

PMLD LINK

Supporting people with profound and multiple learning disabilities

Summer 2010

Sensory
Experiences

Vol 22 No. 2 Issue 66

Registered Charity No. 1121085

The Bulletin of News and Information for Everyone Working with People with
Profound and Multiple Learning Disabilities

Sensory Experiences

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PMLD Link relies on contributions from practitioners, parents, carers and everyone interested in the field.

GUEST EDITORIAL

Summer 2010

Sensory Experiences

A title like this makes us remember, usually with a smile, special moments when young people with PMLD have had an unusual sensory experience.

Whilst exploring the theme of “transport”, the undulations of an inflatable boat brought great delight to several teenagers, seemingly only enhanced when it sprung a leak! But perhaps the most unexpected were the responses to flying in a helicopter. Boarding beneath the rotating blades was certainly exciting, but it was the children with severe visual impairment who responded most to the actual flight, smiling and laughing as it tilted and banked to turn around.

So it is that this issue starts with remembering and we think, smiling, with a potted history of a rather special person’s very varied and lively multi-sensory journey within education!

In fact, this title has attracted a wealth of fascinating and varied articles. We have children with complex needs engaging with dance, taking part in theatrical performances, and creating images and sounds through movement sensitive technology – truly multi-sensory, exciting and moving experiences. Then there is the research into the musicality of children with PMLD and the development of a Music Curriculum to provide a path for possible musical progression.

Focussing on the sense of touch, there is a poignant case study describing the effect of warm, frequent, physical human touch on a child with extreme PMLD and this piece includes a review of the situation on physical contact issues. Touch, and how children with complex needs and visual impairment can be encouraged to explore and find objects, is considered in a later article, and we have a description of new tactile books currently being trialled for these children.

The Multi Sensory Room, is it really necessary? The pros and cons of using a Sensory Room are re -visited and whether other simpler cheaper equipment might be just as effective. Interestingly, another writer describes how she used a simple resonance board to create a communication game with a very young child with extreme PMLD. There are also two thought provoking papers on auditing sensory exposure to reduce stress, and a useful list of resources for helping staff to identify and alleviate an individual’s sensory difficulties.

Finally we celebrate the work of another rather special person, recently awarded for “reaching the unreachable” through Intensive Interaction.

“Sensory experiences” - what a broad title! Thank you so much to everyone who has contributed.

Chris Fuller and Di Foxwell

PMLD LINK Contacts

Subscriptions, information and enquiries

Carol Ouvry
31 Birdwell Road
Bristol BS41 9BD
Tel: 01275 394621
carol.ouvry@talktalk.net

Reviews

Di Foxwell
50 Boness Road
Wroughton
Swindon
SN4 9DT
di@phonecoop.coop

Production

Paul Bramble
The University of Northampton
Park Campus
Boughton Green Road
Northampton, NN2 7AL
Paul.bramble@northampton.ac.uk

Future Issues

Winter Vol. 22 No. 3 Issue 67 Lifelong Learning

Copy date
29th October 2010
Please send your contributions to:
Beverley Dawkins
Beverley.Dawkins@mencap.org.uk

Spring Vol. 23 No. 1 Issue 68 Communication—Speak Up Speak Out

Copy date
25th February 2010
Please send your contributions to:
Alice Bradley
alicebradley@talktalk.net
Or
Ann Fergusson
ann.fergusson@northampton.ac.uk

ISSN 2042-5619

'A short history of shout, glow, jump, taste, smell, touch and wobble-multi sensory education '

Flo Longhorn

I have written three articles for those who are beginning their careers in special education or who have marched through the years of change alongside the author. It is from someone who began working with special children in the 1960's and now has an Old Age Pension, a great grandchild, a bus pass, still works around the world and has an untameable interest in the multi sensory world of very special people. It is totally subjective but I hope an insight into how multi sensory has been inextricably linked to very special people. The articles will look at how things used to be, how things are and will be in the future.



The past

I met my first children with special needs in 1969 when I began my first year of teaching in the east end of London. I had a class of 47 children aged 6 years old, including 20 children who had just arrived from Bangladesh with no understanding of English (and no knickers as I discovered when we stripped for PE) my 9 month old son living in the Wendy House (who did not speak until he was three because the children spoke for him) and 5 children with special needs, unbeknownst to me. I had a nursery nurse for one hour a week. One six year old in my class, Stephen, had autism with elective mutism and I lived with the idea that it was catching like measles until a psychologist told me what autism was all about. At the time, Stephen was a rarity as only 4 children in 10,000 had a diagnosis unlike today when there are 4 in 400 on the spectrum. The psychologist also told me Stephen needed a sanctuary, as it was a busy classroom. So, the class built Stephen a cardboard castle as a project, and whenever he really started to flap, grimace and jump up and down I would ask him to take time in his castle. Now I would know he was so sensory overloaded by the room he needed a sanctuary. I soon realised that Stephen was spending six happy hours in the castle each day and I would fail my probationary year as a result. I had a flash of inspiration, an egg timer. Stephen learnt to pop out of his castle when he heard it go after five minutes. On the last day he was in my class he came to me and spoke for the very first time, I was hooked on special children from then on. Fast forward five years, during which I went to live in Boston Massachusetts, became a head teacher in a Laboratory school at Tufts University (based on an interview about sand and water play) working in an integrated school setting with special needs under fives. Here I learnt about sensory behaviours, observing, seeing the consequences of behaviours



and planning strategies to alter behaviours. The most vivid failure of my time was a four year old called Bo. He put his pointy finger in the electric pencil sharpener, with consequences. On his return from casualty, he proceeded to put his other finger in the sharpener. I quickly learnt about high thresholds of pain and how tactile stimulation is not just about using fluffy materials.



I came back to the UK in the mid seventies, to find that very special children were no longer confined to church halls, they were in school settings, and not only called mentally handicapped but severely sub normal too. The new schools (in very old junior training centres) were run on a medical model and also using behavioural methods such as back chaining an activity (six thousand steps to removing a jumper) or using 'time out' for problem behaviour.

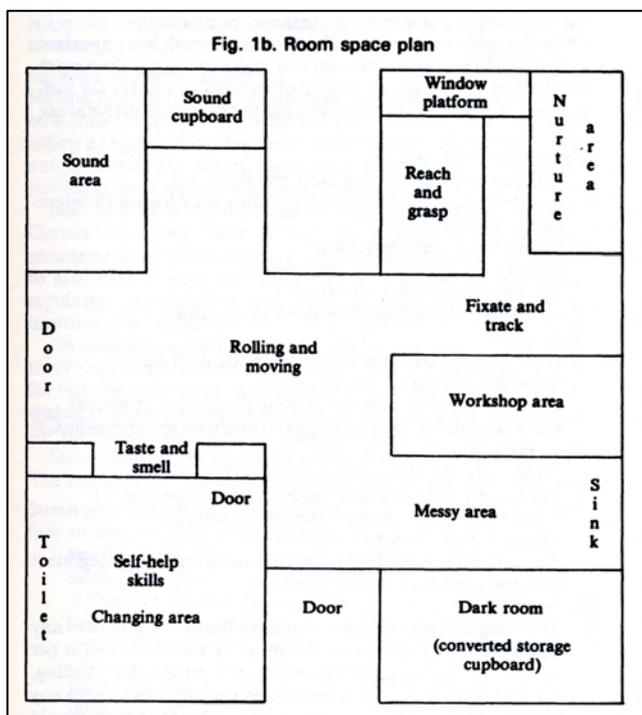
An insight into the first years of special education can be seen firstly in the role of a colleague, who was appointed as a special education advisor. Her first brief contained two items. She had to count the number of chairs in each establishment and to check the quality of the school dinners-which were cooked by the teachers for the pupils! A second insight is when I took on my first UK headship in 1982, taking over from the head who was an unqualified nursery nurse. Multi sensory education began for me here, when I made my first walk around the school and discovered a group of very special children and teenagers, all in a room labelled 'special care'. I thought it was a special boiler room. The room contained twelve pupils aged five to eighteen, one unqualified teacher, one nursery nurse, nappy roll, a set of Ladybird early readers and catalogues to flip through for the less advanced readers. Stunned, I lay on the floor alongside where they were laid on gym mats, and discovered their multi sensory world.



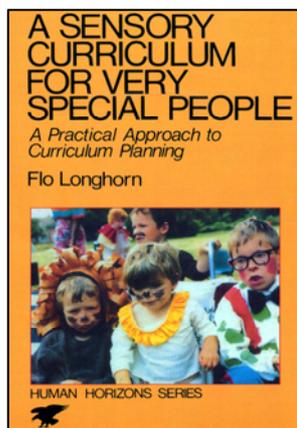
I realised that these pupils were at the simplest levels of development and needed an education that gave them the opportunity to reach out and sense the world around. A more formal education had to wait patiently until they were ready.

The school began to develop the provision to suit these pupils through a team approach developing curricula, room designs and multi sensory spaces. Innovative multi sensory rooms were set up for them within the school, for example, a dark room was created out of the caretaker's cupboard. A rumpus room (now called a soft play area) was installed by a man called Rupert from Wales who slept in the school hall with his work mates, whilst building the room. The total cost was around £1,000, cash in hand.

Class room spaces had designated sensory areas as the curriculum was sensory led not government led. Here is such a plan:



I then wrote the first book on the senses (1984) based wholly on observation of these very special pupils and the talented work of very special educators. This book went out on the special needs 'word of mouth' network far and wide. In 1988 Souvenir Press brought multi sensory approaches to a world audience with the



publication of 'A sensory curriculum for very special people' that is still on sale, and being used, after nearly 25 years.

Multi sensory training was very limited. The first day of training I undertook was in Wallingford for the 'National Spastics Society.' There were so many applicants they had to hire the Corn Exchange. As I put out all my multi sensory materials on the stage, a queue formed outside of members of the general public thinking I was setting up a jumble sale!

To earn income for the school I was next at (as I had bankrupted it through providing everything sensory) we did Saturday sensory days when a letter was sent out by bush telegraph and we had packed events with teachers from Scotland, Wales and Ireland coming to see what multi sensory was all about (accommodation provided by school staff).

The importance of the senses became prominent across the education of very special learners until the National Curriculum arrived.



And at this point, the reader will have to wait to see what unravelled in multi sensory education over the following twenty years.....until the present.

Contact details

Flo Longhorn
Flocatalyst@aol.com
www.sensology.org

Move it groove it beat it feel it hear it sing it shake it rock it be in it

Naomi Rosenberg
Teacher of the deaf for children with complex needs and
Sensory Education Consultant

Dance for Children with PMLD

How can children with PMLD access dance. They may not be able to get up and dance. They may not be able to see people dancing. They may not be able to hear the music. These or a combination of these are our challenges but they are not insurmountable.

Here are a number of ideas for you to experiment with.

Let's get beyond wheelchair dancing where the children are whizzed around. This can be great fun so I'm not putting it down, but how much control and creativity do the children get from this experience? I want music to be the stimulation. We need to make the music really explicit for the children. We need to bring the music right into the foreground so think how you can minimise all the other distractions.

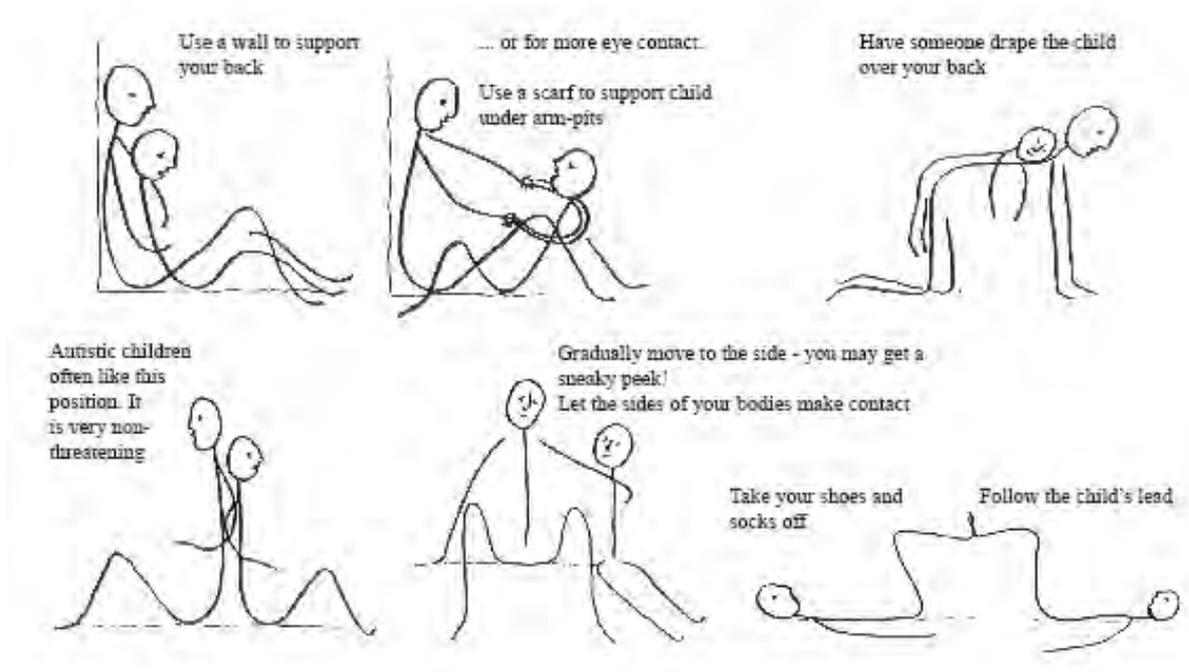
If you are working with a profoundly deaf child, plug the music into a vibrating sound bed or cushion so they will feel the rhythms. Choose music from every genre and from all over the world with good rhythm and melody. Dance is an interpretation of the music. We find the beat and express our emotions in our movement. We can dance alone or in partners or in a group, so dance is also communication and is

important for building relationships. This is why dance is such a wonderful learning tool.

When the child is very little, the best thing you can do is pick her up and dance to music. She can experience the kinaesthetic sense of movement in space. She can experience the closeness of being held and a sense of self worth with good, positive interactions - all this with the joy of the sounds of music in a wonderful shared experience. But what can you do when the child gets too heavy to pick up and dance?

Contact Dance

Find different ways of sitting or lying so you have one or more points of contact. You may also support some of the child's weight so you can sit up against a wall to support your back. Experiment with this to find ones that are suitable for the particular child you are working with. Then rock or sway or wiggle to the music.



Using scarves, lycra loops, ropes for support.

Some children will be able to sit opposite you. Use a scarf or soft belt. Put it behind their back and under the armpits and hold on to the ends. You can now both dance and the child has the support and prompt to move. You can do this sitting or standing if the child is able.

Children with visual impairment may be scared of dancing out in space. They don't know if they are going to crash into something. With the aid of a rope, the mobile child holds both ends and you hang on to the middle. You can then both dance. As the child gains confidence the rope can be lengthened to increase your distance and the child's independence. Then he can just hold one end and know that you are on the other end looking out for him and can find you when he wants to.

Make a lycra loop.

Buy a length of lycra – its hard to say how long because lycra varies in stretchiness and you may decide to make a big one for group activities or a small one for 1:1 or 2:2. Sew the ends together to make a loop and get inside spreading the lycra across you and your partner's back. It's good fun playing with the elasticity and it's nice to have music to move to.

Dance massage

Dance massage uses music as the main focus for massage. The receiver gets a tactile interpretation of the music and the masseur channels her dance through her upper body and hands on the child's skin. Dance massage is a form of intensive interaction where the children have the maximum opportunity to express themselves and be responded to.

Back in 1992, Dance Massage came to me as a bit of a revelation! My husband had come back from work and a long drive with a stiff back. He asked if I'd give it a rub so he lay down in front of the fire. We'd had a glass of wine and some Arabian Rai music was playing. I got out some oil and started massaging his back. I was just drifting off with the music and my massage naturally flowed with the sounds. After

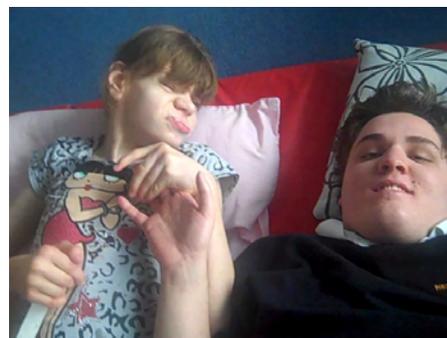
a while he said, "This is amazing. It's like you're dancing on my back." And I thought, that's exactly what I'm doing. And then I



thought of the implications of offering a unique dance experience to the children that I work with.

I was very excited with the concept of making the music very explicit with the tactile interpretation. I wanted the deaf children with PMLD to be able to firstly notice sound and then tune into it and start to listen. I wanted them to find enjoyment in music and to be able to communicate through this dance experience. The massage is the tactile clue to the music. We give hearing aids to the children but if we don't give meaningful sound input it is easy for them to switch off and not start to make sense of the noises they hear. If we can help deaf children to make connections with music it has huge potential for learning to understand speech.

At work, our Complex Additional Needs Team did Swedish massage training and I amalgamated this knowledge into Dance Massage. Dance Massage has a huge advantage over other forms of massage because it is completely intuitive.



Anyone who is free enough to bop about can do it and you don't have to learn movement routines. All you have to do is listen and start feeling the music. Let the dance come from your upper body and channel it down your arms and hands on to your partner's skin. I use plenty of grapeseed oil so my hands can glide over the skin. Don't press or stretch – this isn't physio, just flow with the rhythm and the melody.

While you are dancing on your partner encourage eye contact and smiles. Respond to their



responses. Be totally dedicated to them and think positive thoughts about how much you like them. If the child vocalises, copy. Show you've heard and you appreciate their contribution. Some children's responses are extremely subtle. You will be looking for changes in muscle tone and breathing.

Try not to get distracted or talk to others. Dance Massage is very easy and pleasurable to give and receive but it does require 100% concentration.

Before you start using oil on skin you will need to build up to this with a progression of exercises. First put a dot of grapeseed oil on the child's arm. You will check this for any signs of redness before putting more oil on. You will also need to get permission to massage from parents and discuss any possible contraindications.

Here are some warm up exercises – always do at least two or three before using oil on skin. In this time you tune into listening and trust being in your partnership. Launching straight into massage using oil on skin may be far too invasive so go gently. Some children are very resistant to touch so take tiny steps. Do not impose your touch. If the child resists, stop. Change what you are doing. Try a different part of their body, make your pressure firmer or lighter. Change position. Change the music. Try another of the warm up activities. Usually you will find a way but sometimes the child may be unwell or want to be very active or not be in the mood. Don't worry, try again another day.

Contact dance – rock or sway to the music
Holding the child's arms or legs and dancing
Finger dancing
Patting your partner – experiment with different hand/finger shapes
Stroking with different textures – get a treasure bag and contrast cool metal spoon with fluffy feather or two other contrasts.
Stroking.
Using airflow – fans, puffers, cloths.

Make a Dance Massage CD

Choose a track for each exercise and 3 or 4 more for the oil massage. Choose something jolly to start with, something with a good beat to follow for the patting one, something gentle for finger dancing etc.

Preparation for Dance Massage

- So you've made your CD,
- Got your grapeseed oil in a squeeze bottle with a small nozzle to avoid spills.
- Got some old towels.
- A music system.
- Take a look at the room. Is it warm and comfy.
- Is it quiet – turn off computers and other noisy equipment and put a 'Do not disturb' sign on the door.

Prepare yourself:

- Take off watch, bracelets, rings and wash hands.

