

PMLD LINK

sharing ideas and information

The Environment

Spring 2015



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

Cover picture: Kaela in Discovery Cove, Orlando, Florida

GUEST EDITORIAL

The Environment

From the great outdoors to small corners, from cathedrals to cafes, this subject focus has invited a breadth of contributions about different environments and the overarching commitment to inclusion in all its forms. There are no boundaries to providing access when there are people who are determined that every possible obstruction can be overcome, literally where there's a will there's a way!

Putting the people with PMLD at the centre of any planning has been key in all the opportunities offered and what can be more personalised than sisters becoming involved in ensuring through Circles of Support and Person Centred Planning, that their sibling has the best possible environment.

Later in the issue we see the same compassion and care in the community found in the 16th and early 18th centuries. The vocabulary used to describe people with physical and learning disabilities in those days is shocking and harsh to our ears today, but those close knit neighbourhoods were forceful in ensuring that everyone had equal rights. In sharp contrast is a comment piece on how we never seem to hear about what it must be like for people with learning disabilities in places where their environment has been severely disrupted or destroyed.

We get a glimpse into a community environment and the pleasure to be found in making music with a band in a cafe in Tyne and Wear, and appreciate the passion of two teachers, who share the joy and the freedom of the great outdoors with their pupils. Usually indoors! - making sure that multi-sensory environments actually do fulfil the needs of those who are going to use them and the value of uncomplicated equipment, efficient storage, organisation and again, personalised planning.

From this compact environment we move into the vast space of Westminster Abbey for a totally inclusive event – especially for surprised tourists! - and multi-faith pupils. Then on to a very different venue, the BT Murrayfield stadium in Edinburgh and the celebration of the one hundredth Changing Places toilet in Scotland. Centre stage is the young man with PMLD who, with his family, was very much part of the PAMIS Changing Places campaign. (Please also look in the Report Back section for the first ever Changing Places Conference.)

Equally enthusiastic about accessing all areas are the managers of a Community Hub in Craigavon, Northern Ireland and Swansea 360 Beach and Water Sports centre in Wales. Both have Changing Places toilets and fully accessible facilities and we also learnt about BikeAbility Wales, where it seems that just about everyone can get on a bike! Our Top Websites page lists other providers of this exciting opportunity throughout the UK.

Having wheels and electricity opens up the environment, engagement and motivation to move, for three children in a research study, and for speedier travel, there are tips and practical information about flying with people who need supported access and seating in an aircraft. The Bag Books' Tall Stories project takes us multi-sensory storytelling into adult services and in Sam's Thursday, we see through photographic evidence, how the school day may look from Sam's perspective and this ties in well with the final article which explains and reflects on the value of Action Research, an on-going review of what is happening in any setting and how it could be made even better. We hope you enjoy your journey through all these environments!

Wendy Newby and Chris Fuller

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Sibling experiences of Circles of Support and Person Centred Planning

Julie Calveley

Jemima is 44 years old and lives in a residential home in Havant with two other ladies. She is one of five siblings and has a close family. Her parents and sisters visit regularly and are involved in her care and support. In this interview Jemima's two younger sisters Hannah and Tilly, talk about their experiences of forming a Circle of Support and Person Centred Planning.

How would you describe Jemima?

Tilly: 'Jemima is our big sister. She is the eldest out of the five of us and is super special to us all. I love her wicked sense of humour and the way she laughs and giggles. She cannot use words to talk, but she is very clear about what she does and does not want to do. The thing that she enjoys most is being amongst a group and people watching.'

What is your family like?

Hannah: 'We are all very close. A friend once described the family home using the words 'warm and chaos'! Jemima lives in a home in Havant and we have a family cottage nearby which Mum and Dad bought so we have somewhere to stay when we visit her. Mum and Dad take it in turns to visit Jemima every weekend and we get down to see her as often as possible.'

Can you explain more about the impact that Jemima has had on you and your family?

Hannah: 'Jemima has formed us and we have formed around her. I would say she has formed us as strongly as a parent does. Being a sibling to someone with disabilities teaches you to be tolerant and value difference, because her needs have had to come first. I see the same trait in all of my brothers and sisters - they are all empathic and caring. Our careers and relationships have been shaped by Jemima, as they are characterised by wanting to help other people and make a difference to people's lives.'

A Circle of Support was formed for Jemima in October 2013. A Circle of Support can be described as a group of people who know and care about an individual and give support and friendship and help the person plan for how

they want their life to be now and in the future. Jemima's Circle included her Mum, Dad, two sisters, the home manager, Jemima's key worker, and an independent advocate. With the help of a trained facilitator, the Circle met to embark on a Person Centred Planning process. Person Centred Planning (PCP) is a process of continual listening and learning, focusing on what is important to the person now and in the future, and acting on this in alliance with their family and friends (helensandersonassociates.co.uk **).

What made you want to be part of a Circle of Support and use Person Centred Planning?

Hannah: 'Our parents had, over many years, dipped in and out of Person Centred Planning and had written plans for Jemima. They were aware of its value and wanted to use Person Centred Planning to give Jemima an authentic voice. They wanted to make a real difference to her care. With the support of a facilitator from the organisation that ran her home, we found that there was more to it and that it can be a living process. It is not just about producing a plan, as it also involves the concept of a Circle of Support, and is an on-going process.'

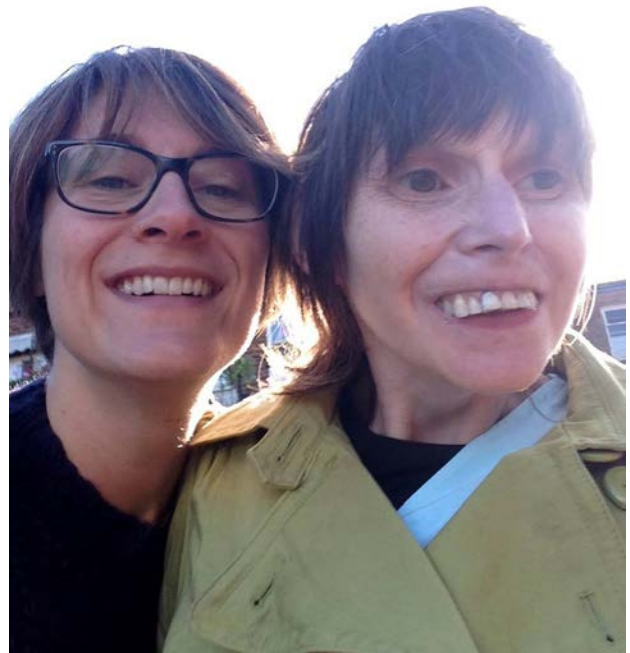
What did the Circle of Support mean to you?

Hannah: 'Bringing together all the people that are important in Jemima's life in one room is incredibly powerful in terms of what Person Centred Planning can deliver. The Circle of Support seems like a safe place to take things to. If something comes up, rather than one person feeling the weight of the responsibility, we can think 'right, let's take it to the circle' and share the responsibility. The Circle of Support meetings give everything a little more visibility and are an opportunity for reports which we might not have seen, to be studied and read, and consideration given to what needs to be changed collectively. The net result of having those conversations in the one room is high consistency in care, because we are all on the same page and therefore do the same thing.'

Tilly: 'Having the facilitated Person Centred Planning sessions was a bonding experience for family and staff and really deepened our relationships. As siblings, we'd usually leave lots of decisions to Mum and Dad and say 'hi' briefly to staff when visiting, but now I am able to sit and chat with the staff and feel that I have a meaningful relationship with them.'

Can you describe how Person Centred Planning was carried out?

Hannah: 'We had four facilitated sessions, which were important because no matter how versed you are in Person Centred Planning and skilled in facilitation it is lovely to be able to talk and feedback and not worry about getting everything down on paper. During the first



session we talked about Jemima as a person and shared anecdotes, laughed and were emotionally moved.

Tilly: 'One of the most powerful moments for me was when we were sharing our experiences of Jemima and I realised that, although I thought I saw Jemima as an individual in her own right, I had a limited view of her which relating to our family. I suddenly saw her as a woman with her own life and I was shocked at my own short sightedness.'

Hannah: 'We captured historical information and anecdotes which seemed to be important for Jemima at home because carers learned about her before they met her. We shared photos which chartered her history. In the latter sessions, we started to develop an action plan.

'It was helpful to have an action plan which stated what we needed to do in between sessions, like gathering and bringing back information. As a Circle we agreed on things that we wanted Jemima to be and achieve, for example leading as active a life as possible. Using those goals as a starting point, it was easy to cascade actions that needed to be taken for her to be able to achieve those goals.'

What were the benefits and outcomes of forming a Circle of Support and of Person Centred Planning?

Hannah: 'A Circle that continues to exist and make decisions for Jemima. Positive relationships have been built with staff and I have increased involvement in



Jemima's care. Personally, I think it is fantastic to engage with key workers and management. I have got to know everyone and now feel comfortable to pick up the phone and speak to staff. I also have a better understanding of what Jemima is capable of doing. We have a clear action plan that makes people accountable. We have produced a multi-media profile which has proved to be hugely helpful for everyone and this is being replicated so that others can also benefit.'

Tilly: 'The most beneficial thing is that the process is not finite but is continuous so that we are always sharing new information. New staff are brought into the Circle and that creates a strong community of people who are constantly working together to better Jemima's life. More importantly Jemima seems happier because people understand her better. People are trying to help her to do things rather than doing them for her, which is empowering for her.'

Did you encounter any difficulties and how were they overcome?

Hannah: 'We can't always agree and not everyone has the same viewpoint. Being in a safe facilitated

environment made it possible to take emotions and bureaucracy out of the situation and arrive at best decisions for Jemima. I was delighted that we were able to improve her life through some simple detangling of facts. Sometimes the idea of doing something different is difficult, but in a supportive environment it is easier to accept.'

What would be your advice to other people who are interested in forming Circles of Support and Person Centred Planning?

Tilly: You need a skilled facilitator in Person Centred Planning. Form your Circle of Support and be prepared to put in some time. This is definitely something to explore. You will learn so much about yourself and the person you are doing it for. It is so powerful. Just do it!'

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The Music Café

Rhod Davies

When it came to creating an environment where people with learning disabilities felt not only welcomed and 'at home' but were also stimulated through music, sound and social interaction, the Soundroom Community Music Project in Gateshead came up with an idea fifteen years ago that has blossomed into a long running project that has every chance of flourishing for many years to come.

The idea of a 'Drop in Music Café' came about through a suggestion at a volunteer team meeting, partly to cater for people with mental health difficulties who used the project. Once this started in year 2000, these sessions very quickly became hugely popular with the learning disability organisations not just in Gateshead but throughout the North East.

The Music Cafe takes the form of twice weekly participative music making sessions on a Monday and Thursday where people can have a cup of tea and snacks or even bring their own food and either listen to the music being made or join in through singing, playing percussion or having a dance. There is a volunteer band

(pictured on page 6) who provide the music backing but participation is encouraged at every turn with service users and staff being encouraged to get up on the mic, play guitar or just enjoy the music standing 'on stage' with the band.

There are also radio mics available for wheelchair users and a much used box of percussion that is handed round, providing further aural and tactile stimulation. Generally the numbers attending are in the region of thirty to forty per session.

The aims of the Music Café include: creating a pleasant and happy atmosphere where people are able to enjoy

themselves without experiencing prejudice or discrimination, encouraging the development of musical skills through participation and offering a platform for untapped musical talent, providing the opportunity for people to perform live in front of an appreciative audience.

Father and son, John and Tony Kew (on page 5) have been attending the Music Café for five years now and like to come because the music is therapeutic for Tony. He responds to the vibrations of the sounds and it also provides much welcomed social interaction for him, seeing friends in an environment where people are conspicuously enjoying themselves.

For other participants it has additionally become a tool for helping them with efforts at life skills as they bring in files of lyrics of songs they want to have a go at singing. Sometimes peoples' vocal efforts are characterised more by enthusiasm than finesse but this only adds to the charm and the goodwill emanating from those attending, ensuring that a positive atmosphere invariably prevails.

"vocal efforts are characterised more by enthusiasm than finesse but this only adds to the charm and the goodwill"

The Soundroom has been functional as a non profit making organisation for around thirty years but has now registered as charity whose object is 'To advance education in music and the arts by the establishment of a venue in Gateshead for the public benefit'. To do this it has facilities for rehearsals, recording and performance, thereby encouraging people to be involved in music as a means of enhancing their quality of life. The project was supported for many years by Gateshead Council Youth



Picture above: Band members from left to right : Dave Robinson, June Irving, Steve Donkin, Eve Jones, Rob Anderson, Rhod Davies

and Community Service but due to cutbacks imposed by central government the project has now lost all funding from this source. The Music Café itself receives no funding and survives through dedicated volunteer efforts, income from the small cover charge to the sessions and fundraising efforts by volunteers.

Future plans for further developments have been discussed but would require a degree of funding to get them off the ground. These include equipment for a music and sound orientated sensory room with interactive devices for generating or affecting sound and light sources through gesture and other means, small group music facilitation workshops and developing a mixed ability band able to play at external fundraising gigs, community festivals and similar events.

Photos by Rhod Davies and Bradley Rochester Smith

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The Beautiful Outdoors

Wendy Newby and Judy Harris

Many people have a wealth of knowledge, understanding and passion for their work, sometimes inspired initially by an outstanding college tutor, and I consider myself very lucky to work with just such a team of experienced teaching staff. This is an interview with one of them.

How did you come to be a teacher of students with PMLD?

Well, as a teenager I helped out with summer play schemes and a weekly 'Gateway Club' for young adults with learning disabilities and it was during this time that I realised I had an affinity with these young people. The communication through smiles, touch and just 'being' with them was second nature. I decided to become a teacher as this was a way I could build on this connection and give input over a longer period of time.

Like you Wendy, I feel indebted to the people who shaped my own knowledge and personal development at the time. I was fortunate to study for a specialist teaching degree at Matlock College under John Attwood, who inspired me to value the individual and always look to make a real difference to their daily lives. During my training I had extensive teaching practice in schools for students with severe learning difficulties, this was in the mid -1980s during a period of huge change for education. Everything and anything seemed possible at this time and teachers had the autonomy to introduce so many innovative multi-sensory practices. The National Curriculum was in its infancy....

Since 1997 I have worked at The Shrubberies School in Gloucestershire and am now the coordinator and lead of the outside learning environment, which is the perfect backdrop for continuing to educate through these early values and sensory channels.

What is important to you?

As educators I think we need to be quietly stable and nurturing in our long term approach whilst being flexible and innovative day to day, to meet the individual needs of the students. We need to remember why we are there. It is vital that the ethos of the school or provision is based on teaching students how to learn and to join them on that journey and not see our role as someone who must instigate a change in them or set a path of predetermined progression. The importance of the relationship between the teacher and the learner, the mutual respect and trust is paramount to me. The formal curriculum as it stands is so frequently not relevant. There needs to be creativity and imagination

on the teachers' part to deliver it in a meaningful way that introduces the earliest of concepts linked to the specified content.

And why is the outside environment particularly important to you?

Primarily I feel that the outside has no restrictions for an imaginative teacher. It is non-invasive when compared the acoustics, artificial lighting, heat and four enclosing walls of the classroom. It frees you up from the carpets and furnishings to keep clean. A patch of ground can take a shower of rice, sand or paint without the need for a follow up with vacuum cleaner or j-cloth.

We have a duck pond with two ducks, Ruby and Bill at school. Looking after them provides a wide range of stimulus that is specific to that activity: the smell of the undergrowth, the sound of the water when filling the pond, Bill and Ruby quacking, handling pond weed, feathers, sifting grain and the tingle of hand sanitizer gel between fingers at the close of the session. These are first hand sensory experiences that cannot easily be replicated inside the classroom. The same can also be said for lying and looking at the random movement of clouds in the sky. Even the most elaborate sensory room cannot reproduce the visual fascination and pleasure gained from watching sun shining through dancing leaves thirty feet above our heads. As practitioners we need to remind ourselves of the richness of these simple experiences and tuck them into our planning with confidence.

I use the nest swing to provide the sensation of endless movement that does not require a sense of balance and allows the students to get their feet off the ground. This provides the immediate opportunity to reinforce language such as more, stop start etc. Changing the rate of movement and the height of the swing encourages responses and indications of likes and dislikes. Two or three friends squeezed on it together give lovely feelings of deep pressure and companionship. And what better natural way to open up the vestibular channels for learning.

What can I say about MUD! There is no limit to its

versatility. Fun and uninhibited indulgence on the part of children and staff is essential in the activities I provide. We use mud to do pretend cooking, build sculptures, leave trails and make marks. We scoop, mix, transfer, fill and empty, hide and find objects in potting compost, crumbly soil or liquid muddy gloop - all activities that help to develop object permanence and conservation in a fun way. Commercial potters' clay from the Consortium mixed with warm water can produce a very smooth, pleasing 'clean' mud that can be reused over and over again.

Water play can be tricky for those with restricted movement or unable to sit around in damp clothing. Supported use of a hose pipe with trigger nozzle is a great way to bypass this. One pull on the trigger sends a powerful jet of water high in the air. It can shower down noisily on to upturned containers. Better still – a willing teacher running through under a colourful umbrella adds to the anticipation, tracking skills and shared laughter.

What is the impact of the outside on learning?

The outside is less a way of learning but more an opportunity to open up curiosity and awaken natural learning processes. Curiosity comes from within. It is powerful stuff and has the potential to stimulate the student to reach out, grab, look, and smell - to really explore independently.

