

# PMLD LINK



sharing ideas and information

Life as an Adult

Summer 2017



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Cover picture: Photograph  
taken by Andy Lord

## GUEST EDITORIAL

# Life as an Adult

**W**elcome to the Summer 2017 edition of PMLD Link. In our call for contributions for this edition we expressed our hope that we could achieve a balance between illustrating the challenges and celebrating the joys of adult life - we hope that you will feel that we have achieved this! We have been delighted and overwhelmed with the number and range of articles submitted and offer thanks to all contributors.

We write this editorial in the aftermath of an election which has produced a hung Parliament, with Brexit negotiations about to start. Quite what the future will hold when it comes to health and social care for adults with PMLD, and others, is uncertain. As we hoped, we have been able to include several excellent articles on health and social care services for adults with PMLD in this issue, written by parent-experts (Jeanne Carlin, Sam Bergin-Goncalves, Mark Neary), social care providers (Michael Fullerton from CMG, Thomas Doukas from Choice Support, Salvador Tedd and Theo Bowstead from Lambeth and Southwark Mencap) and campaigners (Simon Duffy, Bella Travis and Eve Jackson from Mencap and others already mentioned who double up in this role!) These articles highlight the importance of health and social care services knowing who the adults with PMLD using their services are and what their needs and aspirations are. This point may seem obvious to PMLD Link readers but is in fact a crucial one in adult services where people with PMLD may be subsumed within categories such as 'complex needs'. The articles emphasise the importance of personalised support and the need for structures which support families and providers to develop and sustain it. This means also having structures which support ongoing campaigning through local and national groups. We may know a fair amount about what works when it comes to supporting adults with PMLD to flourish, but we are still a long way from ensuring that this knowledge is put into practice everywhere. We would urge readers to heed the call made in this issue to get in touch with Mencap about their experiences, so that it can act on their concerns.

In this issue we also have a number of articles that deal with touch, particularly, to use Thomas Doukas and Leonie Elliott-Graves' phrase 'safe and positive touch'. We found it interesting that touch should emerge as a common theme within the articles and wondered why this was. Perhaps 'touch' serves as a locus of concern - or the locus of a particular concern: should I be trying to enter the world of the person with PMLD (which may be primarily a tactile one) or should I be working to bring them into the wider world (of people who do not have PMLD, where certain norms regarding touch prevail)? This stand-off between lifeworld and normalisation perspectives is perhaps an eternal one for supporters of people with PMLD but clear-thinking contributions such as Janet Gurney's (in her viewpoint piece on using Intensive Interaction in public) and practical ones such as Becky Lyddon's (on managing sensory processing difficulties in everyday life) can help us get beyond it and act. Reflection on our interactions with people with PMLD and others can also be helpful and Sue Hogan's article explains a methodology for shared critical reflection among teachers which we think has applicability across sectors and settings.

The third and final theme of this issue is access to the arts. Practitioners at Access All Areas, Story Massage, Frozen Light, Folk Stories and the Touch Trust share a willingness to 'break down the conventions' (Culturised/Adams, 2017) of artistic spaces and constructs - theatre, dance, storytelling and musical performance - in order to allow people with PMLD access. What they find when they do this is not what some may have feared - that the construct has been lost - but rather than it has been invigorated. This is what everyone has to gain if we commit to a society that includes people with PMLD, and views them as contributors.

As ever, this issue also includes plenty of news items and details of relevant resources, as well as our short courses listing. You can also find useful information in past PMLD articles on adulthood, which Rob has identified for us; you can access these via our website.

Happy reading!

Rachel Parry Hughes, Becky Loney and Rob Ashdown

### Contact Us

#### Subscriptions

Rob Ashdown  
15 Cliff Gardens,  
Scunthorpe,  
North Lincolnshire, DN15 7PH  
info@pmlmlink.org.uk

rob.ashdown@ntlworld.com  
Tel: 01724 852818

### Production

Paul Bramble  
The University of Northampton  
Email: info@pmlmlink.org.uk

**Website:** www.pmlmlink.org.uk  
**Twitter:** @PMLDlink

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# Citizen Network: Promoting Truly Personalised Support for People with Profound and Complex Disabilities

Simon Duffy

I am a professional only in a negative sense. I do not have a significant disability, and I am not currently a carer, but I also have no true professional qualification. Although I do have a doctorate, it is in philosophy. All I have learned over the last 25 years was taught me by disabled people, families, and some very good professionals.

For instance, in 1996 I started the organisation Inclusion Glasgow with the simple idea that I could help people with learning disabilities leave hospital to begin life in the community as full citizens:

- With their own home (not a group home)
- With their own support staff
- With their own budget
- With control over their life and their support
- Living the life that was right for them

The fact that we were able to achieve this with everyone we supported, which included people with the most profound and complex disabilities, was because I was lucky. I had not realised that by offering to provide individualised support for people in hospital we would inevitably be asked to work with people with the most complex needs. I had to learn fast; but I had great colleagues, people with much more experience than me who could help me; and many people also had families who cared about them, who stood up for them and who helped us get things right.

These are three of the most important things that we learned as we developed truly personalised support for people with complex needs:

First, values really do make a difference. It is not enough to care about someone; you also need to have a hopeful and positive vision about their role in the world. I think this means treating everyone as a potential equal citizen. If we see each other as a unique individual, each with a role to play in the community, then we may see potential within the person and seize opportunities to make life better.

Second, leadership matters. We did lots of things to train people, to plan and organise things, and to try and support staff. But in the end the thing that made most of the difference was whether we had found the right person to lead the support team. For people with

complex support needs it was not enough to have good intentions or to just talk about empowerment. You also need the right person to hold things together.

