

# PMLD LINK

sharing ideas and information

Leisure & Pleasure

Summer 2016



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## GUEST EDITORIAL

# Leisure and Pleasure

*“Local authorities should ensure adults with PMLD are able to take part in a wide range of meaningful activities, including employment, education and leisure activities.”*

Recommendation 25: Raising our Sights report [Mansell, 2010]

Leisure is not however something we can leave to statutory providers! Writing this editorial at a time of national turmoil and uncertainty, we are reminded again of just how important it is for all of us to find pleasure in the small things and use leisure time wisely to recharge our batteries. And that is just as important for those people with PMLD whom we love and support.

This issue provides a plethora of different approaches and ideas and we hope you enjoy reading and maybe trying out some of the ideas. Of course to be able to participate in many of the activities described in this issue, the provision of accessible Changing Places toilets is vital. In his article, Martin Jackaman invites us to celebrate the tenth anniversary of this important campaign. An outdoor theme has emerged from many of the contributions we received for this issue. Tanya Silvester shares the experience of horticulture at her school. Donna Wickens and her class take to the seas and Jo and Steve Baker describe a visit to the Calvert Trust. Flo Longhorn’s piece also takes up the seaside theme. Jill Davies and Ana Read provide us with a huge list of possible outdoor opportunities to explore.

Of course you don’t have to leave home to indulge in pleasurable leisure activities. Martin Goodwin introduces us to the addictive pleasures of Pinterest as a means of sourcing practical ideas. Sarah Hall gives us some creative tips for gaining pleasure using a product from your local supermarket. Les Staves reminds us of the importance of starting with simple pleasures and the importance of looking for that all important smile. Bringing pleasure into people’s lives begins with knowing them really well, knowing what is important for them and managing resources. Lucy Dunstan’s report on Changing lives, Michael’s story from Martha Trust and Dreenagh Lyle’s account of managing her daughter’s individual budget will give readers food for thought.

Many of us turn to creative activities in our leisure time and so we have included some examples of where creativity brings joy into the lives of people with PMLD. The highly acclaimed Carousel project is described for us by Becky Loney. Andreia Silva and Jo Grace describe a sensory art project, Rosie Rushton takes us on a musical adventure and Jess Newcombe reminds us that many of our best leisure moments are shared with others. Joel Cahen introduces a highly innovative collaboration between sound and water. Stories are central to all of our lives. Maureen Philip brings us up to date with recent developments at PAMIS with multi-sensory story telling. Emily Ward and her colleague tell us about their exploration of the Great North Wood and a humorous Pete Wells shares a healthy eating story which will surely bring a smile to the faces of many.

And we hope this issue will bring a smile to your face too and re-energise you to go and promote leisure and pleasure opportunities for the people with PMLD you know.

Sue Thurman and Annie Fergusson, Guest Editors

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# 10 years and it's still all cisterns go for Changing Places toilets

Martin Jackaman

Lowri has profound and multiple learning disabilities due to Rett syndrome. She is a wheelchair user and needs complete 24-hour support with all aspects of her care. Lowri wears continence pads which can easily be changed in Nottingham's Changing Places toilet which has plenty of space and a height adjustable changing bench and a hoist to allow her to be lifted from her wheelchair on to the changing bench.



**W**e used the Changing Places toilet, it was brilliant!" says mother Bethan. *"I was able to take both daughters shopping in the morning, have lunch and then go straight on to the theatre, just like anyone else would have done. Without Changing Places toilets it's a nightmare. We try to plan our days around being home for mealtimes because Lowri needs to go to the toilet, meaning we*

*can only spend a few hours away from home. When Lowri was younger we used to put a mat down on the floor of 'disabled' loos and just muddle through – we have countless experiences at eye level of disgusting toilet floors. Now Lowri is an adult I can't lift her out of her wheelchair "*



Bethan and Lowri opened the National Trust Changing Places toilet at Attingham Park in February 2016

In July this year, the Changing Places Consortium will be celebrating our 10th anniversary since the launch back in 2006. To mark this special occasion, we have announced Tuesday July 19th as Changing Places Toilet Awareness Day and we will be working with our sponsors, Aveso, to support the celebrations on this landmark occasion. The focus of the day will be saying a big "THANK YOU" to all the hundreds of Changing Places toilet campaigners and campaigning organisations across the UK who have made the campaign such a success.

It has been their hard work and dedication over the past decade and with vital sponsorship for the campaign from Aveso (who supply and install Changing Places toilets) we now have 840 Changing Places toilets across the UK with further Changing Places toilets in Germany and Australia (the Victoria state government has just announced they will fund a further 15 Changing Places toilets as part of their state disability plan 2016/17). We have enquiries worldwide including active campaigns in Sweden, the Netherlands, the Republic of Ireland and the USA. In the UK numerous leisure venues, shopping centres, airports, railway stations, motorways services, supermarkets, sports stadia, tourist attractions, hospitals as well as endless examples of local community and city centre venues now have Changing Places toilets. High profile venues, such as the O2 Arena, Heathrow and Gatwick airports, Kings Cross and Glasgow Central stations, the Scottish Parliament, Arsenal's Emirates stadium, Old Trafford, Murrayfield, the Eden Project, Cadburys World, Giant's Causeway, Queen Elizabeth Olympic Park, Trafford shopping Centre, and Welcome Break motorway services .... to name just a few all have them. The list is endless!

Changing Places toilets were designed because standard accessible toilets were designed for independent use and not suitable for people with more complex care needs who need carer support and who may require a hoist, a height adjustable changing bench and plenty of space. The campaign was started in Scotland by PAMIS who

produced an excellent video showing parents laying their son or daughter on the floor of a public so called 'disabled toilet' to change their continence pads, something which lacks dignity, privacy and puts carer's health at risk.

In 2004 staff in Nottingham's day centres were frustrated by having to return to the day centre to change continence pads, so a team was created with various professional skills from across Nottingham City Council and NHS. Using information from other initial designs being discussed at the time, we set out to create a layout that would meet the needs of users in the special care unit. The design which the project team called a 'Changing Places toilet' was aimed at all people in our centres who needed carer support to get out of their wheelchair, many needing continence pads changing and also those who could use the toilet but needed carer support for challenging behaviours, balance issues etc.

The layout was test driven using large wheelchairs to ensure all could use it and the carers group fed into that process. It was clear that a smaller size (seven square metres) would work for children, but to suit the majority



Entrance to Nottingham City Centre public toilets

of adults twelve square metres was needed for carers turning larger wheelchairs and accommodating a privacy screen. Carers (both family and professional carers) had pointed out that they too need to use the toilet sometimes but must have their disabled son/daughter and perhaps other family members behind a screen but in the same room. Carers needing the toilet and keeping their loved one safe was previously a major barrier in toilet provision. For residential/day service staff and personal assistants a privacy screen is essential. The Consortium therefore encourages all potential providers and campaigners to meet the British Standard of twelve square metres wherever possible. However, we continue to work with providers and campaigners when the British Standard is not achievable if this is the only option due to space or funding restrictions. Nottingham City Council then included the layout in their new City Centre toilets in 2006.

Changing Places toilets soon became included in the Government Strategic Guide to Public toilets and after much negotiation and some amendments in 2009 the Changing Places toilet was included in the British Standard BS8300. In 2013 it was referenced in Part M of the Building regulations and included details of the Changing Places website [www.changing-places.org](http://www.changing-places.org). Sadly, the Government stopped short of making Changing Places a regulatory requirement.

Research undertaken by Dundee University estimates that well over 250,000 people with complex care needs such as those with profound and multiple learning disabilities, cerebral palsy, people who have suffered head injuries or strokes, motor neurone disease, multiple sclerosis, injured ex service personnel etc all need Changing Places toilets and with major advances in medical science which keep people alive longer the numbers are increasing rapidly.

Visit England are great supporters of the Changing Places campaign and it's great to hear real stories where people's lives are enhanced. As Donna Gately, General Manager of Nottingham's Motorpoint Arena says "*I came across a young women with her sister, who was severely disabled. On Sunday - they had come to see the Olly Murs concert and were very excited about seeing their hero but even more exciting about the fact they didn't need their carer or Mum to travel with them since we had opened the Changing Places toilet. How lovely to give to young people their independence, something most of us take for granted.*"



### Nottingham Motorpoint Arena Changing Places toilet

The future is bright as the campaign gathers momentum as venues realise the need and architects and planners treat this as the next step in away from home toilet provision.

The final words must come from the families;

*“Thank you Welcome Break Gordano services. Due to you putting a Changing Places toilet meant my daughter could go to her great grandma’s 100th birthday celebrations. The venue we knew would have nowhere to change her so with a four hour journey it looked unlikely we could safely take her until we discovered a Changing*

*Places toilet at your service station.”*

*“Before this service station facility my lovely son has always had to use his toilet chair in the back of our car in order to attend vital hospital appointments far from home. No privacy, no dignity and it put both him and me at risk of injury.”*

*“My son and I were very happy that there was a Changing Places toilet in the new Grand Central station in Birmingham. It meant we could have a lovely train ride and spend the day shopping and lunching in Birmingham”*

*“I was able to have a day trip to Nottingham yesterday and not worry about drinking plenty because on the map for tourist information there were plenty of Changing Places clearly marked. Hubby was happy he didn’t have to lift me”*

Changing Places strapline is *“Change one thing and it opens up a world of opportunity”*.

I think these comments say it all!

For further details visit [www.changing-places.org](http://www.changing-places.org)

### Contact Details

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The Changing Places Campaign is sponsored by Aveso (<http://aveso.co.uk/>)

## SUBSCRIPTION RATES Which are you?

Subscribers to PMLD LINK may be individuals such as a family member or a worker in close contact with people with PMLD who want to improve their knowledge and get more information. Organisations may be schools, universities, libraries, charities, businesses, etc. who want to ensure that their employees or members have access to the latest ideas, information and news. Organisations are charged a bit more for their subscription because it is assumed that they will ensure that all of their employees or members have access to the members page of the website where they can access all of the journal issues of the past three years. The differences in rates for overseas subscribers reflects the cost of posting beyond the United Kingdom.

Subscription rates for one year covering 3 issues are: UK Individual £20.00 UK; Organisation: £30.00; Non UK Individual £27.00; Non-UK Organisation: £40.00.

We hope that all readers will want to subscribe to PMLD LINK, but anybody can access information on the website and back issues of the journal up until 2012 by joining as a ‘free subscriber’. See the website’s subscribe page [www.pmlmlink.org.uk](http://www.pmlmlink.org.uk).



## Soil, seeds and smiles

Tanya Silvester

Horticulture has allowed the fundamental values of creative and interactive learning to be experienced through a range of environments and has allowed for a broad topic spectrum to be followed.

**W**hen I was first approached about writing an article highlighting the impact of horticulture within the PMLD curriculum, my initial reaction was from an academic perspective. But as I began to write, it became clear that I was excited not for the educational focus; but to be able to use this as a platform to truly showcase our inspiring and incredible young people.

Within our organisation, the key focuses for our PMLD learners link are to engage, respond and communicate. The sessions are focused around key individual targets linked to these three areas and tie in with the horticulture topic. We consistently encourage exploration, choice making and showing preferences as we believe these are the key elements to ensure they get the most out of the sessions. We do this by having objects of reference to start our sessions to ensure our learners are aware of what we are doing; we have the same object each week to ensure consistency. We have several students with a visual impairment and so tactile objects are a brilliant way to 'set the scene'. We consistently give the students a variety of textures and shapes within the lesson to encourage engagement and work on showing preferences. By repeating particular activities and structuring the lesson in the same way, it

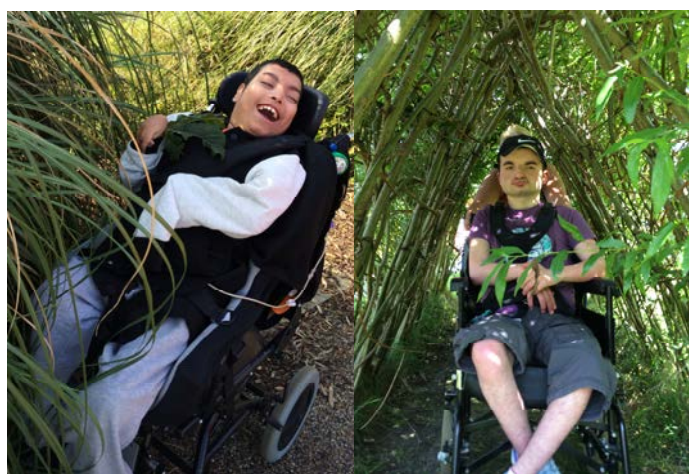
allows the students to become familiar and aware of what is coming and what is expected of them. We always use the structure of 'starter, main, plenary' to our sessions.

We have found that our 'Things that grow in the garden' scheme of work works well. Lots of great resources can be found on [www.twinkl.co.uk](http://www.twinkl.co.uk). We have been able to show whatever vegetable was our focus at different stages as well as explore, smell and taste them. We have incorporated art into sessions through using the actual food sources to mark make with. We can then develop it further and cross over to a cooking session. This allows a process of growth to be followed, as well as recognition of routine to be encouraged. Progression boards linked



to the targets set are also. The picture below is an example of one of our display boards used. The students, as part of the plenary section of our lesson, can watch their flowers grow towards their targets so they can visually see their achievements each week.

The complexities of our learners have led us to create a number of set and familiar bases where most of their academic learning takes place, with consistency of routine and familiar staff. Being within one of those 'bases' I understand the importance of such an environment and am aware of how positive this can be in allowing the students to develop in confidence through being in their 'comfort zone'. But the beauty of horticulture is that it allows for new environments to be experienced, offering time outside with nature, in the



poly tunnel, the green house and sensory garden. Left: Akbar and Right: Luke experiencing different environments, out and about with nature and in our sensory garden.

The horticulture equipment allows for the exploration process to be different from everyday objects. It creates a multi-sensory experience without even trying, with the different temperatures, smells and clothing - not to mention the variety of topic areas on which we can focus. The link to cross-curricular subjects is made easier when thinking in the context of horticulture as a subject area. It enables the awareness of the importance to looking after and nurturing things, watering plants encourages responsibility; fundamental values linked to Living Skills and the topics within it. As mentioned earlier, art and cooking have been massive links for us, especially when working with our P1-3 learners.

One of the biggest positives for us is the range of different experiences that horticulture has been able to give. Our students love to 'get messy' and the vast amount of textures available to explore highlights the enriched ideas that can come from having such a subject in the curriculum. Although we do have specialist staff

working within the subject area, the variety of topic areas paves the way for people like myself, with just a basic understanding, to still be able to create enriching



and stimulating lessons for our learners to access. Zakir, exploring our leek and creating some wonderful artwork.



Akbar showing brilliant preferences through his facial expressions and vocalisations when working with Paul, our specialist horticultural member of staff.

Fundamentally, horticulture embraces continuous encouragement to explore new things. The diverse areas of focus that are linked to it promote an enriched and stimulating environment consistently. Talking from our experiences, the simplicity of just going outside to embrace the elements can have a dramatic effect on the mood and concentration levels of our young people. The most important thing for us is to see our learners focused, engaged and happy, all aspects that are definitely covered within these sessions. For these reasons I believe it is so important for opportunities to embrace all things horticulture to continue, develop and become a bigger part of the PMLD curriculum.

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## The Structured Sensory Art Project goes international: CriARTE

Andreia Silva and Jo Grace

The Structured Sensory Art project was set up by The Sensory Project (Grace 2015a; Grace 2015b) with aims to

1. Provide individuals with profound and multiple learning disabilities (PMLD) opportunities to independently create works of art.
2. Leave a legacy of engagement behind in host settings
3. Create awareness of the abilities of individuals with profound and multiple learning disabilities and of the individuals themselves as artists.

