

PMLD LINK

sharing ideas and information

Making sense of the world

Spring 2014



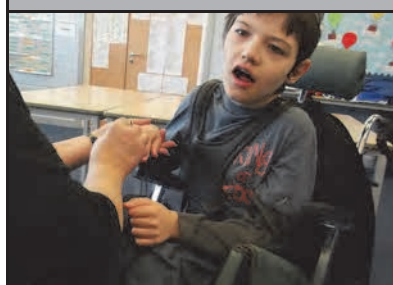
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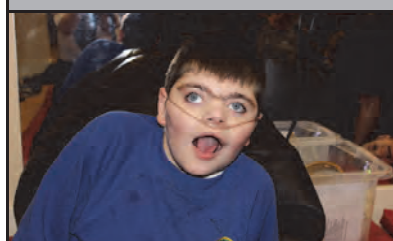
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PMLD Link is a journal for everyone supporting people with Profound and Multiple Learning Difficulties

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GUEST EDITORIAL

Making sense of the world

Our issue begins with an article by Rob Ashmore on the very core of how we ‘make sense’ of anything, our capacity to think. He provides a review of some recent positive developments with regard to developing thinking skills in people with PMLD, and looks back at texts which may have become neglected but are still very relevant.

Simon Jarrett then takes us on a journey through fiction and looks at how writers have portrayed people with learning disabilities, giving them thoughts, actions and characters that aim to show how they would react as events unfold around them and impact on their lives. What happens to them, so often happens in real life today, just as it did then.

We also have two articles which were submitted for the previous issue theme of Well-being but are equally appropriate for this issue. Andrew Colley looks at the effect of the classroom and school environment, of friendships, trips out of the classroom and classroom team togetherness, on pupils’ happiness and their ability to make sense of their world. Carol Wolstenhome, on the other hand, has undertaken to provide a very specific form of interaction with her pupils with ASD and SLD, following her introduction to and enthusiasm for an approach which aims to link neuroscientific research and developmental processes.

Enabling people with learning disabilities to make sense of their world also relies heavily on our ability to see things from their perspective and Helene Abbiss has written about the staff in her organisation recognising the interests of their adult service users and the activities and projects which they have provided to support their passions. Equally it is about recognising their anxieties and ensuring that these are allayed. In a similar vein, Claud Regnard tells of the terrible consequences of not recognising when someone is distressed and in pain and provides an assessment format which will assist in creating a greater understanding and awareness of someone’s needs and how they express them.

Sue Pearson sought to give wary staff the confidence to use Intensive Interaction and explored why many people she was working with felt uncomfortable about using an approach which does not have a clear and observable structure. She then devised a ‘stepping stone’ to support them.

Pupil progress in creating intentional sounds and expressing themselves through the use of Soundbeam, is the focus of Lorraine Painter’s article and Lorna Mainsbridge shares with us the value of working as a collaborative team to improve assessment and recording across a number of schools, using Routes for Learning. To follow this we have slipped in an invitation to be involved in Penny Lacey’s forthcoming Routes for Learning research project.

Finally we have Rebecca Ellis’ very positive experience of being a newly qualified teacher, finishing her year with a really good Ofsted grade and boundless enthusiasm for her work, because of the superb support she had from her mentor and all the staff around her.

Chris Fuller

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Teaching Thinking

Rob Ashdown

Recent Developments

In this very journal, Penny Lacey (2008) pointed out that the teaching of thinking has largely been ignored during the forty years that learners with PMLD have been included in the UK education system. The intent here is to review some recent positive developments and provide an overview of some older but relevant texts which are at risk of being forgotten.

Penny Lacey (2009) reported the outcomes of her own review of the available research literature and sets out a number of conclusions including:

1. Learners with PMLD have enormous difficulties in all processes involved in thinking;
2. It is possible that learners with PMLD develop thinking in broadly the same way as typically developing infants, although their multiple disabilities (sensory, physical, and health needs) will have an impact on learning and may mask their abilities;
3. Progress in learning to think is possible throughout childhood and adulthood;
4. Learners with PMLD will have significant problems with remembering, with perhaps some even experiencing, as if for the first time, people, things and events encountered on a daily basis;
5. Learners with PMLD require an enormous amount of repetition to learn;
6. It is essential to understand the level of cognitive development of each individual learner and what motivates them, in order to build on the learner's strengths when teaching.

The article by Penny Lacey (2009) and a recent book by Peter Imray and Viv Hinchcliffe (2014) [see a review of this book later in this issue of PMLD-LINK] are probably the best, recent UK sources for readers seeking ideas about teaching approaches and, importantly, wanting to improve their knowledge of the research that provides underpinning principles. In their different ways, these authors signal the need for a curriculum that does not focus upon teacher-led activities aimed at achieving a smattering of SMART targets. As regards learners with PMLD, Imray and Hinchcliffe prefer what they call 'process-based learning' (Imray and Hinchcliffe 2014, Chapter 3). They cite Intensive Interaction (Nind and Hewett 2005) as perhaps the best-known example of process-based teaching and learning, where the pace and direction are determined by the imperative to be responsive to the individual learner. Although there must

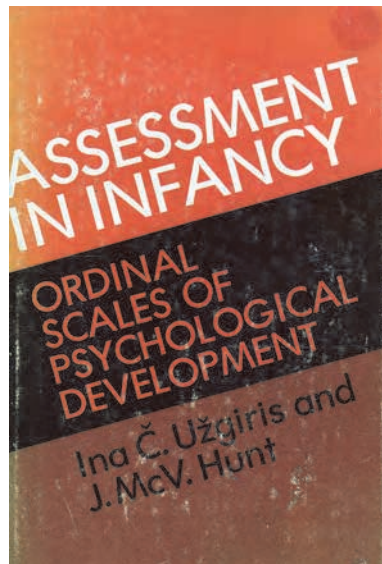
be a 'learning intention' on the teacher's part, it is the process that is key. Activities should provide lots of opportunities for positive interaction between teachers and learners in concrete and meaningful contexts rather than in artificial or clinical ones.

Jean Piaget's complex accounts of cognitive development have had a huge impact (Mitchell and Ziegler, 2013). Of particular interest here is Piaget's descriptions of children's thinking at the so-called 'sensorimotor' stage. There are various accounts of the sensorimotor stage in relation to young children with SLD and/or learners with PMLD, most usefully Carl Dunst (1980) and James Hogg and Judy Sebba (1986). For a more recent overview see Chapter 5 of the book by Imray and Hinchcliffe. (2014). Tellingly, some of Piaget's original approaches to assessment of children's thinking have been re-engineered so that babies and young children performed much better than Piaget would have predicted given their age (Mitchell and Ziegler 2013). Despite these criticisms, Piaget's account does give teachers useful guidance. Lacey (2009) states that most learners with PMLD remain within this sensorimotor stage throughout their lives, even getting 'stuck' on a particular developmental step, but that they can learn through sheer repetition. She notes that it is fine to give learners with PMLD lots of enriching sensory experiences, but teachers should be concentrating on a limited number that are repeated many times. So, in order to provide engaging and suitably challenging activities, understanding the exact level of each learner's level of development is vitally important. Therefore, here are some reminders of a range of valuable tools that can help us understand each individual's abilities and needs.

Uzgis and Hunt's Ordinal Scales of Psychological Development

Una Uzgis and J.McV.Hunt (1975) drew heavily on Piaget's accounts of sensorimotor thinking to derive 'ordinal scales of psychological development' as an

alternative to traditional psychometric tests and in order to provide an instrument that would aid research into infant understanding. The term 'ordinal' refers to the order in which children typically achieve items in the scales. They achieved the delineation of these scales through careful experiments and deliberately disregarded the six



stages or levels of sensorimotor development delineated by Piaget and linked controversially by him and others to specific chronological ages. They identified through their own research situations in which particular infant behaviours could be consistently elicited and used this information to produce ordinal scales for seven domains of development:

- Progress in visual pursuit and permanence of objects – visual tracking of objects and object permanence as reflected in the child searching for an object that has disappeared
- Means for obtaining desired environmental events – intentional behaviour to achieve specific goals
- A. Vocal Imitation and B. Gestural Imitation – imitation of own behaviours and true imitation which is seen as fundamental to the development of language and other aspects of development
- Operational Causality – the developing realisation that the child can cause things to happen and that other people and events can cause things to happen
- Construction of object relations in space – the development of concepts of objects and the effects of their actions on objects and the spatial relations between them
- Schemes for relating to objects – 'schemes' refer to actions, such as mouthing, grasping or banging, which may be repeated and are generalisable to a range of objects.

Dunst's Clinical and Educational Manual for Use with the Uzgiris and Hunt Scales of Infant Development

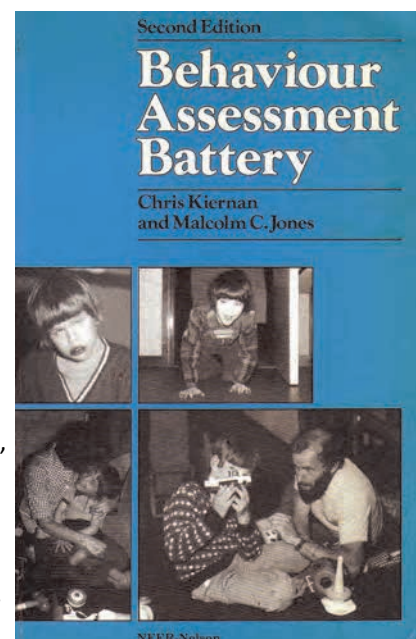
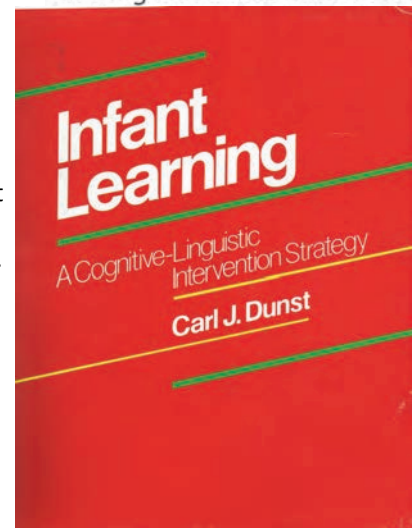
Uzgiris and Hunt had no interest in applying their scales to assessment of learners with PMLD (Hogg and Sebba, 1986) but Carl Dunst (1980) did modify them to make them usable as an assessment tool and as a way of identifying targets for intervention programmes. Dunst

retained the original seven domains (imitation is treated as two domains) covered by the Uzgiris-Hunt scales and the 70 plus items in them. To these he added an additional 50 plus experimental items (denoted with an E prefix) that he inserted into the original scales where he deemed coverage

to be insufficient. In his manual he described directions for conducting assessments and success criteria for each of his experimental items and referred readers to the original scales for details about administration of the other items. Records of the outcomes could be used to assign estimated developmental ages which were derived from a review of the literature and psychometric testing done by Dunst – a clear departure from the intent of Uzgiris and Hunt. Stages similar to Piaget's are also introduced to enable profiling of an individual's strengths and weaknesses. Dunst (1981) also published detailed prescriptions for an intervention programme that could be used in combination with his assessment tool. This scheme seems to be quite relevant to the needs of young children with learning difficulties though I have found no descriptions of its use in the UK.

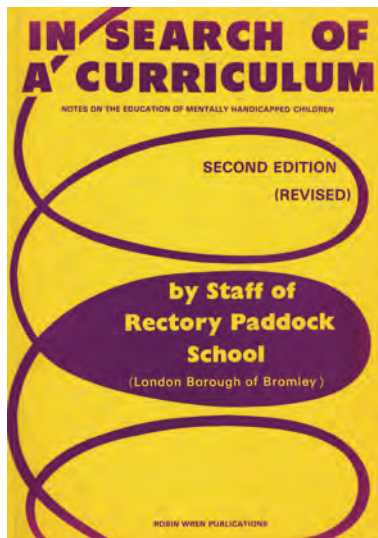
Aspects of behaviour covered by the Dunst and Uzgiris-Hunt scales may be found in the Behaviour Assessment Battery (BAB) developed over several years by Chris Kiernan and

Malcolm Jones (1982). The BAB actually covered a range of self-help, postural, mobility, social and communication skills besides but also addressed aspects of visual inspection and tracking, visuo-motor coordination, exploratory play, search strategies and perceptual problem-solving. The BAB was rather more relevant to



the assessment of the learner with PMLD and it covered teachable behaviours so that it could be used to inform programme development. These behaviours were presented in small steps in lattices which could help teachers to identify end goals and next steps in teaching. The BAB and other publications by Chris Kiernan and his colleagues (Kiernan, Jordan and Saunders 1978; Kiernan, 1981) actually provided a reasonably comprehensive cognition curriculum for learners with more severe learning difficulties, albeit very much in the mould of behaviourist approaches that are now seen as outmoded.

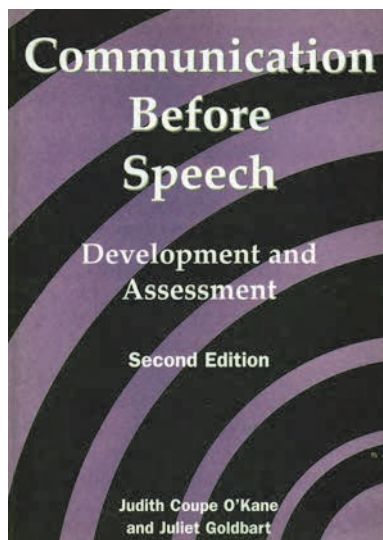
Imray and Hinchcliffe (2014) remind us that in the late 1970s and early 1980s, the Staff of the Rectory Paddock School (1983) described their use of the Uzgiris-Hunt and Dunst scales as a basis to write a developmental curriculum with explicit objectives and teaching strategies. Imray and Hinchcliffe caution



that learners with profound physical and sensory difficulties may not easily progress through this sequence of developmental objectives but that they offer a useful guide. Helpfully, they invite readers who want see the Rectory Paddock package to write to Viv Hinchcliffe at the Drumbeat School in Lewisham.

Communication Before Speech

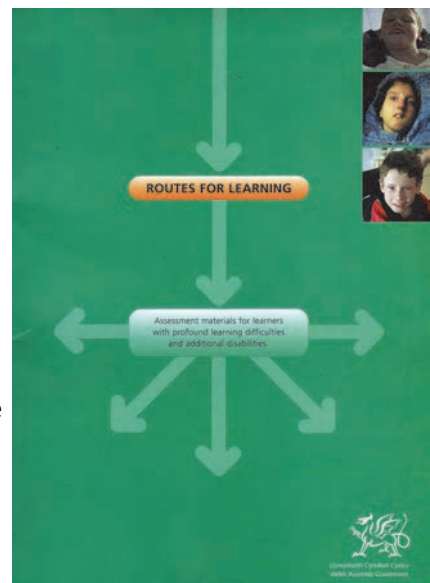
The book by Judith Coupe O'Kane and Juliet Goldbart (1998) is useful for two reasons: (a) their description of the 'Affective Communication Assessment' system and (b) their 'Early Communication Assessment' tool. Lacey (2009) notes that sometimes it is hard to find the strengths of learners with PMLD. She advises that conducting an Affective Communication



Assessment should make it possible to find out which stimuli consistently elicit a response and what form this response takes. As a result, it should be possible to identify a range of motivating activities that can be repeatedly offered daily. If teachers and others are responsive to even the smallest of reactions, then learners' awareness of causality may become established. In addition, Coupe O'Kane and Goldbart deliberately aligned their detailed Early Communication Assessment to the first five levels of the sensorimotor stage and, therefore, it neatly complements the work of Dunst (1980, 1981).

Routes for Learning and Quest for Learning

Penny Lacey (2009) reminds us that the assessment tool, 'Routes for Learning' (Welsh Assembly Government, 2006) has made the task of assessment much easier and this tool has the value of covering both communicative and cognitive developments in the first year of life for typically



developing infants. Note that this does not include many behaviours at the earliest levels and none from the later levels as included in the scales of Uzgiris and Hunt (1975), Dunst (1980) and Coupe O'Kane and Goldbart (1998). Routes for Learning offers a 'Routemap' as a guide to learning and does not prescribe that the identified steps 1-43 have to be completed in a specific sequence or in entirety. Routes for Learning also contains an outline of teaching strategies. There is also the derivative, but more finely honed, Northern Ireland publication called 'Quest for Learning' (Council for the Curriculum, Examinations and Assessment, 2011).

Final Comments

Piaget's view of children was as 'lone scientists', exploring their environment and drawing conclusions about the nature and structure of their world. Lev Vygotsky pointed out that children do not develop in isolation and that enhanced learning takes place when the child is interacting with others. Harry Daniels (2003) has drawn out the implications of Vygotsky's theory for teachers in special schools,

emphasising that they must focus on more than skills building as evidenced in behaviourist and Piagetian approaches to teaching. Schools, he argues, must become settings in which 'learning partnerships' between teachers and learners are actively developed. In a similar vein, the article by Penny Lacey (2009) and the book by Peter Imray and Viv Hinchcliffe (2014) encourage us to re-examine our practices.