- Rub arms, hands, fingers and give them a flick – shake out any tension.
- Try and leave behind whatever is in your head. Put on the music and get the feel of it

Prepare the child:

- Talk about what you are doing and what is going to happen.
- Use a dot of oil on the back of their hand and do a couple of circular strokes This is an object of reference for Dance Massage
- Hearing aids checked and on
- Position child so you will both be comfortable



Now you are ready to start with the warm up activities.

If you want to do something different in your PE lessons and you like the idea of Dance Massage but don't have the confidence to start by yourself, I am available to come to your setting and do a workshop with your class. I will give you a CD with enough tracks to keep you going for a while, some oil and a pack of hand-outs to jog your memory.

Please visit my website for further information and to contact me: www.naomirosenberg.co.uk

Sounds of Intent: exploring how children and young people with PMLD engage with music

Adam Ockelford, Angela Vogiatzoglou, Graham Welch,
Evangelos Himonides and Sally Zimmermann

Introduction

The *Sounds of Intent* project began almost a decade ago, as a joint initiative of Roehampton University, the Institute of Education (University of London) and the Royal National Institute of Blind People. It involves teachers and therapists from across the UK. The project's original aim was to investigate the musical development of children and young people with PMLD, although its remit later widened to cover those with SLD too. Nonetheless, it is the musicality of children with *profound* needs that continues to lie at its heart: the researchers have always believed that if they could get to grips with the musical interests, abilities and needs of young people with PMLD, then their understanding of the musical capacities of other children would fall into place.

In the same year that *Sounds of Intent* got underway – 2001 – the then QCA (Qualifications and Curriculum Authority) published a music curriculum in England for pupils with learning difficulties (as part of the 'P'-levels). However, it seemed that their work was not based on any identifiable music-developmental research. For example, references in the 'Performance Descriptions' appeared to be largely anecdotal and often suggested using music as a means to different ends, such as scaffolding communication or encouraging movement. Although, as you would expect, the *Sounds of Intent* team believe that music has a vital role to play in promoting wider development, we also consider that a curriculum for *music* should principally be about how children develop *musically*. Of course, once this is established, there will be value in 'reading across' to other areas of learning (and we are currently working on this), but our view is that such efforts would be better informed and, ultimately, more helpful to practitioners and parents, if music development in its own right is better understood first.

A fresh start – the *Sounds of Intent* project

Given that, in 2001, *no* research had been undertaken in the field of musical development and PMLD, the *Sounds of Intent* research team decided to start by taking a step back and take a fresh look at the children themselves. This was achieved through systematic observation, using the expertise of a group of practitioners – importantly, both specialists and *non-specialists* in music. For a period of 24 months, we made video recordings of a range of children in action, and noted their musical actions, responses and interactions. We discussed which of these might be representative, exceptional or in any way indicative of musical attainment or progress. As ideas emerged, they were used to inform a new

developmental model, which appeared in several versions.

Our findings were contextualised in two ways. First, in the background, the team used contemporary research as to how musical development 'typically' occurs – which, it was recognised, may (but need not) be the same for children with learning difficulties. Second, the team considered how we all 'typically' make sense of music, using theories from the field of cognitive science, and considered to what extent these may be relevant for young people with PMLD and SLD.

The *Sounds of Intent* framework

These three sources of evidence suggest that there are six key stages in the understanding of and engagement with music by children with learning difficulties. These can be remembered using the acronym 'CIRCLE', and may be summarised as follows:

1. *Confusion and Chaos*
2. *Awareness and Intentionality*
3. *Relationships, Repetition, Regularity*
4. *Sounds Forming Clusters*
5. *Deeper Structural Links*
6. *Mature Artistic Expression*

Those with profound needs tend to function at levels 1–3.

The *Sounds of Intent* team considered various ways in which this pattern of development could be depicted that would make it readily accessible while conveying the idea that one phase builds on those preceding without replacing them. The team also wanted the model to give a general feeling of growth – of moving out into the world from an inner core.

Eventually, the following approach, which uses concentric circles, was adopted (see Figure 1).

The phases are divided into three distinct domains: 'reactive', 'proactive' and 'interactive'. These correspond to 'listening and responding to sound and music', 'causing, creating and controlling sound (including musical sounds)' and 'participating in sound and music-making with others'.

Needless to say, the boundaries between segments are not really as clear-cut as they appear in Figure 1. And while it is possible to read across from one domain to another, to segments that are at the same level (for example, 'encounters sounds', 'makes sounds unknowingly' and 'relates unwittingly through sound'), it is quite possible that a child's profile of development will not display this symmetry; experience suggests that 'reactivity' is likely to lead 'proactivity' which in turn is likely to occur before 'interactivity'.

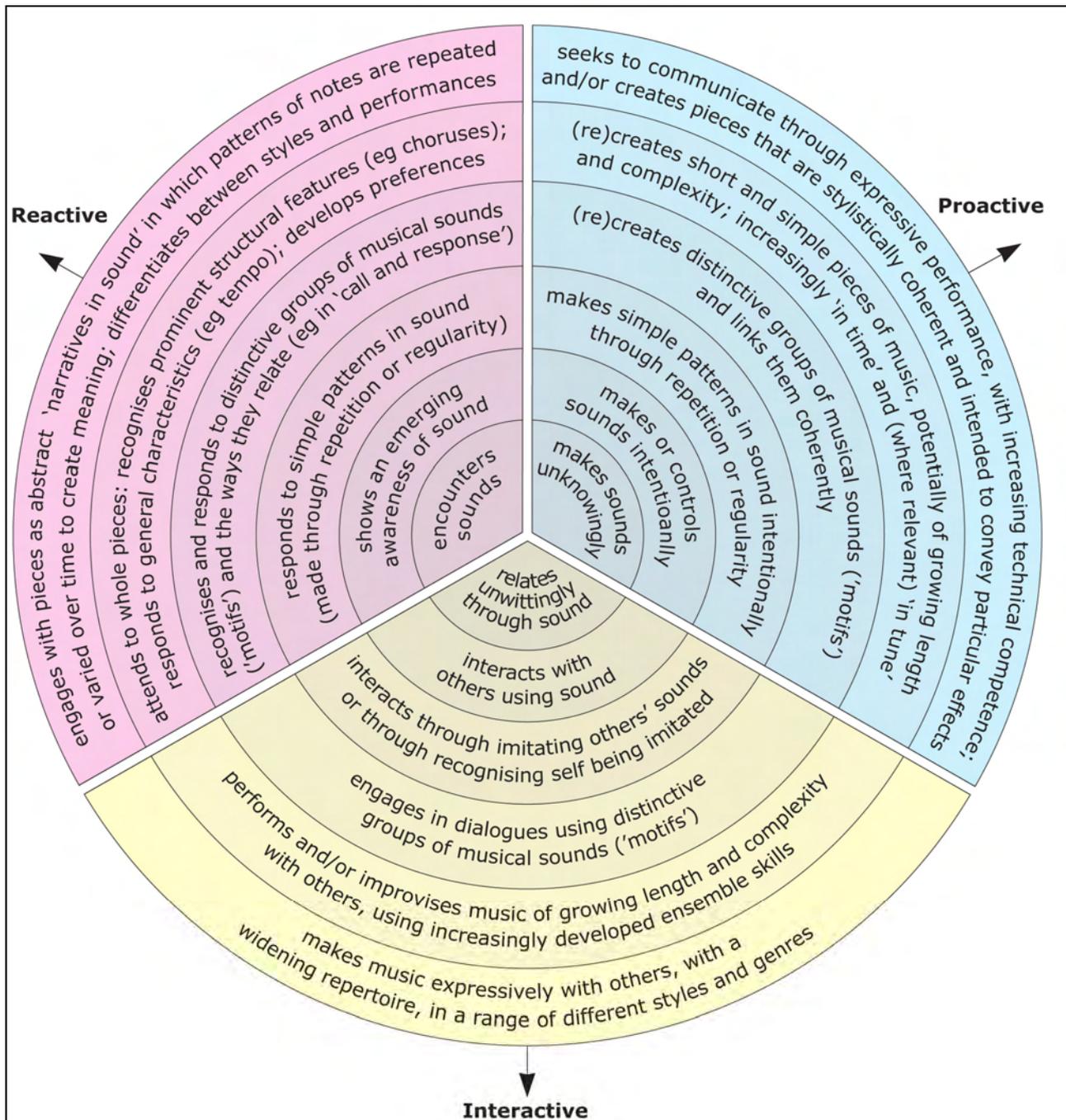


Figure1: Sounds of Intent framework of musical development

Continuing to work closely with teachers and therapists, the *Sounds of Intent* researchers broke down each of these ‘headlines’ into detailed elements (‘A’, ‘B’, ‘C’ and ‘D’). These were intended to enable practitioners to develop a fine-grained account of the level at which their pupils were functioning. Here, for example, are the elements of Level 2 of the framework (Figure 2).

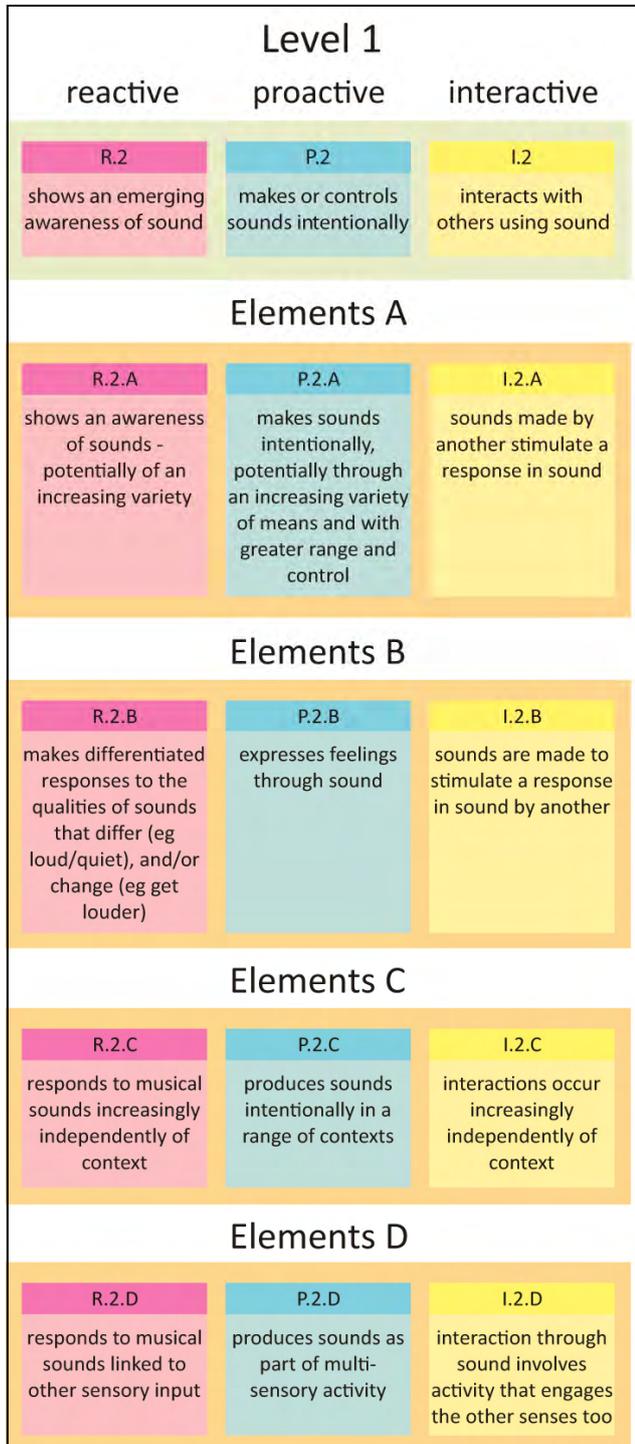


Figure 2

This idea was tested in a number of schools, whose feedback suggested that, in order to be of greatest

value to parents and practitioners (particularly non-specialists in music), the brief description that was captured in each element should be teased apart as follows.

There needed to be:

- (1) a more detailed account of the *observations* that practitioners were required to make in order to gauge that a child was functioning at a particular level;
- (2) *strategies* that would help promote further development (ideally these should be illustrated with pictures, and exemplified with audio and video excerpts);
- (3) *curriculum materials* at the appropriate level for the child concerned;
- (4) *references* to strengthen and broaden the conceptual thinking of practitioners; and
- (5) a simple numerical system that would enable a child’s *attainment and progress* to be gauged in the small steps that were deemed essential to recognise the achievements of those with PMLD.

As a consequence, the *Sounds of Intent* group produced more detailed materials. An example of ‘I.2.A’ (‘sounds made by another stimulate a response in sound’) is as follows (Figure 3).

Next steps

Within 12 months, it is hoped that the *Sounds of Intent* framework will be freely available on the internet for practitioners and parents to use in three main ways:

- (1) as a tool to assess the musical development of children with complex needs, including those with PMLD;
- (2) to promote further development through providing suggestions of ‘what next’ through appropriate resources and teaching strategies; and
- (3) to enable children’s progress to be recorded directly using a small digital video camera and microphone.

The concentric rings (shown in Figure 1) will form the opening page of a software package, with each segment constituting a potential link to its four, more detailed elements (see Figure 2), which will lead in turn to a page showing the material illustrated in Figure 3, complete with the necessary links. Being web-based, the package will facilitate easy communication between schools, the children’s homes and the research centre, thus enabling resources that are found to be useful to be shared easily, and to ensure that evolution of the framework

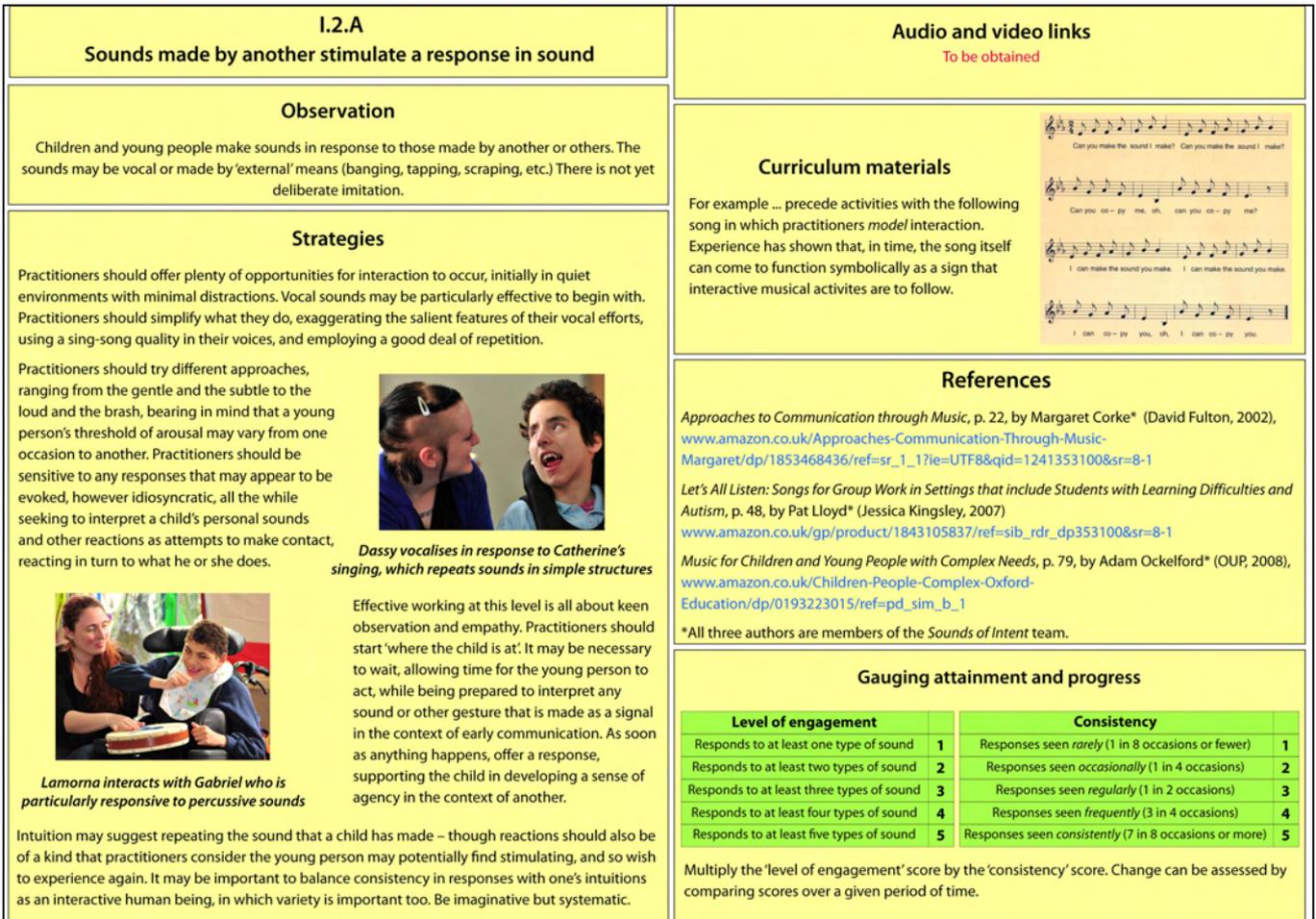


Figure 3

is ongoing, relevant and responsive to changing patterns of need.

The *Sounds of Intent* team are grateful for the generous support of the Esmée Fairbairn Foundation.

Adams and Christina's book is reviewed in this issue (page 45)

For further information please contact

Adam Ockelford
 Angela Vogiatzoglou
 Research Officer, *Sounds of Intent* Project
 Queens Building
 Roehampton University
 London SW15 5SL

a.vogiatzoglou@roehampton.ac.uk

Further reading

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Ockelford, A. and Matawa, C. (2009) *Focus on Music 2: Exploring the Musicality of Children and Young People with Retinopathy of Prematurity*, London: Institute of Education.

The Human Touch: physical contact and making a social world available for the most profoundly disabled

Julia Rhodes
Teacher at Ravenscliffe School in Halifax

Dave Hewett
Independent consultant, trainer and author of publications on communication and Intensive Interaction

'Touch is essential in order to provide sensitive and good quality care for the children and young people we support. Used in context and with empathy, touch supports the development of our natural interactions with the children and young people we care for.'

(McCracken et al 2009)

Introduction

Our sensory topic is touch: physical contact experiences, development and learning through physical contact, communication through physical contact. Our topic is that touch experience contributes massively to emotional, psychological and physical well-being. Our topic is also therefore, that not giving warm, frequent, social touches to people who have PMLD will be bad for them.

The intention of our paper is simple. Firstly, to outline the general case for the use of touch by means of a short, specific, very real case-study. Bethany's needs are extreme, even amongst the group we are thinking about in this journal. However, we nonetheless expect that her issues cause us to think about the needs of all. Secondly, we will restate and review the situation on physical contact issues and people who have severe, profound and multiple learning difficulties, that was set out three years ago by one of us (Hewett 2007).

Bethany

Julia Rhodes writes: Bethany was involved in a serious accident in 2004 which resulted in significant hypoxic brain injury. She has severe motor difficulties and weak head and trunk control. She also has a tracheotomy, a gastrostomy and is entitled to 24 hour NHS nursing support. So, when Bethany joined Year 7 at our School in 2008 it was very hard to see the 11 year old for all the medical paraphernalia and equipment she requires to get through a school day. In fact it turned out to be extremely difficult to get to know Bethany at all. Although the experts state she may respond to visual stimuli we have not been able to observe any consistent responses. Bethany does startle slightly at very loud sounds but no one has been able to assess what she can hear and is therefore

processing. The only movements we have observed Bethany making are jerking of her legs when the soles of her feet are touched and on occasions, moving her head fractionally towards midline when it is supported. She has never vocalised or cried in our presence although she has a phonation valve fitted to her tracheotomy.