The project worked to enable the artists to create in many ways, the most important of which were:

- Mindful facilitation.
- Structured sessions enabling consistent repetition to foster engagement and interaction.
- A responsive studio environment.

Following the pilot, work produced by the participating artists was gathered together to create the Uninhibited exhibition which toured the UK, accompanied by information to raise awareness of the Changing Places Campaign.

Andreia Silva, an occupational therapist at a residential institution in Portugal, attended Jo Grace's Sensory Story Creation weekend at Woodbrooke Study Centre last summer. This workshop included information about The Structured Sensory Art Project and offered access to the Uninhibited exhibition, at the time hosted by Woodbrooke. Inspired, Andreia decided to use the same approach to give her residents with PMLD the same opportunity as the Structured Sensory Art Project artists. Based on her experiences at Woodbrooke, and through ongoing discussions with Joanna, Andreia began developing "CriARTE" in her Portuguese work setting.

Andreia's aim through CriARTE was to provide a stimulating environment that allowed inspiration to grow in the new artists and give them ways to express that inspiration through painting. CriARTE created an inspiring immersive sensory studio experience for her artists, promoting access to creation through a responsive environment and the responsiveness of the facilitators supporting the artists.

CriARTE followed the same principles as The Structured Sensory Art Project but applied its own unique structure within the sessions. CriARTE's first session was a group experience and then subsequent sessions were individual experiences. All the sessions took place in the same familiar room, which was transformed into an immersive environment full of sensory experiences to stimulate seven sensory systems. Each session had a five part structure:

1. Explore light, movement and whiteness.
2. Experience colour, energy, movement, and mess!
3. Explore stimuli relating to different colours, sounds and textures.
4. Independent creation time.
5. Feel what just happened. This part of the session (as with all parts) was as important to the facilitators as to the artists.

Five new artists with PMLD participated in the group and individual sessions. As with the Structured Sensory Art Project CriARTE drew in artistic facilitators who had not previously supported individuals with PMLD. The sessions were an intense experience both for the new artists and the facilitators:

"I felt something that I've never felt before; the way I facilitated him on his process, the interaction that was created. It will change the way I will work with him from now on!"

Facilitator - Social Educator from the residential care facility

"Facilitating the session was really special for me. I hope it had been as special for them (the artists) as it was for me"

Facilitator - Portuguese performing and plastic artist

All of the artists engaged with different stimuli and expressed themselves in different ways through painting. Artists were able to select colours for their paintings through facilitators heeding their preferential engagement with stimuli during the exploratory parts of the sessions. CriARTE allowed the artists to create and express themselves in ways they hadn't tried before; it also strengthened relations between the artists and facilitators. During the sessions some artists smiled, vocalised, made eye contact, touched hands and even



hugged facilitators for the first time. One artist in particular springs to mind, (a gentleman in early middle age), prior to taking part in CriARTE he had only ever looked to interact with his mother, whom he would reach out for and hug. During the setting up of the studio for one of the CriARTE sessions this gentleman reached out for Andreia's hand. She allowed him to take her hand and explore it: he pulled it to his face where he explored it with his mouth in motions half way between a kiss and a bite. This was the first time he had ever reached out to anyone other than his mother. Andreia allowed him to explore her hand for several minutes until he stopped. Later that day he reached out to her again, this time hugging her as he has previously only ever done to his mother.

Andreia says:

"When we create opportunities for this persons to express themselves, to communicate, and when we truly are present in the moment with them, interacting and facilitating them, everything can happen, and what comes out of it, is worth spreading. So the next goal of the project is to take the art produced by these amazing five artists to be exhibited in a local gallery."

## Contact Details

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Jo Grace Email: [sensorystory@gmail.com](mailto:sensorystory@gmail.com)

CriARTE will look to create an exhibition of their work in Portugal, but for the moment the artists are still enthusiastically painting more works!

## References:

- Grace, J. (2015)a Introducing the structured sensory art project. The SLD experience, Issue 72, 18 – 24
- Grace, J. (2015)b The Structured Sensory Art Project. PMLD Link Vol 27. No 3. Issue 82. Pg 10-12



## Meeting funding shortfalls and making a difference: Michael's story

Martha Trust

Martha Trust offers residential, respite and day care for people with profound disabilities at three homes, two in Deal and one in Hastings. Everything we do at Martha, from sailing and horse riding to relaxing in the sensory room, is designed to improve the physical health and emotional wellbeing of the people we support.

In the current climate we, like our peers in adult social care, are facing increasing strains on our finances due to funding cuts. These often impact some of the most vulnerable people in our society. At Martha we are focussed on making up the funding shortfalls we are now facing. We have been collaborating with the families and Case Workers to find ways in which to secure funding. Our physiotherapist, Louise Myeni based at our home, Mary House, in Hastings has seen the benefits of this approach.

Michael has lived at Mary House now for over nine years. For the past year Louise has worked closely with Michael's parents, his Case Worker and local services to assess and identify what his continuing health needs are. The hard work and collaboration has paid off, with Louise successfully securing funding of around £8,500 for new equipment and a further £2,250 for Aquatic Therapy.

As part of Louise's assessment of Michael she started by chatting with staff and Michael's family to find out what

Michael likes to do, and what he has enjoyed in the past but is no longer able to do. It was found that Michael enjoyed standing but was no longer able to. The physical assessments identified he was in desperate need of new equipment. Michael's existing Lying Support had broken pieces. Some of the equipment he was using was almost ten years old and had come with him at the point of transition from paediatric care to adult care, an all too common problem. He also needed a new wheelchair as he had grown since his last assessment. In total it was identified that Michael needed a new Lying Support, made to measure Standing Aid and Commode and a new wheelchair. An application for funding for an Aquatic Therapist to draw up a programme of activity and training for Martha staff to deliver the aqua therapy along with some sensory equipment was also included. Louise realised it was going to be a challenge to secure funding for all these items. Her approach was to compile a report which focussed recommendations on health care needs, around posture and activities incorporating clinical evidence to support her case. The report included links to Government requirements and best practice guidelines. The report was presented to the Case Worker, who was a brilliant advocate with the funders and thanks to her enthusiasm managed to secure the funding Michael needed.

Michael has recently received a new Lying Support, a piece of equipment that ensures a good and safe nights sleep for him, and his new wheelchair with custom moulded chair is supporting him well. A new Standing Aid has also been supplied and the team are working towards safely re-establishing this activity with him. Funding for his aquatic therapy has been provided and it won't be long before Michael can enjoy his time in the pool.

Benefits of securing this additional funding are already making a huge difference to the life Michael is able to lead. He is now able to get more involved in day to day activities which provide greater mobility and independence. Standing is something so many of us take for granted but for those with profound physical disabilities they are rarely able to experience. Clinical evidence shows a real health benefit to standing. From physical benefits like increasing bone density and muscle length through to the huge psychological benefits from just being at eye level with someone, will enable greater participation in activities like cooking.

Louise said that *'The drive for me and motivation to succeed is that we are looking at each person as an individual with an aim to meet their individual needs rather than adopting a generic approach. The co-operation of everybody involved has been key to securing the funding for Michael. From Michael's parents who know his needs better than anyone, with their support*



*and willingness in making up shortfall to bring in services like the engineer to move his case for support along. Success has been about working together across all agencies to ensure the best outcome for Michael.'*

Michael's Mum said *'Michael's welfare and happiness is of the utmost importance to us. To be happy you need to be comfortable. Louise has been the driving force behind investigating, watching and studying Michael's positioning whether it be sitting, lying or standing. She has researched and reported in great detail Michael's needs and requirements. Her fight, enthusiasm and passion to get things right for Michael has paid off and she has got us the funding long over due for the much needed equipment and Aquatic Therapy for Michael.'*

At Martha we are proud to have colleagues like Louise on our team, together we are able to make a genuine difference to the lives of the people we support.

## Contact Details

For more information or to find out more about the work of Martha Trust, please contact Geoff Stiff  
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# Exploring the great outdoors

Jill Davies and Ana Read

Jill and Ana from the Foundation for People with Learning Disabilities have compiled a useful fact sheet on leisure opportunities for children and adults with complex health needs and/or limited mobility which they have generously allowed us to reproduce. Take a look and see if there is something that takes your fancy and get out and enjoy the great outdoors!

## Motorhomes

**M**otorhomes are a great way of getting around and visiting new places. They are ideal for disabled people and their families, friends or carers who are looking for a self-catering holiday, especially since there are various models that have been specially adapted. You have a few options: you could hire a motorhome, buy a new or second-hand one, or adapt an existing vehicle.

### Where to get a motorhome

A number of companies across the UK sell, rent or adapt wheelchair-accessible motorhomes:

- Bruce Trust (<http://www.brucestrust.org.uk/>) has an adapted motorhome for hire, as well as canal barges.
- Coachbuilt GB (<http://www.coachbuiltgb.co.uk/>) sells wheelchair-accessible caravans and motorhomes.
- JC Motorhomes ([http://www.jcmotorhomes.com/motorhomes/keystone\\_raptor\\_disabled.htm](http://www.jcmotorhomes.com/motorhomes/keystone_raptor_disabled.htm)) has adapted vehicles available for hire.
- SimplyWav (<http://www.simplywav.co.uk/vehicles-for-sale/wheelchair-accessible-caravans>) sells accessible vehicles.
- Nirvana Mobility (<http://www.nirvanamobility.co.uk/adapted-accessible-vehicle-sales/adapted-motorhomes-caravans/>) sells accessible vehicles.
- Preloved (<http://www.preloved.co.uk/>) is a website selling second-hand things including accessible vehicles.
- Wheelyindependent (<http://www.wheelyindependent.co.uk/>) has accessible motorhomes for hire.
- WildAx Motorhomes (<http://www.wildaxmotorhomes.com/>) builds motorhomes.

## Hiring costs

**H**iring a motorhome can cost anything from £500 to £1,000 per week, so it's a good idea to shop around before committing to anything. A good place to start looking is your nearest Wheelchair Users Group (<http://www.wheelchairusers.org.uk>). In certain cases, people

with disabilities can buy or hire an adapted motorhome without paying VAT, so do check the HMRC site to see if you're eligible: <http://www.hmrc.gov.uk/helpsheets/vat1615.pdf>.

## General resources

- Disabled Motoring UK (<http://www.disabledmotoring.org/>) the UK charity for disabled drivers, can give you general information on motorhome options.
- MMM Mobility ([http://www.outandaboutlive.co.uk/Motorhomes/News/General/MMM-Mobility-online-now/\\_ch1\\_nw1714\\_pg1](http://www.outandaboutlive.co.uk/Motorhomes/News/General/MMM-Mobility-online-now/_ch1_nw1714_pg1)) is worth a look – it's a free, online, annual guide to motorhoming with a disability.
- Wheelgotravelling (<http://www.wheelgotravelling.info/AboutOurselves.html>) is a blog written by a couple who travel around in a wheelchair-accessible motorhome.

## Trikes

**H**aving your own adapted tricycle is another great means of getting out and about. Trikes can help children with disabilities gain independence and explore, enabling them to truly participate in outdoor family life. What's more, they are recommended by many therapists as a brilliant way of improving muscular development. You can choose from a variety of models designed to meet the specific needs of different ages and conditions. Here is a selection of what is available:

- TomCat trikes are custom-built to suit the individual needs of children and adults with a range of disabilities. For details on the ranges available, from the Classic TomCat Trike to TomCat Trailer Trikes, visit: <http://www.tomcatspecialneeds.co.uk>.
- Mission Cycles' range includes models such as the Mission Piggyback Mk 2, which has been designed to give more stability than the traditional trailer bikes with a single rear wheel. The Piggyback Mk2 will tow with no side-to-side movement, which makes it ideal for children with a balance problem.

For details visit: <http://www.missioncycles.co.uk/child-trikes-c-22.html?osCsid=gm8cd9051jtq7bvcot94tbj6m0>.

- The Mobility Aid Centre has a range of models, including the Therapy Terrier Tricycle. Visit: <http://www.themobilityaidscentre.co.uk/c/23/childrens-trikes-bikes/>.
- Get Cycling Disability provides cycles and cycling support to special schools, community groups and individuals, and supplies new and refurbished cycles to the Family Fund charity. They have a shop in York and they run try-out roadshows across the UK: <http://www.getcycling.org.uk/get-cycling-disability/> and [www.getcycling.org.uk/special-needs.php](http://www.getcycling.org.uk/special-needs.php).
- Many cycle trail centres have adaptive bikes to hire, for example, [www.pedalabikeaway.co.uk/](http://www.pedalabikeaway.co.uk/) in the Forest of Dean. Living Made Easy provides a list of all the charities and organisations that fund equipment for children with limited mobility. For more information visit: <http://www.livingmadeeasy.org.uk>.

### Adventure holidays

For an overview of some of the adventure holidays available in the UK for people with disabilities, have a look at the Disability Holidays Guide: <http://www.disabilityholidaysguide.com/disabled-activity-and-adventure-holidays.aspx>. This online guide enables you to search for a whole range of activities and breaks, with lots of suggestions for children's activities.

Activity centres recommended to us by families include The Calvert Trust, whose motto is 'It's what you can do that counts!' The Calvert Trust supports people with disabilities to have exciting and challenging adventure holidays individually or as a family, helping them to fulfil their dreams and do things they never thought they could do. Whether you're interested in abseiling, archery, canoeing or just exploring the outdoors, the Calvert Trust is the place to go! For details on their range of accessible activities and centres, visit: <http://www.calvert-trust.org.uk>.

Other recommendations are CenterParcs (<http://www.centerparcs.co.uk/>), which offers accessible lodgings in a variety of settings in the UK, and Avon Tyrell Outdoors Activity Centre (<http://www.avontyrell.org.uk/page/home.html>), based in the New Forest, Hampshire, which provides day and residential holidays that are fully accessible.

### Barge holidays

A few charitable trusts specialise in providing self-drive canal boats with specially adapted wheelchair facilities, enabling people with limited mobility to enjoy a holiday with friends or family.

Here are some organisations that offer barge and canal boat holidays:

- The Bruce Trust (<http://www.brucetrust.org.uk>)
- The Lyneal Trust (<http://lynealtrust.org>)
- The Canal Boat Project (<http://canalboat.org.uk>)
- The South Staffordshire Narrowboat Company (<http://www.ernestthomas.co.uk>)
- The Willow Trust (<http://www.gloucesterdocks.me.uk/studies/willowtrust.htm>)
- The Disabled Afloat Riverboats Trust (<http://www.glosdart.co.uk>).

And for a full region-specific list of organisations that provide narrowboats or widebeam boats for people with mobility difficulties, visit:

<http://www.waterwaysholidays.com/blog/accessible-wheel-chair-friendly-boating-holidays/>

### Hiking

Hiking or rambling in the countryside is another popular leisure-time activity.

The Disabled Ramblers offer a wonderful way of getting involved. They help people with limited mobility to get out and explore the countryside, and organise a range of graded rambles according to difficulty and needs. They go out in all weathers and explore many different terrains. Some of the routes are suitable for power chairs or shopping buggies, whereas others require large scooters capable of travelling over rough terrain. Many of their rambles are led by staff who live locally, which is great for learning about the area. Whatever your mobility needs, the Disabled Ramblers can help you have the freedom to explore. For details visit: <http://disabledramblers.co.uk/>.