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People with disabilities are members of society and have the right to remain within their local communities. They should receive the support they need within the ordinary structures of education, health, employment and social services

(United Nations, 1994)

References

Council for the Curriculum, Examinations and Assessment (2011) *Quest for Learning: guidance and assessment materials - profound and multiple learning difficulties*, 2nd edition, Northern Ireland Curriculum, Belfast: CCEA

Coupe O'Kane, J. and Goldbart, J. (1998) *Communication Before Speech: development and assessment*, 2nd Edition, London: David Fulton Publishers

Daniels, H. (2003) 'Vygotsky and the education of children with severe learning difficulties', *SLD Experience*, 37, 40-45

Dunst, C.J. (1980) *A Clinical and Educational Manual for Use with Uzgiris and Hunt Ordinal Scales of Infant Psychological Development*, New York: Pro-Ed Inc

Dunst, C.J. (1981) *Infant Learning: a cognitive-linguistic intervention strategy*, Allen, Texas: DLM Teaching Resources

Hogg, J. and Sebba, J. (1986) *Profound Retardation and Multiple Impairment: Volume 1- development and learning, Volume 2 - Education and Therapy*, Beckenham, Kent: Croom Helm

Imray, P. and Hinchcliffe, V. (2014) *Curricula for Teaching Children and Young People with Severe or Profound and Multiple Learning Difficulties: Practical strategies for educational professionals*, London: Routledge

Kiernan, C. (1981) *Analysis of Programmes for Teaching*, Basingstoke: Globe Education
Kiernan, C. and Jones, M. (1983) *Behaviour Assessment Battery*, 2nd Edition, Windsor: NFER-Nelson

Kiernan, C., Jordan, R. and Saunders, C. (1978) *Starting Off*, London: Souvenir Press

Lacey, P. (2008) 'Retro !', *PMLD Link*, 20: 18

Lacey, P (2009) 'Developing the thinking of learners with PMLD', *PMLD Link*, 15 - 19
Mitchell, P. and Ziegler, F. (2013) *Fundamentals of Developmental Psychology*, 2nd edition, Hove: Psychology Press

Nind and Hewett (2005) *Access to Communication: developing basic communication with people who have severe learning difficulties*, 2nd Edition, London: David Fulton Publishers

Staff of the Rectory Paddock School (1983) *In Search of a Curriculum: notes on the education of mentally handicapped children*, 2nd edition, Sidcup: Robin Wren Publications

Uzgiris, I. and Hunt, J.McV. (1975) *Assessment in Infancy: ordinal scales of psychological development*, Chicago: University of Illinois Press

Welsh Assembly Government (2006) *Routes for Learning: assessment materials for learners with profound learning difficulties and additional disabilities*, Cardiff: Qualifications and Curriculum Group, Welsh Assembly Government

Making Sense of the World People with PMLD in Fiction

Simon Jarrett

No doubt all of us who have encountered and come to know a person with profound and multiple learning disabilities have tried at some point to imagine what they might be thinking. It is natural that as communicating animals we seek out the thoughts and ideas of another person and we can find it unsettling if we are unable to locate them. Augmentative and alternative communication techniques are of course a key part of our attempts to unlock the interaction skills of those we find uncommunicative. However, anyone who has lived or worked with a person with profound disabilities knows that there is a risk of our projecting our own wishes, beliefs and thoughts onto the other person, giving them thoughts which are not their own. These often reflect in some way how we want the world, or the other person, to be.

It is interesting to examine how writers have tackled this problem when it comes to portraying people with profound disabilities in fiction. An important part of the novelist's craft is to project their mind into the minds of the characters they create, to try to understand how another person with specific personality traits would react as events unfold around them and impact upon their lives. They must also try to portray in a credible way how that person interacts with other people, the emotional effect of other people's words and actions and the building, or crumbling, of relationships. They are, in effect, always looking into the minds of those who do not yet have a voice, and then trying to give them a voice. For this reason, their approach to describing what a profoundly disabled person might be thinking, and what others might think about them, is invariably fascinating.

Perhaps the most famous profoundly disabled fictional character is Benjy in William Faulkner's extraordinary 1929 novel *The Sound and the Fury*. In this difficult and highly unusual work, which caused incomprehension and controversy when it was first published, three

narrators give their accounts of overlapping and linked events. One of them is Benjy, a 33 year old man with a profound learning disability who has no verbal communication. Each narrator tells the story of the Comptons, their strange, wealthy, mad, white Mississippi family held together by a retinue of black servants.

Benjy's thoughts tumble out in a stream of blurred impressions of the sights, sounds, smells and voices that surround him. As you read them, it is very difficult to understand in any logical way what he is thinking, or even what he is referring to. Unable to talk, he rocks and screams to try to indicate what he wants. He is bullied by the servants who are left to care for him each day, and he is the despair of his mother who slips deeper and deeper into madness. Yet somehow his words stay with you, reaching you on a very deep level, as you engage with the rhythms and flows of his mind, his way of seeing the world.

He is seen as a useless, unthinking burden by most of the family, but through it all shines the love and friendship of his sister Candace, known as Caddy, the only person who understands him

and his feelings. He likes to look at the fire, yet his mother tries to make him move and face away from it. Benjy becomes agitated, but Caddy understands why:

“Let him stay here mother. When he’s through looking at the fire, then you can tell him.”

“Candace”, mother said, Candace stopped and lifted me. We staggered. “Candace” mother said. “Hush” Caddy said. “You can still see it. Hush”

Mother said “He’s too big for you to carry... you’ll injure your back.Do you want to look like a washer woman?”

“He’s not too heavy,” Caddy said. “I can carry himlet him look at it and he’ll be quiet. There Benjy, look”.

I looked at it, and hushed.

“You humour him too much,” mother said.’

Caddy is his only hope of understanding in this strange and disturbing world, where he is at the mercy of the uncaring, dysfunctional people who inhabit it. When Caddy leaves the family home he is left totally isolated. Each day he screams until one of the servants will take him to the golf course that borders the family home. He becomes terribly excited as each group of golfers approaches. No one understands why this happens, and all are exasperated by his obsession. Only Benjy and we, the readers, know why. As the golfers prepare for their shot they call out ‘caddy!’ to the caddy carrying their clubs – he longs, hopelessly, to see his sister Caddy approaching.

Faulkner, in a difficult, painful but profoundly moving way gives a voice to the voiceless Benjy, allowing what at first appears to be a nonsensical jumble of thoughts and impressions to reveal a person, longing for friendship, love and understanding but barely acknowledged as human by most of those around him.

The American writer Jack London’s short story *Told in the drooling ward* (1910) tells the story of two men, a ‘feeb’ and a ‘drooler’ in a state

institution for ‘idiots’ in California in the early twentieth century. Tom is a feeb, nickname for a feeble minded person, a ‘high-grade’ patient. As part of his high-grade status Tom works as an assistant, unpaid of course, looking after Albert, and other droolers, in the ‘drooling ward’ where people with the most profound disabilities live.

‘Me? I’m no drooler. I’m the assistant. I don’t know what Miss Jones or Miss Kelsey would do without me. There are 55 low-grade droolers in the ward, and how could they ever be fed if I wasn’t around?’

Distancing himself from the other feebs, whom he despises, Tom identifies himself with the staff, not understanding that they see him only as a patient, as much an object of their care as any other patient in the hospital. Yet he shows an uncanny ability to understand the communication of ‘his’ drooler, Albert, in a way that the paid professionals cannot.

‘Miss Kelsey asked me once why I don’t write a book about feebs. I was telling her what was the matter with little Albert. He’s a drooler you know, and I can always tell the way he twists his left eye what’s the matter with him. So I was explaining it to Miss Kelsey, and, because she didn’t know, it made her mad. But some day, mebbe, I’ll write that book.’

The truth about his real situation dawns on Tom when a nurse, with whom he is in love, marries . He runs away devastated at this unthinking rejection, but he insists on taking Albert with him. Despite professing to despise him, he has looked after the voiceless, immobile Albert since he was a boy, and cannot bear to be parted from him. Having to carry Albert up a mountain makes the escape impossible and Tom has to return to the endless life on the ward.

Tom tries to cross the gulf between his world and the world of staff, and fails. The staff, with unthinking cruelty, are astonished that anyone

should see their affection for a 'feeb' as real and meaningful outside the nurse/patient relationship. Without realising his achievement however, he does successfully cross another gulf, into the mind of Albert. London's story suggests that empathy, and the ability to communicate, with a profoundly disabled person have nothing to do with professional authority or some notion of intelligence – indeed these can be barriers to understanding. A sense of solidarity, personal openness, an absence of patronising 'knowledge' and assumptions, are far more important factors.

Fictional representations can be helpful in developing our thinking about profound disability. Faulkner and London are just two of a number of novelists who have tried to enter the mind of the profoundly disabled person. More recently Allan Mayer's wonderfully entertaining and very thought provoking *Tasting the Wind* (2008) tells the story of a group of long stay patients resettled to a community home in the 1980s. Its heroes are two learning disabled men, one of whom has no verbal communication while the other incessantly repeats rhymes which appear to be nonsense. It is part murder mystery, part satire on the world of learning disability, but his great achievement is to show how professionals always seem to find ingenious ways of not listening to what people with learning disabilities, particularly those with profound disabilities, are telling them.

The impact of profound disability in families has also been intelligently examined. Joseph Heller, (the author of *Catch 22*), wrote *Something Happened* (1974) in which the disillusioned, unhappy Bob Slocum, a middle-ranking American advertising executive, has a profoundly disabled son, whom he talks about with unsettling honesty; 'I no longer think of Derek as one of my children. Or even as mine. I try not to think of him at all; this is becoming easier, even at home when he is nearby with the rest of us, making noise with some red cradle toy or

making unintelligible sounds as he endeavours to speak. By now I don't even like his name' The great irony of Heller's novel is that Bob Slocum, just like his profoundly disabled son Derek, struggles to communicate. Derek is an uncomfortable reminder to him of this truth, and he averts his gaze. Fiction can help us to confront the uncomfortable, and to think differently about the familiar.

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References

Faulkner, W (1995) *The Sound and the Fury* [1929] London: Vintage Books

London, J (2008) 'Told in the drooling ward' [1910] in *To build a fire and other stories* Stilwell: Digireads
Heller, J (1994) *Something Happened* p.131 London: Corgi

Meyer A (2008) *Tasting the Wind* YouWriteOn.com

The Well-being of Young People with Profound and Multiple Learning Difficulties in a School Setting

Andrew Colley

This is an article about the well being of young people with PMLD in a school setting. Of course, I hope it has relevance to other settings, but the school setting is what I know best. For the purposes of this article, I am going to focus on one aspect of the broad term 'well-being': Happiness.

Can Happiness be taught? It's a question which received quite a bit of traffic in the media a couple of years ago when it emerged that a private school was offering 'Happiness' lessons to its pupils. It was all jolly good positive publicity for the school, but in fact all that was going on in the classroom was a bit of light behavioural therapy with some of the easier to grasp aspects of meditation.

I don't know the answer to the question: 'Can Happiness be taught?', but I do think that in a setting for students with PMLD it can be modelled and encouraged. External circumstances can be arranged to make it more likely than not that our pupils will be comfortable, calm, and happy. By 'external circumstances' I mean everything which goes on around them: the physical and human environment.

We are all sensitive to our physical environment. The sights and sounds, colours and shapes, the light and the dark, the walls, ceilings and furniture, the 'atmosphere' around us. Young people with complex needs are almost certainly even more sensitive than most not only because they may have additional sensory impairments, but also because in the main the physical environment which surrounds them is usually created by someone else, and someone who doesn't share their unique outlook on the world.

So creating the 'right' environment around our students is essential. Of course, we can rarely know exactly what the 'right' environment is even for just one of our students, let alone in a class of 6 or 7. As a starting point though we can ensure there is enough space for several wheelchairs to move freely, we can make sure the standing frame and the 'Acheeva bed' can be brought in effortlessly and used without disrupting the rest of the room and are a normal part of the everyday

environment. These are priorities when beginning to create the right environment for a class of young people with complex needs.

To a certain extent the original design of the school will either support or hinder the creation of appropriate environments for well-being. I am fortunate at the moment to work in a school which was designed and built just a couple of years before the financial crash and at a time when perhaps there was more money available to invest in the costly link between architecture, design and learning. Everything about the architecture of the school prioritises the well-being of the students. The basic design of the school is circular, with all areas linked by one wide corridor where wheel chairs can move freely. It is actually almost impossible to get lost. As long as you keep moving you will inevitably end up back where you started. That's re-assuring for a start. There is plenty of space too, both indoors and out. Rooms of different sizes with wide doors, high ceilings, plenty of windows and all with access to the outside. Walls are painted in quiet pastel blues and greens and wall displays are understated. There are many open green spaces and paved play areas which are all accessible to the students, and the school also has access to the substantial playfields of the adjoining mainstream secondary school. It's pretty much an ideal environment.

Of course, not all schools are blessed with that sort of design, and less are likely to be in the current financial climate. So we have to be realistic. Many special schools, most special schools even, are limited for space, so what we as teachers should do is make whatever room we have got as spacious and as flexible as possible. As I said before, we can't know what the 'right' environment is for each of our students, but I do think that an open flexible space will probably have a positive impact on a young person's well being simply because

she will feel less restricted, freer to move, to walk and run around. To find her own space and to have options about where she goes. I like to think that a young person with complex needs entering a classroom for the first time should feel it is their own space, their own canvas. A space which encourages independent thought and action. Space which is adaptable so that large or small groupings can be formed easily without having to shift furniture. Space where young people can find a quiet corner. Space where everyone can dance madly on a Friday afternoon. Some in chairs, some on the floor, and some on their feet. It's all part of the learning process, and all contributes to our students feeling they have options, choices in their lives.

It's a 'less is more' approach. So ask yourself: do we need that desk, those tables, that cupboard? How many hard backed chairs do we actually need? Are they creating more problems than they solve?

Light and air are so important too. Natural light if possible, so that changes of daylight, weather and the seasons can be experienced in the room. Real plants, if they are allowed, a safe water feature as well, and maybe bean bags, mats and rugs too.

The décor in the classroom needs to be considered as well. Many young people with complex needs find it hard to process too many visual messages coming off the walls. It may affect their concentration and their behaviour. Just because we are in a school, that doesn't mean that we have to cover the walls with posters, paintings, symbols and assorted objects. A nice calming colour wash on the walls can create a more appropriate, and happier, feeling in a classroom for students with PMLD.

What about the human environment? The people who work with our students. How can they help to promote well being? Everyone in the staff team needs to be aware that they have a duty to ensure that the class is comfortable, safe and happy. Sensitive and dignified personal care of is one of the cornerstones of this, but our duty of care goes way beyond that. We all need to be flexible, realistic and non-judgemental. We must accept our students where they are now in their lives and in their development. We must do whatever we can to make sure every student in the class feels wanted, cared for and accepted. The way we respond to the students will not only impact on their well being and behaviour but will also create an environment for growth and learning.

Of course, it is hard to be positive in the stressful environment of a classroom for students with PMLD if you don't feel positive and valued yourself. As teachers, we must ensure every member of our team feels valued

and empowered, that their skills and responsibilities are recognised, that their training needs are met, and that there is as much commitment to their well-being as there is to the well-being of the students. A big step towards this can simply be by ensuring the whole team meets once a week, if only for 20 minutes, just to share, discuss, and offload. Community trips, social events and special projects with the students can all contribute to creating an emotionally healthy classroom. Allocated breaks during the day are vital too and should never be forgotten or ignored. Nor should a teaching assistant, or teacher for that matter, ever feel ashamed about asking for help, or advice, or a few minutes away from the class. Like the students, the support staff also deserve to work in an environment where they are comfortable and happy, and if the team around the student is calm, know what they are doing and enjoy their day, then as the teacher, I know that the students are likely to have had a happy day too.

It is said that the quality of our friendships is an indicator of our happiness. Unlike maybe in a mainstream setting, we can and must be the students' friends and advocates. A friend is someone who accepts us as we are, through thick and thin. So for the students, many of their teachers and carers will and should be their friends. I don't know if the French writer and philosopher Albert Camus has ever been quoted before in an article about PMLD education, but what he says about friendship sums up nicely for me the starting point for learning and development for our students:

- Don't walk behind me, I may not lead.
- Don't walk in front of me, I may not follow.
- Walk beside me, and be my friend

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Finding Our Unique Place in the World

Helene Abbiss

Adults aged 18 and over with profound and multiple disabilities use Parity for Disability's day services to continue their learning, make social contact and friendships and, out in the community, access varied activities and experiences that are tailored to and reflect their interests, their individual abilities and goals.

