

Availability for Learning: The Forgotten Senses

David Brown
Deafblind Educational Specialist
April 3rd 2018

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.

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).

One of the most important
early assessment questions
we can ask the child is:
“What do you do?”.

“What can you do?” comes
later.

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

It is hereby certified that

David Michael Brown

was admitted to the Degree of

Bachelor of Philosophy

(*Special Education: Multi-Sensory Impairment*)

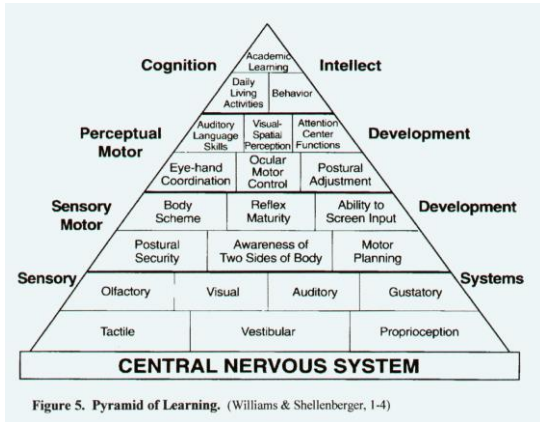
on the ninth day of July 1991

Congenital deafblindness increasingly involves problems with the perception of:

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



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.



'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 - DbI 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 - DbI 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" Dbl Review #42, July-December 2008

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"But if one observes, one will see that the body has its own intelligence; it requires a great deal of intelligence to observe the intelligence of the body."

Jiddu Krishnamurti



The sense of smell (the olfactory sense)

*some children are anosmic – they have no sense of smell

*some children show no awareness of smell even though the sensory system is intact and working

*some children give evidence that smell is an important sensory input for them

*the usefulness of sensory channels like smell and taste might be increased as long as the inputs coming through them are consistent, clear, and meaningful for the child

The sense of smell

*The sense of smell is unique – unlike all our other senses it sends information directly to the limbic system in the brain without any preliminary sorting by the thalamus

*So smell is the sense that puts our brains into the most direct contact with the environment

*Smell can quickly and vividly evoke strong emotions and powerful memories

*The first cranial nerve (the olfactory nerve) responds to unique identifying smells (eg. ginger, orange, cut grass). The fifth cranial nerve (the trigeminal nerve) responds to other aspects of smells (eg. heat, coldness, spiciness, sharpness, sweetness)

Loss of smell can be caused by:

- Advancing age
- Nasal and sinus disease
- Upper respiratory tract infection
- Brain trauma or damage to the cranial nerves 1 or 5
- Neurodegenerative diseases (eg. Alzheimer's disease)
- Certain medications
- Specific damage to the olfactory bulb

Working with the sense of smell

- Strengthen existing smells if possible
- Draw attention to the smells in a way that helps to connect the smell with the upcoming activity
- Use activities that will encourage the child to seek out smells more consciously and deliberately
- Remember that smells remain perceptible for a long time
- Also remember that the sense of smell tires, and the nose begins to lose its sensitivity after exposure to 3 or 4 different smells in succession
- The deliberate introduction of new smells should be done consistently and appropriately after careful deliberation

The 5 taste groups

- **Sweet** – carbohydrates such as sugars (for direct energy) and glycogen (for storage of energy)
- **Salt** – important for absorption of water into the blood
- **Sour** – especially in fruit (generally more appealing to children than adults)
- **Bitter** – (eg. coffee, cocoa, olives, cabbage, dandelion, chicory, quinine. Many bitter compounds are toxic to humans)
- **Umami** (or Savory) – proteins (amino acids)

The sense of taste (the gustatory sense)

- Taste drives our appetite and protects us from poisons
- Taste is closely linked to the sense of smell
- Multiple neural pathways transmit taste information to the brain, so total loss of taste is rare
- Previous visual, auditory, tactile, and smell experiences it can become attached to taste sensations and memories, and so stimulate strong taste anticipatory expectations
- Smell and taste are the two 'chemical' senses
- Between 75% and 90% of what we think of as "taste" is actually a combination of temperature, texture, and (mostly) smell sensations



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".
- The 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

When the proprioceptive sense is not working properly some common outcomes may be (1):

- 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 (2):

- 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 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 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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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

Sensory Diet



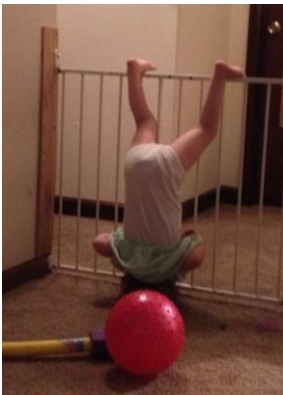
















What can we do to help?