Walking for health ([www.walkingforhealth.org.uk](http://www.walkingforhealth.org.uk)) promotes local organised walks or rambles and often includes accessible routes

### Other leisure opportunities

Here are some links to some other popular activities and resources:

- horse riding <http://www.rda.org.uk/>
- gardening <http://www.gardeningfordisabledtrust.org.uk/>
- swimming <http://www.swimming.org/britishswimming/disability-swimming>
- art <http://www.disabilityartsonline.org.uk/>
- skiing <http://www.skiclub.co.uk/> and <http://www.disabilitysnowsport.org.uk/>
- reading or story-telling – the second generation Kindle by Amazon has a read-aloud function for people who are unable to read but enjoy books and stories <https://www.amazon.co.uk/gp/>

feature.html?docId=1000756063 and you may also want to consider multi-sensory books such as Bag Books ([www.bagbooks.org.uk](http://www.bagbooks.org.uk)) or Joanna Grace's website (<http://jo.element42.org>) which are an interactive resource aimed at those who are unable to read or benefit from books. Stories are told in a very tactile way through actions, smell and touch.

- Accessible Britain (<http://www.accessiblebritain.co.uk/>) is a good source of information on what accessible activities and events are available in your local area.

- PHAB (<http://phab.org.uk/>) runs holiday clubs and provides opportunities for group activities if you want to join up with other families or young people on supported holidays.

#### Contact details

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## Get Involved!

We welcome any contributions to PMLD LINK. We are very flexible in our requirements and 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](mailto:pmlmlink@gmail.com)**

# Go and Pin It! Using Pinterest

Martin Goodwin

Recently I stumbled across Pinterest and have become excited in regard to the many ideas found there to stimulate and enhance opportunities to learn that are meaningful and novel. Pinterest is an online community (via the web or an app) where people share and post ideas.

In this short article I will recommend 10 of my favourite finds from Pinterest and begin to discuss how they might be used with people with PMLD.

**1. Labyrinth** <http://pin.it/bK1v7c1>

A simple game that could promote tracking of the ball and begin to promote hand-eye coordination. I would personally start with two or three holes in which the balls disappear, but the idea made from a cardboard box that has two layers, offers possibility for great shared interaction as you try to navigate the ball successfully round the course and 'whoops –where has it gone?' when it disappears.

**2. Dancing Fairy Ring** <http://pin.it/NVrBbP4>

Dancing is a fun activity, but even more so with props. Props stimulate and can encourage movement. This simple idea uses curtain rings and ribbon strings that flow as they are wafted around.

**3. Marble Runs** <http://pin.it/3ZvcU2r>

A few years ago I used this idea and children of all abilities loved it. Everyone had fun constructing tubing and observing the trajectory of the balls (some bigger than marbles) roll down, in and out of the circuit. It's great to find variations of this simple theme.

**4. Push Ball** [http://pin.it/PCK4Q2\\_](http://pin.it/PCK4Q2_)

This activity uses firm plastic balls that have string threaded through them so that they can be moved along. Balls of different colours can be used and the frame could be placed in different proximities to the person (close or further away) or at different heights to encourage reaching.

**5. Water Station** <http://pin.it/8uoQ33t>

Pieces of unused objects could be salvaged to create this outdoor installation. Water is fascinating and enjoyable to many. This activity allows people to pour water and watch it move through the objects or even make them



move in some way. Water can be made more visible when coloured or use bath soap for extra sensory experience.

**6. Crazy Golf** [http://pin.it/Cqmv\\_Q3](http://pin.it/Cqmv_Q3)

Fancy a round any one? I think this idea has many possibilities; it could be presented as a table top activity where a small group or pair play a round or simply on a tray attached to a wheel chair. Dependent on the ability of the young person a club could be used or even two people could carry out a simple rolling game.

**7. Sensory Bag** <http://pin.it/MbM6vSJ>

Anyone entertaining a person with PMLD on a long day out may see the use of this. On Pinterest I saw a portable bag called a Trabasack that provides a tray and a bag. The bag can be adapted by attaching some sensory objects and toys to provide a portable stimulation centre.

**8. Masher Painting** <http://pin.it/ynSzD7x>

Using different props and tools to make marks with can offer a variety of interesting visual effects. Try a variety of safe cooking implements, using a roller or even a bog brush (clean of course!). The different implements also offer vital opportunities for learning to use a range of tools in fun and creative ways.



**9. Rolling, Rolling** [http://pin.it/Pz\\_fXF3](http://pin.it/Pz_fXF3)

Recently I used this activity to engage some children with PMLD in a space theme. A small ball is placed inside either a big silver or matt bowl or a small Indian curry bowl that you can either watch rotate or help to push a ball around provided a stimulating opportunity. Try using a light ball in a silver bowl for extra effect.

**10. Edible Sensory Balls** <http://pin.it/T4soYLa>

These balls that can be pulled, stretched smeared and even eaten offer a great sensory experience. Jelly is formed in ice ball makers and then the shape can be squelched or splatted. Different colour jellies can be used; the fruity smells will also stimulate.

If you are interested, I have set up a Pinterest board based on ideas and activities that I am personally collecting. Simply search PMLD or Martin Goodwin and you should be able to find it. Even better, why don't you join the Pinterest community; go and pin your ideas!

**Contact Details**

Martin Goodwin

<p>Body shape distortion is not inevitable for people with neurological conditions or multiple disabilities. With correct positioning, body shape distortion is preventable and can even be corrected later in life. The right postural care, throughout the day, can maintain or improve body shape and physical ability. The earlier the intervention, the better – but it is never too late to start protecting and restoring someone's body shape. Costly, and stressful, surgical interventions can also be avoided.</p> <p>This conference brings together key national figures to highlight the need for change, identify what is needed and commit to acting to ensure that people with multiple disabilities do not suffer any more from health problems that are preventable.</p>	<p><b>Speakers include:</b></p> <p><b>Chris Hatton</b> - Professor of Psychology, Centre for Disability Research, at Lancaster University (UK)</p> <p><b>Jenny Whinet</b> - Family carer</p> <p><b>Anna Marriott</b> - Improving Health and Lives Learning Disabilities Observatory (iHal) project manager</p> <p><b>Sarah Clayton</b> - Simple Stuff Works Associates Ltd (a family run organisation with a passion for protection of body shape)</p> <p><b>Joanna Grace</b> - The Sensory Stories Project</p> <p><b>Adam Hoare</b> - Red Embedded Systems</p> <p><b>Suzanne Carter</b> - Physiotherapist Mid Yorkshire Hospitals NHS Trust</p> <p><b>Gail Russell</b> - Independent Occupational Therapist and Seating Specialist</p>	<p><b>'Got My Back'</b> <i>A national conference on the way forward in postural care</i></p>
		<p><b>12th September 10.00am - 3.00pm</b></p>
		<p><b>Venue:</b> <b>The Studio,</b> <b>7 Cannon Street,</b> <b>Birmingham B2 5EP</b></p>
		<p>No one is too disabled, No one is too challenging, No one is too complex, to live an ordinary life.</p> <p><b>To book your place at the conference, please contact us:</b> <b>Tel: 0300 302 0770</b> <b>Email: <a href="mailto:ask@changingourlives.org">ask@changingourlives.org</a></b></p>
		<p><b>[ RED ]</b> <b>EMBEDDED</b></p>  <p><b>Changing Our Lives</b></p>

# Orchard Class News, Foxwood School, Hythe, Kent

Donna Wickens

The highlight for Orchard Class this year has been the opportunity we had to go on a boat trip around Dover Harbour on 15 March. We were lucky to have this experience provided free of charge by the Wetwheels South East charity, who are trying to raise awareness of their hope to buy a boat to be based in the South East.



Please see their website: [www.dover-marina.com/wetwheels/](http://www.dover-marina.com/wetwheels/) or visit their Facebook page: Wetwheels South East - Facebook

## Contact Details

Donna Wickens  
Orchard Class Teacher, Personalisation Leader,  
MOVE and Manual Handling Trainer, and PE Co-ordinator

# A project of shared leisure activities for students with profound and multiple learning difficulties (PMLD) with peer mentors

Jess Newcombe

This article explores the types of activities that were used for students with PMLD and their peers following a year programme of peer mentoring. Activities were carefully selected to create opportunities for working together and to ensure accessibility for students with PMLD and their peers. Activities were chosen to encourage collaboration between peers and students with PMLD which would sustain both parties' interests and create opportunities for communication and for relationships to develop.

## What is Peer Mentoring?

Peer mentoring consists of students from a different establishment (peer mentors) attending a weekly session at a special school to take part in a variety of activities that contribute to achieving an ADSAN qualification at the end of the academic year. The purpose behind the activities is that students with PMLD and the peer mentors work together on the same thing. No-one is 'helping' instead there is an atmosphere of support and togetherness. The activities create opportunities for communication and interaction and provide a focus for working together.

A recent survey identified that 67% of the British public feel uncomfortable talking to disabled people and nearly half do not know anyone who is disabled (Aiden and McCarthy, 2014, p.1). Aiden and McCarthy (2014) suggest that disabled and non-disabled people in Britain believe that everyday interactions may increase understanding and acceptance of disabled people.

## How is it organised?

The peer mentoring sessions took place on the same day and at the same time each week and always followed a similar format. Each activity was a mini project in itself so that all the students knew what they would be doing and knew what to expect each week. The sessions took place in the hall at the special school to provide a suitable space for the amount of people taking part and for ease of access for the wheelchair users and for personal care, along with suitable seating and medication being on hand for students with PMLD. To prevent any bias, the sessions were run by an external agency so that there wouldn't be any prejudices towards either school and so that the students had someone impartial to turn to if there were any issues.

All these aspects (having staff from a different school, the different venue of the hall and an external person running the sessions) each acted as a form of 'object of reference' for the students with PMLD in order to signify a change from the usual curriculum and that the peer mentors would be involved in the session.

## Peer mentors

The peer mentors were students from a social emotional behavioural difficulties (SEBD) school. The project involved 9 peer mentors from the SEBD school and 5 students with PMLD from the special school. Staffing was consistent from each school to support both sets of students; there were 5 staff members from the special school and 4 staff from the SEBD School.

The peer mentors were recruited by the external agency by delivering assemblies at the SEBD School. The students were informed what the project would involve and the needs and requirements of the students with PMLD that they would be working with were discussed.

There was a six week introductory programme which taught the peer mentors about the difficulties that pupils with PMLD may face, such as having pre verbal communication, challenging behaviours, physical impairments and delayed cognitive development.

Once the peer mentors had completed their introductory sessions, the peer mentoring sessions began.

## Peer mentoring sessions

It was made clear to all students and staff that there was no obligation to attend the sessions and that they could cease to attend at any time of the programme. For the students with PMLD this was also the case using an ongoing process. Skanfors (2009) promotes an 'ethical

radar' which uses the principle of 'show no, say no'. This is why it was essential to have familiar staff for each student so that they could identify if there were any changes in behaviours.

Ensuring that everyone wants to be there creates a positive atmosphere that is essential for the peer mentorship sessions. To promote the positive atmosphere peer mentors and students with PMLD were free to choose who they worked with for the activities during the sessions.

This happened naturally and groups formed depending on the activity and who attended the sessions. The groupings needed to be flexible to take into account the nature of the students involved in the programme. Both the peer mentors and students with PMLD had variable attendance.

It took a little while for a cohesive group to form, but after a few sessions the peer mentors that had decided to attend became consistent.

## Activities

The activities for the sessions were planned taking into account the special school's curriculum and termly topic which provided consistency for the students with PMLD. The activities were all adapted from the ASDAN personal development programme working towards the Bronze award. Activities needed to be practical and suit a range of abilities. They needed to be something into which both students could input and hence create a 'working together' ethos.

One activity involved organising and planning a party. This encouraged conversation between peer mentors and students with PMLD on things that they might have in common as part of 'Kids culture' (Corsaro 2003), such as music and foods they like. This activity created chances for students with PMLD to communicate their options and choices about things that are important to them in a conversation style. Then at the party the peer mentors were able to see the students with PMLD's reactions when they liked or engaged in something that

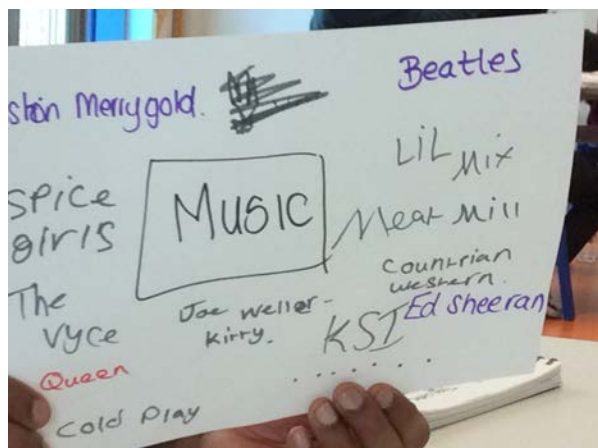
was special to them. This provided opportunities for consistent reactions for the students with PMLD and created opportunities to develop anticipation skills.

Another activity included taking part in a sporting activity. Boccia and football were used as they provided a range of activities that were accessible for all. For football, a specialised ball was used so that wheelchair users were able to 'kick' the ball. There was no formal game of football created, therefore peer mentors didn't become competitive. Instead they passed the ball to the students with PMLD who could then kick the ball or not, kick the ball in the wrong direction or do something entirely different with the ball. I think one student with PMLD even sat on it!

Boccia provided a more relaxed and calmer approach and this did become competitive with different teams. Teams were arranged with a mixture of peer mentor and students with PMLD and were encouraged to sit alongside each other. The game of Boccia was brilliant and made the peer mentors aware of the time necessary for students with PMLD to respond. It helped to develop fine motor and release skills for the students with PMLD. The peer mentors encouraged students with PMLD to handle the Boccia balls and to bowl them as part of the game.



Another activity involved students with PMLD and the peer mentors working together to create a window box, which provided opportunities for choice and decision making. The peer mentors used their knowledge of the students with PMLD's communication methods to offer them choices such as choice of colour and where to put items in order to develop communication and decision making skills. The peer mentors used their knowledge of the students to explore objects with them such as smelling the flowers, exploring lights and watering the plants and watching streamers and windmills blowing in the wind. This activity developed opportunities for close proximity working, including hand-over-hand sensory exploration of plants, soil and ribbons.





### Summary

The main aspect of the project has been the creation of the correct atmosphere to enable positive relationships to develop between the peer mentors and students with PMLD. This has been supported through using consistent staff from both schools and educating and supporting each other about both sets of students. The activities have been used as third objects (Mitchell 1981) to create relationships between peer mentors and students with PMLD and provide opportunities for interaction. All sessions have been positive and seemed to have had an effect on both students and their respective establishments, creating strong links between the schools. All the students appear to have enjoyed the

sessions and those that can communicate in formal ways have given positive feedback. Both sets of students continue to work well together, they now understand the different ways that people can communicate and have developed complex and supportive relationship with one another.

### Contact Details

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You can access these via the buttons on our website ([www.pmldlink.org.uk](http://www.pmldlink.org.uk)). The addresses are as follows:

<https://twitter.com/pmldlink>

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# Musical Adventures: for children and young people with profound and multiple learning difficulties

Rosie Rushton

Big Top Musical Adventures is a community interest company founded in 2014 to provide fully immersive multi-sensory musical experiences for young people with complex needs and their families.

Originally funded by The National Lottery and now by Children in Need the community interest company provides monthly music sessions supporting families to enjoy exploring meaningful music making together. The sessions, based at the Midlands Art Centre, Birmingham are thematic in their creation, and explore music making in an engaging and accessible way.

Big Top was founded to meet the creative and expressive needs of young people with profound and multiple learning difficulties across the Birmingham and the West Midlands. As a music specialist I had worked in a number of special schools, meeting children and young people with an obvious love for music. Music was an interest and motivation that sustained their engagement, which they could share with others and become part of something bigger. So why limit this to the classroom?