Likewise, an appreciation of aesthetics is intrinsic. 'Beauty' is among the oldest of philosophical value concepts. It is not for us to try and teach or define what is right or pleasing to the eye. In this instance I believe we are the facilitators, finding natural patterns, helping to experience the visual or tactile symmetry of natural objects, watching reflections on water, making dens to create interesting internal spaces. Our young people can settle their eyes on whatever brings them pleasure and along the way we have built on their sensory emotions. Sometimes we can trigger a new level of information processing.

It is not a coincidence that many of our youngsters on the autistic spectrum find calm outside. They may regulate their temperature through bare feet, carefully select the perfect grass seed head to flick, or find a natural corner or den to settle in. From this point on I find we enter a different level of learning. There is receptiveness, intensive interaction takes off and the bond is strengthened for the next time.

Have you any tips?

- Having an 'all year round' ethos means the need for quality waterproofs, wheelchair covers and

wellingtons. Try not to let the weather hold you back.

- Have a decent tarpaulin to cover damp ground.
- Plan for seating, lying out of wheelchairs, the potential for shade.
- Have a range of resources specially for activities outside
- Have storage outside as it is hard to get children and equipment out at the same time.
- Be prepared - don't go outside and expect it to happen e.g. gather resources in advance - a bucket of worms or snails, a bag of crisp copper beech leaves, balls of play dough ready to poke twigs in to make hedgehogs, coloured cellophane strips cut ready to dangle from a branch and catch the sun.....
- Plan long term planting to provide a variety of textures and colours of flowers and leaves, good supplies of swishy bamboo for music sessions or tough herbs like rosemary that can be picked and used in collage.
- If in school, have a comprehensive generic risk assessment so that intuitive responses do not have to be stopped by not having one to hand.
- Do not underestimate how any routine indoor activity can come to life by doing it out of doors - stories, parachute games, puppets, PE, movement and music.
- (check out a wireless 'sound cast' for portable/rechargeable music outside)

So what next?

I believe it is essential that we continue to widen the opportunities and experiences for our students to engage with the outdoors. Staff need opportunities to share emerging ideas and support each other with methods for concise recording/evidencing. We have recently applied to join the 'Learning in Nature' collaboration with The Wildfowl and Wetland Trust, Slimbridge, Gloucestershire. This will enable us to work as part of a cluster of local schools to improve learning, have the support from Beacon schools, access each other's school grounds and increase our visits to local natural spaces. There is a commitment to carry out continual professional development and collect data to celebrate the use of the outdoor environment. Exciting times ahead!

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Does your multi sensory room follow the triple 'A' principles?

Richard Hirstwood

Recently, I've been thinking about the principles behind the design of a great multi sensory room. Some designs I've seen are based on cost and/or standard company 'packages,' but the most successful designs are those based on the requirements of the pupils or students who will use the space. Sensory spaces, be they separate sensory rooms or a corner of the classroom or home, must meet the sensory needs of the people who are going to use them. There is a vast array of sensory tools beyond bubble tubes and projectors, but it's not all about the equipment you have! It's how you use the environment, which is of paramount importance.

Here's where the 'AAA' principles of room design fit in - availability, appropriateness and achievability!

Availability

Your multi sensory tools and equipment need to be available when you need them - and to work first time. It's frustrating to reach a 'breakthrough' moment for it to be ruined when you can't find just the right tool or it doesn't work! Good storage and organisation is essential. If you are working with smaller tools like UV torches and Tocki Tubes, then having them stored in an organised box or possibly a tool case will ensure that you know where things are when you need them. It also helps you see when things have not been returned. Remember the old saying 'a place for everything and everything in its place'? I am amazed at how many sensory rooms do not have a storage system for switches, effect wheels and other tools used in the space. They can become very cluttered without good storage and prove to be just too much distraction for some of the users. With both portable sensory kits and sensory rooms, you need to be able to use that tool when the moment strikes, not after searching around for it for ten minutes.

Regular maintenance sessions to check your tools is perhaps not top of the excitement list - but they will save you time (no more disrupted sessions) and money (a stitch in time...) later on! You should have a fault list, either on the wall or in the cupboard, where people can report a faulty lamp or piece of equipment not working. People need to be told that equipment does break and there is no crime in reporting the fact that something is not working. Could this demonstrate a need for a multi sensory room co-ordinator in your school?

Appropriateness

Does your multi sensory room really suit all of the learning styles and needs of the pupils and students



who use it? A sensory space needs to be flexible to enable the practitioner to increase or decrease the amount of stimulus. A visually cluttered room certainly won't suit the learning style of many people with autism. Lots of labels on cupboards and boxes can also prove to be very distracting. Learners with PMLD will often need things closer and more accessible than others. You may need to be able to hang objects from the ceiling like parachutes or sheets for projection. Can you back project your images for the pupil with a visual impairment?

One of the problem areas in many commercial sensory rooms is furniture. Comfortable and correct positioning is very important. Some rooms will have some, and possibly



all, of the walls and floor covered in soft play. But you may need to allow for a way in and space for wheelchairs, as some adults and children will find it much more comfortable to access effects from their chair. Mats should always be removable and dual coloured, ivory on one side and dark blue on the other side, works well. But do you really need mats like this? How comfortable is it sitting on vinyl? I'll bet you don't have vinyl furniture in your house! Would more ordinary furniture be more appropriate?

Colour in a sensory room is something I'm asked about a lot and I could write lots about the subject! The advice I give is ivory white walls will reflect light and dark blue will soak light in. So if you are having either projectors or coloured lights then light colours will be best. A dark wall will be great for using UV and fluorescent objects. I like the idea of three light walls and one dark in a sensory room. A dark floor will also help people see the colour contrast between the walls and floor and so will help them gain visual awareness in the room.

We all know that colour can affect our lives quite profoundly. Coloured lighting is being used more and more in sensory rooms, classrooms and the home. There is much evidence, some of it anecdotal, to say that red makes us stronger, green makes us more passive, blue is a cooling colour and more people argue in yellow rooms than anywhere else. So being able to change the colour of a room is often helpful to achieve a mood. Coloured lighting can be very expensive, but it is coming down in price all the time.

The other thing to consider is being able to blackout your sensory room or part of the classroom. There are lots of options open to you. Have a look at: <http://www.magicblackoutblind.co.uk/> for one of the more novel solutions.

So does making the sensory room appropriate mean that differentiation of the curriculum is easier to achieve in your sensory room? You may have a projector attached to your iPad projecting large images from google earth for a geography lesson, but have you got the small tactile objects available for those kinaesthetic learners in the same session?

Achievability

Does the design of your multi sensory room mean that it allows all practitioners to use the equipment without a vast technical knowledge? Technology is supposed to make our lives easier, but in recent times computer control has often made rooms more difficult to control. People like to work with simple controls which enable them to focus on the child or adult, rather than battling with technology trying to get something working. Simplicity is often the best way forward - why have lots

of complicated to use equipment (that no-one will use) when you can have a few, easy to operate and effective multi sensory tools which will be in continuous use?

The other issue is for the sensory room or space to achieve anything, you have to know what you want to achieve! Targets are very important and every practitioner using the space should know why they are there. They should also know about the individual or group using the room. As many people know, some of our learners need time to get going, some need a short focussed session, some may see better from the left or right and some people don't like pan pipes! So before you take somebody into the sensory space make sure you have an appropriate sensory profile or communication passport stating their likes and dislikes and access needs.

Multi sensory rooms were developed as a tool to create appropriate learning experiences for our learners, not a place for us to battle with technology! As well as simplicity, the key themes we promote at Hirstwood Training for successful multi sensory room design are:

- creation of an exciting, innovative, multi sensory studio/room, which may incorporate a more traditional environment
- the development of a set of 'tools', which offer the practitioner an opportunity to engineer new learning experiences based on the learning styles of the children
- equipment which is easy to control and operate by the practitioner
- a space which enables easy access to curriculum - at any level
- a space to achieve simple control of sensory experiences - by pupil and staff alike

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Surprised by joy: the Westminster Abbey Story

A tribute to Penny Lacey

Keith Park

Sometime early in 2007 I met Penny in London at a conference. She asked what I was working on, so I told her that I had been doing a cycle of stories on Bible Stories in Cockney Rhyming Slang. We both laughed. I said to her, jokingly: 'Well if we can do Shakespeare on stage at Shakespeare's Globe Theatre, maybe we can do Bible Stories in Cockney Rhyming Slang at Westminster Abbey.'

We both laughed again, and then Penny said 'Well, come to think of it, there might be a way, leave it with me, I'll make enquiries.' She did, she waved her magic wand and the Westminster Abbey Story began. In November I received an invitation to bring some children and young people with severe and profound learning disabilities into Westminster Abbey to perform some Bible Stories in Cockney Rhyming Slang, in January 2008.

I had written a series of Bible Stories in a variety of styles, memorably described by one of the teachers there on that first day as stories that ranged from 'the rather quirky, to the rather surreal, to the completely bonkers.' Excellent! I was intrigued. The rather quirky was: 'The Prodigal Son of Peckham Market' done in the style of Del -Boy from the BBC comedy series 'Only Fools And Horses.' When the prodigal son returns, the father says: 'Let's celebrate!/Loads of bubbly/And vin rouge/Lovely jubbly!/Roast potatoes/Fatted calf/Mange tout Rodney!/Cor not 'arf! The rather surreal: 'David and Goliath' done in the style of football chants: 'We are the Philistines!/Israelite losers!/You get up my fireman's 'ose (hose, ie, nose)/Oi you dirtbag!/You want a piece of this!/Come and get it if you think you're hard enough/Oi Oi Oi! The completely bonkers: 'Samson and Delilah' in the style of 'Carry On' films, with Barbara Windsor as Delilah: 'Yoo hoo Samson/Mr Triceps/Where did you get those/Bulging biceps?/Let's have a feel/Oooh wow!/How did you get/So well endowed?' When I repeated all this to Penny, she laughed and said, 'well yes...but the Samson and Delilah one isn't completely bonkers.'

Since that first incredible day, we have been invited to perform Bible Stories in Cockney Rhyming Slang: in The Nave in January and in The Abbey Gardens in July.

And so here are some of the sparks from Penny's magic wand, to show how much she gave to so many. PJ Pilcher, a former student at Charlton Park Academy,

was in the first group to visit Westminster Abbey and soon after that first visit, he gave me the following story that he had written himself, and asked me if it would be 'alright' to perform it at Westminster Abbey. I showed his story to the staff at the Abbey and they invited him to perform it solo at our next visit. He did so, aged 14, with total confidence, in front of about 200 people, to huge applause. Here it is:

The Creation Of The Baby's Birth, in the style of town criers.

Hear ye! Hear ye!
God's creation!
Spread this story
Across the nation!

In the beginning
It was dark
Rushing fishermans (fishermans-fisherman's daughter-water)
Not a spark
Then God said
'Let there be light'
Gordon Bennett!
What a sight!

Hear ye! Hear ye!
God's creation
Spread this story
Across the nation!

That same day
God wanted trees
Flowers and plants
For all to see
Some grew grub
The plants God made
Have a butchers (butchers-butchers hook-look)
They're nicely made

Hear ye! Hear ye!
God's creation!
Spread this story
Across the nation!

Fourth day
And not too soon
God created
Sun and moon
God then created
Chocolate bars (stars)
And spread them around
From Earth to Mars

Hear ye! Hear ye!
God's creation!
Spread this story!
Across the nation!

Fifth day God made
The fishes and birds
For sea and sky
Everyone's heard
Sixth day God made
Animals
And Adam and Eve
He made them all

Hear ye! Hear ye!
God's creation!
Spread this story
Across the nation!

Seventh day
God made the rest
His work was done
It was his best
The Baby's Birth (Baby's Birth-Earth)
Hip Hip Hooray
God made the Sabbath
A special day

Hear ye! Hear ye!
God's creation!
Spread this story
Across the nation!

HALLELUJAH!!!

This is from Tony and Allison Pilcher, PJ's mum and dad:
'PJ always comes home from his performances at Westminster Abbey buzzing! He loves to perform, and as parents it's a great joy to see him perform in such an iconic place. For us and PJ one of the greatest things is seeing the audience reactions. People go to visit the Abbey to look round and end up getting drawn into a call and response cockney rhyming slang bible story! It's

fantastic to see the smiles on the faces of the audience and hear the wonderful comments they make about how much they enjoyed the performance and also how unexpected it was.'

One of my favourite stories is about the time that the group from Stephen Hawking School came to the Abbey. A week before the event, the local authority contacted the school and said that, contrary to their previous promise, there were no buses to take the children to the Abbey on the day of the performance. One of the governors was a taxi driver. He offered to phone his colleagues and 'get them there.' So on the morning of the event, a fleet of black taxi cabs drew up outside the Abbey, and a very large group of children, staff and parents disembarked.

Stephen Hawking School is in Tower Hamlets, London, a community where many people are Muslim, and so on that morning in the Abbey there were many women wearing headscarves. The Westminster Abbey staff watched them all come in and then excitedly said: 'A multi-faith event! Wonderful!'

Diego Navarro, now at Linden Lodge School, writes: Keith Park introduced my class to his refreshing nonsense world of what we could call music for the senses, and invited us to join the cockney chants at Westminster Abbey.

It was a cold February morning and when we went in, the Abbey felt like a freezer. There were at least 100 other students with special needs teachers and assistants from other schools at the heart of the place in a circle, chanting, signing, dancing, being allowed to express themselves in any form while listening to new versions of verses from the Old Testament... in cockney! Of course tourists eventually started to join the group and I am not sure what they thought of us. But one thing I know for sure: whatever they thought, for once, it did not matter. This was our moment. We could understand what was happening. And it did not matter where we were... We all were one. And it felt warm. (Talk about inclusion!)

Since then, we have embraced the philosophy behind the call and response approach to teaching and are grateful that it was accessible to us. Thank you, Penny Lacey, because you had the vision and the courage to challenge the educational system and start a ripple that, at least for some people with the more challenging needs, meant a life worth living. It is now our job to continue your work.

Michelle Lee, from QEII school in Westminster, writes: Westminster Abbey is not a place that most of our students can normally access. It was a privilege to see their looks of wonder as they experienced the twinkle of the sunlight through the stained glass windows, the hum

of people around them, and the smells of the garden. This, coupled with the smiles of pleasure as they heard 200 or more people shouting their names, made it an emotional and memorable experience that many of us will not soon forget. The staff had a superb time rebelling against Abbey protocol shouting their lungs out, in addition to learning about different ways to present difficult concepts to our learners in an engaging and meaningful way.

In July 2014, Priory School's band, Rock Penguins, opened the massive session in the Abbey Gardens. Maria Carrasco-Galdo writes:

"Rock Penguins were invited to play an acoustic gig as part of one of the performances of Bible Stories in Cockney Rhyming Slang at Westminster Abbey in the summer of 2014. The excitement and the thrill of going to such a historic London site for this event are difficult to explain, the fact that Rock Penguins would play there was almost surrealistic.

We had to dodge the tourists, carrying our instruments and, as all the different schools were gathering together, complicit looks and smiles were shared. Rock Penguins were out of their comfort zone but made themselves proud by singing their own songs to over 250 people. The interactive call and response approach works wherever you are and it is highly successful in my school, but what happens at Westminster Abbey takes it to a completely different level.

The quality of the social interaction mixed with the historic surroundings is something I will never forget and I guess neither will the tourists who were lucky to witness it. It is one of the most valuable social events for the community of people with learning difficulties that I have been part of."

Lana Bond and her group of students, from The Bridge School in London, were at the July 2014 event in the Abbey Gardens. She writes:

As a class teacher to a group of secondary aged students with PMLD I am always excited by appropriate trips for the class but there is something truly magical about our visits to Westminster Abbey for the Bible Stories in Cockney Rhyming Slang. Upon arrival the sight of the grand building immediately overwhelms you. To get to the session the group must walk past a beautiful gated garden, a small cloister and through the paved darkened corridors. All the sensory information tells the students they are somewhere new and special and the anticipation builds. The group walk out on to the green and are met by staff and students from other schools. The atmosphere is light-hearted and fun with all the schools coming together.

These rare opportunities for our students are greatly cherished and all who attend know they are taking part in

something unique. On our last visit to Westminster Abbey a member of staff commented 'Isn't it remarkable to see our students and all the others being celebrated for all that they are.'

Les Staves writes

Penny's spirit is the spirit of humanity. It is still with us, and will remain in the ongoing influence of her achievements, and what she inspired in us. She always strove to open minds.

For our special children she knew the reality of the barriers that their conditions presented. She was a force in the eroding of inhibitions of medical models that saw only disability. She was truly an educationist and taught us to seek to find ABILITY and nurture it. There was an underlying humour in this lady from the university. Who else could have humanised the dry processes of 'target setting' as she did with the subversive idea of 'scruffy targets.'

She sought to encourage us to give our children great experiences and see them blossom. It was her mission to overcome barriers by gentle means. Her influence was contributory in enabling Keith Park to grasp the opportunity for our special children to participate in performing the Bible stories in the awesome environment of Westminster Abbey. Awesome is the right word, for in that place words soar with the sounds and echoes, creating an experience where sensory meets spirit. But when the humour she loved in Keith's work also comes into play, spirituality overflows into joy.

It's been my privilege to participate with those people: children, parents, teachers and just passers-by, my privilege to hear them chant and raise their hands together. One of the songs we chanted included the words:

'Love is the key
But where is the door?'

The work of Penny Lacey helped many people turn the lock and open the door.

Here is a tribute from Elizabeth Parker, Head of Education at Westminster Abbey. She writes:

Twice a year for the last seven years the Abbey has hosted a very special event: Bible Stories in Cockney Rhyming Slang. Whether in the Nave in January or in College Garden in summer, Abbey staff, volunteers and visitors have been blessed by the energy and enthusiasm of the hundreds of young people who have come with Keith to share Bible stories. It is the highlight of the year for Education volunteers and staff alike!

