

About a boy

At 14, Mark John had profound and multiple learning difficulties, sensory defensiveness and severe communication difficulties. Through a collaborative Individualised Sensory Environment programme with sensory integration techniques, speech and language therapist *Helen Francis* and occupational therapist *Joanna Lloyd* opened the door to him achieving his potential.

Helen and Joanna write, "This article is dedicated to the memory of Mark John who sadly passed away this summer."

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When we began to work with Mark John he was a 14 year old student who had been at St. Margaret's School for children with profound and multiple learning difficulties (PMLD) and complex health needs for just over a year. He was a non-verbal communicator who had particular difficulties tolerating touch, eye contact and person engagement. He smiled or stilled to listen to familiar vibrating and musical toys near him on his floor mat, and indicated a desire to interact by reaching for a helper's hand to play with them. He complained loudly when sitting in his chair in class groups, and pushed away or shut his eyes to opt out of situations involving people or touch. He used a range of idiosyncratic vocalisations and hand movements, but it was often hard to be sure which sounds were happy and which were a protest.

Mark John appeared to have difficulty co-ordinating his responses, at times smiling and vocalising positively when offered an object, then pushing it away instead of holding it. At other times he would frown and look cross, but then grasp that same object. It was therefore difficult for Mark John to show preferences and for us to understand his choice making. This lack of engagement appeared to be hindering him from achieving his personal and educational potential.

Aims set jointly

At St. Margaret's each student has communication aims for their Individual Education Plan (IEP) set jointly by the class teacher and speech and language therapist. Based on our observations we decided his needs were:

1. To show clear preferences by smiling / reaching, or frowning / pushing away
2. To make clear requests for 'more' by turning toward, reaching or vocalising
3. To use differentiated vocalisations for specific intentions.

Programmes and activities incorporating these would be set up for Mark John by those working with him.

Mark John was assessed by Helen (his speech and language therapist) for participation in an Individualised Sensory Environments (ISE) programme, a technique first developed by Bunning (1995) with young adults with profound learning difficulties who were described as 'hard to reach'. Based on patterns of normal development, infants in the earliest stages of life receive strong tactile, vestibular and proprioceptive input from being held close, wrapped up and rocked, only later showing interest in sights and sounds. Therefore, someone who is still at an early stage of development may be seeking this type of tactile input and is most likely to respond positively when they receive it. Once they are interested they will seek for 'more', and ultimately interact and engage with the one who is providing that stimulation.

Touch is further divided into non-touch, indirect and direct touch, and vibro-touch. Helen videoed Mark John's baseline session; he smiled in response to air-based toys and vibro-based objects, but pushed away massagers and wet and dry objects. He was unsure about swinging and vestibular movement.

The programme then takes the client's favourite objects and uses just five keywords - his name, ready, gone, more? and stop. This avoids distraction, and allows him to direct the session. If he indicates that he likes something and wants more, it is given to him; if not, there is no pressure to respond. Record forms are used for each session. Class staff agreed that Mark John's programme (figure 1) would be carried out at least once a week initially by Helen, who would then train therapy and class assistants to carry out additional sessions. There would be a review after three months.

However, the problem with Mark John's ability to tolerate touch remained, so even the ISE programme was limited in what it could offer him. Lack of tolerance of touch was continuing to impact on his ability to access class activities, life skills (dressing, bathing, moving and handling) and social interaction.

Over the same period, Mark John had been receiving occupational therapy from Joanna. As-

essment through life skills activities and functional activities in the classroom had highlighted:

- His ability to learn, for example he would actively assist by taking his arms in and out of his harness whenever getting in and out of his wheelchair – he learnt the routine.
- He was able to make differentiated responses to touch - for example by withdrawing from light touch and smiling to rough and tumble play. Withdrawal from light touch and the touch of objects including items needed for personal care and toys reduced Mark John's ability to tolerate and co-operate with personal care tasks and to access the curriculum and his environment.
- Mark John responded consistently to some key objects, demonstrating his recognition of those objects for example by consistently closing his mouth to a spoon, and pushing certain toys away while accepting others.
- Mark John demonstrated clear understanding of cause and effect and was able to activate a switch to operate a variety of toys and equipment but was unable to do this consistently due to his sensory difficulties.

Occupational therapy aims and intervention therefore included:

- attending to and following movement of an object,
- to pick up an object and pass it on
- to tolerate a variety of textures.

Combined programme

With both of us feeling that we had reached an impasse, we discussed Mark John and decided to combine the speech and language therapy and occupational therapy aims. We wanted to set up a programme of joint working focused on enabling Mark John to accept tactile input and communicate his preferences more clearly.

We then saw Mark John for a trial period in weekly joint occupational / speech and language therapy sessions to address his tactile defensiveness and difficulty handling sensory experiences. We used a structured approach with a set routine so Mark John was able to learn to anticipate the programme, which

Figure 1 Mark John's Individualised Sensory Environment (ISE) Programme

- Aims:**
1. To indicate like / dislike of an object.
 2. To give a distinct signal to request 'more' of an object or activity.
 3. To engage with a person interacting with him.