Our sessions use distinctive smells, lighting and textures to engage participants in the musical adventure. Each session includes one-to-one hands on opportunities for young people with PMLD to engage with a range of musical instruments in close proximity. The vibrations made by the clarinet, didgeridoo and Hapi Drum are always a big hit, with participants enjoying them played onto their heads and toes! This closeness is necessary for our adventurers, it allows the time and space for them to engage, and respond, and gives us the chance to really personalise the workshop to their needs. Moving onto the free play section everyone is enabled to explore ways of making new sounds, families are encouraged to be creative with how the instruments are used, growing in confidence to be ever less conventional and experimental.

Big Top works with families, with carers and siblings to make music together. It aims to unite in enabling families to take equal parts in the creative process. It provides a safe environment where the creative output of young people with profound and multiple learning difficulties can be shared with their siblings and friends. Where parents and carers can be supported to enjoy music



making and can consider their children as musicians and adventurers. At Big Top music is made with, and not to, young people with profound and multiple needs.

Big Top works with student volunteers from Birmingham Conservatoire to offer shadowing opportunities. These aim to increase the experience and develop the skill sets of future musicians who have an interest in working with children and young people with PMLD and their families. For more information on Big Top Musical Adventures C.I.C get in touch: [info@bigtopmusic.co.uk](mailto:info@bigtopmusic.co.uk).

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# Express Yourself!

Lucy Dunstan

Changing Our Lives (COL) is a rights-based organisation that works in co-production with people with disabilities and people experiencing mental health difficulties of all ages and backgrounds to deliver solutions to each particular need, and strive to achieve positive, individual-focused outcomes around rights, health and social inclusion.

In March 2016 NHS England commissioned COL through the Learning Disability Engagement Grant to support the involvement of people with learning disabilities who are given the least chance to have their say. This is so that people:

- have their experiences listened to
- can be involved in improving healthcare
- can tell NHS England about the issues and challenges that make it harder for them to get the same quality of healthcare as everyone else.

Understanding our own emotional wellbeing is important for us all, but for people with learning disabilities, emotional health is often overlooked, as people tend to see the learning disability first or even label individuals as 'challenging' rather than exploring any root cause.

People with learning disabilities, particularly those with profound and multiple learning disabilities (PMLD) often find it hard to access mainstream services and face difficulties with having their voices heard – particularly in relation to decisions about their healthcare and support. These challenges mean that people with learning disabilities don't get the same quality of healthcare as everyone else. In recent years some people with learning disabilities who have accessed mainstream health services have suffered or died because of neglect or improper treatment. Often health services and supports for people with learning disabilities are seen as the responsibility of "specialist services". In our experience, often these specialisms help perpetuate health inequalities for people with learning disabilities and set people with learning disabilities apart, marking them as different. The consequence of this is that often people with learning disabilities are not seen as the responsibility of mainstream health provision, and so specialist 'empires' grow.

The 'Express Yourself' project enabled young people to communicate their thoughts and wishes by using the arts as a vehicle for self-advocacy as an alternative method of engagement.

Four young people with learning disabilities were supported to facilitate workshops with 16 of their peers,



where issues relating to emotional wellbeing were explored. These young people spent time with a performance poet looking at important words and meanings to see how these could be incorporated into poems.

The poet used beat boxing techniques: young people danced and clapped along performing their own beat boxing and learning about rhythm and rhyme in poetry.

The project also explored different types of communication tools that some young people with PMLD use and how they can be engaged through using these. It also demonstrated the way in which this group of people can be supported to share their ideas, feelings and opinions to shape policy, practice and service development to ensure that mainstream services are designed to work for everyone.

*"This project, working with our students, demonstrated how using a range of tools allowed each participant to create something individual, incorporating their personalities and their own personal style. Through the project the strengths of each student, however varied, were displayed in the most positive way creating a wonderful piece of work. Our experience of this project has been fantastic and has also provided our team with some wonderful ideas about future work with our students due to the positive response that was observed."*

Children's Specialist Speech and Language Therapist,  
Sandwell & West Birmingham Hospitals NHS Trust



A poetry book has been produced as a resource from the project to celebrate the voices of young people with learning disabilities in relation to their methods of communication and their views and experiences of emotional health and wellbeing. 'Z -Cards' have also been produced to illustrate some of the different methods of communication that need to be recognised and valued when embarking on engagement with individuals with PMLD and to highlight the innovative and creative approaches that enable them to explore a richer engagement experience.

Changing Our Lives work is rooted in the belief that no one is too disabled to lead an ordinary life. We don't believe that the lives of people with disabilities should be limited or defined by disability; we are aspirational in our expectations for people with disabilities.

Our work takes a community development approach. We believe, and know, from experience that local people and communities are best placed to find their own solutions to local problems, so we work with people with disabilities of all ages as equal partners to design, deliver and evaluate all of our work. Our work uses a range of person-centred approaches and tools to enable people to have self-determined lives.

We work locally with people with disabilities but we always aim for our work to impact at a national level encouraging improvements in policy and practice development. We focus on finding solutions and achieving outcomes that will result in equality, social inclusion and self-determination.

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Many thanks for your support.



# Lambeth Mencap: Carousel Project

Becky Loney

In 2010 I returned to Lambeth Mencap from maternity leave, to discover that a group of family carers had initiated some ground-breaking work in the borough, resulting in the publication of the Lambeth PMLD Report (Mencap, 2010). This research highlighted the need for major improvements to services in the borough for people with profound and multiple learning disabilities (PMLD). This report followed the Raising Our Sights review (Mansell, 2010), which had previously identified that people with PMLD, on a national level, were at high risk of experiencing inadequate and non-person centred services. The Lambeth PMLD Report echoed Mansell's findings, identifying 31 key recommendations for improvements to local services.

This report was something of a gift to me professionally. I have supported adults with learning disabilities and their families throughout my career, focusing particularly on providing creative services for people with PMLD (local authority day services and voluntary sector). As a Service Manager at Lambeth Mencap, I was supported by a fantastically creative team - we were ideally placed to start addressing some of the huge gaps identified in the Lambeth report.

I met the families who had been involved, to see how we could respond. We agreed to focus initially on the recommendations in the Lambeth report: it clearly stated there were insufficient meaningful activities for people with PMLD in Lambeth

The recommendations the report hoped to see were:

- An increased range of meaningful activities for people with PMLD in Lambeth, including hydrotherapy and sensory activities.
- Creative joint-working with other council departments, to develop activities that are meaningful to people with PMLD and other community groups
- People with PMLD participating in meaningful activities everyday whether outside or inside the home
- Decisions about what activities someone does based on good person-centred planning that has involved the person with PMLD.

Lambeth PMLD Report (Mencap 2010)

I successfully secured funding (London Catalyst fund and the London Borough of Lambeth) for a pilot phase. This work was supported by Lambeth Mencap directors and trustees, together with the five carers of adults with PMLD, who were poised, ready to go, bringing amazing momentum and energy from the very beginning.

The project was ambitious: its aims focused on building a programme of high quality, meaningful activities for adults with PMLD, which would have positive health outcomes for them, and their family carers. Person-centred working was at the very heart of the project, as was close work with families and our professional partners in health and social care. By providing access to increased levels of physical exercise and activity, the broad objectives of the project were to improve access to sustainable services for people with PMLD and to bring about health improvements for people with PMLD, and their family carers.

Saturday Stories was the first of the Carousel activities to be established: a three-hour session, providing a fun social gathering on a Saturday with a focus on sensory storytelling. The following account explains what made the sessions a great place to be at the weekend!

*"Saturday Stories began every week with a familiar welcome song, and a chance for people to settle in, and wherever possible to move out of wheelchairs. Familiar scents filled the room every week, and an object cue of a soft scented heart was given to each person. Everyone had the welcome they could identify with, and over the weeks, a comfortable sense of belonging and familiarity grew. One lady needed months of patient support from staff and her own P.A to be able to move into the room without becoming distressed, we went at her pace and over time, this worked really well for her. The group stretched, arms, legs, fingers, toes, shoulders and faces – warming up with a yawn, a vigorous rub: a good start to any session.*

*We used a variety of stories over the first two years of Saturday Stories, starting with an adapted version of the old favourite, Keith Parks and Nicola Grove's "Odyssey Now". This is a fantastic storytelling resource I'd used in day services in the mid-90's, when Keith and the*

*Lewisham speech therapy team worked with us to develop accessible storytelling for all. Later we developed more ideas: a world cruise on a sailing ship, stopping at a different port every few weeks, to envelop the group in sensory delights and tales from around the world. For example, a trip to Turkey involved turn-taking games, a bit like a gentle "peekaboo" with simple Turkish phrases to greet each other. Whirling dervish music gave people the chance to dance, in and out of chairs, on the floor or standing. Kneading Turkish flat bread gave people a chance to watch the flour float from the sieve, to touch and manipulate dough, and later to taste our joint efforts. Turkish music and a tour of a Turkish market with a box of delights for people to sample and smell. We even made a beautifully tactile collage with Turkish spices and fabrics.*

*Changing position and being out of wheelchairs was important for everyone in the group, and something that was strongly encouraged and supported during every Carousel activity (our aim because of the well-established impact of physical activity on the more general health and well-being of people with PMLD). This meant good communication with families and support staff, to ensure equipment was in place, and people were being safely moved and supported.*

*David Standley, the local specialist physiotherapist from GSTT attended some sessions (highly unusual to have this kind of support on a Saturday!) and gave huge encouragement and advice about the importance of good positioning and postural care. Manual handling was no barrier here.*

*Lunchtime was a communal meal for all. We encouraged everyone to eat together, and even the minibus driver joined in sometimes: it was the weekend, the sessions were long old days for the team, and I was quite insistent that lunchtime was a relaxing time. Not really by design, lunchtime also became a good time to model good practice to support staff: we gently worked with one staff team on the quality of the food provided by the residential home, and introduced other ways of communicating during mealtimes with one woman who was deaf-blind, using hands-on signing. We liaised with the speech therapist involved, and were able to back-up her work with the teams, building on their knowledge and skills, reinforcing good practice.*

*After lunch and personal care, it was time for massage stories: using simple movements, through clothes, to build up simple stories and playful games. We used Flo Longhorn and Andrea Muir's fantastic resource ('Massage Stories, exploring Communication through touch, 2011) to get us started, but Joy, our facilitator's own "Weather Massage" was the favourite with many of the group participants. Then quiet time to sit together*

*and listen to some music, a time for one woman to sing along to guitar or ukulele, and to improvise for the group. The atmosphere was intentionally nourishing for all participants, including families and support staff. Family carers could stay around or leave and have a short break. Staff and P.A's were made welcome, made comfortable, given clear roles and boundaries. Person-centred approaches are for everybody, and staff attending regularly, visibly grew in confidence and let their own playful, creative sides emerge over the weeks and months. If Saturday Stories was going to work, it needed to be a welcoming place for everyone.*

*There was a gentle ending to our three hours together, time for the supporters to reflect on the session for each person: time to collect observations for monitoring, to look at individual responses, what had or hadn't worked, suggestions from staff or carers and ideas for next time. We closed our day with familiar goodbye songs and signs (on-body signing for some): a quiet and nurturing end to the day."*

Saturday Stories became well-established and very quickly became over-subscribed. The pilot funding gave time and insight to build a case for a much bigger and more ambitious project. In 2012 our bid for funding from Guys and St Thomas's Charity (GSTT) to develop the project further was successful. GSTT Charity is an independent charitable foundation dedicated to excellence in health and care in Lambeth and Southwark. We were delighted to receive funding for two further years, 2013-2015.

### **Evaluation of the project**

Lambeth Mencap commissioned an independent evaluation of the project by the University of Northampton, led by Annie Fergusson. Annie worked very closely with the team and myself, unpicking different strands of the project in order to filter what was working, and why. The final evaluation report, launched in April 2016, placed the many achievements and barriers encountered into a local and national context, giving some insight to the learning curve we experienced. This comprehensive and very positive evaluation (Fergusson, 2016) is available on the Lambeth Mencap website for much more detailed reading: [www.lambethmencap.org.uk](http://www.lambethmencap.org.uk). Available to download: <http://bit.ly/28WZJat>

### **Developing the activities**

During the next phase, the project established floor-based dance and movement groups, rebound therapy (movement on trampolines), an intensive interaction project, swimming sessions and one-off taster groups. All came with their challenges involving equipment, transport, manual handling, and staffing, but combined experience and creativity within our own team

and the GSTT health team, meant we worked through these eventually. Some challenges took months to address, but the overall outcome is that people with PMLD in Lambeth now have the opportunity to attend a range of dedicated, high quality, enjoyable and meaningful activities.

The challenges are well-described in the Carousel Evaluation Report (Fergusson, 2016). Annie particularly unpicks the issues around referrals, and the initial slow take-up of activities. This was in part due to the low expectations of many families, so used to coping with very little input from services, but also, the limited awareness and low expectations for people with PMLD from care managers, tight budgets and controls on resource allocation systems within Lambeth- and quite simply, in the earlier days, no data about how many people with PMLD were living in the borough. Despite their very complex health and social care needs: we couldn't tell people about our activities if no-one knew they existed!

The 2016 report describes in detail the many changes the project accomplished. Case studies give personal accounts from the perspective of people with PMLD and their carers and supporters. We experienced so many breakthrough moments with so many incredible people in the course of the journey; the report describes some of these achievements, of which we are very proud. The evaluation summarised the Carousel Project provision offered '*an inspirational model of delivery and of good practice to*':

- Act as champions for people with PMLD, locally and nationally
- Raise the profile of people with PMLD and positively influence the expectations of service providers
- Meet the needs and improve the lives of people with PMLD and their families
- Create responsive, relevant and meaningful opportunities for people with PMLD
- Provide opportunities and support to train and develop the wider workforce
- Establish and sustain high quality provision for people with PMLD
- Positively influence a more inclusive local community, increasingly with fully accessible amenities

(Fergusson, 2016:63)

I very sadly left the project relocating to Yorkshire, but the team continue, working incredibly hard keeping the activities running in this torturous financial climate. The work of the Carousel Project was further endorsed, featuring as a video exemplar of good practice as part of Department of Health commissioned suite of materials (Mencap/PMLD Network, 2013). The 'Raising our Sights,

How to Guides' comprise a set of resources for commissioners, professionals and families demonstrating 'what good looks like' for people with PMLD.

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## LIQUID VIBRATIONS - a practice of underwater deep listening

Joel Cahen

Liquid Vibrations was formed as an extension of the underwater sound art concert series by Joel Cahen called *Wet Sounds*, which began touring UK swimming pools in 2008. Adele Drake, founder and former CEO of Drake Music in the UK, had made the connection between the properties of underwater sound perception and the potential benefits this could have on children with special and complex needs and together with Joel Cahen set up the organisation in 2009.

**U**nderwater speakers are placed inside the pool and sound is heard through them when any part of the head is placed in the water. Additionally, vibrations can be felt in the body when it is in certain proximity to the speaker. The vibrations travel from the water to the bone and stimulate the inner ear directly, and so the listener actually perceives the sounds as if they are heard from inside their head. The result is a perception of sound that is incredibly detailed and immediate. Despite being in a public space the listener can feel as if inhabiting a very private space, a womb-like environment.

Liquid Vibrations has devised sessions at hydrotherapy pools for children aged under 16 with special and complex needs and profound and multiple learning

disabilities (PMLD) who have severe communication difficulties. These innovative musical hydrotherapy sessions focus on interaction in order to build confidence and awareness, promote well-being and promote awareness of the art of music in particular. Liquid Vibrations brings an aesthetic artistic experience to a public to which it may not otherwise be exposed. The artistic experience and the listening activity under leisurely conditions promotes curiosity, relaxation and, at times, a positive change in movement or vocal expression.

