

Why self-stimulation is a good thing, and how and why we should interpret it

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My take on Active Learning & Lilli Nielsen

- Hands off
- Focus on self-image & self-esteem as well as skill acquisition
- TIME!
- Close observation of the child
- The concept of changing the environment to help the child to change
- The concept of the Little Room and (especially) the Resonance Board
- The concept of developmental stages in spatial awareness

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

Whose perception counts?

“The brain, the organ that is responsible for your conscious experience, is an eternal prisoner in the solitary confinement of the skull...and must rely on information smuggled into it from the senses...the world is what your brain tells you it is, and the limitations of your senses set the boundaries of your conscious experience.”

Coren, Porac & Ward “Sensation & Perception” (1984, p2)

We don't see with our eyes -
we see with our brains

When you are assessing vision
– don't think 'eyes, think 'child'

We don't hear with our ears -
we hear with our brains

When you are assessing
hearing – don't think 'ears',
think 'child'

Emotion

- Co-ordinates mind and body.
- Organizes.....
- perception
- thought
- memory
- physiology
- behavior
- social interaction

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.

Sensory Issues

- Information may be missing, partial, distorted, or fragmented
- Over-sensitivity &/or under-sensitivity
- Processing time may be very extended
- Confusion & the need for consistency & predictability
- But.....think about consistency versus variety
- Fatigue
- Communication issues (receptive & expressive)
- Movement & postural differences
- Idiosyncratic behaviors & misinterpretation
- Developmental delay

The Senses

Distance Senses Near Senses

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

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The central nervous system plays the key role in receiving information from these senses, in attending to the information or disregarding it, and in seeking it out or avoiding it.

This process of receiving sensory information begins before birth and is quite unique to each individual.

Although every sensory system is unique, there are some fundamental similarities in purpose and function that they all share:

Every sensory system is responsible for conveying information from the environment to the brain for processing

Obstacles to effective processing can include:

- o malformation or damage of the sensory receptors
- o problems with the nerve pathways
- o brain malformations or brain damage

- Each sense is designed to work simultaneously with all the other senses for maximum efficiency
- If other senses are not working properly or are missing, then the senses that are intact will become potentially more important but also more challenged

Information comes in through the sensory systems and is processed for two reasons:

- to make us aware of stimuli in the environment
- to construct “maps of self and environment for organization and planning” [Winnie Dunn]

“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 motion, and it has very close links with the eyes and vision

‘In the field of deafblind education we have traditionally, and for obvious reasons, focused on the senses of vision and hearing and on strategies for improving the use of any residual function that may be present in both of these distance senses. At the same time we have also paid some attention to the sense of touch as an important information channel that can help to compensate for loss of visual and auditory information. The other sensory systems, the taste, smell, proprioceptive, and vestibular senses, have received very little attention from us, even though together they provide the essential foundation upon which all of our higher vision, hearing, and touch skills are based. These other sensory systems also offer valuable channels to the children for learning and to us for teaching.’

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

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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 - Dbl Review #38, July-December 2006

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'This emphasis on the process of learning, rather than just on the acquisition of new skills, fits in well, as Geegee Larrington points out, with the idea that education for children with deafblindness should aim to develop understanding of concepts and not just teach skills. In this way we now see it as more useful to examine a child's problem-solving abilities, their sensory preferences and sensory hierarchies, rather than simply seeking to discover how many manual signs they can understand, or how many steps they can take unsupported, or how many one-inch blocks they can stack - although outside the small world of deafblind education it is still common to find a narrow focus on this unhelpful quantitative view of development.'

D. Brown - "The Sensory Integration Perspective" DbI Review #42, July-December 2008 19

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 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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When the proprioceptive sense is not working properly some common outcomes may be:

- Inability or reluctance to push up on the hands and arms when laying face down due to an inability to “feel” and control the joints in the fingers, wrists, elbows & shoulders.
- Inability or reluctance to stand and bear weight due to an inability to “feel” and control the joints in the toes, ankles, knees & hips, while also maintaining vertical stability in the spine.
- Frequent use of the arms and hands to prop the head/upper body, or leaning against furniture, walls, posts, trees, or other people.