“This was our moment. It did not matter where we were... we all were one. And it felt warm.”

The rhythms are infectious and the calls and responses challenge us all to shed our inhibitions and be surprised by joy. More than one visitor had a tear in the eye this week. Thank you Penny and all the young people who show us the way.

And finally, a special word of thanks is due to everyone at Westminster Abbey. On the morning of January 15th, as we were all gathering at the Abbey, I mentioned to Elisabeth that Penny had so recently passed away. She

and her colleagues offered to dedicate the performance to her memory. So, in the peaceful silence that followed the 11 o'clock prayer it was announced to everyone in Westminster Abbey that our performance of Bible Stories in Cockney Rhyming Slang was dedicated to the memory of Penny Lacey.

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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 will increase the cost of subscriptions to PMLD LINK in order to cover these increased costs. From January 2015 UK Subscriptions will be £20.00 for individuals and £30 for institutions and organisations. Overseas subscribers will pay £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 journal 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 reduced rate. We recognise that subscribers may still wish to have a printed version of the journal but some subscribers have suggested that they would prefer to have an e-copy as an alternative. 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 the 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:

Winter 2014 Innovations
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



Greg's Day out at BT Murrayfield Stadium!

Julie Taylor

The celebration of the opening of the 100th Scottish Changing Places toilet at BT Murrayfield Stadium, Edinburgh provided Greg with a wonderful new environmental experience!

Greg is 15 and has a very rare genetic condition called Aicardi Goutieres Syndrome. His parents Carol and Victor are determined that Greg enjoys life to the full but in order for Greg to enjoy a day out, away from his normal routine of school and home, there needs to be a comprehensive network of Changing Places toilets in the community.

PAMIS as the founding organisation of the Changing Places Consortium (www.changing-places.org) has recognised the need for these facilities since 1999 and has been working with the other members of the consortium, including Mencap, the Centre for Accessible Environments, CAE and the Scottish Government to increase the numbers of Changing Places toilets across the UK.

The publication by the government of The Keys to Life, the Scottish learning disability strategy in 2013, is a

powerful endorsement of the Consortium's campaign. The strategy recommended the formation of a Changing Places sub group led by PAMIS, which had the specific target of reaching 100 Changing Places toilets by June 2015. The success of this group was highlighted in December 2014 when we were able to celebrate the opening of the 100th Scottish Changing Place toilet at BT Murrayfield stadium well ahead of the time scale set by the Scottish Government.

Carol, Greg's mum, is a member of the Changing Places sub group and together they gave a moving presentation in the prestigious Presidents Suite at the opening celebrations. The day's activities had started with a warm up session with the Trust Rugby International team, and were rounded off with a very professional and moving dance display from Indepen-dance, an inclusive dance company, with dancers donned in their Scottish kilts. Mark MacDonald, MSP, a zealous advocate of the

need for fully accessible toilets, cut the opening ribbon prior to a photo shoot on the hallowed stadium turf in a swirling Scottish December wind! For Greg the installation of a fully accessible toilet made this outing a reality and I am sure that, together with the invited audience, the experience was one we all will never forget!

This of course would all not have been possible without the recognition by BT Murrayfield and Ian Rankin, the Scottish Rugby Union President, of the need for these facilities in order for the stadium to be fully accessible and enjoyed by all.

Carol now has another challenge for 2015, she is hoping to take Greg to a Fleetwood Mac concert in June at the Hydro in Glasgow - however the Hydro has no fully

accessible toilet facilities, despite it being the second largest music venue in the UK. Watch this space..... Carol is on the case!

Contact details

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References

Scottish Government (2013) The Keys to Life: Improving Quality of Life for People with Learning Disabilities. Edinburgh: Scottish Government.

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Is your subscription to PMLD LINK for yourself and do you pay tax? If this is so and if you sign a gift aid form, then PMLD LINK can get an extra 25p for every £1 you pay to us for your subscription, in a tax refund from the government. This will help PMLD LINK significantly.

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Many thanks for your support.

And one thing led to another...

The rather inspired idea of using Changing Places toilets as a springboard for finding out about different environments was emailed around the PMLD LINK editorial group and offers for England and Scotland articles were quickly put forward. This gave the editors Northern Ireland and Wales to explore and we were fortunate as both venues approached responded immediately.

Our community hub in Northern Ireland

From Northern Ireland Catherine Magennis writes our inclusive community hub in Northern Ireland In June 2006 Craigavon Borough Council commissioned an Options Appraisal of three existing community centres in the Brownlow area, Co. Armagh. After a period of public consultations, the Options Appraisal was finalised in May 2008, with Craigavon Borough Council (CBC) committing full costs for the building of a new project. The Architect and Design Team were appointed with the task of “building a Community Hub on a centrally located site which is perceived safe and neutral by all citizens in the area ...”

Brownlow Community Hub in Craigavon, opened in September 2011 and is situated within the heart of Brownlow and wider Craigavon area. It provides a vibrant, friendly and modern meeting place for a wide range of groups and users. The “Hub” (as it is known in the area) offers a diverse range of rooms including a large Main Hall, meeting rooms, training and craft room, dance studio and childcare space.

The Hub also boasts a fantastic “Changing Places Facility”. Changing Places Facilities are different from standard accessible toilets, with extra features and more space to meet the needs of people with profound and multiple learning disabilities. It is a larger room which provides the correct equipment i.e. enough space for the person with the disability and up to two carers, a centrally located toilet with room for carers, a height adjustable adult sized changing bench and shower, a ceiling track hoist which covers the whole room, large waste bin, full length mirror and assistance alarm. This facility helps all people to enjoy and take part in activities that many of us take for granted.

Added to this, staff have received Disability Awareness, Customer Care and First Aid training so that Brownlow Community Hub is able to offer a facility where all members of the community, regardless of ability, can avail of the excellent facilities. Staff have also had the privilege of liaising with local disability groups in order to be able to provide the most efficient community space that we could, and that includes a built in loop hearing system. Because of all this we have been able to accommodate a number of people and organisations that

otherwise wouldn't have been able to book our rooms. For example every year there is a two-week Summer Scheme which caters for young people from the Craigavon Borough with varying abilities.

As well as Hub customers being able to use the Changing Places room every week, we have successfully registered the Changing Places Facility with Adapt NI, which means that we can promote the facility in such a way that as many people and groups as possible can use the services whether or not they wish to book our rooms. For example, an organisation contacted us to ask about using the facility for members of their group whilst they were in the local area on a day trip and we were delighted to be able to fulfil their wishes.

From Wales Kate Hannington told us:

Swansea Bay – Accessible to all

S360 Beach and Watersports is a hub for sport and activity situated in the heart of Swansea Bay. It's a multi-sport facility with an on-site Cafe Bar offering spectacular views out over the beach and being operated by a not for profit company, the profits generated by the Cafe Bar and events, can be re-invested back into the business to offer free or reduced rate sports and activities.

The building and its layout have been designed to allow easy access and manoeuvrability for all, with all the facilities on the ground floor with no steps or lifts. It is also the only beach side location in Wales that has a Changing Places facility. With a 12m² floor space the facility provides extra features and more space than regular accessible toilets, which enables the needs of both users and carers to be met. It includes a full room cover automatic tracked hoist system, an adult sized height adjustable showering / changing bench and a separate shower unit, a toilet, large power-assisted height-adjustable washbasin, safety alarm and retractable privacy curtain, along with all the extras you would expect in a facility of this type. The hoist is suitable for use with a hook and loop system but users do need to bring their own sling. It's clearly signed on the exterior of the building and is available for use during the 360 opening hours, which ensures that it's always a safe and clean environment.

Has anyone with profound and multiple learning difficulties used it I asked? Whilst the facility is used on a relatively regular basis, we are trying to raise the profile to ensure more people will benefit from all that is on offer both at 360 and Swansea Bay. We have had wheelchair users here for an afternoon of kite flying and we have two Landeez wheelchairs that are designed to be used on the beach. Bikeability also loan us their specialist bikes.

Kate had intrigued us by mentioning BikeAbility Wales and so we went on to explore what they offered and this is what Mike Cherry sent us:



BikeAbility Wales 10th Anniversary 2004-2014

Laura Bolton (formerly Lockwood) worked as a Sustrans assistant in David Judd's Environment Centre office, helping to develop cycle routes across South West Wales. On a work camp in Pembrokeshire they met a lady with her son who was blind and, since there was a tandem available, which had been donated to Wheelrights, they took it for him to try out. It was a truly inspirational introduction and it set Laura on a mission.

Laura realised that there was a total lack of cycling facilities for people with disabilities across South West Wales so, in her own time, she looked into schemes developed by Wheels for All, England and Pedal Power, Cardiff, two organisations which provide all ability cycling opportunities. Jointly with Wheelrights Laura acquired a shipping container and, with a selection of second hand tricycles and a couple of specialist cycles, set up at the very accommodating Ramada Jarvis Hotel (now Mercure) on land alongside their car park in Llansamlet, Swansea and so BikeAbility Wales was born.

Our slogan has always been 'Everyone Rides' and over the last ten years we have enabled people from two to ninety two years old to ride on a cycle. Whether they are confined to a wheelchair or fit and able there is a cycle that they can use and skills they can develop.

In the autumn of 2008 it was clear to Laura that the project needed to develop further so she registered BikeAbility Wales as a charity and we moved to Dunvant Rugby Football Club in Killay where we had more

opportunity to expand and link to the National Cycle Network in Clyne Valley. Laura also wrote a number of successful funding bids which enabled BikeAbility Wales to develop outreach work and to purchase a range of specialist cycles, she forged links with Pembrokeshire and Carmarthenshire councils and assisted Neath Port Talbot council in the setting up of their Intandem all ability cycle project .

Sadly in the spring of 2009 Laura died unexpectedly. However, she had created an organisation with a solid board of trustees and established links with a wide range of clients, schools, groups and organisations across South West Wales, so after an initial wobble the organisation has carried on developing.

Today the organisation has over 80 cycles, ranging from wheelchair transporter cycles, hand cycles and tricycles to recumbents, kick bikes and various children's bicycles. Last year we had over seven thousand visits from schools, day centres, youth groups, ethnic minority groups and individual members of the public.

Ten years ago Laura had a vision to develop a Swansea cycle facility and to roll out opportunities for people of all abilities to cycle across the region. We are still striving to make this vision a reality through the Swansea Cycling Facility Group, made up of local cycle clubs, the council and the University based WeCycle project. On a national scale, BikeAbility Wales is a partner in the Wales Inclusive Cycle Forum which promotes all ability cycling across Wales.

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The websites for the organisations Mike has mentioned, Wheels for All, England and Pedal Power, Cardiff, appear on our list of Useful Websites

Having wheels means having fun *and* learning; developmental achievements can occur as a consequence of mobility

Julie Tilbury

It is through motor skills that children learn about the world and become initiators and active participants rather than passive recipients of experience (Kermoian 1998). But if movement is so important, how do we support those pupils with mobility problems to do this?

Some children are able to use walkers or adapted trikes to begin experiencing self-initiated movement, but for others this isn't physically possible and in many schools pupils with PMLD who have mobility problems aren't able to experience any self-initiated movement. This suggests that our pupils who cannot move are at a great risk of becoming passive and developing what Seligman (1975) called learned helplessness. Powered mobility for these students is often only considered if the likely outcome is that they will become independent drivers and is not considered for the development of engagement and participation on their own. Furumasa (2004) argues that children need to have reached a level of cognitive ability, or have acquired a set of prerequisite skills, to access powered mobility. However, (Hardy 2004) argues that developmental achievements can occur as a consequence of mobility.

As teachers of young people with profound and multiple learning difficulties we spend a great deal of time and effort encouraging participation and supporting the development of contingency awareness. Could this be another tool we could use to develop these skills? I decided to look at the effect of powered mobility on the engagement and development of contingency awareness of three of my students.

I borrowed two powered chairs from the Occupational Therapy Department and a third was an old reconditioned chair that one of the engineering team set up for us. I also purchased four large Smoothy switches. I ensured that all the class team were confident putting the children into the powered chairs and that the set up was the same for each child each time. Driving profiles were produced by the class team and the OT's and were included in the training and added to the children's profiles. It was important to ensure that the switches were removed from the child's tray before the powered chair was switched off so that accidental pressing of a switch with no result did not occur, as this could cause an unlearning of contingency awareness (or non-contingency awareness). A timetable was set up to

ensure that powered driving happened on a regular basis throughout the week.

Engagement profiles were written before the study period during activities which elicited both high and low levels of engagement for three of the children, in order to gauge high and low engagement. Then levels of engagement were noted at the beginning of the powered driving sessions and at the end of the six weeks of intense driving sessions.

Freddie* is a six year old boy with severe cerebral palsy, dystonia and a severe form of epilepsy which manifests with seizures approximately 90% of the time. He is not able to walk, sit unaided, talk or use his hands. He benefits (is more engaged) from being supported to be as physically active as possible. Every morning he has stretches and is encouraged to balance when cross legged sitting. Every day he walks in an adapted walker and rides his adapted bike and this continued during the course of the study. He shows high engagement when being physically active.

As Freddie became familiar with the routine of going into the powered chair and moving it, observations showed he became quicker at engaging with the activity. In the first session it quickly became evident that he thoroughly disliked going around in circles or 'twirling' as the occupational therapists described it and would refuse to engage with the activity if this happened. In one instance, a well-meaning adult tried to help him to keep his hand on the switch when going in a circle and he pulled his hand away. We decided to try moving forwards and he settled into it quickly. In the second session he held the switch down and moved 10 metres. After a few weeks of regular sessions going forwards, Freddie began to vocalise quite loudly when the switches were removed and on one occasion when his mum was watching she suggested that he had the 'right hump' with me for stopping the activity and removing it!

Freddie showed a consistent increase in the number of

times he accessed the switch throughout the study and appeared to quickly show his liking for the activity. What was also interesting was that when he heard a voice he was familiar with and they were a short distance away he would activate the switch and although we can only suggest that he was moving towards that person to engage with them, he did do this on many occasions. The TA he was particularly fond of began describing it as 'following her'. She said she felt very proud of him and gave him lots of praise, this reinforced the positive nature of the experience for both of them.

During the period of the study Freddie's engagement in other switch activities has also appeared to improve, perhaps suggesting that he had further developed his understanding of contingency awareness.

Amy* is a six year old girl who contracted congenital toxoplasmosis resulting in severe physical disability, diabetes, epilepsy and she is registered blind. We initially had problems enabling Amy to access the switch, as she also has problems regulating her temperature and therefore needs to be kept warm using thermal clothes, layers and blankets. This makes it difficult for her to move her arms and touch things with her hands. She seems to find this frustrating and can be seen moving her hands under the blankets and becoming stressed under hats and gloves. Despite all the obstacles Amy has a determination to reach out for things and explore them. Unlike Freddie she enjoys moving the powered chair in a circle and seemed to enjoy the speed being turned up. We felt during our observations that her movements were more deliberate than Freddie's. She would repeatedly move her hand, find the switch and apply pressure.

At the beginning of the study Amy was having medicine which sedated her, therefore, although her scores went up significantly this does not give a true reflection of what happened. By the end of the study Amy smiled during the activity and one of the observers described her as being 'very determined to find the switch'. When 'twirling' Amy would hold the switch for up to 30 seconds, release the switch and appear to relax.

Nelson (not his real name) is a seven year old boy with severe cerebral palsy and a severe visual impairment. He has some control over his arm movements and understands cause and effect. Nelson is an enthusiastic little boy who also loves his walker. He was given two switches, one would move him left and the other went forward. The observations made by the teaching assistants involved in the study included the fact that he activated the switches without prompting on several occasions and comments made after the activity showed that several people who had been watching him had become quite emotional, as they were so impressed with

what he was achieving. By the end of the study Nelson was activating the two switches with both hands with no prompting and attending to the results of his actions. On one occasion the powered chair stopped working and he vocalised impatiently, which possibly supports the view that children with severe disabilities are sensitive to cause and effect relationships (O'Brien 1994).

Since he has been using his walker and the powered chair he has become extremely vocal in class and, although this is anecdotal evidence, it perhaps suggests that movement is having a positive effect on him. Something for a future study perhaps?

Advances in developmental psychology have suggested that the domains of child development (motor, cognitive, language, emotional and social), previously thought of as separate and distinct, are closely intertwined and an acquisition in one domain can have a positive impact on others. Equally, restriction within a domain can negatively impact on others (Bertenthal et al 1984).

When we reflected on the results as a team, we were surprised how much of an impact the observations seemed to show. We were even more surprised when I analysed the results and compared the two sets of data. All three children had made significant gains. Amy's results may be an anomaly due to the impact of the medicines she was taking during the first part of the study making her initial score lower than it would normally have been. It may be prudent to repeat the exercise with Amy. However, the other two subjects made significant gains and Freddie almost doubled how much he was engaged in the activity.

A paradigm shift amongst the adults involved in the set up and observations during the study was also significant and cannot be overlooked. The power of achievement amongst the children to change adults' preconceived ideas of what our children are capable of cannot be underestimated. The excitement in the class was infectious and palpable and when I overheard one of the team telling another staff member about contingency awareness and how important it is that the children we work with have control over as much of their lives as possible, I felt we had really achieved something.

