

PMLD LINK

sharing ideas and information

Innovations

Winter 2014



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GUEST EDITORIAL

Innovations

Asking for articles on innovations has clearly inspired you to write. Some of the innovations are new to everyone, such as personal health budgets and education provision for 19-25s or, new to the world of PMLD- such as eye gaze, gesture-based technology and powered wheelchairs. Other ventures might be new to some of you, such as multi-sensory stories and multi-media passports and information books. Two writers have tried out new ways of working with people with behaviour that is challenging, whilst others have described innovative projects such as a new theatre show, working with art installations and using media to assist in life story work. Amongst the new projects are introductions to new ways of thinking about people with PMLD, one challenging the view of people with PMLD as being 'developmentally young' and the other, encouraging playfulness in people with PMLD.

Technology is at the centre of several of the innovations and we are undoubtedly living in exciting times, when it is possible to enable very physically disabled people to control their world with eye movements. As yet this control is limited to simple cause and effect for those with profound learning difficulties but who knows where it may lead. Coupled with learning to use a powered chair, eye gaze could become a gateway to an independence only dreamed of, even recently. Moving oneself is an incredibly important part of exploring the world. We are really good at providing sensory experiences for both living and learning but it is equally important to quality of life also to be able to move around, and experience the world: operate the music source and turn on those interesting looking lights over there.

But of course, technology isn't the only possible innovation represented in this issue. It is particularly good to hear about new ways of using the familiar. Storytelling with people with PMLD has become firmly established over the years, but it is always good to hear of new ideas, either for the stories themselves or for different ways of evaluating their worth. It is particularly refreshing to hear of new storytelling enthusiasm.

One article that possibly challenges us the most fundamentally is that based on the exploration of phenomenology. It is suggested that people with PMLD may have a sense of self built from their body experiences rather than from their cognitive understanding. This perspective on individuals can help to influence our understanding of what it means to be a person. The underpinning theory for this article is not easy to grasp but we can certainly understand the desire to view people with PMLD as much more than a collection of deficits and inabilities.

We continue In the News with the focus on people and practice to inspire innovation to improve the lives of people with PMLD, their families and those who support and enable them. In particular we gratefully acknowledge the important and influential contributions of Alice & Loretto – to PMLD Link and to the wider area of profound and multiple learning disability.

We hope that you enjoy reading the articles in this bumper issue they will certainly keep you going for quite a while! Hopefully the ideas shared here will inspire you to try something new or to try a new take on something you already do. If we have encouraged you to be innovative - please write and tell us about your experiences.

Penny Lacey and Annie Fergusson

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'Ourselves' Installation at Larkrise School © The Roche Court Educational Trust

The Multi-Sensory Project: Art for all the Senses

Mandy Humphreys, Rebecca Churchill and Emma Kerr

The Multi-Sensory Project is a collaboration between The Roche Court Educational Trust and Larkrise School, Trowbridge to provide creative and sensory experiences for children with profound and multiple learning disabilities (PMLD). Art installations are created in the school and are an opportunity for the students and staff to experience, react and respond within these environments, allowing individual expression, communication and very early play skills. The installations occur on average three times a year and are set up for a week in the school for both teachers and pupils to visit and explore. All installations have a theme set by the school curriculum. Rebecca Churchill (Becky), artist in residence at Larkrise School, and Emma Kerr, Education Officer at The Roche Court Educational Trust, work together to use the sculpture and exhibits at the New Art Centre, a sculpture park and gallery where internationally renowned artists are exhibited and the Trust is based, as inspiration for the installations at Larkrise School. The project ensures that modern and contemporary art is brought to those who are least likely to have the opportunity to access galleries in a meaningful way.

Three people who work on The Multi- Sensory Project share below their perspectives on why this project is innovative and exciting for all involved.

Mandy Humphreys - teacher of learners with PMLD at Larkrise School

The Multi-Sensory Art Project was born from a place of passion and continues to be lead by that same emotion. A passion that art for the children in my two classes, all with PMLD, should be appropriate and meaningful to them. Art offered to these children should not be 'finger painting' or something along those lines, as it is not satisfying for anyone involved. From our experience the children didn't like it, it made no sense and some just wanted to eat the paint. Discussions about art and the children's needs, other people's expectations, and our commitment to doing what was right for the children, were held in order to initiate a better arts experience. We held four extensive days of research within the school to build on existing knowledge, knowing this was an opportunity to make a difference. We knew that what the children would respond to was something that would awaken all their senses. We discussed art galleries and exhibitions and how one day these experiences could be accessible to all. We let our thoughts and ideas run away with us but the reality is that we are a very long way off from these ideas and discussions becoming a reality. Becky, our artist in residence made wonderful 'things' and we had all sorts of 'art days' but it wasn't until we talked about the idea of an art installation that we realised this was the direction we should be heading in. We held a 'Bonfire Night' installation in the school hall, which was incredibly successful and led to a run of other art installations of this kind. Throughout the process of making The Multi-Sensory Project what it is today, discussions have continued to take place between all partners, measuring the suitability and impact for our pupils with PMLD and has resulted in an innovative project that we now has the privilege to be a part of. What Becky, our artist in residence, provides for our children is beyond our expectations and while we, the adults involved in The Multi- Sensory Project, know that the project is a truly innovative way of bringing contemporary art to the children (thanks to the collaboration with the amazing Roche Court Educational Trust), the experience of our students is a feast for their senses. The environment, the dome, provides in itself a wondrous thing, the multitude of objects, textures, colours and smells within – all led by the school theme for that term and inspired by, and linked with, artists' work at Roche Court - is truly inspirational. To the children who visit it is a wholly sensory environment where they experience, react, respond and attend. But for the adults involved it is so very much more than that and fulfils an ambition to bring contemporary art to the children in a way that makes sense to them because it demands a reaction from their senses. They are in a world that makes sense to them. What more could we



'Animals' Installation at Larkrise School © The Roche Court Educational Trust

ask for. If it is right at a sensory level, it is right on every other level.

Rebecca Churchill - artist in residence at Larkrise School

Innovation can only come given time, the desire to ask questions and the support to do something with what you find. The Multi Sensory Art Project has been and continues to develop from a desire to create a space for people with a diagnosis of PMLD and their carers. It honours the love and devotion of carers, teachers and parents of learners with PMLD because I hope they see their ideas have been listened to. In a small way this project articulates a value on their lives. It punctuates a largely medicalised and adulterated life with captivating, creative and playful experiences. By connecting the knowledge of teachers, artists and art educators it provides validation. We are all seeking the same outcome yet we all come from different points of the triangle. It is important that we all believe these young people should experience excellent experiences. It allows our voiceless students the opportunity to be heard and it gives our unseen children the chance to be seen. We all believe The Multi-Sensory Project adds to their sense of wellbeing. These art installations bring the whole school and local communities together. It is incredibly important that we value people who don't take part in the world in a way that is considered mainstream. It is a joyful experience to be in the dome with a PMLD student and their carer. Time disappears. Through beautiful intensity a timeless world appears. This is a wealth unknown to most of us.

The project has evolved from many gifts: gifts of time, expertise, space, objects, and lastly money. Gifts in all these forms create bonds because a gift generates gratitude. The installations hope to offer a space of intimate empathy. It brings us closer to a more beautiful world. Many adults have entered the space and have welled up with emotion, as it reminds us that there is nothing more important than just being human, however we are made or look. In our society at present there are many scarcities; scarcity of attention, listening, being seen, touch, love, play.... in amongst these things is a project that honours and holds sacred all the important things, love, art and play. This project shouldn't be innovative, it should be the model for everyday.

Emma Kerr - Education Officer at The Roche Court Educational Trust

The first time I met Becky I knew we spoke the same language, a communication that is like no other, that is ruled by the senses and fuelled by a shared enthusiasm for a particular subject. Our particular interests were two fold: one, an interest in art, the enjoyment of looking at an exhibition or one specific artwork and making connections between yourself, the object and the space around you; and the other was people, making meaningful connections with others by sharing experiences. Our initial meeting was to introduce the Trust to The Multi- Sensory Project. Becky talked through the research and beginnings of the installations and gave us an invitation to join the project, linking our shared ethos of introducing art to all young people.

Since we have accepted this offer it has been a joy to support this innovative project, it has opened up a world of understanding for both parties. There is a direct link now between the high quality art experiences offered by visiting the gallery and sculpture park and the ambitions of the school through the art installations of The Multi-Sensory Project. As a Trust our objective is to encourage the enjoyment of looking at art as well as developing, discussion, analytical and observational skills in this process. It has been useful for us to reflect on the complexities of language and explore all modes of communicating, to make connections between people, spaces and objects. We are one step closer to our shared aim of encouraging and introducing all young people to modern and contemporary art. We know there are currently limitations for young people with PMLD to visit galleries and museums and that is why it is important to take our ideas and ways of working out to the school. The Trust are grateful to all the staff at Larkrise School who have provided a greater insight into the needs of their students. Through their knowledge, understanding and the extensive research carried out by the school we are able to use our own expertise to look at the exhibitions within the sculpture park with all our senses. We are able to translate the sculptures by internationally renowned artists, into objects and experiences within the



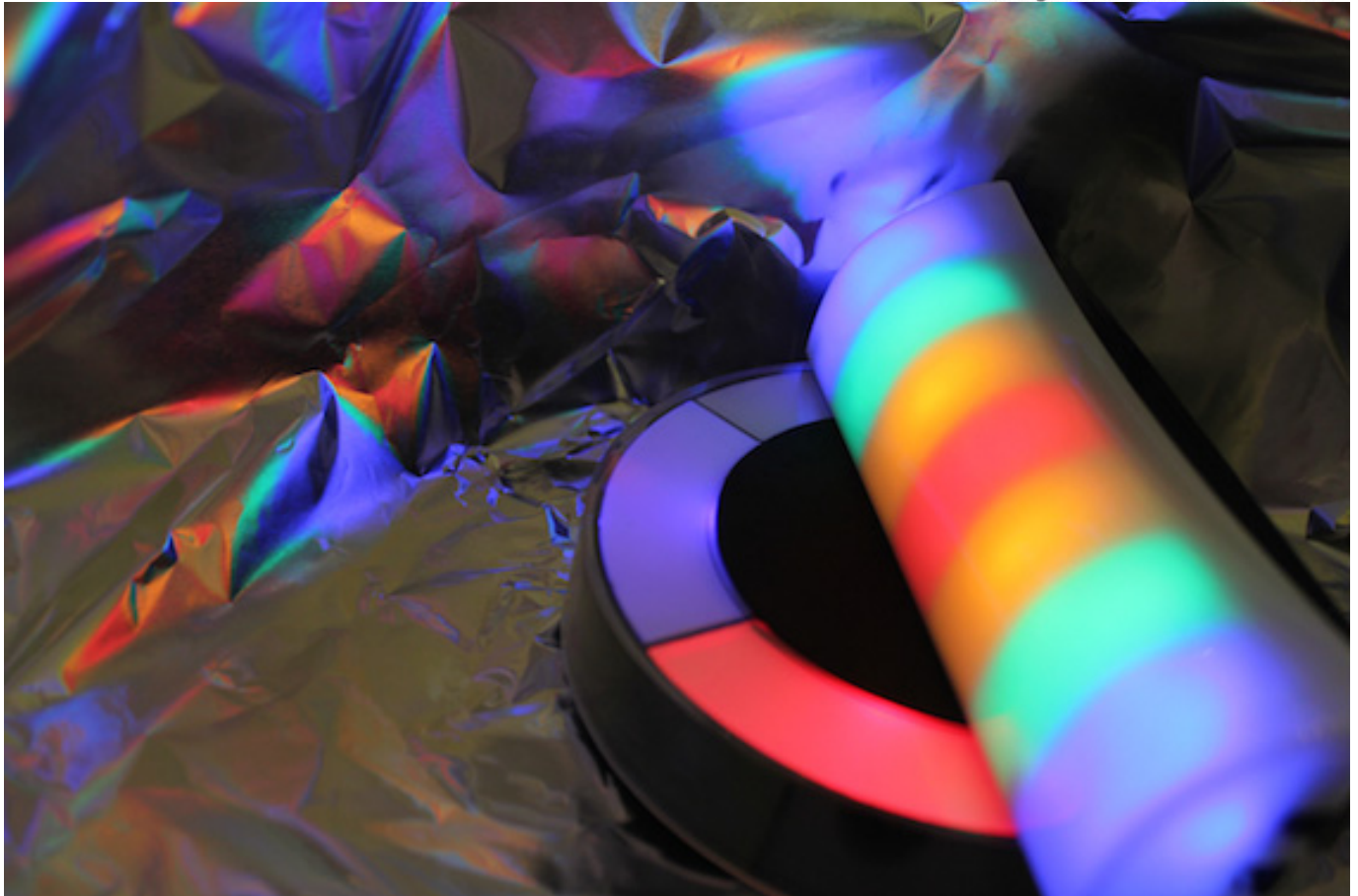
'Colours' Installation at Larkrise School © The Roche Court Educational Trust

dome that bring modern and contemporary art to all the students in the school, in a meaningful and sensory way. We support the school by providing teacher training, teacher's packs and resources for all to find out more about the artists and their ideas, as well as interpretive texts to introduce the installations to all visitors to the school. Some of the more able children within the school have been able to come to the sculpture park and join in this process.

These exchanges between the school and our charity illuminate the abstracted and subjective viewpoints of the world, of both the students at the school and the artists exhibited at the sculpture park. This project promotes the very same language that enabled us to work together in the first place, a communication that is like no other, fuelled by our senses and driven by a passion for art and people.

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Details about the Roche Court Educational Trust and the Multi-Sensory project are online. Available at <http://rochecourteducationaltrust.co.uk/projects-2/the-multi-sensory-installation/>



Creating a multi sensory “Undersea Challenge”

Richard Hirstwood

The ‘Undersea’ challenge is a the basis of a multi sensory session involving number, texture, shape and colour. You can use as much or as little technology as you wish, but many of the “props” are low tech ideas or objects. Try this in a sensory room, classroom, hall or home depending on how big you want it to be. But remember, it can be just as much fun with one person. Each short activity can also be a standalone activity - like reading and exploring just one page of a book!

Begin by explaining that you’re taking a trip to the beach to find out more about fish and life undersea! Set the scene - play the sound effect of waves or some soft sea shanty music.

The sea is blue, sometimes green. How many colours can be seen?

For this activity you will need objects which change colour (try not to use the fibre optics as they come

later.) The bubble tube is a good choice in the sensory room, or a sound to light coaster or bar in a classroom/ small space. Can colour changing Meteorlight balls become a sea anemone? Use the app “Flashlight” for a simple iPad colour matching game with the bubble tube. How about using an Underwater Light Starship to cast gently moving coloured light onto any light surface?

In the deep blue cave, the octopus we did see. But how many legs has he or she?

Here you will need a plastic/soft octopus, a picture of an octopus or an octopus on your iPad - use "Paint Sparkles Draw" so pupils can virtually finger paint their own! Could you create an octopus with different textures on each leg? Perhaps your octopus could live in a black 'cave' umbrella with dangling textured legs to explore? You are in a cave - do you need a torch? Making this a black umbrella would enable you to use florescent objects with a UV torch, making this a white umbrella would enable you to project sea images onto it.

Flat fish, round fish, long fish, short fish. What shape will your fish be?

Various activities would work well here to explore shape/colour/texture or number. Dark paper/card fish painted using fluorescent paints will shine brightly under UV light in the sensory room. Suspended from a rig or umbrella, these would be very effective individually or in number. Perhaps these could be clothes pegged to a net, laying on the floor or hanging on the wall? Using projected images (sea/beach/Finding Nemo) either onto the net/umbrella/wall would add to the theme. For art work to create in the sensory room/dark space, use shadow board and draw onto it with UV light, it's instant and effective - brilliant for drawing your very own sea monster or making your very first mark. You could also use the card/paper fluorescent fish on the shadow board and create a shadow shoal! If you continue to use the sound of waves or sea shanties as background music - could you use a Bluetooth speaker in a car wash mitt so that pupils could 'feel' the music too? A wowee speaker would also do the same thing!

How many fish? Look and see! Let's count them together we'll find its ... 3!

Use a laundry basket with three plastic fish - make this really exciting by using glow-in-the-dark fish! Shine a UV torch onto the fish to make them glow more brightly. Pass the basket around and slowly reveal and explore the three fishy items you have in there. Alternatively, the 3 fish could live underneath an umbrella. Can you find them with your torch? You could also create a 'fish' wheel for a Solar 250 projector or a fish video for a pico/data projector to add to the theme.

Fill the net it looks so bare. How many things can you put in there?

For this you could go back to the laundry basket or get yourself a real fishing net. A great one to use is the hanging storage net from IKEA. If you have lots of fishy things around the children or students, they could post the items in this net.

The magic seaweed shining bright, you really can touch it because it won't bite!

The idea for this one is to do something with your fibre optics, if you don't have fibre optics, try using Scoobies. Lay them over a beanbag to make a giant boulder on the seabed. You could even put them inside the cave 'tent/umbrella' for extra effect.

Find fishy things to put in the wheel. Look really hard you may find an eel!

For this one you need a wheel projector, like a solar 250. Making wheels is very easy, so put little bits of net and string in the wheel and then project these onto your magical umbrella.

Hear the whales and dolphins talk. Now its your turn to make them squawk!

This can be great fun if you have an echo unit in your sensory room, however a small cheap echo mike would work just as well. Or find a box or a bin (clean) which will create echo's. Great to encourage vocalisation!

Finish by getting all the props together and having fun with all of them - or with just the props from the individual activity you have just completed.

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Twitter

We have launched our first steps into the world of social media with our very own twitter account. We plan to keep followers up to date with news and development regarding the journal, and also share relevant news and information. We have had a positive start with lots of engagement and a good number of followers.

Find us on twitter at @pmlmlink

Go-getters' and 'clever little cookies': findings from a multi-method study on playfulness and children with PMLD

Debby Watson

'Passport to Play' was a multi-method, qualitative PhD study carried out between 2010 and 2014, funded by the ESRC. An on-line survey was sent out via the PMLD Network and visits to and/or interviews at eleven sites in the UK were undertaken where there were professionals and families who were knowledgeable about people with PMLD (including arts-based professionals). Following this, multiple observations of five children with PMLD aged 3 to 7 years old were carried out in three different settings. Alongside the observation sessions, interviews were conducted with the children's care-givers at home, school and in a playful setting.

There were many examples in this study where the children were described, as in the title of this article, in positive and even rather beautiful language such as: *'happy to have a go'*, *'has his intellect switched on'*, *'good judge of character'* and *'got a sort of nosiness'*. This indicates that playfulness offers the potential to change perceptions of children with PMLD from passive children who are 'done to' to children who are inherently playful, have personalities, strengths and preferences. By focussing on playfulness, it is possible to concentrate on what children with PMLD *can* do and how their inherent playfulness can be encouraged through joyful interactions.

In the observations of five children with PMLD, it was found that their engagement in playfulness varied between 25% and 82% of the time observed, with the most playful child being the most physically able. However, the relationship between playfulness and physical ability was not straightforward, particularly when engagement in 'active' playful activities was examined. The playful activities that the children were engaged in were divided broadly into two groups – those where the child was passive: for example, watching something or listening to music or where they were actively engaged: for example, shaking a bell or operating something such as an iPad. The activity categories can be



found at <http://www.debbywatson.co.uk/downloadable-resources/>. Two of the children could be described as

having a similar level of impairment, but one had a much higher level of 'active' playfulness than the other and also had a much higher number of what were termed 'strengths'. This suggests that it may not be physical ability alone that influences how much active play a child engages in and that the link between active play and strengths may be important. Eighteen 'strengths' were identified across the children and included: the ability to anticipate, demonstrate a sense of humour, make choices, draw people to him/her and the ability to follow a simple instruction. Not all of the children demonstrated all the strengths, with one child, the least engaged in playful activities, demonstrating the lowest number (3) and the most playful child demonstrating the highest number (15).