After two terms of trying everything in my normal repertoire, I felt defeated and chronically guilty that we were letting Bethany down. She is extremely well cared for, has daily physiotherapy sessions and is fully supported to be present in all activities with her peers but it just wasn't enough. I didn't feel I was connecting with Bethany, didn't feel that I knew her.

Then we re-evaluated with the benefit of attending courses on Intensive Interaction. Gradually, but quickly, we reduced reliance on equipment: sidelyer, standing frame and bulky wheelchair in which Bethany spends the majority of the school day. We went back to basics which was perhaps what I should have done two terms previously.

Question: Where is the best place to work with someone who has extreme difficulties in seeing, hearing and moving?

Answer: Up close - as close as possible to you...

It sounds obvious, but it isn't how I'd been working. Please don't misunderstand me, I had worked closely, sat or stood next to Bethany as she was supported by the appropriate equipment and talked, sung, read, trying to her engage her. We regularly touched, working hand-over-hand to explore objects or play instruments and during massage, but that's how Bethany experienced touch with me - it was

functional and with a purpose. The best place, I now know, to communicate with Bethany is with her as close as possible to myself, either hoisted on to my lap as I am supported by a beanbag chair or lying side-by-side with her head resting on me, in a comfortable place like the waterbed. Yes, we carried out all pertinent consultation with physiotherapists and the moving and handling advisor.

Most people have strategies for seeking another's attention - gesture, vocalising, speech, movements, even more 'exotic communications' (Ephraim 1998). These opportunities are all unavailable to Bethany. However, we have learnt that after being hoisted on to or close to the adult working with her, it is noticeable that Bethany's body and therefore her breathing relaxes after approximately five minutes. There is then a sensation that she 'tunes-in' to you. During these close sessions it is possible to see Bethany's facial expressions change tangibly; somehow she appears more lit-up.

Touching closely is also more important than just an opportunity to communicate. If Bethany hadn't been involved in the accident, as a 13 year old now she would be able to choose close contact with her friends through social interactions such as: hugging, linking-up, whispering secrets and dancing with her friends. Currently she isn't able to do so and this is a way of offering her similar touch opportunities that are part of most people's experiences of growing up.

An emotional closeness to another person may not be the first 'human right' we think of, but in all social environments most people have colleagues or friends they feel close to or feel good just being with. Being in close touch with Bethany, hopefully, allows her to find a similar emotional contact with us. And, yes there are times when Bethany doesn't seem to wish it. There are occasions when Bethany doesn't relax and we take that as a lack of consent and we support her to feel comfortable in a different position or with a different person. On other occasions she relaxes so far that she falls asleep. But who would deny someone the opportunity to fall asleep in someone's arms, on occasions, instead of always alone?

Working so closely also provides sensory information that is otherwise not accessible:

- Your smell and that of your soap, perfume, fabric conditioner, etc.
- The different vibrations of your speech, singing or laughter
- The feel of skin-to-skin contact, the warmth, moistness and million intricacies of touch

These things are hard to achieve when securely supported in large and cumbersome positional equipment.

Then, there are the more deliberate actions that Bethany can be supported to experience; the jiggling, rocking, swaying which provide the 'fun' bits when participating in live music sessions, storytelling or play for most young people in education. Thinking of the wheelchair users I have come into contact with during my career the majority have repetitive movements they engage in at times (or for some the majority of the time) whether it be rocking, tapping, rotating their head or swinging their legs. Bethany can't choose to make any of these actions, so again close touch allows her access to this vestibular movement. Without these experiences Bethany is limited to the motions of being pushed forwards or backwards on a variety of surfaces, or the mechanical movement of a motor vehicle. Again, compare that to the repertoire of movements that most people can choose to engage in when growing up: spinning, swinging, rolling, jumping, frolicking, cycling, diving, swimming, skipping, running, hopping and dancing. The importance of these experiences in learning is starting to be fully appreciated.

The support staff team all feel that offering Bethany experience of touch has enhanced her whole school day and positively affected their practices. Now, instead of quickly and efficiently wiping her face when required, we have slowed down. We give more thought to her experience of the quality of our touch, for instance holding her hand simultaneously to help her connect the experience to us. After 15 months the team all feel they know her better and feel more closely connected with her. More importantly, our use of ourselves as the best sensory equipment there can be, is surely offering her a better quality of life than any amount of comfortable and supportive positional equipment could do.

'Do Touch' and subsequently

Dave Hewett writes: Doing the literature search for this article informed me once more that there is not much written in our field about touch, physical contact, and people who have severe or profound and multiple learning difficulties.

This realisation was also part of the background to the writing of the 'Do Touch' article in 2007 (Hewett 2007). Prior to this, when writing with Melanie Nind, I had always written the physical contact sections in our books on Intensive Interaction (Nind & Hewett 1994, 2001, 2005). When I was once more preparing the literature review for 'Do Touch' in 2007, I was dismayed all over again by the continuing lack of attention in all of the special education literature to physical contact issues.

Subsequent to the publication of 'Do Touch', I received a great deal of correspondence. I was worried that I might, it can be an understandably tricky issue, and I worried that I might especially alarm the child protection bodies. Nothing else that I have ever written has stirred up so much immediate reaction and the responses continue to this day. However, nearly every one of the communications said the same thing – "it's good that someone, somewhere has written this".

The child protection people did contact me. The Churches' Child Protection Advisory Service asked me if they could publish a shortened version of the article in their magazine, 'Caring' (Hewett 2008). They and other bodies had apparently become concerned that their very proper, continuous emphasis on child protection may nonetheless be contributing to an atmosphere of such general anxiety that parenting might be changing, with parents not giving so much formative physical contact and children generally therefore in danger of not being nurtured sufficiently. They wrote an accompanying article to mine own (The CCPAS Team, 2008) stating this case. It contained this very moving and surely totally true sentence:

"Touch is important. Without it, children die inside." (CCPAS Team 2008 p.20)

Despite a continuing lassitude on the part of special education writers and institutions, my subjective observation is that there is a growing sense of positive intent amongst the practitioners I meet and work with. Sometimes I even let myself entertain the prospect that the worst dangers of the likelihood of absolute 'no touch' policies is behind us. I increasingly work with staff teams who feel that they have discussed themselves into a proper and sensible position on the issues of physical contact. There is a growing confidence to articulate and put into practice their sense of intuitive 'knowingness' that not touching people who have PMLD will be bad for them and that giving them social touch in good quantities will be developmentally beneficial in so many ways.

Those members of staff may not be fully conversant with the science on the benefits of touch experience outlined in books such as Field (2001) (see also the Touch Research Institute http://www6.miami.edu/touch_research/). They may not be making access to the growing knowledge of neural development and corresponding cognitive and emotional well-being that is likely to arise from the provision of proper, human touch experiences. See Shore, R. (1997) for a seminal, still pertinent review of brain and nurture issues and Melanie Nind (Nind 2009) on well-being issues for people with PMLD. But, as I have stated, most practitioners I meet trust their mammalian instincts on touch issues and are generally, naturally alarmed by suggestions of 'no-touch'.

Nonetheless, people's human intuitions and any good practice arising from it needs to be backed up by paperwork, and crucially in this area, guidelines and safeguarding. Accordingly, another recent development is guideline writing. We have posted some specimen safeguard and guidance documents on the Intensive Interaction website (www.intensiveinteraction.co.uk). The quote at the very beginning of our paper is from one such, which has been beautifully drafted by an Intensive Interaction co-ordinator team in a residential establishment. I would also recommend, for all sorts of reasons, a thorough perusal of the Northern Ireland Curriculum 'Quest for Learning' materials (CCEA 2009). There are detailed sections on communication and sensory issues.

Contact details

Julia Rhodes
Dave Hewitt
j.rhodes@ravenscliffe.calderdale.sch.uk
daveinteract@hotmail.com

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Oily Cart – Multisensory Theatre

Tim Webb
Artistic Director

How do you make theatre for people who may not be able to see or to hear what is happening on stage? How do you put on shows for people who may become very anxious when encountering new people or situations? How do you create performances for people who may not understand that this is a story and that the actors are pretending to be other people? Why would someone who cannot recall what happened 30 minutes ago want to sit through an hour-long play? These are the questions that drive the work of the Oily Cart.

Oily Cart is a theatre company formed in the early 1980's. The motto on the van reads 'All sorts of shows for all sorts of kids' and over the years we've created work for many different kinds of young audiences, including babies as young as six months old. But since 1988 we have had a particular passion for making theatre for young people defined as having profound and multiple learning disability or as being on the autism spectrum.

Of course these terms, PMLD or ASD, are applied to an immense variety of young people. I'm sure you will find a much more homogeneous bunch of people in the stalls of the National Theatre than you would in any Severe Learning Disability School. So our aim for PMLD audiences is to create performances which offer something to young people with a very wide range of impairments. We know that our kind of theatre has to be multi-sensory, addressing the senses of touch, taste and smell – as well as the theatrical stand-bys of seeing and hearing. Our performances may involve aromatherapy, hand and foot massage, fans, foam and bubbles as well as characters who can be identified by the texture of their costumes, the 'Objects of Reference' they carry, or the scents on the wrist bands they wear.

In our show, DRUM, we use 3 large, 1.5 metre diameter drums as show screens, as light boxes, and also, believe it or not as drums. Towards the end of a performance



we also use them as a form of 'resonance boards', inviting the participants to sit or lie on the drum head, where they can feel as much as hear the sound. This form of deep vibration is delightful for many people, and for those who are deaf blind it can be a vital channel for communication.

We also always address the kinaesthetic sense, the sense that the body has of its own extent and position in space, in our performances and we find this approach very engaging for many, whether defined as PMLD or ASD – or not defined at all. We have performed in hydro pools and on trampolines to find way of communicating via this sense, and more recently we have used various forms of moveable seating, from rocking chairs, to swing seats to suspended seating. In our current show, SOMETHING IN THE AIR, the whole audience, six young people with six companions are flown up in to the air in specially designed safe and comfortable seating, where they swing, bounce and spin, mirroring the aerialists who fly above, besides and below them.

We also know that our theatre for young people with PMLD has to be highly interactive. In other words we need to be able to adapt what we're doing at any time to the requirements of a spectator. For example, in SOMETHING N THE AIR, one young person will want to be winched up high, while another will prefer to stay low; one participant will want to bounce energetically while another prefer to sway gently. Because we work in a very close-up way, we are able to observe the reactions of the young people – and their adult companions – very closely, and continually adjust what they are doing to suit individual needs.

Our theatre must also engage people with cognitive impairments who might not be able to follow a complicated narrative or the development of character. For these audiences I believe that



preparation is the key – and the more the better. We make a ‘Social Story’ for each of our shows which introduces the characters, the setting where it will take place, and the seats the audience will be using, and which also suggests ways in which the participants can prepare for the performance experience or make something which will be used in the show. We make these social stories available as DVDs, as photo-illustrated stories which can be downloaded from our web site and as hard copies posted in advance to schools. In addition, staff briefing sessions form part of an Oily Cart visit to a school wherever possible.

Our briefing sessions and Social Stories also suggest to staff and parents ways in which the immense stimulus of a theatre experience can be followed up, with ideas for practical activities back in the home or the classroom.

The fourth essential factor for the Oily Cart’s form of theatre is that it should be physically accessible. Whether we are working in a theatre, in a school or any other venue, we ensure that the space we are working in is welcoming and accessible. If hoists are not on hand, then we will provide them. We will always make sure that any theatre we are working in has appropriate changing facilities and a place where our audiences can relax before and after a performance. We take care that our programme of work provides a balance of shows that visit schools with those that invite the schools into theatres.

Sometimes schools prefer us to visit them, where all facilities are to hand and there’s less risk of stress for young people and staff. However, though organising a visit to a theatre can be hard work, the benefits of a trip out can be immense.

One question I am frequently asked is, ‘What difference does being in an Oily Cart performance make?’ I think there are probably as many different responses as there are participants, but for me the best thing that happens is when some young person reacts to a performance in a way which surprises, sometimes astonishes, the parents, or the carers who see them every day. ‘Did you see how she gave you eye contact? It’s not often she does that.’ ‘Did you see her reach for that shadow screen? I’ve never seen her so motivated.’ We create complex, highly stimulating situations, and our young audiences often react in quite unanticipated ways. Adult companions can see what particular technique caused this reaction. It’s often something that can be readily reproduced at home or in school. It is also moments like these that help all of us to see these young people, so often labelled with this syndrome or those behaviours, in a very different light.

Tim Webb
Artistic Director
Oily Cart
www.oilycart.org.uk

The role of touch in the learning experiences of children who have PMLD and visual impairment

Mike McLinden and Steve McCall
Visual Impairment Centre for Teaching and Research
University of Birmingham

Introduction

As an introduction to this article it is helpful to consider the Sensory Planner presented in Figure 1. This provides an opportunity for you to think about how we can draw on information through a number of our senses to find out about the world in relation to some important sensory functions.

?										Provide us with <i>incidental</i> information about the world that we can then draw upon if required. As an example think about the cover of this publication – what information have you acquired incidentally about it through vision (eg colour, font size, pictures etc)? What about information acquired incidentally through the other senses (eg smell, texture but probably not taste!)? You can now use your various senses to confirm this information.
Integrate										
Incidental learning										
Explore										
Confirm										
Anticipate										
Alert										
Function		Vision	Hearing		Touch	Smell		Taste		

Figure 1. Sensory Planner: The role of our senses in finding out about the world (adapted from Aitken and Buultjens 1992)

Using the planner consider to what extent each of our senses can potentially:

Alert us to something that is taking place in our environment. Examples include *hearing* a car alarm going off; *smelling* burnt toast in a toaster; *seeing* somebody walking into a room etc.

Help us *anticipate* what is coming next. Examples include seeing a ball coming towards us; hearing the footsteps of somebody walking out of a room etc.

Confirm information received through another sense. Examples include, looking at the coins in a purse to make sure they are the 'correct' ones; feeling a bike tyre to make sure it has sufficient air; smelling a joint of ham to make sure it has not gone off.

Explore something further in order to find out addition information. Examples include close inspection of a picture to look for particular details; feeling a pen to check if it is made of plastic or metal; sniffing in a room to find out where a particular odour is located.

information acquired incidentally through the other senses (eg smell, texture but probably not taste!)? You can now use your various senses to confirm this information.

Integrate information received through the other senses. As we consider further below this is an important role for vision and as such it is often referred to as the coordinating or integrating sense.

This activity provides us with a flavour of how complex the senses are in relation to each of the selected functions. Usually we take much of this sensory information for granted – until perhaps we have reduced information through one or more of our sensory modalities (for example, a blocked up nose, a sore eye, when trying to feel something whilst wearing thick gloves etc). For the purpose of this article an important point to make is that when sensory information is reduced through vision the other senses take on a more important role. Understanding the different ways in which each of the senses work is therefore very important if we are to support a child's learning effectively. The particular focus of this article is on the sense of

touch and its increased role in the learning experiences for children who have learning difficulties and reduced information through the sense of vision.

Significance of touch in a child's learning experiences

It can be argued that a significant feature of children who have learning difficulties and visual impairment is their increased dependency on other individuals to structure their learning experiences, including their interactions with people, objects and different types of sensory experiences, ie *what* and *who* they interact with, the *nature* of their interactions, *where* the interaction takes place, as well as the *duration* of any given interaction (McLinden and McCall 2002). Although we know that adult partners are key in providing learning opportunities to encourage children to become 'active' participants in any given learning activity we are only now beginning to establish what might be considered as 'effective' practice when supporting the learning experiences through touch of children with PMLD.

McLinden and McCall (2002) have outlined a framework to highlight the significance of a child's adult partners when supporting the child's learning experiences through touch. A summary of this framework is presented in Figure 2.

Within this framework, a broad distinction is made between sensory information which is relatively distant to our bodies (for example vision and/or hearing) and information received through senses which provide us with information about the world

which is 'close' to the body (for example, touch and taste). In the absence of consistent information through the sense of vision, information received through the sense of touch will increase in significance in a child's learning experiences.

Given the distinctive ways in which information received through touch is processed in the absence of consistent visual information, it is possible however that the child's learning experiences will provide imprecise information about the world unless these are 'mediated' at a level appropriate to the child's needs. This can have an important bearing on the child's knowledge and understanding of the world at critical stages of development, and each adult partner will need to have knowledge and understanding of his or her role in 'mediating' the child's learning experiences through touch to ensure that these are appropriate to the child's individual needs. In mediating these experiences it is helpful to outline some guiding principles that are respectful of the way touch works and which can be drawn upon when supporting a child.

Before we look at these principles we can consider a short scenario in a special school classroom for children with PMLD with a particular focus on a short interaction between Jamie and Mary. Jamie is a thirteen year boy with motor difficulties that affect the use of his legs and upper limbs. He has limited independent movement in his arms but can independently hold and manipulate objects with support. He also has a severe visual impairment which means that although he can see objects and faces when they are close to him (ie within 10 cm of his eyes) he has significantly reduced opportunities

- | |
|--|
| <p>1. The learning experiences of a child who has PMLD and visual impairment will incorporate a range of sensory information, some of which will be distorted in quality and/or quantity. In order to work effectively with the child, the adult partner requires knowledge and understanding of the child's level of sensory function, namely how the child receives, interprets and consequently acts upon different types of sensory information during a given task.</p> |
| <p>2. In considering how a child processes and acts upon sensory information, a broad distinction can be made between information received from a distance (for example through vision and hearing), and information received close to the body (for example through touch and taste). In the absence of consistent information through the distant senses, the information received through the close senses increases in significance in a child's learning experiences.</p> |
| <p>3. For a child who is more reliant on information received through the close senses, his or her learning experiences can provide imprecise information about the world if they are not mediated at a level appropriate to the child's needs. This can have an important bearing on the child's knowledge and understanding of the world at critical stages in early development.</p> |
| <p>4. The child's adult partner will need to have knowledge and understanding of his or her role in mediating the child's learning experiences through each of the senses to ensure that these are appropriate to the child's individual needs.</p> |

Figure 2: Four related themes guiding the development of effective sensory learning experiences (adapted from McLinden and McCall 2002)

to use vision to find out about the world at a distance (ie beyond 10 cm). His teaching assistant Mary has supported him for two years and each morning as part of the usual class routine introduces him to his tactile timetable for the day. This consists of a book with a selection of tactile symbols that are used to represent the various daily timetable activities.

Mary is aware of the need to think carefully about how Jamie's senses can be used to provide him with useful information. She appreciates for example that he is only able to gather limited information about the world at a distance through vision and so is more reliant on hearing and his close senses. She also appreciates that his close senses work in very different ways to vision, and if she suddenly presents an object to Jamie without informing him in advance he will withdraw his arms and may be reluctant to participate in the session. Similarly, he tends to startle easily and can burst into tears if there is an unexpected sound in the classroom. Prior to her morning interaction with Jamie therefore Mary considers how he gathers sufficient information through his senses to know:

*Who are you?
Where are you?
What are you planning to do?
What do you want me to do?*

The following transcript is based on a real life observation (although the names have been changed) and is used to illustrate how Mary structured the short introductory session to ensure it was appropriate to Jamie's needs.

