**Availability for learning for children with multi-sensory impairment**

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**Presenter Challenges**

* Theory of practice?
* Form and content
* Depth of focus and exclusion
* Breadth of focus and inclusion
* Range of age and ability

**Proposition 1**

That deafblindness includes the most complex conditions that we know, and the unique combination of true multisensory impairment with multiple other anomalies (some of them potentially life threatening) can lead to extreme variability in functioning and periods when the child may be unavailable for attending and learning.

**Proposition 2**

That the right educational program for each child with deafblindness never already exists but must be created. The program must be fitted to the child, not the child to the program.

**Proposition 3**

That a successful & appropriate educational program begins, and depends upon, skilled assessment which is flexible, on-going, and sensitive. Every child with deafblindness can be assessed successfully provided the people doing the assessment know what they are doing.

**Proposition 4**

That anyone responsible for designing and delivering a child’s educational program needs some familiarity with deafblindness which is kept up to date. With the increasing amount of information about deafblindness now available this is perfectly feasible.

**Sensory Diet**

**My take on Lilli Nielsen and Active Learning**

* Hands off
* Focus on self-image and 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 idea of the Little Room and (especially) the Resonance Board

**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

**My take on Jean Ayres**

* The theory of sensory integration
* The idea of sensory modulation, enhancing, and inhibiting
* The idea of observing children closely to see which sensory inputs they seek and which they avoid
* From her successors (especially Pat Wilbarger), the idea of the sensory diet
* The connection between sensory inputs and levels of arousal

**Key principles of Sensory Integration Therapy**

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

**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

**Deafblind Strategies**

* Follow the child!
* Know the child!
* Individualise!
* Do with not for!
* Create conversations!
* Use a multi-sensory perspective (for assessment & teaching)!

Supporting Availability for Learning: Student-Centered Biobehavioral Assessment and Intervention for Children and Youth with Deafblindness/ Multiple Disabilities

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**Availability for learning**

* Arousal level/ bio-behavioral state
* Assessment
* Self-regulation / self-stimulation
* Internal and external factors
* Medical issues(health, energy, pain, nutrition, meds)
* Motivation/ meaning
* Previous experience
* Sociability
* Communication
* Current range of expressive behaviors
* Being understood
* TIME!

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

**Complexity**

* Size of the population
* Multiple etiologies
* Range of vision and hearing loss, and of ability
* Neurological issues
* Variable functioning
* Multiple additional anomalies
* Medical issues & priorities
* Many specialists needed/involved
* Scarcity of professionals skilled in assessment and teaching
* Technology (medical, sensory & educational)

**NCDB National Child Count 2019**

<https://www.nationaldb.org/products/national-child-count/report-2019/>

* Total 11,335 children
* Many different etiologies (CHARGE is the biggest with 1033, CMV, hydrocephaly, microcephaly, birth asphyxia, meningitis, head injury, “complications of prematurity” (1050)
* 87% of children have at least one additional disability (eg. orthopedic, cognitive, behavioral, complex health care needs, speech & language impairments) and 42% have 4 or more additional disabilities.

**21 CHARGE issues which can contribute to fatigue**

* Visual impairment
* Hearing impairment
* Vestibular dysfunction
* Poor proprioceptive perception
* Poor tactile perception
* Low/high muscle tone
* Skeletal malformations
* Breathing problems
* Poor nutrition
* Anaemia
* Hypoglycaemia
* Hypothyroidism (slow metabolism, low energy)
* Sleep problems
* Heart problems
* Constipation
* Gastro-intestinal issues
* Migraine
* Dental issues
* Joint pain (growth related?)
* Seizure disorder
* Medications
* Poor self-regulation

**We must always remember that in reality**

**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 + etc

**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.

**We don’t see with our eyes - we see with our brains**

When you are assessing functional vision – don’t just think ‘eyes’, think ‘child’

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).

**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>

**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.

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

**Deafblindness/Multi-sensory impairment**

**Congenital deafblindness increasingly involves problems with the perception of:**

* + Vision
	+ Hearing
	+ Touch
	+ Proprioception
	+ Temperature
	+ Pain
	+ Vestibular
	+ Smell
	+ Taste



Figure 1 Pyramid Graph of Central Nervous System (Pyramid of Learning, Williams & Shellenberger, 1-4)

“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 Proprioceptive Sense**

* + Helps us to plan, position, and grade our movements without looking to see what we are doing.
	+ The word means “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.

**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.

**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.

**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.

**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

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.

**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



Figure 2 Labeled image of the Vestibular System (From Coleman, J.R. [Ed.]. Copyright 1990)

**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.”

**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

**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 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.

**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.**

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

Jean Ayres (1979) - Sensory integration and the child

This is normal viewing posture…

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



Figure 3 Image of a child laying upside down with his head hanging over the front of a couch.

**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

**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, through any sensory channel, that we seek which facilitates our functioning

**My thoughts about sensory inputs & self-stimulation (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 to us than others at certain times
* Most children with deafblindness are not in touch with (or do not feel) their bodies very well

**My thoughts about sensory inputs & self-stimulation (2)**

* We all self-stimulate to maintain alertness, to wake up, to calm down, to maintain postural control, to get/keep 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 deafblindness self-stimulate in mostly normal ways – but often with more intensity, more persistence, and for a longer period of their lives than “normal”

**My thoughts about sensory inputs & self-stimulation (3)**

* 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

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

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

**“Exploring executive functioning”-Amanda Kirby**

* + Activation – organizing & prioritizing, initiating, getting started
	+ Focus – sustaining & shifting, completing
	+ Effort – regulating alertness
	+ Emotion – managing frustrations, modulating emotions, keeping perspective
	+ Memory – remembering, accessing recall, recognizing & remembering a sequence
	+ Action – monitoring & regulating self-action without impulsivity, or poor context or poor pacing

**So, what am I saying (about all of us)?**

* + 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

We know that external factors in the environment can have a profound impact on a child’s behaviour, so one way we can modify what the child is doing is to change features of the environment.

**Key elements in the environment**

* + People
	+ Time
	+ Space

Tony Best (Juli 1998) Structuring the Environment. DbI Review,4‐9

**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 (eg. jumping, massage, swimming)
	+ Binding (eg. spandex pressure vest)
	+ Good physical support & appropriate postures for efficient functioning

**What helps? (2)**

* + Variety in postures and movement (eg. horse riding)
	+ 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)

**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

**Teaching Strategies**

* + Individualization
	+ Relationships
	+ Stress Control
	+ Positioning & support
	+ Motivators
	+ Pacing
	+ Consistency
	+ Routine-based
	+ Adaptations
	+ Appropriate communication/ language
	+ The Just Right Challenge

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