As levels of playfulness do not seem to be entirely determined by physical ability, it was interesting to look at what factors may enable it to thrive. In order to do this, it was important to look at the cyclical nature of playfulness and what is termed here as 'mindful interdependency'.

The playfulness cycle

The cyclical nature of playfulness has been recognised by others, including McConkey (2006) and Else (2009). However, in children with PMLD, the signs of playfulness may be very subtle and in order to understand the playful process a 'Playfulness Cycle' has been developed (Watson and Corke, forthcoming). The cycle includes stages of: permission and preparation; attunement; the 'offer' of playfulness; recognition of the signs of playfulness; co-regulation; playful response and re-attunement.

Although it is possible for playfulness in children with PMLD to be child-led, motivated by some inner drive, another child or a particularly engaging toy, this study has shown that it is likely that children with PMLD will also often need a 'trigger' from those around them, which is why the 'offer' of playfulness encompasses playfulness coming from the child or from another adult or child. The study has shown that playfulness is less likely to happen in an environment that does not 'permit' playfulness and that a number of things should happen to create an atmosphere that is conducive to playfulness. This includes ensuring that the child is physically and emotionally ready for play, with the play partner feeling comfortable about being playful and also making sure that the surroundings are the best they can possibly be for a particular child. The signs of playfulness will be very individual to each child and may be very subtle but are likely to include one or a combination of:

- Physical signs – subtle changes in facial expression, stiffening, increased movement of body and eyes, finger flexing, relaxing, flapping, postural change

- Emotional signs – twinkling eyes, open-wide eye gaze, smiling, laughing, raised eyebrows, open mouth, tongue out, increased expressive vocalisation, happy sounds
- Social signs – moving nearer, reaching out, increased eye contact, leaning towards

In practice, the playfulness cycle may be long and drawn out with, for example a great deal of time spent in preparation or repetition, or may be, as one participant in the study said, 'fragile and fleeting'. Whatever the playfulness looks like, it is likely to be recognised as a joyful moment of shared pleasure. It was interesting that only three of the items that participants suggested as being important attributes when encouraging playfulness in children with PMLD could be termed 'skills' which require actual knowledge or training (knowledge of child development and disability, Intensive Interaction skills and dramatic and musical skills). The most important attributes were reported to be items such as knowing the child well or personality traits such as the ability to be playful themselves or perseverance and patience. As a play therapist in the study said:

'I think just being a human being to another human being is the most powerful thing. You, using your voice, your eyes, touch, can engage a child and light their fire really.'

One of the mothers in the study said that her bench mark for choosing carers was if they enjoyed Christmas. She meant by this that she would employ people who were willing to put a lot of effort into and enjoy the preparation for and the process of play, rather than focus on the outcome, which may, like Christmas, be over relatively quickly!

Mindful interdependence

An over-arching theme in this study came to be termed 'mindful interdependency'. It was clear that, in order to encourage playfulness, children with PMLD needed the people around them to focus on what was happening 'in the moment', whilst being aware of the influences of other factors on their interactions at three levels: within, around and beyond the child.

We have seen that playfulness in children with PMLD can be described as 'fragile and fleeting' and, considering some of the substantial barriers to playfulness that exist, it is in many ways remarkable that children with PMLD are playful at all. This study shows that they emphatically *are* playful, with only very rare exceptions such as when a child is in a permanently sleepy state. However, without attention being paid to all the aspects of mindful interdependency, playfulness is unlikely to thrive in children with PMLD to any great extent. This may mean that the active, engaged involvement that they appear to

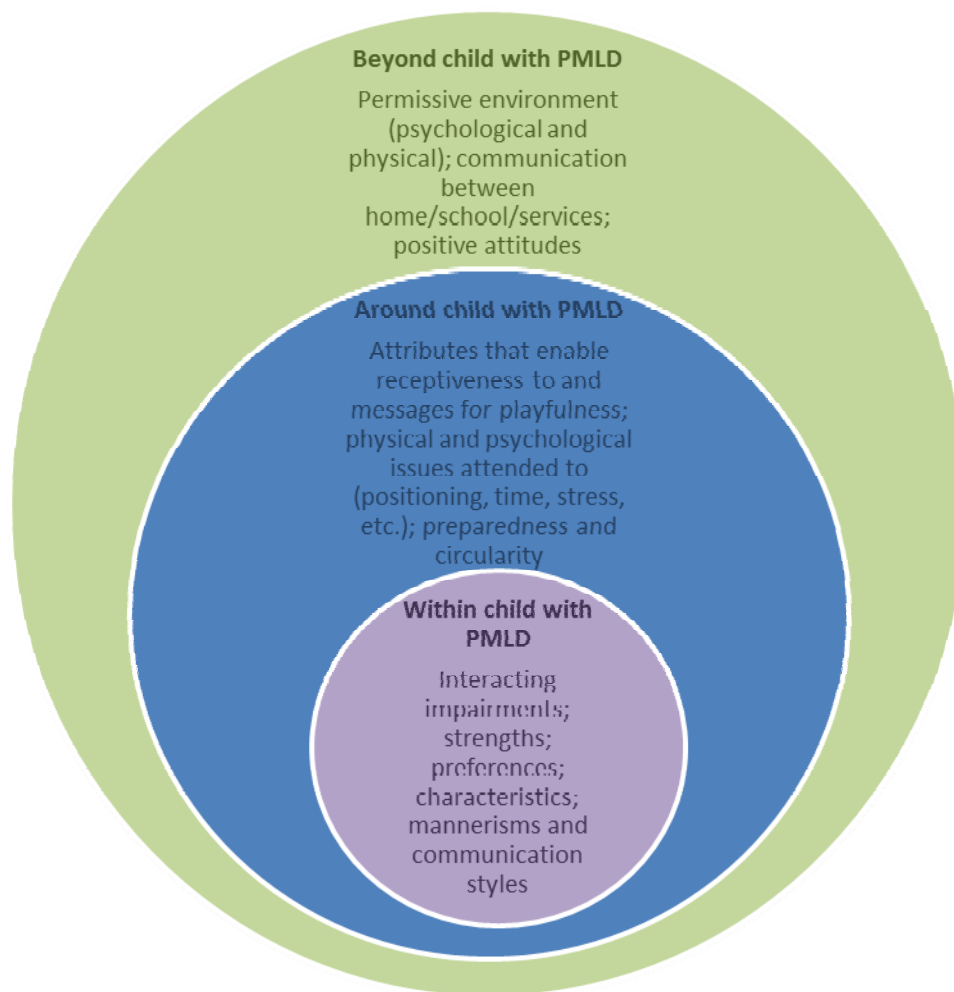


Figure 1. Mindful interdependency – encouraging playfulness

need to build strengths may be seriously compromised. Children with PMLD have to endure many unpleasant medical procedures and playfulness provides a vital balance, connecting them with others in a fun way that is desirable, pleasurable and achievable. Although an awareness of issues within, around and beyond the child are useful, there is no need to provide a manual for playfulness, just wanting to do it, finding your own playfulness and tuning in to the child is usually enough!

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Innovative Personalised Learning

Laura Mills and Beth Harper

Meadowgate School has embraced the changes in the school demographic which shows an increase in the number of pupils with PMLD over the last couple of years. As a result of this, the School reviewed its provision and introduced a more meaningful and responsive curriculum for learners with PMLD. The curriculum follows four strands; communication, physical development, cognition and self-help. The curriculum is currently under evaluation as part of Masters level research. The emphasis for the whole school this year is on personalised learning; we already feel this is present in our provision for learners with PMLD.

In order to meet the needs of learners with PMLD Meadowgate School has a plethora of resources and interventions. The process of designing a personalised package begins with an Affective Communication Assessment (ACA) which provides a wealth of information on pupils' motivators and their catalogue of responses. Activities and lessons are then planned from the information gleaned from this assessment. The curriculum is then beginning to evolve with the child at the centre. Targets are established for each of the curriculum strands and implemented at every opportunity across their school day. These targets are always shared with parents / carers to ensure that they are appropriate. The range of interventions addresses communication developments through to physical, self-help and independent skills. These interventions are not used in isolated sessions within their timetable they are sewn into every opportunity to learn in order to promote lifelong generalised learning. We at Meadowgate are proud of the unique, child-centred packages which every pupil with PMLD receives.

T.I.M.E (Touch, interact, motivate and engage) routines are a by-product of the work done on improving the provision at Meadowgate School and promoting the combined approach of interventions. T.I.M.E incorporates music cues, familiar routines, communication, relationship building, body awareness and most importantly, a child's preferred motivators. They are utterly pupil-led. Background work has to be done to establish the favourite music, massage tools, positioning and communication in order to establish an engaging T.I.M.E routine. The most effective outcomes from the routines occur if they are carried out daily. T.I.M.E routines are best suited to the learning styles of youngsters with PMLD; familiarity, following cues, predictability, clear expectations and consistent responses. Adaptations are made to each routine as





learning develops, for example introducing a choice or a different movement. It is important to record significant developments after sessions in order to plan future learning outcomes and to know when to make changes to the routine. One of the first T.I.M.E routines piloted at Meadowgate School was for a twelve-year old young lady with PMLD (called M here). At the time, M liked lively dance music, she liked close contact with a supporting member of staff and she preferred touch to her feet. Using this information a six-track routine was devised for M. Every track has an objective and instructions about movement and touch. The routine is written in a scripted format, as shown below.

M's TIME Routine

M is to be hoisted out of her chair onto the bean bag. Please remove her shoes and socks. Each action / interaction is to last the duration of a track. The change in track is the indicator for a change in the touch. Throughout the sequence please use Intensive Interaction techniques to encourage communicative interactions and exchanges.

Learning intentions:



- To build relationships with familiar staff
- To anticipate within a familiar routine
- To communicate preferences and 'more'
- To build on attention
- To facilitate body awareness





Track	Guidance and Intended	Photographic responses
Kylie – Can't get you out of my head	M to be positioned in front of you, pat her on the body and sing along.	
Maroon 5 – Moves like Jagger	M to stay in same position, sway body, hand under hand dance movements to music.	
One Love – Getting over	M to remain on bean bag, staff to move position. Use the ocean drum under her feet, slowing when the songs slows increasing bounce according to song's pace.	
Cheryl Cole – Promise This	Use the vibrating massage tool on M's lower body; feet and legs.	

The Saturdays - Higher	Use baby oil and firm touch to massage M feet.	
The Wanted – Come out again	M is to be left just to listen to the final track under a soft blanket. A photograph of Max her favourite boy band star.	

M's T.I.M.E routine proved to be very powerful in engaging M and achieving the desired outcomes. After this other pupils were identified that would benefit from a personalised routine and work was carried out to develop them. The present routines are more directive and clearer to users.

R's T.I.M.E Routine

	Track	Guidance and Intended Outcome	Photograph
On body	Wind beneath my Wings	LO: to show a consistent response when choosing a preferred item from two. R is to choose between a pom pom or voile. Look for R's facial expressions once he has experienced both items on his hands and face.	
	Don't Worry about a Thing	LO: to follow physical cue to bend and stretch his limbs. Give R a choice between arms and legs using touch, look for a movement to suggest a choice. One leg at a time bend and stretch followed by arms moving up, down and out.	

Alerting	Lego House	LO: to show a consistent response when choosing a preferred item from two. Again let R experience the singing bowl and shell shaker, including to his lips. Look for the biggest response and then use that item. To experience sound and vibrations to different parts of his body especially his face and hands. Introduce (on-body sign) tapping on his hand to encourage him to vocalise or smile for 'more'. Give him opportunities to track the item as well.	
	Dance with Me Tonight	LO: to anticipate his favourite action. Place hot water bottle on his chest so he knows what is coming. Start tapping on legs building up to firm beat on chest. Ensure pauses as he gets very excited and can hold his breath. This also helps clear his chest.	
Calming	Enya – Memory of trees	LO: to relax to a calming action. Slide in behind R so he is in a fully supported seating position and begin head massage using tool. A firm and rhythmic action required.	
	Over the Rainbow	LO: to stretch out and be aware it is the end of the routine. R will shake and stretch out independently. Staff member steps away to do recording and tidy up.	

Due to the changes in the profile of pupils at our school we now have a primary class exclusively of learners with PMLD. We are determined to continue personalised learning packages and T.I.M.E has been implemented as a whole class approach; with shared music but individual sequences. T.I.M.E is just one example of how Meadowgate School has embraced innovative personalised learning, the principles are incorporated into all areas of the PMLD curriculum. The main focus is always how pupils are communicating and physically

accessing their learning. Meadowgate School's forward thinking and innovative approaches really do make a difference to the lives of our youngsters with PMLD. This is an exciting journey for us all!

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Developing Innovations investigating the impact of a 1:1 multi-sensory story on the learner in comparison with ongoing sensory sessions: A case study investigation

Josie Arnold

The responsibility for practitioners working with learners with PMLD is to provide a rich and meaningful sensory curriculum, of which multi-sensory stories are an important part. I had limited knowledge of multi-sensory stories (MSST) and I wanted to increase the sensory learning opportunities of a specific learner in my class. I wanted to investigate the impact of MSST on the learner, in comparison with ongoing sensory sessions. I was interested to find out whether the MSST engaged the learner more, elicited stronger responses to stimuli and was more enjoyable than a general sensory session

MSSST creates a context in which the learner with PMLD and the storyteller can engage in a familiar, shared focus using a carefully structured narrative and a selection of interesting sensory objects (Goldbart and Caton, 2010). Repeating the story regularly over a long period of time is important as the brain requires this in order to build strong neural pathways (Longhorn, 2011). MSST offers opportunities for close observation of learner's responses and communications, where progress and development can be tracked and recorded. Sensory objects are chosen, in order to capture the learner (Caldwell, 1991). MSST has the potential to motivate learners because the storytelling is enjoyable for both the learner and the storyteller.

The learner I worked with had Cerebral Palsy and spastic quadriplegia with increased muscle tone in his arms and legs. He was visually impaired, with his best vision to the upper left. He had some use of his left arm and hand. He was often drowsy or asleep. For all curriculum subject areas he was at Level P2

He had a 30 minute sensory session in a small, quiet room, while on his Acheeva Bed, twice a week. This took place in the morning, an hour after he had received his medication.

Before the innovation

In my first week at the school, I took over the 30 minute sensory sessions. The sequence of sensory experiences was determined by the class teacher and related to the learner's Individual Learning Targets looking at the Ipad and requesting his favourite song by touching the screen; activating the fan with a press switch and exploring a range of sensory objects, such as bubble wrap etc. Each item was handed to him to explore.

I devised a 'Behaviour Responses Record' to complete during all sessions and a 'Wakefulness and Vocalisation Record' to record the learner's behavioural state daily.

During the innovation

I developed my own MSST of 'The Wind Blew' by Pat Hutchins (1974) personalised for my learner. I read the story and presented my learner with the objects to explore. I made notes on the 'Behaviour Response Record'.

After innovation

I compiled an 'Overview of Responses' incorporating all the raw data of responses for each of the different types of behaviour exhibited during both the sensory sessions and the MSST in order to analyse results. This was difficult to analyse as there were only 2 sensory sessions before the innovation, 8 sensory sessions and 6 multi-

sensory story session during this study, making it difficult to compare numbers fairly. Therefore, I converted the data into a mean number for each session. This made comparisons easier, although the minimal numerical differences made it difficult to draw secure conclusions. I listed details of all stimuli used in both sessions against the different behaviour responses.

Findings

Wakefulness and vocalisations

From the analysis of my records, I discovered that before the innovation started the learner was awake for only 2 out of 3 of the sensory sessions. He made no observed vocalisations during these sessions or during the day. After the innovation started, he was awake for 7 out of 8 sensory sessions, vocalising in all 7 sessions, even if only briefly. He continued to be vocal during 5 of the days when a sensory session had taken place. During the MSST, he was awake for 5 out of 6 sessions, vocalising in just 3 sessions. However, the vocalisations during 2 of the sessions were for long periods. He continued to be vocal during 4 of the days when a multi-sensory session had taken place. There appeared to be a general increase in his wakefulness and vocalisations once the MSST had started. It is possible that this increased level of sensory interaction with the learner has had an impact on his wakefulness and vocalising.

Analysis of the differences in wakefulness and vocalisations

The time of day could be a factor in the differences of wakefulness between the MSST and the sensory sessions. The MSST always takes place at 11.15 am. Before the innovation, all 3 sensory sessions took place at this time. However, after the innovation started, only 3 out of 8 sensory sessions took place at that time.

The learner's body position could affect wakefulness in the sessions. All of the 6 MSST sessions took place on the Acheeva bed. Only 3 of the 8 sensory sessions took place while he was on the Acheeva Bed in a recumbent position; 5 sessions took place while he was upright in his chair.

The setting could influence wakefulness. All the MSST sessions took place in the small, quiet room. Only 3 of the sensory sessions took place there; 5 of the 8 sensory sessions took place in the hustle and bustle of the classroom. Perhaps the sounds of the other pupils and staff affected his general alertness.

In 3 of the 5 MSST the learner vocalised, however, these were plentiful and lengthy. In all the sensory sessions the learner made vocalisations, though some were very brief. Is quantity or quality of vocal response more significant?

Analysis of visual responses

The results suggest that the learner turned his head towards the sensory object more during the MSST than during the sensory sessions, although there was an increase in response between the sensory session before the innovation and those during. He also turned his head away from objects more during the MSST than the sensory session. He tracked more objects during the sensory session than the MSST.

Analysis of auditory responses

There was considerably more 'stilling' to the sound of objects during the MSST. This may have been because these objects were new to him and he did not recognise them. Ware (2003 p62) describes this as a 'quieting response' which is common for a learner who has a visual impairment. It is possible that the sound was new to him and interested him.

Analysis of tactile responses

There was considerably more active exploration of objects with his hand during the MSST than the sensory session. Again it could be that these objects are new to him and he did not recognise them. He held objects for much longer periods during the sensory session than during the MSST. It is possible that he recognised them and enjoyed the sound or feel of them in his hand and in his mouth. In the same way he took objects to his mouth for further exploration far more often than he did during the MSST.

Analysis of other responses

Interestingly, during the MSST there seemed to be an increase in body movement and also more observed 'stilling' of body movement. 'Stilling' may be a more receptive state for the learner as he listens. His body movement could have been involuntary, or when connected to his more vocal times it could have been a more excited, interested response in the objects.

There were no smiles recorded in the sensory sessions before the innovation. However, both sensory session and the MSST elicited smiles, with the story eliciting slightly more. During this study the smiles felt like breakthrough moments, where connection and communication were very real. The only frown in all 16 sessions occurred during the sensory session when I held his hand with a duster handmit.

No vocalisations were recorded during the sensory session before the innovation was introduced. However, both the MSST and the sensory sessions elicited vocalisations, with actually with more during the sensory session. This may be because the learner's favourite objects are included in this session.

Finally, the number of self stimulatory or self-comfort behaviours was higher during the MSST, especially 'thumb sucking'. I understood this to mean that the learner had finished or lost interest in an object. Again this could relate to the fact that nearly all the objects in the story were new to him, this could have been challenging, causing him to retreat into his own 'safe' world.

The use and analysis of the 'Behaviour Responses Record' during the sessions confirmed to me the need for continuous detailed observation when working with a learner with PMLD.

Conclusions and recommendations

This was a single case study focussing on one specific learner. My conclusions may be relevant for other learners but due to the nature of my research, they cannot be formally generalised.

Both MSST and sensory sessions make valuable contributions to the curriculum of learners with PMLD. For my learner, they had a positive impact on his learning, responses, communications, exploration of the environment and enjoyment in school. Increasing the amount of 'sensory work' within the school week has had a positive impact on his wakefulness, alertness and communications.

