Deafblindness, Self-Stimulation, and Availability for Learning

AER Webinar

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Key principles of Sensory Integration Therapy

- The Just Right Challenge
- The Adaptive Response
- Active Engagement
- Child Directed

Some important concepts

- Sensory modulation, enhancing, inhibition, sensory hierarchies
- Sensory diet, self-stimulation
- Level of arousal

Jan Van Dijk (1966)

"In the educational atmosphere I describe, the child holds the central position, the teacher 'follows' the child and, when the child responds, the teacher is present to answer the child's request"

My take on Jan Van Dijk

- Follow the child
- Observe
- Identify & use motivators
- Time & pacing
- Credit behaviors with meaning
- Respect and seek the opinions of others
- The conversational approach
- The child's preferred modes of communication
- Build relationships

Common to all 3 gurus

- Child focused
- Child led
- Hands off
- Meticulous observation
- Meticulous interpretation
- Focus on guaranteed success (but with a challenge)
- Focus on the child's positive self-image & self-confidence
- Recognition that sensory functioning depends upon many issues
- Opposed to received opinions of the time

We must always remember that everything joins up!

Self determination + Sensory perception + Self image + Emotional competence + Self regulation + Executive function + Availability for learning + Previous experience + Expectations & Motivators + Communication & language + The attitude and behavior of others

Natalie Barraga (1976)

Visual functioning is related in part to the condition of the eye. More explicitly, visual functioning is determined by the *experiences*, *motivations*, *needs* and *expectations* of each individual in relation to whatever visual capacity is available to *satisfy* *curiosity* and accomplish activities for *personal* *satisfaction.*

Most people focus on the child's disabilities, but close attention to their abilities, and to the things that they do, can reveal more about the difficulties they face and the strategies they use to function effectively.

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).

The increasing complexity of deafblindness and the changing nature of the population of children with deafblindness

Personal conclusion after more than 30 years of scientific and practical work

"The multi-sensory impaired person is a unique human being with a unique line of development, who is more dependent on the professional's willingness to accept this and act accordingly than any other group of disabled persons."

Jan Van Dijk (2001). My Own Evolution.
https://nationaldb.org/library/page/1962

Deafblindness involves many more senses than just vision & hearing, and it is not enough only to consider the tactile sense as a compensatory channel.

The brain is connected to the body through the senses

I believe that most children with deafblindness are not in touch with/ do not feel their bodies very well

*Communication with one's own body

*Communication with one's immediate environment

*Communication with the wider world

The Senses

Distance Senses *Near Senses*

- Vision
- Hearing
- Smell
- Taste
- Touch
- Vestibular
- Proprioception

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All the senses are designed to work simultaneously, supporting and confirming each other, but also at times in competition with each other. We have to develop the ability to modulate the information coming from all our senses so that our brains can focus on some sensory inputs while inhibiting and ignoring others, in a constantly shifting pattern. This is known as sensory integration. If one sense is impaired or missing then the other intact senses will become more important and acquire a compensatory role, but initially they will be more challenged. If more than one sense is impaired or missing the task of achieving and maintaining good sensory integration will become increasingly difficult.

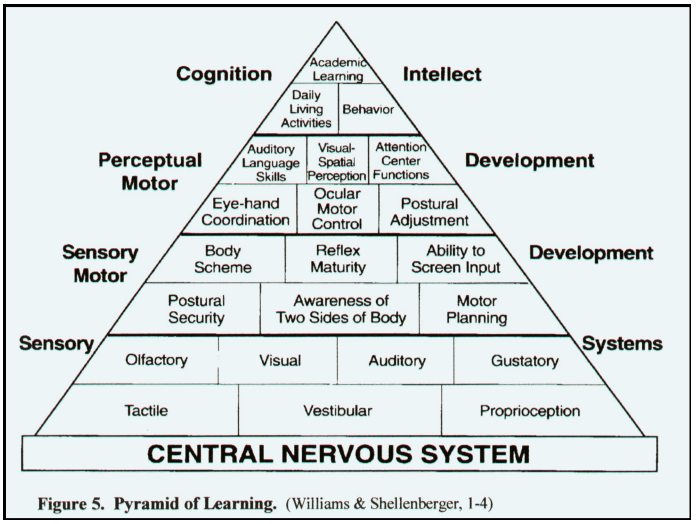

Figure 5. Pyramid of Learning. (Williams & Shellenberger, 1-4)

"When people think about muscular activities, they usually think of things like aerobics, weight-lifting, swimming, hiking, wrestling, and so on, but they rarely think about using vision, even though vision is a sense that depends upon very good control and coordination of many different muscle groups if it is to be used effectively."