Knowing who you are. *"Hello Jamie its Mary here. (Mary pauses and waits for Jamie to turn his head towards her. He turns his head and smiles at Mary)."Good morning Jamie nice to see you this morning. I'm just going to sit down next to you."*

Knowing where you are. *"Jamie. I'm going to put my hand next to yours on your tray. Listen carefully." (Mary places her hand on the wheelchair tray alongside Jamie's hand but not touching it). "Can you find my hand on your tray?" (She taps her left hand gently on the tray. Jamie reaches out to locate Mary's hand with his right hand). "That's right Jamie, that's my hand. Can you find the ring on my finger?" (Jamie explores Mary's hand with his right hand and locates the ring. He scratches it gently with his right index finger and smiles). "That's right Jamie – that's my ring".*

Knowing what you are planning to do. *"Shall we have a look at your timetable for the day now? I've got your timetable here. Listen carefully while I take it from my lap and put it on your tray." (Mary stops talking and allows Jamie to listen to her movements*

as she locates the timetable on her lap and moves it to his tray).

Knowing what you want me to do. *"Jamie, listen carefully now. If I tap the timetable three times on your tray can you reach out and find it?" (She taps it on the tray and leaves it for Jamie to locate. Jamie reaches out to locate it with his right hand). "That's right Jamie, that's your timetable. Shall we open it now and find out what we are going to be doing today?"*

We can now draw on this short scenario to consider a number of guiding principles that are helpful to think about when supporting a child's learning experiences through touch. These principles draw upon the work of Hodges and McLinden (2004) and McLinden and McCall (2002). They are not meant to be definitive but rather provide the basis for discussion when reflecting on your own practice. Indeed you may well be able to add to this list once you start this process of reflection.

Guiding principles to consider when supporting a child's learning experiences through touch (adapted from Hodges and McLinden (2004) and McLinden and McCall (2002).

Alerting a child to what is about to happen

Before touching a child first alert them to fact that you are about to touch them – if necessary tell them who you are so as not to keep them guessing. Touching a shoulder or hand without alerting a child can easily frighten them. Consider for example how Mary introduced herself to Jamie and 'invited' him to locate and touch her hand.

Ensuring consistency

In the potentially inconsistent sensory world created by PMLD consider how you might ensure a high level of consistency in the approaches used by the different adults to support a child's learning experiences. Examples might be the use of consistent language to introduce yourself prior to interacting with the child. In the scenario presented above Mary used a very similar approach each morning with Jamie to ensure consistency in her interactions with him.

Encouraging 'active' touch

Although 'hand-over-hand' guiding strategies can be useful (for example to draw a child's attention to particular features of an object), think about how such strategies can be supplemented with opportunities for the child to feel the object independently with reduced adult support. Touch works most effectively when the child or young person is provided with opportunities to examine the object or to locate objects independently. As an example, placing an object near to a child's hand to encourage him or her to reach out to it rather than

physically taking the child's hand to the object; shaking the object inside a small tray or box and asking the child to reach out and find it etc. For children who are unable to independently hold or manipulate think about what opportunities can be provided for them to act on an object with guided support (a golden rule is not to 'do the doing' for the child if at all possible!)

Non-threatening touch

If you have ever been touched on the back without knowing who is behind you, you can begin to imagine how threatening touch can be. Rather than doing things to children through touch think instead if opportunities can be provided to 'invite' the child to join in with activities involving touch. Importantly, also ensure there is an opportunity for a child to withdraw if she or he does not wish to participate. It is all too easy to think that effective learning through touch for a child with a severe visual impairment can only occur through direct adult contact with the child, for example introducing an object to a child using hands-over-hands guiding strategies. It is important to consider however whether opportunities can be provided for less directive approaches – when for example, the child has the chance to examine an object without always being physically guided by the adult. Mary's interactions with Jamie illustrate this point nicely – he was able to reach out to touch her hand and could withdraw his own hand at any point.

Predictable touch

Think carefully about your speech to ensure it is carefully matched with touch thus providing the child with a predictable and secure experience. It can be difficult for a child to process your speech and focus on touch at the same time. In the scenario above consider how Mary informed Jamie about what was about to happen then paused briefly while it happened. If you are going to undo a seat belt for example, you might first inform the child of what you are going to do prior to actually doing it (rather than informing the child *whilst* you are doing it).

Purposeful touch

Before touching a child think carefully about the purpose of the interaction. As noted above, it is all too easy to 'do the doing' for a child when in fact there may be other opportunities for the child to be more actively involved in an interaction. In the scenario above, care was taken with all interactions that involved intimate contact with Jamie. Touching therefore was not arbitrary but had a purpose, in this case to enable Jamie to access his tactile timetable and begin preparing for the day.

CONCLUDING THOUGHTS

Within the wide range of educational needs created when profound and multiple disabilities includes visual impairment, the role of touch in a child's learning and development can easily be neglected. Indeed practitioners and researchers are only now

beginning to appreciate the complexities as well as the subtleties of this powerful sense. Through careful reflection on your own practice you can begin to appreciate the importance of your own role in mediating a child's sensory experiences in order to promote effective learning opportunities. You can also consider how these experiences need to be structured to ensure they are respectful of the subtle differences in the way each sense provides us with information about the world.

Contact details

Mike McLinden
m.t.mclinden@bham.ac.uk

Steve McCall
s.mccall@bham.ac.uk

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Tactile books – for everyone

Marion Ripley
Director, ClearVision

The value of books at every stage of a child's (and an adult's) life is undisputed. Books bring pleasure, stimulate the imagination, increase vocabulary, pass the time, convey information, amuse, provoke and entertain. How much of this can we bring to a young person who, because of sensory and learning disabilities, is not able to engage with books in the same way as other children? This is the challenge faced by the ClearVision library as we try to develop a loans collection of tactile books for young people with PMLD and visual impairment.

The ClearVision library The ClearVision library was set up in the mid-1980s to provide braille and print children's books for young children learning braille to share with sighted classmates and family. What started as a few books in a box has now become a national resource with over 13,000 adapted mainstream picture books which are lent to over a thousand families, schools, libraries and visual impairment services all over the UK. We now stock books for babies through to newly-fluent readers and we also have books labelled in Moon (an easier alternative to braille – see www.moonliteracy.org).

Tactile books In the year 2000, in response to demand, the decision was taken to start a loans collection of hand-made tactile books. We now have over a thousand of these wonderfully stimulating books available for schools and education services (but not families) to borrow.

With more and more new members joining the library to borrow tactile books for children with multiple disabilities and visual impairment (MDVI) we are keen to develop books which are especially designed to meet the needs of these students, who may not ever be readers but who can still benefit from books.

An initial meeting was held with teachers and support staff from the Harris Centre for young people with PMLD at Linden Lodge School. These professionals were convinced of the need for books for the students they work with and they provided invaluable information and ideas on what was and was not needed. It was agreed that whilst the format of a tactile book might be very different to that of a mainstream book, it should nevertheless have 'a beginning, a middle and an end' and it is this which differentiates a book from a toy, a playmat or a box of multi-sensory items.

Many of these children will have physical disabilities which may greatly inhibit movement. The books will need to offer sensory rewards for the slightest movement and may need to be presented to the

child's skin rather than the child exploring it by touch. Sounds would be valuable, as would dangling items. The books should be short. Ideally the pages should be removable so that they can be used one at a time if this is more appropriate. The books will definitely need to be washable.

These books should not aim to 'teach' a concept or a skill. They will not be used to promote literacy; the text, if any, will be there solely for the adult supporting the child. The primary aim of the books we are designing is to stimulate and possibly achieve some kind of engagement with, and response to, the book.

As a result of these discussions we have now produced two prototypes which are being trialled with students with PMLD and a visual impairment. If you would like to try out either of the books, do please get in touch.

Choosing Mittens This book consists of a front cover and four mitten-shaped pages which the student's hand can be slipped into. The lining of each mitten is different and only the last one has a desirably cosy lining – which has also appealed to a squeaky mouse to be found inside the mitten.



On the back of the cover page (which is not a mitten) there are dangling balls which can be used to caress the student's hand, arm or cheek. The pages can be detached and used separately. Elastic straps have been added so that



the page can be attached to the student's equipment (eg safety belt) where it might be encountered through random or intentional movement. The mouse's dangling tail on the final page can be trailed across the student's skin.

Barefoot Ben For students whose toes are more mobile or more receptive than their hands we are trialling a couple of 'floor books' (featuring Barefoot Ben and Jemima Jane) to be explored with feet. Facing pages present matching surfaces (for example rubber matting, artificial grass, velvet, etc) and the last page has a toe tickler. A simple narrative links the pages.

Floor book about here if it reproduces well enough

Two books which have been in our library for a long time have proved popular with these students. *Five*, by Ann Gardiner, is simple and robust. With each page turn one more hole is revealed with the reward of a squeaker to be pressed. *The Giant's Boot* features a giant who keeps finding improbable everyday items in his boot. The rhyming text is predictable and engaging and the story can be acted out with a real boot and



real objects to prepare the student for the book with its lifelike thermoformed illustrations. Until recently this book was available for sale from RNIB but it has now, unfortunately, been discontinued. *Five* and *The Giant's Boot* can both be borrowed from the ClearVision library.

Have you any ideas? If you know of a book – or anything remotely resembling a book! – which has gone down well with children and young people with MDVI we would very much like to hear from you. Similarly, if you have any ideas which you think would work well please share them with us. We may be able to turn your idea into a book for the ClearVision library! Most of our tactile books are hand-made by craft groups, Women's Institutes, students, church groups and individuals. We have also had copies made by women in the sewing workshops of three prisons.

Together we might be able to come up with something great!

Contact Details

Marion Ripley
ClearVision children's braille library
Linden Lodge School
61 Princes Way
London SW19 6JB.
Tel: 020 8789 9575.
www.clearvisionproject.org
info@clearvisionproject.org

Meaningful participation for people with PMLD

Mandy Williams

Sensory cooking, sensory drama, sensory art, sensory garden, sensory room What does the word “sensory” written before the activity or place imply? All activities and places inherently provide opportunities for sensory experiences. A “sensory-focused approach” refers to manipulating the sensory elements of any activity to support and enhance a person’s participation. Some people need a lot of support to participate in any activity. People with profound and multiple learning disabilities (PMLD) often prefer specific sensory experiences provided by everyday activities or self-engagement. They may also focus on the immediate, the “here and now”, each step of the task rather than the outcome of the activity. Using a sensory-focused approach in combination with knowledge of the person’s communication strategies, skills and interests can effectively support the person to engage in activities in ways that are meaningful to them.

“We are all sensory beings, yet our experiences are unique” Dunn (2008). We describe our experiences in sensory terms using words such as hot, rough, smelly, quiet, and yummy. We also describe how the experience makes us feel, for example, happy, frightened, challenged or anxious. We vary in the amount and type of sensory information we each require to perform everyday activities. If we have difficulty processing sensory information it can impact on our ability to participate in everyday life (Sensory Processing Disorders). To provide meaningful, enjoyable sensory experiences for people with PMLD the support person requires knowledge and skills in applying sensory-focused interventions. This technique is prescriptive. The sensory elements of activities, the environment in which they are conducted, and the behaviour and presence of the support person are “manipulated” to match the person’s sensory preferences and strengths. A sensory-focused approach individualises the levels (thresholds/intensity) and durations (time) of specific sensory experiences within activities.

Task analysis is used to create a skill-task “match”. It ensures the person’s sensory preferences/strengths, communication strategies, skills and interests are matched with the levels and types of support that they will require to participate at each step of an activity. Task Analysis enables the support person to create individualised experiences that provide optimum opportunity for the person to be an active participant. Providing activities using this technique creates a script for the support team. It ensures consistency of support. Consistency of support helps the person anticipate, often reduces their anxiety and behaviours of concern and highlights more interactive opportunities with the person’s communication partners.

An example:

David prefers deep touch (tactile), is reactive to loud or sudden noise (auditory) and dislikes strong smells (olfactory). David used to avoid having a shower. He would hide or self abuse at shower time. Concerned about his behaviour the support staff completed a task analysis. At each step of the task they considered how they might enhance or reduce specific sensory elements.

David now enjoys having a shower. Support staff indicate “shower time” using an object cue that provides lots of texture (tactile) when handled – a body buffer. David now leads the staff to the bathroom! A fan removes any strong odours prior to David’s arrival at the bathroom. His nightly showering routine now includes lots of deep touch opportunities such as lumpy soap, body buffers, textured face washers, nail brush, a pulsating shower head and textured towels and bath mats. A sign on the bathroom door prevents sudden interruptions (auditory). Any conversation relates specifically to the activity. The staff have stopped using the radio (auditory) in the bathroom. Consequently David can now concentrate on what support staff are saying/signing and follow one and two step instructions. Staff introduce soaps and shampoos (smell) that David has smell tested and selected on a shopping outing. Showering is now a positive experience for David and his support staff have been surprised and delighted at the interactions and skills he now demonstrates.

Contact Details

Mandy Williams
 Senior Clinician – Occupational Therapy
 Communication Resource Centre – a service of
 Scope
 Victoria, Australia.
www.scopevic.org.au

Contact details : mwilliams.crc@scopevic.org.au

Choosing what to do and making it happen Decoda and the Music Gym

Tom Smurthwaite
Technical Director

The Music Gym is an interactive sensory environment designed for and by people with complex needs. Over its five year history it has changed by design and by suggestions from members and their support staff.

At the time of the Music Gym's conception sensory rooms were generally soft, colourful and gentle sounding places where calming effects were laid on the user. While accepting the benefits of this approach, Decoda believed that interaction was



essential for the person to be able to take control. To enable people with severe autism and/or challenging behaviour to become involved, it was felt that a large space was needed: space to move around and use excess energy, to observe others and to feel safe.

So once a week a large gym is converted into a magical environment with the help of inflatables and technology. A maze in red, orange and white layers invites wheelchair users as well as walkers to explore its depths, and the images and sounds inside are changed by their banging on the walls. The bright orange bouncy castle can be for wild jumping or for just calmly sitting and experiencing gentle undulating movements that activate technology to trigger songs. There's a multi-coloured fabric gazebo with eight seats which can vibrate and a white igloo made of parachute material, open at the top and kept erect by a quiet blower.

In the igloo camera software allows anything in the camera view to be active. Different areas are highlighted and made live so that movement triggers sound and these sounds can be individual instrument sounds, a drum beat, bass, guitar, keyboard, or vocal and they are all linked to be in the same key, and same beats per minute.

We took a Wifi keyboard apart and attached the parts to switches on a board instead of a keyboard and this switch board can be adjusted to any height so that it is accessible to all. This triggers different images and films that are projected on to a wall. Security lights with lighting gels creating different colours, ultra sonic beams, motion sensing and capture from simple webcams are all used, and controlling the space with technology – currently five computers! - has helped to cut down the need for switches and their cables and keep the space free of tripping hazards.

The whole atmosphere of the Gym is changed and triggered by movement. If there are active people in the hall the sounds and images have a different intensity to those created by less able members. So the mood of the Gym changes depending on who is there. This adds the benefit of staff being able to choose the best time for their visit dependent on their clients' preferences.



The Music Gym in Hastings now has 80 members, some of whom have been coming from the first day. Through demonstrations at national exhibitions and events and by word of mouth the reputation of the Music Gym has spread nationwide. Because of the volume of enquiries they receive, Decoda now provides advice, training and equipment to enable other organisations to set up their own sensory environment.

Contact Details

Decoda
01424 439192
enquiries@decoda.org
Websites: www.decoda.org and www.musicgym.org

The role of the Multi Sensory Room/environment in 2010

Mark Gray
 Dual Sensory Consultant

In 1995 the author co wrote the bestselling Practical Guide to Multi Sensory Rooms with Richard Hirstwood. In this article prior to the publication of his new book, Mark Gray reflects on the past fifteen years and the development of multi sensory rooms and the use of them with people who have profound and multiple learning disabilities.

When our book was first published in 1995 there was no New Labour and the Valuing People white papers, no person centred thinking, personalisation, or individualised budgets.

Special schools, hospitals and day services were still the main places where these rooms could be accessed and where most people with PMLD spent their days. Fifteen years on the education and Adult care landscape is radically different but the Multi Sensory Room seems to have somehow endured, but sadly not always in the best interest of those who may be experiencing it.

Rooms now can be found in hospices, mainstream schools, leisure centres, children's wards in hospitals or resource centres for the disabled, care homes for the elderly and the industry has expanded and developed, some old companies have gone, other new ones have developed. The equipment companies have slightly modified old designs and you now have different projectors etc. but essentially though not much has changed.

The reasons Richard and I wrote that book were fundamentally to stop these things being built without thought, used without thought, and planned without thought and in the course of my research into this field again, another book is long overdue.

The sensory room is a great resource, however it needs to be used as a tool with clear objectives and planning and when working with individuals you have to ask, do you need a room or a particular piece of equipment.

There seem to be several common traps that people fall into.

1. The integration/ show case trap The integration trap is a result of complying to disability discrimination legislation and enabling people with PMLD or autism to access and experience something of meaning within a curriculum or service. The MSR looks great in the service brochure but no thought or investment was made in how it was going to

be used, the equipment is usually suggested by the sales rep against a budget that was allocated, it appeals to the great and the good and potential parents hoping to use that service.

- 2. The inherited trap** Equipment has been saved from a building closure and passed on to another service because it was expensive and needs to be used. No one has done any training on it but with a bit of common logic it's plugged in and played with but with no thought as to how it might be applied. In other cases a previous installation comes into new use as the main service has changed but nobody knows how to use it except to switch it on.
- 3. Been on a course but we've got the wrong type of room/ equipment.** Essentially number two but someone finally finds out how to use the space only to find it does not suit the curriculum or service aims for the individuals they are supporting.

Avoiding the traps is actually easier than it seems, if you don't have a room or equipment stop right there and ask yourself what do you want the person with PMLD to get from a sensory approach?

The list that follows outlines when we might need or use this type of equipment, and it doesn't have to be MSR equipment. Toys from fairs, markets, and toshops are equally effective.

1. Assessing sensory function

Vision/ hearing/ touch

Ask yourself the following:-

What do you want to know about the person's sensory responses to the environment and how well do they use their sensory function ability?

What equipment can you achieve this with?

Does the assessment need to be in a peripatetic situation or in a specialist location?

2. Exploring cause & effect

Switching /reach and grasp

What equipment gives the right effects that motivate the individual to switch it on or off?

Will the room equipment do it or are there other simple switch alternatives?

How programmable are your switch controllers to achieve the desired effects?

Does it need to be portable or in a fixed space?

3. Are we looking at leisure or work?

How a space is used is important, work implies some assessment goals and outcomes that mean you need to know how they are measured, and which bits of equipment will achieve it for the individual. It also assumes that you know how the equipment works and what its sensory properties are?

If its leisure it can be passive and relaxing or interactive and explorative.

How does the individual enjoy leisure?

How do you know?

4. Communication and choice

How is the equipment named? Signed? Pictured? or objected?

How does the individual choose their activity?

5. Group or individual access?

Some people can be over stimulated in rooms particularly with everything on at once and this might be too much for them. What strategies and preparation have you put in place?

How will you design or develop individualised person centred access?

6. Themes & sensory story telling

A good use of a room is as part of sensory story telling or drama experiences but this requires preparation and thought and planning, however "Tac Pacs" can be just as effective.

Essentially the rooms and companies have changed a little in fifteen years, the equipment updated, but the key issue remains planning and application. Investment in initial training and time in the development of new projects that are user or curriculum led, will save a lot of mistakes and potential traps further into the future.