Whether these have long lasting effects can only be assessed after a more prolonged period of observation and continuing data analysis. The charity is providing



training sessions to staff at schools which would enable them to integrate the practice in their curriculum.

This brief piece includes extracts from a detailed article submitted by Joel Cahen. The work of Liquid Vibrations has been kindly funded by Arts Council England, Big Lottery, SEMPRE, Milton Keynes Foundation, Sound Connections, Henry Smith Foundation, Bailey Thomas Trust, Onassis Cultural Foundation and The Beacon Institute University of Kent. The creative pleasure created by Liquid Vibrations is hard to capture on paper, even with these photographs which Joel has kindly provided.



To find out more, you can visit their website <http://www.liquidvibrations.org.uk/> or watch the excellent YouTube clip [https://www.youtube.com/watch?v=b9g\\_9t98mFQ](https://www.youtube.com/watch?v=b9g_9t98mFQ)

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## **PMLD LINK is a ‘not for profit’ charity**

PMLD LINK is a ‘not for profit’ charity (UK Registered Charity No: 1121085) and its trustees and editorial board are all volunteers who give their services for free. All profits from the sale of the journal and all donations are used to maintain the production and posting of the journal, the development of the website and the management of Facebook and Twitter for networking and information sharing.

Any information about potential grant applications and any donations are welcome. Currently, PMLD LINK needs money to support its ‘*Far and Wide Project*’ which aims to communicate with potential new subscribers to bring these services to the attention of families and carers, adult day centres, residential homes, and small self-help organisations that are harder to reach, as well as to schools and other charities.

Donations to PMLD LINK can be made via the ‘donations welcome’ button on the home page of the website ([www.pmlmlink.org.uk](http://www.pmlmlink.org.uk)). If you can offer support or want to make further enquiries, please contact us. Email: [info@pmlmlink.org.uk](mailto:info@pmlmlink.org.uk)



## All in the same direction

Dreenagh Lyle

I have managed my adult daughter's Individual Budget for almost ten years. This article is not a testimonial to personal budgets; it is about acknowledging the significant changes a truly person-centred and therapeutic approach can make to an individual's life in any setting.

*'If we don't know who we are talking about how can we know what the issues are?'*  
(Samuel and Pritchard, 2001, pp34-44)

### Background

Eight years ago my daughter was described as 'violent', 'aggressive' and 'extremely challenging'. 'Refused' was the word most used.... 'Odyssey refused to go out', 'Odyssey refused to engage', 'Odyssey refused her lunch', 'Odyssey refused to get on the bus', 'Odyssey refused to get off the toilet'.

Why do people now want to work with her? Why do I have such good staff retention and rare absences? What are we doing now that people were not able to do in the past? Odyssey is still the same person. She still has her meltdowns and crises, but rather than try to quell her behaviour we try to support her to manage her feelings. We try to understand the world as she experiences it. We acknowledge the impact of her multiplicity of conditions and impairments on her health and well-being. For example, Personal Assistants (PAs) acclimatise to sounds that upset her – because she lashes out or head butts

when she cannot cope. Workers are now aware of her sensory hyperacuity [sensitivity to sound] so are not confused by being attacked for no apparent reason, as they used to see it.

### Consistency & Clarity = Trust

The first step was to develop trust. Odyssey had years of people (including me) lying to her to get her to eat, stand, sit, have her blood tests done, get washed, dressed or get on the bus. Her entire life was inauthentic. Everybody around her was acting AS IF she understood everyone perfectly. Why do we persist in this lie?

I decided we would be very clear about Odyssey's perspective in any situation. Because her mood, feelings, sensory acuity and levels of anxiety can be 'all over the shop', we had to provide her with a sense of consistency. She needs repetition in order to predict what will happen next. We have stuck to a strict routine of indoor and

outdoor activities including specific outings. We have a routine that everyone observes. No one has the attitude, 'I know how to handle her'. We don't want to 'handle her' we want her to want to engage with us. We exercise clarity in our verbal overtures to her and in our understanding of what we are doing to support her and why. There is no point obtaining specialist input from speech and language teams (SALT) or functional analyses of behaviours by psychology / behaviour support teams if the support guidelines they produce are not understood and followed.

Workers need to feel psychologically supported and valued in their role. I go through the specialist guidelines with staff, explaining why we use them, impressing on them how important it is to follow them to the letter. We also devise our own guidelines when teaching indoor tasks, or for accessing swimming or for travelling on the underground or simply walking to the park. We regularly unpick them to see where we can tweak something or alter it entirely. But we all agree and understand that the consistency of our approach is essential for Odyssey.

### Task breakdown

Choosing a task to engage in with Odyssey encourages a sense of ownership of the process. PA's work with her rather than do things to her. This subtle shift in approach creates a sense of partnership between Odyssey and her care workers rather than them seeing her as a passive recipient of care.

Using this approach she has attained these listed skills.

- Will place her cup/glass on the floor, without prompting.
- Will seek out PA and place her cup in their hand, if unfinished.
- Will carry cup /plate from couch in living room to kitchen (open plan) with verbal / audio prompting.
- Will press the kettle button with verbal / audio prompting.
- Will pick up clothes from floor (meaningful exercise for her knees) carry them down hallway and place in laundry basket with verbal / audio prompting.

Since Odyssey must feel her PAs 'appear' out of nowhere, I came up with an idea for her to bring the outside in. Hence she

- Will respond to doorbell and make her way from couch to door with physical / verbal / audio prompting.

Odyssey tolerates household sounds since we have encouraged her to be in control by pressing the 'on' button on the hoover and toothbrush. She 'hoovers' the hallway/lounge with her PA.



She also let's us clean her teeth now. This has generalised to the dentist. Pillow and toothbrush are clear Objects of Reference for her (Ockleford, 1994). She will sit awkwardly, anxious and clenched. Simply touching the back of her head with a pillow is enough for her to relax and lay back.

People love to tell me Odyssey 'understands everything I say', but she doesn't. A clear example of this is the 'open your mouth' approach. We all used cheerful, pleasant, cajoling tones and Odyssey just clamped her mouth tighter and tighter shut. In the past dentists have simply given up, advising 'she'll have to come in for general anaesthetic'. One visit a nurse held a toothbrush to her mouth and hey presto, she opened so wide we were all taken aback.

### Food and Eating

Imagine you are totally blind, lost in your own sensorial world, curled up in a ball quite happily listening to music, when suddenly someone grabs you and forcefully attempts to walk you, by telling you to 'get in the kitchen'. The kitchen has a different floor surface (noisy laminate compared to the carpet in rest of the house), there is a radio badly tuned to a station staff prefer, blaring out loudly and staff are also shouting to other people to 'get in the kitchen, now'. How does any of this signify that a meal is about to take place?



Compare to someone standing near to the same woman and musing aloud in exaggerated tones, about 'oooh I'm feeling so hungry. I wonder if it's nearly lunchtime. Who's going to make lunch.' And then, in order to gradually include her 'I wonder if Odyssey is feeling hungry, maybe we could both have something to eat'.

Depending on Odyssey's anxiety levels you could encourage her with an Object of Reference (i.e. an actual olive or lump of cheese) or suggest she joins you in the kitchen as you prepare her meal. This is done with a constant description and occasional olives or cheese as before, until you are ready to sit at the table to eat your meal.

This is the gist of her guidelines and a meaningful way of alerting her to the notion of food and eating. And it works! Ten years ago Odyssey was a diagnosed anorexic and weighed less than 35 kg, today she weighs 55kg.

### Physiotherapy and deep tissue massage

Incrementally introducing water and aloe vera juice to Odyssey's diet has been life changing. No more gigantic bowel movements every three weeks. The toilet still gets blocked but not nearly as often. Hurrah for water, aloe vera juice AND proper colonic massage. Who knew Odyssey would love massage so much? With immense insight, patience and skill our wonderful physiotherapist has worked once a week for five years. Strangers approach me saying, 'your girl has come on, isn't she lovely and straight these days' or 'I remember

when she'd just lie down in the road screaming. That's all changed hasn't it?'

### Music therapy

Odyssey has been attending Nordoff-Robbins for weekly music therapy sessions for four years. She attends with her older sister (herself a qualified OT and a musician) and according to her therapist the progress she has made was not expected! Imagine someone who previously had real difficulty even entering the building, compared to the woman now who, on a good day will excitedly chatter or even burst into pealing song when she hears her therapist's voice.

### Containment

Finally, the notion of 'containment' (after Bion, 1967). Without going into the theoretical background, it is worth observing that people like Odyssey have great difficulties containing their emotions. They may intuitively seek out something like 'holding therapy'. They want to be wrapped up and contained. We have found that weighted blankets wrapped around Odyssey have the same effect. In fact we have now progressed from the weighted blanket to a soft throw, which she likes to be wrapped in head to toe.

### Conclusion

My reason for the title is because I believe the most important aspect of any attempt to instigate truly person-centred approaches is an emphasis on team working. We need to be proactive in our recruitment and development of suitable support staff. This means being clear and honest about an individual's needs. I believe the most important aspects are developing a relationship and consistently following guidelines. Once the relationship has been built the guidelines can be ever so slightly stretched or tweaked, depending on the day.

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## Connecting with stories - connecting with communities

Maureen Phillip

Storytelling is an age old tradition and one of the best ways to share information, instruction, education and learning. Stories help communities to engage and interact and most of all stories are fun. Multi-sensory stories are a great way to communicate and engage with people with profound and multiple learning disabilities (PMLD). This article offers a glimpse into the PAMIS storytelling activities over the last few months.

### **Loretto's storybox**

Storytelling is one of our oldest art forms. It stimulates the imagination and builds a sense of community between tellers and listeners. Stories from the oral tradition are told *"eye to eye, mind to mind and heart to heart"* and PAMIS have for some time been working to develop multi-sensory stories that enable people with PMLD to have access to their culture through story. In our current storytelling project PAMIS is developing a story resource in memory of PAMIS founder Loretto Lambe, whose passion for books and stories was almost as well known as the work she undertook on behalf of people with PMLD and their families.

Working with Claire Hewitt, a remarkable storyteller and musician, we have designed a resource that will engage people with PMLD and enable them to connect with the oral storytelling tradition using appropriate sensory stimuli as well as rhyme, rhythm and music. We want this resource to capture the essence of Loretto and her love of helping people to engage and communicate with people with PMLD in an effective and fun way. Claire and Maureen Phillip from PAMIS visited Ireland and spent a few days exploring Sligo with two of Loretto's sisters. We gathered stories from the landscape of Loretto's childhood and listened to her sisters recall stories from the past. The development of Loretto's story box has been a wonderful experience and the process itself demonstrates the power of story.

In the making of this resource, one woman's story has connected so many communities and her story is as powerful in death as it was during her lifetime. The Camphill Community at Corbenic near Dunkeld are making a lot of the sensory stimuli for the story and are recording the music for the CD to accompany the story. James is helping with the weaving of a storyteller's waistcoat and we have Jane the basket weaver creating a creel for the story and Gennie is designing the story box. People want to be involved in creating a part of this memory and that is such a wonderful legacy.

The learning disability community at Corbenic have wholeheartedly embraced this project and have opened their doors to host a storytelling and music day following the completion of each of the three sensory stories we have developed. PAMIS also work in partnership with Tayberry Storytellers from Tayberry Enterprise in Dundee. Tayberry storytellers all have learning disabilities and undertake a storytelling apprenticeship in multi-sensory storytelling. The story apprentices undergo training at Dundee REP and PAMIS and they tell multi-sensory stories to adults with PMLD at the White Top Centre in Dundee.

The development of Loretto's story box has enabled PAMIS to offer the Tayberry Storytellers an opportunity to be involved in the process and to receive training and continued personal and professional development through their involvement with the project. Tayberry join PAMIS at the Corbenic story and music sharing days and the communities exchange experiences. Recently Tayberry Enterprise was awarded government funding to expand the storytelling project to other areas of Scotland and Loretto's story box project has helped the existing storytellers to expand their knowledge, experience and practice of storytelling which will enable them to help the new storytellers joining the project.

In terms of connecting communities, the legacy of multi-sensory storytelling that Loretto began in PAMIS, she is most certainly continuing and if anything it is growing stronger. Loretto's story box will be complete by the end of this year and will be shown at the PAMIS International Conference next year, where all the communities that have come together to develop this amazing resource will be performing the stories in her memory. One woman, one story, one resource but many threads and stronger communities have been created as a result of the production of Loretto's story box.

## Instructional stories

When talking about stories building communities, it is also great to see the library that was started with the PAMIS Real Lives: Real Stories story project continue to expand and develop and enhance learning skills for students too. Students on placement at PAMIS



from Glasgow Caledonian University and Dundee University working together across the disciplines of Occupational Therapy, Teaching and Social Work to produce instructional multi-sensory stories for children with profound and multiple learning disabilities. The students worked with a group of children from Grange primary school in Monifieth, Angus to develop a multi-sensory story about their trip to hydrotherapy. Amanda Scott, the principal teacher, for special education in the county of Angus asked if this story could be developed for the pupils to help prepare them for their forthcoming hydrotherapy trip. The students loved it. They worked together following a visit to the school and the hydrotherapy pool that was to be used for the sessions and they produced a wonderful story that charted the children's journey to the pool, the experience in the pool and they also produced an activity analysis to accompany the story to highlight the benefits of the activity. It was wonderful to see how the students gained knowledge and understanding of not only children with profound and multiple learning disabilities but knowledge of hydrotherapy and the benefits of the activity to the children. Working together as a group, the students learned so much from each other.

In terms of community connection the story connected with community on so many levels. Students from differing disciplines connected with each other and learned from each other. The connection made between the students, the school and the pupils was wonderful. Everyone gained learning from this experience and

everyone connected with each other in a valuable and fun way. The parents drove some of the children and staff to the pool and there was the opportunity for parents to get into the pool with their children if they wished. Most of all the children gained a story about a favourite activity and the principal teacher gained additional information through the activity analysis that added value to the story by highlighting the benefits of hydrotherapy in terms of the improved physical and emotional well-being the activity offers.

Still on the theme of multi-sensory stories for schools in Angus, PAMIS have been very busy over the last few months duplicating and making lots of stories to enable the schools in Angus to have a library of stories they can use anytime and with ease. This venture came about following a very successful story week during PMLD awareness week last year when PAMIS developed stories in Brechin High school and Carlogie Nursery to raise awareness of profound and multiple learning disabilities.

Last year children in the Enhanced Support for Learning Department at Brechin High School had fun helping to put together a multi-sensory story about going to the swimming pool and nursery children at Carlogie primary school nursery, in Carnoustie helped make a story umbrella for a child with PMLD who was starting the nursery. This was great fun and everyone enjoyed it so much that the storytelling grew and the principal teacher

for special education in Angus decided to purchase stories for the schools, some of which were duplicates of the growing up stories that were part of the PAMIS sensitive stories project. Again the power of stories to connect communities was obvious as volunteers came forward to offer assistance making up the story boxes and PAMIS staff and volunteers were busy for weeks, sewing, sticking and making wonderful story boxes for the schools in Angus. The story making continues with students currently working with the schools on multi-sensory stories about transitions. These stories will be used to support pupils leaving high school to attend college and for children moving from primary to secondary school. Again the storytelling legacy left by Loretto continues to inspire and teach future generations. For more information about PAMIS storytelling activity see the PAMIS Blog.