- 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.



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

60 minute lecture on the
proprioceptive sense
by Dr Tom Jessell
Columbia University

“The body teeters on the edge of
catastrophe”

Vestibular problems and their
implications for children
with deafblindness

David Brown
Deafblind Educational Specialist

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The vestibular sense....

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

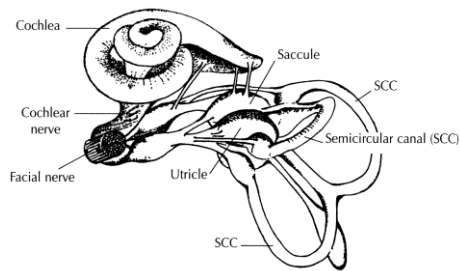


Figure 6.2. The vestibular system. (From Coleman, J.R. [Ed.]. Copyright © 1990. This material is used by permission of Wiley-Liss, Inc., a subsidiary of John Wiley & Sons, Inc. *Development of sensory systems in mammals*. New York: John Wiley & Sons, p. 343.)

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.”

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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 Type 1, CHARGE)
- Family history of vestibular issues
- Cochlear implants
- Lack of use - movement issues, fear, ill health

Vestibular problems may adversely effect:

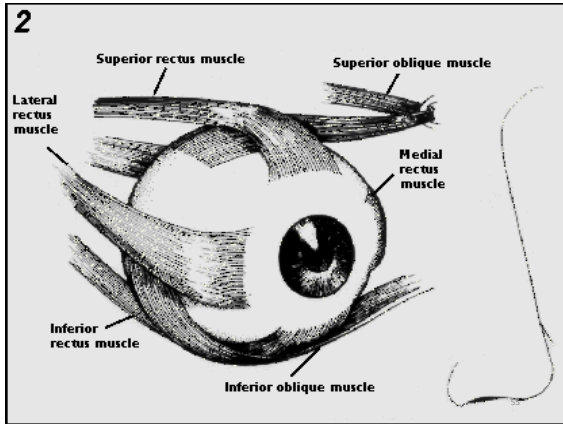
- Organisation of ALL sensory information
- Postural security and muscle tone
- Use of vision
- Reception & processing of sound
- Remembering auditory and visual sequencing
- Memory development
- Speech & language development
- Bilateral coordination
- Behavior
- Breathing, feeding, digestion, nutrition
- Sociability
- Self-regulation

Vision and the Vestibular Sense

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“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*

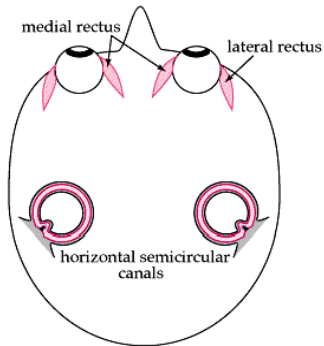


Vision drives posture

The vestibulo-ocular reflex (VOR)

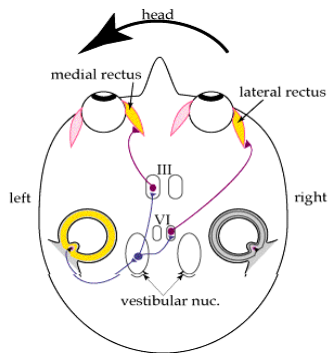
In normal head movement the eyes move in the opposite direction to the head, and at the same speed, to stabilize the retinal image

The Vestibulo-ocular Reflex (1)



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The Vestibulo-ocular Reflex (2)



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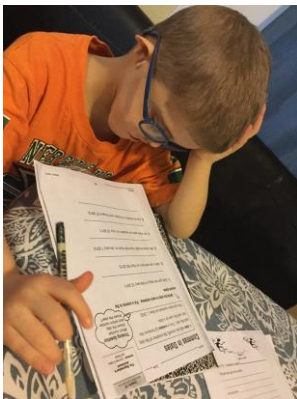












Where is my head?

Head weaving

Head binding (hat, sweatband, scarf, string, sock, bucket, box)

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.

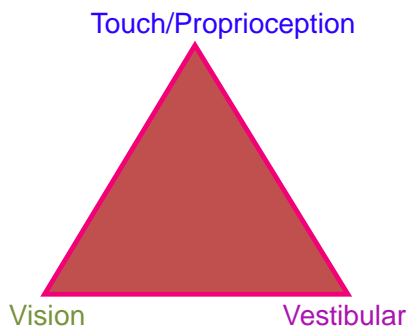
How do we achieve balance?