MSST has allowed my learner to experience new stimuli in a safe environment. Sensory sessions which took place daily have allowed him to engage and 'play' with objects that he knows and likes. In both MSST and sensory sessions he needed essential time to explore, process and respond to stimuli. In MSST the practitioner has to take the lead, however, in sensory sessions the learner has more opportunity to share control. In both sessions, there is the possibility of enjoying the 'process of doing with and being with' (Caldwell, 1991 p92) thus developing a positive and trusting relationship.

The time of day, the setting for the session, the learner's body position, health issues, medication, as well as levels of tiredness, all impact on the learner's responses to sensory work. These should continue to be monitored and taken into consideration when reviewing practice and progress. Knowing and identifying the range of a learner's behaviours is crucially important for understanding his/her affective and cognitive states. There are also practical considerations in preparing and delivering a MSST. Straying from the guidelines for MSST as suggested by PAMIS may or may not have a negative impact on learning. However, an expressive voice is essential for carrying the emotion of the story, differentiating it from a sensory session.

During and after the innovation there was much to celebrate in my learner's achievements in terms of his choice-making, expressing his likes and enjoyment, as well as dislike and disinterest. Smiles and lengthy vocalisations were a wonderful reward for me, the practitioner, furthering the two-way process of communication. Both the MSST and the sensory sessions will continue for my learner as 'deep learning takes time, and often a considerable amount of time' (Imray and Hinchcliffe, 2014 p75).

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Personal Health Budgets

Jill Davies

This year, NHS England saw the introduction of Personal Health Budgets (PHB) for those living in England who have long-term health conditions. As a number of children and adults with Profound and Multiple Learning Disabilities could be entitled to receive a PHB, this article aims to inform people about this new initiative.

What is a Personal Health Budget?

A Personal Health Budget (not to be confused with a Personal Budget, although the two can be combined) is an amount of money allocated to a person by the NHS to meet the costs of their assessed healthcare and support needs. A personal health budget gives people more flexibility and choice over the range of health services or care they receive. It has been piloted across England and evaluation has demonstrated that people receiving one had an improved care related quality of life and psychological well-being, and it also improved the quality of life for families too. Children and adults already receiving NHS Continuing Healthcare have a right to ask for a Personal Health Budget, and with the new SEND Code of Practice, children with special education needs or disabilities may be offered a combined Education Health and Care Plan, with funding committed from each of the responsible authorities.

How do you get one?

It's best to contact your GP, care manager or Continuing Care coordinator in your local area. A care or support plan is developed with key health professionals or a local voluntary support organisation and then signed off by the local NHS Clinical Commissioning Group. The plan sets out your health and care needs and how much money is set aside to pay for those.

How to manage it?

The budget can be managed by the NHS, which will co-ordinate the services and budget for you (this is called a notional budget); through an organisation independent from you and the NHS, for example, a voluntary organisation that holds the money on your behalf or an Independent User Trust (this is called a third party arrangement); or you can receive a health care direct payment (you can opt for a direct payment organisation to help you manage the direct payment.)

What can it be spent on?

A Personal Health Budget is used to meet the healthcare needs of the individual, and is in this way different from a

Personal Budget, which is used to meet social care and support needs. It may be used on any healthcare service set out and agreed upon in your care plan, for example, nursing care, physiotherapy or equipment.

Can I combine a Personal Budget and Personal Health Budget?

It may be possible to combine the two, and thus further streamline the funding system. If you wish to explore this possibility on behalf of the person you are caring for, you should ask the person who is organising their Personal Health Budget. In some cases, the assessment, planning and monitoring elements may similarly be joined up.

Examples in practice

Nasrat's story

Nasrat is 11 and has muscular dystrophy type 2. She attends a mainstream secondary school and receives a personal budget that includes health funding, because her needs at school are health-based. A personal assistant comes to her home and helps get her ready for school, accompanies her in the taxi to get to school and remains with her all day, going home with her at the end of the school day. Before she had the personal budget, Nasrat had no support at home and was falling behind on her school work when she was unwell. Now she has support to keep up with her studies even when she isn't at school and also has continuity of the same person supporting her at home and school.

Pete's story

Pete has fragile diabetes, autism and a high level of learning needs. Pete has always required lots of support to keep healthy due to his diabetes. When he was about to leave school things came to a head. The college he wanted to attend said they would not give him a place unless he had someone with him at all times. The Transition team from the local authority who were supporting Pete and his mother knew that their area was piloting the new personal health budgets. They worked with Pete and his mother to draw up a support plan and it was agreed that he was to be given a combined

personal health budget and personal budget for social care to support him throughout the week. The support plan was developed by the Transition team using person centred approaches, and helped Pete, his mother to develop a detailed plan of the kinds of activities and support he needed during the week and what kind of person would be best suited to support him. The plan a budget was agreed and Pete now employs three male personal assistants to support him for over 30 hours per week. They are trained to give injections and to read Pete's blood sugar levels, and this means he can attend his local college.

The budget is managed for them by a charity that provides information and support to people using direct payments and personal budgets. They supported Pete and his mum in recruiting the personal assistants employed to support him; they organise payment of these workers and calculate the tax to be paid so his mum doesn't need to worry about that.

Conclusion

Personal health budgets have the potential to give children or adults and their family more control over the kind of support and care that is appropriate for them. The stories from the examples above have demonstrated that it was possible to improve links between home and school, especially if personal assistants can work between the two; ease pressures at transition to adulthood if the family keep same support team; fund

specific equipment or therapies, e.g. wheelchairs, postural care support, sleep systems and finally, give families greater say over who supports the child/family.

Where to go for further information

PeopleHub CIC is a personal health budgets network. The aim is to give a voice to people and family carers, to connect and empower people and to influence the development of personal health budgets, see:

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

The NHS has provided a Personal Health Budgets website, providing information and support to those wishing to learn more about the service, see:

<http://www.personalhealthbudgets.dh.gov.uk/>

Personal Health Budgets: Including people with learning disabilities, is a guide to find out how people with learning disabilities can benefit, see: <http://www.thinklocalactpersonal.org.uk/library/Reports/TLAPIncludingLD.pdf>

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Introducing the Sensory Story Project

Joanna Grace

Sensory stories combine concise text with rich sensory experiences, enabling narratives to be shared with individuals with profound and multiple learning disabilities (PMLD). They are a resource I first encountered when working in a school for students with severe and profound special needs. I was delighted to discover them because they enabled me to include students with a wide range of needs in a shared time together. Using a sensory story was the first time that I, as a teacher, had been able to connect in a meaningful way with my students with PMLD. I was thrilled to discover ways sensory stories could be used to develop communication and understanding in my students.

Last year, after daydreaming about it for eleven years, I set up the Sensory Story Project on Kickstarter. My aim was to create a set of affordable sensory stories which families would be able to use themselves. I had a smaller secondary aim of creating stories that would be age appropriate across a range of ages, partly because I wanted adults with PMLD to have access to stories that were age appropriate to them, but more because I was thinking of the people around those individuals. If a story shared is of interest to peers, of interest to the facilitator, then that leads to a more inclusive experience. A lot of research has been conducted into the benefits of the story telling space; it's been found to be a space where we bond, where we feel braver and more confident. I wanted all those benefits to be available to individuals with PMLD and I felt they would be if people wanted to share their stories with them.

The Sensory Story Project was a success thanks to its 155 backers. Doing the project afforded me the time to read the research surrounding sensory stories and to read about what others have done in this field. I am enormously grateful for the support I received from people with experience in this area who shared their insights, expertise and knowledge with me, or who challenged me to answer particular problems. The project succeeded by standing on the shoulders of these giants (if you are curious many of their names appear among the list of project backers which is displayed on <http://jo.element42.org>). My highest goal was to create the stories, and that was achieved. I had not imagined what would happen next. I had not considered what some of those supportive giants might have in mind for me in the future.

Last year creating the stories felt like a huge goal, but since then the project has transitioned into a bigger

adventure so that that initial ambition, to create five stories, now seems small. I have written about the project itself and about sensory stories in many places, so rather than repeat myself here I wanted to write and tell readers about the ripple effect from the project. When I sit and reflect on all that has happened it gives me a lot of hope for inclusion in the future, I hope that readers will feel the same.

Here are a few of my personal highlights from where the Sensory Story Project has taken me, and is taking me, since it's launch:

Having the time to read through all the research I could lay my hands on with regards to sensory stimulation and sensory stories enabled me to create training days and conference presentations aimed at increasing awareness about what sensory stories can achieve and how best to use them. I've spoken to learning disability nurses, families, student teachers, schools, and adult care providers. Every minute of it has been a pleasure, but working with the adult care providers and talking one on one with parents has proved to be the most moving. A parent of a 2 year old with PMLD explained to me that since their child was born they have had to learn so much to do with their medical care that they had rarely had the chance to do something fun together. They found sharing sensory stories enjoyable and were reassured by the knowledge that it was also a beneficial activity for their child. During one of my adult care training events a carer told me that they had never considered attempting to communicate with the individual with PMLD in their care. This wasn't through a lack of care on their part, they were clearly very dedicated and very fond of the person for whom they provided care, they simply had not realised it was possible. When I followed up with them a few months later they were thrilled to report the responses they had

received from their client during story telling sessions. It can be easy to forget that this sort of basic change in expectations is still needed in many settings.

Early this year the Historic Royal Palaces in London set up their sensory palaces initiative, which looks to make the Palaces they manage more inclusive places for individuals with learning disabilities, mental health problems and dementia. As a part of this initiative I wrote a sensory tour (a sensory story told on the move) of the King's State Apartments at Kensington Palace. This can be shared by people ahead of their visit to the palace to prepare them for what to expect, or afterwards to help them secure memories of their visit. The palace staff received training in how to facilitate the tour in a meaningful way, and an amazing perfumer created the smell of Georgian sweat to give the tour an unforgettable nasal punch. Currently the tour is only open to partner institutions who already work with the palace as it is just a pilot, but I am excited that such a big organisation is looking for ways to welcome and engage individuals with PMLD.

I've seen inspirational parents take the stories and run with them. One that springs instantly to mind is James Gordon who was probably the Sensory Story Project's number one cheerleader whilst it was live on Kickstarter. James is the father to Daryl who is profoundly autistic. Recently he sent me this picture of himself sharing Daryl's favourite sensory story with his class. It's fantastic to see James participating in his son's school life like this, and lovely to know that through his father Daryl is able to share something he loves with his peers.

I was invited to take part in the Imagine Children's Literature festival by Inclusive Minds, an organisation looking to improve the representation of individuals with special educational needs and disabilities in literature.

Earlier this year, thanks to the ever insightful Janet Cobb of Jan-net (One of the Sensory Story Project's backers) I had the pleasure of hearing Sarah Clayton of Postural Care CIC speak at a Choice Support families event. Sarah wrote in the Wellbeing issue of PMLD link (Vol 25 No 3) about the importance of good Postural Care for individuals with PMLD particular at night time and it was on this topic that I heard her speak. After the event we collaborated to create three sensory stories that support good Postural Care. These stories lead people through a routine of body positioning alongside the narrative and sensory stimuli. We hope that they can be used to make getting into a beneficial body position engaging, even fun. Used during the day they can help people to practice



feeling comfortable in a position that is suitable for them to sleep in, and used as a bedtime story they will hopefully set experiencers up for a good night's sleep that does not damage their bodies.

From September I will be working with Specialist Speech and Language Therapist Rebecca Leighton, of Elenbi-Uk consulting and Bradford District Care Trust, to conduct research into the impact of sharing sensory stories with adults with PMLD. Rebecca has also taught me a lot about the benefits of multi-sensory work with individuals with Dementia which has been fascinating.

Later this year Jessica Kingsley Publishers will be publishing a book about sensory stories which draws together the research I based the project on and contains five sensory stories which can be resourced at home.

This time last year I barely dared hope that I would get to create the stories at all. Looking back on all that has happened since then is staggering. I have no idea what will happen next, plenty of hopes, but I've learned that the future is wonderfully unpredictable. My overriding hope is that the stories will be able to continue to contribute to a more inclusive world for individuals with PMLD.

Sensory story project website: <http://jo.element42.org>
Postural Care CIC website: www.posturalcareskills.com/courses

Sensory Palaces website: <http://www.hrp.org.uk/KensingtonPalace/educationandcommunity/Adultlearning/sensory-palaces>

Jan-net: <http://www.jan-net.co.uk/>

Inclusive Minds website: <http://www.inclusiveminds.com>

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Using Innovative Approaches to Addressing Challenging Behaviours

Kirstie Rees

This article details how functional analyses can be combined with innovative, strength-based approaches to assess and address the challenging behaviours of children and young people with PMLD. This ensures that all those working with a pupil are informed in the process and that focus is placed on developing a pupil's communication and independence skills, in addition to enhancing staff-pupil interaction.

Pupils with severe learning disabilities and PMLD may employ a very limited repertoire of behaviours to communicate a variety of needs. This is why it is important to involve all those who work closely with a pupil when trying to establish the reasons for more challenging behaviours.

Traditionally, educational psychologists have carried out functional analyses to define the function that the behaviour serves for a pupil and to identify the processes responsible for maintaining it (Hanley, Iwata and McCord 2003). In reality, however, time constraints may prevent a sufficiently in-depth observation of a pupil in different settings. Consequently, a psychologist obtains the perspectives of others by carrying out interviews with staff or parents or by asking the teacher to complete an ABC (Antecedent, Behaviour, and Consequence) chart. This involves the recording of descriptions of a sample of occurrences of antecedent behaviours (A), the target challenging behaviour (B) and consequent events (C).

The assessment informs interventions which aim to alter environmental factors, eliminate behaviours and replace them with behaviours which are more appropriate. In accordance with positive approaches to behaviour support, it is important, too, that an analysis of behaviours highlights a pupil's existing skills and informs preventative strategies which seek to develop a pupil's communication skills and ability to make choices.

The Use of Video and V.I.G

With the increased use of iPads in classes for pupils with PMLD, video can be used as a means of providing further analysis of a pupil's behaviour in a given context. Caldwell (2006) proposes that the use of video can be beneficial in noting significant behaviours overlooked in an interactive session. Video Interactive Guidance (VIG) is an intervention where clients are

guided to reflect on short video clips of their own successful interactions, often with a child. The facilitator, often an educational psychologist, actively engages those involved in a process of change (Kennedy, Lander and Todd 2011).

In my own work, I have created 'micro clips' of pupils and staff in class, focusing on those instances, however brief, which demonstrate a time when the challenging behaviour is less evident or when the pupil is engaged in an activity. These clips are shared with parents and with staff who then reflect on what they are doing or what the pupil is doing that makes this interaction go well or ensures a pupil's active engagement in an activity.

The techniques employed during this process have been adapted from *'the seven steps to attuned interaction and guidance'* which are used with parents to develop attuned interactions with their child (Kennedy 2011: 30). During each clip, I describe the content, share what is seen, and ask others to respond and contribute their own ideas about ways in which examples of positive interaction can be further developed or how a pupil may be encouraged to make further choices etc. The chart below describes a clip discussed with a support assistant who was working with a 13 year old girl with poor joint attention skills (*See Diagram 1 on p22*).

Solution Oriented 'Pupil Forum'

Focusing on a pupil's skills and motivators can also be done successfully in a group context. Increasingly, I facilitate solution-focused '*pupil forums*' in schools, involving both teachers and support staff working with a pupil. Solution-focused approaches in educational psychology are derived originally from solution-focused therapy, a 'strengths-based' therapy model (De Shazer; 1985), which uses a set of linguistic techniques to increase positive behaviours (termed 'exceptions') and to

Clip- Area	Comments	Possible Areas to Develop	Challenges
Pupil 'B' looking at iPad – watching support assistant's index finger tracing patterns on screen .	<p>'B' stills (listening to instructions when support assistant says the word 'push?'). Support assistant uses hand-over-hand to encourage 'B' to trace colour across the screen. Allows 'B' waiting time to respond.</p> <p>On two occasions, B echoes the word 'push.' Once, she traces colour across screen without support. At one point, she pauses, looks towards support assistant and smiles.</p>	<p>Encouraging 'B' to practise this skill using this game and with named support assistant.</p> <p>Look for other examples of eye contact, smiling.</p> <p>Fading use of hand-over hand over time</p> <p>If appropriate, move on to developing more structured turn taking: Support assistant has a turn; stops, waits, says: 'B' then gives iPad over to 'B'. (Watch to see if 'B' can then initiate her turn?)</p>	<p>'B' responds better in a quiet environment and on a visual iPad activity. Focus on doing activity on iPad first</p> <p>'B' responds better when given attention from one member of support whom she knows well.</p>

develop the use of effective coping strategies. The focus is on changing future behaviours and on empowering those involved in the process to generate their own solutions.

The 'pupil forum' combines the structure and techniques of solution-focused strategy meetings recommended by Redpath and Harker (1999). Each section of the meeting is timed, beginning with a section on the challenging behaviour to be addressed. This ensures that those working closely with the pupil have the opportunity to clearly define the identified behaviour and clarify its frequency and intensity as well as the impact of

environmental factors. However, rather than placing significant emphasis on 'problem-talk', the major focus of the meeting is on those strategies which are already working and on 'exceptions':- times when the pupil does not exhibit the challenging behaviour.

The diagram 2 below shows the structure of the meeting and a brief example of information shared.

The process leads towards a joint construction of strategies to be used in the classroom and to a clarification of roles and settings, e.g. the context in which named staff will carry out an agreed strategy or

Pupil Forum Structure

A: Behaviour Causing Concern (be specific)

Grabbing staff and peers on arms with hands. This behaviour can occur in all settings; more frequent in noisier environment. Sometimes occur when pupil 'A' is approached from behind. Happens more frequently when outside of base class.

B: Times when the Situation is Better (Exceptions)

In quieter environments. During morning routine

C. Strategies that you are already using when working with this pupil.

Prepare 'A' for an event, change etc. by using a symbol and 'first, then.'

D. Future Planning/Agreed Strategies

Allow 'choosing time' after morning routine in smaller, quiet room next to base class. Two named support staff/teacher involved in carrying this out. Use of two symbols to make choice – include motivators. All staff to use low, tone of voice and allow waiting time.

Diagram 2.

intervention. Such meetings aim to empower all those involved in the process and involve them in the creation of a positive behaviour plan.

In my own work as an educational psychologist working with pupils with severe learning disabilities and PMLD, I have supplemented the use of functional analyses of challenging behaviours with strengths-based approaches. Both the use of video and solution-focused pupil- forums have ensured that an eventual behaviour plan aims not only to reduce or eliminate behaviours but to develop a pupil's communication and independence skills. Throughout the process, staff are afforded the opportunity to reflect on ways of increasing instances of positive staff-pupil interaction.

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Powered Mobility For Young People With PMLD

Lizz Platt

When we first started using switches to enable the students in my class to drive their chairs, several people in our working environment were sceptical. Some didn't see the point of enabling a young person to move their chair along a track in school if they couldn't do it outside the school environment, and others couldn't understand why we would offer this opportunity to students who have multiple and complex physical, medical and sensory needs.

However, since observing my students using switches in order to move their chairs, many of these same people have changed their points of view. Not only have they observed students, previously unmotivated to press a switch, now keeping their hands, head (or whatever part of their body that is best for them) pressed down on a switch for increasing periods of time, but they have also seen the JOY this activity can produce!

Adam, a young man in my class, was bedridden for over 18 months due to complications following spinal surgery. He is visually impaired, non-ambulant and has cerebral palsy, with some movement in his upper limbs and head. He has a startle reflex, which means that when he concentrates on positioning his arms and hands to press his switch, a sudden, unexpected noise can cause his arms to fly apart, and he therefore has to start all over again.