The service users, we call them students, use the charity's minibuses to go out regularly on trips that they choose. Some students use the service from Monday to Friday, others attend for a half-day or more, depending on whatever suits them best. Although 'going out' can mean just a pub lunch, shopping or bowling trip, it is often something more inventive and specific to a student's personal preferences and personality. Staff think about activities from a fresh perspective, that of the student.

For people with limited mobility or impaired eyesight, a walk in the park might not be very rewarding, but staff will engage these students in a sensory walk by giving them flowers, plants, acorns etc. to hold and feel and smell, talking about and exploring each item with them. One student clearly shows her dislikes, a rough piece of bark or something slightly wet or slimy, will be quickly dropped!

Another student has a fascination for machinery. She is intrigued by large clocks, the generator on an ice cream

van, the sound of a train, and hand driers are a particular joy! As with any favourite activity however, she also needs to be prepared for when it is coming to an end and so we take with us a large clock with working hands and the last ten minutes coloured in red, then she can see that it must soon be time to leave. A special trip for this student involved visiting Abinger Hammer, a historic clock in Surrey, where she watched and listened as the clock struck the hour.

the minibus driver's seat. Finally they took the scarecrow with them on a tour of all the other scarecrows at the Festival and people seeing the scarecrow shouted out or commented on it. It ended its journey in an allotment a few miles from the day service, where students could still see it when their bus passed by and one student's parents would take her to see it when they were in the area.



Out in the community activities are often tied in with creative projects. For the Hayling Island Scarecrow Festival, students were supported to make a scarecrow. A duvet cover was laid on the floor and someone drew around a staff member lying on top of it. The shape was cut out and sewn together and students were helped to stuff straw inside to make the body of the scarecrow. He was dressed in clothes from a charity shop and students painted patches of colour on his clothes, supported either hand over hand, or with extended paint brushes. They decorated his hat and made accessories, a cardboard pocket watch and flowers cut from foam material. Three of the students went with the scarecrow to Hayling Island in the minibus. They looked for places for him to pose for a photo: in a 'phone box making a call, peering round a beach hut, sitting in the cafe and in

We find that themed projects are also a great learning opportunity and lead to all kinds of activities. A student with an interest in transport worked on a project over a number of weeks. Supported by staff, he went online and visited the library to research his project, and in craft sessions he was helped to make models of vehicles from Top Gear. He then went on a 'Minibus Mystery Tour', where he told the driver which way to turn by pressing Big Mac switches with 'left' and 'right' recorded on them. After touring the day service six times! they managed a circuitous route to a town four miles away before it was time to turn back. When staff learned that the Formula One movie *Rush* was being filmed locally, they went with him and two of his friends, persuaded their way on to the set and were all rewarded with close-up views of historic racing cars. With one of his friends he

also visited nearby Mercedes Benz World to see the fine wheels on display.

The transport-loving student, though non-verbal, is particularly outgoing. He connects with others through his easy laughter, strong sense of fun, and his obvious enjoyment of their company, but there are also students who are anxious about trips out and social contact. They are not necessarily non-verbal, nor are they the people with the most limited movement. With these students we take a gentle approach, trying to understand why the person is anxious and attempting to address the issues. Often we will plan short trips so that they know they will be back before lunchtime, as often the anxiety appears to be about being late.

The student who loves machinery and hand driers only very gradually progressed to enjoying a day out. We believe that this changed because she was able to get to know the staff and other students and, as staff grew to know her better, they were able to suggest things that she was likely to find interesting. For a while it was important to discuss a possible trip with her a week beforehand, but now they can be a lot more spontaneous.

Sensory stories can be another good way to prepare for the outside world, showing someone what they might encounter on a particular outing. Staff created a sensory story about a trip to the sea that included a range of props: sand, sun cream, sun hat, bucket, spade, bowl of water, bag of shells, a hand held fan to simulate a roller coaster ride, and fish and chips – this was either made for lunch or the students sniffed a bottle of vinegar. We used recorded sounds for seagulls, an ice cream van, a fairground and a car, and students could choose to eat an ice cream or smell a bottle of vanilla flavouring.

Not every activity will suit everyone's disposition and staff need to know the students well enough to judge. A local science museum, for example, has displays that are not easily accessible but one of our more outgoing students is happy for staff to manoeuvre his chair into a position where he can reach an interactive display. A more nervous student may well feel uncomfortable in that situation. An aquarium has proved to be a really successful outing for many students, the bright lights illuminating the tanks making it easy to watch the colourful fish. Interestingly, although we expected all the sensory experiences of an amusement arcade could well be too much, staff were surprised to find that quite a few people enjoyed all the noises and bright lights. In planning activities out and about, staff not only ask the student where they would like to go, but also who they would like to join them. Familiarity and friendships between the students develop a great deal through their proximity within the day service. Almost all activities,

both within the service and without, help the bonds to grow. Focusing on everyone's individuality, and making sure people's interests, personality and preferences are brought out, inspires everyone to engage. Students often show mutual affection and make it clear that they enjoy a particular person's company.

To promote interaction, time is taken at the start of each morning for students and staff to enjoy a drink together and staff encourage conversation about what people have been doing away from Parity and what has been going on at home. All students, both verbal and non-verbal take part, and staff ask questions to keep the conversation flowing. The verbal students may describe what they did the night before or at the weekend and one may tell everyone what DVD or TV programmes he watched or which of his flags (he has a huge collection) is flying from the flagpole in his garden. Another student may talk about something he has bought. For the non-verbal students, staff will read each person's Homebook (a notebook used to share information between the day service and the family or carers) about what they have done and this is introduced into the conversation. For example, someone will say, 'And R_____ has been to Windsor at the weekend' and then ask her questions about it, to which she can give yes or no answers or point to the symbols on her communication tray. One student sometimes has a message recorded by a parent on his talker, as well as notes in his Homebook. When a verbal student is talking about what they have done, a non-verbal student will sometimes attract attention to indicate that they would like something in their Homebook or diary to be mentioned, as they have done something similar. Sharing opinions and experiences in this way seems to work well, helping the students to build their understanding of each other as well as of the outside world.

A number of students travel together regularly on Parity's minibuses between their home and the day service and staff on the bus make sure they keep the 'banter' going, to encourage people to connect. Several long-term friendships have developed in this way. Having familiar friends can give a student the impetus to meet more people. One student sometimes meets up at the weekend with one or two others that he has made friends with at Parity, and they will go together to an activity like a local 'accessible' disco and meet more people.

The freedom to spend time relaxing or doing activities on a mat on the floor is another chance to connect and build on friendships. Those with limited mobility are given the opportunity to sometimes share their space on a mat with another and we have one person who smiles widely and clasps her hands together whenever a certain student sits beside her. For his part, this student does not

react well if anyone else tries to 'muscle in' on his companion! We have found that people who are not typically mobile will become very mobile just to get over to someone they know, gradually sliding or rolling themselves across the floor, and staff will be flexible to allow students to be spontaneous, and will adapt the activity if a new opportunity to learn or to connect arises.

One student who had been using the service over a period of time proved to be much more aware of others and what they were doing than was previously thought. She did not appear to be interested in anyone and was not keen to take part in group activities. However, when a painting by another student fell off the wall, she said "the painting's gone" and made it clear that she did not like the change and wanted it put back up. A staff member told her whose painting it was, and that they would have to ask that student about it. Nobody realised she even knew who the student was, but as he passed by she reached out and said, "ask him about putting the picture back up."

A large proportion of the students have their own Facebook page, another way to connect with others they know. Here they can also participate in their social network, 'liking' or voting and otherwise expressing their personalities and preferences.

Like many adults, some students are flirtatious and clearly pay special attention to students that they find particularly attractive. Also like any person, they sometimes find themselves competing for attention! Many students also show that they are perfectly capable of another important aspect of human relationships, empathy. One student who is normally boisterous has demonstrated that he is very aware of other people's different temperaments. On occasions he has gradually moved himself closer and closer to another student and very gently pressed his nose up against hers. He is often gentle with others, and seems to know when he needs to be. Staff constantly witness students expressing interest, concern and sympathy for others and when someone is having an epileptic seizure, for example - care is taken to reassure any students affected, as well as looking after the person involved.

A low turnover of staff at Parity means that they get to know each student extremely well and it appears to us that with the right attitude from staff or carers, people will feel encouraged to express themselves and engage. As well as addressing their physical needs, we feel it is important to attend to their psychological and emotional well-being, for them to be recognised as individuals as well as their feeling part of a group. With the right support and an understanding of each student's method of communication, there seem to be a great many opportunities for people with profound and multiple

disabilities to make sense of the world.

Parity for Disability's day services were established by a group of parents in Hampshire in 1991. They wanted their sons and daughters, who had profound and multiple disabilities and who had reached school-leaving age, to continue to have opportunities to enjoy a good life. They planned and created a place where their loved ones could continue to learn, develop and socialise, as well as having their physical well being and communication needs addressed.

Although the services have evolved from supporting just six people with profound and multiple disabilities to supporting 35, staff remain focused on the individual. They are employed on a one-to-one basis to help ensure that each student has the support they need to pursue the same quality of life to which we all have a right.

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Can Anyone Hear Me?

Claud Regnard, Dorothy Mathews and Lynn Gibson

A young lady of 20 with severe learning disabilities, no formal speech and complex physical problems was taken by her mother to the local GP on numerous occasions. On the first visit the mother described that she thought her daughter had:

- Pain which appears to be in the lower back
- Distress on being touched and on activities such as opening bowels
- Getting worse over time
- Keeping them awake at night
- Been there for about 4 weeks

The GP prescribed analgesia and told mother to come back if it did not get better. Eventually extremely frustrated and worried about her daughter's continued pain and loss of function the mother took her daughter to the emergency department (A&E) and refused to move until something was done. The daughter had a large tumour on her spine which was beyond treatment and she died some months later.

Unfortunately we hear far too often of similar cases. This is despite media attention, government papers and reports all expounding upon the rights of people with learning disabilities and their carers. Why is it then that people and their families and carers are still not heard by many clinicians, professionals and the public? Could it be down to the belief that people who do not communicate using words are not saying anything?

Communication

...."it is an interaction where two or more people both send and receive messages and in the process both present themselves and interpret the other." Deux and Wrightsman (1984)

The word "Communication" comes from the Latin word "communicare", which means "to share" or "doing together".

Therefore could it be said that "Communication is the key to self expression and can be seen as signals or messages with or without words which an individual shares with others"

Words for most people are important windows on our thoughts, feelings and action. They can facilitate belonging; inform social activities, as well as form bonds of love, trust, and security. Words may also convey embarrassment, forgiveness, distress and pain. But what

of those people in society who cannot use this form of self-expression either through lack of ability or knowledge of a language?

We know there are many groups of people who have widely differing capacities for receiving, understanding, remembering and expressing their experience through language. Meaningful effective communication therefore depends on the ability of people to recognise and translate the many different cues available and not just those verbally expressed.

For this group of people understanding their "language" is therefore fundamental in providing good effective care.

Identifying Distress

A common theme in the case described and many others is that important diagnoses were missed due to a lack of meaningful communication. We know that untreated symptoms cause distress to the individual, therefore correct and timely identification of distress will lead to enhanced diagnosis, better symptom control and ultimately much improved health care.

How is it that the mother in this scenario instinctively knew that her daughter was in distress when the professionals erred on the side of caution or disbelief?

Carers are intuitively skilled to identify distress cues but have little confidence in their observations. They can observe what is not expressed verbally and by using these external markers of internal states can intuitively know that something “is not right”. Documenting the signs and behaviours of distress is one way of increasing carer confidence, which can ultimately lead to better patient care, but how do you document what can be a very subtle language?

Disability Distress Assessment Tool



Disability Distress Assessment Tool (DisDAT)

The Disability Distress Assessment Tool (DisDAT) is an observational tool developed over the last 12 years by members of a palliative care team working with people with learning disabilities. It documents content and distressed states and can be very successful in identifying such cues. Regnard et al (2007)

Much research in this area has tried to identify pain and to help in this process a number of pain tools have been developed but this sits uncomfortably with the lack of evidence that pain has any unique signs or behaviours. A well known concept is that “Pain is what the person says it is”. However this narrow thinking can change into “If an individual can’t communicate, they don’t have pain”. DisDAT makes no assumptions about the cause of distress, but enables carers to identify the cause and document the context of the distress.

DisDAT can be used in a variety of situations. For example, it can be completed prior to its possible use with the involvement of friends and family or be used in crisis situations to monitor the effect of any intervention. Including other significant people in the completion of the tool makes it is less likely for the professionals involved to “miss” any symptom that relies on verbal reporting and thus appropriate symptom control can be delivered, monitored and evaluated.

Therefore by using DisDAT, it can ensure that the carers’ knowledge and contribution to any discussion regarding “what is wrong” is accepted, and acknowledges the vital role they play in advocating on behalf of the people for whom they care.

Summary

We believe that distress shouts at us though signs and behaviours and that individuals use the same ‘vocabulary’ of signs and behaviours for different causes of distress Regnard et al (2003)

Carers have the skill to identify distress, but sometimes little confidence in those skills; however confidence in identifying distress can be increased by documenting changes and presenting these to those who are “listening”.

In our scenario the mother was right, she knew something was wrong but no-one could hear her, therefore is it not our duty and every patient’s right for people to really communicate and that means we need to share and work together.

Just imagine if all involved in this scenario had thought creatively, used the family’s knowledge and never assumed anything, how loud the sound would have been.

Distress may be hidden but it is never silent!

DisDAT is available for anyone to use for free on www.disdat.co.uk

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References

Deaux K, Wrightsman LS (1984) Social Psychology 5th edn. Brooks Cole, Monterey, California

Regnard C, Matthews D, Gibson L & Clarke C (2003) Difficulties in identifying distress and its causes in people with severe communication problems. *International Journal of Palliative Nursing* 9 (4) 173–176.

Regnard C., et al (2007) Understanding distress in people with severe communication difficulties: developing and assessing the Disability Distress Assessment Tool (DisDAT). *J Intellect Disability Res.*; 51(4): 277-292.

Making Sense Stories

Sue Pearson

I work as a Speech and Language Therapy Assistant in adult learning disabilities. Part of my role is to work with staff teams to establish interactive approaches to support communication and relationship building - approaches such as Intensive Interaction.

It has been a steep learning curve! I imagined that all I needed to do was to tell people enthusiastically about these clearly effective principles and they would be implemented.

Well, as often happens, it was not that simple. Despite the evidence and their seeing new and exciting responses from service users, some staff and services are just not comfortable with the free flowing intuitive nature of this kind of approach, and so we began to ask people why it was that they found it so hard to take on board.

Briefly, these were some of the barriers that came up:

- People feeling self conscious about adopting unusual and unfamiliar ways of communicating
- Not being able to apply a set of theoretical principles to the reality of the workplace
- Feeling that they weren't 'doing' anything
- Finding it really hard to abandon [or at least not rely on] the use of WORDS for interaction

Given that we know that this kind of approach relies considerably on relationship building, in order for it to succeed both sides of the relationship must be considered. Both service user and their communication partner need to feel happy and comfortable for this to work.

We then went about trying to find some practical answers to some of the very real difficulties that members of staff were experiencing. I wanted to find a kind of 'stepping stone' into a way of practising the responsive, flexible, user led communication required for employing interactive approaches comfortably and that is how Making Sense Stories came about.

We know already that interactive story telling (e.g. Bag Books multi-sensory stories and the work of Nicola Grove) can form the basis of many happy two way interactions. 'Making Sense' Stories are similarly interactive and sensory based.

The stories take the form of a simple short story or poem or song that can be repeated. It might only consist of a few sentences – though it can be longer if appropriate. The form of the story entirely depends on the individual for whom it is written. It incorporates their sensory preferences, communication style, what engages them, gets their attention, and what initiates a positive response. Anything, in fact, that seems to make sense to that person, even if we do not know why.

The story contains predictable points where the listener has an opportunity to respond in their own way to whatever cue in the story they recognise or find engaging. Pauses are built in – the reader is literally instructed to STOP and WAIT. The prompt to stop is written into the story as a prompt so that the reader is cued in to observe what might be a very tiny response. We begin planning the story by talking with someone who knows the person really well. Carers carry around a wealth of knowledge which is often not easy to document. These things can be very quirky and specific to the individual and may not be things that are easily recognisable as significant. Collecting information and thinking about what would be included in the story is an integral and vital part of the process. Hopefully it will give staff an opportunity to think in depth about someone, and to observe them carefully, even if they know them well.

Here are some examples of the questions we might ask:

- What do you do to let her know that it's you? Do you use a funny voice, a song, do you use a specific way of making contact?
- What do you do to make her laugh?
- How do you comfort her?
- What does she do to get your attention?
- How does she let you know she's had enough?
- 'What things does she respond most positively to?
- When is she most relaxed/happy/engaged? How do you know?
- What do you do when it's just you and her, – are there familiar routines that you have together?

