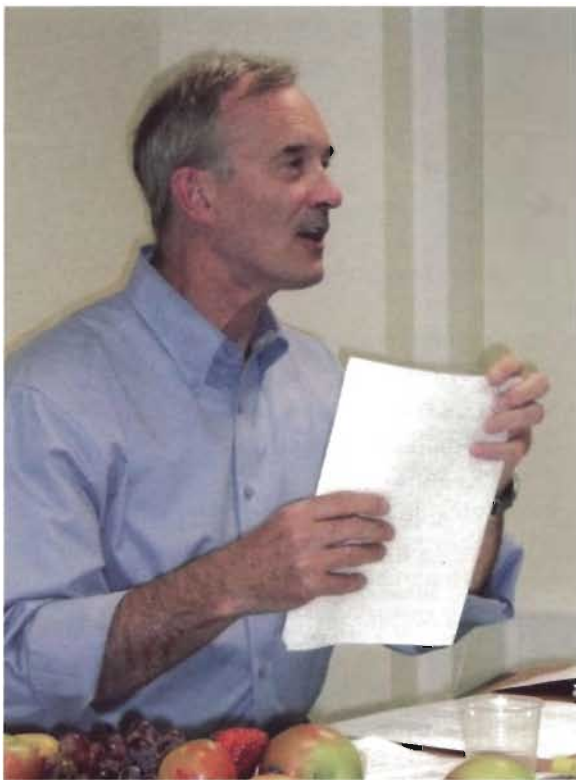


The sensory integration perspective and what it offers us in the field of deafblindness

David Brown from California DeafBlind Services concludes his article

Adapting the therapy approach to allow for deafblindness

Whenever I recommend a Sensory Integration evaluation for a child I tend to call it “a Sensory Integration-type approach”,



and I also suggest that ideally it should be instigated by a trained occupational therapist if this is possible, although it can take a long time to locate and involve a suitably trained therapist. I stress the need for flexibility and creativity and teamwork otherwise the Sensory Integration Therapy approach may not be productive, especially if

the occupational therapist feels unable to assess a child with no language, whose inner drive might be low, whose awareness of external stimuli might be very under-developed, whose movement abilities might be very limited, or whose processing time might be extremely long. Sticking closely to the classic approach will not work at all for most children with deafblindness. Significant adaptations will need to be made to the assessment procedures and also to the way that the therapy program is introduced to the child, but it is perfectly possible to adhere to the principles laid down by Jean Ayres even when working with a child with the most severe multi sensory impairments. If the child is not actively seeking and rejecting sensory inputs by themselves then the assessment will need to involve administering certain stimuli to the child to see what happens.

When requesting a sensory integration evaluation it is very helpful to the therapist to have a list the precise behaviours that have lead to a suspicion of sensory integrative difficulties so that they will be helped to know in advance what at least some of the key issues might be. With children with

deafblindness some of the most commonly encountered indicators of sensory integrative dysfunction are, for example, behaviours like:

- seeking very strong sensory inputs like self-biting or scratching, skin picking, spinning, rocking, bouncing, shoulder shrugging, leg swinging, hyperventilating, hand flapping, self-slapping, light-gazing.
- sensory defensiveness (such as always withdrawing from touching soft textures, or turning the eyes away from light).
- abnormally low or high pain thresholds (such as rejecting certain sensory inputs as if they are painful, but apparent non-awareness of certain other sensory inputs which for others might be painful, and never crying or seeming to hurt whatever happens to them).
- apparent variability or inconsistency in sensory perception abilities (like rejecting all textures in the mouth apart from pureed food, but mouthing of all kinds of non-food items e.g. stones, wood, cloth, soil, or the absence of chewing and biting on solid foods, but excessive chewing and biting on non-food items, often with persistent teeth grinding).



- unusual postures (like needing regular periods horizontal or upside down, twisting the limbs tightly around each other, or always needing to have the head supported).
- distractibility.
- persistently disturbed sleep patterns.
- problems with regulating arousal levels (often too drowsy or too over-excited, and maybe alternating extreme over-activity with extreme burn-out).
- in the early years, extreme postural insecurity when placed in a sitting or standing position by an adult, or when moved unpredictably, but pleasurable responses to strong rhythmic movement experiences (e.g. rocking, bouncing, swinging) if the body and head are well supported.

- inconsistent or inappropriate use of pressure when touching or grasping with the hands, often described as the child being very 'rough' or 'clumsy' or 'aggressive', and generally poorly graded movements.

Of course any one of these behaviours could be the result of other causes than sensory integration dysfunction, so it is important to remember to observe over time and to share and discuss observations with others to develop an agreement on the best way to proceed. But the existence of several of the types of behaviour on this list would strongly suggest sensory integration difficulties.