Due to the tiny numbers and limited scope of this study, it is difficult to draw conclusions. However, quantitative data gathered suggests that increased opportunities for self-initiated movement have had a positive effect on the engagement within the activity of at least two of the subjects of the study. Motor skills enable children to learn about the world and their impact on it. When these are limited all areas of a child's experience and development are affected. I believe that an important part of my job is to enable pupils in my class to become

initiators and active participants rather than passive recipients. It promotes development in all kinds of interconnected areas, encouraging self-awareness and enabling them to begin to experience and begin to understand the impact they have on their environment.

The argument for powered mobility to be more than a functional skill is an interesting one and deserving of more research. There are quite obvious practical and financial implications of providing powered mobility to the most complex students. Many of the bodies who provide money for powered chairs will only do so if a child has the potential to become an independent driver (Kuhn 2007). Many schools/parents will not be able to afford powered mobility. However if, we can support children to have more control and become more proactive, they will be more motivated to take control and this could have a profound impact on their cognitive development.

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Winter Issue ~ Innovations

Apology

The members of the editorial board would like to apologise to both Liz Platt and Julie Tilbury for our error in the Winter 2014 issue of the journal.

We wish to make the following correction;

The article, *Powered Mobility for Young People with PMLD*, was written by Liz Platt who is a teacher at the Chailey Heritage School, email lplatt@chf.org.uk, and not July Tilbury, as printed originally in this edition.

Please accept our sincere apologies.



Jim , Pete, their mum and the Virgin airlines accessibility manager outside the mock-up aeroplane.

When flying becomes a reality

Jill Davies

As this edition of PMLD Link is published, many of us will be thinking about our summer holidays. We all like to plan ahead for our holidays, but for those with physical impairments, holidays that involve flying can seem like an impossible dream.

A little while ago I had the pleasure of accompanying two teenagers and their mum at the Virgin Atlantic Airways base near Gatwick airport. The trip was planned because they had concerns about how they would be able to fly now that they were growing into young men and can no longer be carried by their mum and dad on to the aeroplane. The boys both have mobility impairments and one of them is unable to support his upper body. They were thinking ahead to when they were older and how can future personal assistants help them as wheelchairs cannot be used on aeroplanes. We spent two hours in a built to size mock-up aeroplane with the airline's Passenger Accessibility Manager who

showed, demonstrated and let us try out the travel systems available. Then one of the young men who is able to manoeuvre himself, tried out the wheelchair used by Virgin Atlantic that can fit through the aisles, while his brother who cannot support his upper body was positioned in the aeroplane seat by a Burnett Body System and a Crelling harness. We found out that children also have use of a Meru chair and, in some cases, the wheelchair frame can be used on top of the seat (this wasn't an option for us as the seat was tilted too far forward). We also learned really useful information about when to contact airlines about the needs of the person (as soon as possible) and that is it

essential to make contact with the airport special assistance team as soon as you reach the airport because they have 'service providers' who assist with lifting and handling people and equipment on board.

The young men and their mother left with much more confidence knowing that their dream of flying is now a reality with the knowledge of what equipment and support airlines and airports can offer passengers with disabilities. The family are about to fly to New York this year and perhaps in a future edition we will hear about their experiences. We also learned how motivated and enthusiastic some airlines (big thanks to Virgin Atlantic) are in making sure everyone has the chance to fly and do those ordinary things we all take for granted.



This is Jim trying out the Burnett body system and Crelling harness

Top tips for flying

Below are a few handy tips on planning a flight for people with limited mobility:

- Taking your wheelchair on the plane

You can't take your own wheelchair into the passenger cabin of a plane. It will be stored in the hold of the plane. Speak to your airline to find out what help they'll provide when boarding the plane.

- Travel systems

The Burnett Body Support is a large cushion filled with polystyrene beads designed to offer adapted seating support. A pump is attached and the air evacuated, enabling the cushion to mould perfectly to the shape of the person seated in it, offering comfort and support where it is most needed. When air is reintroduced, the cushion returns to its natural shape once again.

The Crelling harness 'model 27' is approved for aircraft use. It is a full 5 point harness designed to offer additional support in single seats and aircraft seats. Three sizes are available depending on the age of the passenger.

MERU travel chairs are postural seat inserts which support children who cannot sit independently.

Try b4u fly, <http://tryb4ufly.co.uk/>, is a service that provides adults and children with the unique opportunity to trial specially designed aircraft seating support for children, young people and adults with disabilities for use on airlines. They also have a hire service so people can practise using the equipment ahead of the flight.

- Your rights

Under European law, people with disabilities and other people with reduced mobility have legal rights to help when travelling by air. There is detailed information about this on the Equality and Human Rights Commission (EHRC) website.

Further information

The Foundation for People with Learning Disabilities has produced a factsheet packed with handy tips on planning a flight for people with limited mobility, see: <http://www.learningdisabilities.org.uk/content/assets/pdf/resources/flying-factsheet.pdf>

The equality human rights services has produced a booklet called 'Your passport to a smooth journey', see: www.equalityhumanrights.com/airtravel

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Please take me outside

Coryn Memory

Currently I work for a charity called Connect, setting up user led peer support groups for people with long term health conditions, undertake supply work in a local special school and provide Intensive Interaction training. Until last summer, however, I was a teaching assistant and Eco Coordinator at St Rose's School in Gloucestershire.

This is a fantastic school for children and young people with complex disabilities and medical needs, and it was during my time there that I was often stunned to see the effect that being outside had on our pupils with PMLD. Students struggling with sensory overload would calm, the bored or sleepy would revive, the sullen would laugh and the tactile defensive would reach out to touch a flower or tree. I worked with one young boy on the autistic spectrum who became a different child when I took him on our "Wednesday Walks". We had a routine of going to see, hear, smell and feel the small but noisy waterfall in the local park and then he would climb the hill and do various rolls and runs down it, invariably getting muddy hands. We would feel the giant cedar trees and smell whatever plants were around and in this way he practised coping strategies for his hypersensitive hearing – the noisy waterfall, and his tactile defensiveness - muddy hands and tree bark. His proprioception and balance also improved with running and rolling down hills and playing wheelbarrows.

The day that was something of an epiphany for me was a spring morning when he had been taken out of Mass at school because he was getting too stressed. I took him to the woods in the park where the Ransome (wild garlic) was growing in abundance. I thought the sight and smell may overwhelm him, but no, this is what this hypersensitive, hyperactive, tactile defensive six year old on the autistic spectrum did; he took my hand, got me to lie down with him on the carpet of wild garlic and ran his hand through the flowers and smelt them as we both lay gazing up at the shafts of sunlight flickering through the branches and watching butterflies dancing around us - pure magic!

It is times like this that have convinced me that nature is by far the best resource we have for people with PMLD and indeed autism and many other conditions. Modern technology, sensory rooms etc. are great and have their uses, but the following poem is a look at how we can use nature to help people with PMLD every day of their lives.

Take Me Outside

Turn off the flashing coloured lights,
Take me outside to see the sights
Of sunlight playing through the trees
And branches dancing in the breeze.

Turn off the ultra violet light
I know you want to help my sight,
Just take me out to night time skies
Stars will work magic on my eyes.

We've heard that whale CD all year,
Take me outside and let me hear
The babbling stream down in the park
The birds, the bees all leave their mark.

Turn off the toys that buzz and ring
My ears love to hear nature sing.
Bonfires crackle, hiss, bang and pop
Nature's teaching just doesn't stop.

Please turn off the vibrating bed
Take me outside to rest my head
Upon the bark, the grass, the Earth
Within these things there's much more worth.

I don't need a "sensory wall"
To feel the spray from a waterfall
Or crunch the leaves up with my hand
And get the feel of warm, wet sand.

Take me outside, let me just be.
Take me outside to feel and see.
Take me outside and we can share
All of Earth's beauty, if you dare.

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Negotiating the World: People with PMLD in the Past

Simon Jarrett

The subject of people with profound and multiple learning disabilities in the past has always been an elusive one. Did they survive into adulthood? If they survived, what sort of lives did they lead? How were they seen by others? How did they manage the environment of the pre-modern world?

It can seem very difficult to answer these questions about such a marginal group, who leave no written record and occupy a place on the very fringes of society. This absence of evidence has led some to speculate that babies with multiple disabilities were allowed to die at birth, either because in the absence of modern medicine they could not survive or, because of poverty or superstition, people did not want them to live. Yet sometimes we do not look hard enough at what is in front of us. There is a small amount of evidence that suggests such people did live into adulthood and were supported by those around them. Two court cases in particular, one from the sixteenth and one from the eighteenth century, offer us a tantalising window onto the lives of people with profound disabilities in the past.

During the reign of Elizabeth I (1558-1603) a gentleman called Henry Bushley left his lands to his son, also called Henry. Young Henry was, in the harsh language of the times, 'a monstrous and deformed cripple.' As he grew up it became clear that he was also 'an idiot'. Responsibility for Henry's education and protection were handed over to a guardian. After Henry's father died and he inherited land and property, things started to go wrong. A group of men took him away from the care of his guardian. The records say, he 'was carried upon men's shoulders to a place unknown and there kept in secret'. He was later carried in front of a judge, where he acknowledged – possibly by gestures in answer to questions - that he wanted to sign all his lands over to one of the group, a man called Botham. The judge allowed the transfer. Botham then sold them on to a farmer, for personal gain.

Shortly after this Henry was taken before the Court of Wards, a special court established by Henry VIII, which determined whether a person was an 'idiot or lunatic' and if so, took responsibility for their care but also took possession of their lands. Determining that Henry was an 'idiot' they issued an order for the return of his lands, because by law, as an idiot, he had no capacity to sign them over to anyone else. This is what happened next:

'to try to determine this case the said deformed idiot was sent out of the Court of Wards, to be shown to the Judges of the Common Pleas and to the jurors. And being brought upon a man's shoulders the judges, when they heard that the judge who took the fine [the transfer of the lands] was never worthy to take an action but notwithstanding this, and altho' the monstrous deformity and Idiocy of Bushley was apparent and visible, yet the fine stood good.'

This meant that the court agreed that Henry lacked the capacity to transfer his lands and the earlier judge should not have allowed him to do so. He was clearly being exploited by his abductors. However, the court ruled, reluctantly, that once a judge had made such a decision and the transfer of land had been made, it could not be overturned. Henry had lost his lands, and would never get them back.

This case tells us a number of interesting things. We learn that a highly dependent person with multiple disabilities, born into a reasonably wealthy family in the sixteenth century, was accepted and cared for by the family. Henry's father made arrangements for a guardian to care for him after his death and, most importantly, left him his lands and property. He was afforded the same status as any other eldest son was given at the time. Secondly it is clear that a person with this level of impairment was seen as subject to the process of law. He was carried before a judge to gain an order to transfer his lands, he was brought before the Court of Wards to determine whether or not he was an 'idiot' and he was taken from the Court of Wards to the Court of Common Pleas to challenge the earlier decision.

Although the outcome of all this legal process was, in the end, not good for Henry, the very fact that legal process was followed indicates that he was afforded legal respect. Of course what is shocking to us is the fact that he was exploited and all his possessions taken away from him by a group bent on taking advantage of this vulnerable young man. However it is clear that there was

also a group who were in direct opposition to these exploiters, who supported and fought for Henry, and who took the case to court. It was a common feature of the time that anyone seen as vulnerable who came into possession of wealth, not just 'idiots', but also 'lunatics', widows, marriageable girls and orphans could be a target of those who wished to get hold of their inheritance. Modern cases in the Court of Protection – our contemporary successor to the Court of Wards – demonstrate that it was not just a sixteenth-century phenomenon for vulnerable people to be exploited financially.

Finally Henry's case reveals to us how a person with multiple disabilities negotiated the environment of the time. They were, quite literally, 'carried on men's shoulders.' Henry was carried into and out of each of the courts he attended. There were at this time very early forms of wheelchair used by people who did not have the use of their lower limbs. These were hollowed out bowls in which the person sat and then propelled themselves by pushing along with small wooden blocks held in each hand. They were, however, used more in towns and cities than in the countryside, where there were at least passable roads and pavements to enable their use. They also involved the capacity to self-propel which Henry, due to his intellectual as well as physical disabilities, may well not have had. The solution, therefore, was simply to carry him, even as an adult.

A century and a half after Henry Bushley's case we come across another person with multiple disabilities, this time in a trial at London's central criminal court, the Old Bailey. This 1725 trial, in the reign of George I, involved the prosecution of a plasterer called Samuel Street for the rape of seventeen year old Elizabeth 'Betty' Harvison. Betty was in court for the hearing and was described by her mother Rebecca as follows;

'the child, you may see, is a Dwarf, and an Idiot, and what makes the Misfortune the greater, she wants the Use of her Limbs so much, that she is forced to be carried like an infant.'

Like Henry, Betty was clearly carried from place to place. The case was that the mother and some friends had been drinking in an alehouse, accompanied by Betty. They decided to move on elsewhere and left her in the alehouse with the accused, Street. On their return she had gone missing: she was found with Street near a churchyard and when her mother was undressing her for bed, she discovered that 'she was ruin'd, bloody and, by all Circumstances, had been ravish'd.' Street was arrested by the local watchman, with bloodied clothes. After testimony on Betty's behalf from four witnesses and three midwives, the watchman and a surgeon, the jury acquitted him of rape. The judge then immediately

ordered Street's re-arrest on a lesser charge of assault with intent. He was found guilty, fined a substantial twenty marks (roughly sixteen pounds, equivalent to several months labourer's wages) and imprisoned for six months.

In this trial we see how a network, in one of London's poor districts, was formed around the young Betty to care for her. The constant care and attention she needed was given principally by her mother - 'and when we came back ... I undress'd her to put her to Bed' – but also by a network of others. It was a male neighbour who 'carried the Child' when the group went drinking and his wife who searched for and found her when she went missing. The accused Samuel Street, in whose care Betty Harvison had been left with disastrous consequences, was a lodger of the neighbours. It was accepted that Betty would be present at social interactions.

Her strangeness and difference, however, were openly discussed. Another lodger in the neighbour's house was called in specifically to see her, 'she being indeed a sort of strange Sight'. She was reassured by the group around Betty that 'I need not be afraid to look upon her, for her limbs were as straight as mine'.

Betty Harvison experienced love and care but also feelings of fearful curiosity. The amount of legal process and formal intervention in this case, once the accusation of rape had been made against Street, was remarkable. Three midwives examined her. They were meticulous in their investigations; 'I search'd the Child two Days after the Injury. I believe a Man had made use of her... a Man had entered her body about three inches.' We do not know the motivations of the Jury who acquitted Street 'upon the whole' of the rape of Betty Harvison: their use of this phrase suggests they suspected he was guilty but felt it could not be fully proved. However the reaction of the Judge was to order an immediate retrial on a new charge and when Street was found guilty of the assault his punishment was harsh.

This glimpse of eighteenth-century life is revelatory, in that it shows a young woman with multiple disabilities at the heart of a group of London poor, who cared for her and saw her as a part of their lives. Furthermore, when she came to the attention of the judicial system, her humanity and her membership of the community were recognised in a series of decisions and actions by different people, some of whom knew her and some who did not. These included accepting that her violation was rape, seeking justice, arresting the accused, bringing in expert opinion, ordering professional examination, proceeding with a trial, offering testimony on her behalf, ordering a retrial and sentencing harshly once guilt was established. All this took place in her presence as she sat gazing at the proceedings going on around her in the Old

Bailey. Betty was totally dependent on those around her, but her humanity was accepted by them, and she was loved. Her treatment in the trial process, and the thoroughness with which her case was investigated, compares favourably with the enormous difficulties the modern justice system seems to encounter when faced with abuse charges involving people with profound and multiple disabilities.

These two trials show us that people with multiple disabilities did indeed live into adulthood in previous centuries. Despite the language used to describe them, which sounds so harsh to modern ears, they had networks of family and community support, people who loved and cared for them. They were also faced by those who wished to exploit and abuse them, but they did not face them alone. Their parents encountered problems of similar complexity to families today: mobility, vulnerability, care and, of course, what would happen after they died. Like families today they faced up to these problems, fighting tooth and nail for justice and support for their much-loved children.

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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, photographs 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

Spare a thought

Peter Limbrick

I think of my environment as the space around me and all the things and people in it. My environment influences me and I influence my environment. A teacher starting in a new school finds herself in a new environment and the school environment is changed by having her in it. It is the same for a new child in a class - both are changed and gradually settle into a new balance or pattern. Whether we have disabilities or not, when our environment is favourable we can grow, learn, contribute, feel good about ourselves and enjoy life. When we live or work with people with PMLD we do all we can to create and maintain this favourable environment.

Environments can take a sudden downturn and then any one of us can become a victim of our new environment and not a constructive contributor to it. Think of a young girl with mental illness kept in a police cell for a few nights because there is nowhere else, or of a man with learning difficulties doing time in prison miles away from family and friends. It is easy to imagine, if we do not already know from practical experience, that sudden changes in our environment can bring great vulnerability - even threats to life and limb.

When I hear news of an explosion in a market square in Iraq or Syria, I wonder if some of the people caught up in it had a disability and how they coped - if they were not killed, that is. I wonder what it is like to be blind or deaf or wheelchair-bound in a housing estate in Gloucestershire flooded overnight or in a village in Pakistan washed away in heavy rain. Such sudden losses of favourable environments seem to be coming thick and fast because of both human conflict and climate change.

From natural disasters and man-made catastrophes around the world we see victims in their tens or hundreds of thousands. The media offer them up to us in the UK as pitiful humanity but not as individual adults and children. Amongst them must be some people with autism, some with mental illness, some with sensory or physical or learning disability and some with combinations of impairments.

My point is that we never know how many people with disabilities are involved because they are not counted. Because they are not counted they are discounted with little or no thought given to them whether they have had to stay in the disaster area or have ended up in a refugee camp.