Contact Details

mark@markgrayassociates.co.uk

Mark's new book "The definitive practical guide to Multi Sensory Rooms and their use" will be published in the autumn by Quay Books and will be available through www.markgrayassociates.com

Mark Gray Associates

" for all your specialist communication training & sensory function assessment in PMLD" for details contact Mark Gray on 0115 9732540 web site www.markgrayassociates.com



MarkGrayAssociates

Soundabout Sparklers

A Music and Communication Group for families with children of three and under with PMLD and diverse needs using Resonance Boards and simple resources

Sue Simmonds

In a desire to support people with PMLD throughout their lives, Soundabout has expanded its training programme and family sessions to include specific work with babies, young children and their parents, carers and siblings.

This article focuses on how a collaborative approach between Soundabout and The Leys Children's Centre in Oxford has explored the value of music and communication groups for children, parents and carers of children of three and under with PMLD and other Special Needs.

Jay

Jay (pseudonym) was six months old when he came along for the first time with his Mum to a Baby Soundabout session. He was blind and had a severe hearing impairment. He did not move independently and did not make a sound.

Jay had a life limiting condition and had not been expected to live beyond six months. Mum and Dad were living with this uncertainty.

For Jay's mum expecting her first child had been an exciting and wonderful time. She and her partner had taken time to make the decision to have a child and had made many plans. The birth of Jay brought shock and trauma, and along with that a sense of loss mingled with feelings of guilt and inadequacy. She seemed in a state of shock and joylessness. Her first comments to me were 'This is Jay..... He can't do anything'.

It seemed at first glance that he was especially unresponsive. Certainly her attempts to engage with him had left her dispirited because of his lack of reaction or response. It was hard for Mum to continue to play and interact with Jay because there appeared to be no feedback. Communication is a reciprocal event that takes place between two people and Jay was not responding.

We chatted for a long time and I talked about how Jay might enjoy the sensation of vibration. We lay him on a blanket on the little resonance board. We continued by tapping close to one side of Jay's head. It seemed to us that he may just have noticed. We couldn't say for sure but we felt positive about a response.

Jay's Three Games

We tapped gently and sang his name and I noticed a flaring of his nostrils in the pause. 'Look, look' I said, and mum watched. 'He's responding to your voice. Can you see?' She had seen, but had not appreciated that she may need to look for such small signals.

Jay responded to a long scratch down the resonance board by minutely moving his fingers. We built a rhythmic pattern and each time we stopped there was a slight movement. We sang 'scratch, scratch, scratch, scratch, scratch, scratch, scratch.....Jay is (waiting for the response) *moving his ...fingers*' and we touched his fingers. Mum said she had never noticed him move his fingers before and was visibly moved.

Our third game was a rhythmic tapping close to Jay's feet and singing along to the tune of 'Knees up Mother Brown'. An unlikely melody for a baby, but it has a great beat. We sang, '*Tapping by your toes, tapping by your toes, tapping, tapping, tapping, tapping, tapping by your..... (wait for a movement,...yes) toes*' and touched his toes.

Jay had shown us three games that he seemed to enjoy. There was now an opportunity to repeat those games and notice whether the responses were the same.

We left time for Jay to process and respond within a silence filled with anticipation. We tuned into his simple communications by careful observation of his tiniest responses; and by setting aside expectations, and building upon these tiny movements, Jay showed us that he had noticed. This reinforced for him that his signals were meaningful and made something happen.

Together we explored possibilities. We recorded the 'games' that Jay had shared with us so that we could use them again hoping that we may begin to notice whether Jay showed signs of recollection.

Once again I had been reminded of the importance of setting aside expectations and to be inventive and intuitive. Giving focussed time to observe and build upon those things that Jay could do and liked to do, provided the sensory experiences which triggered a response.

The mood had changed. We felt positive. Mum and Jay went away with three ways to share an interaction and show Dad.

Groups for Families

My experience with Jay and his Mum confirmed my belief that there was a need to create a welcoming and comfortable place which parents of babies or young children with PMLD and other special needs, could visit to share in enjoyment of their child. They could also come to gain information, ideas, and support, and perhaps to befriend one another, and that this could happen either individually or in a small group. Contact with the local Children's centres revealed that in many cases parents of children with PMLD and those with diverse needs were not visiting the centres, and that the centres were not specifically catering for these families.

Leys Children's Centre

At the Leys Children's Centre in Oxford Inclusion worker Ruth Donaldson was thinking along similar lines. Her work involved meeting families at home and supporting them in visiting the centre. She wished to find a way of creating a specific group for those families with children with PMLD and other complex special needs. It seemed obvious that we work collaboratively. Ruth is employed at the Children's Centre as Inclusion worker with a specific role to visit and support those parents in the community whose children have additional complex needs and PMLD.

Ruth and I brought our different skills to the session. Her knowledge and experience of teaching children with a range of diverse needs, of working with families, and her professional contacts provided a broad area of support for families.

My particular focus is in enabling the development of communicative relationships and a sense of wellbeing. Through these shared interactions children can discover ways of engaging with the world outside of themselves using simple sound and spontaneous music making. Basic techniques engage and motivate children to become responsive.

Resonance Boards and Group Sessions

I have a particular love of the resonance board as a tool for enabling children to explore listening, sound production, body awareness, self motivated movement, a sense of control and a sense of belonging. A most important feature is its accessibility to all for creating and experiencing sound and vibration - and the role it plays in creating a medium for shared enjoyment and play. I wanted to use the boards as part of our Sparklers Music and Communication sessions to create a feeling of togetherness.

The sessions have developed a set time structure. Parents arrive at ten or soon after. This remains flexible to accommodate differing needs. Coffee and chat forms the first part of the session and I take responsibility for playing with the children so that parents can spend times with Ruth who can offer help and support. Sometimes an outside speaker comes along to provide valuable information and learning, or we set up an activity to share working towards creating our own communication kit bag.

At a particular time we put resonance boards down on the floor surrounded by cushions and all gather on and around. There is a sense of being invited to join in and that joining in can be by: being present,

Sparklers: Music and Communication Sessions. Outline of the contents of a session

- A structured welcome establishes familiarity.
- Children's names are called and responses are acknowledged.
- Spontaneous changes in pace and sound relate to children's reactions and responses whether vocal or as movement.
- Songs about what is happening highlight individual's actions, with repetition and pauses to discover who is interested.
- One to one play builds upon basic communication techniques.
- Each has a chance to influence events either intentionally or unintentionally
- A sensory focus is highlighted such as: hearing, listening, looking, touch, movement, sound production.
- Simple resources enhance play such as: scarves, small elastic loops, scrunchies, and a treasure box of sounds.
- A relaxed ending adds voice sound to a heartbeat.
- Acknowledgement of each person's contributions is positive and specific.

by looking, listening, noticing, relaxing, vocalising etc. Everyone participates at a pace and in a way that suits them and there are no fixed expectations. Rhythms and vocal sounds support the session to create a playful atmosphere in which each individual feels comfortable and is enabled to initiate an idea and demonstrate a preference.

We have planned the sessions to include specific experiences such as a focus on listening or looking, body awareness, touch etc. with ideas to take away. We also timed the session to fit in with the 'Stay and Play' group at the children's centre hence providing opportunity for shared play and friendship.

Parental Support

The group sessions have been successful in as much as parents continue to want to come along. Sometimes there may be one or two children and at other times several more. We intend to limit the group to about four or five families so that there will

be time for individual children's needs in a safe intimate environment. If there are more interested families we may need to create another group! There is something very important and special about being part of a group, which shares in the enjoyment of each others company.

If you are interested in Soundabout Sparklers, or the work of Soundabout generally and the role that it plays in providing training in schools and other centres for families through music and communication please contact.

Contact Details

Sue Simmonds
Soundabout Trainer

suesimmonds@soundabout.org.uk
www.soundabout.org.uk

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It Just Made Sense

Anita Bradshaw
SEN Teacher, Isle of Wight

In these days of constraints on budgets, specialists all too often have such large caseloads that their actual input regarding individuals is as minimal as most systems will allow. Teachers often find themselves faced with spending days, weeks or months with children that need, and are waiting for, help from Physiotherapists, Occupational Therapists, Educational Psychologists and Speech and Language Therapists.

The sad fact is, not only do some pupils go through school with their difficulties undiagnosed, but the very nature of their difficulties often go unrecognised by many staff who come into contact with them. Those exhibiting so called 'challenging behaviour' will often have their behaviour logged, monitored and in some cases have programmes set up to modify them. But all too often the underlying cause for the behaviour is not found because staff are looking in the wrong place.

One common area of difficulty is sensory issues. Finding out if a pupil has difficulties relating to Sensory Processing Disorder (SPD) or Sensory Integration difficulties (SI) is usually through referral to an Occupational Therapist (OT). However, very limited access to an OT means long waits for appropriate support and relief from those difficulties. Until schools all follow a model in which every site houses resident health and other well-being specialists as well as teachers, help will rarely be close at hand, either for professionals who need time to discuss their concerns over individual pupils or for the pupils.

Pupils showing signs of distress potentially linked to SPD/SI are common in special schools. Many people with learning difficulties have problems associated with SPD (Eide and Eide, undated; Kranowitz, 2005; Biel and Peske, 2009; Woliver, 2009). Diagnoses known to have related sensory difficulties include; Attention Deficit Hyperactivity Disorder (ADHD), Dyslexia and Dyspraxia, Angelmans, Asperger Syndrome / ASD, CHARGE, Childhood Disintegrative Disorder, Coffin-Lowry Syndrome, Williams Syndrome, Down's Syndrome, Elective Mutism, Fetal Alcohol Syndrome, Non-Verbal Learning Disorder, Prader-Willi Syndrome, Epilepsy, Rett Syndrome, Fragile X, and some anxiety disorders.

A recent audit at a special school on the Isle of Wight found that 52% of the pupils have conditions sometimes linked to Sensory Processing Difficulties, yet despite several of these pupils displaying behaviours which are often associated with SPD, only a handful of pupils have activity plans or

'Sensory Diets' designed to alleviate these problems. Awareness of Sensory Integration difficulties and SPD has since been raised within school and several pupils have been highlighted as needing assessment and input from an OT. There is no disputing the fact that OTs are highly trained specialists whose experience and expertise is invaluable. Every child who needs OT assessment and/or support should get support. But, while recognising that no books or videos can replace OT input, in the interest of doing what you can to help the students, a 'stop gap' measure was sought.

Focusing initially on a group of pupils with severe learning difficulties (SLD), all showing behaviours which indicated possible SPD, a team within the school purchased several books with the hope that they would give the staff (and parents) involved a better understanding of the difficulties the pupils were experiencing, why they reacted in particular ways to certain stimuli and what could be done about it.

The books purchased needed to meet two criteria; they had to:

- A) help define SPD and offer checklists to identify the nature of the sensory difficulties individuals were experiencing and/or
- B) offer simple exercises/games that could be used or adapted for use, without risk or contraindications, to alleviate some of the pupils' possible discomfort/difficulties.

From the books purchased relating specifically to Sensory Processing/Sensory Integration, seven core books were used which together gave an overview and deeper understanding of SPD: Yack, Aquilla and Sutton (2002), Bogdashina (2003)*, Kranowitz (2005), Kranowitz (2007)*, Larkey (2007)*, Longhorn (2007)* and Horwood (2008)*. All seven have checklists to help recognise specific areas of difficulty. Five of these(*) have photocopyable checklist materials. Of these, Bogdashina's (2003) checklist gave the clearest breakdown of an individual's difficulties, the results shown on a graph highlighting the seven senses; vision, hearing, tactility, smell, taste, proprioception and vestibular.

However, many of the checklist questions are difficult to answer for someone else and are not always appropriate for SLD, let alone PMLD.

In terms of finding and recording responses to stimuli, the checklists in Longhorn (2007) were the most useful and the '**Sensory Happiness**' and '**Sensory Unhappiness**' checklists in the same book, which provide staff with a sensory 'pen-portrait', are invaluable as quick and specific guidelines for working with individuals in terms of both avoiding discomfort and for building tolerance. This is especially useful for individuals with PMLD. **The Social Skills Checklist** (Yack et al., 2002) also builds an informative portrait of the child.

While in no way as accurate as the screening offered by an OT, using the various checklists proved helpful in terms of identifying which areas individual pupils needed most help with. For ideas for sensory activities, again, seven core books were focused on:

Sensory Circuits (Horwood, 2008) - this is more appropriate to mainstream but adaptable and very well set out. Provides a very clear guide to understanding sensory processing and sensory integration difficulties.

Practical Sensory Programmes for Students with Autism Spectrum Disorder and other Special Needs (Larkey, 2007) - nicely set out and easy to use. Also has a section on using sensory activities for Positive Behaviour Support which is very useful.

Sensology Workout (Longhorn, 2007) - PMLD focus. Lots of ideas for planning, resource banks, assessment and monitoring. Also contains a CD with printable documents, instructional slideshow and a 'visual wakeup' slideshow which the pupils love, even if some of the staff claim they can't look at some of the slides!

The Out of Sync Child has Fun (Kranowitz, 2006) - lots of ideas. A really useful grid at the back of the book linking all activities to areas for sensory development. Aimed at physically able children but some of the activities can be easily adapted for SLD and some for PMLD. Kranowitz's latest book, published in May 2010, is more user friendly than this.

Starting Sensory Integration Therapy: Fun Activities That Won't Destroy Your Home or Classroom (Arnwine, 2007) - messy but fun. Not aimed at PMLD/SLD but many of the activities are easily adaptable. Very little in the way of information regarding SPD/SI.

101 Games and Activities for Children with Autism, Asperger's and Sensory Processing Disorders (Delaney, 2009) - although this book is

clearly laid out and very useful for planning lessons for more able pupils with sensory difficulties, it offers little in the way of a guide to SPD/SI and many of the activities are not easily adaptable for PMLD.

Early Intervention Games; Fun, Joyful Ways to Develop Social Skills and Motor Skills in Children with Autism Spectrum or Sensory Processing Disorders (Sher, 2009) - clearly laid out and very useful. Activities that are adaptable for PMLD, clear info on SPD/SI, adaptable for lesson planning. Generally a really good buy.

In terms of meeting the needs of pupils with PMLD, **The Sensology Workout** (Longhorn, 2007) was found to be the most suitable. It is specifically written with PMLD in mind. It is laid out in clear, easy to follow sections and comes with a CD which has useful checklists and other similar resources, as well as a comprehensive and detailed slideshow which can be used for training purposes. From the teachers' perspective, the author provides a useful chapter on assessment and recording, which includes target setting and links to the National Curriculum. Longhorn also directs readers to some really useful contacts and resources. As a bonus, the binding is particularly helpful (it is provided ring bound) as the pages stay open when you are trying to use them! In terms of working with PMLD, if you can only buy one book... buy this one.

Back on the Isle of Wight, the pupils involved in the initial stages of this 'stop gap' are enjoying more physical stimulation in terms of vestibular, proprioceptive and tactile sensory input. Using information from the checklists, a sensory diet based on individual needs is now in place for several pupils and more staff are becoming involved with delivering appropriate sensory activities. Class bases were subjected to an environmental audit which highlighted the need for greater sensitivity with regards to environmental factors such as noise levels and lighting, as well as clutter which can be responsible for visual overload. More awareness is evident in classes in terms of monitoring reactions to visual, auditory, gustatory and olfactory sensory input and making adaptations where needed.

For some of the pupils, the combination of physical input and environmental change has had a positive outcome in a relatively short time. As understanding of Sensory Processing Disorder and using Sensory Integration techniques continues to increase within school, key staff are looking into further adapting ideas from these books to help pupils with PMLD and ensure that all pupils benefit from this sensible solution.

Contact Details

Anita Bradshaw
anitasbradshaw@yahoo.co.uk

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Building Conversation Partners through Intensive Interaction

'The work of Pheobe Caldwell'

Sonia Debbat
Concept Training

WHEN people use the phrase, 'put yourself in their shoes' we would all like to say we try, but very few of us have the patience, skill and understanding to actually do it. One of Concept Training's elite, intensive interaction expert, Mrs Phoebe Caldwell is one of those extraordinary people who can position herself in the world of another and use this invaluable skill to help them. In fact, on many occasions Phoebe's knowledge and skills have significantly changed people's lives. While others are often confused and frustrated by a loved one or someone else's actions (particularly if they do not function in an expected way i.e. some people with autism and or severe learning disabilities), Phoebe works to break through the barriers and helps people build a bridge to the world around them.



At 76, Phoebe recently won the Times/Sternberg award for her work to improve the outlook for people with severe autism and/or severe learning disabilities. The Award celebrates the achievements of people aged 70

or over who have done most for society and good causes in their older age. Phoebe uses a method called Intensive Interaction to reach people and she is keen to teach others how to combat the social isolation of people with autism and or severe learning disabilities. She offers courses and training through a company called Concept Training, who are a leading national and international training provider, in partnership with Edge Hill University.

Intensive Interaction is a technique that uses the non-verbal or semi-verbal adult or child's individual body language to communicate with them. It is not just what they do - but how they do it that is important. Although interventions may start with imitation, they progress to building up conversations through answering and response. Since the brain is now presented with signals that it recognises easily without having to go through a distorted processing system, this helps reduce their stress levels so that their brain can function more effectively. As communication improves, the distressed behaviour tends to decrease. This approach helps sufferers and their families to understand each other and the disorder while improving everyday life.

Phoebe explains, "In our brains we have mirror neurons, which gives the body a motor response to what it recognises. For example, when you yawn, people around you get a sensation, which is similar. Another example is when you spend time with someone with depression you tend to change your mood to their level. We get over a million inputs per second into the brain and we filter out the unnecessary but some people's brains can't cope with this and they become distressed by the resulting sensory overload. The brain also finds it difficult to switch off, so a sound may continue in the brain long after its source has discontinued."

Most of the people living with conditions such as autism, severe or profound learning disabilities or sensory dysfunctional conditions have great difficulty translating the sounds and surroundings around them and this can cause them to be frightened, disturbed and it even may cause physical pain. Phoebe is keen to stress the Intensive Interaction method is not "simply copying" but responding to ensure their senses don't get overloaded. Making conversation out of body language, something familiar to the individual, allows these people to express themselves and communicate with others.

Using Intensive Interaction Phoebe reaches the unreachable. Instead of trying to force them into 'our' world she works through what speaks to the brain and gets in touch using familiar body language and senses. Describing the condition Phoebe says, ".....the brain is like a kaleidoscope where the pattern never settles. I use body language to tune into people..... It's easy to learn". With one child in 97 born on the autistic spectrum and this increasing the more severe the learning disability is, many of us will know someone affected by the condition. Phoebe is keen for people to know that

this technique can and does work. She has helped people she has met for the first time in a matter of hours whereas those around them have got nowhere in years.

A couple from Wales invited Phoebe into their home in hope of helping their son Steven. Steven was born with severe learning disability, epilepsy and autism. As an adult he has never developed speech. Steven's mother was thrilled by the difference Phoebe made. "The two days phoebe spent with us as a family and with Steven's care staff, proved to be what I can only describe as 'amazing'. We were taught to understand the sounds and gestures that Steven makes and shown how to respond to them. Over the last few weeks, Steven has progressed and continues to be more vocal each day".

Phoebe graduated as a biologist and then went to work in a learning disability hospital. With 35 years of experience in this field of work she received a Rowntree fellowship where she studied different approaches for working with learning disabilities. She was strongly influenced by the late Geraint Ephraim, a psychologist at Harperbury Hospital in Hertfordshire. Ephraim was in fact Phoebe's supervisor for four years and he introduced Intensive interaction in the 1980s. Phoebe says, "From him I learned to look at what my conversation partner was doing and particularly, how they were doing it. Is he

calm, or getting upset? I learnt to use his or her activity as a language out of which to build affective and empathetic conversations that tuned into how he or she was feeling, promoting emotional engagement." Author of eight books, she has also made training dvds on helping those with severe learning disabilities, addressed conferences, initiated research and worked with a large number of parents and professionals.