- What does she like to do?
- How do you know that she is enjoying/not enjoying something?
- What can she do? It doesn't matter how small it is.
- Are there things/sensations that she doesn't like?
- Are there things you are just not sure about?

As part of the planning conversation we also talk about good observation and trying to look at things from the person's point of view. It is important to get lots of detail in order to understand exactly what the person is enjoying about an activity or interaction. For example a support worker may say that someone enjoys 'watching films.' When we explore this further, it seems that she picks out a DVD box from the choice offered. Actually she likes manipulating the box, listening to the sound as it clicks open and shut. It also seems that a member of staff usually sits with her when the film is on – really close so that she can lean on them. 'Watching films' in this case means something very different.

Once we have collected this information and spent some time really thinking about things from the service user's view point, we can begin to put some of their interests and preferences into a story.

The stories will obviously involve some words – this allows the staff member to remain in their own communication 'comfort zone' but in a controlled way. This also hopefully reduces and controls their use of words and leaves space to try out some other communication methods that may well be more meaningful to the individual than words – their own sounds/ movements, sensations that they enjoy and respond to. I have included a short example of a story at the end of this article.

This means that:

- The storyteller has a practical, concrete activity to share with an individual and the staff member will feel that they are 'doing something.'
- The 'script' will help the staff to feel relaxed and confident. Unfamiliar ways of approaching communication can be tried within this 'safe' activity at a person's own pace.
- The stories can be used alongside approaches like 'Intensive Interaction' as an alternative interactive activity or a practical step into two way shared communication.

We encourage communication partners to make and keep notes at the end of the story, to remember what worked /didn't work, what changed etc. This reflection is likely to lead to stories changing and developing over time as responses and preferences move on. Choices can be built in if appropriate or they can be used as a way of

trying something new by adding in a little surprise at the end of the story. There are many ways in which they can be used but the key to their success is that they are led by the individual for whom they are written.

An example of a Making Sense Story

Information about Jane for her story

She giggles if you whisper in her ear. [Also cheers her up if she's upset]

Responds to 'where are your eyes'

'Where are your ears'

'Where's your nose'

[Maybe knows more than that]

Likes music – ask mum if she's got a favourite song

Likes to bang on the table or arm rest of her chair

Will pat your hand

Has good grasp using right hand

Has good hearing

Sees things better up close

Likes water play

Likes a hand massage

Likes you to sit with her

DOESN'T like people shouting

Puts her hand in her mouth if she is beginning to get upset

This is how the story might look.....

A Story for Jane

*NB. the words written in ordinary font are the words to the story, those in **bold** are the instructions*

It was half past seven in the morning.

Jane was in bed, warm under the covers. **[put a cover over Jane and tuck it in]**

The clock was ticking. **[hold up the clock to Jane's ear]**

Jane's mum whispered her name to wake her up. **[whisper into Jane's ear]**

Jane yawned and rubbed her eyes. **[emphasise the word eyes and encourage Jane to point to her eyes]**

Jane's mum took her hand, and patted it gently. **[take Jane's hand and pat her palm, gradually as Jane becomes more familiar with the routine she may offer her hand. Start to give her time to do this]**

Jane patted her mum's hand to say 'hello'. **[Jane is able to do this so offer your hand and give her time to respond]**

Jane's mum helped her to get up. **[Take off the cover]**

When she was dressed and sitting in her wheelchair it was time to brush her hair. She brushed it herself for a while. **[offer the brush to Jane and give her some time to have a go at brushing her hair]**

Then her mum finished off and put it in a pony-tail. **[Brush Jane's hair and put it in a pony-tail for her]**

It was time to wash her hands.... **[Give Jane a bowl of warm water with some scented soap. Support her to put her hands in the water. Give Jane a few minutes to play in the water until she indicates she has had enough]**

And put on some hand cream **[rub some cream into Jane's hands]**

After breakfast Jane listened to some music whilst she waited for the bus. **[Play piece of music on tape]**

Her mum gave her some bells to play. **[hand Jane some bells]**

Jane heard the sound of a horn outside. **[sound horn]**

Jane heard the noise, but her mum didn't because she was busy in the kitchen. Jane wanted to let her mum know that the bus for the Day Centre had arrived; she shook the bells. **[Encourage Jane to shake the bells]**

But her mum didn't hear.

She did it louder! **[Repeat shaking bells]**

Her mum still didn't hear!

Her mum came out of the kitchen to see what all the noise was about. Just then there was a knock on the door **[Knock on the table]**

It was the driver to take Jane to the day centre!

For more information about this kind of interactive storytelling and how it can be used to support the use of other interactive approaches, please feel free to contact me for more details.

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References

Intensive Interaction: www.intensiveinteraction.co.uk
Bag Books: www.bagbooks.org

Grove, N (2013) Using Storytelling to Support Children and Adults with special Needs. Routledge Publishers

Members Area of the PMLD Link website

In the last issue we apologised for the fact that some subscribers were having difficulty with accessing the Members Area of the PMLD LINK website.

We have now transferred many of the back issues of PMLD LINK journal to the public part of the website with the exception of issues from the past three years.

If you still have difficulties in accessing the Members Area or if you have any queries about the content of any past issues, please contact Rob Ashdown. E-mail: rob.ashdown@ntlworld.com



HANDLE (Holistic Approach to Neuro Development and Learning Efficiency): Using this approach with students with PMLD

Carol Wolstenholme

When considering the well-being of people with PMLD what seems to be central is the need to have a holistic approach to their needs. The need to work closely with other professionals and families is obviously of utmost importance.

As a teacher and lead professional working with students with PMLD in a school I value any contact from other professionals. I am extremely fortunate to have close links with others working within the field of PMLD. Not only do I find this very helpful and supportive but I have often found meeting and discussing ideas with

those working in other areas of special education, especially that of ASD, also very useful. This has been particularly beneficial through my link with Sharon Gabbitas, the Assistant Head of Kisimul School, who for many years has enthused about the benefits of HANDLE (Holistic Approach to NeuroDevelopment and Learning

Efficiency) for her students with ASD, SLD and challenging behaviour. This outstanding school's latest Ofsted report stated, 'The school's Holistic Approaches to NeuroDevelopment and Learning Efficiency (HANDLE) prepares students for learning through therapies and developmental programmes to meet their needs. This is fully integrated into pupils' daily programmes' (Ofsted 2012, p.4)

HANDLE was created by Judith Bluestone who used the activities she developed to help her overcome the difficulties she faced herself with ASD and neurodevelopmental issues. Bluestone's profound understanding of how the nervous system operates led her to form the HANDLE Institute in 1994. When we consider the needs of our students with PMLD and their underdeveloped systems I can see much similarity with Bluestone's explanations of developmental processes based on neuroscientific research. I considered how such an approach might benefit my students and one year ago attended The HANDLE Approach Introductory Course Level 1 and 2.

I want to encourage those of you who work with students with PMLD to consider attending a HANDLE course and to start using some of the activities with your students. Obviously liaison with parents/carers to enable them to give their informed consent is very important as is a discussion with health care support around the activities a student may be doing. I believe my students have benefitted from the HANDLE activities which can be done at any time in the day, but I have found it helpful to do them at the start of a lesson as preparation for learning. Most of the activities should only be done once a day. I will now give you some examples of the activities we do with our students and show how one student, Ben (pseudonym) has responded to these.

The students in my class have had the opportunity to participate in HANDLE activities at the start of a lesson since last November. A twisty straw is used by those students who can suck. This helps interhemispheric integration (communication within and across the hemispheres of the brain). This can also encourage the eyes to converge and therefore aids the development of focusing and binocular functioning, light sensitivity, sound sensitivity, tongue and lip control, facial muscle tone, and bowel and bladder control. Ben can suck through a twisty straw and uses this at break times and lunch time. As this helps develop the use of the sphincter muscles in the body I hope this will help Ben with the stomach problems he experiences. It is difficult to tell whether this has had an impact so far. Ben will focus on objects and symbols within his field of vision. He does appear to be focusing for longer periods of time. This may not be in direct response to HANDLE but I do feel that it is a contributing factor.

Ben has participated in the 'Hug and Tug' activity [for details go to http://www.handle.org/about/sample_activities/hug-and-tug.html]. Ben enjoys this and smiles in anticipation and will hold out his fingers when we start chanting "hug and tug". He smiles or laughs when his fingers are 'hugged' and will look towards his hands and listen to the adult working with him. 'Hug and Tug' enhances interhemispheric integration and articulation. It is also useful in promoting differentiation of fingers, one from another and also one hand from another. It helps to strengthen muscle tone in the fingers, stimulates reflexology points for the sinuses, jaw and mouth, integrates tactile sensations in the hands, enhances proprioceptive input in the fingers and may also calm and focus the individual. This also provides the opportunity for touch and therefore tolerance of tactile stimulation. Ben is improving in these areas of development.

Ben participates in the 'Seated Clapping' game. This activity enhances differentiation (moving body parts without moving others), lateralization (establishing dominance and awareness of left and right), bilateral integration and interhemispheric integration. It also works on improving visual-spatial functions and integrating them with other functions in a rhythmic pattern, incorporating a tactile component that helps to organise the sensations on the palms of the hands. The adult faces Ben so he can easily reach out to touch her extended hand and an adult prompts him by moving his arms towards the other adult. The adult and Ben (with physical prompting) clap their hands at the same time and then reach with one hand to touch each others' hands without reaching across Ben's midline. After doing this a number of times the adult and Ben (with physical prompting) touch hands and at the same time touch their knees with the other hand. They repeat this and develop a rhythmic clap and tap pattern, making sure that neither hands cross Ben's midline. Ben has developed from a clenched fist, to opening all of his fingers on both hands, moving them with physical prompting to touch the other adult's hands, to needing only a light touch prompt to lift his hands. He will then move them towards the adult working with him. Ben smiles and laughs when he does this activity. I believe this has also helped Ben's fine motor skills. He will now explore objects using both hands and is putting his hands together and touching objects at the same time with both hands, almost at the stage of passing an object from one hand to another. He has just begun to pass an object to an adult and not just lift or push it away. Ben will explore objects for longer and the use of his left hand has improved greatly. I believe this is in response to these activities.

Following a conversation with HANDLE Therapist, Pam Broughton, I have just begun the activities 'Counting

Four' and 'Buzz Snap.' 'Counting Four' involves tapping on the shoulders and legs and can help rhythmic synchronicity, regularising brain patterns to help prevent seizures. One shoulder is tapped four times with the adult's right hand and then both shoulders are tapped at the same time and then the other shoulder with the adult's left hand. The same pattern is repeated on the knees. This is repeated again, starting with the shoulders. 'Buzz Snap' increases kinaesthetic and proprioceptive input in the fingers, helps to desensitize tactile hypersensitivity, increases muscle tone and circulation in hands, and enhances differentiation of individual digits. It has been reported to improve visual focus and have other positive affects on vision. The adult holds Ben's dominant arm and with her thumb on the back of his hand and her index finger on Ben's palm, presses her thumb and index finger together at the base of Ben's thumb where it meets his wrist. Whilst continuing to squeeze and moving toward the tip of Ben's thumb she will shake his thumb vigorously from side to side whilst saying "bzzzzzzzz." When the adult's thumb and finger reach the tip of Ben's thumb the adult stops shaking Ben's thumb, lifts it slightly and, whilst squeezing tightly, snaps quickly off the tip of Ben's thumb as she says "snap!" She then goes back to Ben's wrist and follows the same routine for each finger on his dominant hand, from his index finger to his little finger. After completing this pattern on Ben's dominant hand and gently enveloping this hand for a few moments in her hand, the adult repeats the sequence of this activity on Ben's non-dominant hand. Ben has responded very well to 'Buzz Snap,' laughing and vocalising as his fingers are touched. This activity elicits the most positive response from Ben while it is being done, than any of the others. He laughs in anticipation and then giggles as his fingers and thumbs are shaken and he hears "bzzzz" and then anticipates the "snap." As this activity follows acupuncture meridians, stimulates Reflexology points and provides pressure on acupuncture points students may not tolerate this activity on certain days when there is stress or tenderness in a given area, such as the sinuses. Obviously we are led by our students and honour any response to stop.

At this point it is important to mention that HANDLE works on the principle of 'gentle enhancement'. This builds on the neuroscientific research that overloaded systems shut down. We therefore have to monitor each activity and watch for any signs of stress or 'state change'. The signals to look for are reddening of the ears, change of facial colour, change in breathing rate or depth, change in muscle tone, loss of visual focus or glassing over of the eyes, worsening of an activity once it is becoming integrated or if the students appears to be disorientated or dizzy. Any activity must be stopped at the first sign of state change.

As I continue to use HANDLE activities I am hopeful that they will have a positive affect on all of my students. Ben is progressing well in the areas we are focusing on and in his 'Routes for Learning' targets. I do believe that in the time I have been using HANDLE activities with my students with PMLD, I have seen them respond positively and show progress in ways they may not have, had they not participated in them.

I would highly recommend reading 'The Fabric of Autism - Weaving the Threads into a Cogent Theory' (Bluestone, 2004). Although focused mainly on issues around ASD, I believe we can learn a lot from Judith Bluestone's insights and theories in relation to sensory-motor development and put these into practice with the people with PMLD we work and live with. It is essential that people have training before attempting to complete any of these activities with their students or families. I have been able to disseminate the HANDLE activities I have been taught within my own school. It is important for those trained to ensure that people are doing the activities correctly when they first start doing them. Just reading a description of how to complete an activity is not sufficient and it is important to understand why we are doing an activity and the effect it may have on our students.

For more information on HANDLE and a list of practitioners and training go to <http://www.handle.org>.

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References

Bluestone, J. (2004) *The Fabric of Autism: Weaving the Threads Into a Cogent Theory*. Bend, Oregon: The HANDLE Institute.

Bluestone, J. (2010) *Introductory and Basics Activity Manual*. Bend, Oregon: The HANDLE Institute.

Ofsted (2012) *Kisimul School : Independent school standard inspection report* Available at www.ofsted.gov.uk/publications/090070

Using a Soundbeam to Increase Interaction and Responsiveness in Young Children with Severe and Profound Learning Difficulties

Lorraine Painter

My MEd Inclusion and SEN research dissertation investigated using a soundbeam to develop interaction and responsiveness in pupils with SLD or PMLD. A soundbeam uses sound waves to allow individuals to experience and interact with music. Being sensitive to the slightest movements, the soundbeam enables individuals with complex physical or sensory needs to have control over the sounds and silences made and independently achieve and experience success in their learning (Ellis 1997; McPhail 2003).

I carried out a series of case studies involving six children aged 3 and 4 years, with severe or profound learning difficulties. I wanted to explore if using a soundbeam could enhance learning and lead to the development of early communication and cognitive awareness. The six children were all non-verbal, functioning within the sensori-motor stages of development and working within the first four P levels. Despite their individual needs all the pupils appeared happy, motivated by the sounds and enjoyed using the soundbeam. Through the sessions they showed increasing interactions with us and responsiveness to the soundbeam.

As a volunteer, I was supported by a familiar member of staff to ensure the medical and emotional needs of the children were met and they were happy and confident during the sessions. Initially all the children remained in their chairs, positioning the soundbeam sensor to be triggered through natural movements. Each child explored and experienced the soundbeam without any intervention from us, being praised and encouraged, but not aided to make movements. Any other sounds, such as speech, were kept to a minimum allowing the children to be 'in control and immersed in sounds' (Ellis 1995). Gradually through the sessions, imitation was introduced and we began to interact more, but the children remained in control; the sessions being led by their unique and individual needs. All responses from us were aimed at creating a positive and responsive learning environment.

The ambulant children had the opportunity to move freely about the room and choose to interact with us or use the soundbeam. I was interested to discover if there was any increase in interaction times or responsiveness during the study, inferring that the soundbeam was a useful tool to develop this. Accurately timing when the pupil was engaged with the soundbeam enabled me to measure this. For those children with more severe physical and sensory impairments, using the soundbeam to enable reflexive movements such as a blink, to become a means of communicating, was the main focus of the sessions (Aird 2001; Ware 2003). These children remained in their chairs to reduce the risk of a carer moving and making the sounds and to help them understand that they were in control of the session. The sensor was set at a 90 degree angle to the pupil with the range set at its smallest length and the number of divisions (range of notes made by one movement) to its largest. Having the sensor set in this way also allowed any head or facial movements to trigger the beam, but would enable the child to move out of the beam if they wished and create silences. It was also important that they were not startled by any sudden sounds. To achieve this I often joined in, starting to play with the volume quite low, introducing each sound before turning the volume up slightly and allowing the child to take over. I also played turn taking games with the pupils, allowing them to create sounds followed by me, to initiate some social interactions.