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When the proprioceptive sense is not working properly some common outcomes may be:

- Feet stamped or slapped repeatedly on the floor when cruising or walking to maximize the tactile and proprioceptive sensation (“feeling the feet”).
- Later on, walking tip-toe to maximize the pressure input through the feet, ankles, calves, knees, thighs and buttocks (another way of “feeling the feet”).
- Clumsy, poorly coordinated movements, often with self-taught correction strategies.

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When the proprioceptive sense is not working properly some common outcomes may be:

- Use of too little force, or excessive force when touching, patting, grasping, pushing or pulling things, or lifting and placing things - may often drop objects.
- Seeking strong pressure or stretching 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 body parts with cloth or string or rubber bands, pulling the teeth and lower jaw downwards, 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.

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<http://media.hhmi.org/hl/08Lect3.html>

60 minute lecture on the proprioceptive sense by Dr Tom Jessell

What can we do to help?

- Consult with an Occupational Therapist (preferably trained in Sensory Integration therapy), a Physical Therapist, and an Adapted Physical Education Teacher, and implement their suggestions.
- Deep pressure massage, brushing protocols, and rhythmic joint stretching and compression.
- Use of weighted clothing, heavy blanket across the lap when seated, heavy shoes, heavy bed covers.

What can we do to help?

- Acceptable binding eg. in a blanket, tight gloves, tight socks, spandex clothing.
- Specific exercises to improve proprioceptive awareness.
- Chewing gum or 'chewy' items.
- Hydrotherapy, horse riding, crash mat, climbing frame, trampoline, wrestling.
- Do not judge - respect the child and work to boost their confidence.

The vestibular sense....

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

Vestibular organs

- Located in the bony chambers of the skull in the inner ear
- 3 semi-circular canals positioned in different planes for rotational movements
- Otoliths (Utricule and Saccule) for linear accelerations

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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

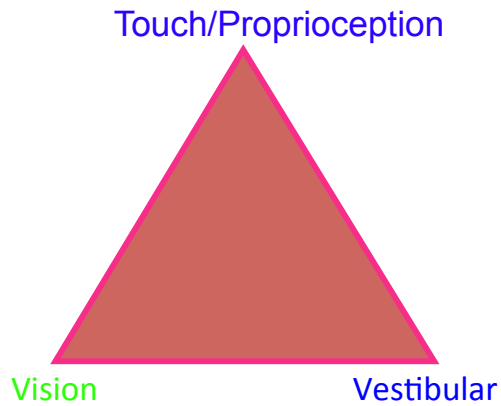
How do we achieve balance?

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)

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The Equilibrium Triad



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A Redundancy for Balance

[Brain and Spine Foundation Online](http://www.brainandspine.org.uk)

http://www.brainandspine.org.uk/information/publications/brain_and_spine_booklets/dizziness_and_balance_problems/index.html

When one of the three parts of the Equilibrium Triad does not work or work well, the other two can compensate.

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

Jean Ayres

Vestibulo-ocular Reflex (VOR)

- Normal head rotation: eyes move in opposite direction of head to stabilize retinal image (VOR)
- Conflicting sensory information from visual and vestibular senses is a problem

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This is normal viewing posture...

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

“Sensory Integration” means...

1. A neurological process
2. A theory developed by Jean Ayres
3. A treatment approach developed from Ayres’ theory

Jean Ayres defines Sensory Integration (1989)

“..the neurological process that organizes sensation from one’s own body and from the environment and makes it possible to use the body effectively within the environment. The spatial and temporal aspects of inputs from different sensory modalities are interpreted, associated, and unified. Sensory integration is information processing...The brain must **select, enhance, inhibit, compare, and associate** the sensory information in a flexible, constantly changing pattern; in other words, the brain must integrate it.”

Ayres’ theory

That the environment has a crucial impact on brain development, that the brain changes in response to external stimuli, and that experiences resulting from sensory inputs and the child’s responses to them affects brain development.

