“Self-regulation and self-stimulation: The Emotional Heart of the Child”

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Congenital deafblindness increasingly involves problems with the perception of:

- Vision
- Hearing
- Touch
- Proprioception
- Temperature
- Pain
- Vestibular
- Smell
- Taste
The central nervous system plays the key role in receiving information from these senses, in identifying it, in attending to it or disregarding it, and in seeking it out or avoiding it.

This process of receiving sensory information begins before birth and is unique to each individual. After a normal pregnancy a newly born baby already has experience of processing sensory inputs, and regulating their own arousal levels.
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:
- malformation or damage of the sensory receptors
- problems with the nerve pathways
- 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
Jean 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.
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
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
KEEP CALM AND FINGERS CROSSED
I believe that posture should be included as a “self-stimulation” and/or a “self-regulation” behavior.
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.
Urgency of intervention questions

Observe, record, analyse, and discuss the behavior to try to interpret it, then answer these questions in increasing order of urgency for intervention:

1. Is this a behavior that just bugs you personally, so that it can be accepted and ignored?
2. Is this a behavior that seems to help the child to function in a positive way, so that it can be accepted and ignored?
3. Is this a behavior that seems to help the child to function in a positive way, but could be reduced, or replaced by another better behavior?
4. Is this a behavior that is undesirable and needs to be reduced or replaced over time?
5. Is this a behavior that needs to be prevented immediately?
What helps the body/brain connection? (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 the body/brain connection? (2)

- Variety in postures and movement
- Rest (or activity) 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)
What is stress for?

- Stress helps us to work out and try to deal with the many challenges that life presents to us.
- If it is time limited then it is a normal, indeed an essential, process.
- It protects us from harm and it also helps us learn to protect ourselves.
- Without it we would fail to acquire many vital life skills.
- Helps us to take risks and build skills.
What is stress for? (Continued)

- Helps us learn how to cope, and how to remain calm but alert (known as self-regulation)
- Provides opportunities for acquiring a memory bank of successful strategies
- Helps to develop effective problem-solving abilities
- Keeps life interesting
- Provides motivators (eg. walking independently & unsupported, jumping off the couch, watching a horror film, mountaineering, giving a conference presentation)
“You should relax less.”
When, and why, can stress be bad?

- Stress should be time limited to be helpful. Extended periods of stress result in stress hormones remaining active in the body for too long, and they can cause damage to the body.
- The developing infant brain is especially at risk.
- Prolonged stress can result in blood pressure problems, heart disease, diabetes, depression and associated self-abuse, poor memory, and a range of other mental health issues.
- Inability to deal with stress effectively leads to feelings of helplessness, and may keep an individual in a state of hyper-arousal or hypo-arousal.
“Excessive Stress Disrupts the Architecture of the Developing Brain”
Protective Factors (from Cathy Nelson)

- Secure attachment
- Good physical health
- Strong social network
- Responsive environment
- Feelings of competence
- Clear patterns of arousal & relaxation
- Physical exercise
- Relaxation opportunities
- Temperamental characteristics
Key concepts in understanding social and emotional development

• Feeling safe, secure, and understood makes successful learning possible
• The adult-child relationship is the key to the child’s resilience
• Physiological, emotional, and behavioral resilience is the key to development
• Nurturing care-giving provides genuine dialogue for the development of attachment & mastery of self-regulation
• Brain research shows that lack of “goodness of fit” may lead a child to be prone to distress and to increased regulation problems
“Goodness of fit” (1)

It is critical to brain development, secure attachment, and eventual self-regulation of emotions and behavior
“Goodness of fit” develops if…(2)

the child can demonstrate their physiological and emotional needs, and familiar people can note and respond to these needs.
Occurs naturally if the adult has learned to read and respond to the infant’s cues, and if the adult’s current life circumstances are not overwhelming and provide the necessary social, emotional, and economic support.
Risk factors

- The child’s temperament is intense, cues are sporadic, resistant, or inconsistent
- The above may lead to increased sensitivity, proneness to distress, and self-regulation issues
- Neurological and sensory difficulties may interfere with attachment
- Multiple issues result in altered social and behavioral competencies in both infant and adult
- Social and environmental issues impinge on the infant-adult duo’s ability to interact in typical ways
<table>
<thead>
<tr>
<th>Why are you thinking?</th>
<th>Was I bone?</th>
<th>Why I go to school?</th>
<th>Why are you laughing?</th>
<th>Why are I good?</th>
</tr>
</thead>
<tbody>
<tr>
<td>I play with my friends.</td>
<td>I was ill.</td>
<td>I have a new friend.</td>
<td>I am happy.</td>
<td>I am sad.</td>
</tr>
</tbody>
</table>
Stress

- What does it look like?
- What makes it happen?
- When does it happen?
- What helps?
- Try a Personal Passport kind of approach
“Self-regulation may be defined as the capacity to manage one’s own thoughts, actions, feelings and physiological states in adaptive and flexible ways across a range of contexts. Self-regulation involves both the initiation and maintenance of behavioral change in addition to inhibiting undesired behaviors or responding to situational demands.”

Jude Nicholas (2017) Hartshorne, Nicholas “Self-Regulation in Individuals with CHARGE Syndrome” DbI
Well-regulated and poorly-regulated
Self-Regulation in Individuals with CHARGE Syndrome

Timothy S. Hartshorne and Jude T. Nicholas

DbI
DEAFBLIND INTERNATIONAL
www.deafblindinternational.org
The authors propose a four-dimensional model of self-regulation:

- Self-regulation of Cognition
- Self-regulation of Behavior
- Self-regulation of Emotion
- Physiological self-regulation
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.

Tim Hartshorne
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?
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
Key principles of Sensory Integration Therapy

1. The Just Right Challenge
2. The Adaptive Response
3. Active Engagement
4. Child-directed
Sensory Dysfunction & Young Children

• Attention & Regulatory Disorders
• Sensory defensiveness
• Activity Levels (Disorganized, Immobile, Repetitive/Stereotypical, Clumsy, Over-exciteable, Needing strong sensory inputs)
• Behaviors
The specific objectives of Sensory Integration Therapy are:  (Karen Nagel)

- Achievement of an alert, calm state
- To promote the organization of the Central Nervous System
- To enhance the child’s ability to regulate and adjust the sensations from their environment
- To increase conceptual development
Assessment Questions
D Brown “Follow the Child” (2001)

- How do you feel?
- What do you like?
- What do you want?
- What do you do?
Characteristics of self-determination include the following:

✓ An awareness of personal preferences
✓ The ability to set goals
✓ The ability to use the skills one possesses to achieve goals
✓ The ability to evaluate progress toward a goal and learn from experience
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?
Remember (after Hartshorne)

• Behaviour offers you a message, so it can be a regarded as a form of communication (if you wish)

• Children with complex multiple disability may have great difficulty with their ability to self-regulate, and their behavior may be their attempt to manage

• Multiple disability and sensory integration problems can significantly impact the child’s ability to self-regulate
Finally (after Hartshorne)

• 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 something to replace it with that will serve the same function.
• Try to make sure that the child knows that you know what they are communicating.
• Always respect communication.