaptive and flexible ways across a range of contexts”
Jude Nicholas, CHARGE Accounts, Summer 2007

Self-Regulation
- Managing the threshold of arousal
- Processes of self-control
- Both suppressing & encouraging, and inhibiting & promoting
- Supporting homeostasis of the system
- Critical to development
- Tim Hartshorne

Slide 25
“After air to breathe, postural security is our next most urgent priority.”
- Jean Ayres
Why might movement be difficult? (1)

- Orthopedic issues: Skeletal/ Muscles & tendons/ Brain (ie. Cerebral Palsy)/ Poor quality connective tissue
- Sensory issues: / Blindness/ Deafness/ Vestibular/ Proprioceptive/ Tactile
- Drugs/medication
- Seizures
- Breathing problems
- Nutrition issues (feeding problems, poor absorption of food, low energy, poor bone growth & poor muscle growth)

Why might movement be difficult? (2)

- Stress
- Depression
- Fear
- Low expectations
- Poor awareness/poor motivation
- Distractibility
- A vicious circle – all these issues create movement problems, but also movement problems can compound and exaggerate these issues

Slide 29
I believe that many children with DeafBlindness are not in touch with/ do not feel their bodies very well

Slide 30
“The only function of the body is to carry the brain around”
- Thomas Edison

Slide 31
- Communication with one’s own body
- Communication with one’s immediate environment
- Communication with the wider world

Jean Ayres and the idea of the “Sensory Diet”
We commonly see postures involving…

- the head
- the legs
- bending/stretching
- hanging
- the hands
- planking
- propping
- squeezing
- climbing

Where is my head?

- Head weaving
- Head binding (hat, sweatband, scarf, string)
- Head holding/ tapping
- Head pressing (or head standing!)
- Jaw clenching
- Teeth grinding
- Biting/ chewing

Early mobility

- Rolling
- Side-winding
- Back scooting
- Bottom shuffling
- 5-point crawling
- Regular crawling
Walking

- Walkers
- Rolling gait
- Flat feet/ bent knees
- Foot slapping
- Tip-toe walking
- Feet roll inwards/ knees knock together
- Arms extended to the sides or in front
- Fingers crossed/hands clenched
- Eyes fixed on a visual target ahead

What sensory inputs can the following behaviours provide?

- hand flapping
- rhythmic blowing
- grinding the teeth
- standing & spinning
- rubbing things on the head
- sitting & rocking
- playing with saliva/poop

Slide 38
Once a child’s sensory needs and preferences has been established, how can this information be used in teaching them?

Why is all this so important, and why should we be observing for it?

- To understand the child’s challenges
- To gain a more accurate idea of the child’s needs
- To appreciate the child’s adaptive behaviors
- To be able to introduce the essential child to other people

Why is all this so important, and why should we be observing for it?

- To be aware of the fundamentally important things which often get overlooked or forgotten
- To remember that everything the child does takes more time, more planning, more energy, more concentration, and more attention, than it does for other children
- To realize that things that look crazy might really be functional and clever adaptations
What helps? (1)
- Activities which improve muscle tone and controlled movement and reinforce the body/brain connection (eg. Tai Chi, yoga, climbing, dancing)
- Deep pressure inputs (jumping, massage, swimming
- Binding (eg. spandex pressure vest)
- Good physical support & appropriate postures for efficient functioning

What helps? (2)
- Variety in postures and movement
- Rest periods for re-organization
- Controlled environments
- Self-taught and taught strategies
- Strategies that are motivational
- Appropriate vocabulary (for body parts, for physical feelings, for emotional states, for desired activities)

So....?????
- Getting the brain in better contact with the body for improved postural security
- Preparation for attending and learning
- Stabilizing the visual field
- Self-regulating
- Alleviating physical discomfort/pain (constipation, opening airway, etc)
- The importance of sensory inputs, positioning, & posture/movement

Slide 44
Observing how and when a child self-stimulates will offer invaluable insights into who they are and how they work, for assessment, teaching, behavior management, and relationship building

Slide 45
If it isn’t dangerous or illegal, ask “What does it mean?”, and then intervene to try to answer that question, NOT to stop the behavior as the primary aim
So what am I saying today???

- We all self-stimulate for very good reasons
- The multi-sensory perspective is crucially important
- Sensory issues inspire and initiate behaviors, then social meaning is acquired later
- The concept of the sensory diet can provide us with insightful and powerful strategies
- Sensory needs and sensory inputs control attentional priorities
- Notice posture and movement requirements!
- These things apply to all of us
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Figure 3 TSBVI logo.

Figure 4 IDEAs that Work logo and OSEP disclaimer.

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