I always suggest that if an occupational therapist is approached they should feel free to speak to me and

other people involved with the child so that we might be able to help them with the "flexibility and creativity" referred to above, since they have not been trained to use this approach with children with deafblindness. It is reasonable to expect a therapist to take up this suggestion since an interview with family members and others who know the child well forms an important part of the 'sensory history' part of classic sensory integration assessment.

In the meantime, while we are waiting for therapy input, I am very likely to help the family and members of the child's professional team think about the child in multi sensory terms derived from Ayres' ideas, then look for activities and inputs that seem to help with the concerning behaviours, along with all the appropriate

Above: Anders

cautions about the need to go carefully and the need to OBSERVE to see what is happening as a result of what is being done. The ideas that I recommend are very often activities used in 'classic' Sensory Integration Therapy (eg. deep pressure massage, rhythmic joint compression, a range of large movement activities, the use of weighted clothing). Doing these things carefully with a child while you observe meticulously to see what happens to them as a result, both during the session and afterwards, is valuable research for the highly complex and varied population of children with whom we are working these days.

Anders and
his intervenor,
Nirtin



Sensory Integration Dysfunction

Sensory integration dysfunction appears to be very common in the population of children with deafblindness, and significant difficulties caused by impaired and poorly modulated sensory systems are very common. Many behaviours, some of them apparently contradictory, like those I have already mentioned, could indicate the need for sensory integration assessment and treatment by a trained occupational therapist.

Some typical ideas suggested by a therapist following a sensory integration assessment include brushing protocols, rhythmic joint compression, deep tissue massage, vibrotactile input, sucking and blowing activities, textured and/or heavy bed clothing, Lycra clothing for extra pressure input, a range of large movement activities like swinging spinning or rocking, and the use of weighted clothing. A variety of outcomes might be anticipated from implementing these techniques, including improving the child's ability to notice and attend to sensory information in the environment, improving muscle tone, improving awareness and tolerance of touch, improving attention span and decreasing distractibility, reducing the need for self-injurious behaviour, improving sleep patterns, and generally increasing the child's ability to remain both alert and calm in stressful situations.

This kind of sensory integration perspective might be needed, regularly or periodically, throughout the individual's life and should never be automatically regarded as a one-time 'fix'. Experience strongly suggests that every person with deafblindness would benefit from having a regular sensory integration assessment and program under the supervision of a suitably qualified occupational therapist.

Many children with deafblindness need extended time to process information, and often develop techniques that they use to establish a firm physical, emotional, perceptual, and cognitive "base" each time before they respond. Successful teaching frequently depends on allowing for this need and spending some time alerting the child to the fact that you are there, who you are, what you are going to be doing together, how and where it will be done, and so on. The child may need considerable time, and assistance, in establishing a secure and stable physical base as a first priority in every communicative interaction.

Anecdotes

The following anecdotes of children with CHARGE syndrome are examples of behaviours that were considered to be "challenging" by family or school that were solved or avoided, or moved to the non-challenging category, by taking a multi sensory view, based upon our knowledge of all the sensory difficulties associated with CHARGE. In



Making a salad

many of these examples there was a clear need for sensory integration assessment and programming along with the other strategies mentioned:

- A young child who was said to be self stimulating “all the time” was actually practicing and developing his mobility and orientation skills, and using vision and touch to explore objects, very creatively. While doing this he needed to get onto his back on the floor to reorganize his sensory system with brief episodes of limb shaking and hyperventilating every 10 to 20 minutes.
- A child in kindergarten was often self-abusive when he got distracted and over-aroused by incidental touch and air movement caused by people repeatedly walking behind his chair. Once his chair was placed with its back securely against a wall he was less self-abusive and more amenable to social interaction.
- People were concerned when a young boy began to insist on the unusual idea of wearing band-aids wound tightly around the tips of all his fingers and thumbs every day. He was expressing his need for more and stronger pressure and tactile inputs as a part of his sensory diet.
- Every morning in a pre-school program a student refused to sit on the floor with the rest of her class to watch the teacher sign a story. Her missing vestibular sense, low muscle tone, and poor tactile and proprioceptive feedback made unsupported floor sitting an insecure and exhausting posture for her, which demanded all the energy and attention that she wanted to put into following the story. When an appropriate chair was provided the student sat and attended with great interest and a growing level of participation.
- Many children who were unable to sit on a regular chair and attend to an activity for very long

showed an extended attention span and better visual, fine motor, and cognitive functioning once given chairs with footrests and armrests. One child rarely used the armrests for his arms but instead sat with his legs spread wide and his outer thighs pressed hard against the sides of the seat, the extra tactile and pressure input giving him the requisite equilibrium to function effectively in the upright seated position.

in the school gym in winter, but was unwilling or unable to play it outdoors when the summer came. The absence of strong vertical visual markers to aid his equilibrium outdoors (remember the Equilibrium Triad) made it impossible for him to maintain a secure upright position while also running around looking for and kicking a ball. The ability to participate in such complex physical activities outdoors did not develop until significant adaptations were introduced.