Three separate sensory systems
 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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From Jean Ayres
"Sensory Integration and the Child"

"When the vestibular system does not function in a consistent and accurate way, the interpretation of other sensations will be inconsistent and inaccurate, and the nervous system will have trouble 'getting started.'"

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From Carol Stock Kranowitz
"The Out-of-Sync Child"

"Gravitational insecurity is manifested by abnormal distress and anxiety in reaction to falling or the possibility of falling. It is a primal fear."

"Indeed, our need to know where we are in relation to the earth is more compelling than our need for food, for tactile comfort, or even for a mother-child bond."

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Dr George Williams "Balance in CHARGE"
CHARGE Syndrome Foundation manual

Vestibular function has a role in:

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

Dr George Williams "Balance in CHARGE"
 CHARGE Syndrome Foundation manual (cont.)

Vestibular function has a role in:

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

Early effects of poor vestibular function in children with CHARGE syndrome

David Brown, American Journal of Medical Genetics March 2005

- Low muscle tone ("floppy muscles")
- Poor head control, and poor ability to resist gravity
- Strong postural insecurity when held upright or carried around
- Marked preference for being flat on the back
- Delayed mobility and unusual movement patterns (eg. back-scooting, side-winding, butt-scooting, rolling, 5-point crawl)
- 'W' sitting for broader, more secure base, and to free up the hands
- Better visual, auditory, and fine motor skills in supine than in the upright position
- Poor bilateral coordination, with hand and eye dominance either total or missing
- Fatigue after trying to resist gravity for periods of time

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

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

Jean Ayres

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Early mobility

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

5-point crawl



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





This is normal viewing posture...

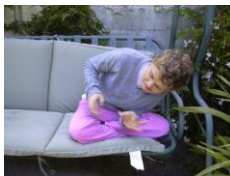
...when you have
no vestibular
sense, upper
visual field loss,
poor tactile &
proprioceptive
perception, & low
muscle tone.



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What can we do to help?(1)

- Respect compensatory behaviors as functional, and help the child to make their own choices. Do not attempt to remove these compensatory behaviors until their function has been established.
- Suggest Occupational Therapy (preferably trained in Sensory Integration therapy) and a Physical Therapy evaluation, and implement the therapist's suggestions.
- Pace activities to facilitate optimal functioning and to minimize fatigue and stress.



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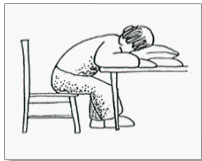
What can we do to help?(2)

- Work that improves the functioning of other sensory channels can help to ameliorate the impact of vestibular difficulties.
- Handle younger children to minimize stress (eg. use anticipation cues, use appropriate speed & direction of movement, provide physical support for head and limbs).



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What can we do to help?(3)



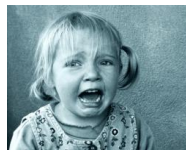
- Always make appropriate physical support available & encourage the most effective postures for functioning
- Allow periods of movement or repose, as appropriate, for reorganization of the whole body and all its sensory systems.



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What can we do to help?(4)

- Isolate lines of text (eg. large font on screen, typoscope).
- Observe for indications of under-arousal or over-arousal and know what to do about it (if the child cannot do this themselves).
- Think about the total demands made on the child by every activity in every situation (ie. think multi-sensory).



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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)


“The only function of the body is to carry the brain around”

Thomas Edison

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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



5 Lessons in Life from Dr. Seuss

1. Today you are You, that is truer than true. There is no one alive who is Youer than You.
2. 'Why fit in when you were born to stand out?
3. You have brains in your head. You have feet in your shoes. You can steer yourself any direction you choose.
4. Be who you are and say what you feel, because those who mind don't matter and those who matter don't mind.
5. Today I shall behave, as if this is the day I will be remembered.

*Communication with one's own body

*Communication with one's immediate environment

*Communication with the wider world

"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.















So, what am I saying today?

- Everything joins up – there may be many unsuspected influences at work.
- Sensory functioning therefore depends upon, and varies in relation to, many things.
- There is a fundamental sensory hierarchy to which we are all subjected (remember the Pyramid of Development).
- 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 and hearing 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.

...and what else am I saying today?

- *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 power and the importance of sensory inputs, positioning, & posture/movement
- *Sensory needs and sensory inputs control and determine attentional priorities
