

Sensory Integration and the Child with Fragile X

Presentation by Janette Bell, Clinical Specialist in Paediatric Occupational Therapy, Fife Primary Care NHS Trust to the Fragile X Society Scottish Family Conference, April 2000

This report outlines an extremely summarised and simplified exploration of Sensory Integration: what it is, what it means and its relevance to the child with Fragile X.

Sensory Integration is both a theory of development and a therapy approach. It is an approach that many occupational therapists will use with children with specific difficulties dependent on their needs.

Occupational Therapy with Children

"Occupational Therapy aims to enable children to maximise their potential developmentally, physically, psychologically and socially, through the use of purposeful activity".

Paediatric occupational therapists using a combination of theoretical frameworks may assess and treat the child's:

- fine motor skills e.g. handwriting, manipulative skills
- gross motor skills
- cognitive skills e.g. memory, attention
- visual perception
- sensory awareness
- self care skills
- behaviour
- social skills
- play

The above are explored in relation to the child's functional skills and concerns highlighted by parents/carers, the child and/or school.

Sensory Integration

Sensory Integration is a developmental theory developed by an American Occupational Therapist, Dr Jean Ayres over 35 years ago. It is based on the idea that Sensory Integration is a developmental process that results in the brain being able to process and combine sensory information which enables us to function within our world:

- it is a process of organisation and interpretation of sensory information by the brain (it is the organisation of sensation for use)
- it is a foundation for learning
- it is a developmental process and in therapy sensory information is co-ordinated, sorted and interpreted according to the individual's needs to act in response to his/her environment

Through movement we learn about direction and balance, how to maintain and how to move from one position to another. This system is closely linked to the visual system. When the vestibular system is ineffective, information can be misinterpreted and thus responses may be hyper-responsive or hypo-responsive.

Tactile: involves two types of touch - protective and discriminative. Protective touch may result in avoidance or seeking of a given situation/stimulation e.g. reflex withdrawal from a hot plate; "flight, fright or fight" responses etc. Discriminative touch helps us discriminate between objects. When the tactile system is ineffective, information can be misinterpreted and thus responses may be hyper-responsive or hypo-responsive (as with the vestibular system described above).

The hyper-responsive child may for example:

- dislike crowds
- dislike noise
- have an adverse response to touch e.g. light touch
- dislike "lining up" in playground/at school
- avoid getting hands dirty ... dislike messy play
- dislike rooms with lots of stimulus
- be a fussy eater, due to texture dislikes or over-sensitive to tastes
- dislike unexpected movements e.g. swings in the park etc
- have difficulty discriminating between noises

The hypo-responsive child may for example:

- seek stimulation
- may be withdrawn and be sluggish in demeanour
- "go on forever" on playground equipment
- love messy play but this can often end up "out of hand"

Sensory Integration as a Therapy Approach:

- tends to be individual
- is child directed but within structure
- needs to have the "just right challenge"
- follows a developmental process
- needs to take account of priorities and concerns
- involves a rich environment with large play equipment
- the emphasis is on whole body movements
- allows opportunity for integration of all senses
- needs movement through space
- needs to be fun
- has access to a quiet area
- has the overall aim to develop function

For the child with Fragile X they may not necessarily require specific Sensory Integration therapy. It is more likely and more appropriate that some of the principles of Sensory Integration could be implemented on a day-to-day basis. This can be done through exploring the child's sensory diet and how through adaptation some difficult behaviours may be reduced or more easily managed. This can be achieved through principles of "calming" and "modulation".

Calming and Modulation:

Calming and modulation are achieved through specific sensory input which can be seen or described as:

- “heavy work”
- deep pressure touch
- slow rhythmical movement and sound
- neutral warmth

Some practical ideas are outlined and it is hoped these will be useful for everyday situations with your child where the above principles regarding sensory processing dysfunction is apparent or where difficulties exist.

It is important to establish when and why behaviours occur. Thus, by monitoring you can begin to identify situations/occasions where your child can have difficulty with sensory processing. These will often be the occasions when a child will act up, for example in the supermarket, in response to being overloaded by all the sensory information around them – visual, auditory, and uncertainty of the process and sequence of events as opposed to just not liking shopping. Or when shopping in town due to crowds, lack of control over environment, scared of being bumped etc which can cause the child with poor sensory processing considerable distress (possibly due to difficulties with proprioceptive and tactile systems). Or the swing park due to the child disliking sudden movement or spinning and/or with a possible fear of heights, which may be related to vestibular processing difficulties. Equally the difficulties may arise when trying to leave the swing park where the child is hypo-responsive and sensory seeking. Difficulties with sensory processing will often present through emotional and/or behaviour responses. Behaviour, therefore, can often be misinterpreted, hence the importance of accurate assessment.

Practical Suggestions for the Sensory Diet

The following will hopefully give some practical ideas to help with management of some of your child’s behaviour. It is important not to force any of the following on your child as each child will respond in an individual way and what is right for one child may not be right for another. Often it can be a process of trial and error.

General Principles

- Observation and monitoring of behaviours is essential to assessment to establish whether difficulties are or are not felt to be due to problems with sensory processing
- Consistency
- Routine
- Preparation for change, for events etc. Often the use of visual cue cards will help the child to understand the sequence of events and prepare them for the activity they are to be involved with, for example a photo of the supermarket followed by photos which outline the sequence.
- Use of a calm, quiet, unobtrusive and controlled approach (not always easy!!)
- Remember deep pressure is calming and modulating thus prepare the child for touch and use firm, slow movements, for example using a “feely” mitt with a deep brushing or stroking motion down their arm, back or soles of their feet has a calming effect.