In *The Plague*, a novel by Albert Camus, Dr Rieux is trying to explain to a rather cynical acquaintance why, as a doctor, he is working so hard day and night to help plague victims and why very many other townspeople are freely volunteering in sanitary groups. He says, '... there's no question of heroism in all this. It's a matter of common decency. That's an idea which may make some people smile, but the only means of fighting a plague is - common decency.'

When disabled people of any age have their favourable environments snatched from them in wars and extreme weather in any part of the world, common decency suggests we should acknowledge them and count them. While counting, or at least knowing likely incidence, must be the beginning of any work to return each disabled person to the most favourable environment possible, it is also the first step in bringing these very vulnerable children and adults into public consciousness and recognising their plight.

For related information please visit: <http://www.teamaroundthechild.com/war-zone.html>

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Peter Limbrick is an international consultant in disability and author of *Horizontal Teamwork in a Vertical World: Exploring interagency collaboration and people empowerment*, published by Interconnections in 2012.

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Taking Stories into Adult Environments, the Tall Stories Project

Stuart Cummings

As young children, nearly all of us will have had a story read to us at nursery, school or home and thoroughly enjoyed it. Then we begin to be able access stories in a variety of different ways, reading a book or watching a film, and the need for a storyteller to interact with us and hold our attention, becomes less important. As a result, we tend to see storytelling in the traditional sense as something for children, which is not really the case. For example, we still tell each other stories about things that have happened during the day, we pay to listen to comedians regale us with funny made-up stories, and what is watching the news if it is not storytelling?

However for those adults who are unable to read and whose limited language comprehension skills can make following a film or television programme difficult, the most meaningful way of accessing a story is through multi-sensory storytelling. Using short stories and simple short sentences that are repeated, together with various multi-sensory experiences, a story is brought to life in a way that is meaningful, even if the language is not understood.

Two years ago, I went to a London care home to deliver storytelling and training. When I arrived I waited in their

lounge and with me was a young woman with PMLD, who had been left in front of the television, supposedly watching the Olympics. However, what she was actually doing, was sleeping. She had no real concept of what was happening on the screen. What she was seeing was too detailed and busy and she couldn't understand what was being said. There were no sensory cues to bring meaning to what she was seeing and so she had decided that sleeping was more interesting. A few minutes later, I started a multi-sensory storytelling session. She opened her eyes almost immediately and not only joined in fully for the next half hour, but clearly enjoyed herself.



Four weeks later I watched the same lady thoroughly enjoy a storytelling session delivered by one of her carers. The carer had quickly grown to love telling the stories because they realised that they would get responses and reactions from their residents rarely seen before, if at all. They were now seeing sides to the personalities of their residents that they had no idea existed. It was this that made me realise just how big a difference Bag Books' Tall Stories Project could make to the lives of adults with learning disabilities.

Bag Books, established in 1993 to produce multi-sensory books specifically for people with profound and multiple learning disabilities, has always looked to include several adult titles in its range or adapted its existing titles to suit adults. However, whilst Bag Books was also delivering a range of storytelling and training services, these were almost exclusively involving children and not adults. Indeed, other than a regular booking at a residential home in west London, there was very little happening with adult services. This was something the organisation was very keen to change.

When I joined as Director of Services in January 2010, the charity had recently started its Telling Tales Project funded by the Big Lottery Fund, which was training librarians in multi-sensory storytelling. The funding for this was due to last until the summer of 2011 and we were keen to follow it up with another major Lottery-funded project and, seeking to expand our work with adults, decided to look into developing a piece of work that would train staff in various adult services such as day centres and residential homes. We started a pilot project in late 2010, developed it with further tranches of funding over the next couple of years, and in January 2013, began using the Lottery funding that would see us work with seventy-two centres a year for three years.

At each centre or home, we work with two or three trainees - although occasionally they try and squeeze another one in! - over three sessions and in each of these, tell stories to a group of service users. At the first session, our storyteller/trainer delivers the storytelling and then provides a training session which explains how to do it and covers the theory behind multi-sensory storytelling. At the other sessions, the trainees are encouraged to run the storytelling themselves with support from the trainer as required. Before the training begins, each centre is provided with two free multi-sensory books to keep and to use during the training and for practicing between sessions.

From the pilots it was clear that the majority of adult services were unaware of multi-sensory storytelling. One trainee in Newcastle even described it as a "totally new concept". It also became increasingly apparent, just how little funding adult services have compared to children's services. Every centre I approached practically bit my

hand off at the offer of free training and many would check several times that it was free, they were so unused to being offered anything that didn't come at a price and their budgets were clearly very limited.

The initial feedback we received from trainees was excellent with 93% of trainees on our Lottery-funded project in 2013 rating the training as very good, and 7% rating it as good. However, what was perhaps even more impressive, were the results of a follow up survey we carried out at the end of 2013. In the centres that had received the training, all of them said that they had continued with the storytelling, with the vast majority running weekly sessions and some daily. Better still, when asked how many staff were running story sessions, the figure was twice that of the number of staff we had trained, suggesting that the trained staff had passed that training on to others. The following quotes are typical of much of the feedback we have received:

"Very enjoyable experience for myself and also for the listeners who took part. Really inspiring watching the reactions of the listeners. What a great concept of storytelling - would highly recommend." (Trainee – Abbots Wood Day Service, Shropshire)

"I wasn't sure how it would be received by our service users, and was very pleasantly surprised how much they enjoyed each story. I think it is very beneficial and they will get a lot of enjoyment from future sessions." (Trainee – Castle House, Scarborough)

"It was nice to see some of the less interactive service users responding to the Bag Book. It was noticed that they were looking to each other to see their reactions in anticipation. The Bag Book was done with a large group but the story was not lost. The repetitiveness of the story helped them to have a better understanding. Proved very enjoyable and effective for all the people we support." (Observer – Cranmer Day Service, Wolverhampton)

The project has been a huge success. In 2013, 255 adult services staff received training, and 1,593 adults with learning disabilities attended storytelling sessions - not including sessions that trainees ran themselves outside of the project. Incidentally, we do still have some spaces left on the project for next year, though not in London or the South East.

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A Thursday in Sam's Life at School

Julia Barnes

Trying to establish the perspective of learners with complex needs on their school experience is now regarded as best practice but in reality is very difficult to achieve (Ware 2004). This activity leads educational practitioners to abandon some preconceptions – for example, our focus on the academic curriculum - and to consider the sensory, physical and emotional impact of each school day. The snapshots presented here remind us of the unique individuality of each young person and the need to ensure that our educational approach truly does put the learner at the heart of what we do.

Sam is a 14 year old with a strong mischievous personality who with his mum enjoys supporting Leeds Rhinos. He has complex needs, cerebral palsy affecting all four limbs, a shunt in situ, brittle bones, epilepsy, is registered blind but has some vision close up and receives liquids and some nutrition through a gastrostomy. We explored Sam's school experience through participant observation: a volunteer shadowed him throughout one school day, taking 200 photographs from Sam's perspective, using an approach developed by Kaplan and colleagues (Kaplan and Howes 2004). After discussion, 27 photographs were selected as representative of his day in chronological order, using captions which explained in his voice what was happening e.g. 'I'm in the sensory room for ICT but the overhead lights are bothering me.' We were surprised how much information we elicited from the exercise. We have included a selection for this article.

Physical Support Needs

Sam has a high level of need and frequently two or three people were involved in taking his coat off/ putting it on or positioning him in different equipment. However the people supporting him often did it in a 'fun' way which Sam enjoyed, such as employing the pillow used to position him in his side-lying board in a 'pillow-fight' with him. It was clear from Sam's facial expressions that he has a strong rapport and opportunities for the most 'human' or phatic communications (Hewett, 2012) with people who support him frequently.

Specific Responses

Sam responded by smiling and laughing clearly during activities he enjoyed such as wheelchair dancing, live music, going over bumps in the road and rebound therapy. On two occasions he seemed to find the lighting in different rooms uncomfortable and communicated this by covering his eyes with his left 'useful' arm. He also communicated discomfort by placing his left hand behind his neck at his hairline and each time he did so someone responded to make him comfortable. This was

interesting, as, although we are aware when Sam is uncomfortable, we did not have a key signal. Rather, it was more of an intuitive feeling on our part. Now we can inform people less familiar with Sam that this is a signal he uses to express discomfort. We also were surprised by the number of photos in which he has his eyes shut until we realised that he does so to process a question or new/unexpected experience. We were previously unaware of this response.

Staff and Peers

We noticed also that Sam often appears with staff in the photographs rather than with his peers. Because of Sam's communication difficulties over the years he has been at the school he has formed stronger bonds with the staff than his classmates. Other learners do interact with him, support him to use a communicator and chat to him. However none of this was captured on this particular day.

Communicating his Experience

Sam was supported to use an iPad to show the slideshow of photographs at his Annual Review to his mum and the professionals attending. They saw what Sam's school day looks like, what he likes, dislikes and how he communicates his preferences. Sam was really animated during his presentation and this format empowered him to communicate HIS experiences clearly to others (Mencap, Bild and the Renton Foundation, 2011) including professionals who had not met him previously. They were all very positive about this insight into his school day. At his mum's request Sam took a paper copy of the photographs and captions to share with his extended family (Carpenter, 2010) so he could show them what his school days are typically like.

The slideshow was also used to support his transition into the next Key Stage and to inform his communication passport (Millar and Aitken, 2003).

It is a particularly challenging task to gain insights into

the school experience of learners with complex disabilities. Here, tracking Sam and adopting his perspective on the world allowed us to grasp the importance of environmental and physical aspects which we might not otherwise have considered – the effects of light for example. We also learned much from what was absent in the photos, for example, the presence of peers, highlighting what may be a real ongoing issue for young people who are so dependent on staff to mediate their experiences.

A Thursday in the life of Sam



1. On the bus to school



2. It takes 2 to take my coat off



3. I'm not bothered about the school nurse giving me fluids



4. I love twirling around during wheelchair dancing



5. My nose is itching so I've stopped joining in –my hand's behind my ear



6. Julia itches my nose



7. Tony plays the sound of music and I sing along



10. Lights out and with a little help I press the switch to make the disco ball go



8. Quick nap now I'm in my side-lyer



11. I need help to get back into my chair comfortably



9. I'm in the sensory room for ICT but the overhead lights are bothering me



12. There's time for a quick pillow fight



13. I can smell dinner



16. With Linda's help I hold the spoon while eating my pudding



14. First mouthful – I'm never sure



17. On the bus – initially the strap was digging into my neck but I moaned to let Julia know



5. Linda's asking me if I've had enough of my main course



18. Going over the bumps in the road is great when I'm prewarned



19. A sigh of relief as I am hoisted out of my chair onto an air bed



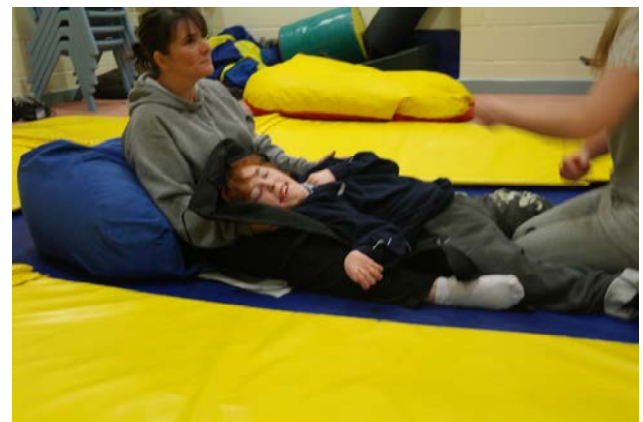
20. I laugh at Daniel's antics on the trampoline especially his monkey impressions



21. The overhead lighting bothers my eyes so I cover them with my arm



22. My turn on the trampoline but I am moaning so that Julia knows that I am uncomfortable



23. They slide me down and straightaway I am more comfortable



24. "with a 1.....a 2.....and a 3"



25. I've gone quiet and I'm holding my neck so Julia knows that I am uncomfortable again



26. Back in my chair again ready to get back on the bus to school



27.and onto the bus for a snooze into school

With special thanks to Lucy Ratcliffe who accompanied Sam through his school day taking the photographs.

Contact Details

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NEXT ISSUE

Summer Vol. 28 No. 2 Issue 81

A Celebration of Penny Lacey

Do you have any stories to share?

If so, contact the editors:

Rob Ashdown and Helen Daly

rob.ashdown@ntlworld.com

Action research: when the practitioner becomes the researcher

Penny Lacey

Because Penny had talked to me on many occasions about her enthusiasm for action research I eventually asked her to write about it for TAC Bulletin readers. Action research appeals to me as a way for people living, working and playing with people with PMLD to contribute to the store of relevant, practical knowledge. Rob Ashdown has kindly shortened Penny's essay for this issue of PMLD LINK. *Peter Limbrick*

What is action research?

Fundamentally, action research is about practitioners investigating and evaluating their own work (McNiff and Whitehead, 2006). It provides a framework for developing what practitioners do and one of the most important aspects of the approach is its capacity to enable practitioners to change their practice (Taylor, Wilkie and Baser, 2006).

Although the textbooks use slightly different terms, there is a consensus on the importance of action research for bringing about change that is based on evidence.

The power of action research

Carr and Kemmis (1986) suggest that action research can be distinguished from the everyday action of practitioners because:

- it is more systematic and collaborative in collecting evidence on which to base
- rigorous group reflection
- it is about problem-posing as well as problem-solving
- it is motivated by a quest to improve and understand the world by changing it and
- learning how to improve it from the effects the changes have made
- it is research by people on their own work to help them improve what they do

Most importantly, research is characterised by the systematic and deliberate way in which data is gathered and analysed. Most action researchers would claim that they have been able to change and develop what happens in their practice, improving their understanding of that practice and often changing their underlying beliefs.

Certainly from my own experience of using action research, it has enabled profound changes in the way that I view my practice. For example, I used action research to develop a one-day course in collaboration for

multi-disciplinary teams (delivered many times) within which I gradually improved my engagement with the participants to maximise the short time I worked with them. My initial dependence on 'telling' participants became what I called 'teaching through comment'. I encouraged the participants to talk about their practice and then used my understanding of collaboration to comment on that and encouraged them to suggest how they might improve. I wanted to be an effective facilitator for their learning so that when they went back to work they had themselves planned what they were going to do. From the data gathered from my own reflections and participants' opinions, I achieved my aim of helping participants to improve their practice as well as improving my own.

The process of action research

Action research is part of the toolbox of reflective practitioners who need a systematic way of researching what they are doing. McNiff and Whitehead (2006, p 8) suggest that the systematic process encourages researchers to:

- take stock of what is going on
- identify a concern
- think of a possible way forward
- try it out
- monitor the action by gathering data to show what is happening
- evaluate progress by establishing procedures for making judgements about what is happening
- test the validity of accounts of learning
- modify practice in the light of the evaluation

There are likely to be several cycles such as this as different aspects of the original concern are trialled and evaluated. It might be said that action research is never complete because a good reflective practitioner never stops asking questions and seeking evidence of their practice. However, in practice, the researcher usually has to stop at a certain point to write up what has happened and share that with colleagues.

When to use action research

M McNiff and Whitehead (2006, pp 13-14) also helpfully suggest when to use action research:

1. To improve your understanding.
2. To develop your learning.
3. To influence others' learning.

They also suggest questions that are useful to begin your enquiry:

'How do I?'...or 'How can I?'...and 'What is happening here?'

The first question emphasises the importance of the researcher as the centre of the research. Certainly in the type of action research recommended by McNiff and Whitehead (2006), the practitioner-researcher is paramount. They encourage researchers to develop their own living educational theories whilst transforming their practice. Also emphasising the importance of practitioner-researcher, Robson (2011) suggests that improvement and involvement are central to action research. He writes of:

1. Improvement of practice.
2. Improvement of the understanding of practice.
3. Improvement of the situation in which the practice takes place.

Collaborative action research

Although the most important results of action research are centred around the practitioner-researchers themselves, there is a strong emphasis on co-operative, collaborative activity. In my own study, it was the development of the course and my teaching approach that were central but I was also trying to influence other people's practice. The success of my project was based on how well I had changed the practice of others. That is not so in all projects but in order to be fully effective, action research should be, at the very least, shared with others.

Part of the validation of the study is sharing and justifying what happened with peers who can evaluate the worth of the process. I worked with colleagues at the University of Birmingham to achieve this in my study. Not only did we discuss data collection and where to go next but colleagues also observed my teaching and gave me feedback. I wrote up the whole project as part of my PhD thesis which was then, of course, validated through the marking system.

Whether or not action research is part of an award-bearing course, one of the best ways of informing others of what is happening is to include them in the research right from the beginning. Research in the classroom could involve colleagues or even the pupils themselves to help the practitioner-researcher to devise the study, develop the data-gathering tools, collect the data and

help to understand what it means. This can be a powerful experience for anyone who collaborates in the study and potentially more influential in terms of changing practice in an organisation.

Getting started on a project

I have already mentioned the importance of 'How can I...?' questions and when students find it hard to locate a good topic I usually ask them to brainstorm all the things that really puzzle them or annoy them about their practice. What keeps going wrong? One teacher wanted to improve the time-keeping in her classroom. She worked with pupils with profound learning disabilities and was frustrated by the amount of time that was spent on positioning pupils, fetching resources and completing unimportant tasks. So she asked the question 'How can I increase the amount of time for learning in my classroom?' She went round the action research cycle several times before she and her support staff felt that they had made a significant difference to their own work. They timetabled the use of equipment, purchased and filled boxes of resources and generally became more aware of the purpose of individual activities as opportunities for learning. They realised, for example, that care sessions around going to the toilet were actually excellent learning moments on which they then capitalised. It was interesting that although the emphasis was on how to speed up what they saw as interruptions to learning, in actual fact they understood that these times had the potential to be more productive than they originally thought.