<https://sites.dundee.ac.uk/multi-sensory-storytelling/>

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## NEXT ISSUE

Winter Vol. 28 No. 1 Issue 83

### Health Matters

Do you have any stories to share?

If so, contact the editors:

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# Soundtracks and the Great North Wood

Emily Ward

Sarah Glover, Emmie Ward, Coralie Oddy and Keith Park have formed a collective – Soundtracks - to provide multi-sensory storytelling, poetry, music, song and dance workshops for adults with severe and profound and multiple learning disabilities on the theme of The Great North Wood.

## **Sarah writes about the The Great North Wood – its history and the sensory stories**

**O**h the trees grew all around, even in, your own home town... I first found out about The Great North Wood when studying for my MA in Museums and Galleries in Education. Looking at area map excerpts through different time periods I became intrigued by the time before the palace and park and in particular with John Roque's 1746 map of London. I found a copy of Roque's map in Lambeth Archives and this map clearly marks 'The Great North Wood' in large lettering over Norwood and Dulwich. I am fascinated by the wood and the stories it holds. I am particularly interested in the mix of tangible and intangible history of the area and I am passionate about helping to make local heritage accessible to as many people as possible. Key aspects of life in The Great North Wood are used as starting points during the sessions – the nature and characters of the wood. We have always left these aspects open for development during the sessions – and the learning has been for us as project creators as much as for the students.

We are beating, beating, beating the bounds... we are beating, the bounds... The wood was centrally made up of Oak trees, and boundary oaks such as the Vicar's Oak (that no longer stands) were important landmarks. People would have visited these oaks when taking part in the annual tradition of beating the bounds when the parishioners walked along the lines of their parish boundaries to make sure that they asserted which land was theirs. We celebrated the beating of the bounds in our April session. This included using real sapling wands and processioning around a symbolic (hand drawn) tree while singing a song we created.

Have you seen Margaret Finch? They call her the Gipsy Queen.... Names continue to tell a story, such as Gipsy Hill, which refers to the gypsies who once held summer encampments in the area. The most famous of these gypsies was Margaret Finch who was given the name 'Queen of the Gypsies'. Day trippers from all around visited the gypsies, apparently including Samuel Pepys' wife, Elizabeth in 1668. The thought of excited day trippers going to have their fortunes told and the festival

feel that must have been, provided us with lots of stimuli for songs, drama and music on the theme.

Stand and deliver, your money or your life... I am familiar with The Highwayman being taught in schools from when I working as a teaching assistant in a school. We didn't use the poem in this project. However, the highwaymen who would have roamed The Great North Wood were the first characters we introduced. The drama developed during the sessions. Sometimes we were all the highwaymen and sometimes one or two highwaymen and highwaywomen collected treasure from the rest of the group. This was supported by song and the words: 'Stand and deliver!'

It was a long time ago... I was first introduced to sensory stories at a day workshop with Joanna Grace at a Diversity in Heritage Group meeting. I had always been interested in how to make museums, galleries and heritage sites more accessible and had a fair amount of experience in education and disability. However, this was the first time that I learned about a clear, practical, interesting and instant way to get started. I then attended a training weekend with Joanna Grace. As well as learning more about developing and telling sensory stories, I also met Coralie Oddy. Coralie also had an interest in The Great North Wood and we resolved to write a sensory story on the theme.

It was the time of The Great North Wood and the trees grew all around.... Sensory stories are usually made up of about ten parts/sentences and throughout the story you try and cover as wide a variety of senses as possible, so that each sentence has a sensory experience connected with it. Our sensory story was the starting point for the themes we covered and continue to use during the sessions. We first thought about what we could use to represent the wood itself. We wanted to create the feeling of immersion in the wood and Coralie had the idea to use a hoop with leaves that dangle from it. We could then place the hoop over the heads of individuals so that they would truly be immersed in the leaves. The hoop proved helpful in creating a special atmosphere in the sessions. It helps us begin with a sense of calm and familiarity. This, combined with Emmie's beautiful flute

playing means that there is a mystical feeling of being transported to the wood.

The trees grew flowers which bloomed and turned into rich, juicy berries...The theme of woodland has given us a bountiful amount of ideas. Sensory stimuli are used throughout the story and the whole session. However, in each session at some point in the story there is a prolonged period for sensory exploration. We take around a variety of stimuli to participants including visual stimuli such as laminated pouches filled with coloured water and small objects; as well as touch stimuli of gak and various kinds and water beads in water. We always have a couple of scents on offer.

### **Coralie writes**

**H**ighwaymen hid in the woods. You could hear the sound of horses' hooves and running feet.... Gaining an understanding of what different individuals respond well to (or perhaps do not enjoy) has been really important for developing the sessions. In one group, we found that a wide circle arrangement was important to give some individuals space, whereas another group developed a real sense of intimacy by having the story circle brought tighter. Some individuals have developed their confidence in participating by being offered the chance to add extra sensory layers to what is now a familiar story (such as using clapping sticks to create a 'tick tock' sound during the part of the story 'It was a long time ago...'). Others have shown subtle signs of greater engagement as the weeks have progressed. One visually impaired individual who found noisy stimuli difficult, really benefitted from experiencing the story in terms of different kinds of touch on her arms and hands – light tapping fingers for rain fall, for example. It also gradually supported her to engage more fully with other sensory aspects of the story – she was happy to smell differently scented gels and hand creams when used within the context of hand massage, and matching speed and intensity of touch to music being played seemed to increase her tolerance of these sounds. Another individual who tended to wander and rummage through people's possessions during the sessions was able to have her needs met and be included within the 'action' of the story by having leaves scattered in front of her, which she carefully picked up and placed in a bag for us to scatter again. Following and accepting the preferences of individuals has been helpful in supporting them to try new sensory experiences. Experimenting over time has been key!

### **Emmie writes**

**I** have recently completed my PG Cert in Sounds of Intent (Adam Ockelford 2008) at Roehampton University. Originally designed to enable children with PMLD to access music, Sounds of Intent 'maps' musical behaviour and development and divides musical

expression into three distinct but interdependent areas: reactive (listening to music), pro-active (making music) and interactive (making music with others). It emphasises an individual approach to musical expression in which the student is guided along at their own pace and direction.

Our aim in the sessions was to provide an array of interesting sounds for people to listen and respond to. This included the words in the stories, the rhythmic call and response of Keith's poems and chants as well as instrumental music and songs and soundscapes to create the atmosphere of birds singing in the woods or wind blowing through leaves. When working with students with PMLD who might not be aware of sound as a separate entity it's important to try out lots of different sound experiences and observe their response. One of the most important sounds for them to hear is their own vocal sounds. With this in mind some of the songs in each session are adapted or purposely created to include vocalisations, which everyone sings together. Students also consistently respond to hearing their name so we use their name not only in hello and goodbye songs but in songs that relate to parts of the story as well.

It's really important to make sure that sound is as different as possible from the background noise many of our students experience in residential homes where the tv or radio can be playing almost constantly. To do this, we have to bring the music over to people and sing and play close to them accompanied by lots of engaging eye contact, expression and a "live" sound. I also make sure that I provide lots of drama and contrast in playing quiet, louder, slow and faster and that there is a variety of sounds created from a range of instruments and voices to create changes in "timbre". Stops and starts are also utilized to create drama and to remember that "silence can be as important as sound!"

To help students with PMLD make sounds using instruments, body or voice (pro-active domain) we initially reflect back involuntary sounds to highlight awareness of them, if the student is not making sound intentionally. The next step is to find accessible ways to make sound and to enable people to have as much control in doing this with minimal support. We have lots of different instruments so people can experience the soft and resonant sounds of djembe drums or the pure metallic sound of a tone chime. We have lots of small shakers and hand held percussion instruments that are easy to hold and string them on to belts if the player does not want to hold the instrument for too long. This way it can be held and released at the player's will. For tuned instruments we've had great fun with a small child's accordion and playing guitar chords on 'garageband' on the ipad.

**The Chant Of The Great North Wood**

Our students with PMLD have different musical preferences and we constantly review how we can accommodate their needs within the class. Some students find it very difficult to relax within the class unless there is some music. For other students especially with sensory processing issues we have to be aware that loud sounds can be distressing and we have to make sure the volume of the music does not become too loud. The real joy comes in making music and sound interactively and Keith's poems and chants do this beautifully. Working with Keith has inspired us to look for call and response songs and to create our own songs within which there is turn taking between music makers and a rich musical conversation emerges. It's really important to leave time and space to, as Keith says, to "see what happens." During the sessions we have learnt to look for "magical moments". One of these was when we sang: "come and gather" a "campfire" song (written by Sarah) where we all sat close together in a circle around a flickering fire on the ipad. Something about the closeness and swaying to the music created a wonderful connection and calm between everyone. Another was when we marched around the room chanting and holding birch wands and re-enacting the ancient tradition of "beating the bounds" There was a feeling of excitement and energy amongst our students. Is it the music, the movement, proximity to one another? We're still figuring it out but when these moments happen we know we're on to something good!!

**Keith writes**

**O**ur aim is to bring music, song, poetry, dance and storytelling together in a creative and accessible format for adults with severe and profound and multiple learning disabilities. Both Sarah and Emmie are singers and musicians with a vast knowledge of folk song. Sorted! And here, as a taster, here is our chant of The Great North Wood. This can be performed as a poem using call and response but also as a circle dance, as the words suggest, or as both together. Emmie has set it to music, so it is now a song: and so then, of course, we can perform it as a song, a poem using call and response, and a dance, all at the same time. We have also had guidance from British Sign Language users and teachers so in addition the chant is signed. An interactive poem, sung to live music, danced and signed at the same time. A Guardian reporter, should one ever come and join us, might describe the workshop as an example of 'Gesamtkunstwerk.' We just think of it as 'putting it all together'.

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If come you can  
 Then come you should  
 To join us all  
 At the Great North Wood  
 Hand to hand  
 Each to each  
 We dance around  
 The copper beech  
 Eye to eye  
 So we can see  
 Us dance around  
 The old oak tree  
 If come you can  
 Then come you should  
 To join us all  
 At the Great North Wood  
 Side by side  
 Come and go  
 We dance around  
 The mistletoe  
 Toe to toe  
 You and me  
 We dance around  
 The rowan tree  
 If come you can  
 Then come you should  
 To join us all  
 At The Great North Wood  
 Circle dance  
 Beneath the sky  
 Our circle  
 Has no I  
 Root and tree  
 Flower and leaf  
 The Great North Wood  
 Beyond belief  
 If come you can  
 Then come you should  
 To join us all  
 At The Great North Wood

# “The best time ever!” Our visit to the Calvert Trust

Jo and Steve Baker

“Best time ever!” Just one of the comments we had from a group of 6 pupils, who took up the opportunity to visit the Calvert Trust, Keswick in the Lake District, in May this year. During the weeks leading up to the visit, the pupils, some of whom have multi-sensory impairments, worked together, preparing for the activities that they were going to undertake. We explored what it is like to be in a canoe, what ropes, helmets and carabiners feel like and just how dark a cave would be.

**B**right and early on Monday morning, we set off, waving bye to some teary Mums and Dads! On the way we stopped at Morecambe for a picnic lunch, with a sea view and beautiful sunshine, though it was rather windy!

On arrival at the Calvert Trust, we settled into our accommodation and unpacked, before a hearty 3 course meal. To finish the day we had a lovely session in the hydrotherapy pool, having fun splashing the adults and unwinding in the Jacuzzi bubbles, whilst looking at the views over Bassenthwaite Lake.

During the week, we took part in so many fantastic activities, all fully adapted to meet the needs of these young people, 5 of whom were wheelchair users, some with additional complex medical needs.

One of the many highlights was sailing on a catamaran across Windermere. The views were exceptional and some of the pupils joined in with steering and pulling the ropes on the sails. It was very peaceful and relaxing until 2 RAF fighter planes flew overhead – what a sight!

Another activity everyone enjoyed was travelling with horses – either through carriage driving or horse riding. The pupils enjoyed meeting the horses, grooming them and then riding through the local woods and countryside. The pupils learnt to hold the reins and to make the horses Stop and Go!

The pupils spent an enjoyable afternoon taking part in bushcraft skills - learning to light fires with flint and steel and toasting marshmallows. They also enjoyed a competitive archery session, with adapted bows to enable everyone to be able to release the arrows – some managed to hit the bullseye and beat the staff too!

A real highlight was the rock and ropes activity. Some pupils used a controlled descent zip wire through the trees of the woods, some abseiled in their wheelchairs

down a slope and others enjoyed climbing up the ropes and swinging in the air!

Our final activity of the week was a wheelchair assault course - crossing wobbly bridges, ramps and through dark tunnels. To end the week we danced the night away at the disco!

During the week, we had the privilege of watching each of the 6 young people develop and flourish. They took part in activities that they have never done before, with enthusiasm and courage. They overcame obstacles and challenges and we have all left with wonderful memories that I am sure will last a lifetime!

## Contact Details

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# Rachel's Cat

Les Staves

One of the best loved stories I use in my training is about holding and sharing a silver egg that chimes like a meditation ball, with Rachel. She was a child who had no spoken language or independent mobility, very little clear vision, perhaps she could see moving light and shadow. Her hands were usually curled and rarely extended voluntarily, so she was not easily able to be an explorer of objects.

***How can we know how she feels about her perception of things around her, or what does she even know of the room in which she is placed?***

One day she had been brought into the classroom late by the Nurse who parked her chair near the door, whilst I was doing registration turn taking with kids sat round a table. When I called her name from the register and looked across I could see she had not been listening to the group conversation but had been sitting for a while weaving her hands in front of her face, I think she was playing with light from the window. I realised I needed to bring her into the group circle.

As I approached her chair a chiming egg that was by chance in my pocket was making a chinking sound and I noticed that she paused the waving and seemed alerted to listen. I thought she was aware someone was approaching. As I kneeled beside her wheelchair she inclined her head towards me. I had the silver egg in my hand and I traced it against her finger tips and spoke softly about it being shiny and smooth. We were both enjoying sharing it, speaking and listening together, as she vocalised with me. Gradually it worked it into the palm of her cupped hand and she retained it. She had moved from sharing to 'having', in a few moments, but what is the experience of 'holding', like for her? I said 'Come on then love, let's go' and wheeled her to the table. She held the egg and when we got there I tapped her hand on the table top and she released it.

***I wonder what Rachel makes of this world. It's hard for me to conceive her experience. We can all enjoy our surroundings, the slow setting sun or a woodland glade, what pleasure does Rachel have, what is her emotional experience?***

One day I visited her home and whilst we were having a cup of tea, her Mother got up and put the cat on Rachel's lap. Rachel lifted both hands and let them rest on the back of the purring cat. Her face beamed.

***How has she learned to smile?***

Now I am not a cat lover but I recognised her experience. When you rest your hands on a contented cat through the silk of its fur you can feel every bone of its back, they are delicate, its purring vibrates to you and in the rise and fall of its breath you can feel life is delicate. I could see in those moments Rachel was loving sharing feeling the life of her precious friend the cat; just as I have done holding my grandchildren. I am sure whatever people say about her measureable cognitive abilities, she has an inner life. She indisputably has personality, she is an important part of her family, though not the kind of child they were expecting, her coming created dimensions they never knew about, some hard and some joy.

I am proud to be part of a community that has come to recognise that the inner worlds of very special children are important. That pleasure I can receive through my eyes at sunset or in the bluebell wood has equally important value perceived through other channels. You people who realised there is sensory curriculum have enhanced worlds of perception, you are special yourselves.