For contact details. 01524 832828 or email info@concept-training.co.uk, then in a box Concept Training - training programmes for anyone working or living with people of all ages who have special needs. Further details with regards to our courses, dates, venues and consultancy services are available on our web page. www.concept-training.co.uk

Winter Vol. 22 No. 3 Issue 67

- Lifelong Learning -

The copy date for all articles, information and news for the Winter 2010 issue is the 29th October 2010

Please send contributions to:
Beverley Dawkins
Beverley.Dawkins@mencap.org.uk

Spring Vol. 23 No. 1 Issue 68

- Communication - Speak Up Speak Out

The copy date for all articles, information and news for the Spring 2010 issue is the 25th February 2011

Please send contributions to:
Alice Bradley
alicebradley@talktalk.net
Or
Ann Fergusson
ann.fergusson@northampton.ac.uk

Articles can be long or short and they are welcomed from carers or professionals alike – we value YOUR experience and views. Please contact us if we can help you in any way. If you have any pictures or photos to include we would love to see them (providing we have permission).

Future Focus: Lifelong Learning

Guest Editors
Beverly Dawkins & Rob Ashdown

In the next issue of PMLD-Link we would dearly love to be able to publish accounts of opportunities for 'lifelong learning' for adults with PMLD. By 'adults', we mean from 18 years upwards. By 'lifelong learning', we mean any opportunities for people to continue to develop their knowledge and understanding and enjoyment of the world that they live in.

The recent report, '*Raising our sights*', by Professor Jim Mansell (see the Spring 2010 issue) highlighted the opportunities that further education can provide for adults with PMLD to continue to grow and develop. The report shows that only a minority of them have access to further education provision possibly because of a shift in priorities towards award-bearing courses. Further education for these people may even be mistakenly viewed as just 'day care' rather than education. Yet we know that there are some really good examples of truly excellent practice that you could recount.

By using terms like 'education' and 'further education' we do not want to limit your accounts to the more traditional ideas of what constitutes lifelong learning. We continue to learn throughout our lives [and often unexpectedly] and we want you to share examples of lifelong learning in the very broadest sense... *wherever* and *however* it happens.

Everyday activities in the community can provide many opportunities for learning. As Professor Mansell noted, the imaginative use of personal assistants and individual budgets means that adults with PMLD can spend more time doing activities they enjoy in the community. However, as local authority day centres are replaced with community-based activities, families supporting adults with PMLD are often extremely anxious about the adequacy of alternatives and concerned about whether the person will have enough meaningful things to do. It is important that, as traditional day centres disappear, we can celebrate initiatives that show that people can access safe and stimulating bases from which they may go to enriching and meaningful activities at different settings during the day. Whether or not an activity is meaningful or a learning opportunity will often depend on the attitudes and efforts of those supporting someone with PMLD. The most influential situations are going to be in person-centred contexts where there are positive relationships and enabling practices.

While good practice does exist, Professor Mansell highlighted prejudice, discrimination and low expectations as obstacles to its wider implementation. As he was at pains to point out in the report, most of the work required to tackle these obstacles does not require large amounts of extra resources. What are required from government and local authority planners and workers are empathy, imagination and willingness to make reasonable adjustment to policies, procedures, rules and priorities to ensure that adults with PMLD and their families get the opportunities they deserve.

We would love to hear your examples of inspirational practice whether you be a family member, a personal assistant, a further education teacher, a member of staff in an adult learning service, a representative of an independent organisation, etc. What does work well for adults with PMLD in your experience? What are the obstacles you face? How are you overcoming these? Can any of you provide a story about how a person has benefited from opportunities for further education?

Please send us your contributions on anything related to 'lifelong learning' preferably in RTF (Rich Text Format) or 'Microsoft Word'. Thank you.

Beverly Dawkins, Mencap, 123 Golden Lane, London EC1Y 0RT (e-mail: beverley.dawkins@mencap.org.uk)

Rob Ashdown, St. Luke's Primary School, Grange Lane North, Scunthorpe, DN16 1BN (e-mail: head.stlukes@northlincs.gov.uk)



PMLD Network Email Forum A Digest of Discussions April 2010 to July 2010

The PMLD Network forum is an open email discussion group which focuses on issues relating to PMLD. Here is a summary of the key themes that have come up on the forum over the last few months:

1. 'Specially 4 you church'

A parent who lives in Gloucestershire said that she had seen information from her local Baptist church which may be of interest to some Gloucestershire residents. She said she didn't know if other Baptist churches in other areas were doing the same thing. In 2009 the church launched a 'fresh expressions of church' outreach. Part of this has been to create a 'Specially 4 You Church' - a gathering one Sunday a month, for people who like a simpler service, in particular for those with a learning difficulty. Carers are also very welcome. More information on www.minchbc.org.uk

Responses included:

- Someone said it was terrific to see this Baptist Church initiative. They said that they had people with moderate, severe and profound and multiple learning disabilities in their congregation who enjoy the services in their own way. They said it is great that people with learning disabilities can become part of the community.
- Someone said that they are pleased to see some information about spirituality, disabled people and carers. They said this is something that professionals do not seem to recognise. They said that the spiritual side of life can seem inaccessible in all sorts of ways, for example, no ramps, service too long, family ignored, or expected to carry on life as previously. They also said it may become inaccessible, for example, families can no longer attend, disabled person is too ill. They said they were pleased to see things like 'Specially 4 You Church', Causeway Prospects, L'Arche, Through the Roof, Disabled Christian Fellowship, Carers Christian Fellowship, who have thought about this and provided for carers and people with a disability, for example, through their own communities, fellowship, holidays, adapted church services and newsletters.
- 'Specially 4 You Church' sounds wonderful. I hope this gets going in many more places and is enjoyed. I certainly would like to be part of that community as for some years now I am slowly awakening to the fact that no matter how hard I try I am unable to attain acceptance from the

community I live close by to and church is no different after all these are the very same people.'

- Someone said that they think what the church (at its best) can give is a sense of belonging, warmth, hope. Their own experience is that the experience of disabled people and their families is very mixed. They said it is inspiring to hear of the Specially 4 You Church, but sadly it is common for people to be left out. Their feeling is that we all need, at a deep level, to know that we are valued. It is not policies or procedures that give us this sense of our own value - it is each other. Their work is not based in religious thought but it emphasises human values and kindness. They seek to create communities in which no one is left out. They are currently setting up the 'Togetherness Foundation' to celebrate and inspire more people to be together. For more information see: www.frameworks4change.co.uk

2. Interested in using MOVE programme

Someone based in Lancashire said she was interested in using the MOVE programme. She wanted to hear how others have got on introducing it, persuading people and whether there are any disadvantages/ advantages/ success stories. She also wanted to know if it would be possible to visit a school where it is used.

Responses included:

- 'We have just started the MOVE programme in the SLD/PMLD school where I work. A member of each class attended a two day training programme and the physio staff are also involved. I feel that this has been needed for sometime and I have already seen progression in some of my class members. If we can maintain the same level of enthusiasm and commitment I have seen so far, these children will go from strength to strength.'
- 'I am a teacher who has been using the MOVE programme for 10 years our school is a regional centre of excellence for MOVE and I would be happy for you to visit in addition there are some special schools in Lancashire already using MOVE who you might want to visit. The Disability Partnership (trading as MOVE Europe) who oversee the development of the MOVE programme are a rich source of support: http://www.move-europe.org.uk/About_MOVE/index.html

3. Setting up a PMLD classroom

- Someone from an international special needs school in China said that more children with PMLD were joining, and that they were going to set up a PMLD classroom next year. They said they lack experience and resources in China and they wondered if anyone could give them some tips, for example, any particular things they should purchase or consider, information about conductive education and whether it works well in a PMLD class. They also asked if anyone is using ASDAN with pupils with PMLD.

Responses included many tips and suggestions:

- Contact the Centre for Special Needs Education and Research (CeSNER) at Northampton University. They have expertise within this area as well as an excellent Special School nearby that is involved in Conductive Education. <http://www2.northampton.ac.uk/education/home1/cesner>
- Ideally it would be worth someone visiting the UK as this is very specialist provision that requires carefully consideration.
- 'Exploring Access' is a publication about meeting the needs of children with complex needs and visual impairment, in terms of the classroom setting and the physical environment. http://onlineshop.rnib.org.uk/display_item.asp?n=11&c=481&sc=54&id=773&it=2&l=3
- 'There is an approach called Intensive Interaction, which I think you would find extremely useful: <http://www.intensiveinteraction.co.uk/>'
- The Welsh Assembly Government published some useful guidance called 'Routes for Learning', which include a DVD which illustrates the levels described and a comprehensive set of Additional materials which give general guidance in issues around working with students with PMLD. <http://wales.gov.uk/topics/educationandskills/curriculumassessment/additionaleducationalneeds/routeslearning/?lang=en>
- The DfES have a pre-entry curriculum for literacy and numeracy: http://www.dcsf.gov.uk/curriculum_preentry/
- Find out about the MOVE programme: www.move-europe.org.uk
- 'Creating a responsive environment' by Jean Ware emphasises the key role that developing communication must play in your work and provides a kind of introductory training pack around these issues.
- <http://www.amazon.co.uk/Creating-Responsive-Environment-Profound-Difficulties/dp/1853467340>

- Raising our sights: services for adults with profound intellectual and multiple disabilities'. The report can be downloaded at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_114346
- Centre for studies on Inclusive Education: www.csie.org.uk

4. Comments, compliments, complaints

Someone asked if there is a requirement that an organisation (particularly a service provider) should have a "Comments, compliments, complaints policy" for their organisation? They said that they have been in touch with a service provider who said they didn't have a written policy on this.

Responses included:

- 'Certainly a care service provider, if it's registered with CQC, should have a written complaints procedure which can be requested and should be provided prior to any service provision. Most service providers also have some form of compliments documentation as well.'
- 'Each service provider should be able to give you a copy of their policy and a named person to complain to.'
- 'Care homes, by law, have to have such procedures and policies. These are set down in the Care Home Regulations 2001 (Regulation 22, Schedule 4(11)): <http://www.opsi.gov.uk/si/si2001/20013965.htm>. Failure for a care home operator to comply with these is a criminal offence and should be reported to the Care Quality Commission. The requirement to comply is not the case with supported living.'
- Someone else said: 'Supported living is regulated (although not by CQC) and they have to go through very stringent annual inspections run by local authorities'. Someone else said 'the annual inspection by local authorities which you cite is not that "stringent".'
- Someone else said 'there is a rigorous annual check on Supporting People providers and I have been involved in this. The selection process is also very rigorous and anyone who does not come up to the mark will not get the contract. For details of the Supporting People programme see: http://www.direct.gov.uk/en/DisabledPeople/HomeAndHousingOptions/SupportedHousingSchemes/DG_4000297'
- 'All schools should have one and should be made available on request in addition to a reference in the school prospectus.'

New PMLD Link website coming soon!



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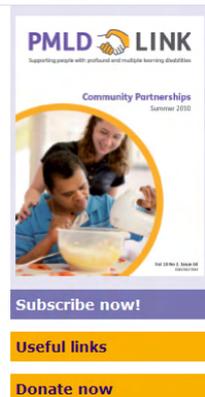
Homepage

PMLD Link is a journal which shares good practice in supporting children, young people with profound and adults with profound and multiple learning disabilities (PMLD)

It covers a wide range of issues to inform and support the day to day work of families, carers and professionals in the home, schools and colleges, and adult settings.

PMLD Link welcomes written contributions, including articles, information sharing and news about people with PMLD. We also welcome requests from readers for particular information.

PMLD Link is published three times a year. Subscribers receive a hard copy of the journal in the post and can also view the journal on-line.



5. Changing Places toilets in hospital

Someone was trying to find out where Changing Places toilets are in the UK, especially in the North West. She said she finds it quite distressing that when she takes her daughter to an outpatient appointment that there are no suitable toileting facilities for her. She needs a Changing Places toilet with a height adjustable changing bench with hoist and a room large enough to accommodate her bespoke wheelchair and two carers.

Responses included:

- 'If you go onto the Changing Places website, there is a map of all the Changing Places loos that are available in the country: http://www.changing-places.org/find_a_toilet.aspx'
- 'There are now 141 across the UK and more being added most weeks. There are 13 in the North West.'
- 'There is definitely one in the Trafford centre in the North West.'
- 'Some hospitals like Hallamshire in Sheffield have one and others are drawing up plans but it really helps if local people lobby and refer the hospital to the changing places website www.changing-places.org'

[places.org](http://www.changing-places.org).' They suggested people could email the Chief Executive and refer them to the weblink and video clips <http://www.mencap.org.uk/case.asp?id=448>

- Information about Sheffield Changing Places on the Signpostsheffield website: www.signpostsheffield.org.uk/changingplaces
- 'We're not quite in the North West, but there's a very strong Changing Places campaign going on in Derbyshire. You can contact Chris Jones for up to date info: Chris.Jones@derbyshire.gov.uk'

To take part in discussions please join the PMLD Network Forum at http://www.pmldnetwork.org/about_us/join.htm

Visit the PMLD Network website at www.pmldnetwork.org

NEWS

The Beacon Hill Film

The Beacon Hill Film Project has been nominated for a highly prestigious National Lottery Award in the "Best Arts Project" category. That means, that out of the hundreds of Lottery funded arts projects around the country, we are in the TOP TEN!

The project enables young people from Beacon Hill Sixth Form in North Shields, who have severe learning difficulties or autism, to make their own films from script to screen. The students are involved at every stage of the production process, including scripting, filming, editing, acting, prop making, costume design, graphics and the music soundtrack. Described by Barry Norman as "enchanting", the project is a proud recipient of the First Light Award for Best Original Music (presented by 'James Bond' composer David Arnold) and in April, the group won the National Young Filmmakers Award.

WE NEED YOUR HELP and all it takes is A FEW SECONDS of your time! One or two clicks of your mouse! We need your vote to make it through to the finals - the winner will be featured on a special BBC 1 programme, which of course would be a huge publicity boost for the project and would be a fitting reward for all the project staff and young people's hard work.

VOTE FOR US by clicking http://www.lotterygoodcauses.org.uk/awards/shortlistitem.cfm?id_category=1&id_entry=92 or <http://snipurl.com/x8t3e>

Alison Chalmers learning disabilities.federation@virgin.net

To view one of the productions - The Pirate and the Mermaid follow this link - you will not be disappointed - its really worth it. <http://www.youtube.com/user/bhillfilm#p/a/u/0/KHWeSdyQeWA>



Salt Review

An independent review of teacher Supply for pupils with severe, profound and multiple learning difficulties.

The review found that due to medical advances, the growing number of learners with severe and profound learning difficulties and the needs and complexity of these learners had

escalated in recent years. The latest figures from the DCSF being 29,000 pupils with SLD and 9,000 with PMLD across the system and three quarters of these being educated in special schools.

Headteachers and academics in this field are disproportionately older than in mainstream and there is a danger of losing a great deal of experience and wisdom in the next few years.

With no clear pipeline for the supply of SLD/PMLD teachers, school leaders, academics and Ofsted inspectors, following the removal in 1989 of specialist training routes for special educational needs, HMI reports show a severe drop from 1986 when more than 200 new teachers from 11 four year full-time B.Ed courses qualified to teach pupils with SLD, to just 15 by 1994.

To find out more about the **Salt Review** visit: <http://www.dcsf.gov.uk/saltreview/downloads/SaltReportRevisedFinal.pdf> (and Publications, page 40 in this issue)

And, most importantly, the **Proposed Implementation Plan:** <http://www.dcsf.gov.uk/saltreview/downloads/implementation-plan.pdf>



Get it right: campaign for equal healthcare for people with a learning disability in Learning Disability Week 2010

Learning Disability Week is a national awareness week run by Mencap every year.

It's a great chance to get involved and raise awareness about the issues that are important to people with a learning disability, their families and carers.



Learning Disability Week 2010 runs from Monday 21 to Sunday 27 June. The focus of the week is campaigning for equal healthcare for people with a learning disability.

People with a learning disability experience poorer health and poorer healthcare than the general population and because of this they are being denied their basic human rights.

Mencap is working in partnerships with a number of organisations to change this, and help healthcare professionals work towards better health, well-being and quality of life for people with a learning disability.

Download the Getting it right campaign pack,
<http://www.mencap.org.uk/page.asp?id=14883>
which has everything you need to help campaign during Learning Disability Week.

Seeability launches new eyecare factsheets for people with a learning disability

At the start of Eye Health Awareness Week (14 June) and Learning Disability Week (21 June) SeeAbility launched a new series of easy read factsheets on eye care and vision for people with a learning disability.



Around 1 in 3 people with a learning disability have a sight problem. Unidentified sight problems seriously

undermine people's quality of life and lead to avoidable sight loss and increased dependency.

The factsheet series aims to make it clear how to look after your eyes for people with a learning disability and their carers. They were devised in consultation with a focus group of people with a learning disability.

The first factsheets to be released are 'Having an Eye Test' and 'Wearing Glasses'. Each is packed with full colour illustration and uses clear simple words.

In 'Having an Eye Test' people can learn about why they need an eye examination and what happens at the opticians practice. 'Wearing Glasses' backs up the eye care message and explains about choosing and using glasses.

Martin Thomas is Manager of the Lookup Information Service. He says, "The factsheets give information to supporters to help them explain to the people they support about eye examinations and why they may need to wear glasses. The imagery used gives people with a learning disability the chance to prepare or to ask questions too."

Download copies of these new factsheets for your practice from the 'Easy Read' section of the Look Up website: www.lookupinfo.org

THE CHILDREN'S TRUST, TADWORTH IS A GREAT PLACE TO WORK!

Surrey-based charity The Children's Trust, Tadworth has been named one of the UK's top 50 workplaces in a UK-wide survey.

Featuring in the Best Workplaces 2010 list, created by the Great Places to Work Institute, is a prestigious accolade for the Trust which was judged against some of the UK's biggest and best companies. The award scheme which has been running for the last five years surveys 1.5 million employees annually to create its top 50 list. It recognises and congratulates best practice and the importance of being a good employer.

The Children's Trust has a workforce of more than 500 staff who provide care, education, therapy and rehabilitation to children with multiple disabilities, complex health needs and acquired brain injury. Its workforce includes doctors, therapists, nurses, care assistants, teachers, fundraisers and a variety of support functions. It also benefits from the support of around 400 volunteers who give their time freely.

The Children's Trust was recognised for the ways it involves its employees in the organisation, promotes diversity and shows appreciation and recognition for good works. Around two-thirds of the Trust's workforce was surveyed as part of the judging process.

Andrew Ross, The Children's Trust's Chief Executive, said: "The Children's Trust can only be as good as its people. We have previously won awards acknowledging that we are an excellent charity and nursing organisation to work for but this is the first time we have been judged against all-comers. We are honoured to have this award in recognition of the pride that we all feel in working for the Trust."

The results were published in the Financial Times, The Guardian and British Airways in-flight magazine Business Life.

Hospital fined for "avoidable" death

A hospital trust has been fined for failings that led to the death of Kyle Flack



The governing trust of Essex's Basildon University Hospital has been fined £50,000 for health and safety failings that led to the death of 20-year-old Kyle Flack.