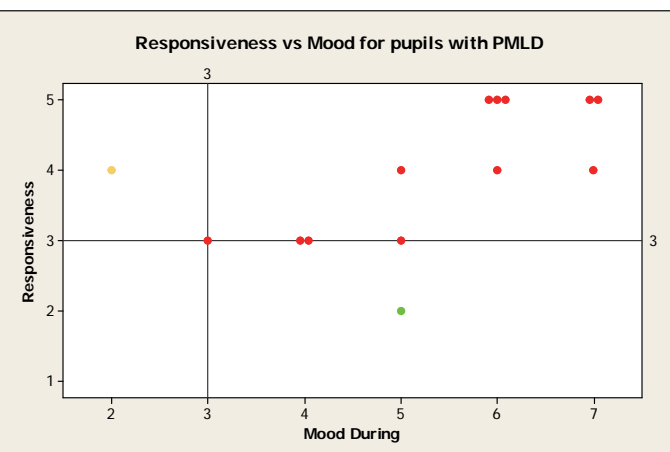
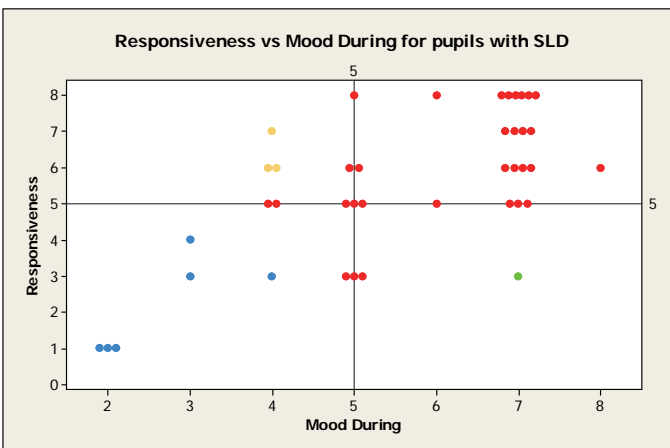
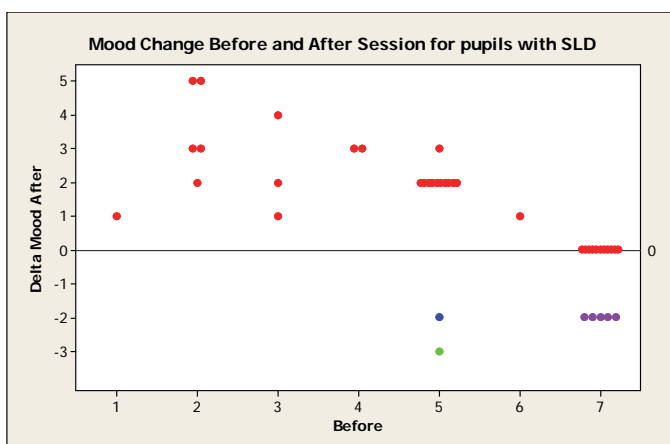
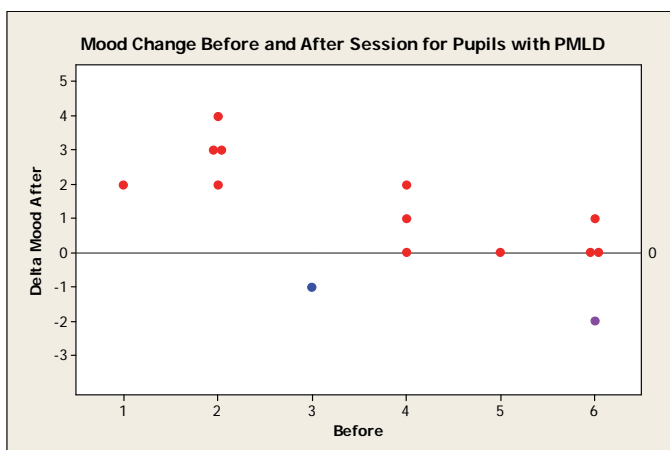
I used the same starting set up each week, changing the sounds during the session depending on how the child

was responding. I always spoke to them and allowed them to choose if they wanted a new set up, before changing the sound. One child with very complex needs involved in the study, who remained passive during most class activities, seemed to understand he was creating the sounds and showed his enjoyment through smiles and vocalisations. On one occasion, he had been unwell prior to coming to soundbeam and quite sleepy, but during the session was very alert and responded by producing lots of head movements, side to side and up and down, vocalisations, smiles and also arm movements. During this session, I introduced the drum set up and he responded very well to this, showing obvious enjoyment in playing the drums. He continued to respond and interact with the soundbeam for many minutes. I believe he also appeared more focused and interested during other sessions when the drum set up was used, showing an obvious preference for this sound.

Most soundbeam sessions lasted for around 15 minutes, but the timing was not restricted and again led by the child and how they responded. Analysis of the data however, showed that when the pupil was unsettled or not responding as well, sessions were often longer, increasing to 22 minutes on one occasion. We always aimed to end the session positively. Unless the child was so distressed it was unethical to continue, we would give them time to settle, gently encouraging, and allowing them to come to soundbeam in their own time. They were not under pressure to complete the task within a given time scale, often necessary during a school day. Allowing the pupils to make movements in their own time and get a response in sound for these movements, was crucial to their understanding of being in control.

Research suggests a link between a pupil's happiness and their ability to learn (Longhorn 2002). Recording changes in behaviour, such as being alert or more awake, becoming happier or settling more quickly were important measures during my research. Collecting information on a pupil's mood before, during and after the sessions allowed me to investigate if soundbeam could enable a pupil to become or remain happy and in a positive state for learning. My results showed, on most occasions the pupil's mood either increased during the sessions or remained high, showing that soundbeam was a useful tool to sustain or increase mood.

I was also interested to discover if there was any relationship between pupil mood and their responsiveness, and my analysis showed a strong correlation between these. When the children were in a positive or happy mood they responded well, increasing their enjoyment and mood during the sessions. If however the child was drowsy, asleep or distressed, not in a positive state for learning, they did not respond. This analysis was significant to show the importance of the



pupil being in a positive mood to enable them to respond well to sessions. Using this data alongside the results shown for mood could signify that soundbeam could be a useful tool, not only to increase responsiveness but also to enable children to become in a positive state for learning, remain in that state and be engaged for longer. When the pupil's mood was considered low it was more difficult to engage them with soundbeam. However it was likely the pupil would be unresponsive to any session while in this state.

My results for mood and responsiveness can be seen on the graphs on Page 24. The reference lines show where the moods and responses were considered to be positive. Observational notes allowed for understanding to be attributed to the significant data points on the graphs; those falling outside the positive boundaries, such as the pupils being unwell, distressed or distracted by external events.

Even though my research was a small scale study, I believe I was able to provide an environment where the pupils were in control and showed enjoyment in their learning. They were engaged for extended periods of time and began to develop their interactions and communications with us. My positive results showed the soundbeam was a useful tool to develop interactions and responsiveness and could be used to give pupils the opportunity to develop interactions, communication and contingency awareness.

References

- Aird, R (2001) *The Education and Care of Children with Severe, Profound and Multiple Learning Difficulties* London; David Fulton Publishers
- Ellis, P (1995) "Incidental music: A case study in the development of sound therapy" *British Journal of Music Education* 12 p59-70
- Ellis, P (1997) "The music of sound: a new approach of children with severe and profound and multiple learning difficulties" *British Journal of Music Education* 14 (2) p173-186
- Longhorn, F (2002) "Assessing Happiness for Very Special Learners" *The SLD Experience* 33 p21-23
- McPhail, P (2003) *The Soundbeam in Special Education: Movement into Music* Oxford; Soundabout
- Ware, J (2003) *Creating a Responsive Environment for People with Profound and Multiple Learning Difficulties* London; David Fulton Publishers

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Improving the Assessment and Recording of Outcomes for Pupils with Profound and Multiple Learning Difficulties through Collaborative Working

Lorna Mansbridge

Cambridgeshire PMLD cluster group is made up of representatives from the six special schools across the county; Spring Common, Meadowgate, Samuel Pepys, Highfields, Castle and Granta. Cambridgeshire is a rural county with an increasing population and a need for more special school placements. The current demographics of the six Special Schools show an increase in pupils with complex needs beginning their educational journey. This project concerns the assessment and recording for these pupils. In doing so it highlights the importance of collaborative working and achievement that can be gained through partnership opportunities.

The Cluster Group was a means of sharing experience and expertise between special schools and exchanging ideas on practice. Consequently, a shared vision and framework was quickly established. Through regular meetings and discussions practitioners were able to identify an ongoing concern regarding the assessment and recognition of progress for pupils with profound and multiple learning difficulties.

In the early stages of the collaboration a proposal was made and funding secured via the Cambridgeshire Cluster and Partnership Projects to address this assessment issue. Hence the Cluster Group Project was the vehicle to formulating an action to facilitate change.

The Cluster Group defined the rationale for the project as:

- Current assessment systems in schools do not allow for very small steps of progress shown by pupils with complex learning needs.
- Current assessment systems focus on linear progression and do not acknowledge 'the spiky profile' of children with complex needs.
- There are a variety of approaches to curriculum and assessment for pupils with profound and multiple learning difficulties in schools across the country. Some of these approaches are outlined in articles and journals.
- Accurate recording of evidence is vital to allow judgments to be made; greater use of video evidence would be beneficial.
- Staff new to a special school often have little or no experience of working with pupils with most complex needs and lack confidence.

Consequently the aim emerged:

- Consistency of assessment for pupils with profound and multiple learning difficulties
- Make use of latest developments and research
- Secure evidence base for assessments
- Increase staff confidence.

Action was to include visits to observe other outstanding practices in special schools, ensuring these were from varied locations across the country. These schools included Beatrice Tate Special School the London Borough of Tower Hamlets, St Johns in Bedford, and Willowdene in Greenwich. Members of the group observed outstanding practice and expertise and learnt about assessment tools and procedures. They reported back to the group their findings and elements were then assimilated into the work of the group. Penny Lacey, lead consultant from University of Birmingham, was

invited to lead a meeting to provide guidance on current PMLD curriculum and assessment.

Through evaluation of Penny Lacey's input and the various school visits it became apparent that Routes for Learning was the most appropriate tool to integrate into an overall assessment system. In discussion, it was felt that numerical evidence was not a useful way of looking at formal targets and that focus should be on trying to quantify what is 'occasionally', 'frequently', 'consistently' and 'generalised'. This would result in more formative evidence. The cluster group then established four clear assessment criteria in order to evaluate the acquisition of each individual skill as defined in Routes for Learning. This enabled data to be generated which could contribute to the whole school achievement and assessment. The criterion was as followed; occasional, frequent, consistent and generalised. Consequently once a skill was observed in numerous situations it was considered 'generalised', hence achieved. This meant that data was quantifiable and objective, perceiving progress in a non-linear fashion. Ultimately, the cluster group had produced an assessment framework, policy and guidance which could then be trialed in each of the participating schools.

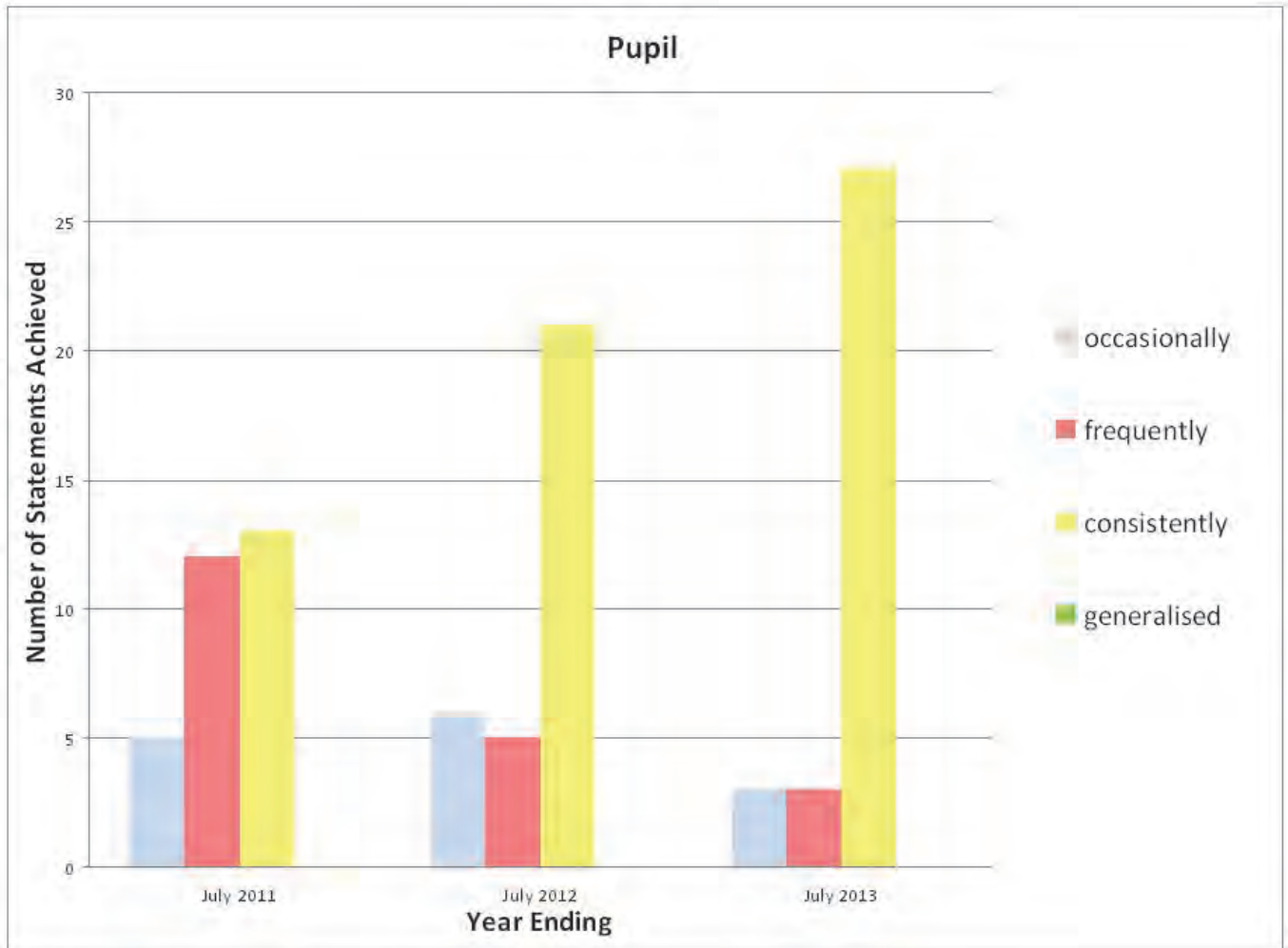
Results: Graph 1: (see page 28)

Achievement can now be adequately observed and interpreted. Graphs demonstrate the skills learnt against the assessment criterion which can be supported by video evidence through a hyper link. Such graphical presentation of achievement can reflect learning over longer periods of time.

Conclusion (What have we achieved and what we have learnt):

Primarily, the main outcome was that one assessment system is now being used in each of the Cambridgeshire special schools; Routes for Learning, which will allow for moderation and comparisons as well as small steps of progress not shown in existing systems. Importantly, assessment is now more individualised. The progress is shown in a visual way which can then be shared with parents and is easily interpreted. The system also allows for next steps to be identified.

The results could only have been achieved through collaboration and partnership working which suggests that such projects are of immense value to the enhancement of educational practice and should be continued. The funding from Cambridgeshire supported the developments of the project. Another impact has been the elevated confidence in the staff supporting pupils with complex learning needs who can now record focused observations against the detailed framework.



	July 2011	July 2012	July 2013
occasionally	5	6	3
frequently	12	5	3
consistently	13	21	27
generalised	0	0	0

Results: Graph 1

Furthermore, the Cluster Group Project's achievements and aims were presented in the Cambridgeshire Cluster and Partnership Projects 2012 - 2013 which raised the profile of children with Profound and Multiple Learning Difficulties and their learning capabilities.

Schools involved in the Cluster Group are keen to continue even though the Cambridgeshire Cluster Group Project and funding has ended. Further developments have already been identified; work on the use of IT as a means of enriching PMLD provision, and assisting assessment within it.

The Special School Cluster Group Cambridgeshire

With special thanks to

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Routes for Learning Research an opportunity to contribute

Penny Lacey

The University of Birmingham is conducting research into the impact on schools of using Routes for Learning. Routes for Learning is an assessment tool based on child development, which covers both cognition and communication. It is suitable for use with any learners who are functioning at a very early stage of development, usually associated with typical infants in the first 18 months of life.