He has recently been able to sit up in his wheelchair for increasing amounts of time, and lately he has started standing in a standing frame for up to 10 minutes a day. We started his driving experience by mounting his own wheelchair onto a powered platform base, which could move along a track in the floor (a bit like Scalextrics!). A round switch was fixed onto his tray in front of him and connected to this platform base, and when he pressed this switch, his chair moved along the track.

Adam was timetabled to drive during quiet times of the day to try and reduce his startle reflex. The sessions were an immediate success and whenever he caused his chair to move he gave the biggest smile, which was soon followed by squeals of delight and laughter! For one of the first times in his life he was in control of his own movements!

We then talked about how to give Adam a sense of where he was when he drove from the Hall and along the

corridor past different rooms. The person supervising his driving would always tell him, but our ingenious engineers wondered how he would react to auditory descriptors and lights, which would activate as he drove up to them. We tried it, and the look of amazement, followed by absolute delight, was confirmation for us that Adam was gaining great delight from this activity! He worked so hard to press his switch and he demonstrated to us a clear understanding of cause and effect without startling at the sounds and lights he was able to produce. It is still early days as to whether he will be able to predict his route and know which room he will drive to next, but his motivation, effort and clear enjoyment make this activity worth it!

Finally, I would say to all those people who think it is a waste of time because he may not be able to do it when he leaves school – so what? Life is for living and enjoying. Many of the young people in my school live in the moment with little understanding about their past and future, and if we can make their present a joyous one, then that has to be good – doesn't it?

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Lizz Platt

'whenever he caused his chair to move he gave the biggest smile'

Challenging the Developmental Reductionism of 'Profound and Multiple Learning Disabilities' Through Academic Innovation

Ben Simmons and Debbie Watson

In this paper we show how developmental definitions of 'PMLD' in the academic literature can reduce children with PMLD to the status of 'non-persons'. We highlight some of the innovative dimensions of our work which challenge this status quo. These include the application of new theory and research methodology, and our studies of the social interaction of children with PMLD. We argue that these aspects of our research help reinstate the value of children with PMLD in the academic literature and arguably have important practice implications. However, we conclude that much more work is needed in our fight against the exclusion and degradation that some children with PMLD face.

Part 1: Developmental definitions of 'PMLD' and the classification of non-persons

Developmental definitions of PMLD

Within the research literature, children with PMLD are typically understood as experiencing global developmental delay. The abilities of such children are often compared to those of the infant insofar as children with PMLD are described as being at the preverbal stage of development (i.e. the earliest stage of development which ends about a year after birth). A range of descriptors are used in the PMLD literature to indicate that some children fail to reach developmental milestones associated with later infancy. For example, children with PMLD have been described as being pre-volitional (they lack the ability to move) (Farrell 2004); pre-contingency aware (they do not show awareness of cause-effect relationships) (Ware 2003); and pre-symbolic (they do not intentionally communicate meaning to others) (Coupe O'Kane and Goldbart 1998).

In our view, describing children with PMLD primarily in terms of developmental deficits dehumanises them and potentially leads to their exclusion and degradation. Whilst this may sound dramatic and controversial to some readers, we wish to give context to our view by drawing on two contemporary areas of research: debates

in bioethics about what it means to be a person, and the findings of the *Confidential Inquiry* (Heslop et al. 2013) into the premature deaths of people with learning disabilities.

Personhood, non-persons, and the right to life

The current developmental definitions of children with PMLD lead to questions about the extent to which these children demonstrate 'personhood'. In the field of bioethics, Personhood is used as a measure to determine who counts as a person (and who - or rather, *what* - counts as a 'non-person'). According to the philosopher David DeGrazia (2005), the term 'person' refers to "*beings with the capacity for certain complex forms of consciousness*" (p. 3, *original italics*). He continues:

The term refers paradigmatically - that is, without controversy - to normal human beings who have advanced beyond the infant and toddler years. Such human beings are certainly beings with the capacity for complex forms of consciousness, for they are psychologically complex, highly social, linguistically competent, and richly self-aware (DeGrazia, 2005:3).

Do children with PMLD enjoy the 'complex forms of consciousness' that DeGrazia refers to? If the developmental definitions of 'PMLD' are to be believed,

then no children with PMLD have progressed beyond the pre-verbal stage of development hence they are not 'linguistically competent' (they cannot speak to tell us their stories). They are not 'highly social' in the sense that they are described as lacking the capacity to communicate with intent. Nor are they 'richly self-aware' since this involves learning how other people perceive us (they are without intersubjectivity).

The importance of personhood

The debate about the definition of personhood is important because it relates to the value of life, and impacts upon the distribution of rights and entitlements. For example, recent high-profile reports have documented the health inequalities that people with learning disabilities face in NHS care which undermine the right to life. It is estimated that 1,238 children and adults with learning disabilities die preventable deaths each year in NHS care (Glover and Emerson 2013). Furthermore, the more severe an individual's learning disabilities, the more likely they are to die a preventable death because of a lack of appropriate healthcare (Heslop et al. 2013). Given the situation, it is not unreasonable to suggest that the prejudice children and adults with PMLD face stems from the view that some are not identified as being people at all.

Part 2: Innovation - addressing dimensions of personhood in our work

In this section we outline three aspects of our work (Simmons and Watson 2014) which contribute to understandings of the 'personhood' of children with PMLD. This includes the application of philosophy to develop insights about 'self-awareness', the development of research methodology which shows 'voice' is not the same as 'linguistic competence', and on-going research about the sociability of children with PMLD.

Phenomenology: towards a theory of 'self-awareness'

Following dissatisfaction with developmental definitions of children with PMLD, we began to enrich our understandings of personhood by reading the phenomenology of Maurice Merleau-Ponty. Phenomenology is the study of the structure of experience, and Merleau-Ponty's (2002) work explores the role of the body in that experience. An important concept for Merleau-Ponty is the idea of the "corporeal schema" (p. 164) or 'body schema'. The body schema is our experience of the body that emerges through interaction with the world. When we normally think about our bodily experiences we tend to think of our body image (i.e. what our body looks like to us and other people). In contrast, the body schema is more of an intuitive feel that we get from our bodies. The philosopher Evan Thompson (2007) gives an example:

...not only do we feel the things we touch, but we feel ourselves touching them and touched by them. When I pick up a cup of hot tea, I feel the hot, smooth surface of the porcelain and the heat penetrating my fingers, and these sensations linger for a time after I have put the cup back down on the table (Thompson 2007: 250).

As the above quotation suggests, the body schema is the experience of our embodiment, and this can emerge in action (e.g. picking up a cup of tea). We are aware of being hot or cold, but we are also aware of our body's position and movement, and whether and which parts of the body are being touched. This awareness is instant – if we stub our toe we know that we are in pain, and we know where it hurts without having to think about it.

What does this mean for children with PMLD? It means that children with PMLD may have an embodied sense of self that is yet to be explored through research. There is little published work about how children with PMLD experience themselves in relation to the world, and what experiences they find meaningful in relation to their body and the actions they perform. It also leads to an important (and unanswered) question. If children with PMLD experience themselves through their interactions with the environment, then to what extent do opportunities to interact with *different* environments lead children to learn more about themselves?

Richly interpretivist methodology: having a 'voice' without being 'linguistically competent'

Another area of our work focuses on the development of research methodology which illuminates the meaning of children's actions. Our approach relies on researchers working with children with PMLD in real-world contexts, utilising the knowledge and expertise of others who know the child well. This demands time and resources as well as a great deal of skill and capability to 'see' the child from the perspectives of others. We strongly believe 'voice' does not simply mean 'speaking' ('linguistic competence'). Instead, voice can mean children's preferences, opinions, and agency expressed over time and across contexts. This is at the core of our approach described below.

Our approach is comprised of three methods. First, the researcher runs focus groups with family members and professionals in order to determine how a child acts and the meaning people ascribe to those actions. This provides an initial 'lens' which guides the researcher's interpretations of the child. Second, the researcher engages in a period of 'participatory observation'. This involves the researcher learning about the child by supporting him/her during their daily routines (perhaps by acting as a teaching assistant or support worker). During this time, the researcher engages in reflective conversations with other members of staff about his/her

interpretations of the child. Finally, the researcher engages in 'non-participatory observation' in order to write 'vignettes'. Vignettes are the main source of data. They have a narrative, story-like structure that preserves chronological flow and offer a vivid portrayal of the events in everyday life. The aim is to write vignettes 'live and in the moment', making detailed descriptions of children's interactions. These vignettes are shared with others (parents and professionals close to the child) and the interpretation of the vignettes negotiated.

Exploring the sociability of children with PMLD

Finally, we are involved in research which explores the social engagement of children with PMLD using the above methodology. We are investigating how different educational environments (mainstream and special) afford children with PMLD opportunities for social interaction, and how children with PMLD respond to these opportunities to interact. This research began with the first author's PhD work (Ben Simmons). During the research, Ben observed an eight year old boy with PMLD called 'Sam' one day a week in a mainstream school and one a day a week in a special school over an academic year. The research found that Sam eagerly engaged with his mainstream school peers, experienced opportunities to express his social awareness, and both acquired and rehearsed his communication skills. For example, in his mainstream school Sam participated in affective playful exchanges with others which were characterised by mimicking and turn-taking. He learned to initiate social interaction by stroking or tapping children's arms, and near the end of the project he used this strategy to initiate interaction with his special school peers. We consider Sam to be 'highly social' given the findings. Whilst the research involved only one boy, it does raise questions about whether it is appropriate to automatically assume all children with PMLD lack social awareness and intentional forms of communication. It also suggests the need to provide children with PMLD with diverse contexts so they can demonstrate and express their abilities.

We are currently extending our research with funding from the British Academy to explore how children of different ages (pre-school to post-16) engage with different school environments and will report the findings in due course.

Conclusion

In this paper we have argued that developmental definitions of 'PMLD' can reduce children with PMLD to the status of 'non-persons'. We have highlighted how aspects of our academic work address the situation in relation to the concepts of 'self-awareness', 'linguistic competence', and 'sociability'. Whilst we feel that our work is innovative, we recognise that there is a long way to go before children with PMLD will be fully accepted as

'people' in their own right. We call on readers to take up the debate about what it means to be a person, and to continue to challenge the developmental reductionism of the label 'PMLD'.

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Using Innovations within Technology to Help Manage Care

Hannah Young & Brenda Garrard

Technology will play a crucial role in meeting the Scottish Government's 2020 Vision, which foresees the integration of health and social care. PAMIS staff share insights into their latest project that taps into the potential of technology to help manage long-term conditions.

We have already seen the benefits of using technology to facilitate communication with people with profound and multiple learning disabilities. By operating applications on the iPad and other tablet devices, we can also use technology creatively in the real world. For example, Hirstwood Training Ltd provides training across the UK in using tablet technology to create stunning multi-sensory environments. These advancements can improve a person's quality of life. PAMIS are now exploring the use of technology to assist in the management of complex aspects of care.

PAMIS' Manage IT Project has been funded by Alliance – Health and Social Care Alliance Scotland – the main aim of which is to enable parent carers to better manage the long-term conditions of their son or daughter with profound and multiple learning disabilities, through the use of technology. The team help family carers to develop skills in using technology and help to increase their knowledge and understanding of its potential for managing care. Parent carers have been supported to use applications, including one application being developed by the project, to record and manage important information on their son or daughter's health; e.g. medication, seizures and behaviour.

To date, the outcomes of the project have exceeded far beyond expectations. The Team has recently been working with parents to develop a digitalised version of PAMIS' Personal Communication Passport. This has meant that important information about the person's communication and medical care needs can now be shared through pictures, videos and sound, viewable on a range of electronic devices. The interface provides a seamless interactive eBook. Parents have been central to this work and have been involved in creating a template from which parents can create their son or daughter's digital passport. This technology can be used anywhere. It does not rely on information systems within the hospital setting, day care centre and school which are often not easily accessible or not read by carers or professionals.

Empowerment and confidence are some of the experience of those parents involved in the project. One participating parent shared that her son had over 100 carers over fifteen years that he has required care. She has experienced great difficulty in repeatedly training new carers in the often complex procedures involved in his care. Her anxieties were clear, particularly in relation to future hospital admissions, "How can I leave him, even for five minutes?". She continued, "But with this [the digital passport], at least I know that all the information on how to care for him is there". This parent is certainly not alone in her concerns, many parents worry about the lack of due care and attention for their son or daughter whilst in hospital. She views the electronic passport as resolving some of these concerns.

The potential of technology to assist family carers in their role of providing care and support has largely gone unrealised, but this will soon change with recent advancements in tablets and phones that are getting increasingly better at communicating and illustrating. They will answer difficulties faced by many carers in administering, recording, organising and sharing information around the care of their son or daughter. Digital passports, for example, will not only empower family and paid carers, but can be used to provide guidance and training to others. Using technology as a training tool for visual impact and guidance, has real potential to positively the way that we provide and manage care for people with profound and multiple learning disabilities.

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The Eye Gaze with young people with PMLD

Liz Platt

The Eye Gaze enables the young people in my school the opportunity to move images and create patterns on a screen in front of them using the movement of their eyes and/or head. This has proved revolutionary for the young people in my class with PMLD who can make very little voluntary and intentional movements, and who are all in wheelchairs.

The discovery that facing towards a screen and making minimal movements can cause changes to shapes and colours is awesome! It has given some of my students their first real experiences of being in control, without needing someone to work with them using physical prompts. It also meant that they could cause things to happen without needing to press a switch.

One student in my class, who is able to move her head and one hand, is able to use different activities (e.g., 'New Faces') on the Eye Gaze, and she can maintain concentration for short periods of time (She is often easily distracted!). During 'New Faces' she has to look at the screen in order to cause the faces to make various sounds and change visually. The accompanying sounds certainly help to encourage her to continue looking at the screen, and she particularly benefits when able to do this in a quiet and darkened environment.

Another student was very motivated to look at the Magic Carpet templates on the Eye Gaze, e.g. she can make flowers move to reveal a picture underneath by simply looking at them. This was especially useful to me as it showed me *where* she was looking.

Another student in my class was very engaged by the 'Flare' option on the Eye Fx games, which he was able to activate simply by looking at the screen. This was especially effective in the sensory studio, which could be made dark, so that the flare effect was particularly effective. The resonating floor in the studio resonates ALL sounds made on equipment, which meant that another student lying on this floor could feel the sounds being made with the Eye Gaze! (A lovely shared activity!)

On a cautionary note, I became aware, with another particular student, that I was possibly *misinterpreting* what was happening. This student appeared to be causing the 'Flare' to move around the screen when her eyes were in front of the screen. (She is registered blind

with few responses to visual stimuli). We all became very excited at the possibility that she could actually be *seeing* the 'Flare'. However, we started to realise that although the Eye Gaze was responding to her *eyes*, she may not be actually *processing* what she saw on the screen. She has nystagmus, and it is more likely that it was this involuntary movement of her eyes that was activating the eye gaze, not her own intentional eye movements. I felt mortified as I was in danger of giving her Mum false hope about her visual abilities.

Whilst I am very excited about the possibilities Eye Gaze has to offer, I am also aware that in my excitement I may possibly overlook some of the hazards. For example, I would definitely recommend that parents and carers try out the Eye Gaze for themselves in order to experience what it is like to use. I know that myself and the TAs at school have found the 'Flare' option incredibly bright and almost painful after a few minutes, and because of this we have decided to limit the amount of time our students have looking at the screen. We also found that our eyes felt very strained from looking, and this might be the same for our students.

However, despite any reservations, I do genuinely believe that the Eye Gaze definitely has wonderful potential if used for short periods of time with young people with PMLD who are able to use their vision enough to fix and focus on visual stimuli. It offers them a sense of achievement and well-being, not least because their attempts are rewarded by a change in the images in front of them, but also because the TAs I work with are always so enthusiastic about the effects the students produce on the screen!

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Victoria College

Justine Sims

This last year we realised our hopes and dreams in being able to provide young adults with Profound and Multiple Learning Difficulties a brand new 19-25 College provision located in the heart of Northfield in Birmingham, on the same site as its partner Victoria School. Through a successful application to the Education Funding Agency we have had over a million pounds spent on making what was once an inaccessible building into our new, bright and truly accessible college environment. This grant gave us the start of our journey, enabling us to then develop all aspects of our 19-25 city-wide provision for PMLD learners.

Victoria College offers a curriculum which provides Community Enrichment opportunities, Health and Well-Being, Accredited Pathways and with the Student Voice at the very heart of it. Our courses are designed for learners with Profound and Multiple Learning Needs who are ready for further education opportunities. Learners at Victoria College have a bespoke package, tailored to their individual needs, which not only assesses their current achievements on entry, but inspires, informs and

develops them to achieve their aspirations for the future, enabling them and their families to be informed and in control of their future lives within their communities. Victoria College works very closely with families at every step of the learner's journey.

Birmingham City Council has supported the development of this new provision and along with other special schools BCC has financially funded this as a two year pilot.



Since then we are now in the final stages of formalising a partnership agreement with Bournville College, our local FE provider. This will enable us to continue to provide our high quality provision in a partnership arrangement from Year 3 and beyond.

Year 1 saw us admit our very first cohort of 5 then becoming 6 learners. Soon the word had got out and already at the start of Year 2 we have 16 learners with one out-of-Birmingham placement. Applications have already been received for our 3rd year September 2015! Our maximum capacity is 40 learners.

‘still at the beginning of our journey towards excellence’

We continue to develop our new provision and know that, although we have achieved so much in the past two years, we are still at the beginning of our journey towards excellence. We are always sourcing new funding streams to gain extra resources to enrich our environment for our learners. This, to date, has included



being able to fund a brand new sensory room, a further learning space for our students which is due to start being built this term and fundraising which is well under way to develop a new outdoor learning environment. We have also purchased our own college buses to ensure that our students are able to access community enrichment opportunities.

The greatest success in our first year has been the engagement, achievement and enjoyment of our learners. This is clearly evidenced daily as they enter Victoria College ready for the new and exciting challenges that they are presented with.

We welcome visitors to the College and host a number of open events across the year.

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Emerging Gesture Based Technology

Anthony Rhys

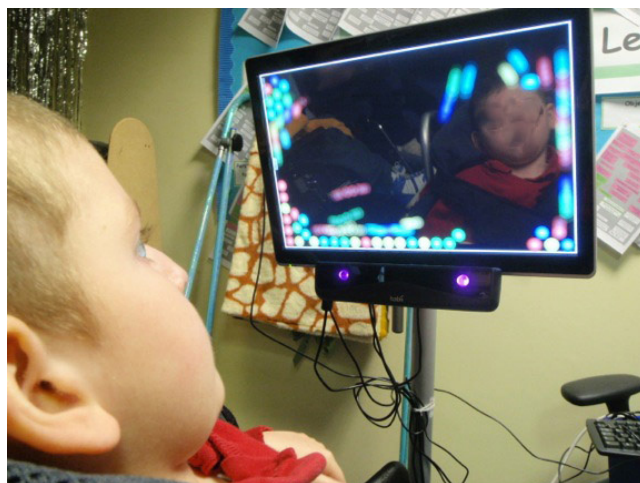
Trinity Fields School and Resource Centre is located in Ystrad Mynach. We have 126 pupils on roll aged 3-19 and we serve the County Borough of Caerphilly. Our pupils mainly have severe learning disabilities (SLD) and profound and multiple learning disabilities (PMLD).

I am a class teacher and the ICT and Sensory Co-ordinator for the school and since 2011 we have been focusing on using emerging technology to increase the independence of our pupils with more severe PMLD and SLD. During our inspection in November 2012 Trinity Fields School was given Sector Leading Practice by Estyn for our use of gesture based technology to support the learning of pupils with SLD and PMLD and this work continues.