Kyle was quadriplegic, had cerebral palsy and had a learning disability. He died from asphyxiation on 12 October 2006 after his head became stuck between the bars of his hospital bed. The jury at an earlier inquest concluded that his death was contributed to by neglect.

Officials from Basildon & Thurrock University Hospitals NHS Foundation Trust had previously pleaded guilty over failures that led to Kyle's death. In addition to the fine the hospital trust was ordered to pay £40,000 costs during the sentencing at Basildon Crown Court.

The Health and Safety Executive had prosecuted Basildon University Hospital for failing to adhere to health and safety laws. In a statement it said that the hospital trust had no system in place to assess the risk to patients from bed rails: "Despite Kyle's size he was placed in a bed with adult spacing bed rails. Had the rails been suitable for Kyle it would not have

been physically possible for him to get his head through any gap."

Kyle's mother Gill said: "Despite the challenges Kyle faced, he led a happy and fulfilled life. The very people responsible for his care and well-being failed him. We are utterly devastated by the loss of Kyle."

Mark Goldring, Mencap's chief executive, said: "Tragically Kyle's death was entirely avoidable. We now want to see a real change from healthcare professionals to ensure that people with a learning disability receive good quality care and are safe in our hospitals.

"We recognise that the hospital trust has taken some steps to try and ensure this does not happen again including the recent appointment of a learning disability liaison nurse. We will continue to campaign until people with a learning disability are given the same healthcare as everyone else and their needs taken seriously."

'Getting it right' is Mencap's campaign for equal healthcare. Find out more and download a campaigns pack at <http://www.mencap.org.uk/page.asp?id=14883>. This year's Learning Disability Week (Monday 21st June to Sunday 27th June) focused on 'Getting it right'.

New GMC guidance on end of life care launched

The General Medical Council (GMC) has published new guidance for doctors, 'Treatment and care towards the end of life: good practice in decision making' Which provides a framework for good practice when providing treatment and care for patients who are reaching the end of their lives.



David Congdon, Mencap's head of campaigns and policy said:

"Mencap's Death by Indifference 2007 report has shown that too often the human rights of people with a learning disability are ignored and they are discriminated against. Making assumptions about a patient's quality of life has had serious consequences and in some cases has resulted in premature death.

"Mencap welcomes the GMC guidance on treating patients towards the end of their life, which makes it clear doctors cannot discriminate against patients because of their disability or make judgements about their quality of life. It is crucial that doctors are making 'best interests' decisions in line with the law and listening to the views of family members."

Judge approves cancer treatment by force in mental capacity case

Mencap praises the decision to allow doctors to assist a patient with a learning disability.

A High Court judge has given doctors permission to use force if necessary to operate on a woman with a learning disability who lacks the capacity to make decisions about her healthcare.

The Court of Protection heard on 26th May that the 55-year-old woman, known as 'PS', needs a life-saving cancer operation but has failed to attend hospital because she has a phobia of hospitals and needles.

Judge Sir Nicholas Wall said in his ruling that if the NHS trust seeking to treat 'PS' failed to persuade her, it may be necessary to sedate her to get her to hospital for the operation.

The decision was praised by David Congdon, Mencap's head of campaigns and policy, who commended the actions of the health professionals involved. "This is an unusual case and we are very encouraged that health professionals have taken the right steps to ensure the patient receives the treatment she needs," he said.

"We believe that people with a learning disability have the same right to treatment or to refuse treatment as anyone else. However, in this case, where the patient clearly lacks the mental capacity to make the decision herself, it is right for the courts to decide based on her best interests."

Mencap's Death by indifference report in 2007 highlighted a similar case of Emma Kemp, who had cancer and was denied treatment because she would allegedly have found it difficult to cope.

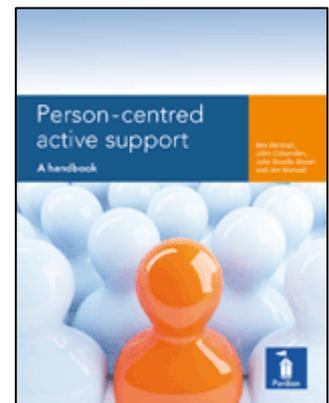
The 'PS' case is only the second case from the Court of Protection to be made public, after the media won the right to report on cases for the first time in April. The court was set up in 2007 under the Mental Capacity Act, and deals with cases involving the welfare of people who lack the capacity to manage their own affairs.

RESOURCES

Issues of implementation and achieving success

Bev Ashman, John Ockenden, Jim Mansell and Julie Beadle-Brown

This handbook will provide additional information on implementing person-centred active support. It can be used to support the multi-media training resource but it can also be read independently. Utilising examples, tools and experiences from a range of organisations and services, this book will provide the reader with additional



information on a range of implementation issues. It will also provide examples and suggestions to help readers successfully support people to participate in meaningful activities and relationships.

Vital information for: front-line care staff, first-line managers, professionals, advisers, trainers and others working with staff to improve the support they provide to people with learning disabilities.

Format: handbook (approx 200pp)

Available: June 2010

Price: £25.00

Order code: E014

ISBN: 978 1 84196 272

Publisher: Pavillion

PUBLICATIONS

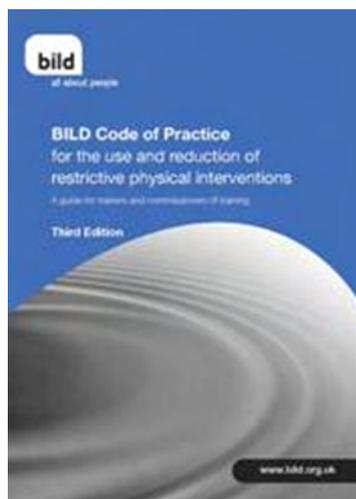
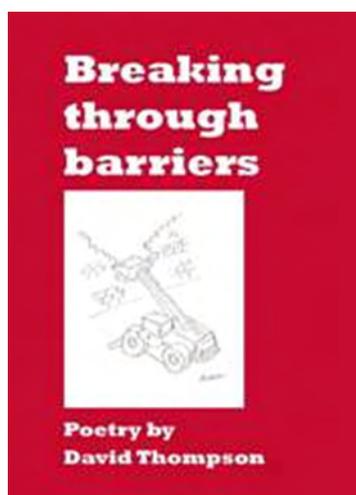
**Author:****Publisher:**BILD**ISBN:**
978 1 905218 10 3**Pub Date:**
2010**Price:**
£18.00

BILD Code of Practice for the Use and reduction of restrictive physical interventions Third Edition

Around half of all people with learning disabilities and challenging behaviour are subject to physical interventions. High quality training, to increase staff skills and confidence and reduce injuries among staff and people who use services, is therefore critical.

**Author:**
David Thompson**Publisher:**
BILD**ISBN:**
978 1 905218 12 7**Pub Date:**
2010**Price:**
£5.00

Poetry breaking through barriers to understanding

Breaking through Barriers is the work of David Thompson, a Wolverhampton man who uses his poetry to tell us about his life and the role his love of the English language, his Jamaican heritage and his cerebral palsy have played in what he sees and what he writes.

**Author:**
Nicola Grove**Publisher:**
BILD**ISBN:**
978 1 905218 09 7**Pub Date:**
2010**Price:**
£30.00

Learning to Tell - a handbook for inclusive storytelling

To support the development of inclusive storytelling, this new and exciting resource from BILD has been specifically designed to help people to find personal meaning in traditional stories, and so make links between a legend and their own lives. The resource aims to enable people who are marginalised through communication and language difficulties, to develop skills in narrative and story. The role of stories in their lives is the same as for everyone else – stories are fun and interesting, help you to make friends, understand the world and develop your imagination.

REVIEWS

Title: Practical Behaviour Management Solutions for Children and Teens with Autism: The 5P Approach.

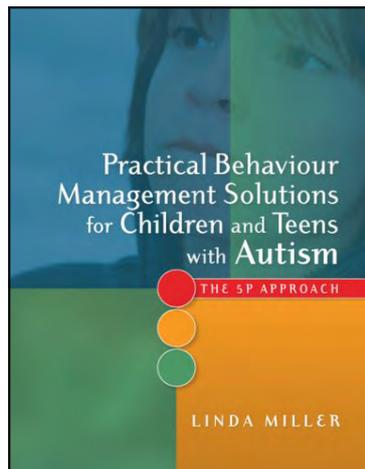
Authors: Linda Miller

Publishers: Jessica Kingsley Publishers

Pub date: 2009

Price: £19.99

ISBN: 1849050384



This is a book designed for parents, teachers and others who wish to provide a well planned, informative and consistent behaviour management approach for the children and young people they work with. With an overview of recognising and understanding difficulties and behaviours often associated with Autism Spectrum Disorders, and with clearly written sections on communication, behaviour, sensory and environmental issues, teaching techniques and cognitive and theory of mind issues, the author aims to put a new spin on dealing with an old problem in the form of a framework designed for, and 'tried and tested' by, teachers and parents.

The 5P approach is laid out in a simple format which has easy to use photocopiable materials to guide the process. With flowcharts designed to provide a continually building profile of pupils which facilitate positive behaviour in the long term rather than quick fix solutions, the 5Ps - Profiling, Prioritizing, Problem Analysis, Problem Solving and Planning are clearly defined in well presented individual chapters and as stages within this progressive and logical framework.

The title of the book tells us this is mainly aimed at pupils with autism, and this is the strength of the book. However, the profiling forms and flowcharts are very useful for framing discussions and would be of use in most situations (including for PMLD) when determining the reasons behind behaviours, whether they challenge or not. But, despite these positive aspects of the approach, given the level of understanding required by the child/young person in relation to the behaviour management techniques/strategies, it is difficult to see how several of the stages of the intervention framework, such as 'managing my feelings and behaviour', could be used with pupils with PMLD.

Reviewed by

Anita Bradshaw
Special Needs Teacher from the Isle of Wight

Title: Fuzzy Buzzy Groups for Children with Developmental and Sensory Processing Difficulties: A Step-by-Step Resource

Author: Fiona Brownlee and Lindsay Munro

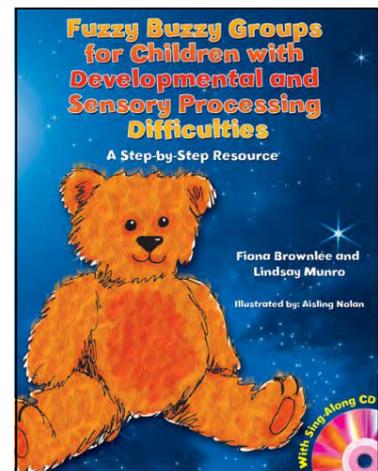
Illustrated by: Aisling Nolan

Publishers: Jessica Kingsley Publishers

Pub date: 2010

Price: £19.99

ISBN: 1843109662



This book does exactly what it states on the cover, delivering a clear step-by-step guide to running a 'Fuzzy Buzzy' group. Based around the concept of a teddy bears picnic it is aimed at children in early years with sensory processing and cognitive difficulties, taking the children on a fun and exciting journey.

The book was developed when the authors (both occupational therapists) struggled to find suitable resources for children with sensory processing difficulties. They developed the Fuzzy Buzzy Group programme, which was tried and tested with great success. The results of the research were then published in the College of Occupational Therapists, Specialist Section, Children, Young People and Families Journal (Brownlee and Munro 2005, 2006).

The concept of the book is that a group of children (up to eight children in a group) join together in a designated area. The room is set out in the same way every week (suggested floor plan included), and the children all have a teddy or favourite 'Fuzzy toy' with them. During the sessions the children explore surprise sensory items with their hands and feet, discovering object permanence, turn taking, experiencing new tastes. The children learn to tolerate sounds, textures, build levels of concentration and boost their confidence. Each part of the session is accompanied by a specific piece of music (disc provided at the back of the book along with song sheets to photo copy).

The book is well presented giving clear, concise information categorised under bold headings. The information is easy to read, comprehensible and free from jargon, making it readable for both professionals and parents.

Everything you need to know about running the group is in this book, including an insight into child development / delay and sensory processing

difficulties. There are resource lists, song sheets, information, templates and planning and recording sheets. As stated at the beginning, the book offers every thing you need to run a group.

Although the book is aimed at early year's children, it would work well with children with PMLD too; the weekly group always follows the same format and includes lots of singing and sensory exploration. However some deliberation is needed before working with less ambulant children, but ways around this could be found.

Reviewed by

Christine Scott
 Special Needs Nursery Nurse
 Percy Hedley Foundation

Title: Exploring the Musicality of Children and Young People with Retinopathy of Prematurity

Author: Adam Ockelford and Christina Matawa

Publishers: Institute of Education

Pub date: 2009

Price: £12.99

ISBN13 9780854738618



Whilst working as music teachers with blind or partially sighted children, Adam Ockelford and Christina Matawa were struck by the highly developed musical skills they observed in many of these children. In this book they present evidence drawn from parental questionnaires, case studies and observation which supports their ideas. Amongst other findings are accounts of how blind children are often highly motivated to explore and learn to play instruments in a nonconventional way and the finding that a large number of them develop Absolute Pitch compared to sighted children.

Using evidence from the book's focal study and previous work, the authors are keen to show how blind people with learning difficulties may still have relatively advanced skills in the area of musicality and that their learning difficulties need not be a barrier to developing these further.

Of particular interest to those working in the field of PMLD are Ockelford's accounts of teaching musical skills to blind children with learning difficulties. Beginning by following their lead and developing rapport within a musical context he has been able to move gradually toward a more conventional teacher-

pupil relationship and teach some technical skills for playing instruments. In addition, case study of a young man with profound learning difficulties shows how the 'Sounds of Intent' framework can be used to assess and describe musicality from its earliest stages, providing a structure for planning ongoing work. I would recommend this book to anybody teaching music to individuals with PMLD, especially those who wish to find out more about the 'Sounds of Intent' assessment framework.

Reviewed by

Lucy Van Walwyk.
 Speech and Language Therapist

Title: Autism and Intensive Interaction: Using Body Language to Reach Children on the Autism Spectrum (DVD)

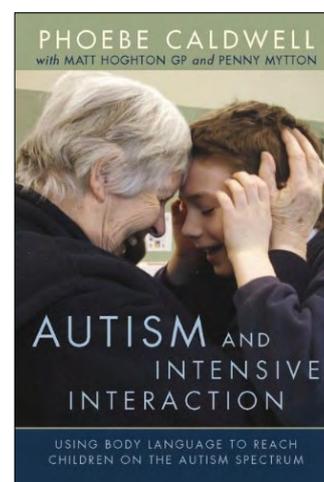
Author: Phoebe Caldwell

Publishers: Jessica Kingsley Publishers

Pub date: 2010

Price: £19.99

ISBN: 978-1-84905-088-3



This DVD is the latest publication of Phoebe Caldwell. Phoebe has worked for over thirty five years with people with severe and profound learning disabilities and autistic spectrum conditions of all ages. She believes passionately that as many people as possible, especially family members, should be aware of the simple ways in which they can interact with people considered difficult to reach. Intensive Interaction is one powerful way of doing this. The DVD focuses on her use of this approach in a school for children with autistic spectrum disorders and learning difficulties. Her previous DVD 'Creative Conversations' focussed on the use of Intensive interaction with people with multiple disabilities.

The pack itself is well produced and contains well filmed examples of Phoebe and staff at the school using Intensive Interaction with some of the children in classroom settings. Included in the pack is a simply written leaflet giving some background and providing a guide to the film. The DVD itself is broken into three parts, each with further sub sections, easily navigated on screen by the menu – very useful when using the DVD in training for example.

The first two sections cover issues related to sensory differences in people with autism and issues of age appropriate behaviour and the use of touch. Both have

application to people with profound and multiple learning disabilities as well as autism. The third section is a completely unedited piece of film where a young child, Jamie, moves from an apparent disinterest in interacting with the adults present in the room into a delightful exchange with Phoebe using a range of non verbal interactions.

Although not specifically aimed at people with profound and multiple learning disabilities this DVD is a useful addition to a range of DVD material now available illustrating the use of Intensive Interaction. This DVD illustrates an approach that can be of real value to any person marginalised from important human contact due to their complex communication needs and will be of interest to anyone interested in the emotional and communicative well being of people with complex communication needs.

Reviewed by

Sue Thurman
Communication Concerns
Speech and Language Therapist and freelance consultant and trainer

**INTERCONNECTIONS
ELECTRONIC
BULLETIN**

**About Children and Young
People (0 - 25) with
Disabilities / SEN**

Note: You can receive the whole bulletin as an e-mail attachment if you request it by sending a message to p.limbrick@virgin.net. To view the listings www.icwhatsnew.com

**Peter Limbrick
Interconnections
E-Mail: p.limbrick@virgin.net
Web: www.icwhatsnew.com**

Do you know someone with PMLD?

Are you a parent who's child has PMLD?

Can you share your skills with others?

PMLD Link is a voluntary group that works with individuals who have PMLD. We are looking for new enthusiastic members to join this working group in developing the journal in sharing knowledge in the area of PMLD.