Elliott (1991) describes the activity of 'reconnaissance' where the practitioner-researcher attempts to describe and explain the facts of the situation under scrutiny. The student in the time-keeping example began by timing the events of the day and trying to explain why basic organisation was taking so long. The simple answer was that equipment was not stored well and was hard to find, or was being used by another child. The teacher discussed the situation with the support staff and together they devised what they were going to do.

One of the first actions to take in an action research project is often to find out what others have said about your situation. Is there advice in the professional literature? Is there any previous research that sheds light on the situation? What aspects of the topic do other people think are important? Undertaking a brief literature review can be very helpful and essential if the project is part of an award-bearing course. Usually though, a single analysis of the literature is not sufficient and every new action step can bring new need to consult with what others have said on the topic. The literature on classroom management was important at the start of the time-keeping project but it became less important as the staff began to realise the potential of seemingly

unimportant activities to pupil learning. It was then important to consult with the literature on Intensive Interaction (Nind and Hewett, 2001) to consider how best to use it as part of toileting procedures.

Once these first enquiries have been taken, it is necessary to think of the first action step. Elliott (1991) suggests that often this is a cluster of activities rather than neatly one per action cycle. McNiff and Whitehead (2006, p 131) suggest that three questions are useful at this early stage (and again at other steps):

1. What data am I looking for?
2. Where will I look for the data?
3. How will I monitor my practice over time?

To answer the first question, practitioner-researchers need to be focused on the research question which is likely to become more refined as the project develops. For example, if the original concern is 'How can I work more collaboratively in a multidisciplinary team?' this may develop into something specific such as 'How do I learn how to work collaboratively?' and 'How can I organise my time to enable team meetings to occur regularly?'

Collecting and analysing data

There are no special ways to collect data in action research as the umbrella nature of the approach enables many different data collection methods to be used. Although the approach is more often associated with collecting words rather than numbers, either and both can be used.

Often practitioner-researchers want to show numerical evidence for claiming that change has occurred and so they choose a test to administer at the beginning and the end, like a pre-test, intervention, post-test experiment. Even if measurement is employed, usually there is other data which describes what is happening, enabling the researcher to look at the quality of what is happening as well as measuring changes.

Data can be collected in various ways including observation, interviewing participants, administering written questionnaires, keeping field notes and participant diaries, focus groups and sociometry. Documents can be analysed, for example those concerning risk assessments or therapy programmes. There are, of course variants amongst the aforementioned methods. For example, observation can be participant or non-participant; structured or unstructured or somewhere in between; it can be videoed; it can be carried out by the researcher or another person; it can be based on a published scale or devised especially for the project. Decisions need to be made and ideas put into action.

When I developed the collaboration course, I mainly used a field diary, questionnaires, participant observation, non-participant observation (of me) and interviews with course participants and their managers as data-gathering tools. I found that these tools provided me with a 'triangulation' of perspectives on the course. Triangulation is usually used to examine a phenomenon from more than one point of view. It does not have to refer to three. Two could be sufficient or it could be many more.

Analysing the data is perhaps the point at which some action research projects founder. Often there is a considerable amount of data and this can be overwhelming for practitioners used to making instant decisions based on what they see or hear. As with any research, the researcher needs to get to know the data very well, reading and rereading so that the main ideas can surface and be checked for validity.

The final stage is very important and usually involves writing up a report or presenting research to a live audience. Clarity is of paramount importance whether the report is an academic dissertation, a summary for a funding body or a PowerPoint presentation to work colleagues. Cautious claims are also important. Action researchers can be over enthusiastic in their claims, forgetting that their projects are situated very firmly in their own contexts and cannot be generalised. Generalisation is not necessary, though, for an action research project to be useful for others. Practitioners find accounts of other studies really helpful for reflecting on their own situations. They can also be spurred on to carry out studies of their own.

Conclusions

Action research has fundamental principles but is incredibly flexible. It is founded on making changes in practice and can provide a framework for practitioners to make these changes in a systematic way. Critics of the approach suggest that it is not sufficiently rigorous to be considered as serious research (e.g. Gibson, 1985; Lewis, 1987). For their evidence they cite insufficient self-critique and examples of poorly designed studies that have little to offer the world as they are too specific to one situation to be useful to others. It also could be said that action research is little different from 'reflective practice' (Pollard et al. 2002) which one might expect of every teacher, nurse, therapist and social worker. Indeed starting from reflective practice can be very productive for novice action researchers. Usually what shifts reflective practice into action research is collecting and analysing data systematically and then sharing the process and results in a public manner such as a written paper or a presentation.

Action research is a powerful tool and is not difficult to

put into practice, though it is usually time consuming if taken seriously. The 'living educational theories' described by McNiff and Whitehead (2006) can be as important as the actual changes you can bring about in practice, as developing your own theories and principles are vital to providing lasting change which can be transferred from situation to situation. Hopefully the short introduction in this article can help you, the reader, to start your own project and develop your practice in a systematic and thoughtful way.

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The Complete article

The full version is freely available here to read and download:

<http://www.teamaroundthechild.com/allnews/researchsurveys/1035-action-research-when-the-practitioner-becomes-the-researcher-an-essay-by-dr-penny-lacey.html>

Richard Hirstwood is going to pop small equipment 'info-bites' into each issue of PMLD LINK and here's one for Spring 2015! Sound and Vibration



For those people seeking sound and vibration experiences, here is a great idea - the 'WoWee' speaker.

It's small and costs around £30 and can be re charged via the USB cable supplied.

Place the speaker on to a hollow object like a box, or better still, a resonance or clonker board and you will feel incredible vibrations! It can be used on any surface and even pressed on to the frame of a wheelchair, you will feel your favourite tunes vibrating through the frame!

Richard Hirstwood

FUTURE FOCUS

A Celebration of Penny Lacey

As you know, Penny Lacey died on 12th January of this year. Many people reading this will have read the notice that was posted with the Winter 2014 issue in January or may have attended the memorial service organised by her family and held in Coventry Cathedral on 11th February.

Penny made a huge contribution to PMLD LINK as the Chairman of Trustees, as a member of the Editorial Team and as a regular contributor to the journal. She was absolutely dedicated to improving the lives of children and adults with PMLD and their families. Therefore, the Editorial Team have decided to make the Summer issue of the PMLD LINK journal (to be published in July of this year) a celebration of Penny's achievements.

We intend to reproduce a few of her past articles for PMLD LINK but the editors would be very pleased to receive any contributions that will help us to celebrate Penny properly.

We would like to include personal anecdotes from those of you who knew her and memories of things she achieved, said and did, no matter how short your piece may be. We hope that these vignettes would help illustrate Penny's humour, passion and enthusiasm. We would also like to include people's articles on best practice working with children and adults with PMLD that will help to make plain the enduring legacy of Penny's research, her teaching and her published work. We believe that Penny made a huge contribution to curriculum improvement in schools, to articulating the rights and needs of people with PMLD, to promulgating effective joint working by different agencies and voluntary organisations, to establishing inclusive provision such as inclusive libraries, and to developing different services and educational approaches.



We are sure that many of you will have been helped and inspired by Penny to develop your own innovative practices in your own particular settings and we hope that you would feel able to contribute an account to this celebratory issue that shares your experiences.

Please let us know as soon as possible if you would like to make a contribution. We will need your written contributions by 23rd May. Let us know if we can help you with sharing your stories – we are happy to assist!

Rob Ashdown and Helen Daly

e-mail - rob.ashdown@ntlworld.com



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](https://twitter.com/pmlmlink)

PMLD Network Forum

A Digest of Discussions

January to March 2015



Bella Travis

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.

Resources and reports

NHS England FAQ on 'Introducing personal health budgets beyond NHS Continuing Healthcare'
www.personalhealthbudgets.england.nhs.uk/News/item/?cid=8845

Department of Health factsheets on the Care Act 2014
The DH has updated Factsheet 6: Reforming how people pay for their care and support and added a new Factsheet 13: Appeals policy proposals to their series of Care Act 2014 factsheets:
www.gov.uk/government/publications/care-act-2014-part-1-factsheets

New advice for delivering care and support planning under the Care Act 2014
Think Local Act Personal (TLAP) has published a guide for councils. It describes the principles people want in a care and support planning process, the elements that need to be in place and recommendations to help councils be both Care Act compliant and person-centred in their approach:
www.thinklocalactpersonal.org.uk/News/PersonalisationNewsItem/?cid=10466

SEND code of practice: 0 to 25 years
The Department for Education has published statutory guidance on the special educational needs and disability (SEND) system for children and young people aged 0 to 25:
www.gov.uk/government/publications/send-code-of-practice-0-to-25

AFASIC factsheets on the SEND reforms
A series of 7 factsheets for you to download on navigating your way through the SEND reforms - a guide for parents of children with speech, language and communications needs:
www.afasic.org.uk/news/free-downloads/

New Mental Health Act code of practice
The code of practice for the Mental Health Act 1983, which provides guidance for professionals, has been revised:
www.gov.uk/government/publications/code-of-practice-mental-health-act-1983

Contact a Family's free guides and information for parents and carers
They have written summary factsheets on two of their guides: 'Claiming Disability Living Allowance for Children' and 'Personal Independence Payment – A new benefit for disabled people aged 16 and above':
www.cafamily.org.uk/news-and-media/free-guides-for-parents-and-carers/
Visit their new Family Life advice pages written by parent advisers:
www.cafamily.org.uk/advice-and-support/family-life/
Read their new handbook for parent carer forums which explains what knowledge and skills parent carers will need to run a successful forum:
www.cafamily.org.uk/media/816817/support_for_parent_carer_forums_parent_carer_forum_handbook.pdf

The Challenging Behaviour Foundation's new information sheet: 'Getting an Education, Health and Care Plan'
EHC Plans replaced statements of Special Educational Needs (SENs) in September 2014. CBF's new information sheet aims to cover everything that family carers need to know about the changes:
www.challengingbehaviour.org.uk/cbf-articles/latest-news/ehc-plan-info-sheet.html

The Challenging Behaviour Foundation's Spring 2015 newsletter: 'Driving Change: Rights & Choices'
www.choiceforum.org/docs/cbfspr.pdf

News and other information

The world of PMLD will mourn the loss of Penny Lacey

Tributes to Dr Penny Lacey:

www.swisscottagedrc.org/the-world-of-pml-d-will-mourn-penny-lacey/

www.telegraph.co.uk/news/obituaries/11392897/Penny-Lacey-educationist-obituary.html

www.ucet.ac.uk/6331

Request for information for the next IHaL 'reasonable adjustments' report

The Improving Health and Lives (IHaL) team are preparing their next 'reasonable adjustments' report and the focus is cancer screening services for people with learning disabilities. This will be an update of their 2012 report.

Please send any good practice examples, resources to link to, and examples of what has gone wrong for people in the past and what could be done better to:

anna.marriott@ndti.org.uk

Manchester Airport is opening new Changing Places facilities in each of its three terminals

The facilities have been designed to meet the needs of passengers who have profound and multiple learning disabilities and others with severe disabilities who need the support of at least one carer, providing them with a safe and easy toilet facility to use when travelling through the airport. Access will be provided via the telephone next to each facility and is controlled by the Customer Contact Centre. To pre-notify the airport of a requirement to use the facilities, passengers or carers can contact the team on 0330 333 0304.

Read full article: www.manchesterairport.co.uk/manweb.nsf/content/ManchesterAirportLaunchesChangingPlacesFacilities

First 10,000 high-need services users gain control of their own integrated health and social care budgets

NHS England and the Local Government Association have named the first eight sites that will, for the first time, blend comprehensive health and social care funding for individuals and allow them to take control of how it is used. The first wave of the Integrated Personal Commissioning (IPC) programme will go live on 1 April 2015. The individuals involved in the sites, including people with learning disabilities, will be able to take control of their budget to deliver an agreed care plan.

See full article: www.england.nhs.uk/2015/03/09/ipc-sites/

Health services and care homes to display CQC inspection ratings

New rules introduced to Parliament will result in hospitals, GP surgeries and care homes having to display the inspection rating that has been awarded by the Care Quality Commission (CQC). This is to improve transparency. The ratings tell the public whether a service is outstanding, good, requires improvement or inadequate. This is a legal requirement from 1 April 2015. For more information: www.cqc.org.uk/content/display-ratings

Carer's Allowance earning limit to increase from April 2015

From 6 April 2015 new regulations will mean the earnings limit for Carer's Allowance will increase from £102 to £110 per week.

For more information on how the earnings rules work visit the Carers UK website: www.carersuk.org/help-and-advice/financial-support/help-with-benefits/carers-allowance

Supporting carers to stay in paid employment

Ministers have launched a series of pilots exploring ways to help carers balance work with their caring responsibilities. For more information: www.gov.uk/government/news/supporting-carers-to-stay-in-paid-employment

'Totally Wrong List'

Learning Disability Alliance (LDA) England says 'After many years of slow progress for people with learning disabilities things are now going backwards. This is totally wrong and unnecessary, so we've put together a list of all the different things that are wrong – a totally wrong list.' learningdisabilityalliance.org/totally-wrong-list/

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

REPORT BACK



Changing Places and Official Sponsor Aveso host campaigner day success at prestigious Proact Stadium

Following another highly successful year for the Changing Places campaign, there are now over 700 Changing Places registered in the UK which include major Airports, Premiership Football Clubs, Supermarkets and Hospitals as well as a range of Changing Places successes overseas in the USA and Australia.

Changing Places are an essential facility for nearly a quarter of a million people, including those with profound and multiple learning difficulties and their carers, where a standard accessible toilet does not provide the correct equipment required by the user. A Changing Places toilet (that complies with BS8300:2009) is fitted with a Hoist, Changing Bench, Peninsular Toilet, Grab Rails and a Wash Basin as well as enough space for turning and carers. Changing Places make a substantial difference to thousands of people's lives each day by offering the correct facilities for changing and toileting to give more people the opportunity to plan days out and use a safe and reliable facility.

The very first Changing Places Conference took place on February 21st 2015 at 10am at Chesterfield FC's Proact Stadium

The Event was an informative and collaborative day which included a number of experienced and respected guest speakers including Accessible Derbyshire, The Joshua Wilson Brain Tumour Charity, Visits Unlimited, Euan's Guide, "Hop, Skip and Jump" and stories from families that need Changing Places. We wanted to bring everyone together to share their stories and experiences of life with and without Changing Places toilets. It was an opportunity to celebrate the work of campaigners and venues who have embraced Changing Places, including our first "People's Choice Changing Places Award."

Changing Places and Aveso welcomed all campaigners to the event to find ideas, support and information on how the Changing Places campaign can and will continue to grow and how everyone can get involved to achieve this. After all, Changing Places would be nowhere without the hard work and support of the campaigners and experienced families.

Rossanna Trudgian, from Mencap, and Co-chair of the Changing Places consortium commented; *"Since the campaign launched, we have seen hundreds of Changing Places toilets installed across the UK, including at key transport hubs like Heathrow airport and Kings Cross station, stadiums like Wembley and the Emirates, as well as hospitals, concert arenas and city centres. The availability of Changing Places also helped make the London 2012 Olympic and Paralympic Games the most accessible games to date! So much of this success is because of Changing Places campaigners like those who attended the conference. Champions of our cause. The Changing Places Conference is about honouring and celebrating everything they do to help spread awareness and recognition of the true value of and need for Changing Places toilets.*

However, whilst progress has been made, more are needed if we are to meet the demand for Changing Places toilets and to see them in all public areas so that nobody ever has to be changed on a toilet floor. We hope that the Changing Places Conference marks the first of many events like this so that we can continue to spread the word about Changing Places far and wide."

The Changing Places Conference 2015 took place in partnership with the official sponsor Aveso who provide technical advice and equipment for Changing Places. The Proact Stadium, which was the chosen venue for this conference, is fully accessible and has a full Changing Places fitted by Aveso. It's commitment to accessibility was recognised when it came 3rd in the People's Choice Changing Places Award, sadly beaten by Arsenal's Emirates Stadium - suppose that's to be expected when Chesterfield FC takes on the Gunners!

About our Sponsor: Aveso

Aveso is the proud sponsor of the Changing Places campaign, working to make the specification of Changing Places disabled toilets and equipment a simple task. Our aim is to make the provision of a Changing Places toilet seamless and easy, starting with free impartial expert advice through every stage of design, supply, installation and maintenance of all the items needed. Aveso is a dedicated company which has specialist expertise in Changing Places and specialist equipment, our mission together is to help the Changing Places Campaign achieve its target of 1,000 registered Changing Places Toilets within the next three years - We are committed to Making Changing Places Happen.

The sponsor of the event, Avesco, seeks to make the provision of a Changing Places toilet and equipment a simple task. They provide free expert advice through each stage from design to supply, installation and maintenance of all the items needed. The Changing Places campaign aim, is to achieve one thousand registered Changing Places toilets within the next three years.