The school is also part of a larger group of special schools in the UK organised as a Professional Learning Community. We meet up termly and share examples of technology that are working for our pupils. In the digital age one of the most important principles of our work is that it is shared with the wider community as quickly as possible. We do this through a series of Wiki information sites online. Most of the group also have a lot of input with social media, especially Twitter, which allows for great networking opportunities and instant sharing of ideas and resources.

Basically we get hold of new and emerging technology, which is usually gesture based technology that uses movement as the main control input, and trial it in classes with pupils. We have been using the Kinect motion sensor, eyegaze technology, the Leap Motion hand sensor and iPads in our classes. We are currently trialling the use of eye tracking technology to assess the



cognitive and visual abilities of some of our pupils with PMLD and we will soon be trialling the new Kinect V2 motion sensor and the Oculus Rift virtual reality headset.

Our focus has always been on increasing what our pupils can do independently. Whether that is being able to choose something with an eye gaze system or creating music with their body movements with the Kinect, it is always focused on developing their potential. All this work does require some knowledge of the technology being used but more importantly it requires a good knowledge of the pupils' needs and what their potential can be. Using this new technology needs an atmosphere of trial and error, a 'give it a go' attitude and some lateral thinking as in the main it's not been done before. Through practical trials in classrooms with real pupils we are finding out what works and what doesn't. We've had a few eureka moments (usually preceded by long periods of frustration) but the opportunities that the technology can bring are immense and it is an exciting time to be teaching our pupils.

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Words Fail Us

Noelle McCormack

'Words Fail Us' is the working title of a 3-year PhD research studentship I began in April 2014. The studentship is based at The Rix Centre, University of East London. It is linked to a wider project to develop a digital and living archive of learning disability history, which is led by the Open University, in collaboration with the University of East London and the University of Leeds.

Many years of personal experience facilitating life story work with people with learning disabilities has highlighted the challenges of engaging those with profound and multiple learning disabilities (PMLD) in this area. However, it is important their stories are included, and that practical and ethical approaches are developed to facilitate and encourage representation. My PhD research will explore what it means in practice to make life story work with people who experience profound and multiple disabilities. In doing so I will consider some of the ethical, legal, practical and technical issues involved in including the life stories and experiences from people with PMLD in the digital archive, alongside the work that is being conducted by the wider team.

Telling and sharing stories: the implications for people with PMLD

If, as is often said, we frame ourselves in narrative and use stories to make sense of and give coherence to our lives, what happens when the means by which stories are related to ourselves and each other are unavailable, 'when we as tellers are unable to create, elaborate, revise, and scrutinize our own lives by telling stories? Does such a person lack an identity and a sense of self?' (Hyden 2008: 38). What does this mean for someone who has a profound learning disability?

Life story work has been demonstrated as providing a wide range of benefits to individuals with learning disabilities, including for example, increased self-esteem (Atkinson and Williams 1990), validation of identity (Hewitt 2000), and establishing reciprocal relationships and improvements in the quality and continuity of care through the implementation of person-centred approaches (Middleton and Hewitt 2000). The development of life story books is recommended for people with profound disabilities as a way of seeing their lives differently, within a 'continuum' rather than exclusively in the 'here and now', however there are very few research projects about the lives of this minority group (Hewitt 2006).

One of the main reasons for this lack of involvement is because of life story work's reliance on verbal communication and the abilities of people with PMLD are usually limited to nonverbal sounds, movements and gestures. In addition, because these nonverbal communication repertoires are often understood and interpreted by a very small group of people it is extremely difficult to get to know people with PMLD independently. In the past, people with PMLD have participated in life story work by being 'present' while others have constructed stories on their behalf. The stories of those speaking with vicarious authority are rarely challenged although it is arguable that the stories being told are the subject of inference and projection (Ware 2004). When I have supported people with PMLD to make life stories one of the first things I do is invite their close family to contribute in whatever way they can, by bringing in photos, sharing stories and anecdotes and creating timelines. How else can we begin to find out about the lives of people who are unable to 'tell' their own stories?

It is understood that people with a diagnosis of PMLD have not reached the 'declarative stage' of language development. Declarative communication demonstrates 'directive and intentional interactions with others' (Larkin 2007). Therefore, it follows that people with PMLD are unable to *tell* their stories. However, those who are familiar to people with PMLD provide conflicting accounts: 'they tell me everything' (Goode 1997). I'm curious to explore what this means- to tell a story. There may be many ways in which people with non-verbal communication abilities, however limited, are telling us about themselves, but not within the criteria defined in language development.

Carnaby's (2004) comprehensive review of research about the lives of people with PMLD indicates shifts in the approach to researching communication abilities, following inclusive principles that improved communication is 'possible for everybody', communication needs to be 'integrated and functionally relevant' (2004: 9) and that we need to increase our

understanding of the 'multimodal' nature of communication. We all communicate differently depending on how 'at ease' we are, where we are, who we are with, how motivated we are. It would appear that in order to fully comprehend and appreciate the communication abilities of people with PMLD it is necessary to spend long periods of time along side them and that any communication tools used are fit for purpose.

Developments in new media technology

In recent years there have been major innovations in new media technology. Affordable and accessible products such as digital cameras and tablet computers using touch screen and eye gaze methods are opening up new opportunities for communication and inclusive research approaches are being developed as a result. The Rix Centre at the University of East London is pioneering what is described as 'multimedia advocacy'.

Young people with learning disabilities are growing up with an ease and confidence in the applications of various new media devices and are learning new ways to communicate choice and control. It is important to note the rapidity of recent technological development and the possibilities it provides for independent research, production and self-advocacy. Do these opportunities extend to those with a diagnosis of PMLD?

Increasing involvement

Pragmatic ways of increasing the involvement of people with PMLD in decision-making and consultation as examined, for example, in 'Involve Me' (Mencap 2011), are being rigorously researched and presented in accessible formats. Recently the Economic and Social Research Council funded a project that aimed to critically evaluate the quality and challenges of inclusive research and design with learning disabled people (Nind and Vinha 2013). In her paper, 'Inclusive research: where does it leave people with PMLD?' Nind (2013: 23) discusses the many difficulties of involving people with PMLD in the research process and the importance of not glossing over the challenges in the excitement of 'a celebratory narrative and a new orthodoxy emerging'. However, new research approaches using innovative approaches, for example, mobile interviewing and visual communication methods are being used to overcome some of these challenges (Ledger 2012, Boxall 2010).

My initial proposal set out to explore whether new media technologies could offer meaningful opportunities for people with PMLD to participate in life story work beyond being present as witnesses to constructed biographical accounts of their lives. My intention was to recruit up to ten adults with PMLD and investigate how new media tools might offer opportunities for

engagement. A constructive conversation with the mother of an adult child who has profound disabilities, during which she offered me a large box of archived personal records detailing the many and various communication 'experiments' her daughter had participated in over the years, helped to refine and shape my research approach.

I have decided to examine my research questions in the context of the lifetime of communication assessment and intervention that people with PMLD and their families have experienced. I plan to do this by working in partnership with people who have PMLD and their circles of support to establish how communication has happened in the past and is happening now, and then match those individually identified nonverbal repertoires of communication with appropriate tools - new media and others, to develop opportunities for participation in the different stages of life story work. The research design, supported by methods required for a deep, drilled-down and qualitative approach, has resulted in my decision to work with a smaller number of participants and their circles of support. By working with three families over a twelve-month period, I hope to explore my research questions in a way that may not be representative, but will be useful and meaningful for those involved and will contribute to the development of some practical methodological approaches about how to include people who have PMLD in the telling of their stories.

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Continued on page 38

Matthew's Book

Ken Pugh

'Matthew's Book' is a small project that appears to have generated a big response. Matthew Prosser is a man with profound disabilities. The project began when Trish Bailey, who manages learning disability services for the Humber NHS Trust, suggested that I talk to Matthew's parents, Tony and Tricia, about making a guide to his care. (Trish knew that I had an interest in using the iPad to support people with learning disabilities.) In conversation with Tony and Tricia a plan came together to make a multi-media guide to Matthew and his care needs.

We took the plan to a meeting of some of the key professionals who work with Matthew and they gave the idea their full support. The task then, over the following weeks, was to put together the contents of 'Matthew's Book'. The first full version of the book on Matthew's iPad appeared in March 2014 and there have been several updates since.

The book has five chapters:

- an introduction and guide to using the book
- an account in pictures and video of Matthew from birth to the present day. This includes over 800 photographs of Matthew which document his history and the progress of his condition (Lennox Gestaut Syndrome)
- a detailed description of Matthew's care needs and how they should be met
- a video-based account of the activities that Matthew enjoys
- a list of contacts - all the people who are important in his life, including those on whom he relies to provide support and services.

The book combines text, photographs, video, audio interviews, and existing documents to make up the most comprehensive account to date of who Matthew is and what he needs in his life. For example, in the care needs chapter, his epilepsy management plan sits alongside videos, made by Tony, which allow support staff to identify the subtle differences between different types of seizure activity and the different actions to be taken in response.

Professional support for the book has been outstanding. Claire McGregor, for example, Matthew's physiotherapist, worked with us to make a video showing how to position and lift Matthew in his chair and into

bed. Contributions to the book have been made by all the main services Matthew uses.

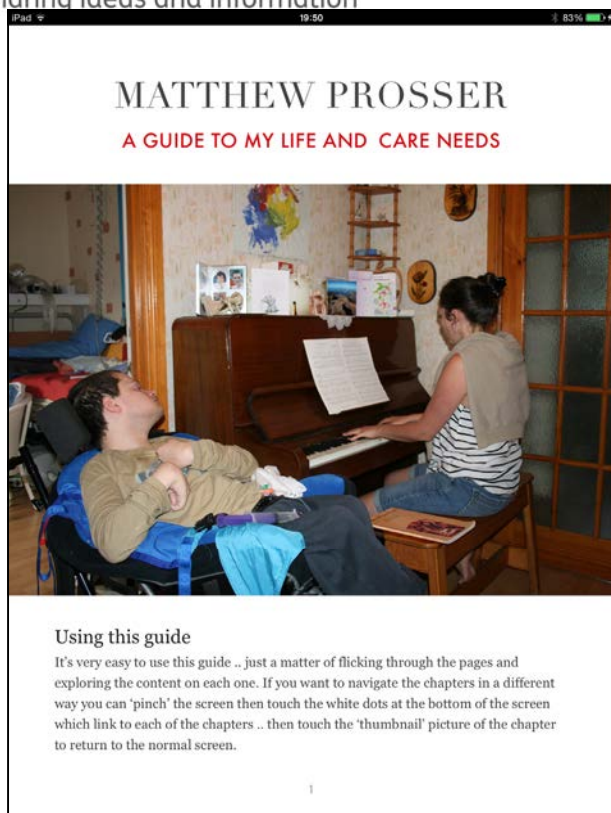
Tony and Tricia have made much of the content themselves including Tricia's through-the-day description of Matthew's requirements which includes videos of some of the basics like cleaning his teeth.

So now Matthew has a readily accessible resource on his iPad that will follow him wherever he goes, including hospital, to ensure that all staff working with him can quickly find out about the essential aspects of his care and what good practice means for him. Just as important, the guide will help staff to get to know and interact with him, creating a better prospect of a positive and engaged relationship.

Technical aspects

The photographs, videos and audio interviews, together with relevant text have been collated in book form on a Mac computer using Apple's free iBooks Author software. There is no limit, other than the memory of the device, to how many books like this may be held on an iPad.

As things stand iBooks Author can only run on a Mac with system OS 10.7 or higher. The iPad to which the book is exported requires the iBooks app which is free from the app store (it comes ready-installed with new iPads). At present iBooks created by iBooks Author won't open on iPhones. The other software used was Mac's Garageband to edit the audio interviews and iMovie to edit the videos. These are relatively cheap from Apple's app store for Mac. Like all Mac software, these programmes are intuitive to use to a degree but, particularly with iBooks Author, it will pay to spend a little time learning how to use it. Add-on 'widgets' to complement the iBooks Author software, for example, allowing the author to



include PDF documents in a book are available free from Bookry (<https://www.bookry.com>).

Matthew's book takes up 1.5GB of memory but that includes 29 pages, 17 videos, 5 quite lengthy audio interviews and over 800 photographs. (We really should have taken more care to convert the larger videos to smaller file sizes.)

All the photos, videos and audio interviews were done by non-experts using non-specialist equipment. Most of the videoing was done with an iPhone or an iPad, sometimes fixed to a tripod using an adaptor. iBooks like Matthew's can be shared electronically but with Matthew's book being so large we found it difficult to use Dropbox to share the file. iBooks can be exported into PDF format but the interactive features like the video are lost.

We're looking to make a short 'how to' video in Spring 2015 but if you need more information before then, please get in touch with me.

The response to Matthew's Book

Tony and Tricia presented the book at the national CIPOLD conference where people gave it an enthusiastic reception. It has since been to the Hull Learning Disability Partnership Board, the Board of the Humber NHS Trust and various other meetings where people have been nothing but positive. Over 3,000 visits have been made to the Matthew's book page on the Design for Care website ([http://](http://designforcare.wordpress.com/projects/matthews-book-2/)

designforcare.wordpress.com/projects/matthews-book-2/). So far, there have been no negative comments.

It has created a spark in people's imagination. The same approach has been suggested for transition planning, care plan reviews, electronic hospital records, staff training and so on. Using an iPad in this way allows us to quickly learn about a person and how to respond to their needs in a way that paper documents do not. People who have looked at Matthew's Book, even briefly, feel they have an appreciation of him as a person. In contrast, wading through Matthew's paper documentation, even if we're familiar with the terminology of his condition, is an unenlightening exercise.

Next steps

The Humber NHS trust has commissioned 10 more 'books' for people with a range of needs and ages. From this we will learn more about how to make multi-media care guides well and how they can be used to provide practical benefits.

Our interest is in making the process of book-making easier and more intuitive. Matthew's Book was made on a Mac computer and exported to an iPad. We'd like to be able to make books directly on an iPad or any other similar mobile device. We want this to be an approach that families and professionals can use with few complications. To this end, we have asked software firm Maldaba to assist.

Also, we want to find ways in which the use of such multi-media guides can be embedded in the everyday working of health and other professionals. Imagine, for example, a hospital that holds rich, multi-media information about 30 or 40 people with complex needs who regularly use their services, or a transition team that works with families and young people to create highly personal multi-media guides that form the starting point for planning for adult life. There are issues here to do with ICT systems, data sharing and ownership, person-centred planning, cross-agency working, professional roles and so on. Experience tells us that if we're not careful, organisations will find a way to encumber a simple idea with all kinds of bureaucratic paraphernalia. More positively though, the response from organisations to date, particularly the Humber NHS Trust, has been nothing but encouraging.

Finally, our work with Matthew has helped us in thinking about a wider range of bespoke iPad/tablet applications for people with learning disabilities and their families. The essence of Matthew's Book is that it helps us to learn about Matthew the person and from there on how we can contribute effectively to his wellbeing. Faced with what, apparently, is a life full of complexity, we quickly find ways of doing the right thing for him. We are

Swimming



Here I take to the pool .. aided by my two brothers, Christopher and Jonathon

Listening



Listening to the piano, played by my sister, Arwen

Story-telling



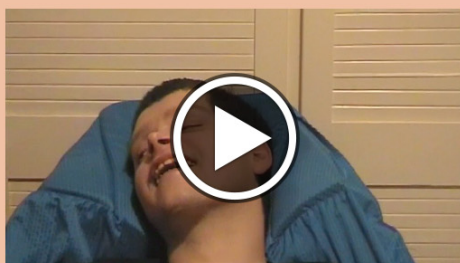
My carer/p.a. reads to me

Listening .. part 2



.. and here I am listening to Arwen on my iPad

Moments at home



A youthful me at home with my family

Cycling



Trying out the bikes at East Park

currently looking at how tablet computers can be used to enable people with learning disabilities to understand, appreciate and act on detailed information about their specific health needs. This follows the same theme of using different media on a tablet to 'package' and make decipherable information that, at first, looks complex and confusing.

Contact Details

Ken Pugh worked with Tony and Tricia to compile and sort the content, and to work out its format and structure. Ken is currently a Freelance Project worker but has worked previously for Hull City Council Adult Social Care Services and for Mencap. Email: pugh51@me.com.

Trish Bailey is a manager with Humber NHS Trust. Trish came up with the idea for the book. Tony and Tricia Prosser are Matthew's parents. They have provided a large part of the book's contents including videos they made especially for the book.

Words Fail Us References

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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 a 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, which will appear 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.

Email: pmlmlink@gmail.com

‘Sit with me, talk to me’

How the use of multi-media advocacy supported a brighter future for a nineteen year old learner coping with PMLD and presenting challenging verbal behaviour.

Julie Jackson

Katy (not her real name) is a nineteen year old young lady with profound disabilities, a wheelchair user and with significant brain damage. She has visual impairment, severe epilepsy and on - going health issues too. And whilst coping with all this and probably because of it, she has developed behaviours deemed to be challenging such as shouting swear words. What started as an occasional ‘bad day’ developed quickly to be every day and at what seemed like at any time without obvious reason. We were just reacting to her behaviour not pre-empting it and in some cases we were inadvertently fuelling the fire by responding to the challenging behaviour and thereby reinforcing it. Professional medical advice was sought to check if Katy had Tourette syndrome but the historical, educational and medical notes suggested that the learner had control over her expressions.

Katy’s use of swear words were so loud and frequent that she was not being taken out into the community by her carers at the residential home and even her parents said she was ‘showing herself up’ and they did not like taking her into cafés - one of her favourite places. It was becoming increasingly obvious that instead of Katy’s world expanding at a time of transition into adult life, it was in fact contracting. So Katy’s inappropriate communication became the object for change but information was needed to decide how to do this.

The Case Study

First, I and my team had to step back, observe and find answers for a few questions:

- What exactly was happening when swearing was heard?
- When was she doing it and what seemed to be the reasons?
- What might I implement to affect a reduction of the inappropriate language?
- What method can I use to monitor the whole project?

Getting started: using an ABC chart

To ascertain what was happening when we heard swearing, an Antecedent, Behaviour, Consequence chart (ABC) was used to gain an insight into the possible causes of the swearing by recording the actual events before, during and immediately after. Katy was shown to have different reasons for swearing and received inconsistent responses and it became obvious that she exhibited increased inappropriate language at specific parts of the day too, so the focus moved on to answering the question: When does Katy swear?

Using event sampling

Thomas (2013: 239) described an event sampling system that, when referenced with time, would allow me to get a measure of when during the school day we were hearing inappropriate language from Katy. This form of sampling removed the need for wordy descriptions. It was easy for all to use and it opened up the possibility of data being organised, compared and easily correlated.

So when was Katy swearing?

In Figure 1, data gathered from the event and time samples was interpreted as showing three areas of increased swearing during the day and these areas over the course of several weeks seemed to be fairly consistent. At first glance they were thought to be obvious transitional issues. But comments gathered alongside the event sampling illuminated areas for probable micro triggers, suggesting different reasons for each area but with the same outcome – swearing. The micro-triggers we were aware of included amongst others, when she was having to wait, being on her own, being with the wrong person, being spoken to in the wrong position or manner, noise levels, quick movements, confusion about her routine, dislike of the activity, seizure and excitement.

An Educational Psychologist suggested that Katy was swearing when she needed interaction but it could also be that swearing was entertaining, gave arousal, and when the feeling it created became over-stimulating, regulation of it was lost and the swearing escalated into the behaviour that was becoming a barrier for Katy. One obvious part of the data in Figure 1 surprised us by indicating very clearly the high amount of inappropriate use of expression on arrival in school when compared with the rest of the day. So my next question became: Was there a correlation between a high event of swearing on entry to school and what happened for the rest of the day?