If you think this is you please get in contact with us

Alice Bradley
alicebradley@talktalk.net

Short Courses and Conferences

Date: On-going
 Title: Training for practitioners and families to protect body shape
 Location: Programme being piloted across England with PCTs
 Contact: Pam Truman
 pam.truman@skillsforhealth.org.uk

September

Date: 10th/11th
 Title: PMLD – profound and multiple learning disability or PMLD – Positive and meaningful learning and development
 Location: Glasgow
 Provider: Concept Training
 Contact: See provider details

Date: 20th – Glasgow 29th - London
 Title: Practical & Effective Ways of Using Multi-sensory Equipment
 Provider: Concept Training
 Contact: See provider details

Date: 24th/25th
 Title: Rebound Therapy for SEN, Open College Network, NVQ Level 2
 Location: Newcastle upon Tyne
 Provider: Equals
 Contact: admin@equalsoffice.co.uk

Date: 27th/28th
 Title: Sleep Practitioner Training for health professionals working with families of children with disabilities
 Location: Birmingham
 Provider: Handsel Trust
 Contact: joanne@handseltrust.org

Date: 28th – Birmingham 30th - Liverpool
 Title: Intensive Interaction: connecting with people who are difficult to reach
 Provider: Concept Training
 Contact: See provider details

Date: 29th
 Title: TA Day – Sensory Processing Issues
 Location: Sunfield PDC, West Midlands
 Provider: Sunfield PDC
 Contact: See provider details

Date: 30th
 Title: Intensive Interaction
 Location: Sunfield PDC, West Midlands
 Provider: Sunfield PDC
 Contact: See provider details

October

Date: 6th
 Title: Sensibility Training
 Location: Sunfield PDC, West Midlands
 Provider: Sunfield PDC
 Contact: See provider details

Date: 8th
 Title: Access to Mathematics for Pupils with Very Special Needs
 Workshop leader: Les Staves
 Location: London
 Provider: EQUALS
 Contact: admin@equalsoffice.co.uk

Date: 8th
 Title: Intensive Interaction: Connecting with People Who are Difficult to reach
 Location: London
 Provider: Concept Training
 Contact: See Provider details

Date: 8th October
 Title: Making Sense of Multi Sensory Learning
 Location: Newcastle
 Provider: Florich Productions
 Contact: See provider details

Date: 12th
 Title: Creating Exciting Low tech Multi-sensory Sessions
 Location: Birmingham
 Provider: Concept Training
 Contact: See provider details

Providers Details

BILD

British Institute of Learning Disabilities
 Champion House, Green Street,
 Kidderminster, Worcestershire DY10 1JL
 Tel. 01562 723025
 E-mail: learning@bild.org.uk
 website: www.bild.org.uk

Concept Training

15 Beach Street,
 Morecambe,
 Lancashire LA4 6BT
 Tel. 01524 832 828
 E-mail: info@concept-training.co.uk
 Website: www.concept-training.co.uk/

Date: 12th
 Title: Risk Assessments & Behaviour
 Location: Sunfield PDC – West Midlands
 Provider: Sunfield PDC
 Contact: See provider details

Date: 12th
 Title: The Autistic Spectrum – when things are not straightforward
 Location: Chorley
 Provider: Concept Training
 Contact: See provider details

Date: 12th/13th
 Title: TAC System Training – to make the best use of limited resources and to take the strain off infants, families and practitioners
 Location: London
 Provider: Interconnections
 Contact: Peter Limbrick
 Tel: 01497 831550
 Email: p.limbrick@virgin.net

Date: 13th
 Title: Intensive Interaction: Connecting with People Who are Difficult to reach
 Location: Chorley
 Provider: Concept Training
 Contact: See provider details

Date: 14th
 Title: The Sensory Curriculum
 Location: Birmingham
 Provider: Florich Productions
 Contact: See provider details

Date: 15th
 Title: Communication and Sensory Assessment
 Location: Nottingham
 Provider: Florich Productions
 Contact: See provider details

Date: 20th – Birmingham 21st – Taunton
 Title: Practical & Effective Ways of Using Multi-sensory Equipment
 Provider: Concept Training
 Contact: See provider details

Date: 21st
 Title: Pre-Requisites to Learning
 Location: Bristol
 Provider: Florich Productions
 Contact: See provider details

Date: 21st
 Title: The Autistic Spectrum – when things are not straightforward
 Location: Glasgow
 Provider: Concept Training
 Contact: See provider details

November

Date: 4th London 10th Leeds/Bradford
 11th Liverpool 17th Doncaster
 Title: Practical & Effective Ways of Using Multi-sensory Equipment
 Location: London
 Provider: Concept Training
 Contact: See provider details

Date: 4th
 Title: Pre-Requisites to Learning
 Location: Liverpool
 Provider: Florich Productions
 Contact: See provider details

Date: 5th
 Title: Waking the Senses
 Location: Manchester
 Provider: Florich Productions
 Contact: See provider details

Date: 8th / 9th
 Title: Sleep Practitioner Training for health professionals working with families of children with disabilities
 Location: London
 Provider: Handsel Trust
 Contact: Email: joanne@handseltrust.org

Date: 10th
 Title: Working with Music and Autistic Spectrum Disorder
 Location: Birmingham
 Provider: Concept Training
 Contact: See provider details

Providers Details

EQUALS

PO Box 107, North Sheilds,
 Tyne & Wear, NE30 2YG
 Tel. 0191 272 8600
 Email: admin@equals.co.uk
 Website: www.equals.co.uk

Sunfield PDC

Clent Grove, Clent,
 Nr. Stourbridge,
 West Midlands DY9 9PB
 Tel. 01562 883183
 E-mail: pdc@sunfield.org.uk
 Website: www.sunfield-school.org.uk/courses.htm

Date: 12th
Title: Sensory Play and Leisure in the Multi-Sensory Environment
Location: London
Provider: Concept Training
Contact: See provider details

Date: 17th
Title: Introduction to Sensory Rooms & Studios
Location: Newcastle
Provider: Florich Productions
Contact: See provider details

Date: 17th
Title: Profound and Multiple Learning Disability – engaging children in learning
Location: Birmingham
Provider: Concept Training
Contact: See provider details

Date: 18th
Title: Successful Multi-Sensory Sessions
Location: Birmingham
Provider: Concept Training
Contact: See provider details

Date: 18th/19th
Title: Conference: Children with visual impairment and autism – furthering understanding of research and practice
Location: London
Provider: RNIB
Contact: Sona Molnarova
Email: children@rnib.org.uk

Date: 19th
Title: Creating exciting Low tech Multi-sensory Sessions
Location: London
Provider: Concept Training
Contact: See provider details

Date: 23rd
Title: Successful Target Setting
Location: Bristol
Provider: Florich productions
Contact: See provider details

Date: 25th
Title: Play for People with Autistic Spectrum Disorder
Location: London
Provider: Concept Training
Contact: See provider details

December

Date: 1st Birmingham 3rd Nottingham

Title: Introduction to Sensory Rooms & Studios
Provider: Florich Productions
Contact: See provider details

Date: 2nd
Title: Success with people with Autistic Spectrum Disorder
Location: Leeds/Bradford
Provider: Concept Training
Contact: See provider details

Date: 6th
Title: Pre-Requisites to Learning
Location: London
Provider: Florich Productions
Contact: See provider details

Date: 7th
Title: Sex and Relationships Education (SRE) with Learning Difficulties and Disabilities
Location: Manchester
Provider: Equals
Contact: admin@equalsoffice.co.uk

Date: 8th 9th 10th
Title: 3 Day SLD Induction. Day 1: Language, Literacy and Communication. Day 2: Challenging Behaviour and SLD. Day 3: Development and SLD
Location: Sunfield PDC – West Midlands
Provider: Sunfield PDC
Contact: See provider details

Providers Details

Florich Productions

Tel. 01524 42 63 95
Email: flocatalyst@aol.com
Website: www.multi-sensory-room.co.uk

RNIB Children's Services

58-72 John Bright Street
Birmingham B1 1BN
Tel: 0121 665 4235
Email children@rnib.org.uk
Website: www.rnib.org.uk/shortcourseschildren

LONGER COURSES (with accreditation)

Updated July 2009

MA in Education

SLD1 & SLD2: Pupils with Severe and Profound and Multiple Learning Difficulties (Contexts & Understanding)

This module addresses the requirements of the Teacher Development Agency (TDA) National Special Educational Needs Standards (Core 1a – 1e, Extension 2.i – 2.iv.). It is directly related to the module Curriculum and Teaching – Pupils with Severe and Profound and Multiple Learning Difficulties which addresses further standards. The module provides students with an opportunity to gain an understanding of those influences which impact upon the learning, development and management of pupils with severe and profound and multiple learning difficulties. **Module: EDUM081 For further Details:** The University of Northampton. Tel: 01604 892192. E-mail: admissions@northampton.ac.uk

MA in Education Physical Disabilities: Contexts & Interventions

This module provides opportunities for those with QTS and professional qualifications & experience in services for children to engage in structured critical reflection, exploration of key substantive issues and overarching policy determinants in respect of children and young people with physical disabilities. The module encourages both the development of enhanced understandings of the dimensions of physical disability, with regard to both their theoretical bases and the policies and practices invoked in meeting identified needs. **Module: EDUM058 For further Details:** The University of Northampton. Tel: 01604 892192. E-mail: admissions@northampton.ac.uk

MA in Education Physical Disabilities: Curriculum Issues

This module provides students with opportunities to investigate, critique and evaluate a range of curriculum approaches in the field of PD. It engages students in debates concerning the relevance and practical efficacy of recent guidance & legislation in PD-related issues, and offers an in-depth series of curriculum-focused activity which is intended to enhance both the understanding and the practice of those working with children and young people with PD. **Module: EDUM059 For further Details:** The University of Northampton. Tel: 01604 892192. E-mail: admissions@northampton.ac.uk

MA in Education Understanding Multi-Sensory Impairment

This module addresses the requirements of the Teacher Development Agency (TDA) National Special Educational Needs Standards (Extension 2.i – 2.iv.). It is directly related to Pupils with Multi Sensory Impairment (MSI) The module provides students with an opportunity to gain an understanding of those influences which impact upon the learning, development and management of pupils with multi sensory impairment. It provides professional development for teachers and other professional colleagues working in an area of low incidence need and addresses priorities established by Local Authorities, individual teachers and others working with children and young people who experience MSI. **Module: EDUM054 For further Details:** The University of Northampton. Tel: 01604 892192. E-mail: admissions@northampton.ac.uk

Certificate in Higher Education (CHESL): Supporting Learners with SLD/PMLD

During the course we will be looking in detail at the needs of learners who are known to have severe or profound and multiple learning difficulties. They may also have other additional or associated disabilities, such as physical or sensory impairments. The course will examine topics of both a theoretical and practical nature to provide students with a greater understanding about this group of learners. Together with a broad range of strategies and approaches that can be applied to practice. The sessions will include lectures, workshop activities, discussion and some visiting speakers. **For further Details:** The University of Northampton. Tel: 01604 892192. E-mail: admissions@northampton.ac.uk

BSc in Professional Practice (Learning Disability Pathway)

The School of Health & Social Care, University of Chester, BSc in Professional Practice (Learning Disability Pathway) - includes forensic, mental health/learning disability, challenging behaviour, older person with LD and epilepsy modules (plus others) **For further details:** University of Chester Telephone: 01244 511471 (Pat Palser), 511472 (Monica Davies) or 511473 (Ann Ashford) Email: p.palser@chester.ac.uk, monica.davies@chester.ac.uk, a.ashford@chester.ac.uk

PGCert, AdCert.

Early Years: Sensory and Multiple Needs—This programme begins in January

Distance education.

This programme enables professionals to work more effectively with young children with sensory and multiple needs. Participants may be teachers, who may already hold a specialist qualification in visual impairment, deafness or multisensory impairment; specialist speech and language therapists; health visitors; social workers; carers or others working with young children with sensory and additional needs. **For further details:** University of Birmingham Dr Liz Hodges on 0121 414 4873 or email: E.M.Hodges@bham.ac.uk

AdCert, BPhil, PGCert, PGDip, MEd.

Learning Difficulties and Disabilities (Severe, Profound and Complex)

Distance Education

This distance education programme has been developed for the range of staff who work with people with severe, profound and complex learning difficulties, for example teachers and lecturers, nurses, therapists, psychologists and support staff.

It is primarily about the learning and development of children and adults with severe, profound and complex learning difficulties, particularly in the areas of cognition and communication. Education, in its broadest sense, is seen as a key topic but other areas covered include health, therapy and social care. An important central theme is multi-agency collaboration and course participants will be expected to develop and reflect on their collaborative work as part of course. All the course assignments are grounded in reflective and evidence-based practice and are driven by the individual professional development needs of participants.

The modules are as follows:

1. Understanding Learning Difficulties and Disabilities
2. Interventions for People with Learning Difficulties and Disabilities
3. Learning Difficulties and Disabilities: Communication and Behaviour
4. Working Together to Meet the Needs of People with Learning Difficulties and Disabilities
5. Learning Difficulties and Disabilities: Life Long Learning
6. Either: Special Studies in Special Education or Practitioner Inquiry in Education

For further details: University of Birmingham Dr Penny Lacey, phone: 0121 414 4878 or email: p.j.lacey@bham.ac.uk

AdCert, BPhil, PGCert, PGDip, MEd.

Multisensory Impairment (Deafblindness) - Distance Learning

This programme enables teachers and others working in education related fields to work more effectively with learners who are deafblind (multisensory impaired). Some students are teachers working with children or adults, but others are from social services, medical, or residential work. A one-year programme can lead to the awards of Advanced Certificate or Postgraduate Certificate.

- A two-year programme can lead to the award of BPhil, or Postgraduate Diploma.
- A two-year programme with a dissertation can lead to the award of an MEd.

Students working on BPhil or Postgraduate Diploma programmes with some additional activities can, on successful completion, be recognised as meeting the requirements of the DfES for the mandatory qualification for teachers of children with multisensory impairments. **For further details:** University of Birmingham Dr Liz Hodges on 0121-414 4873 or email: e.m.hodges@bham.ac.uk

MSc and Graduate Diploma in Learning Disability Studies -Distance Learning

If you are currently working with people with a learning disability and are interested in updating and expanding your knowledge of theory and practice, this course provides an opportunity to learn alongside other experienced professionals from a wide range of backgrounds.

- Is designed for experienced professionals involved in the care of adults and children with a learning disability.
- Is a distance course, involving the use of specially-prepared texts, annual weekend schools, and local tutorial groups.
- Assesses ability through small practical assignments and a dissertation of 15,000 words based on original research.
- Can be completed in one-year (full-time) or between two and five years (part-time).
- Leads to a Masters of Science degree after the completion of all assignments and the dissertation, or a Postgraduate Diploma for the completion of the assignments alone. **For further details:** University of Birmingham Dr Stuart Cumella, Division of Neuroscience on 0121 414 4507 or email: S.Cumella@bham.ac.uk

Adults with learning disabilities who have significant and complex needs

The School of Psychology at the University of St Andrews offers a Post Graduate Certificate by open/distance learning: "Adults with learning disabilities who have significant and complex needs". This consists of four distance learning modules, chosen from six, and is available to staff with a professional qualification or a first degree.

- Challenging behaviour
- Mental health
- Offenders with learning disabilities
- Older people with learning disabilities
- Profound and multiple disabilities
- Vulnerability, victimisation and abuse

The programme leads to further qualifications at Diploma and Masters level.

For further details: University of St. Andrews <http://psy.st-andrews.ac.uk/people/personal/mc1/>

Dr Martin Campbell email: mc1@st-andrews.ac.uk

Undergraduate and Postgraduate Courses in Profound and Complex Learning Disability

The course is studied by distance learning plus attendance at an Autumn Study School at the University of Manchester.

The course accent is on moving towards increasing choice; developing community presence and participation; and increasing respect for individuals with complex needs. **This approach underpins all aspects of course delivery.** The course has three aims:

- To support the professional development of people working with children and adults with complex disabilities.
- To empower course participants to advocate for people with profound and complex learning disabilities.
- To enable course participants to develop knowledge and understanding of key issues in the field.

For further details: The University of Manchester, Lesley Jenkins Phone: 0161 275 33337 Email: pld.distance@manchester.ac.uk

Information about the course can also be found on the website: www.manchester.ac.uk/education/pclid

MSc in Advanced Practice (Learning Disabilities)

The School of Health & Social Care, University of Chester, MSc in Advanced Practice (Learning Disabilities) - includes generic modules in research and inter-professional working plus 3 LD specialist modules (socio- political themes in LD; developmental perspectives on LD; profound & complex needs).

For further details: University of Chester

Telephone: 01244 511471 (Pat Palser), 511472 (Monica Davies) or 511473 (Ann Ashford)

Email: p.palser@chester.ac.uk, monica.davies@chester.ac.uk, a.ashford@chester.ac.uk

BPhil, PGDip and MEd Inclusion and SEN

Year 1 Learning Difficulties and Disabilities (Severe, Profound and Complex)

Year 2 Autism (Children) or Autism (Adults)

Distance Education

This two/ three year course contains 6 modules and students study the required number from this list for their chosen award plus a dissertation.

1. Understanding Learning Difficulties and Disabilities
2. Interventions for People with Learning Difficulties and Disabilities
3. Learning Difficulties and Disabilities: Communication and Behaviour
4. Special Educational Needs of Children with Autism *or* Autism (Adults) Understanding and Working with the Continuum of Need
5. Curriculum and Treatment for Children with Autism *or* Autism (Adults) Intervention, Care and Education
6. PGDip includes a practical project based on your work

MEd includes a research methods module and a dissertation

For further details: The University of Birmingham, Penny Lacey p.j.lacey@bham.ac.uk or Helen Bradley h.bradley.2@bham.ac.uk

MSc Profound and Complex Learning Disability and Postgraduate Certificate/Diploma Profound and Complex Learning Disability

Distance Learning

Course aims

- To provide an increased knowledge and understanding of children and adults who have complex needs and/or sensory impairments.
- To empower those directly concerned with this group to advocate for the rights of the individuals concerned. To enable this to happen by providing current information relating to cognitive, emotional, physical, sensory and social needs.

Course Structure

Courses are delivered by Distance Learning over a period of 1-3 years (including an extra year of independent study for MSc. Students undertaking their dissertation). The MSc and Postgraduate Diploma are also available full time (distance learning) over 1 year. The written materials are underpinned by a variety of Study School formats during this time. Student support is also provided by email and telephone contact with the academic tutors. There are no examinations and the course requires approximately 3-4 hours private study per week.

For further details: The University of Manchester, Emma Hardy Phone: 0161 275 3463 Email:

emma.hardy@manchester.ac.uk

Website: www.manchester.ac.uk/education/pclid

PMLD-Link is an informal journal for practitioners and carers working with people with profound and multiple learning disabilities (PMLD), of all ages and in all situations. It is published three times a year and covers a wide range of issues of interest and practical use in the day-to-day work of practitioners, parents and carers in schools, colleges, adult provision, in the home, and many other settings. In recent years the scope of the articles has been widened to include all professions and services, and to cover issues pertaining to all groups, including occasional articles by practitioners and parents from overseas.

PMLD-Link is a grass roots publication and depends on written contributions from parents and carers, teachers, psychologists, special support assistants and workers in all settings. The contributions may be:

- short papers
- news of individuals, families or other groups
- information sharing
- requests from readers for information or useful addresses

PMLD-Link also includes:

- information and reviews of resources or publications and reports on conferences and research
- listings of courses and events relevant to the area of PMLD.

It enables readers to create networks, and provides a forum for contact with others involved in the field.

The editorial team is drawn from a variety of settings and currently includes:

Rob Ashdown	Head Teacher at St. Luke's Primary School, Scunthorpe – a special school for children with complex learning difficulties aged 3 to 11 years.
Alice Bradley	Freelance training and development worker.
Beverley Dawkins	National officer for profound and multiple learning disabilities Mencap.
Julia Dixon	Early Years Advisor and parent of young adult with PMLD.
Ann Fergusson	Family member with learning disability; research and teaching in severe / profound and multiple learning difficulties at the University of Northampton; Research Associate for University of Cambridge <i>What About Us?</i> Project.
Di Foxwell	Coordinator of Clinical Education and Practice Development – BHCT NHS Trust and Distance Regional Tutor for Birmingham University on two learning disabilities programs.
Chris Fuller	Teacher in mainstream and special school with children with PMLD. Founder and director of Bag Books until her very recent retirement.
Penny Lacey	Co-ordinator of the University of Birmingham course in severe, profound and complex learning difficulties; freelance consultant; family member with severe learning difficulties
Loretto Lambe	Director of <i>PAMIS</i> - an organisation in Scotland working with people with profound and multiple learning disabilities, their family carers and professionals who support them.
Wendy Newby	Ten years experience working as a qualified nurse with children with learning difficulties and severe physical disabilities, now teacher and curriculum co-ordinator at St. Rose's School, Stroud and studying for a Masters in learning difficulties and disabilities.
Carol Ouvry	Retired special education teacher, trainer and consultant in the field of PMLD. Previously editor and administrator of <i>PMLD-Link</i> .

There is also a consultation group to assist in commissioning articles from all regions of the UK and overseas and, to ensure a wide coverage of topics. The administrator of *PMLD-Link* is Paul Bramble, The University of Northampton, e-mail: paul.bramble@northampton.ac.uk

Information for Subscribers: *PMLD Link* is published in three issues per year.

Subscription prices for 2009 are:

Annual Subscription	United Kingdom	Outside United Kingdom
Personal/individual	£15	£20
Organisation	£20	£30

(NB. Subscriptions run from January and copies of all issues already mailed this year will be sent)

If you wish to subscribe, or to receive a sample copy of *PMLD-Link* please contact:

Carol Ouvry, *PMLD-Link*, 31 Birdwell Road, Long Ashton, Bristol BS41 9BD. Telephone: 01275 394621 e-mail: carol.ouvry@talktalk.net

Publisher: The University of Northampton

Disclaimer: Views expressed by contributors to *PMLD Link* are their own and do not necessarily reflect the policies and opinions of the editorial team

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