Equipment

A variety of 'motivating' items listed below – use a different selection each time

Chosen Categories:

1. Air based (indirect non-touch contact)
2. Vibro-based (indirect vibro-contact)

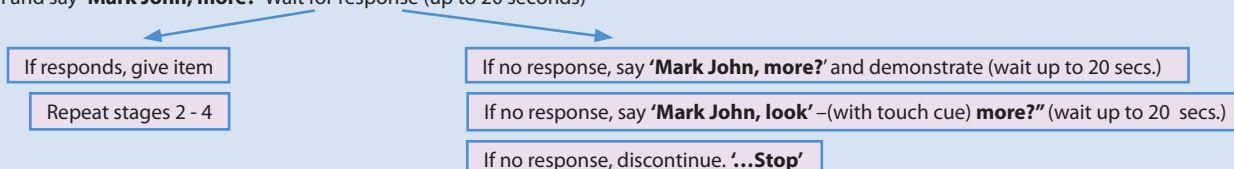
Suitable Objects – eg:

- Japanese fan, puffa toys, battery fan
Vibro-tube, vibro-massagers, vibro-toys

Procedure

NB Spend a brief time chatting to Mark John before starting and after finishing the programme. Note his response before, and after, the session. Record responses on form below. **Apart from this 'chat time', only use the words outlined below during the programme.**

1. Select the required number of objects from their chosen categories (see above).
2. Present item and say 'Mark John, ready?' and demonstrate – ie give fan, or turn on vibro toy and let him feel and respond
3. Withdraw item and say 'Gone'
4. Show item and say 'Mark John, more?' Wait for response (up to 20 seconds)



Programme Record Sheet											
Stimulus/Activity	Smile	Turn towards	Look towards	Reach	Mouthing	Vocalise	Still	Grimace	Turn away	No response	Other (Specify)
Introductory conversation											
1st object:											
.....											
1st time											
more (1)											
more (2)											
2nd object											
.....											
1st time											
more (1)											
more (2)											
3rd object											
.....											
1st time											
more (1)											
more (2)											
4th object											
.....											
1st time											
more (1)											
more (2)											
Closing conversation											

combined sensory integration and ISE techniques.

Sensory integration theory and practice was originally devised by Dr Jean Ayres (1979) who defined it as 'the organisation of sensory input for use' and suggested that dysfunction in sensory integration occurs when the brain cannot organise and connect or integrate sensory messages. She advocated deep pressure through joint compression and muscle compression as these are thought to be accepted as calming and organising.

We wanted to see if this approach would help Mark John to organise his responses to sensory input and so to tolerate touch. We offered him a choice of toys / activities as part of his ISE programme. The aims were for Mark John to tolerate touching / holding these for longer, and for his communication signals indicating pleasure or refusal to become clearer.

With the sensory integration programme, Mark John's initial strong resistance to deep pressure, touching and being touched was gradually replaced by calmness and anticipation, even pulling the Lycra sheet – a tool used for deep pressure input - around himself and giving positive vocalisations on one or two occasions. The communication approach used in the ISE programme (using few key words, and allowing Mark John to request 'more' of particular activities), was incorporated into this too. His calmness and anticipation

began to carry over into the class activity which followed immediately after this programme.

We recorded Mark John's responses to the ISE programme each session. After 3 months we took a further video and evaluated it against his Individual Education Plan communication aims; it was clear that Mark John was making progress. As his sensory tolerance increased, so we were able to offer him a wider range of motivating activities such as air based toys, vibrating objects and deep pressure massage. As his motivation increased, so did the opportunities to engage with him.

All our students are assessed and reviewed annually using the St. Margaret's Developmental Curriculum (2006). At Mark John's annual review we found:

1. Communication

Mark John had achieved all his communication objectives after carrying out our programme for 5 months. His new aims were to demonstrate understanding of five to ten familiar words, to give distinct signals to request attention or 'more' in a range of situations, and to consistently use differentiated vocalisations for specific intentions.

2. Life Skills

Progress had been made in sensory tolerance and his mother reported that his increased tolerance of touch had allowed him to achieve several life

skills objectives. His new aims were to actively tolerate dressing (by not resisting; responding by pushing arm through clothes / bending arm to remove clothing).

3. Parents' report

His mother was pleased to note that he had begun to make eye contact with her and his father, which he had rarely done before.

We concluded that this trial had been effective, and we would develop the programme and continue for a further year. We explained our intervention to Mark John's mother, and she was keen to carry out a similar approach at home.

Clearer repertoire

We continued the joint speech and language therapy and occupational therapy sessions and extended them to twice weekly with support from class staff. Mark John began to show enjoyment of some new activities and developed a clearer repertoire of positive (smiling, laughing, high pitched vocalisations, hand-clapping) and negative (frowning, low pitched vocalisations, pushing away) responses. We were able to shape one of his vocalisations into a specific 'uh' signal to request more, and this was used throughout other daily activities in class with success. One year on, the most exciting change was that Mark John was now clearly engaging