Routes for Learning is a formative assessment in that, following observations, learners' behaviours can be plotted on the Routemap. From the map, teachers can gain an understanding of the learners' current strengths and needs and this then informs their teaching. For example, a learner clearly shows examples of contingency awareness (simple cause an effect) with sound making objects and so the teacher provides her with a range of different soundmakers to enable her to build up her repertoire.

Routes for Learning was published in 2006 and some schools have been using it since that time. Others have only just started using it in their practice but from my contact with a range of schools, momentum is gathering and it is the right time to evaluate how it is being used so we can share information across the sector.

We have already got more than 60 schools interested in contributing to the research and hope to find even more. We have applied to the Nuffield Foundation for some funding to employ a researcher but we are intending to conduct the research whether we have funding or not. No funding would mean that the study could not be as extensive as we would like but nevertheless, we would expect it to yield some useful results.

Our intentions are to design an online survey to find out

Who is using Routes for Learning?
How they are using it?
Whether it has influenced their curriculum and / or teaching
Whether it has made any difference to children's progress

Following the online survey, we want to select some

schools to provide more detail through interviews, observations and analysing records. If we get funding for a researcher then we will conduct 10-12 case studies but if we don't then I will visit as many schools as I have time for and they are likely to be those that are close to Birmingham!

From the data we collect, we are intending to share practice across schools. We should be able to write case studies to illustrate what schools are doing, as well as give facts and figures about who is doing what. I will also write an article for PMLD Link, probably in the Spring issue in 2016. How about that for forward planning!

If you would like to be part of this research, go to <https://www.surveymonkey.com/s/TTQFZ7T> and fill in your details.

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A Newly Qualified Teacher in a Class of Pupils with Complex Needs

Rebecca Ellis

Last year, I was lucky enough to complete my NQT (Newly Qualified Teacher) year working as a teacher of PMLD at the West SILC (Specialist Inclusive Learning Centre) Farnley Partnership, a centre for students with Complex and Multiple Learning Needs. Many special schools are not willing to take NQT's, preferring to employ teachers with mainstream experience alongside experience of SEN. However, our principal and head of site 'took a chance on' me for which I am very grateful. My prior experience had been from working at weekend and holiday play schemes and as a support worker for children with a range of disabilities, as well as a peripatetic woodwind teacher in secondary and primary schools.

I had completed an Early Years 3-7 PGCE which gave me good grounding in child development, but not many insights into appropriate teaching methods for the students with PMLD which I would now have in my Key Stage 3 class of seven. However, I came with enthusiasm, a willingness to learn and a desire to dismiss previous notions of a formal curriculum for these pupils. The ethos at Farnley is very much about Personalised Learning for all pupils, and my first job was to get to grips with Personalised Learning Plans (PLPs). These focused on

core aspects identified in the pupils' statements that needed to be addressed, and key communication and functional skills.

These targets were addressed through personalised curriculums based on the MOVE program, Intensive Interaction, sensory exploration, social and peer interaction and early learning skills. The curriculum and assessment models we use at Farnley are constantly being reflected upon, and I was part of the development

of new child centred target setting sheets, that helped us develop the PLP targets into small steps. This made it easier for progress to be seen over time, especially when that progress is often small. This year, we are working to develop a robust assessment system which will record this progress, particularly for those students who are post Routes for Learning (an assessment map created by the Welsh government for students working at p1-3 in the P-scales).

As part of my allocated NQT time, I visited other classes within our SILC and other local special schools. This experience was invaluable in helping to share the good practice of other professionals, and to see a wide range of learning environments for pupils with PMLD. The lack of specific teacher training for SEN and PMLD other than post graduate courses, meant that having the time to do this was essential in helping to develop my skills beyond those I had gained from my PGCE. Attending courses and the regional support groups on Intensive Interaction was not only useful in extending my knowledge but in converting me to a full blown II enthusiast.

I also used my NQT time to reflect on my progress against teacher's standards, something I am now using as part of performance management and the introduction of performance related pay. Being a reflective practitioner is not always easy but is essential when trying to ensure that one is offering the best learning environment to students with such complex and often changing needs.

I would not have survived or enjoyed my NQT year as much without the support I received from my mentor, head of complex needs and especially my learning support assistants. LSAs can sometimes be unsung heroes in many schools and I made and continue to make a point of appreciating mine regularly. They guided me through the children's daily routines of postural and personal care when I first started and helped me to get to grips with the day to day classroom management that is the core of PMLD teaching. One is an enhanced Intensive Interaction Practitioner, and I learnt a great deal from working alongside her good practice in this area.

About half way through the year the day to day realities of the complex needs of the students I worked with, the professional responsibilities outside the classroom such as Annual Review Meetings, and the general emotional and physical toll of the job began to affect me. This is when I learnt what I believe is an important aspect of any teacher's role: the work life balance. The advice I give to any friends who are now student teachers or NQT's is to find it sooner rather than later when you are already starting to suffer. Getting the paperwork done is important, but not as important as the day to day work with the students. Having an early night keeps you going midweek, seeing friends and family and leaving the house, keep you balanced. When you are at your best the students obviously get the best out of you.

OFSTED arrived in July just to keep us all on our toes until the end of the year. It was a useful, if slightly scary,





experience to be observed by an OFSTED inspector as an NQT, but the positive feedback was a confidence boost. The Centre achieved a 'good' overall and we were able to be productive and enjoy the last few weeks of term. Fortunately, being observed regularly by my mentor meant that I was used to being watched. Feedback from these observations had helped me develop my practice and to finish the year with an 'outstanding' grade.

Now I am at the end of the Autumn term with the same class as last year and I feel I am ready to look beyond my classroom to the wider school. It was necessary as an NQT to give myself time to develop my skills towards being a good classroom practitioner and to do as much as I could for my pupils. This year, I am beginning to use my musical background more and developing the music provision across the whole site. The impending move away from statements to the Education Health Care plan is a hot topic of conversation. We already work very closely with other professionals, including school nurses, physiotherapists and speech and language therapists, as

we try to address the needs of the whole child. The EHC is meant to encourage and develop this work further, but as services are being cut significantly around us, there is a concern that already good systems may degenerate. Challenging times may be ahead, but safe to say that they will never be dull and it will always be a privilege to work with such amazing students.

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References

MOVE - <http://www.themovepartnership.org.uk/>
Intensive Interaction - <http://www.intensiveinteraction.co.uk/>
Routes for Learning - <http://wales.gov.uk/topics/educationandskills/schoolshome/curriculuminwales/additionaleducationalneeds/routeslearning/?lang=en>

Top websites for this issue

Foundation for People with Learning Disabilities

<http://www.learningdisabilities.org.uk/>

The Foundation seeks to influence government and local authority policies and services so that they better meet the needs people with learning disabilities, their families and carers. It also raises awareness of learning disability issues amongst the wider public and provides information, resources and services that help people with learning disabilities lead fuller lives.

Mencap

<http://www.mencap.org.uk/>

Mencap offers a range of support services which enable people with learning disabilities to enjoy a variety of meaningful activities

BILD the British Institute of Learning Disability

<http://www.bild.org.uk/about-bild/aboutbild/>

BILD helps to develop organisations which provide services, and the people who give support, in order to ensure that people are supported with dignity and respect and can make choices and decisions about their lives.

Frozen Light

<http://www.frozenlighttheatre.com>

This is a theatre company with charitable status which provides an accessible and theatrical environment in public theatres, for people with PMLD.

Oily Cart

www.oilycart.org.uk/

Oily Cart creates innovative, multi-sensory and highly interactive productions for young people with profound and multiple learning disabilities.

Bag Books

<http://www.bagbooks.org>

Bag Books produces multi-sensory stories specifically designed to 'make sense' to children, young people and adults with PMLD.

PAMIS

PAMIS provides support for people with profound and multiple learning disabilities (PMLD), their family and carers and interested professionals. Their newsletter is available at:

<http://www.pamis.org.uk/email.view.php?id=14>

http://www.pamis.org.uk/cms/files/pamis_spring_e-news_2014.pdf

FUTURE FOCUS

Transitions

Most of us have strong memories of significant events in our lives – the first day at school, for instance, ours or our children's, our first job, moving house and so on. Times of change can bring anticipation, excitement, but often also anxiety and uncertainty about the future. For people with profound and multiple learning disabilities and their families, transitions present both opportunities and challenges. Transitions from pre-school to primary, to secondary, to adult life. The first time a child or young person has a holiday away from the family, a move out of the family home into other accommodation. The particular needs of later life, changes in health and family situations.

In the UK the word transition has become more formally associated over recent times with the process of moving from adolescence into adulthood, from education and children's services into adult services, although there will have been several other transitions prior to this. You may have had experience of such 'transition planning', as a parent or a worker. What went well, what needs to be changed and what advice do you have for others, whatever their role? How can the young person concerned be as fully involved as possible? How can we ensure that transition planning carries over into positive action?

A recent advertisement for a local authority transitions worker highlighted the importance of working across the traditional boundaries of statutory children's and adult services and promoting an integrated approach to the

management of transition planning. In your experience, what are the essential ingredients of smooth transitions?

Whatever the nature of the transition, we know that effectiveness depends on several things: the central involvement of families, good communication, a coordinated approach, sound working relationships and respect for one another's knowledge and experience. What is your experience as a family member, a worker, volunteer or friend in relation to these issues? Is information easy to obtain, provided in the right way and does it help? Is it equally accessible to minority communities and the majority population? Do you know of a particularly well coordinated approach to transition, at whatever stage in a person's life? An example you feel other people should know about? And what about the challenges any transition brings – what support has worked well and what else is needed? How can we best communicate with children and young people about what is happening now and what is likely to happen in the future, reassure and support them?

Please share with us your experiences, ideas, thoughts and advice about transitions, at all stages of life. We welcome all contributions, not only articles but also short pieces, recommendations of websites or written materials, your tips and suggestions. We look forward to hearing from you.

Please send your contributions to Sue Thurman s.hurman@ntlworld.com by 31st may 2014. Thank you.

GIFT AID

Is your subscription your own personal one and do you pay tax?
If so, by signing the gift aid form we can get an extra 25p in every £1 you pay to us in tax refund from the government. This makes a significant contribution to our finances at no cost to you.

If you subscribe through PayPal you can download and print off the Gift Aid form from the PMLD Link website or use the one on the subscription form on the back page, and send it to Rob Ashdown, 15 Cliff Gardens, Scunthorpe, North Lincolnshire, DN15 7PH

If you can't remember if you have already signed the Gift Aid form, just sign it again – we can check whether you are on the gift aid record.

Thank you to all personal subscribers who have already done this.

Development and Subscriptions Manager

The PMLD LINK Trustees wish to engage a freelance worker to act as a Development and Subscriptions Manager.

There are two parts to the role: (a) increasing the number of subscribers to the journal, thereby benefitting a greater number of people with profound and multiple learning disabilities (PMLD) and their families, and (b) administration of subscriptions. It is a particular aim to bring the journal to the attention of many more organisations, especially service providers of all kinds for children and adults.

It is envisaged that increasing subscriptions will involve the use of modern computer technology. The person appointed will use social media technologies and develop website materials to publicise the journal as well as contacting organisations directly via e-mail and raising awareness through articles and promotions at relevant exhibitions and conferences.

This is a part-time freelance post. The person appointed must be able to work from his/her own home or other base and must have ready access to the Internet and e-mail facilities. It is expected that, *on average*, the time commitment will be for the equivalent of one day per week (or 345 hours per year).

The person appointed will be self-employed and must be responsible for their own tax returns, insurance, etc.

The PMLD Link Trustees believe that the person appointed will gain many benefits from the opportunity to work closely with PMLD Link's experienced and diverse team, liaising with the varied contributors to the journal, as well as engaging with people at conferences and through other activities.

To download a job description, person specification and other details, please go to the PMLD Link website (www.pmlmlink.org.uk) or email rob.ashdown@ntlworld.com.

The PMLD LINK Trustees look forward to receiving your letters of application.

PMLD Network Forum A Digest of Discussions January – March 2014



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.

Research for Masters thesis paper about post-school provision for students with PMLD in England

A student from Germany asked if anyone was able to share information about post-school provision for students with PMLD in England. She said she was interested in hearing from anyone who works in 19+ education, work, training, sheltered workshops, day care, community based learning, community activities or other provision for people with PMLD. She followed this message up with one asking specifically about what work support was available for people with PMLD.

Responses included:

- 'Us and a Bus' explained that their work with people with PMLD focuses on people's need and desire to connect and interact in a way that is meaningful to them, and on creating opportunities for life-long learning, to explore how communication skills and sociability can continue to develop over a life-time.
- Someone from a service which provides specialist day services and therapy for those leaving education said 'we are finding that our waiting lists are growing and people are prepared to travel further to access our services, particularly since the move towards purely community-based services.'
- Someone said that people with PMLD are generally not able to carry out a meaningful job of work. They said that there are of course exceptions to this but these are generally few and far between. They said 'surely more emphasis should be placed on finding activities to fill leisure time, rather than placing pressure on employers to find token jobs for people with PMLD. In my view, this exacerbates the prejudices that people have.'
- Someone else said, 'It is a struggle to find out about work because it is so rare and not documented...I see all these amazing people working extremely hard throughout their lives at surviving, socially interacting with the world around, developing leisure pursuits, seeking means of communication to others and so on...leaving little time to pursue a traditional career... They also spend a lot of time training new care assistants or key workers!'. The person gave a list of jobs they have known about over the years, which they said have been held by people with PMLD very successfully. They said 'they are jobs observed in the UK (unpaid), Luxembourg and Belgium (where they were paid the same salary as other workers plus a pension). Their jobs were very carefully chosen by working out what would be sensory and pleasurable for them in an ongoing work situation.' The list included:
 - 'Naomi works in a garden centre run by her parents, she plants seeds with a pointy finger, fills pots with compost, washes and recycles pots, feeds fish.....'
 - 'Jena works in a very posh bank in Luxembourg, she is desperately obsessed with shredding paper so is employed to shred used bank notes and confidential papers, in an adapted shredding machine. It is useful that she cannot read.'
- Someone replied, 'Reading those examples is very delightful and actually shows what it is about: taking the wonderful skills people have and using them for finding something worthwhile to do.'
- Someone else said, 'I've known of one person with PMLD who works – some sort of food tasting/ quality control role which involves eating things and showing if you think they're nice or not – she loves it and had been doing it for some time when I met her, but that's one job and there are thousands upon thousands of people with PMLD in the UK!'
- 'I did wonder what sort of jobs people with PMLD would be able to access. I work in a school with many children who have PMLD. Their actual awareness of the world is extremely limited as are their physical abilities. Yes, they do need to have a place in society but it needs to acknowledge their needs and give them the support they need to have fulfilling lives which meets their needs.'
- The student who posted the original message said, 'I really believe that people with PMLD can work and contribute to society - it just really depends on what your vision and definition of work is.'

- Someone else said, 'At Chelmsford College in Essex in the UK, they use the term 'vocation' to refer to the kinds of things a person with PMLD/ complex needs might do in their adult life. I think this is an excellent term because although it does encompass paid work it is also about meaningful and fulfilling activities which might enrich their lives. In reality it is extremely unlikely that some one with complex needs will ever undertake paid work, but this does not lessen them in any way or mean they are not able to take a valid place in society. An unpaid vocation can be just as fulfilling as a paid job.'

Resources

Thinking Ahead: A planning guide for families

<http://learningdisabilities.org.uk/our-work/family-friends-community/thinking-ahead/>

Planning for the future can be daunting for people with learning disabilities and their families. The Thinking Ahead guide helps families to think about and plan for the future. It provides information and practical ideas for gradually planning and putting things in place so that families experience less stress and anxiety about the future.

Confidential Inquiry DVD

www.youtube.com/watch?v=hQXzcDbaVxc

The team who ran the Confidential Inquiry into premature deaths of people with learning disabilities has worked with The Misfits Theatre Company to make a DVD which presents the findings of the Confidential Inquiry through the stories of John, Bill, Karen and Emily.

Health Charter for Social Care providers

<http://www.vodg.org.uk/health-charter/health-charter-home.html>

The Charter is designed to support social care providers to improve the health and wellbeing of people with learning disabilities, working in partnership with their health colleagues, family carers and people with learning disabilities themselves.

'Personal health budgets: Including people with learning disabilities' by Sue Turner and Alison Giraud-Saunders

http://www.thinklocalactpersonal.org.uk/_library/Reports/TLAPIncludingLD.pdf

This guide has been developed from work with three sites and a network of individuals and organisations who are supporting the roll out of personal health budgets to people with learning disabilities.

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

NEXT ISSUE

Spring Vol. 26 No. 2 Issue 78

- Transitions -

Do you have any stories to share?