**Contact Details**

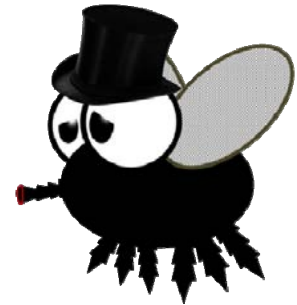
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# Two Fat Flies in a Puddle of Sick (A healthy eating story)

Pete Wells

- 0 Yuck! Look over there, it's a puddle of sick!  
Lumpy and smelly and sticky and thick!  
Here come two flies, Derek and Vic,  
They've come for a yummy, fly picnic!
- 1 Two fat flies in a puddle of sick,  
One called Derek, one called Vic!  
Victor found a piece of pie,  
And gobbled it up, what a greedy fly! (Feel fly)
- 2 Two fat flies in a puddle of sick,  
One called Derek, one called Vic!  
A piece of carrot is what Derek chose,  
Because it smelled just like a snowman's nose. (Smell/taste/feel mashed carrot)
- 3 Two fat flies in a puddle of sick,  
One called Derek, one called Vic!  
Victor found a piece of lolly pop,  
And gobbled it up! Oh, he couldn't stop! (Taste lollypop)
- 4 Two fat flies in a puddle of sick,  
One called Derek, one called Vic!  
A piece of sweet corn was Derek's treat,  
Yellow and juicy and so, so sweet! (Feel a corn on the cob/popcorn?)
- 5 Two fat flies in a puddle of sick,  
One called Derek, one called Vic!  
Someone else has come for a cheeky neb,  
sticky Web! (Feel furry/rubber spider/eight torches/ "Oh oh!" Eight hungry eyes in a on bigmack, netting over students)
- 6 Two fat flies in a puddle of sick,  
One called Derek, one called Vic!  
Victor couldn't resist some wobbly jelly,  
So he guzzled it into his chubby belly! (Hands in jelly)
- 7 Two fat flies in a puddle of sick,  
One called Derek, one called Vic!  
Some broccoli was Derek's next tasty treat,  
Green and healthy and good to eat! (Feel/smell/print with broccoli)
- 8 Two fat flies in a puddle of sick,  
One called Derek, one called Vic!  
Next Victor munched on some old kebab,  
And added to his tummy, a bit more flab! (Smell/taste kebeb meat)
- 9 Two fat flies in a puddle of sick,  
One called Derek, one called Vic!  
Derek ate some chewed banana, the healthy thing,  
As an eight legged creature, came down on a string... (Track spider on thread)
- 10 One big spider on a puddle of sick,  
Two fat flies better fly away quick!  
Healthy Derek got away, he was lean and thinner,  
But poor Victor became a spider's dinner! (Massage students like they're being gobbled up!)



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## Sarah's Sensory Starters

**F**un with Gelli Baff products!  
These are a great resource. Mix gels with water for a coloured, jelly-like texture – but make sure to measure water accurately. Once created why not...

- Put it in a bowl, bath, tray, paddling pool – explore with hands or feet...or whole body!
- Make a dinosaur swamp
- Make creatures in the sea
- Use with books like The Big Red Bath for a really sensory story!
- You can buy aromatherapy infused gels for a spa treatment in your bath.
- Some have colour-changing properties; some glow under UV light - use a UV torch.



Alternatively use ordinary jelly - present it and explore in different states-jelly cubes, jelly powder, runny jelly, firm set jelly



- Put jelly in bowls, tuff trays, standing frames bowls, bath, paddling pools, trays.
- Use different colours and add scents

- Use utensils to play with jelly - fork, whisk, potato masher
- Use fingers and your toes to explore it
- Add interesting things to it – then find them and fish them out
- Use jelly moulds-use a rabbit at Easter , use a witches hand at Halloween
- Make moulds from recycled packaging
- Make a fish tank full of jelly and put fish sweets/ toys in it
- Fill straws with jelly to make jelly worms!
- Let jelly set to make different layers of colour
- Make traffic light jelly with red, orange, green.
- Scoop out oranges and fill with orange jelly.
- Use sparkly, glittery jelly.
- Use jelly powder to add scent to a picture .
- Lemon jelly powder in paint adds another dimension to your picture of a lemon.
- Put a small amount of jelly powder in a balloon, blow it up .... and then let go to release the scent!



You can buy Gelli Baff and Smelli GelliBaff from most supermarkets, toy shops or the internet.

### *Willows Sensory Service 2 for 1 Offer for PMLD LINK readers*

*This voucher entitles the bearer to a free place on one of our courses when accompanied by 1 paying adult.*

*Courses are £100 per person.  
Contact us now to book your session.*

*This voucher must be used before the end of July 2017*

*Facebook: Willows Sensory Service  
Tel: 0121 243 4223  
e-mail: sarah.hall73@virgin.net*

*73 Binley Close  
Solihull  
B90 2RB*

Use the Voucher Code – PMLD LINK 1



## Sun sea and sand for everyone

Flo Longhorn

**T**his week I went to the Belgian beach on my bike to enjoy the sand, sea and sunshine. Whilst sitting at the beach bar with a friend (of course)! we noticed a group of rather special young men arrive for their special day at the beach.

They were going into the sea in special beach wheel chairs. This is part of summer activities along the Belgian

coast to enable everyone to have the same opportunity of dipping toes into the sand and sea.

It would be incredible if this happened along the coast of the UK..... dreams of things to come?

Below is a description of the coastal initiative which offers not only the beach wheelchairs but good access and also trained helpers.



### ***Everyone can enjoy the sea and beach***

With Sun, Sea ... Carefree wants to realise the Province of West Flanders accessible beaches. We do this together with Intro and six coastal municipalities (Nieuwpoort, Middelkerke, Ostend, Bredene, De Haan and Zeebrugge).

To give everyone the chance to enjoy the sea and the beach, we are working on accessible infrastructure and trained assistants.

### ***Appropriate infrastructure***

On and around the open beach we strive to adequately reserve parking spaces, accessible tram stops, clear signage, an accessible beach access, a paved path on the beach to the hard sand, alone platforms, an accessible toilet, accessible changing room and shower with lift and high changing bed, special beach wheelchairs for on the sand or in the water..."



The initiative has made some new initiatives this year such as :

- putting in an accessible road from the tram stops
- accessible toilets, shower and change room
- paved path on the beach

**Trained assistants**

- to assist with transferring people to a beach wheelchair, to assist with personal care, to accompany people from point of arrival to the beach, ..
- they can be addressed on the beach or called in advance

**Contact Details**

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*“Happiness is toes in the sea, seagulls over head and.....*

*a drink at the bar with everyone else!”*



# FUTURE FOCUS

## Health Matters

**O**ur theme for the Winter issue is Health Matters

It is some time since we had an edition of PMLD LINK exploring the broad issues of health, yet this area is fundamental: health status directly impacts on every aspect of quality of life for everyone. By the very nature and complexity of profound and multiple learning disabilities (PMLD) we know with certainty, health status will always play a very significant part in the lives of these individuals.

Our 2009 issue of PMLD LINK, included articles describing health-related issues at both ends of the continuum – from best interest decisions around invasive procedures through to some very practical, day to day issues, for example on the basics of managing epilepsy; ensuring people were adequately hydrated; their nutritional needs met [either through an appropriately textured, well-planned diet or via enteral feeding]; advice on maintaining good oral health was given its rightful importance. This issue also offered a challenge to the concept of what ‘good health care’ looks like for people with PMLD. Would that look the same today, in 2016? Have we achieved that?

In our 2013 issue we had a broader focus on Well-being, yet almost the entire Winter edition of PMLD LINK, shared innovation and challenge to issues of healthcare – again full spectrum, from DNR decisions and more on invasive procedures, promoting positive mental health and well-being, developments in postural care practices, through to the importance of good primary healthcare and getting it right in GP surgeries. Are we there yet?

Sadly there is still much ground to be established before we have adequately addressed the difference in health status of people with PMLD from the rest of the population. To overcome these inequities, the challenge

remains for fundamental and reasonable adjustments around access to responsive and good quality services to meet the needs of people with PMLD - in order to address premature and preventable deaths. In 2016, people with PMLD should not be dying as a consequence of complications from constipation, distorted body shape or nutrition.

We hope you will share articles and experiences on healthcare - whether in response to meeting needs through daily routines or, more specialist services. We welcome contributions that challenge and champion the need for appropriate and responsive healthcare for every individual with PMLD.

For our Health Matters issue of PMLD LINK we are very fortunate to have Sue Turner join us as a Guest Editor. Sue is Learning Disability Lead for National Development Team for Inclusion (NDTi). As part of her role she also works for the Public Health England Learning Disability Observatory (NDTi are one of the partner-organisations making up the observatory).

She has been a regular contributor to PMLD LINK. Her most recent article (Spring 2016 issue of PMLD LINK) shared her research on the inequalities of personalisation for those with the most complex needs.

Annie Fergusson, Beverley Dawkins and Sue Turner,  
Guest Editors

**Please send all contributions by 24 October to:**

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**STIMULATE YOUR SENSES**

**NEW SUPER SENSORY 1K!**

## Want to take part in something Super Sensory?

Parallel London | 4th September 2016 | Queen Elizabeth Olympic Park |  
100m, 1km, 5km, 10km, Super Sensory 1km

**P**arallel London is the world's first fully inclusive fun push/run and free family festival at the Olympic Park this September. This national celebration of diversity aims to give everybody the opportunity to take on an inspiring challenge together, regardless of age or ability. Run, walk, wheel, push or be pushed – anything goes!

The emphasis of Parallel London is on fun and inclusivity.

We've joined forces with inclusion and sensory engagement expert Jo Grace to create an exciting new challenge for the senses – the first mass participation Super Sensory 1km!

This race encourages participants to exercise their senses over a course comprised of all kinds of sensory experiences, from sounds and smells, to textures and colours.

See our table and course map below for a full list of the sensory delights in store!

Great fun for all ages and abilities, the Super Sensory 1k is specifically designed to engage all participants to the fullest, including those who engage with the world in a primarily sensory way and welcome the opportunity to rehearse a situation before entering it

- Individuals with profound and multiple learning disabilities
- Individuals on the autistic spectrum
- Individuals who need sensory support in order to be able to remember an event. This may include people with late-stage dementia or specific brain damage

Participants who need a helping hand are very welcome to bring a buddy free of charge to push, guide or simply accompany them on the course. Of course the sensory world is a lot of fun and sensory stimulation supports everyone's memory, so if you are wondering if this event is for you, yes it is! Do join in.

The Super Sensory 1k can be 'trained' for, just like any other race. It can also be re-run through the senses after the event back at home or at school using the same stimuli to help participants connect with the memory and relive the experience of the day. 'Training' for the Super Sensory 1km will support sensory participants to be able to fully engage on the day. The sensory experiences have been chosen to be as engaging as possible to maximise the opportunity to participate.

The Super Sensory 1km will take part alongside the other Parallel London races. You are free to complete the course at any speed but we anticipate it taking between 15 minutes for the incredibly speedy and up to an hour for those making the most out of the experience.

You will also be able to explore the accessible attractions in the free family festival, which will showcase a multitude of accessible attractions, entertainment and workshops for participants and spectators of all ages. Among which you will find Jo, Parallel London’s ambassador and founder of The Sensory Projects, who will be running a warm-up workshop for our sensory athletes before the race and another workshop for the participants' supporters after the race.

We welcome families and friends to come along and cheer participants on and enjoy a fantastic day out. There will be quiet ‘chill out’ areas on site and Changing Places toilets are available.

You can find more information here: <https://parallellondon.com/super-sensory-1k/>

	Spoken cue	Sensory experience	Sensory systems stimulated by the experience
START 	Ready steady go!	Starter horn Movement starts	Auditory Vestibular
100m 	Ready steady here we go! Red -Ready!	Red balloons Red ribbons	Visual
200m 	Ready steady here we go! Steady, steady, steady!	Massage bug	Proprioceptive
300m 	Ready steady here we go! GOOOoooooooooooo!	Rallying cries of GOOooooOO-woah-oh from everyone!	Auditory
400m 	We will keep a steady pace.	Clapped beat Inflatable clappers	Auditory Proprioceptive
500m 	We will roll a steady race.	Massage bug	Tactile Proprioceptive
600m 	We won't get in a spin; no we won't get in a spin.	Spin Circle	Vestibular
700m 	We will keep on going taking deep breaths in.	Eucalyptus oil	Olfactory
800m 	Rolling beneath a heavy load.	Bean bags	Proprioceptive Tactile
900m 	Together we roll this sensory road!	A jubilant colourful, noisy, crowd of other racers. Fresh orange segments. Celebratory hugs. Medals.	ALL!

# REPORT BACK

## 2nd Annual Intensive Interaction Conference, Glasgow- June 2016

The Intensive Interaction Conference held recently was well-attended with a full room of practitioners, or would-be practitioners on a recent sunny day in Glasgow. Presentations from Julie Calveley, Maggie Ellis and Jules McKim all stressed the importance of the use of video in our work, to allow us to review, evidence and support our work. Jules McKim showed a powerful case study of a man who was almost unrecognisable between the two sets of video. Kelly McArthur, a teacher in an ASD school noted that a particular challenge for teachers is to spend time when it is NOT objective led. Us in a Bus attended a great session with Graham Firth on embedding Intensive Interaction within our organisation, and he led a good discussion on how to move operational and organisational barriers to using Intensive Interaction more actively.

Victoria Goody, Chief Executive, Us in a Bus

## Positive choices conference March 31st and April 1st 2016

Who is your superhero? This years theme was 'Inclusion Superheroes'. Wonder Woman (Helen), Batman (Jonathan), Superman (Dave) and 'fiona' were in attendance alongside hundreds of inclusion superheroes. Staff and students from across the British Isles gathered together for the annual two day Positive Choices conference, hosted this year at the University of Nottingham.

The varied agenda brought something for everyone, day one 'cafe' style offerings gave delegates the opportunity to get up close with project teams, service providers to explore their work.

Day two brought a variety of presentations from leaders and practitioners shaping services including Anna Kennedy OBE, Debra Moore, Jane Cummings, Jim Blair, @WELDNurses and a powerful performance from Mixit [<http://www.mixitdays.com>]

PMLD LINK banner sparked interested in the journal and the work of practitioners supporting people who have a profound and multiple learning disability, sited alongside colleagues presenting the new flash cards for the (CTR's) Care and treatment reviews@TC4LDP [<https://www.england.nhs.uk/learningdisabilities/ctr/>] and @SeeAbility [<https://www.seeability.org/>] who brought along a variety of valuable accessible resources; conversations focuses on health and wellbeing and of course the exciting sensory world in which we live and work. Joanna Grace delighted students and staff with her immersive sensory storytelling [[@jo3grace](http://jo.element42.org/sensory-stories)]

You can find out more by following @PCConf #PC16 <https://positive-choices.com/>

Jillian Pawlyn

# RESOURCES

## Interactive Storytelling Tips and Ideas

PowerPoint presentation from Keith Park with simple tips and ideas to assist you with writing your own interactive stories and to make sure they are fun!

[https://www.youtube.com/watch?v=rWDAvfyhK\\_Q&feature=youtu.be](https://www.youtube.com/watch?v=rWDAvfyhK_Q&feature=youtu.be)

## Sheridan Forster videos

Explore some of the great resources and news items from the website of our regular author, Sheridan Forster. <https://sheridanforster.com.au/news/>

For example, she shares a very valuable, video clip justifying why there is a need to describe people who have a profound learning disability and to explain how they experience the world differently. She aims to do 'positive justice to people with profound intellectual and multiple disabilities, enhancing understanding, respect and consideration of them and those people who support



them'. Scroll through her many excellent ,thought-provoking items and articles...some you might recognise from PMLD Link.