David Brown (2010) *Vision Issues for People with CHARGE Syndrome*

Vision drives posture

"The Forgotten Senses"

PROPRIOCEPTION	VESTIBULAR
The receptors are in the muscles and joints throughout the body	The receptors are in the Inner Ears
Tells us about the position of our body and all of our limbs, and if anything is moving	Tells us about head position & the pull of gravity, detects motion, and it 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.

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Why does it go wrong?

- Injury
- Surgery
- Arthritis
- Cerebral palsy & other sorts of brain damage
- Abnormal muscle tone (too stiff or too floppy, or alternations between these two extremes)
- Poor circulation
- Commonly associated with tactile, vestibular, and visual difficulties
- Lack of use

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'….we do know from experience that difficulties with vestibular and proprioceptive functioning, in particular, always need to be addressed first if the children are to make the best possible progress in using touch and residual vision and hearing effectively. Knowing about these 'other' (I would say 'forgotten') senses will give you a different way of looking at yourselves and at other people, and should also help to make children with deafblindness less puzzling in their behaviors.'

D. Brown - DbI Review #38, July-December 2006

When the proprioceptive sense is not working properly one common outcome may be:

Seeking strong pressure, stretching, or twisting inputs, eg. squeezing into tight spaces, crossing or twisting limbs around each other, twisting a foot or a leg around the leg of a chair, binding parts of the body with cloth or string or rubber bands, pulling downwards on the teeth and lower jaw, grinding the teeth, tapping the teeth, hand clapping or flapping, leg swinging or kicking, hanging from a bar, jumping up and down, banging the head, hammering objects, standing on the head.

The vestibular sense….

- tells us about head position & the pull of gravity
- tells us which way is "up"
- detects motion
- links very closely with the eyes and vision, and with proprioception

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

Jean Ayres (1979)
Sensory Integration and the Child

"The vestibular system is the unifying system. All other types of sensation are processed in reference to this basic vestibular information. The activity in the vestibular system provides a framework for the other aspects of our experiences."

Vestibular problems will adversely effect:

- Organization of ALL sensory information
- Postural security and muscle tone
- Use of residual vision
- Perception & processing of sound
- Remembering auditory sequencing
- Memory development
- Speech/Language development
- Behavioral challenges
- Bilateral coordination
- Breathing, feeding, digestion, nutrition
- Sociability
- Self-regulation

How do we achieve balance?

Three separate components make up the "Equilibrium Triad":

- Input from the eyes (vision)
- Input from the muscles and joints (proprioception)
- Input from the vestibular organs (vestibular)

Vision and the Vestibular Sense

The Vestibulo-ocular Reflex (VOR)

In normal head movement the eyes move in the opposite direction of the head, and at the same speed, to stabilize the retinal image

"Children often adopt specific postures (e.g., horizontal with both legs bent and one ankle up crossing the other knee, or legs tightly crossed, or fingers crossed or bunched together, or hands fisted, or arms folded). These postures provide essential extra tactile and pressure information to the brain about where the child's limbs are in space, and also confirms for them that they are securely "fixed" and not moving or floating around."

Brown D, (2005) American Journal of Medical Genetics 133A, pp 269

These postural behaviours have always been present but largely unseen. When they are noticed there is often amusement because the postures seem weird, or the child is corrected with no attempt to understand or recognise or honour what the posture means and what function it serves.

This is normal viewing posture…

…when you have no vestibular sense, upper visual field loss, poor tactile & proprioceptive perception, & low muscle tone.

Before and after walking has been attained 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

You fix the body……
to fix the head……
to fix the eyes……
so you can use your vision in the best, most reliable, and most comfortable way possible.

Functions of these postures

- To locate the body (especially the head)
- To confirm postural security
- To stabilise the body, to stabilise the head, to stabilise the eyes for visual tasks
- To ease the discomfort of chronic constipation
- To open up the airway
- To self regulate

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

*The importance of sensory inputs, positioning, & posture/movement

*Sensory needs and sensory inputs control attentional priorities

*These things apply to all of us

I believe that posture should be included as a "self-stimulation" and a "self-regulation" behavior

"After air to breathe, postural security is our next most urgent priority."

Jean Ayres

In a nutshell, what am I saying?

- Everything joins up – there may be many unsuspected influences at work.
- Functional vision therefore depends upon, and varies in relation to, many things.
- There is a fundamental sensory hierarchy to which we are all subjected.
- Vision is a directional sense so body awareness, postural control, orientation, attention, and stamina are all required (all these are probably compromised by deafblindness).
- We can help to prepare children to use their vision optimally by improving these things.
- With their spontaneous behaviors, especially their postural behaviors, children might be showing us the best way to work with them, the best way to present materials, and the most energy-efficient ways to proceed.

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