If so, contact the editors:

Helen Daly: hd.castor@btinternet.com

or

Sue Thurman: s.thurman@ntlworld.com

The copy date for all articles, information and news for the **Summer issue is the 31st May 2014**

REVIEWS

Title: Curricula for Teaching Children and Young People with Severe or Profound and Multiple Learning Difficulties: Practical strategies for educational professionals

Authors: Peter Imray, Viv Hinchcliffe

Publisher: Routledge

Publication date: 17th October 2013

Pages: 272

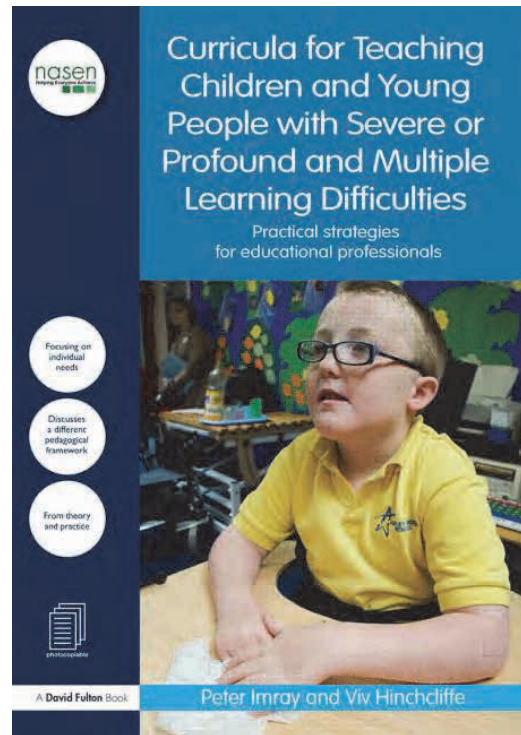
Price: £29.99

ISBN: 978-0-415-83847-4 (Paperback)

Peter Imray is a freelance trainer and advisor and Viv Hinchcliffe is Head of Drumbeat School and ASD Service, Lewisham. They argue that the National Curriculum, despite best intentions, has failed children and young people with Severe or Profound and Multiple Learning Difficulties. They believe that there is a need for separate and distinct pedagogies to be formulated for these learners and that a modified version of a mainstream type curriculum is simply not appropriate for ensuring meaningful learning. They say that they do not believe in a broad and balanced curriculum for some learners with complex needs, including those with PMLD and some with SLD. Their view is that schools do not have enough time to offer all these learners an experiential curriculum and must focus on delivering a highly personalised curriculum, which must be relevant. They emphasise the need for a focus in the curriculum on fundamental learning skills such as communication, thinking and problem solving.

This book provides guidelines and support in key curriculum areas for both learners with PMLD and learners with SLD. As regards learners with PMLD, the key chapters are about:

- A Cognition Curriculum, including neo-Piagetian descriptions of development at the sensori-motor stage and an important discussion about 'learned helplessness' and strategies for reducing this.
- A Communication Curriculum, including presentations on Intensive Interaction, the use of cues, the uses of ICT and the value of new approaches to literacy.



- A Physical Curriculum, covering physiotherapy, positioning, massage, movement, drama and dance, mobility.
- A Care Curriculum, stressing that it is an essential feature of the school curriculum and not something to be done in as little time as possible and a distraction from the real business of education.
- A Sensory Curriculum, extending use, understanding and control of the senses to allow exploration of the world as fully as possible.
- A Creative Arts Curriculum, with descriptions of meaningful ways of teaching dance, art, drama, music and literacy for enriching curricula.
- A Citizenship Curriculum, including what is practical in terms of sex and relationships education and the important role of adults in teaching love, not in a sexual sense, revisiting ideas about establishing the value of human contact and interaction expressed by proponents of Gentle Teaching and Intensive Interaction.

Early chapters set out the authors' beliefs about the needs of these learners with PMLD and SLD, perhaps with the greatest emphasis on those with more profound learning difficulties. They provide their rationale for their attitude to the National Curriculum, which they regard as a 25 year failed experiment, and associated issues surrounding schools' accountability for learners' progress as determined by Ofsted and through the use of P-scales

for assessment. They also provide their viewpoint about the problems inherent in skill-based learning approaches, with an emphasis on SMART targets, and their preference for process-based learning with Intensive Interaction being a recurrent example of this type of learning and approach to teaching. They also provide discussion of some interesting examples of approaches to relevant assessment and recording for recognising achievement.

On the whole, the various chapters are written in accessible, common sense and non-academic language and provide thought-provoking overviews of teaching approaches and underpinning principles for relevant curricula that should enhance and enrich the learning of these children and young people. Each chapter contains useful references for texts that for readers who require more details. For these reasons, this book probably should be regarded.

Perhaps, at times, statements may seem unduly acerbic and some of their arguments are polemical, attacking the beliefs of people who have well-developed, alternative views, especially surrounding the value of an inclusive national curriculum. Yet, this is a highly practical contribution to curriculum development in schools. It is also an intellectually stimulating book which deserves to be widely read, not just by teachers, but by anyone who is concerned to develop the best possible education for learners with PMLD and SLD.

Hewett, D and Firth, G (Eds) (2012) Intensive Interaction: Curriculum Documents for Schools Pukeridge: The Intensive Interaction Institute

This resource contains both useful example paperwork to support Intensive Interaction and general information that can underpin Intensive Interaction practice in schools. In the Introduction, the editors say that they aim to assist school managers with the documentation required to support Intensive Interaction in practice.

The folder is divided into 14 Sections and I think it will be helpful for readers for me just to list those.

The story of Intensive Interaction
Recognition and endorsement of II
II Curriculum rationale
General Communication Curriculum rationale
Classroom guidelines
Recording sheets
Example of IEP
Child-centred Learning and Activity Session (CCLAS) rationale
Early Learning rationale
Statement on developmental pertinence
Specimen school policy on touch and physical contact
Intensive Interaction FAQ
The published research summaries document
A glossary of II terms
There are also another 6 empty sections that can contain schools' own policy documents.

There is no doubt that this is a really useful pack. If you are struggling to write policies around Intensive Interaction, you will find help in many of the sections and will be able to produce a coherent document in no time! The recording sheets alone are incredibly helpful. I went through them, looking for easy record sheets to recommend we use in our school. There are several different formats to choose from and each set has a summary of the purpose of the sheet/s, the data type, the potential audience and tips on usage. The example IEP is real useful as well.

With my academic hat on, my personal favourite section is number 13 where you can find the published research summaries. There are 19 summaries ranging from 1991 to 2009. In the introduction to that section, it states that you can ask Graham Firth to send you updated copies (graham.firth@nhs.net). The summaries are followed by a reference list of many other papers. It is a fantastic resource!

Judging by the amount of work that has gone into this pack, it is not surprising that the price tag is £200. I think schools will find it money well spent.

Penny Lacey
University of Birmingham and Castle Wood School,
Coventry

RESOURCES

Friends for Life Learning Disabilities Development Project

New guide to help young people with learning disabilities to manage their feelings better.

Today the Foundation for People with Learning Disabilities has produced a guide on ways to adapt the internationally recognised and World Health Organisation endorsed FRIENDS for Life programme to help children and young people with learning disabilities to manage their feelings better.

Although children and young people with learning disabilities have higher rates of emotional and behavioural problems than their peers without learning disabilities, research shows they have less access to services and support.

The Foundation for People with Learning Disabilities worked with Rowena Rossiter, Clinical Psychologist, in collaboration with Hazel Court School and the CAMHS-LD Family Intensive Support Service in Sussex Partnership Foundation Trust, on a small development project to enable the FRIENDS for Life programme to be accessible for children and young people with learning disabilities. The adaptations were planned to consist of simplified materials with high visual and low verbal content to make the sessions more meaningful.

Developed in Australia, the FRIENDS and Fun Friends programmes build resilience by helping children and teenagers cope with feelings of fear, worry, and depression by teaching cognitive, behavioural, and emotional skills in a simple, well-structured format. Based on Cognitive Behaviour Therapy, the programmes enable children and young people to learn about the links between their thoughts, feelings and behaviour.



Jill Davies, Research Programme Manager at the Foundation for People with Learning Disabilities, said: "By adapting the FRIENDS for Life programme we hope that more children and young people with learning disabilities are able to better manage their feelings and achieve a greater sense of wellbeing."

The guide is based on experiences of trialling some of the FRIENDS for life activities with a group of young people with learning disabilities. It also includes what has been learnt to date from the adaptation. It is aimed at all professionals working with children and young people with learning disabilities in: Education (e.g. teacher, learning support assistants, learning mentors, educational psychologists, speech and language therapy assistants) Health (e.g. school nurses, community nurses, clinical psychologists, speech and language therapists, communication assistants, mental health practitioners) The voluntary and community sector.

To download the guide please visit: <http://www.learningdisabilities.org.uk/>

Learning Disabilities Good Practice Project

The report gives people who commission, design and deliver services a better understanding of how to improve the lives of people with learning disabilities. Details of the services were collected by the National Valuing Families Forum and the National Forum for People with Learning Disabilities, as requested by Norman Lamb, Minister for Care and Support, in November 2012.

More than 80 examples were received, and 6 services were selected because they demonstrated important indicators of good practice. They are described in detail in the report.

Published: 28 November 2013 by Department of Health
<https://www.gov.uk/government/publications/learning-disabilities-good-practice-project-report>



IN THE NEWS

Putting the pieces together

Learning Disability Today has produced a special supplement on autism and challenging behaviour, sponsored by Tough Furniture, which we are pleased to make available for you to read in full here. This supplement addresses some of the key issues in managing challenging behaviour and autism. These include the influence of the built environment on reducing stress and anxiety, how active support and positive behaviour support can work together to reduce challenging behaviours, and some tried-and-tested tips that can be introduced into your practice from parents, carers and practitioners.



Every edition of Learning Disability Today discusses and examines important, topical questions for those living and working with learning disabilities, including autism and challenging behaviour.

<http://edition.pagesuite-professional.co.uk/launch.aspx?pbid=e4a21eec-0761-424e-8a05-cd5c8166cea7>

Papering over the cracks: the impact of social care funding on the NHS

Demand for both NHS and social care services is increasing rapidly, due to growing demographic pressure from an ageing population and an increasing number of people living with complex care needs. Funding is not keeping pace with demand.

This Briefing outlines the current demographic and financial realities of social care and how these impact upon the NHS.

It shows the additional pressure that will be put upon the health and care system in the coming years; and it sets out the NHS Confederation's recommendations for a lasting solution for the funding of social care and a redoubling of efforts to integrate care. We are calling for a cross-party consensus on solving the challenges raised.

Download Publication: <http://www.nhsconfed.org/Publications/Documents/papering-over-cracks.pdf>

Alternatively try: <http://sn.im/28omsr6>

The Max Card Scheme provides more affordable days out for looked-after children and children with disabilities

Max Cards entitle users to discounts at over 250 venues throughout the UK. Attractions such as zoos, museums and bowling complexes kindly offer free or discounted entry, for up to 2 adults and 2 children (aged up to 19) travelling with a Max Card.

Our cards last two years from issue date, and are distributed via the local authorities, charities and selected schools, **predominantly in Yorkshire and the West Midlands**. However, due to the success of the scheme in the pilot regions, we are rolling the Max Card out on to a national level, and will be contacting venues and councils in the surrounding areas over the coming months. Please keep checking our website 'partners' section to see if your council have opted to join us at www.mymaxcard.co.uk.

For updates on new venues and councils, please like our facebook www.facebook.co.uk/mymaxcard or twitter page @mymaxcard, to keep up to date with our latest progress.

If you have any queries at: please contact Natasha Lee-Johnson at hello@mymaxcard.co.uk

A little bit more about Frozen Light

Artistic Director Amber Onat Gregory explains why she and co-artistic director, Lucy Garland decided to move their show 'Tunnels' - a show for teenagers with PMLD - into theatres.

"Tunnels did a special schools tour as part of its development in London, Devon and East Anglia. Although we felt like we had created a larger scale production, performing in a school still had its drawbacks. Schools are very busy places and this means that a lot of the theatricality can be lost whilst trying to adapt to different spaces in school buildings. Tunnels explores a different world, and we wanted that world to be explored in the serenity of a theatre. We also wanted to give our audience, young people with Profound and Multiple Learning Disabilities (PMLD) the opportunity to see theatre in a traditional theatre environment as there are very few theatre opportunities that are accessible.



Theatres are making their venues more accessible with ramps, toilets, hearing loops, sign interpretation, and even programming relaxed performances for audiences with autism. All of this is absolutely fantastic but there is still minimal work being programmed specifically for audiences with PMLD. People with PMLD often find it difficult to access mainstream theatre shows for many reasons: the stage is too far away; the text is complicated; the only senses that are really used are sight and sound (very difficult for people with sensory impairments) and you are expected to sit in one spot and stay silent. All of this on top of large audiences and mobility needs makes mainstream theatre almost unapproachable. Creating work for an audience who are not your average theatre goers is extremely liberating as so many of the usual theatre traditions are taken away, which gives you a lot of artistic freedom when creating the work.

By having multi-sensory elements throughout the show we have been able to create an accessible and theatrical environment that responds to the needs of this group. Most of the multi-sensory elements are performed as an individual interaction between audience member and performer [and] the show takes place in the round so that the audience can be in close proximity to the action and are almost a part of the set themselves. Being in the round also gives us the opportunity to create collective sensory moments where the audience can experience a sensory moment all together."

For more information:

Web: www.frozenlighttheatre.com Email: info@frozenlighttheatre.com

A brand new show from Oily Carte!

Developed with support from Ockham's Razor, Oily Carte have devised **THE BOUNCE**, a new multi-sensory and highly interactive show for young people aged 3-19 years who have Profound and Multiple Learning Disabilities or who are on the Autism Spectrum.

Using trampolines, video projection and live music with a Middle Eastern flavour, they will be exploring bounce in all its forms from gentle to exuberant, carefully adapting performances to the specific requirements of each participant. The show comes with on-line resources to help audiences prepare for and follow up on the live experience.

THE BOUNCE is on tour from 8th September to 29th October.

Email: alison@oilycart.org.uk or call 020 8672 6329.

Poor implementation of Mental Capacity Act fails people with a learning disability

On Thursday 13 March, a House of Lords Committee published a report looking at whether the Mental Capacity Act 2005 is working as intended. The report found that the Mental Capacity Act is not widely implemented and the Deprivation of Liberty Safeguards are not fit for purpose.

To address its findings, the Committee recommend that responsibility for implementing the Act is given to an independent body, and that the Deprivation of Liberty Safeguards are reformed.

Mencap said they welcome the recommendations, but believes that to ensure 'implementation' of the Mental Capacity Act 2005, professionals need to know they will be properly held to account if they fail to follow the law.

"The Mental Capacity Act was a visionary piece of legislation for its time, which marked a turning point in the statutory rights of people who may lack capacity", the report says. It also added that the Act "placed the individual at the heart of decision-making." The report went on to say that "The Act had suffered from a lack of awareness and a lack of understanding. For many who are expected to comply with the Act it appears to be an optional add-on, far from being central to their working lives."

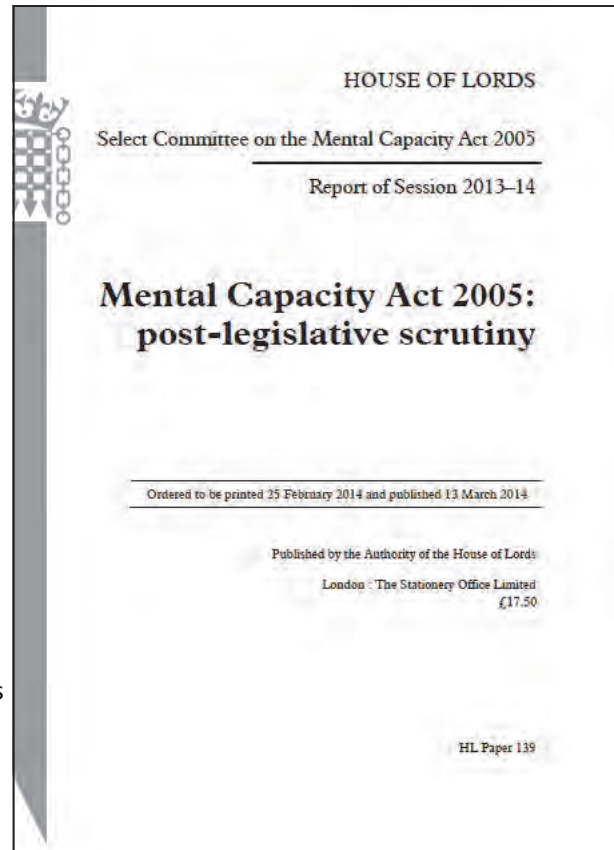
Beverley Dawkins, Mencap specialist advisor said, 'We welcome all the recommendations of the Committee, particularly to set up an independent body to drive forward implementation and the need to review and reform the Deprivation of Liberty safeguards.'

Alongside work to ensure the law is embedded in practice, we want serious consideration given as to what sanctions should be applied, when there is failure to follow the law.