<https://sheridanforster.com.au/2016/05/23/people-with-profound-intellectual-and-multiple-video-in-online-training/>

## Online free training from Australia

Well and Able - Improving the Physical Health of People with Intellectual Disability'. Another resource shared by Sheri is a fantastic, free online learning course from Australia, focusing on the health of people with intellectual disabilities. To take part: <https://www.edx.org/course/well-able-improving-physical-health-uqx-able201x>

## IN THE NEWS



## GSK in partnership with the Kings fund IMPACT Award

PAMIS is delighted to share our news about our recent GSK in partnership with the Kings fund IMPACT Award for excellence in community health. We are immensely proud that we as one of 10 charities in a field of over 400 were acknowledged for the leading work we do to improve the health of the people with profound and multiple learning disabilities across Scotland. The award provided a robust and rigorous assessment of us as an organisation and focused on excellence in the six areas of IMPACT. These are:

- Innovation - leadership, creativity and initiative in addressing current challenges in healthcare access and delivery
- Management - efficient use of resources; quality of management processes; equality of opportunity; clear objectives and plans; strength and financial effectiveness of the organisation
- Partnership - working effectively with others (members, users, voluntary, private and public sector partners etc.); willingness to share 'best practice' and to learn from others.
- Achievement - measurable results achieved; numbers of people benefitting; a reflective approach to evaluation of work; measurement and monitoring of performance, being able to report outcomes and impact.
- Community focus - involving and responding to users and the community; openness and provision of information; adaptability to changing circumstances and needs
- Targeting need - awareness of community issues and priorities; having a detailed understanding of the target community; ensuring services are accessible and focus on people in need.

We also know that we have had the best educators - people with profound and multiple learning disabilities and their family carers. Profound means deep, wise, expert and knowledgeable. People with PMLD have taught us how to care, how to act with compassion, how to work as a team and how to make human connections. We are indebted to them, and their family carers, for their contributions and support that enabled us to make the IMPACT for the award.

The award has also given us access to an amazing leadership resource and network. We have already benefited from 3 days with leading experts in the field of: finance; governance and risk; impact; evaluation; and leadership. This is an ongoing development programme from the Kings Fund and GSK and provides an opportunity to network and work with leaders in the field.

We were also given the opportunity to work with a film crew and the link below will take you to our film first shown on the iMac screen at the science museum in London!

<http://www.kingsfund.org.uk/audio-video/2016-gsk-impact-awards-pamis>

Our work will continue to benefit from this award and we are also keen to share the learning and resources with partners and other organisations. Do get in touch if you want to meet to discuss any aspect of the award or our work, we will be delighted to speak with you.

## HOME – A new show from Frozen Light



For the first six months of 2016 Frozen Light have been busy in the rehearsal room and office planning and devising for our new show HOME. We are really excited that HOME will premiere at bOing international family festival at The Gulbenkian, Canterbury on 27th and 28th August. We visited bOing last year with The Forest and it was brilliant. If you live near or can get to Canterbury on that weekend, you should, there is so much for everyone to enjoy. Following on from the premiere we will be going on a small East of England Autumn tour (dates at the bottom). HOME will then be doing a much larger nationwide tour in Spring 2017. We are currently working hard trying to ensure we reach as many people with PMLD across all corners of the country as possible. Dates for this will be announced soon so keep your eyes on our website and social media.

Other exciting news, The Forest will be visiting the Edinburgh Fringe Festival from 22nd – 25th August. We will be performing the show at 10.30am at Pleasance Beyond in the Pleasance Courtyard. We are really excited to be working with The Pleasance on this as we believe that this will be the first show specifically for audiences with PMLD to ever visit the Edinburgh Fringe Festival. If

you live in Edinburgh or fancy a trip to the Fringe Festival, please come and see us there!

Home Autumn tour 2016

22nd/23rd/24th September – New Wolsley, Ipswich

28th/29th September – Colchester Arts Centre

3rd/4th October – Key Theatre, Peterborough

6th/7th October – The Garage, Norwich

12th/13th/14th October – Harlow Playhouse

[www.frozenlighttheatre.com](http://www.frozenlighttheatre.com)

facebook- /frozenlighttheatre

instagram- /frozenlighttheatre

twitter- @frozenlight

## Learning Disability team win awards for creating new app



Tracey Helliwell, Learning Disabilities Liaison Nurse, said: “The app will allow us to take this to the next level and it’s very exciting to know that it will be developed and introduced to Barnsley Hospital.” The team at Barnsley Hospital recently picked up the prizes during the Digital Health Design Challenge in collaboration with a digital design agency (Barnsley, UK) Barnsley Hospital’s Learning Disability team designed a new app recently which will improve care for people with learning disabilities when they visit the South Yorkshire hospital.

Technology innovators, health professionals and patients were at The Digital Health Design Challenge to co-create

new products for the NHS. The teams involved looked at a wide range of patient care challenges which had been identified by local NHS trusts.

The event was arranged through the Connected Healthcare programme which was introduced by the Digital Media Centre, through Barnsley Council's Enterprising Barnsley business support programme.

### **How the app was created**

**T**he idea for the app came from the already existing 'hospital passport' which was created at Barnsley Hospital and is given to all vulnerable patients. The hospital passport helps in aiding hospital staff to look after those with learning disabilities and includes significant information about the patient, likes and dislikes and any changes that the patient may need. The hospital passport is currently in a paper format and the new app will allow staff to collect this information and data on a digital platform which will be more usable for staff when accessing patient information.

The app will help people with learning disabilities communicate their sometimes complicated needs to improve their experience of treatment and care.

### **'Fantastic achievement'**

**T**racey Helliwell, Learning Disabilities Liaison Nurse, said: "This is a fantastic achievement for our team and our hospital and we are extremely proud. It's been a great experience to work with the design team at HMA and we are very excited to take our hospital passport to a digital platform.

"It's so important that, as staff, we can understand a patient's everyday needs and wishes and the passport has already enabled us to recognise a person's health and social needs, allowing us to adjust our care accordingly. The app will allow us to take this to the next level and it's very exciting to know that it will be developed and introduced to Barnsley Hospital."

The app is currently being developed for use within Barnsley Hospital and the team hopes that it will be rolled out within the trust very soon. The ambition is to introduce the app to the public with some engagement activities during National Learning Disability Week which will take place during the week commencing 20 June 2016. <http://www.hitcentral.eu/british-journal-healthcare-computing/learning-disability-team-win-awards-creating-new-app>

## **NEXT ISSUE**

Winter Vol. 28 No. 1 Issue 83

### **Health Matters**

Do you have any stories to share?

If so, contact the editors:

Annie Fergusson, Beverley Dawkins and  
Sue Turner

E: mail:

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**Copy date 24th October 2016**

# Previous articles on leisure

## Inclusive Libraries

During childhood, schools are usually the main place for inclusive literacy activities and, in some areas, colleges for young adults. For most adults, however, there is often nowhere other than the public library to access books and computers. This is due to the demise of day centres for adults with learning disabilities and well-intentioned attempts to improve the daytime opportunities in the community. Penny Lacey and colleagues worked with librarians in an action research project to enable them to meet the needs of people with SLD and PMLD. They were conscious that inclusive literacy requires much more than a good stock of picture books or specialist resources such as 'Story Sacks' or 'Bag Books'. Therefore, they trained library staff to support these people in a range of inclusive activities.

Issue 60 (p.17) includes an article from Penny Lacey about the Inclusive Libraries project at its inception and Issue 67 (Spring 2010, p15) contains details about the outcomes of the completed project. In the latter issue (p19) Nina Martinez writes about Lifelong Learning with Bexley Library Service.

## Music Activities

There have been some articles in PMLD LINK which describe projects to make available live Music for Leisure (as opposed to music education in school environments.) In Issue 71 (Spring 2012, p. 18) Robbie Campbell describes the work of the Joy of Sound which is an inclusive music and creative arts project providing workshops and equipment to enable people to enjoy taking part in music making and other arts activities. The Joy of Sound website is at [www.joyofsound.net](http://www.joyofsound.net). Issue 80 (Spring 2015, p.5) has an article by Rhod Davies about a drop-in Music Café developed by volunteers from the Soundroom Community Music Project in Gateshead ([www.thesoundroom.org.uk](http://www.thesoundroom.org.uk)). In Issue 62 (Spring 2009, p.11) Martin Goodwin and Cath Edwards describe the process of working with a group of children and young people with PMLD their paid carers at a local authority care to develop their play and leisure skills through various creative arts opportunities. This involved both playing with the children and young people and training their carers and modelling appropriate techniques.

## Active Lifestyles

The Scottish Charity PAMIS has shown through its work in providing and promoting accessible leisure activities just what is possible. Its Freestyles project has developed an information pack and DVD showing people with PMLD taking part and enjoying various leisure activities in the community. This resource can be used to encourage, support and train other leisure providers in the community to include people with PMLD in their activities. For more information on this project or a copy of the DVD and booklet, contact PAMIS at Dundee or tel 01382 385 154 e: [pamis@dundee.ac.uk](mailto:pamis@dundee.ac.uk). In Issue 71 (Spring 2012, p.12), Alana McDicken and Lesley McClaren describe PAMIS' inclusive leisure projects.

In Issue 80 (Spring 2015, p17) there is an article from various contributors including an account of BikeAbility Wales which is a charity that provides cycling opportunities to people of all ages and levels of ability in Swansea ([www.bikeabilitywales.org.uk](http://www.bikeabilitywales.org.uk)). An increasing number of places are making available specialist cycles which are specifically designed to allow people to experience the freedom and empowerment of this physical activity safely. And if you still doubt the value of the great outdoors, just consider Cory Memory's plea and poem on p24 of Issue 80.

## Making Leisure Provision for People with Profound and Multiple Learning Disabilities

There are not many books on leisure provision for disabled people, let alone for people with PMLD. However, there was an excellent book, edited by James Hogg and Judith Cavet, which reflected on the potential benefit for people with PMLD of a number of different leisure activities from gardening to aromatherapy, drama to microtechnology, and many more. It also offered guidance for running and developing leisure provision. Although 20 years old and outdated in parts, this is still a useful resource and it is possible to obtain a secondhand copy at a reasonable price. Perhaps your local library can access a copy for you.

Reference: J. Hogg and J.Cavet (1995) (eds) *Making Leisure Provision for People with Profound and Multiple Learning Disabilities*. London: Chapman Hall

# SHORT COURSES & CONFERENCES

September		November	
Title:	Intensive Interaction with Phoebe Caldwell	Title:	Develop your sensory lexiconary
Date:	6th	Date:	18th
Location:	Glasgow	Location:	Birmingham
Provider:	Concept Training	Provider:	Joanna Grace
Contact:	info@concept-training.co.uk	Contact:	sensorystory@gmail.com
Title:	'Got My Back', a National Conference on Postural Care	Title:	Concentrating on Communication
Date:	12th	Speakers:	Carol Allen and Peter Imray
Location:	Birmingham	Date:	4 <sup>th</sup>
Provider:	Changing our lives	Location:	Manchester
Contact:	ask@changingourlives.org	Provider:	EQUALS
Title:	PMLD - Profound And Multiple Learning Difficulties	Contact:	www.equals.co.uk
Date:	20th	Title:	Supporting mental well being for students with PMLD
Location:	Glasgow	Dates:	11th and 23rd
Provider:	Concept Training	Location:	London
Contact:	info@concept-training.co.uk	Provider:	Joanna Grace
Title:	Develop your sensory lexiconary	Contact:	sensorystory@gmail.com
Date:	29th	Title:	Sensory Communication
Location:	Exeter	Dates:	14th Manchester, 15th Birmingham, 18th London
Provider:	Joanna Grace	Provider:	Hirstwood Training
Contact:	sensorystory@gmail.com	Contact:	richardhirstwood@gmail.com
<b>October</b>		Title:	Positive Sensory Approaches for Autism
Title:	Learning outside the classroom – taking the curriculum outside	Dates:	21st Manchester, 22nd Birmingham, 25th London
Date:	10 <sup>th</sup>	Provider:	Hirstwood Training
Location:	Birmingham	Contact:	richardhirstwood@gmail.com
Provider:	Concept Training	Title:	PMLD - Profound And Multiple Learning Difficulties
Contact:	info@concept-training.co.uk	Date:	23rd
Title:	PMLD - Profound And Multiple Learning Difficulties	Location:	Manchester
Date:	12th	Provider:	Concept Training
Location:	Chorley	Contact:	info@concept-training.co.uk
Provider:	Concept Training	Title:	Supporting mental well being for students with PMLD
Contact:	info@concept-training.co.uk	Date:	23rd
Title:	Supporting mental well being for students with PMLD	Location:	London
Date:	17th	Provider:	Joanna Grace
Location:	Birmingham	Contact:	sensorystory@gmail.com
Provider:	Joanna Grace	Title:	Massage in the Special School
Contact:	sensorystory@gmail.com	Date:	15 <sup>th</sup>
		Location:	London
		Provider:	EQUALS
		Contact:	www.equals.co.uk

Subscription prices are:

<b>UK:</b>	Personal	£20.00	Organisation:£30.00
<b>Non UK:</b>	Personal	£27.00	Organisation:£40.00

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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:

- |                            |   |
|----------------------------|---|
| <b>Rob Ashdown</b>         | Former teacher of pupils with severe and profound and multiple learning difficulties and special school Headteacher.  |
| <b>Jeanne Carlin</b>       | Disability Retired Disability Consultant and a parent of a young woman with PMLD.   |
| <b>Helen Daly</b>          | 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.  |
| <b>Jill Davies</b>         | 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.   |
| <b>Beverley Dawkins</b>    | Beverley Dawkins, OBE, has worked with children and adults with a learning disability and their families for over 30 years. She is a qualified Speech and Language Therapist and has an MA in 'Applied Psychology of Learning Disability Services'. Before becoming Chief Executive Officer of Generate she worked for Royal Society Mencap, campaigning for the rights of people with PMLD.  |
| <b>Ann Fergusson</b>       | Annie is a senior lecturer in the SEN & Inclusion team at the University of Northampton, teaching on undergraduate and postgraduate courses relating to severe, profound and multiple learning disabilities. Her research interests relate to person-centred working, meaningful participation and the voice of the individual in promoting positive mental health and wellbeing. She works one day a week in a special school with a role for training and looking at impact. Annie has a brother with a learning disability. She is a family member of the Learning Disabilities Mortality Review Programme Advisory Group. |
| <b>Rachel Parry Hughes</b> | Lecturer in Social Work, Goldsmiths, University of London, researcher in the field of profound and multiple learning disabilities   |
| <b>Becky Loney</b>         | Becky has a background in running creative services for adults with PMLD within the voluntary and statutory sector and she established the Lambeth Mencap Carousel project. Becky is passionate about intensive interaction and sensory storytelling, and spreads the word by training staff teams in high quality activities and creative approaches.  |
| <b>Wendy Newby</b>         | Deputy Headteacher at The Shrubberies School, Stonehouse, Gloucestershire. This is a school for students with Severe and Profound Learning Difficulties   |
| <b>Jill Pawlyn</b>         | Jillian Pawlyn has a background in Learning/ Intellectual Disabilities Nursing and is an enthusiast and advocate of Technology Enhanced Learning. During her years as a registered nurse Jillian has developed a specialist interest in the health needs of people with a learning/ intellectual disability in particular those individuals who have Profound Intellectual and/or Multiple Disabilities (PIMD/ PMLD). She is a member of both the national and local PMLD Networks  |
| <b>Sue Thurman</b>         | 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.  |
| <b>Bella Travis</b>        | Policy Lead, Mencap   |

# 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](http://www.pmlmlink.org.uk)

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