Changing Places Development Officer
Mike Le-Surf

T: 020 7696 6019 Tuesdays, Wednesdays and Thursdays

M: 07887 643371

Website: www.changing-places.org

Top websites for this issue

Inclusive cycling: BikeAbility Wales, Pedal Power, Wheels for All

<http://www.groundwork.org.uk/Sites/northwales/pages/pedal-power-northwales>

<http://www.cardiffpedalpower.org/>

sportwales.org.uk/.../bike-project-puts-pedal-power-intandem.aspx

www.bikeabilitywales.org.uk

www.cycling.org.uk/wfa/intro

www.changing-places.org

Location map and national register of all fully accessible Changing Places toilets

enquiries@naturalresourceswales.gov.uk

Also have a look at their Twitter link

fe.England@forestry.gsi.gov.uk

fcscotland@forestry.gsi.gov.uk

enquiries@nationaltrust.org.uk

enquiries@wwt.org.uk

customer.services@canalrivertrust.org.uk

saw@thefirmcomms.com

Provide a site map for a range of attractions to explore across the world!

pressoffice@londoneye.com

liz.edwards@legoland.co.uk

nicole.fenner@madame-tussauds.com

liz.west@alton-towers.com

<https://m.youtube.com/watch?v=3zYK3BW9Oow>

This is Sensorium theatre group taking their multisensory work to Sydney Opera House with some youngsters with profound and severe learning difficulties enjoying the whole drama

www.pmlidnetwork.org for anyone who doesn't know the network hosts a really good forum

REVIEWS

Title: My Doo-zy, My Friend, Our Journey.

Authors: Julia Barnes and Heather Clarke

Pages: 171

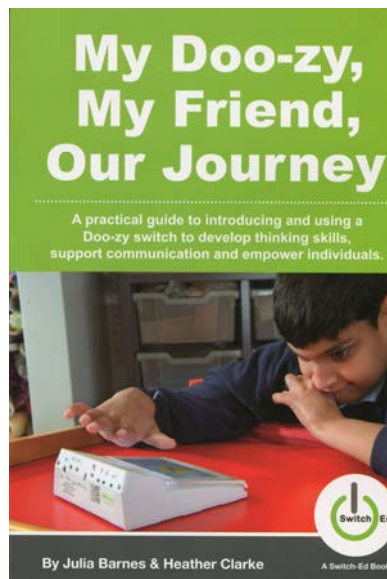
Publisher: Switch-Ed

ISBN: 978-1-62890-322-5

Published: 2014

Cost: £20.00 (discounts available for purchase of multiple copies)

A switch communicator specifically designed for users who have severe or profound learning difficulties and additional disabilities. This is a sophisticated device that has a range of built-in programs and features which make it an excellent tool for empowering users. The switch is available from Switch-Ed (<http://www.switch-ed.co.uk>).



This book is not a user manual for Doo-zy. Instead, it is a quite inspirational guide to introducing and using Doo-zy to support the development of thinking, communication and environmental control skills of individuals. It has been written by a teacher and a speech and language therapist who clearly have a great understanding of the significance of these skills for children with PMLD as well as many practical ideas for the use of Doo-zy and its various features, to best effect. They have written the book in a style which is accessible to all – not just teachers and speech and language therapists but also support staff, other therapists and key workers, and parents. Much of what they have written is just as applicable to adults with PMLD as children. The book is attractively designed and has many excellent colour photos of students from their school using Doo-zy and interacting with adults.

The core of the book is 21 chapters, each focusing on an aspect of skill development, and colour coding for the chapters shows whether there is a cognitive, communicative or environmental control focus. Crucially, each targeted skill is related to steps on the routemap for the Routes for Learning Assessment Tool. They are also

linked to the P-Scales since these are so widely used in schools. The authors rightly stress that the ordering of the 21 chapters does not imply a linear route that each individual must work through and also that each individual must be given the opportunity to learn at a pace that suits them. Indeed each chapter starts by encouraging readers to think about what is actually involved in learning the targeted skill and its importance as well as where the individual must be in terms of their development in order to benefit from the activities described in the chapter. The many activities are best conceived of as illustrative since they will require adaptation for each individual but they are obviously tried and tested and engaging activities. They take the user from learning how to control Doo-zy through to using Doo-zy to operate motivating things (e.g. bubble tube, lamps, MP3 player, TV, moving toys) and to improve their participation in activities and their communication with others to make requests, secure attention, make choices and express preferences.

If you have or are going to get Doo-zy switches, this book is strongly recommended because it will help you to use Doo-zy effectively and with understanding. Not only can it be perused alone but it would be an excellent reader for an in-house training package.

Rob Ashdown

Title: THE PMLD AMBIGUITY: Articulating the life-worlds of children with profound and multiple learning disabilities

Authors: Ben Simmons and Debbie Watson

Pages: 243 + xvi

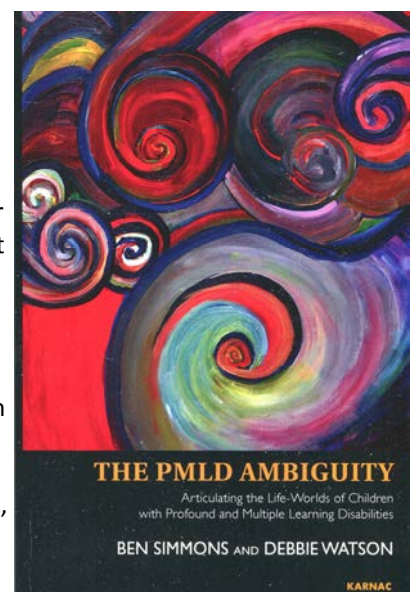
Publisher : Karnac Books (www.karnacbooks.com)

ISBN: 978-1-7804903-4-2

Published : May 2014

Cost: £23.99 (Paperback or e-book)

The article by Ben Simmons and Debbie Watson in the Winter 2014 issue of this journal provides a taster for some of the content of this book. However, reading that article is no substitute for coming to grips with this book which will challenge readers on many levels. In it, the authors argue that the



conventional ways in which currently we think about and interact with children described as having PMLD and our usual approaches to educating them, unduly constrain their development and our abilities to listen to and learn about them. At worst, they suggest, this results in exclusionary practices, such as segregated education in special schools, simply because it is presumed that they are too disabled to participate in and benefit from mainstream life.

The book is based on Ben Simmons' MSc and PhD research and is undoubtedly scholarly employing vocabulary and deploying ideas which readers will find both stimulating and taxing. I would caution that readers need to have a good grasp already of the theoretical underpinnings of educational approaches derived from behaviourism or cognitive psychology. The book does have helpful chapter and section summaries and appropriately revisits some of the more complex concepts but, undoubtedly, a challenge for the authors must be how to make their ideas more accessible if they are going to influence practice. This book most certainly requires careful reading and rereading in places.

The book starts with an exploration of common understandings and definitions of PMLD. While the authors acknowledge that there is literature that seeks to establish the strengths and capabilities of children with PMLD and their rights, they argue that these children are more usually reported as highly adult-dependent and lacking in the cognitive and communication skills which are considered to be prerequisites for effective learning and socialisation. This emphasis on developmental deficits is presented as potentially dehumanising, not showing them as children first and foremost, and it is suggested that consigning them to segregated provision outside the mainstream results in limited opportunities for stimulation and development. There follows two chapters providing overviews and analyses of commonly used interventions in schools that have been heavily influenced by behaviourism and cognitivism. As regards behaviourism, particularly radical behaviourism, in the view of the authors, little has been contributed to general understanding of children with PMLD, although they find value in some later research into behaviour states and happiness and their influence on learning. As regards cognitivism, the authors provide a useful comparison of several theories about the development of social cognition and communication in very young children and show how approaches used in the UK (such as Intensive Interaction and Responsive Environments) have been influenced by these dissimilar schools of thought. Again, the suggestion is that cognitivism is not sufficient to explain facets of the behaviour of children with PMLD and unduly emphasises their cognitive and linguistic deficits. The authors next introduce phenomenological theory, particularly that of Merleau-

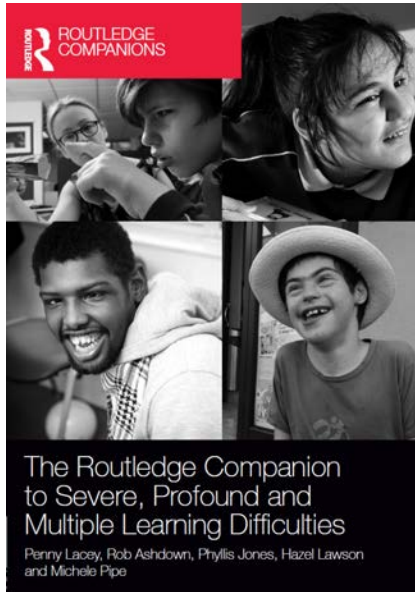
Ponty, and seek to convey the insights offered by philosophical notions of how the world is experienced through our bodies and how these processes may be meaningful and yet not involve discernible consciousness or cognition. Our experience of the world is in terms of how we interact with it and different opportunities to interact with the world lead to alternative senses of self and others and different opportunities to flourish. The authors use these phenomenological ideas to direct us to rethink about the life worlds of children with PMLD.

The authors go on to describe the development of methodology that they recommend for principled research aimed at providing an account of the experiences of children with PMLD. They stress the value of groups of people who know well the research participants (the children) coming together regularly to share their different views and arrive at a consensus of what children's behaviour and experiences mean. They are in favour of long-term rather than short-term research and of observers compiling detailed vignettes of children's interaction with their environment. The book reports Ben Simmons' own research project examining the experiences of a young boy with PMLD both in his special school and in his mainstream school. Over a year, one day per week in each setting, Ben meticulously recorded hundreds of vignettes to share with significant others in order to formulate a common understanding of what he recorded. Just ten of these fascinating vignettes are presented in the book illustrating emphatically that this child with PMLD engaged with the world in ways far more complex than might have been predicted, especially in the mainstream school environment.

This is a book about human interaction and social development rather than a book about teaching approaches. Throughout the book comparisons are made by the authors to show how behaviourism, cognitivism and phenomenology, as characterised by them, can or cannot contribute to our understanding of the behaviour and lives of children with PMLD. A key message is that it is a mistake just to rely on any one perspective. The authors see themselves as charting new territory in seeking to understand the life worlds of children with PMLD borrowing eclectically from different disciplines. This certainly represents a real departure from the conventional perspectives in the PMLD literature and, therefore, their ideas may well have implications for researchers, teachers and others concerned with this arena of education. Further research and time alone will tell. Bearing in mind caveats for readers expressed above, this book is strongly recommended.

Rob Ashdown

The Routledge Companion to Severe, Profound and Multiple Learning Difficulties is a timely and rich resource with contributions from writing teams of acknowledged experts providing a balance of both academic and practitioner perspectives. The book has the core purpose of informing and



supporting everyone who is interested in improving the quality of education and support for children and young adults with severe, profound and multiple learning difficulties (SLD/PMLD) and their families. The chapters cover topics related to the rights and needs of children and young adults from 0-25 years, crucial features of high quality education, characteristics of integrated provision and effective and sensitive working with families to ensure the best possible outcomes for their children. Crucially, the voice of the learners themselves shines through. Historical provision that has had an impact on developing services and modern legislation aimed at improving provision and services are also discussed.

This text is an essential read for students on courses and staff working in and with the whole range of educational settings catering for children and young adults with severe, profound and multiple learning difficulties, not just for teachers but also for support staff, speech and language therapists, physiotherapists, psychologists, nurses, social workers and other specialists.

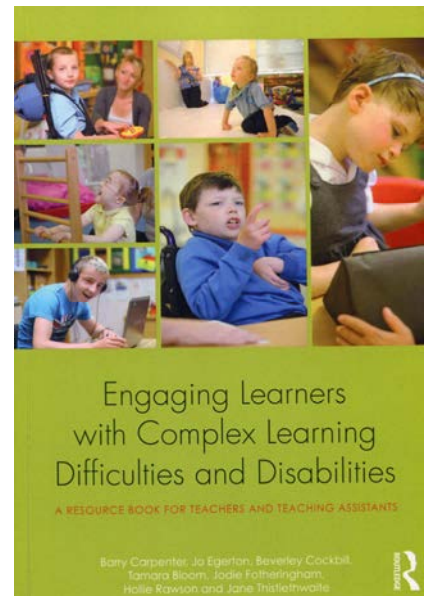
The book is edited by Penny Lacey, Rob Ashdown, Phyllis Jones, Hazel Lawson and Michele Pipe

It is due to be published in mid-April. There are 428 pages plus illustrations
Hb: 978-0-415-70997-2 | £140.00
Pb: 978-0-415-70998-9 | £31.99

20% Discount Available when ordering from www.routledge.com - enter the code IRK69 at the checkout. For more information visit: www.routledge.com/9780415709989

RESOURCE

Engaging Learners with Complex Learning Difficulties and Disabilities: A resource book for teachers and teaching assistants has been written by a team of writers: Barry Carpenter, Jo Egerton, Beverley Cockbill, Tamara Bloom, Jodie Fotheringham, Hollie Rawson, and Jane Thistlethwaite.



This book was published in February by Routledge. A full review of this book will appear in the Summer issue of PMLD LINK. Children and young people with Complex Learning Difficulties and Disabilities (CLDD) have co-existing and overlapping conditions which can manifest in complex learning patterns, extreme behaviours and a range of socio-medical needs which may be new and unfamiliar to many educators. Their disengagement from learning can seriously challenge even the most experienced teachers. Learners with PMLD are a small but important minority within this diverse and large group.

This book is important because it provides school practitioners (teachers, therapists, psychologists, support staff) with details about the Engagement for Learning Framework which has been developed and trialled over several years in a range of educational settings (both special and mainstream). It provides a means of assessing, recording and developing personalised learning pathways and demonstrating progression for all of these learners with CLDD. Practitioners working with learners with PMLD will be able to apply the approach. The book provides the assessment tools and case study examples showing how to ensure the best possible outcomes for these learners.

The paperback edition costs £26.99 (ISBN: 978-0-415-81274-0)

IN THE NEWS

New mental health rights proposed by minister Norman Lamb

Proposals to give more rights to people with learning disabilities, autism and mental health conditions are to be unveiled by the government. Care Minister Norman Lamb said the changes would put people in charge of their care, and promote community support as an alternative to hospital. Mr Lamb admitted many families felt "their concerns are ignored".

At Winterbourne View, a private hospital near Bristol, the BBC's Panorama programme exposed abuse of patients by staff in 2011 and ministers pledged to move patients out of hospitals and into community care, after this scandal. Last month the National Audit Office said the government had failed to honour its pledge, because it had underestimated the "complexity and level of challenge" involved in discharging so many patients into the community. He said that his proposals, which are being put out to consultation, would strengthen people's rights to challenge decisions made about their care, and make it "much harder" to admit people to hospital when there was better support available in the community. The consultation, to take place in England only, will also consider changes to the way the Mental Health Act applies to people with learning disabilities and autism.

Other measures could include having a named professional in charge of sharing information with an individual and their relatives, and a new duty for local authorities to check the amount of community support available for people at risk of being sent to hospital. The Lib Dem minister said the reforms would improve accountability in the system, "so there can be no excuse for people falling through the gaps between services". The Mental Health Act applies to England and Wales and any changes to the legislation would need to be agreed by Welsh government if they were to apply in Wales. He added: "This is fundamentally about transferring power to people and away from institutions. We have to end the horror of families feeling that they aren't listened to, that their concerns are ignored. Just because an

individual is sectioned under the Mental Health Act shouldn't mean that the family is excluded."

In a joint statement, Jan Tregelles, chief executive of Mencap, and Viv Cooper, chief executive of the Challenging Behaviour Foundation, said: "We welcome the government's recognition that a serious imbalance of power exists within the system, leading to the voices of individuals and their families often being ignored, with devastating consequences." But they warned that changes in the law "could take years" and are not guaranteed.

Source: http://www.bbc.co.uk/news/uk-politics-31759094?dm_i=6N7,3820M,P83NH,BKUSG,1

Would you like to get out to more gigs?

Gig Buddies is a scheme which matches up adults with a learning disability in Sussex to a volunteer befriender who has a similar interest in music and other cultural events, to go out together on a regular basis.

Every buddy has a full criminal records check and will be trained and informed about how to best support the person with a learning disability. The project operates all over Sussex, including Brighton and Hove, Worthing, Chichester, Lewes, Uckfield, Eastbourne and Hastings.

See here for more information: <http://stayupdate.org/gig-buddies-project/>

SEND reforms Guide

AFASIC: has produced a series of 7 factsheets for you to download on navigating your way through the SEND reforms - a guide for parents of children with speech, language and communications needs:

- Factsheet 1 - Introduction
- Factsheet 2 - Speech, language and communication needs
- Factsheet 3 - The Children and Families Act 2014 ...
- Factsheet 4 - What is the Local Offer?
- Factsheet 5 - What is Education, Health and Care (EHC) Plan?
- Factsheet 6 - What are personal budgets and direct payments?
- Factsheet 7 - What is mediation?

<http://www.afasic.org.uk/news/free-downloads/>



Announcing the premiere and tour of The Forest

Following on from our article in the last issue of PMLD Link we can now announce that our new show is entitled *The Forest*. *The Forest* is a multi-sensory theatre show for teenagers and adults with PMLD. It will premiere in May at the New Wolsey Theatre, Ipswich on 22nd and 23rd May 2015. Tickets for the Friday are already sold out but there are still tickets available for the Saturday shows. After the Ipswich premiere *The Forest* will tour to over 25 theatres across the country in Autumn 2015. We will be announcing the tour dates on our website shortly.

The Forest is an intriguing multi-sensory tale that immerses the audience in a world full of new sights, sounds, smells and sensations. *The Forest* follows two characters; Thea and Robin, who are trapped in lives filled with daydreams and secrets. Thea and Robin both crave an escape from their everyday routines. One day they are drawn into the dark and mysterious forest and find themselves on an unexpected journey of self-discovery filled with surprising encounters and experiences that change their lives forever.