We are concerned that professional regulators are not taking failures to adhere to the Mental Capacity Act seriously enough. No single health care professional has been properly held to account for failing to adhere to the Act – even though the consequences can, and have, been life threatening and even fatal. For real change to happen, professionals need to know that there will be serious repercussions for failures to carry out their legal duties.'

Mencap's health campaigning has highlighted how serious the consequences can be when the Act isn't followed, such as where proper 'best interests' decisions are not made. Many people with a learning disability, for example, don't receive the treatment they need because of misheld beliefs or a failure to involve families when making best interest decisions.

Read the House of Lords Committee report www.publications.parliament.uk/pa/ld201314/ldselect/ldmentalcap/139/139.pdf



Poor guidance threatens to undermine potential of Children and Families Act

The Children and Families Bill has received Royal Assent in the House of Commons and will come into effect from September 2014. Over the past year, Mencap has worked alongside its sector partners in the Special Educational Consortium (SEC) and Every Disabled Child Matters (EDCM), to ensure the legislation is fit for purpose.

Now Mencap is calling for greater attention to be given to the draft Code of Practice, which could undermine the potential success of the new legislation.

Mencap warns that the time frame for implementing the reforms is also cause for concern, with professionals having just a few months' notice of their new obligations before they are expected to meet them. Mencap is now working to ensure that anyone affected by the Act is aware of the changes and understands what the changes mean to them.

Key changes to the SEN system

Described by the government as one of the biggest changes in special education for three decades, the Act aims to transform the system for children and young people with special educational needs (SEN) by placing families at the centre of decision making. It sets out requirements that education, health and care services should work together to provide joined up support across all areas of a child or young person's life.

The Act replaces SEN statements with Education, Health and Care (EHC) plans, and the system will run from birth to 25, rather than ending when a young person leaves school. The Act also introduces a Local Offer of information for families covering the education, health and social care support available locally.

Successful amendments to the Act

Mencap and others fought successfully for a number of key amendments to the Act, including:

- Making health bodies responsible for meeting a child or young person's health needs as assessed in their new EHC Plan
- Ensuring that a child or young person's social care needs are met if they are listed in their EHC plan
- Making the government formally review the appeals/complaints process and look at ways to make it easier for parents to appeal across education, health and social care
- Strengthening the ability of young people with an EHC plan to remain in education or training beyond the age of 18 if they wish to do so.

Our work doesn't stop here

Dan Scorer, Head of policy and public affairs at Mencap said, 'After working to make sure the legislation has the potential to improve life outcomes for children and young people with a learning disability, we now need to shift our focus to the quality of the guidance, which is fundamental to making this a reality. Disappointingly, the Code of Practice is by no means fit for purpose. The guidance does not tell professionals what they need to do in order to support children with a learning disability under the new system and this threatens to undermine the good intentions within the Act. We need to get this guidance right, and fast, as the legislation must be implemented from September this year. With the clock ticking, improvements to the Code of Practice are urgently needed so that professionals know what is expected of them.'

Find out more at:

www.mencap.org.uk/campaigns/what-we-campaign-about/children-and-young-people/children-and-families-bill

We Welcome any Contributions to PMLD Link

We are very flexible in our requirements for contributions to the PMLD LINK journal.

Articles are usually between 1 and 4 pages of A4 single-spaced, regular font size. This usually equates to between 350-1500 words. However we are happy to accept shorter or longer pieces. Ideally, we want you to have the opportunity to discuss what you want, rather than tie you to a fixed number of words.

Our readers are family members, carers and range of professionals working across child and adult services, so any specialist terms used should be clarified. Articles vary from those with a research/academic focus to those that are very practical in nature. It is useful to include references and contact details to enable readers to follow up information – and they do!

As this is the only journal dedicated to people with PMLD, it is important that your article is specifically related to them. If appropriate, give examples of the work in practice and how it could be applied elsewhere. We can include images, photos or samples of materials, in black and white only, if this is appropriate and where relevant permissions are given. Please send a completed consent form with your article (downloadable from the PMLD Link website).

We also welcome short informative pieces about new resources, books, websites, events, courses and news in general.

NEXT ISSUE

Spring Vol. 26 No. 2 Issue 78

- Transitions -

Do you have any stories to share?

If so, contact the editors:

Helen Daly: hd.castor@btinternet.com

or

Sue Thurman: s.thurman@ntlworld.com

The copy date for all articles, information and news for the
Summer issue is the 31st May 2014

The SLD Experience

The British Institute of Learning Disabilities (BILD) regularly publishes a journal called 'The SLD Experience' which is aimed at parents and practitioners working with and caring for children and young people with severe learning difficulties (SLD) in mainstream and special schools. To find out more about the journal go to the BILD website (<http://www.bild.org.uk/our-services/journals/sld-experience>).

In 2013, there were 3 issues of SLD Experience. These contained a number of interesting articles of relevance to people working with children and young people with PMLD. Some apply to the whole population of learners with SLD/PMLD; some apply specifically to learners with PMLD. We hope to produce fuller accounts of relevant articles in the News section as each issue is produced in future.

Spring 2013 (Volume 65)

'Listening and responding to children with PMLD – towards a framework and possibilities' by Martin Goodwin. Provides a rationale and strategies for listening and responding to learners with PMLD and recording what occurs. 'Specialist support services received by pupils in special (SLD) schools in England: level of support received and head teachers' perceptions of usefulness' by Matthew Rayner and Dawn Male. Reports a survey of a large sample of special schools for learners with SLD/PMLD which provides a picture of the availability of a range of specialist services, with some indications that at least some services are inadequate and that there are difficulties in co-ordination between services.

'Developing children services to improve the quality of life for children and young people with severe learning difficulties' by Mark Fox. Discusses how children and young people may be given a genuine say about the services they receive. Demonstrates what work is needed to ensure that they are enabled to express their own opinions. Accepting and acting on their views pose significant challenges. 'Recent Research' by Dawn Male. Provides a summary of a piece of research by Hannah Young, Maggi Fenwick, Loretto Lambe and James Hogg in which multi-sensory storytelling was used as an aid to assisting children and young people with PMLD.

Summer 2013 (Volume 66)

'Person-centred transition planning, preparation and support for young people with severe to profound complex needs' by Dawn Cameron. Royal School Manchester (RSM), Seashell Trust is a non-maintained residential special school for young people with severe to profound complex needs and very little communication. Focus of this article is on smaller scale transitions and person centred support provided for each young person, including a Transition Tracker to identify students at high risk during transitional periods, daily transition passports to facilitate smooth transitions, one page profiles and 'important to me bags' which contain labelled and explained pictures/photos/objects representing something that is important to the individual.

'Can the P scales give a sufficient and accurate assessment of progress for pupils and students with severe or profound and multiple learning difficulties' by Peter Imray. Focuses upon how pupil progress should be measured and provides a critical analysis of the utility of the P Scales in particular and criticises DfE/Ofsted perspectives on what constitutes appropriate progress.

Autumn 2013

'Alternatives assessment and pupil progress indicators to the P scales for pupils and students with SLD or PMLD' by Peter Imray. An equally stimulating (but controversial) follow-up to his earlier article on curriculum and assessment for pupils with SLD and PMLD. Argues that, although P scales might form a small part of a legitimate assessment 'portfolio' for learners with PMLD and SLD, they are only just one of a range of indicators of progress, including the 'Routes for Learning' materials.



SHORT COURSES & CONFERENCES

Providers Details

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/

EQUALS

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

Hirstwood Training

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

Sense

Jackie Bishop and Rachel Johns
Tel: 01179 670 008
Email: jackie.bishop@sense.org.uk
rachel.johns@sense.org.uk

Title: **Practical & Effective Ways of Using Multi Sensory Equipment**
Dates: March 28th Birmingham, April 29th Glasgow, May 5th Cambridge, 20th London June 10th Manchester, 16th Doncaster, 17th Middlesbrough
Provider: Concept Training
Contact: See provider details

Title: **Conference: Broadening our Horizons**
Date: 28th – 29th
Location: Melbourne
Provider: Intensive Interaction Down Under
Contact: Email: iid3@ammp.com.au
Web: www.ammp.com.au/iid3

Title: **Intensive Interaction Course**
Dave Hewett
Dates: 28th Birmingham, June 6th Barnsley, 27th Watford
Provider: Intensive Interaction
Contact: www.intensiveinteraction.co.uk/courses-events/co-ordinator-course/

March 2014

Title: **Big Macs and Beyond**
Date: 28th Oldham
Provider: Shelagh Crossley Training
Contact: info@shelaghcrossleytraining.co.uk
Mob: 07919250037

Title: **Introducing an easy and effective Target Setting System**
Date: 28th London
Provider: Hirstwood Training
Contact: See provider details

April

Title: **Conference: Bridging Research and Practice in Early Childhood Intervention**
Date: 3 - 6th
Location: Antalya, Turkey
Contact: Website: <http://www.iceci2014.com/eng/kayit.php>

Title: **This is My Childhood: There will be no other – The importance of Early Years Intervention**
Date: 4th
Location: Bristol
Contact: BASPCAN
<http://www.baspcan.org.uk/events-national.php>

April		Title:	Annual Massachusetts Early Intervention Consortium Conference 'Celebrating 35 years'
Title:	Great Design (tips and tricks on designing courses offline)	Date:	7-8th
Date:	11 th	Location:	Marlborough, MA
Provider:	BILD	Provider:	Massachusetts Early Intervention Consortium
Contact:	Tel: 0117 985 6949 Email: info@thebild.org	Contact:	Email: services@percs.info
Title:	Designing the future – 2014 International Conference on Intellectual and Developmental Disabilities	Title:	2014 BILD Positive Behaviour Support Conference
Date:	April 28 th – May 1 st	Date:	8 th – 9 th
Location:	New York	Location:	Scotland
Provider:	YAI	Contact:	Email: learning@bild.org.uk
Contact:	Conference manager: abbe.wittenberg@yai.org	Title:	From sensing to thinking: literacy, communication & numeracy for learners with pmlid or profound autism
Title:	Practical & Effective Ways of Using Multi Sensory Equipment	Dates:	9 th London. 12 th Manchester
Dates:	<u>April</u> 29 th Glasgow, <u>May</u> 5 th Cambridge, 20 th London	Providers:	Flo Longhorn and Les Staves
Provider:	Concept Training	Contact:	FPLcourses@aol.com www.flolonghorn.com
Contact:	See provider details	Title:	Intensive Interaction
May		Date:	Dave Hewitt 9 th
Title:	Interactive and Multi-Sensory Storytelling	Providers:	EQUALS
Dates:	2 nd Manchester, 9 th Birmingham, 16 th London	Contact:	See provider details
Provider:	Concept training	Title:	Learning Outside the Classroom
Contact:	See provider details	Date:	12 th
Title:	Planning a new curriculum for sld and pmlid learners: ways forward	Location:	London
Dates:	<u>May</u> 7 th London, <u>June</u> 11 th Leeds	Provider:	Concept Training
Provider:	Peter Imray and Flo Longhorn	Contact:	See provider details
Contact:	FPLcourses@aol.com www.flolonghorn.com	Title:	Open Day for Professionals at The Children's Trust
Title:	Advances in research in intellectual and developmental disorders: the effectiveness of complex interventions	Dates:	<u>May</u> 15 th , <u>November</u> 13 th
Dates:	27 th	Location:	Tadworth, Surrey
Provider:	Royal Society of Medicine	Contact:	opendays@thechildrenstrust.org.uk k Tel: 01737 365890
Contact:	Chanel Roachford Tel: 020 7290 3942 Email: intellectualdisability@rsm.ac.uk	Title:	Ipads, apps for special learners – embedding into curriculum – with a sprinkle of sensory magic!
		Dates:	<u>May</u> 15 th London, 20 th Leeds, <u>June</u> 19 th Leicester
		Providers:	Flo Longhorn and Ian Bean
		Contact:	FPLcourses@aol.com www.flolonghorn.com

Title: Date: Location: Contact:	Atypical Developmental Pathways: 4th Paediatric Neuropsychology Symposium 19 th – 23 rd London: UCL Institute of Child Health Magdalena Pytlarz m.pytlarz@ucl.ac.uk Tel: 020 7905 2675/2699 Danille Dansey d.dansey@ucl.ac.uk	Title: Dates: Provider: Contact:	Intensive Interaction: Building relationships with people who have profound learning disabilities and complex needs Jane Gurney <u>June</u> 11 th Birmingham, <u>July</u> 10 th London Concept Training See provider details
Title: Date: Location: Provider: Contact:	Play for People on the Autism Spectrum 20 th Chorley Concept Training See provider details	Title: Dates: Provider: Contact:	Sensory solutions for autism and challenging behaviour 17 th Bristol, 18 th London, 19 th Birmingham Hirstwood Training See provider details
Title: Dates: Provider: Contact:	Active learning: hands on creative learning for learners with sld/pml. <u>May</u> 22 nd Leicester, <u>June</u> 5 th London Flo Longhorn Keith Park Sarah Hall FPLcourses@aol.com www.flolonghorn.com	Title: Date: Location: Providers: Contact:	Intensive Interaction: Access for All 20 th Milton Keynes Intensive Interaction Institute and Leeds and York Partnership NHS Trust Learning Disabilities Directorate www.andrewsimscentre.nhs.uk or email: andrewsimscentre.lypft@nhs.net or Tel: 0113 85 55638
June		July	
Title: Date: Provider: Contact:	Technology for Learning 4 th BILD Tel: 0117 985 6949 Email: info@thebild.org	Title: Date: Location: Provider: Contact:	4th IASSIDD Europe Congress – the programme will have an inclusive format to include people with intellectual disability 14 – 17 th Vienna Universität Wien Tel: +43 1 4277 17677 Email: congress@univie.ac.at Web: http://iassidd2014.univie.ac.at/
Title: Date: Provider: Contact:	Intensive Interaction: Sensory Issues and Communication Using Body Language 9 th Chorley Concept Training See provider details	Title: Date: Location: Provider: Contact:	26th Annual Meeting of the European Academy of Childhood Disability 3 rd – 5 th Vienna, Austria EACD Website: www.eacd2014.org/information/information.html
Title: Date: Location: Provider: Contact:	The UK Intensive Interaction Conference 10 th Milton Keynes Intensive Interaction www.intensiveinteraction.co.uk/conferences/		

LONGER COURSES (with Creditation)

MA Education

Pupils with Severe and Profound and Multiple Learning Difficulties (P1: Contexts & Understanding P2: Curriculum & Teaching)
The modules address the requirements of the Teacher Development Agency (TDA) National Special Educational Needs Standards
The course 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.

For further Details: The University of Northampton. Tel: 08003582232 Email: study@northampton.ac.uk

MA Education Physical Disabilities (P1: Contexts & Interventions P2: Curriculum Issues)

The first module (P1) provides opportunities for those with QTS and professional qualifications and 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 second module (P2) provides students with opportunities to investigate, critique and evaluate a range of curriculum approaches in the field of physical disabilities. It engages students in debates concerning the relevance and practical efficacy of recent guidance and legislation in physical disability-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 physical disabilities.

For further Details: The University of Northampton. Tel: 0800 358 2232 Email: study@northampton.ac.uk

MA 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.

For further Details: The University of Northampton. Tel: 0800 358 2232 Email: study@northampton.ac.uk

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

This course aimed at Teaching Assistants will look in detail at the needs of learners who are known to have severe or profound and multiple learning difficulties. These learners 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: 0800 358 2232 Email: study@northampton.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

BSc in Professional Practice

BSc in Professional Practice - includes forensic, mental health/learning disability, challenging behaviour, older person with LD and epilepsy modules. Students will be provided with an educational experience, tailored to their particular requirements, so as to gain professional experience. This will enable them to work collaboratively and flexibly within health and social care systems.

For further details: University of Chester Tel: 01244 511000 Email: enquiries@chester.ac.uk

MSc in Advanced Practice

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). This course is suitable for health and social care professionals who would like to develop higher levels of professional knowledge and expertise in their sphere of practice.

For further details: University of Chester Tel: 01244 511 000 Email: enquiries@chester.ac.uk

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

AdCert, BPhil, PGCert, PGDip, MEd.

Severe, Profound and Multiple Learning Difficulties

Blended Learning (a combination of online and occasional weekend study on campus)

The Severe, Profound and Multiple Learning Difficulties blended learning programme has been developed for a range of professionals/practitioners who work with children and adults with learning difficulties in educational settings across the severe and profound range (SLD/ PMLD). The programme covers issues for staff who work in any education and learning services and has particular emphasis on working together to meet needs. The programme aims to help participants to study systematically, critically and in-depth, aspects of educating children and adults with severe, profound and multiple learning difficulties. Participants are encouraged to research and reflect on their own practice, carrying out small-scale research leading to developments and innovation.

For further details: University of Birmingham, Dr Penny Lacey (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

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