In answer to this Figure 2 seems to show that there was no correlation. This supports the idea of the micro-triggers and means that whatever was causing the high incidence of swearing in the first hour was not necessarily causing the inappropriate expression across the rest of the day. So armed with the early formative information the question became:

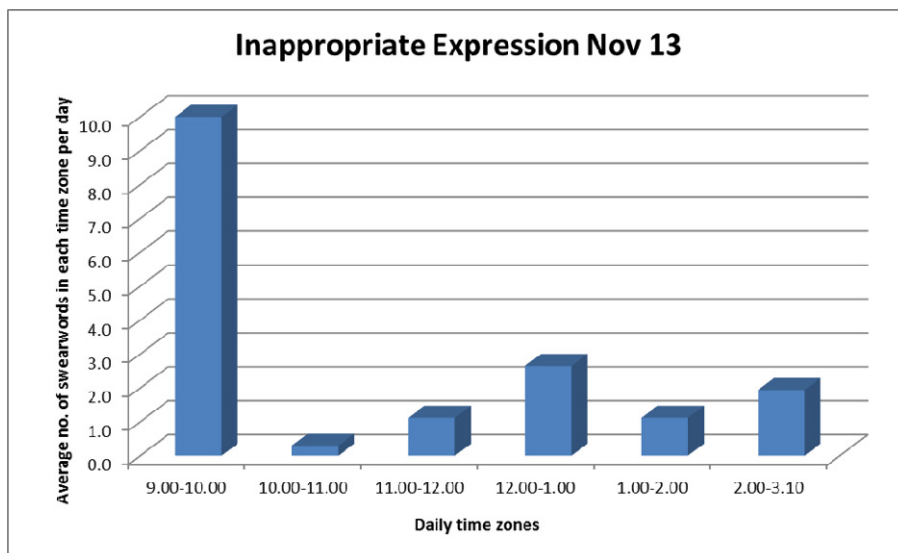


Figure 1: Average of 17 Swear Words Per Day



Figure 2

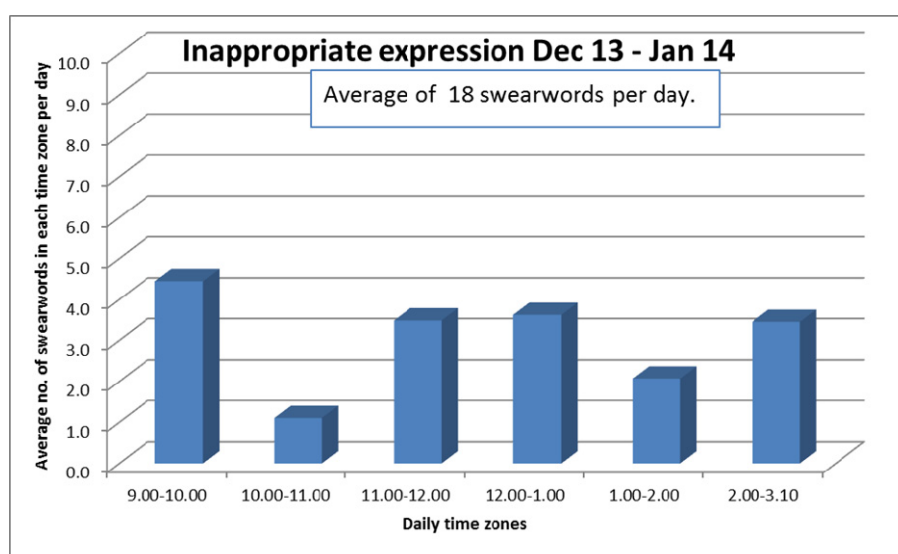


Figure 3

What could be implemented 9.00 - 10.00am daily in school, to affect a reduction of the inappropriate language?

A class based 1:1 shared reading activity was trailed on entry to school, and initial results presented through a second graph (Figure 3) were interpreted as showing a reduction of 50% during the 9.00-10.00am hour.

However the data also showed a surprising increase in swearing seen across the rest of the day and the average remained almost the same! Added to this Katy's engagement with the shared reading activity reduced and the challenging verbal behaviour increased again between 9.00 and 10.00am according to the event sampling sheets. Comments collected suggested this was due to the noise and movement linked to the entry of other learners into class.

So the decision was taken to greatly reduce the probable trigger stimuli of noise and movement by going, on entry to school, straight through to the school kitchen where Katy would be able to request grapes and a drink from a favourite adult. The adult had instructions to wait quietly in the room with Katy and physically supply the items requested by Katy and when she used key words only.

This action started on the 04/02/14 and the data (Figure 4) could be interpreted as showing an increase in the challenging verbal behaviour in the first hour instead of a decrease which is what we were actually seeing when she was in the kitchen. This happened because the hour had been split into two half hour slots but the data collection did not specify this division and Katy found the return to class for registration, difficult. However, to assist some form of data comparison I decided to keep the six identified times consistent to maintain a holistic overview. What was interesting was the considerable rise in the average swearwords heard – the possible reasons being hormonal pain and loss of routine due to several absences from school.

We were at this point when, during the low sensory demand session between 9-9.30am that Katy unintentionally initiated the idea for the development of self-advocacy when she looked clearly at the adult and said the words 'sit with me', 'talk to me'. Katy's words prompted our use of Multi-media advocacy in an attempt to stimulate her functional language through the use of video, photos, sounds and communication, presented on a Tablet device and featuring the learner talking about

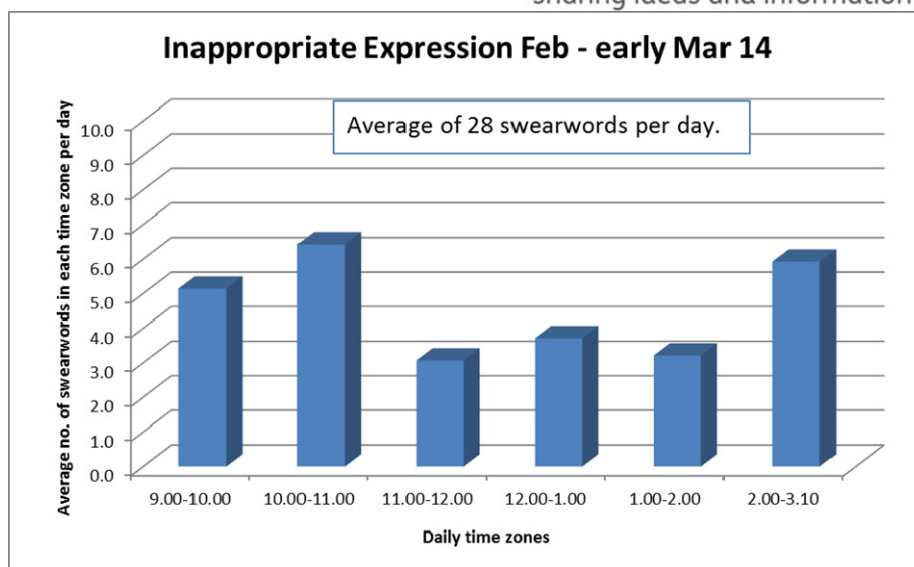


Figure 4

specific parts of her day with a familiar adult. This idea came from the 'Involve Me' project (Mencap no date) started by Mencap in partnership with British Institute of Learning Disabilities (BILD) and with support from the Renton Foundation. The project was facilitated by The Rix Centre, a charitable research and development group whose aim is to use ICT to change through empowerment the lives of people who have learning disabilities not least by enabling articulation of 'what life is like for them' (Tilstone, 2000: 155).

So Katy's request for interaction and her known interest in iPads provided the most likely means of improving appropriate expression. And the target times would be those moments of the day in Figure 3, showing the highest consistent recordings of micro-triggers- 9.00 – 10.00am, 2.00 – 3.10pm and the hour between 11.00-12.00 noon in readiness for lunch. So the question then became:

'How will the use of increased opportunities for self-advocacy through the use of motivational ICT at the three identified times during each day, be designed to reduce Katy's use of swear words?'

The combination of self-advocacy and multi-media began with a flip video camera on 24/02/14 used to record all conversations between Katy and a favourite adult during the focus times. The video evidence was edited along with photos of herself and people she would be seeing next and placed onto a Tablet device which was then shared with her from the 10/03/14 to the 04/04/14, daily during the three selected hours, as part of her preparation for transition. The idea was to involve Katy with daily life choices, have a motivational way of expressing her likes and dislikes and have the opportunity to see her own image, hear her own voice

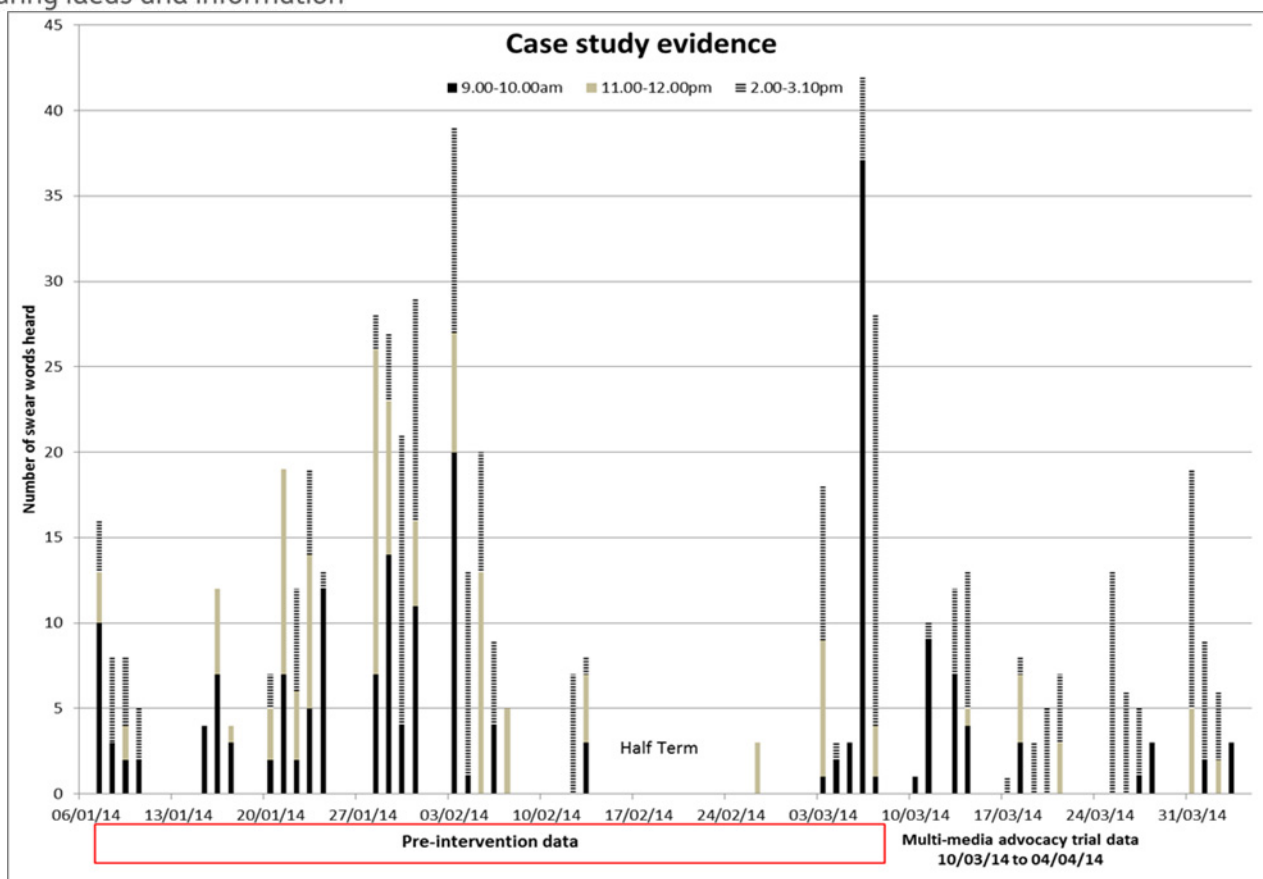


Figure 5

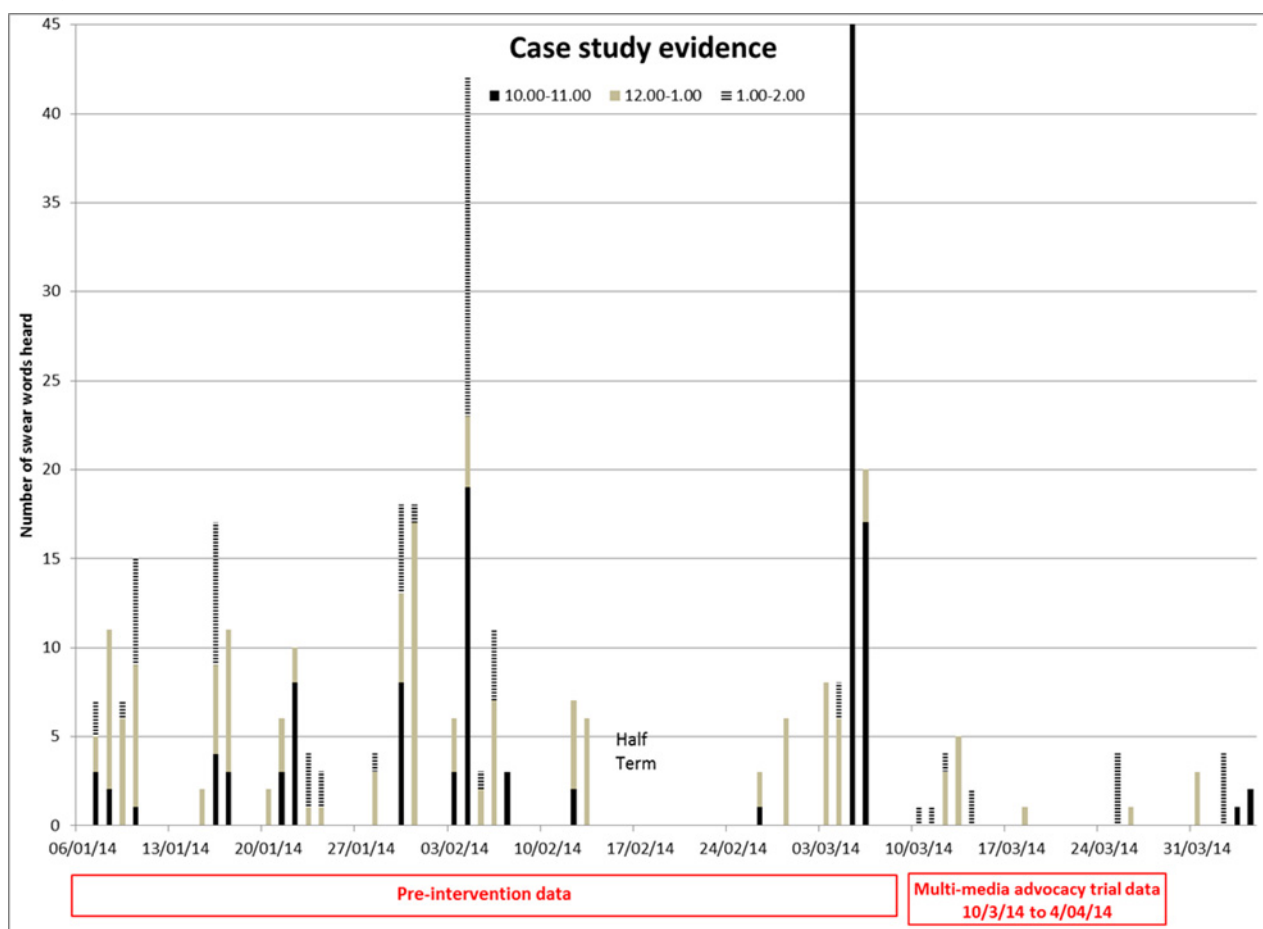


Figure 6

and to see herself with another person, being listened to and being centre of attention in a positive way.

So has the use of Multi-Media Advocacy had any impact on Katy's challenging verbal behaviour and how do I know? Summative assessment of the case study is supported visually by data (Figure 5) from the week beginning 06/01/14 through to the week beginning 31/03/14.

The data in Figure 5 could be interpreted as showing a notable reduction of swearing in the 9.00-10.00am and the 11.00-12.00pm hours. Event sampling indicates the 12/03/14 and 04/04/14 scored the only zeros in the three areas being focused on with the multi-media approach. All other blanks are absences from school which are most likely having an impact on her development overall. However other interpretations for the slight improvement could be sleepiness due to a reoccurrence of seizure activity seen in week beginning 17/03/14 or the hormonal swing which occurred the week beginning 03/03/14.

The data suggests that the 2.00-3.10pm hour has not been affected as positively and reasons for this might include Katy struggling to cope with her birthday celebration or her transition on Friday 14/03/14 and 21/03/14 to a residential venue instead of going home.

A comparison was made between the data from those hours when multi-media was used and those when it was not available, with an interesting outcome (see Figure 6).

The interpretation of Figure 6 data could be that the multi-media approach used in the three identified hours may also be having a positive effect on the whole day because of the time people are spending with her, talking to her and making her feel 'good to be with' – a result described by Thomas (2013: 141-2) as the Hawthorne Effect and supported by Whait (2011: 20). Or it could be that the changes are not related at all to the innovation and instead Katy feels well and is interested in the class activities and lunch. However given that both graphs have similar reductions at similar times it seems reasonable to suggest an aspect of the innovation was reducing Katy's need to swear and this may be demonstrated through the data in the final graph (Figure 7).

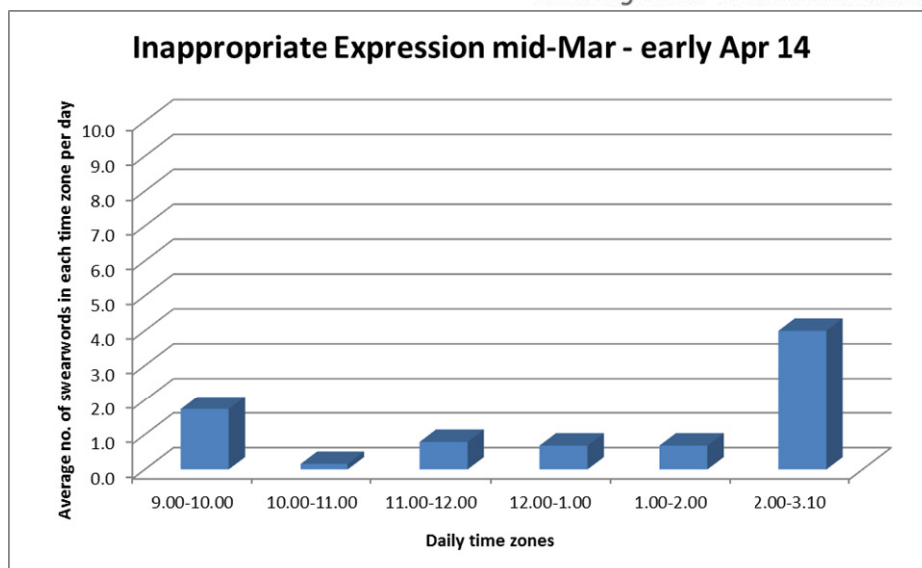


Figure 7: Average of 8 swearwords per day

The data contrasts well with Figures 1, 3 and especially 4. Even so it cannot be assumed with certainty that the changes are directly because of the multi-media advocacy idea but it does look favourable. Issues still exist with home time transitions, which could inform the study direction.

Conclusion

This case study originated due to concerns about Katy's world contracting because of her challenging verbal behaviour. The initiation of multi-media advocacy, seems to have supported an effective reduction of inappropriate expression in just one month of trial and it may have achieved this by giving Katy reasons, means and opportunities to start to use her voice and gain interaction in a constructive way as suggested in the Involve Me project evaluation (Mencap 2011). Limitations are that specific findings only apply to Katy, many variables were beyond my control and that time restrictions meant the study only produced a month of evidence and was totally class based.