Daily Routines

Dressing:

- Some clothing may cause an adverse reaction: be guided by your child, some will prefer short and some long sleeved clothes.
- Textures may irritate
- Labels, seams etc may irritate, thus cut out labels, wear socks inside out etc.
- Some children will cope better in tighter fitting clothes. Use of lycra cycle shorts and tight T-shirts may give the child more information to their body with regard to body position and thus make them feel more secure and “grounded”. This gives a constant deep pressure effect which has a calming effect on the brain - and thus on behaviour.
- Children who are tactile defensive may easily overheat and their perception of what is warm may differ to yours.
- A child who needs help to dress may find it distressing or alerting if the adult’s touch is too light, thus use firm consistent pressure in your contact with the child.

Bath time:

- A child who is over-responsive to touch may hate baths, hair washing etc. Again use of deep pressure principles can help, for example use firm drying actions with towel or wrap the child tightly in their towel to dry them, apply gentle but firm pressure around scalp before washing hair and use a massaging action for the shampoo.
- Often children who are hyper-responsive cope better with warm baths as opposed to a shower.
- Try a large beach towel to dry your child.

Bedtime:

- Have a consistent routine
- Allow time for the child to relax prior to bed, for example a warm bath, wrap in a towel
- If age appropriate read a story or play soothing music
- Reduce stimulation at this time, for example no excitable games once dressed for bed
- Use some deep pressure activities, for example brushing with firm pressure down back or arm
- Children who are over-responsive often prefer heavy blankets on their beds or to be tightly tucked in or wrapped up in their duvets.
- Have gentle lighting in the room

Mealtimes:

- Consider seating and posture – the child will cope best with their feet flat on the floor or on a box with their back against the back of the chair or use a cushion.
- Foods can evoke varying responses and can be alerting, calming and/or regulating (organising)
 - Alerting foods include spicy, sour, bitter, hot or crunchy foods
 - Calming foods include sweet flavoured foods/drinks, especially when sucked – thus often use of a straw can help
 - Regulating or organising foods include foods that require chewing
- Activities involving blowing, for example blow football, bubbles etc can help to increase muscle tone around the mouth, help control of drooling and aid proprioceptive processing.

Car Journeys:

- Allow the opportunity for stretching
- Sucking and chewing sweets can help
- Ensure your child is “comfortable” in the clothes they are wearing
- Have a small quiet toy or soft toy for comfort
- Use of headphones and personal stereo with favourite music

Play:

Encourage play and activities that allow for deep pressure, these include running, jumping, twisting, push, pull, rolling type activities, for example

- Trampolines
- Tug of war
- Pillow fights
- Wheelbarrow games – with child walking on hands whilst feet held
- Any push or pull activities
- Commando crawling
- Games played with child lying on stomach, supported by forearms or lying on settee whilst weight bearing through arms to play a game on the floor
- Roll child up in blankets, rugs etc
- “squashy” games
- Sit and bounce balls or “space hoppers”
- Swing ball, punch bags etc
- Body rolling games
- Tactile games, for example play with finger paints, shaving foam on a tray or on bathroom tiles
- Wedging clay or play with clay – pulling clay apart
- Playdough

Environmental Considerations:

- Consider decoration in the bedroom, often the child will cope with calm wall colours and limit the number of posters and visual stimuli in the room
- Test out different aids for calming, for example headphones, music that is soothing and rhythmical, lighting, reduction of visual stimuli
- Have a “den” or quiet “safe” area for your child where they can feel secure and contained. Often children will find these themselves, for example under the table. Make a safe area that is appropriate for the individual child, for example a wendy house or tent with large beanbags and cushions inside
- At school these would also be appropriate or use a “learning booth” for the older child
- Allow the child to help carry bags or help digging in the garden
- Carrying books at school

N.B. any “heavy work” type of activity will help the child to promote feedback to the brain from joints and muscles. The processing of this information in the brain has a modulating and calming effect on behaviour and the emotional system.

Shopping:

- Prepare the child
- Use visual prompt/cue cards/ photos
- Allow the child to push the trolley or lift the heavy objects in and out of the trolley
- Use of a personal stereo with headphones can help reduce the noise factor
- Give the child a rucksack with a book in it to carry on their back
- Carry the shopping

I hope the above gives some useful tips.

It is important to test things out and listen to your child/adolescent, with your eyes as well as ears. NEVER force any sensory stimulus as this can cause an adverse reaction. Each person may have a different response to many of the above, after all sensory processing is an extremely individual experience even to those without any sensory modulation/processing difficulties!

Reference:

Ayres, J (1979), **Sensory Integration and the Child** Western Psychological Services, USA
ISBN 1-885477-25-5

Recommended reading:

Kranowitz, Carol Stock (1998), **The Out of Sync Child** Penguin Putnam Inc., USA
ISBN 0-399-52386-3

“Occupational therapy and sensory integrative therapy for individuals with fragile X syndrome”
by Dido Green – chapter 15 in **Educating Children with Fragile X Syndrome** edited by Denise Dew-Hughes, Routledge Falmer (*available from the Fragile X Society*)

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