- A different teenager was unwilling to go outside during school recess because of problems with glare and photophobia that impacted mobility and orientation, as well as limiting his ability to participate in signed conversations. This difficulty was eventually solved by the provision of tinted glasses and a sun visor.
- During Orientation and Mobility sessions a teenager was refusing to stand still to receive spoken/signed instructions, but the problem was solved when the student was allowed to stabilize himself by leaning against a pole or a tree or a wall, or by placing one hand on the instructor's shoulder during these conversations.

I want to conclude by talking about a few aspects of sensory integration that are especially relevant to many of the children with whom I am currently working.

Sensory modulation, enhancing, inhibition

When our sensory systems are well modulated we can function effectively with all the many sensory messages coming into our brains from the world around us. But the complex and never-ending task of having to 'select, enhance, inhibit, compare, and associate' sensory information is extremely difficult for children with deafblindness. In particular, it might be very hard for them to know which sensory stimuli need their conscious attention and which do not. As a way of coping with this challenge many of the children I see are 'one-thing-at-a-time' people, able to focus on only one sensory input at a time, or maybe two at the most, and switch their brains off to the rest, so that the multiple complexities of life are simplified right down to basics. For these children true sensory integration might be an unattainable goal and our best help might be to create carefully structured environments for them within which they are supported in this process of simplification. Minimizing distractions and removing competing sensory inputs is an obvious first resort to use with these children, and, although we never say 'never', this simplification may become a life-long need, just as it is to some extent for all of us.

Sensory diet

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- A girl was described as very disruptive during sessions that required the class to sit still and participate in a signed lesson with the teacher for up to 30 minutes. When the teacher used a strategy of asking the student to move periodically to carry out small chores during these sessions (to fetch a pen, open a door, bring a book, take a paper to the school office) the disruptive behaviours largely ceased.
- A teenager enjoyed, and was quite good at, soccer

idea that we all need varied sensory inputs at different times for different reasons, the way that we also need nutritional inputs of food and drink. The idea helps us to see children's behaviours as fulfilling essential sensory needs rather than just being 'self-stimulating' or 'self-abusive' or 'avoiding'. Jan van Dijk taught us decades ago that the best way to begin to teach a child with persistent rocking behaviour might be to join them in their rocking and even help to facilitate it to enhance and intensify the stimulation (in this case primarily proprioceptive and vestibular) that the behaviour provided for the child. He was emphasizing the need to begin by forming a positive and supportive relationship with the child, but from Ayres' point of view the idea also facilitates better functioning for the child by giving them more of the very sensory inputs that they are so obviously seeking through the rocking. Both van Dijk and Ayres believed that the child should be an active and communicating partner in these interactions, never the purely passive recipient of sensory stimulation, and the adult was to remain alert and attentive to the child, never the mindless hand that rocked the boat or pushed the swing or stroked with the brush or whatever.

Level of Arousal

This concept has been mentioned a lot throughout my presentations, and it offers invaluable ways of thinking about children learning and attending

“Experience strongly suggests that every person with deafblindness would benefit from having a regular sensory integration assessment and program under the supervision of a suitably qualified occupational therapist”

and recognizing and remembering. There are different but similar descriptions of the spectrum of arousal, and one that I often use comes from the 'Carolina Record of Infant Behaviour', which is helpful when thinking about people of all ages, not just infants, and it shows the spectrum running from the most alert and excited state (Uncontrollable agitation) to the least (Deep sleep):

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

Knowing how to identify where a child is on this spectrum at any given moment, knowing where they need to be on the spectrum in order to achieve a specific goal, and knowing how we can help them to move themselves, or how we can move them, up or down the spectrum, is one of the most relevant insights that we can cultivate in our work with children with deafblindness. This is an area of assessment and teaching where familiarity with Jean

Ayres' work has special resonance. No one level on the spectrum is inherently 'better' than any other, each can serve a useful purpose, but being at some levels will facilitate better functioning than being at others for different people with different needs and different goals. For example, I am inclined to do better with my work when I am at the 'Fussy awake' or even the 'Mild agitation' levels of arousal, but I have a colleague who needs to be at the 'Quiet awake' level for optimal work output. I knew a child with deafblindness who was very visual in her behaviour and functionally completely deaf when she was at the 'Active awake' or 'Fussy awake' levels of arousal and had plenty of energy. Only when she got really tired and reached the "Drowsy" level of arousal did she abandon using her vision for moving around and, flat out on the floor, attend to stimuli coming in through her hearing sense, and do it remarkably well considering the nature of her hearing loss. She reminds us of the dangers of making generalized assumptions about children, and that 'knowing the child' is the best guiding principle in our attempts to educate children with deafblindness.