The research has emphasised what a team event this is and how much of what we do or don't do affects Katy. Perceived personal care roles are changing and the staff can creatively discuss Katy's communication and have opportunity and permission to check out their ideas. The next intention is to effectively communicate findings from the case study with everyone involved with Katy and including her too, so as to develop confidence and increase knowledge of approach and enable Katy to use her expanding voice to influence her adult life. Something she seems to be starting to do because on 27/03/14 the parents said she was 'talking a lot'.

Contact Details

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Useful Websites

British Institute of Learning Disabilities
www.bild.org.uk

Renton Foundation
www.mencap.org.uk/therentonfoundation

The Rix Centre
www.rixcentre.org

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FUTURE FOCUS

The Environment

We hope this theme will inspire writers to contribute myriad interpretations of the word and to consider anything from global and geographical matters, the natural world, uncontrolled and controlled environments, immediate surroundings and wider experiences, including issues regarding environmental perception.

Scene, setting, situation, atmosphere, location, background, our environment has the potential to affect us in many ways. It can give us comfort, pleasure, excitement and security but it can also give us pain, anxiety and fear and the subject is especially pertinent to people with PMLD who very often have little or no choice about where they are placed.

The environment can open up their world. For example, I recently took a class of young people to the Westonbirt Arboretum in Gloucestershire. To feel and smell the bark of the trees, the wind on their faces and to hear the trees whistling and the rustling of leaves, all provided a stimulating environment and a lot of fun! As a carer, parent, grandparent, aunt, uncle or member of staff, have you visited anywhere that has been a success?

It may be that you have set up a fantastic environmental control system that you could share or have been innovative in designing a sensory room or other interactive space. Have you provided activities about the environment in early years,

school, college or adult service that you can share? We will consider articles about the environment in any context.

Encouraging people with PMLD to engage with their environment can sometimes be a challenge and to understand how and what they perceive is vital. It is, therefore, important that we consider innovations, activities, resources and interventions that allow us to provide safe but stimulating environments for people with PMLD, as well as providing our own imaginative, interesting, pleasurable and fun activities for them, about the environment.

Please share your experiences with us and our readers, ideas, thoughts and advice. We welcome all contributions, not only articles but also short pieces, websites you can recommend or written materials, your tips, suggestions and photographs. We very much look forward to hearing from you. Copy deadline please, 14th February 2015!

Please send your contributions to:

Wendy Newby wennynewby@aol.com

or

Chris Fuller fuller.chris@hotmail.com

PMLD Network Forum A Digest of Discussions August to December 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.

Questions asked

Personal health budgets

Someone said they had recently attended a review regarding the care of a family member who has PMLD. They said he is presently supported by 50% health funding and 50% social care. They said he loves swimming and now has very little movement in his limbs. They said their family have used savings to build him a small therapy pool at home but this is no longer used as it is difficult to lift him in and out of it now that his health has declined. The family member said they thought that a combined personal health and social care budget would be ideal for funding the pool maintenance and purchasing a hoist, as well as tailoring activities around his personal needs. However they were told at his review that he was only eligible to have the 'care' element of his budget to spend as a personal budget (12 hours per week) as he does not have the capacity to make decisions regarding the utilization of a combined health and social care individual budget. They wanted to know if this was correct.

Response:

'This sounds all wrong - if your child lacks capacity to make a decision then a best interest decision should be taken - if it can be shown that the hydro pool would help your child's health then it is up to the health authority, using the best interest process correctly, to say how they are going to meet this needs. They cannot exclude the need if it is identified as such, they cannot exclude a personal budget without going through the best interest process - so does hydro help with constipation, pain, allow a range of movement that cannot be achieved outside the pool, help with movement outside after the hydro experience etc. Your views are important in this process.' For further information on the best interests process they suggested contacting HFT.

Encouraging distance around wheelchair

Someone said that a parent recently asked them if they were aware of any accessory that could be fitted to the sides of a wheelchair. The aim being to discourage individuals in the community or in the school environment from walking directly beside the wheelchair as this causes his son to hit out as he does not like people close to him.

Responses:

- 'My immediate thought when I read this was that maybe a cycle flag either side might work. I have seen cyclists with a flag sticking out of their bikes, which is to encourage others to keep their distance. It is red plastic and has a round or flag shaped head. I would think you could buy it in any bicycle shop or on the internet.'
- 'I thought this too and perhaps a laminated sheet attached to back section of wheelchair saying please leave a wide space when passing chair. Print in large clear letters which stand out.'
- 'I'm guessing this young man has a learning disability, is maybe autistic, and possibly has sensory problems? If you can access a learning disability OT with knowledge of sensory processing, they might be able to come up with some strategies for him to cope better and for parents/staff to have a better understanding of why he's responding like he does.'

Advice about Spinal surgery

A parent asked if anyone had supported someone with severe learning disabilities and autism through major spinal surgery. They said that their son who is in his 20s, has developed a spinal curvature that is progressive and the doctors feel he will need spinal surgery. They said they were not sure if he will need to lie flat after surgery for a while, but if he does, this would be very difficult to achieve without sedating him, as he may well try to move or sit up as soon as he is awake, based on his behaviour when he has had surgery or dental treatment in the past. They said 'Has anybody experience of supporting someone who would not have the capacity to understand and co-operate with treatment and have they had a successful outcome on surgery? How did they go about this?'

Responses:

- Having a daughter with the same level of disability I can say the only way would be sedation until the surgery is sufficiently healed for him to move.'
- 'I only have experience with one young person living with autism who developed scoliosis and a marked rotation with rib flare. Although very active during the day, at night she went fast asleep, mainly due to medication as well as tiredness. She was very deeply asleep in her "comfortable" position with a weighted blanket on top of her and

did not move position for a few hours. What worked for her was to let her go to sleep as usual and then when she was deeply asleep she was repositioned and the sleep system put in place. The snug fit resembled the weighted blanket so she slept for a few hours in a supportive position. After 4 weeks there was an improvement in reducing the rotation, the scoliosis and the rib flare.' They also said 'We managed to avoid spinal surgery for our son by reducing his scoliosis using the sleep system. It's just as important post surgery to avoid the positions that helped develop the scoliosis in the first place though.'

- Sarah Clayton from Postural Care Skills said: 'This is an incredibly difficult decision to make. I understand completely the reasoning behind surgical intervention in relation to protecting the person's vital organs and for some individuals it is the only solution. Before going down this route however I would urge you to make sure that you have explored every conservative option available including therapeutic night positioning - this would involve looking at your son's preferred sleeping position, assessing how this position is contributing to his body shape and developing a person centred plan to explore the possibility of adopting a less destructive position with additional support in bed. This is obviously complicated if a person finds it difficult to understand what is being asked of them - as would be the case following major surgery. Whether you go down the surgical route or not it would be helpful to look at your son's sleeping position as this is a big driver for body shape distortion if the person does not move very often in the night.' She said 'Even if a person has undergone surgery you need to support them to change their night position in the long term as there is a need to protect the rods and to prevent problems in the future. If you wanted help with this or to talk it through please don't hesitate to get in touch.' She also said 'There are some great scoliosis groups on Facebook - it might be worth taking a look and finding out from people who have undergone the surgery what the whole process is like? The Scoliosis Association (SAUK) is also a good organisation for support and information.'
- A teacher who works with young people with complex needs said 'I have known four young people in their mid to late teens with severe learning difficulties who have had this operation. I wouldn't want to comment on your son's potential outcomes in particular as I am not medically trained, but I am sure he will be well supported by the surgeons and medical staff. It is a big operation, but in all the cases I have known the outcomes have been very successful and have led to a marked improvement in quality of life.'

Resources

Accessible Britain Challenge: toolkits on creating inclusive communities for disabled people

Toolkits with advice for organisations and individuals to help disabled people become full and active participants in their community.

<https://www.gov.uk/accessiblebritain>

Resources from Special Needs Jungle on the Special Educational Needs and Disability (SEND) system

Flow charts

Flow chart: Part 1, SEN Support

Flow Chart 2: Requesting an Education, Health & Care Assessment - Special Needs Jungle

Flow Chart 3: Conducting an Education, Health & Care Assessment

Flow Chart 4: The Flow Chart for if you disagree with SEN provision (or lack of it)

<https://storify.com/SpecialNdsJungle/all-our-new-send-system-flow-charts-together>

All about the Independent Supporter

In the new SEN system, parents can ask for support through an Education, Health and Care Assessment by an Independent Supporter.

<http://www.specialneedsjungle.com/sen-reform-independent-supporter/>

Letter from Children's Minister Edward Timpson to teachers, colleges, LAs and parents about the SEND reforms:

<https://www.gov.uk/government/publications/special-educational-needs-and-disabilities-send-reform-letters>

KIDS new guides to help navigate the SEND reforms for families, providers, commissioners, and Family Information Services.

Making it Personal 2: resources for SEND reforms
<http://www.kids.org.uk/News/resourcesforsendreforms>

National Family Carers Network launches their new website:

www.familycarers.org.uk

Contact a Family resources

See a full list of their new and updated guides, including 'Preparing for Adulthood' and 'Getting social care services when your child has additional needs':

http://www.cafamily.org.uk/media/761493/publications_list_october_2014.pdf

Children and Young People with Complex Health Needs - one-stop booklet for families

Free to download from the Foundation for people with learning disabilities website:

<http://www.learningdisabilities.org.uk/publications/children-young-people-complex-health-needs-booklet-families/>

Disability Rights UK – Care Act resource page

This is a list of online resources about the Care Act: <http://www.disabilityrightsuk.org/how-we-can-help/independent-living/care-act-resource-page>

Reports

Reducing premature mortality in people with learning disabilities: effective interventions and reasonable adjustments

A new IHAL report on effective interventions and reasonable adjustments for reducing premature mortality in people with learning disabilities has been published by NHS England: <http://www.improvinghealthandlives.org.uk/news/news.php?nid=2696>

Invasive healthcare procedures

A national quality framework to ensure people with PMLD receive comprehensive health care through the delivery of invasive health care procedures: http://www.pamis.org.uk/cms/files/ip_strategic_framework_2014.pdf

Carers at breaking point

This Carers UK report examines the experiences of carers who have been pushed to breaking point by caring without the right support. It is based on the experiences of over 5,000 carers: <http://www.carersuk.org/for-professionals/policy/policy-library/carers-at-breaking-point-report>

Response to Health Select Committee's report on long term conditions

Government response to the Health Select Committee's report into the care, treatment and support of those with long term conditions. <https://www.gov.uk/government/publications/response-to-health-select-committees-report-on-long-term-conditions>

Other

'Passport to Play' study

Summary of findings from Debby Watson's study on playfulness and children with PMLD. Download from www.debbywatson.co.uk

Action demanded to tackle learning disability discrimination

A Mencap public opinion poll has highlighted a huge strength of feeling on the urgent need to tackle learning disability discrimination and exclusion. The findings were released as Mencap launched its 2015 General Election campaign. Find out more, including how you can support the campaign:

<https://www.mencap.org.uk/news/article/action-demanded-tackle-learning-disability-discrimination>

Choking in people with learning disabilities: what can be done to reduce the risk?

Article on The Learning Disabilities Elf website: <http://bit.ly/1rCYDq>

Premature deaths of people with learning disabilities – reflections on Department of Health progress report

Article with link to progress report on The Learning Disabilities Elf website: <http://bit.ly/1pDqvV>

New online Carer's Allowance application system

A new digital application system means that carers can now apply for their allowance at a time that suits them. For more information: <http://bit.ly/1vg7TCq>

How the government is supporting carers

Find out about new rights under the Care Act, projects to support carers and more <https://www.gov.uk/government/speeches/how-the-government-is-supporting-carers>

Review of SEND disagreement resolution arrangements

The Department for Education and the Ministry of Justice are to lead review of SEND disagreement resolution arrangements as required by the Children and Families Act 2014. The review will start in April 2015 and a report on the outcome of the review must be laid before Parliament by May 2017. Amongst other things, the review is expected to cover:

- the effectiveness of local special educational needs and disability (SEND) disagreement resolution and mediation arrangements
- the effectiveness of local complaints procedures for resolving complaints from parents of children with SEN or disabilities.
- <https://www.gov.uk/government/news/send-disagreement-resolution-arrangements-review>

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

Visit the PMLD Network website at www.pmlldnetwork.org

IN THE NEWS



Update from Frozen Light

From January to June 2014 Frozen Light were on tour with their show *Tunnels* for teenagers with PMLD, which we have talked about in previous issues. *Tunnels* toured to 18 venues across the UK and reached over 400 people with PMLD plus an additional 500 carers, friends and family. Out of those 400 audience members with PMLD we discovered that 41% had never accessed the theatre before. This was something that we had suspected but seeing the actual figures, collected from carers and families filling out feedback forms, we were quite shocked. This really cemented for us the need to continue to create accessible multi-sensory theatre for audiences with PMLD and to work with theatres to programme more accessible shows.

We learnt in July that we had been successful in our bid to the Arts Council England to create a new show for audiences with PMLD. We have also been funded by The Stanley Thomas Johnson Foundation and The Bruce Wake Trust towards this project. Without this funding we would be unable to create our work to the high quality of theatre that we aspire to create and which our audiences also deserve. At the end of August 2014 work began on our new show - title yet to be announced. This new show will be for teenage and adult audiences with PMLD and will tour to theatre venues across the UK. We created *Tunnels* for teenagers but had many adults with

PMLD access the show. Due to their being such limited accessible arts opportunities for adults with PMLD this is an audience that we really hope to develop with this new show. The story will have a universal theme that both adults and teenagers can enjoy and of course will include a lot of multi-sensory interactions both collective and 1:1, live music and sign.

We are really excited for this new show which will tour in Autumn 2015. If anyone has any theatre that they would like us to visit or know of a theatre that may be interested in our work please let us know (info@frozenlighttheatre.com) as we are keen to work with new venues on developing their accessibility. We will also be working with community groups and parent and carers forums to ensure that we are creating a show and a day out experience that meets our audience's specific needs. If anyone is interested in this or has a group that might want to give us five minutes of their time again send us an e-mail, we want to talk to as many people as possible so we can provide the best theatrical experience possible.

By Lucy Garland
Frozen Light
info@frozenlighttheatre.com
www.frozenlighttheatre.com

An Appreciation of Alice Bradley

By Carol Ouvry

Alice Bradley has just retired from the Editorial Team of PMLD LINK journal. The breadth and depth of experience in learning disability that Alice was able to bring to the Editorial Team of PMLD Link will be much missed.



During her career she has worked in many different roles. She started teaching in mainstream and special schools in Glasgow, Toronto and London. Here she was the teacher in charge of Paddock Junior School (then known as an SLD school) and this is where I first met her as my manager and mentor.

Since then she has worked for many different organisations, much of which involved travelling abroad, firstly with VSO setting up multidisciplinary training (Learning disability) and assessing VSO projects in Thailand and later providing training and consultancy in international development and disability for several organisations across Africa and Asia including Cheshire Homes, British Council, and Save the Children among others.

She spent several years with the University of Wales Institute, Cardiff teaching on undergraduate and postgraduate courses in the Faculties of Education and Health and Community Studies. More recently she has been a tutor for the Open University in Health and Social Care and Education.

She has also written and edited training materials for BILD and the Scottish Qualifications Authority and engaged in voluntary work for many organisations of which PMLD LINK is just one. Many of these projects have involved fundraising, an area of her expertise that has been invaluable to PMLD LINK.

PMLD LINK grew out of education, but has, over the years, developed to embrace all services involved in improving the lives and wellbeing of people with PMLD

of all ages. Alice's expertise admirably represents this breadth of vision and she has given unstintingly of her time and energy to further the development of PMLD LINK which has changed, during her association with it, from an informal newsletter to the highly valued journal you all receive today.

Loretto Lambe Retires from PAMIS

By Julie Taylor, Information Officer at PAMIS

After 22 years, Loretto Lambe, Chief Executive of PAMIS announces her retirement.

Loretto founded PAMIS in 1992 with limited resources but a lot of commitment and support not only from Professor James Hogg - her husband, but also an expert group of governors.



The first years were difficult! The lucky break came when PAMIS was awarded a grant from the Scottish Executive to develop a family support service for three areas in Scotland. Many of these original families have remained with us from the onset and PAMIS has supported their sons and daughters from young children to mature adults.

From small beginnings with Loretto as the only staff member, PAMIS now has a staff team of 20 and is going from strength to strength. This is entirely due to the vision and leadership shown by Loretto. Her legacy is enormous.

Loretto has tirelessly campaigned for the needs of people with profound and multiple learning disabilities and their families. Her shoes will be extremely difficult to fill!

However following interviews late September PAMIS is delighted to announce that Jenny Miller, a long established friend and supporter of PAMIS has been successfully recruited and will start at the beginning of 2015. Jenny currently works for NHS Education for Scotland but has a wealth of experience of working with people with a learning disability and has been a Director on the Board of PAMIS for a number of years.

Change in Subscription Rates

The current subscription rates for membership of PMLD LINK have been maintained since 2011. However, postage and production costs for the PMLD Link journal are rising. Therefore, regrettably, we shall need to increase the PMLD LINK subscriptions in order to cover these increased costs. From January 2015 UK subscriptions will be £20.00 for individuals and £30 for institutions and organisations and overseas subscriptions will be £27 for individuals and £40 for institutions. We hope that you agree that this is still a good price to pay for membership of PMLD LINK.

A subscription to PMLD LINK will bring the following benefits: three issues of the high quality PMLD LINK journal during the 12 month period of a subscription, and access to the members' page of the website which allows members to access downloadable versions of back issue since 2011. Organisations are able to share these PDF versions widely with their own members.

Future Developments

During the coming year we will explore with you whether there would be any advantage in producing an online edition at a somewhat? reduced rate. We recognise that most subscribers will still wish to have a printed version of the journal but some subscribers have indicated that a digital copy would enable them to create wider readership and awareness throughout their services. We will send you a survey in due course to ascertain your views before making a decision.

We will also explore ways of improving the PMLD LINK website and introducing Twitter feeds to alert subscribers to developments in the fields of education, health and social care of children and young people with PMLD. Again, we will seek your views about possible developments

Back Issues Remaining

We have a limited number of copies of back issues remaining which are available at £5 per copy. The following are available:

Summer 2014 Transitions
Winter 2013 Well-being
Summer 2013 Human Rights
Winter 2012 Technology
Summer 2012 Family and Friends
Winter 2011 Therapies
Summer 2011 Sharing Perspectives
Spring 2011 (reprint) Speaking Up – Being Heard

All enquiries about subscriptions and back issue should be made to: Rob Ashdown at 15 Cliff Gardens, Scunthorpe, North Lincolnshire, DN15 7PH / e- mail: rob.ashdown@ntlworld.com

Summary of the latest issue of SLD Experience

Volume 69, Number 1, Summer 2014

An evaluation of the Complex Learning Difficulties and Disabilities Engagement Profile and Scale as a measure of engagement for children and young people with profound and multiple learning difficulties

Clare Chalaye and Dawn Male describe a study which aimed to evaluate the use of the Complex Learning Difficulties and Disabilities (CLDD) Engagement Profile and Scale (EPS) with children with CLDD. This scale has been published by the Special Schools and Academies Trust (SSAT) after research conducted in 2009; the documents are available on the SSAT website (www.ssat.org.uk/). The definition of pupils with CLDD includes pupils with profound and multiple learning difficulties (PMLD), the chosen group for this study. The EPS is easily accessible and can be used by a variety of staff working with learners with PMLD and the authors were keen to find out whether it is possible to use the EPS with the confidence that it is a reliable measure of pupil engagement.