The Forest went through its first stage of development in August and September 2014. During this development we worked closely with our new set designer, Stephanie Williams, who is designing a versatile sensory set that will be integral to the production. We go into the second stage of rehearsals in May 2015 leading up to the premiere.

Leading on from the premiere we will be working with a number of community groups that work with people with learning disabilities, devising new strategies to engage with people with PMLD in our work. We are really passionate about creating a show that is as engaging for the families and carers and as it is for the person with PMLD, making it an inclusive experience for the whole audience. If you would like to work with us in this area please get in touch.

We have been lucky whilst developing *The Forest* that many trusts and foundations have given us the generous funding we need to tour our work to as many venues and reach as many people as possible. *The Forest* development and tour has been supported by many grant giving groups including: Arts Council England; Hugh Fraser Charitable Trust; The John Thaw Foundation; D'Oyly Carte Charitable Trust; Odin Charitable Trust; Mercers Charitable Trust; Bruce Wake Foundation; Stanley Thomas Johnson Foundation; Boshier Hinton Foundation and The Eastern Counties Educational Trust.

We just want to take this opportunity to thank them, as we really could not create our work or reach as many people as we do without them.

Please check our website and social media for *The Forest* tour dates and we look forward to seeing you on tour!
Lucy Garland, Frozen Light

www.frozenlighttheatre.com
info@frozenlighttheatre.com
www.facebook.com/frozenlighttheatre

@frozentheatre #theforest

Extract from Think Local Act Personal

Getting the sums right - How to sustainably finance personal health budgets is a new briefing paper published by the NHS Confederation today in partnership with Think Local Act Personal.

The 11-page document includes case studies from organisations which have already introduced personal health budgets and sets out how organisations can address financial challenges when implementing them.

Personal health budgets can be either a direct payment to the person, a notional budget or a real budget held by a third party and give people a greater say in how money for their care is spent.

Source and full article at <http://bit.ly/1x8h9pA>

E- Learning Course 'About Me'

Over the past year we have developed products for carers, with the help of carers. For a limited time we're able to invite carers to try our e-learning course for free, to help us make sure we've got them right.

Supported by Innovate UK and in partnership with embrace-learning, we recently developed an e-learning course that carers can do online, on their own computer or laptop.

The course is designed to help carers cope with stress, recognise their own health needs and maintain a healthy lifestyle while caring.

It also shows carers how to build a network of support with family, local communities, employers and external agencies, as well as providing up-to-date information on assessments, benefits, services and support.
<http://bit.ly/1zZL5p1>

Summary of the latest issue of SLD Experience

Volume 70, Number 1, Autumn 2014

In this issue there is just one article that is relevant to young people with PMLD. 'Communicating through dance in a special educational needs secondary school' is written by Julia Barnes, a teacher at Ravenscliffe Special Needs School in Halifax and Sue Coe who works as a dancer, country dance caller and dance teacher. Julia decided to develop wheelchair dancing for her students with PMLD and was put in touch with Sue. Developing wheelchair dancing required a number of innovations: doubling the time for each dance move because of the limitation of moving the chairs around and making sure changes of direction were not too sudden; eliminating difficult moves; pairing each dance with a specific tune; and so on. Throughout the dances the adults are not simply 'pushing' the students, they are there to enable them and enhance the experience for them, for instance, by on body signing for visually impaired students to allow them to anticipate a move involving a left or right turn, by inserting a pause to build their anticipation, and by mirroring the students' tapping or vocalising to acknowledge them. Staff members were even given experience of dancing as a wheelchair user to convey how disorientating it might be for students if not done well. Choice and expressing preferences are built in, for instance, with students being given the opportunity to choose either their 'pusher' or their dance partner. At a later stage, to combat a shortage of staff, more able and reliable students were trained to become 'Wheelchair Buddies' which gave the students with complex needs enriching opportunities to interact with their peers and benefitted the Buddies themselves. The authors note that the Buddies have quite naturally extended these interactions beyond the wheelchair dancing sessions and may be seen chatting with their dance partners.



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 Sheilds,
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

April

Title: **Intensive Interaction: Building Relationships with people who have profound learning disabilities and complex needs** 20th Dublin, 23rd Taunton, May 20th Birmingham, July 9th London
Dates:
Provider: Concept Training
Contact: See provider details

Title: **Sensory Gardens & outdoor play**
Dates: 20th Manchester, 21st Birmingham, 24th London
Provider: Hirstwood Training
Contact: See provider details

Title:	Positive Ways of Changing Behaviour
Dates:	<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
Provider:	Concept Training
Contact:	See provider details
Title:	The Young Child Expo and Conference
Date:	22nd -24 th
Location:	New York City
Provider:	Fordham University Graduate School of Education and Los Niños Services
Contact:	www.youngchildexpo.com/nyc-conference/
Title:	Early Years Workshop: An Exploration of the Characteristics of Effective Learning for Young Children with SLD
Date:	24 th
Location:	London
Provider:	EQUALS
Contact:	See provider details
Title:	Learning Outside the Classroom – Taking the Curriculum Outside
Dates:	<u>April</u> 27 th Chorley, <u>May</u> 19 th London, <u>July</u> 7 th Birmingham
Provider:	Concept Training
Contact:	See provider details
Title:	Tablets, Teachers and Technology
Dates:	<u>April</u> 27 th Manchester, 28 th Birmingham, <u>May</u> 1 st London
Provider:	Hirstwood Training
Contact:	See provider details
Title:	Practical & Effective Ways of Using Multi-Sensory Equipment
Dates:	<u>April</u> 28 th Middlesbrough, <u>June</u> 10 th London, 11 th Manchester, <u>October</u> 5 th Dublin, 6 th Belfast
Provider:	Concept Training
Contact:	See provider details
Title:	Bereavement and Loss
Date:	<u>April</u> 30 th and <u>May</u> 1 st
Location:	Dundee
Provider:	PAMIS
Contact:	Email: pamis@dundee.ac.uk Tel: 01382 385154

<p>Title:</p> <p>Dates:</p> <p>Provider:</p> <p>Contact:</p>	<p>A big sensory conference. Planning a sensory education for special learners: back to basics. Flo Longhorn, Jo Grace 29th Birmingham, <u>May 6th</u> Exeter, 8th Bristol, 19th London Flo Longhorn See provider details</p>	<p>Title:</p> <p>Date:</p> <p>Location:</p> <p>Provider:</p> <p>Contact:</p>	<p>Massage in the Special School 12th Manchester EQUALS See provider details</p>
<p>Title:</p> <p>Date:</p> <p>Provider:</p> <p>Contact:</p>	<p>Very special maths-emergent learning and approaches to teaching maths. Les Staves 30th Manchester, Flo Longhorn See provider details</p>	<p>Title:</p> <p>Dates:</p> <p>Location:</p> <p>Provider:</p> <p>Contact:</p>	<p>Next Steps in Promoting Positive Behaviour <u>May 12th</u> and <u>June 2nd</u> Birmingham BILD Tel: 0121415 6970 Email: learning@bild.org.uk</p>
<p>May</p>		<p>Title:</p> <p>Dates:</p> <p>Provider:</p> <p>Contact:</p>	<p>Creativity rules OK! Sensing and learning through the arts <u>May 14th</u> Birmingham, 21st London, <u>June 18th</u> Manchester Flo Longhorn See provider details</p>
<p>Title:</p> <p>Date:</p> <p>Location:</p>	<p>Oily Cart Theatre company professional training opportunity (see July 27th) Applications by 29th May London</p>	<p>Title:</p> <p>Date:</p> <p>Location:</p> <p>Provider:</p> <p>Contact:</p>	<p>Eye gaze, I pads, apps and switches: teaching tools peomoting quality of life and independence. Ian Bean 15th London Flo Longhorn See provider details</p>
<p>Title:</p> <p>Date:</p> <p>Location:</p> <p>Provider:</p> <p>Contact:</p>	<p>Conference: Positive Behaviour Support – the human rights perspective 6,7, and 8th Dublin BILD Tel: 0121415 6970 Email: learning@bild.org.uk</p>	<p>Title:</p> <p>Date:</p> <p>Location:</p> <p>Provider:</p> <p>Contact:</p>	<p>The Pacific Rim International Conference on Disability and Diversity: “Deep Impact” 18 -19th Waikiki, Hawaii Pac Rim www.pacrim.hawaii.edu/node/1</p>
<p>Title:</p> <p>Date:</p> <p>Location:</p> <p>Provider:</p> <p>Contact:</p>	<p>Making sense of literacy for special learners Les Staves 8th London Flo Longhorn See provider details</p>	<p>Title:</p> <p>Dates:</p> <p>Location:</p> <p>Provider:</p> <p>Contact:</p>	<p>Special School Conference for Headteachers, Senior Managers, Chairs of Governors/Managers, Local Authority SEND Officers 18th or 19th Solihull, West Midlands Dr Michael Farrell and Richard Aird OBE Dr M Farrell Email: dr.m.j.farrell@bopenworld.com</p>
<p>Title:</p> <p>Dates:</p> <p>Provider:</p> <p>Contact:</p>	<p>Making ‘sense’ of sensory learning 11th Manchester, 12th Birmingham, 15th London Hirstwood Training See provider details</p>	<p>Title:</p> <p>Date:</p> <p>Location:</p> <p>Contact:</p>	<p>2015 IASSIDD Americas Regional Congress ‘Activate Change 4Disability & Diversity’ 21st – 22nd Honolulu, Hawaii Web: https://iassid.org</p>
<p>Title:</p> <p>Dates:</p> <p>Provider:</p> <p>Contact:</p>	<p>Using Soundbeam to Support the Curriculum and Communication 12th Dublin, 15th Belfast Concept Training See provider details</p>		

<p>Title:</p> <p>Dates:</p> <p>Provider:</p> <p>Contact</p>	<p>PMLD: Profound and Multiple Learning Disability – engaging children in learning</p> <p><u>May 21st</u> Birmingham, <u>June 11th</u> London</p> <p>Concept Training</p> <p>See provider details</p>	<p>Title:</p> <p>Dates:</p> <p>Provider:</p> <p>Contact:</p>	<p>Secular, religious and sensory approaches to spirituality for special learners</p> <p><u>June 4th</u> Birmingham Cathedral, <u>July 15th</u> Westminster Abbey</p> <p>Flo Longhorn</p> <p>See provider details</p>
<p>Title:</p> <p>Date:</p> <p>Location:</p> <p>Provider:</p> <p>Contact:</p>	<p>Diversity and disabilities: Improving health outcomes for black and minority ethnic young people and adults with intellectual disabilities.</p> <p>26th</p> <p>London</p> <p>Royal Society of Medicine</p> <p>www.rsm.ac.uk/events/ldf01</p> <p>E: intellectual.disability@rsm.ac.uk</p> <p>Tel: +44 (0) 7290 3942</p>	<p>Title:</p> <p>Dates:</p> <p>Provider:</p> <p>Contact:</p>	<p>Sensory Play for All</p> <p>12th Birmingham, 18th London, 26th Manchester</p> <p>Concept Training</p> <p>See provider details</p>
<p>Title:</p> <p>Date:</p> <p>Location:</p> <p>Provider:</p> <p>Contact:</p>	<p>27th European Academy of Childhood Disability Annual Conference: New ways new moves</p> <p>27th – 30th</p> <p>Copenhagen</p> <p>EACD</p> <p>https://www.eiseverywhere.com/ehome/96503</p>	<p>Title:</p> <p>Date:</p> <p>Location:</p> <p>Provider:</p> <p>Contact:</p>	<p>Conference: Children’s Rights and Early Intervention</p> <p>8 – 10th</p> <p>Stockholme, Sweden</p> <p>International Society on Early Intervention (ISEI)</p> <p>http://depts.washington.edu/isei/</p>
<p>Title:</p> <p>Date:</p> <p>Location:</p> <p>Provider:</p> <p>Contact:</p>	<p>11th European Paediatric Neurology Society Congress 2015 on metabolic, movement, neuromuscular disorders, neuropsychiatry, neurorehabilitation</p> <p>27th- 30th</p> <p>Vienna</p> <p>EPNS</p> <p>www.intercongress.de</p>	<p>Title:</p> <p>Dates:</p> <p>Location:</p> <p>Provider:</p> <p>Contact:</p>	<p>Play Therapy Conference 2015: “Minding Metaphors”</p> <p>13th</p> <p>Kenilworth, Warwickshire</p> <p>Play Therapy United Kingdom</p> <p>www.playtherapy.org.uk/ConferencesandEvents/Conferences.htm</p>
<p>June</p>		<p>Title:</p> <p>Dates:</p> <p>Provider:</p> <p>Contact:</p>	<p>Switch Access on iOS Devices!</p> <p>17th Birmingham, 19th London</p> <p>Hirstwood Training</p> <p>See provider details</p>
<p>Title:</p> <p>Dates:</p> <p>Location:</p> <p>Provider:</p>	<p>Communication with people with Learning Disabilities</p> <p><u>June 3rd</u> and <u>November 18th</u></p> <p>Birmingham</p> <p>BILD</p> <p>Tel: 0121415 6970</p> <p>Email: learning@bild.org.uk</p>	<p>Title:</p> <p>Date:</p> <p>Location:</p> <p>Provider:</p> <p>Contact:</p>	<p>BILD Accreditation Scheme – Induction Workshops</p> <p>17th</p> <p>Birmingham</p> <p>BILD</p> <p>Tel: 0121415 6970</p> <p>Email: learning@bild.org.uk</p>
<p>Title:</p> <p>Dates:</p> <p>Provider:</p> <p>Contact:</p>	<p>Secular, religious and sensory approaches to spirituality for special learners</p> <p><u>June 4th</u> Birmingham Cathedral, <u>July 15th</u> Westminster Abbey</p> <p>Flo Longhorn</p> <p>See provider details</p>	<p>Title:</p> <p>Dates:</p> <p>Location:</p> <p>Provider:</p> <p>Contact:</p>	<p>Writing a Behaviour Support Plan</p> <p><u>June 18th</u> and <u>October 29th</u></p> <p>Birmingham</p> <p>BILD</p> <p>Tel: 0121415 6970</p> <p>Email: learning@bild.org.uk</p>

<p>Title:</p> <p>Dates:</p> <p>Provider:</p> <p>Contact:</p>	<p>Using Happiness as an intervention in Behaviour Support Plans June 19th and October 30th Birmingham BILD Tel: 0121415 6970 Email: learning@bild.org.uk</p>	<p>Title:</p> <p>Date:</p> <p>Location:</p> <p>Provider:</p> <p>Contact:</p>	<p>Training to help you help sleep-deprived families 9 – 10th Birmingham Handsel Project www.handseproject.org.uk/sleep1.html</p>
<p>Title:</p> <p>Dates:</p> <p>Provider:</p> <p>Contact:</p>	<p>Designing and assessing a creative curriculum June 19, Birmingham, 26th Manchester, July 3rd London Hirstwood Training See provider details</p>	<p>Title:</p> <p>Date:</p> <p>Location:</p> <p>Provider:</p> <p>Contact:</p>	<p>The BILD Positive Support Coaches Programme 14,15, and 16th Birmingham BILD Events Team: Tel: 0121 4156970 Email: learing@bild.org.uk</p>
<p>July</p>		<p>October</p>	
<p>Title:</p> <p>Date:</p> <p>Location:</p> <p>Provider:</p> <p>Contact:</p>	<p>Introduction to Independent Advocacy 8th Birmingham BILD Tel: 0121415 6970 Email: learning@bild.org.uk</p>	<p>Title:</p> <p>Date:</p> <p>Location:</p> <p>Provider:</p> <p>Contact:</p>	<p>‘Accessibility, Diversity and Inclusivity: The Journey Continues’ 22nd and 23rd Toronto, Canada OAICD www.oaicd.ca</p>
<p>Title:</p> <p>Date:</p> <p>Location:</p> <p>Provider:</p> <p>Contact:</p>	<p>Creating with the Cart – professional training Opportunity 27th – 1st August London Oily Cart Theatre Company oilies@oilycart.org.uk</p>	<p>Title:</p> <p>Date:</p> <p>Location:</p> <p>Provider:</p> <p>Contact:</p>	<p>Writing a Behaviour Support plan 29th Birmingham BILD Events Team: Tel: 0121 4156970 Email: learing@bild.org.uk</p>
<p>August</p>		<p>Title:</p> <p>Date:</p> <p>Provider:</p> <p>Contact:</p>	<p>Using happiness as an intervention in Behaviour Support Plans 30th BILD Events Team: Tel: 0121 4156970 Email: learing@bild.org.uk</p>
<p>Title:</p> <p>Date:</p> <p>Location:</p> <p>Provider:</p> <p>Contact:</p>	<p>Sensory Story Creation Weekend 28th-30th Birmingham Woodbrooke Quaker Study Centre gillian.pennington@woodbrooke.org.uk</p>	<p>November</p>	
<p>September</p>		<p>Title:</p> <p>Dates:</p> <p>Provider:</p> <p>Contact:</p>	<p>Multi sensory ideas, recipes and resources 9th Manchester, 11th Birmingham, 13th London Hirstwood Training See provider details</p>
<p>Title:</p> <p>Date:</p> <p>Location:</p> <p>Provider:</p> <p>Contact:</p>	<p>18th SSBP International Research Symposium Education day 3rd Research Symposium 4th – 5th London The Society for the Study of Behavioural Phenotypes www.ssbpcconference.org</p>		

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, email: isen@contacts.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, email: severeprofoundandmultiplelearningdifficulties@contacts.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 Langworthy l.langworthy@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 Langworthy l.langworthy@whitefield.waltham.sch.uk



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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
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.
Bella Travis	Policy Lead, Mencap

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

PMLD LINK

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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