Key principles of S.I. therapy

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

SENSORY INTEGRATION ISSUES

- Extreme sensitivity (or under reaction) to touch, movement, sights, or sounds
- Distractibility
- Social and/or emotional problems
- Activity level that is unusually high or unusually low
- Physical clumsiness or apparent carelessness
- Impulsivity, or lack of self-control
- Difficulty making transitions from one situation to another
- Inability to unwind or calm one's self
- Delays in speech, language, or motor skills
- Delays in academic achievement

[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 suppresses & encourages, and inhibits & promotes
- Supports homeostasis of the system
- Critical to development

Supporting self-regulation

- Because self-regulation skills are hard for children with significant & complex disabilities to develop
- We have to provide the external support for what will become an internal self-regulatory process

Managing the threshold

- With a regulatory disorder, the child is challenged to manage
 - Cognitive – motivated vs. unmotivated
 - Behavior – hypoactive vs. hyperactive
 - Emotion – reactive vs. passive
 - Physiological – overload vs. underload
- These can be related to problems with executive function: initiate, sustain, inhibit, shift, complete.

Some important concepts

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

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What is 'self-stimulation' ?

- The constancy of sensory feedback.
- Any sensory input that we seek which is not directly the result of a specific activity (such as making coffee, drinking from a glass, getting dressed, walking).
- Any sensory input that we seek which facilitates an activity but is not an inherent part of it.

My take on Jean Ayres & Sensory Integration theory & Therapy (1)

- The constancy & inter-relatedness of sensory inputs
- The senses connect the brain to the body
- Sensory inputs have a significant & direct impact on arousal levels
- Some senses may be more important than others
- Most children with deaf-blindness are not in touch with/do not feel their bodies very well

My take on Jean Ayres & Sensory Integration theory & Therapy (2)

- 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
- Sensory deficits and poor sensory perception make children with deaf-blindness self-stimulate in mostly normal ways – but often with more intensity, more persistence, and for a longer period of their lives than “normal”

My take on Jean Ayres & Sensory Integration theory & Therapy (3)

- For various reasons children with deaf-blindness 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

The 9 levels of arousal
(Carolina Record of Individual Behavior)

- Uncontrollable agitation
- Mild agitation
- Fussy awake
- Active awake
- Quiet awake
- Drowsy
- Active sleep
- Quiet sleep
- Deep sleep

1. Where are you on the ladder of arousal?

2. Where do you need to be?

3. How can you get there?

Using the ladder

- ❖ Fewer steps
- ❖ Individualized vocabulary
- ❖ Words/ symbols/ pictures
- ❖ Re-visiting/ social stories
- ❖ Role play
- ❖ What do you like/need?

Self-Regulation

Can we help the individual to recognize and deal with excessive levels of over-arousal or under-arousal, in socially acceptable ways? If self-regulation is difficult, can the individual learn ways of asking for help?

Jobs for us

- “Reading” (ie. observing & interpreting)
- Making connections
- Helping the individual “feel” their body
- Providing an increasingly precise vocabulary of emotions/states
- Directing the individual’s attention
- Reminding the individual of strategies
- Matching/sharing experiences & feelings

Yes, I believe that posture should be included as a “self-stimulation” and/or a “self-regulation” behavior (especially for people with CHARGE syndrome)

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

This is not easy!

- Learning to read behaviour can be challenging and it takes TIME to get it right
- Recognising and interpreting subtle behaviour requires keen powers of observation and interpretation

Remember

- Behaviour tells you something. It can be a form of communication (if you wish)
- Children with multiple disability may struggle with their ability to self-regulate, and their behaviour may be their attempt to manage
- Multiple disability and sensory integration problems can significantly impact the child's perception and understanding of the world.

Finally

- Do not attempt to change a child's behaviour until you understand what it means and why the child is engaging in it.
- Do not try to eliminate a behaviour until you have an alternative to replace it with that will serve the same function.
- Endeavour to make sure that the child knows that you know what they are communicating.
- Always respect communication

What sensory inputs can the following provide?

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

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

In my work with children with CHARGE I am always thinking about their "sensory comfort" and their "sensory confidence".