The EPS is designed to support interventions aimed at increasing the engagement for learning of pupils with CLDD. Staff observations are recorded in seven areas of pupil behaviour identified as indicators of engagement. These indicators of engagement are carefully defined and each engagement indicator is rated and scored from 0–4, with 0=no focus; 1=low and minimal levels – emerging/fleeting; 2=partly sustained; 3=mostly sustained; 4=fully sustained. These scores are then summed to yield a total engagement score. Qualitative comment can be added in response to the question: What happened/ what didn't happen and why?

The authors point out that if the EPS is a reliable measure of the engagement of pupils with PMLD, then there should be no differences in engagement scores recorded by staff for the same learner according to factors such as familiarity/ unfamiliarity with the learner; levels of training; experience of working with pupils with special educational needs (SEN) generally and PMLD specifically; professional role (e.g. teacher or teaching assistant). The study was carried out in two schools. Video footage of two learners separately interacting with their class teacher was viewed by participant staff from both schools who had to record their observations of both learner's engagement. Comparisons were made of the agreement between staff about overall scores for each child on the EPS, taking into account different staff characteristics.

Results from the data analysis showed wide variations in total EPS scores awarded to each pupil by the staff. In general, the authors' overall conclusion was that there was such inconsistency in ratings by staff that the EPS was not a reliable measure of the engagement of these two pupils with PMLD. Surprisingly, there were no significant differences according to whether or not training in the use of the EPS had been received, although there was a trend for staff who had received training in the use of the EPS to return somewhat lower total EPS scores for both learners.

Since there is a question about the reliability of the EPS as a quantitative measure, the authors call for further research before the decision to implement these tools widely in schools is made.

Ten heads are better than one: Improving collaborative practice for teachers of pupils with profound and multiple learning difficulties

Sandy Turner and Joanna Ciuksza describe collaborative work between teachers of PMLD in ten special schools in Surrey. A networked learning community called SPAN (this stands for SLD, PMLD and Autistic Network) has promoted action research, with the research co-ordinators group becoming a catalyst to promote and embed teacher-led enquiry in their own schools.

Over the last ten years a continuing increase in the PMLD population in these schools has been observed and dissatisfaction has grown with skills based learning as a teaching approach. A process-based model is favoured whereby the learner is



placed at the centre of their learning and the pace and direction of the teaching is guided by the learner. In seeking to move from a largely standardised curriculum to a personalised one, the PMLD focus group within SPAN has provided advice and support to their colleagues. For instance, one of the schools in the network, shared an Excel spreadsheet they had produced designed to demonstrate quantitative progress of students through the Routes for Learning Pathway. The document is easy to complete; it automatically tallies a numerical and percentage score indicating quantitative progress through the assessment tool; and it shows clearly the pattern of learner progress. As a result, other schools in the network using the Routes for Learning Assessment introduced the spreadsheet to their schools and it has also been shared further afield with special schools via the SLD Forum.

The authors conclude by asserting that such collaborative practice can 'relieve feelings of professional isolation and engender joint practice that motivates and assists teachers to discover and utilise the most effective teaching, learning and assessment strategies for this unique pupil group'.

Hydrotherapy: the benefits and challenges of current practice

Nicola Vann is a Paediatric Physiotherapist. She presents an account of water-based therapy and its supposed benefits. She is concerned about the lack of objective evidence from clinical research to support its use because we live in an age where provision and continuation of a service is dependent on objective evidence for its benefits. She describes the Halliwick approach. She discusses the high costs of outfitting and maintaining hydrotherapy pools, the lack of access to pools in schools outside school hours and the closure of many hospital-based pools. She concludes that clinical experience suggests that hydrotherapy would be beneficial to many people with varying degrees of disability but that much of the evidence is purely subjective. In order for NHS guidelines to change to advocate hydrotherapy, more clinical research is needed.

MOVE Partnership at Wyvern Academy

Sue Marshall at Wyvern Academy which is a school for children and young people aged between 3 and 19 years with severe and complex learning needs. Wyvern Academy is also a MOVE Centre of Excellence and Sue with support from Dianne Rickard and Nigel Carter (respectively Director and Chief Executive of MOVE) describes the origin and purpose of the MOVE programme and through a case study illustrates how it influences the development of teaching and learning at the Wyvern Academy.

When a child dies: the parents' story

This moving piece is a contribution by Tracy and David Creighton parents of Sally, a young girl who had profound learning difficulties and very complex health needs. With support of Fliss Kyffin, Assistant Editor for the SLD Experience, they describe what Sally was like as a person, her needs and her interests. They describe what it was like to lose their child and the reactions of others to their loss, including the large number of times they had to tell people about her death. They even note how some people seemed to go out of their way to avoid talking to them.

When discussing what is an acceptable reaction, they say 'If you only take one message away having read this article, that should be: don't ignore the grieving family as they really don't want to be isolated and abandoned. They want to talk about their child with everyone who had the pleasure of spending time with him or her. Every snippet of experience, or little stories about them, are so important – as a parent, you have a thirst to know everything about your child when they were away from you.'

They describe as ideal the reactions of the primary and secondary schools to which Sally had gone. It means much to them that both schools immediately contacted them when Sally died and what they did to help her peers at school remember her and create lasting memorials to her for the staff and pupils. They value the fact that Sally's friends wanted to talk to about Sally and the teachers talked about what they had done with Sally and produced pieces of her work along with photographs.

Sally's brother Joshua has the same chromosome disorder as Sally which manifests itself as a severe learning disability though he does not have the complex health needs. They describe how they had to explain clearly to Joshua that Sally had died and was no longer coming back. They say it was confusing for him when people started telling him Sally was 'in heaven' and argue that everybody must consistently giving all children the same blunt message, more so in a multi-faith community.

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

Flo Longhorn training

Email: fplcourses@aol.com
Website: www.flolonghorn.com

January 2015

Title: **Sense Intervenor Course**
Dates: 5 days, dates to be confirmed
Location: Manchester
Provider: SENSE
Contact: jackie.bishop@sense.org.uk

Tel: 0117 967 0008

Title: **Implementing the Children and Families Act**
Date: January 2015 14th Northampton, 30th London, March 20th London
Provider: SENSE
Contact: jackie.bishop@sense.org.uk

Tel: 0117 967 0008

January

Title: **How to do Positive Behaviour Support**
Date: 15th
Location: Birmingham
Provider: BILD
Contact: Tel: 0121 415 6970
Email: learning@bild.org.uk

Title: **Sensory Play For All**
Dates: January 15th London, June 12th Birmingham
Provider: Concept Training
Contact: See provider details

Title: **Kickstarting thinking and problem solving for special learners.** Peter Imray
Dates: January 2015 16th Liverpool, 20th Leicester, February, 9th Birmingham
Provider: Flo Longhorn
Contact: See provider details

Title: **The pros and cons of using medication with children and adolescents with developmental disorders.**
Date: 22nd
Location: London
Provider: The Royal Society of Medicine
Contact: www.rsm.ac.uk/events/ldf01

E: intellectual.disability@rsm.ac.uk

Tel: +44 (0) 7290 3942

Title: **Personal social education for special learners: the power of touch.** Flo Longhorn, Andrea Muir
Dates: January 23rd Leicester, February 6th Birmingham
Provider: Flo Longhorn
Contact: See provider details

Title:	Eye gaze, Ipads, apps and switches: teaching tools peomoting quality of life and independence. Ian Bean	Title:	Living Literacy in Special Schools – working with literacy in the P levels
Dates:	<u>January</u> 23 rd Birmingham, 30 th Manchester, <u>May</u> 15 th London	Date:	6 th
Provider:	Flo Longhorn	Location:	Loughborough
Contact:	See provider details	Provider:	EQUALS
		Contact:	See provider details
Title:	Communication with people with learning disabilities	Title:	Cerebral Visual Impairment
Date:	24 th	Date:	11 th
Location:	Birmingham	Location:	Leicestershire
Provider:	BILD	Provider:	SENSE
Contact:	Tel: 0121 415 6970 Email: learning@bild.org.uk	Contact:	jackie.bishop@sense.org.uk
			Tel: 0117 967 0008
Title:	A new sld curriculum: Latest state of play. Peter Imray	Title:	Understanding learning disabilities
Dates:	<u>January</u> 26 th Manchester, <u>February</u> 2 nd London	Date:	11 th
Provider:	Flo Longhorn	Location:	Birmingham
Contact:	See provider details	Provider:	BILD
		Contact:	Tel: 0121 415 6970 Email: learning@bild.org.uk
Title:	The Big Autism Play Day	Title:	Communication with people with learning disabilities
Dates:	26-27 th Manchester, 28-29 th London	Date:	24 th
Provider:	Hirstwood Training	Location:	Birmingham
Contact:	See provider details	Provider:	BILD
		Contact:	Tel: 0121 415 6970 Email: learning@bild.org.uk
Title:	Creativity rules okay! Sensing and learning through the arts	Title:	Positive Ways of Changing Behaviour
	Keith Park, Sarah Hall, Flo Longhorn	Dates:	<u>February</u> 26 th Leeds, <u>March</u> 24 th London, <u>April</u> 20 th Dublin, 28 th Chorley, 29 th Manchester <u>May</u> 14 th Glasgow, <u>June</u> 22 nd Birmingham, 26 th London
Dates:	<u>January</u> 29 th London, <u>February</u> 5 th Birmingham, 12 th Manchester	Provider:	Concept Training
Provider:	Flo Longhorn	Contact:	See provider details
Contact:	See provider details		
February			
Title:	The mental capacity Act and making decisions – it's my health!	Title:	Using data in Special Schools
Date:	6 th	Date:	30 th
Location:	London	Location:	London
Provider:	BILD	Provider:	EQUALS
Contact:	Tel: 0121 415 6970 Email: learning@bild.org.uk	Contact:	See provider details

March		Title:	Using Soundbeam to Support the Curriculum and Communication
Dates:	Practical & Effective Ways of Using Multi-Sensory Equipment <u>March</u> 2 nd Glasgow, 9 th London, 10 th Birmingham, <u>April</u> 28 th Middlesbrough, <u>June</u> 10 th London, 11 th Manchester	Dates:	<u>March</u> 23 rd London, <u>May</u> 12 th Dublin, 15 th Belfast
Provider:	Concept Training	Provider:	Concept Training
Contact:	See provider details	Contact:	See provider details
Title:	Making sense of literacy for special learners Les Staves	Title:	Multi Sensory Approaches to Teaching and Learning
Dates:	<u>March</u> 3 rd Manchester, 13 th Birmingham, <u>May</u> 8 th London	Date:	5th
Provider:	Flo Longhorn	Location:	Norwich
Contact:	See provider details	Provider:	Collective Learning
Title:	Learning Outside the Classroom – Taking the Curriculum Outside	Contact:	louise.reeves@dioceseofnorwich.org
Dates:	<u>March</u> 3 rd Birmingham, 17 th Glasgow, <u>April</u> 27 th Chorley, <u>May</u> 19 th London	Web:	www.dioceseofnorwich.org
Provider:	Concept Training	Title:	PMLD: Profound and Multiple Learning Disability – engaging children in learning
Contact:	See provider details	Dates:	<u>March</u> 5 th Chorley, 6 th Glasgow, 10 th London, <u>May</u> 21 st Birmingham, <u>June</u> 11 th London
Title:	Intensive Interaction: Sensory Issues And Communication Using Body Language	Provider:	Concept Training
Dates:	<u>March</u> 3 rd Glasgow, 12 th Chorley	Contact:	See provider details
Provider:	Concept Training	Title:	Using Sensory Stories to Enhance the Learning and Development of Students with PMLD
Contact:	See provider details	Date:	12 th
Title:	Intensive Interaction: Building Relationships with people who have profound learning disabilities and complex needs	Location:	Cardiff
Dates:	<u>March</u> 13 th London, 24 th Nottingham, <u>April</u> 20 th Dublin, 23 rd Taunton, <u>May</u> 20 th Birmingham, <u>June</u> 9 th London	Provider:	Collective Learning
Provider:	Concept Training	Contact:	colette.pitts@collectivelearning.co.uk
Contact:	See provider details	Web:	www.collectivelearning.co.uk
Title:	Early Years Workshop: An Exploration of the Characteristics of Effective Learning for Young Children with SLD	Title:	Very special maths-emergent learning and approaches to teaching maths. Les Staves
Dates:	<u>March</u> 20 th Bristol, <u>April</u> 24 th London	Dates:	<u>March</u> 16 th Leicester, <u>April</u> 30 th Manchester, <u>May</u> 15 th Birmingham
Provider:	EQUALS	Provider:	Flo Longhorn
Contact:	See provider details	Contact:	See provider details
		April	
		Title:	A big sensory conference. Planning a sensory education for special learners: back to basics. Flo Longhorn, Jo Grace
		Dates:	<u>April</u> 29 th Birmingham, <u>May</u> 6 th Exeter, 8 th Bristol, 19 th London
		Provider:	Flo Longhorn
		Contact:	See provider details

Title:	Living Matters for Dying Children – delivering care, quality and compassion for children with life-limiting conditions.
Date:	14 th & 15 th
Location:	Birmingham
Provider:	Together for Short Lives
Contact:	Te: 0117 989 7813 Email: conference@togetherforshortlives.org.uk

May

Title:	Massage in the Special School
Date:	12 th
Location:	Manchester
Provider:	EQUALS
Contact:	See provider details

Title:	Secular, religious and sensory approaches to spirituality for special learners. Keith Park, Flo Longhorn
Dates:	May 14 th , June 4 th , 11 th
Locations:	(TBC) Manchester, Birmingham Cathedrals, Westminster Abbey
Provider:	Flo Longhorn
Contact:	See provider details

Title:	Special School Conference for Headteachers, Senior Managers, Chairs of Governors/Managers, Local Authority SEND Officers
Dates:	18 th or 19 th
Location:	Solihull, West Midlands
Provider:	Dr Michael Farrell and Richard Aird OBE
Contact:	Dr M Farrell Email: dr.m.j.farrell@btopenworld.com

Title:	27th European Academy of Childhood Disability Annual Conference: New ways new moves
Date:	27 th -30 th
Location:	Copenhagen
Provider:	EACD
Contact:	https://www.eiseverywhere.com/ehome/96503

Title:	11th European Paediatric Neurology Society Congress 2015 on metabolic, movement, neuromuscular disorders, neuropsychiatry, neurorehabilitation
Date:	27 th -30 th
Location:	Vienna
Provider:	EPNS
Contact:	www.intercongress.de

Title:	2015 IASSIDD Americas Regional Congress 'Activate Change 4Disability & Diversity'
Date:	21st – 22 nd
Location:	Honolulu, Hawaii
Contact:	Web: https://iassid.org

Title:	Diversity and disabilities: Improving health outcomes for black and minority ethnic young people and adults with intellectual disabilities.
Date:	26 th
Location:	London
Provider:	Royal Society of Medicine
Contact:	www.rsm.ac.uk/events/ldf01 E: intellectual.disability@rsm.ac.uk Tel: +44 (0) 7290 3942

June

Title:	Children's Rights and Early Intervention
Date:	8 th -10 th
Location:	Stockholm
Contact:	International Society on Early Intervention http://depts.washington.edu/isei/2016conf.html

Title:	Intensive Interaction Co-ordinator Course Dave Hewett
Dates:	(21 days in 7 blocks of 3 days) June 9 th -11 th , September 15 th -17 th , November 10 th -12 th , 2016 January 9 th -21 st , March 8 th -10 th , May 10 th -12 th , July 5 th -7 th
Location:	Malvern, Worcestershire
Contact:	www.intensiveinteraction.co.uk/events/coordinators.php

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

SEN Foundation Degree at Whitefield Schools and Centre in partnership with Kingston University

The SEN Foundation Degree is a higher education qualification which combines academic study with work-based learning. It provides a training pathway for those who would like to remain in work whilst studying for a higher education award. The degree is specifically designed for professionals working with children and young people in educational settings who have additional learning needs. You will have an appropriate Level 3 qualification and at least two years' post-qualifying experience and must be working at least 16 hours per week in an educational setting with children from birth to nineteen years. Course start date: September 2014

For further details: Whitefield Schools and Centre, Louise Langsworthy l.langsworthy@whitefield.waltham.sch.uk

Postgraduate Studies at Whitefield Schools and Centre in partnership with Kingston University

The Postgraduate Certificate, Diploma and Masters programmes are delivered at Whitefield Schools and Centre in partnership with Kingston University, London. The Certificate course runs for one year and the Diploma runs for two years. Both years carry 60 "M" level credits, allowing access to the third year Masters Degree that takes the form of an educational action research project.

The *Diploma and Certificate* courses are practitioner based and there is a requirement that students are working, either as a paid member of staff, or in a voluntary capacity for at least two days a week with children or young people with special educational needs.

The *Masters programme* is also practitioner based but there is no requirement for work to be but students can be accepted straight on to this programme (subject to an official transfer request and University approval) if they already have the appropriate number of credits at "M" level.

Whitefield can also offer the mandatory qualification for teachers of pupils with [Multi-Sensory Impairment \(MSI\)](#). Teachers undertaking this course complete two years of study as above, addressing the mandatory standards for this course, followed by a four week assessed teaching placement working with MSI pupils in a recognised centre of excellence.

Course start date: September 2014

For further details: Whitefield Schools and Centre, Louise Langsworthy l.langsworthy@whitefield.waltham.sch.uk

Subscription prices for 3 issues are:

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PMLD Link is an informal journal for practitioners and carers working with people with profound and multiple learning disabilities (PMLD), of all ages and in all situations. It covers a wide range of issues of interest and practical use in the day-to-day work of practitioners, parents and carers in schools, colleges, adult provision, in the home, and covers issues pertaining to all groups, including occasional articles by practitioners and parents from overseas. It enables readers to create networks, and provides a forum for contact with others involved in the field. The contributions may be:

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

About Us

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

Rob Ashdown	Former teacher of pupils with severe and profound and multiple learning difficulties and special school Headteacher.
Jeanne Carlin	Disability Retired Disability Consultant and a parent of a young woman with PMLD.
Helen Daly	Mum to a young Adult with PMLD, previous career in Further Education for 20 years - including Curriculum Team Manager for Inclusive Learning and Developing an Improving Choice Programme for people with Complex Needs. Currently involved in carers groups in the Eastern Region, Learning Disability Partnership Board and associated projects.
Jill Davies	Research Programme Manager for the Foundation for People with Learning Disabilities. Jill recently completed a Dept. of Health project on Meeting the needs of children with complex health needs. She facilitates the UK Health and Learning Disability Network.
Beverley Dawkins	OBE Chief Executive of Generate
Ann Fergusson	Researcher and tutor for severe learning difficulties and PMLD courses at The University of Northampton. Trustee of National Family Carers Network. Ann also has a family member with a learning disability
Chris Fuller	Founder and former Director of Bag Books: multi-sensory stories for people with PMLD, and previously special education teacher
Rachel Parry Hughes	Lecturer in Social Work, Goldsmiths, University of London, researcher in the field of profound and multiple learning disabilities
Penny Lacey	Coordinator of the University of Birmingham course in severe, profound and multiple learning difficulties; adviser and coach to staff in Castle Wood School, Coventry; freelance consultant; Penny has a family member with severe learning difficulties
Loretto Lambe	Founder and former Chief Executive of <i>PAMIS</i> an organisation in Scotland working with people with PMLD, their family carers and professionals who support them. Loretto has worked supporting people with PMLD for most of her adult life. Although recently retired she will continue to work and campaign for a better life for people with complex disabilities.
Wendy Newby	Deputy Headteacher at The Shrubberies School, Stonehouse, Gloucestershire. This is a school for students with Severe and Profound Learning Difficulties
Sue Thurman	Former NHS Speech and Language Therapist for adults with learning disabilities with a particular interest in PMLD. Now writes and trains about communication and is a Registered Intermediary assisting vulnerable witnesses to communicate at police stations and courts.

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



sharing ideas and information

PMLD Link is a journal for everyone supporting people with profound and multiple learning disabilities.

Visit www.pmlmlink.org.uk

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