Third, families were the best guarantors of quality. Too many organisations see families as a problem, as too challenging or as a threat. But in my experience it was families who kept things right: providing information, challenge and ultimately holding us to account. It is families that remain, long after the well-intentioned professional has moved on to their next job.

More recently I was able to work as Governor at the special school in Sheffield, where I now live. Over the course of a few years we were able to radically redesign the transition process and to make use of individual budgets for health, education and social care. This meant we could put families in control of the whole transition process. One story sticks out from that time which sums up these three principles very well.

Katrina's son Jonathan has complex health needs. He has a tracheostomy and needs to take a breathing unit with him at all times. He suffers from severe epilepsy, which requires rectal medication for treatment. He has severe curvature of the spine, is double-jointed and has hypotonia. His health assessment described him as having severe learning disabilities, severe behavioural problems, global development delays and no speech. He also has bilateral deafness and eczema. In the last 3 years before leaving school Jonathan spent 150 days in hospital with breathing problems.

After leaving school Jonathan had support that was recruited and controlled by his mum, and funded by an integrated personal budget. There were no more stays in hospital; he had a job where he was valued and earned several qualifications; his life changed for the better. The key to all of this seems to have been:

- The positive attitude of Jonathan and his family, finding a life of meaning in the community
- A team that focused on his needs, spotting and



resolving health problems quickly and preventing crisis

- Great support and leadership from a mum who would only accept the best for her child

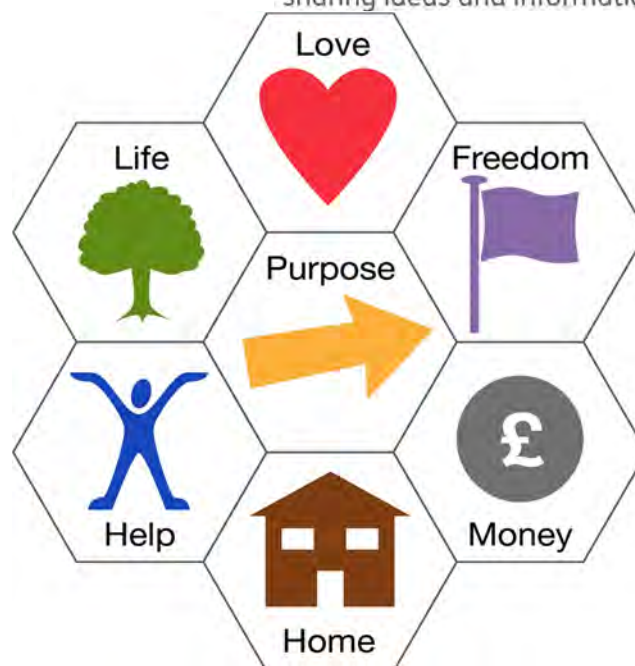
It is seeing these kinds of changes that had made me so passionate about trying to amend the direct payment system in England when I was leading In Control between 2003 and 2009. I wanted to make sure that families could control direct payments (which had often been forbidden) or be able to commission support from service providers that they could trust. In practice only some things have changed. Families can now get more control, but too often there is a lack of decent support and the severe cuts to local government have now left the social care system in crisis. There is still so much work to be done.

One of the things that I had hoped to see, with the introduction of personal budgets, was greater use of the kind of personalised support that we had developed in Glasgow. I thought that it would be a natural extension of personal budgets to see support providers start to work in a more personalised way, working with and for families. I was very surprised that progress was so slow. Most service providers continued to work for the commissioner, not for the family. Support is still inflexible, it is not truly personalised and people's lives are still far too constrained.

So, over the past year, I have been trying to think how we can help change this. We started by carrying out an international survey on personalised support, where we discovered some very interesting things:

- There are many examples of service providers offering highly personalised support from all around the world.
- There are organisations in Canada, Scotland, Australia, the Netherlands and the USA that have been working in this way for over 20 years.
- Many of these organisations were established by families.
- Most organisations are small and community-based.
- Many share management responsibilities, allowing families to take control of the parts the service that they want to.

So, it appears that there are organisations able to personalise support who are also willing to work in partnership with families. But they remain scattered and disconnected. Most families are not aware of the existence of this kind of personalised support and are forced to take on all the onerous responsibilities and uncertainties of managing everything for themselves. Alternatively they must hand their child over to a service provider who will provide unimaginative support and



give little control to the family.

To my mind this seems like a problem we can solve. If more families know that good support is available, then they will be able to find better support and to demand better support. If the organisations who provide personalised support start to learn from each other and teach each other, then we can grow the level of personalised support we need.

But we need a network - a way in which good people can connect, share and learn together. We also need this network to be inspired by the values of citizenship and inclusion. We need to see possibility in the lives of every individual, in every family and also in the organisations and professionals who can, when they respect people and families, play such a useful role. It is for this reason we decided to establish Citizen Network.

Citizen Network is not just about personalised support. It is a way of connecting all of us who care about the ideals of inclusion in the modern world: how we treat each other, how we act ourselves and how we welcome others into community. It will certainly be inspired by all that disabled people and families can teach us, but there is also much we can learn by welcoming refugees, migrants and people of different races and different gifts into our communities. Citizenship for all means welcoming and nurturing the gifts that everyone of us has inside of us and creating a world where those gifts are recognised and shared.

### Contact Details

Simon Duffy  
Director of the Centre for Welfare Reform  
Email: [simon@centreforwelfarereform.org](mailto:simon@centreforwelfarereform.org)

### More information

Individuals and organisations can join Citizen Network for free: [www.citizen-network.org](http://www.citizen-network.org)

There is lots of published research about Personalised Support on the Centre for Welfare Reform's website: [www.centreforwelfarereform.org](http://www.centreforwelfarereform.org)

Some of the key reports include:

Animate (2014) *Individual Service Funds*. Sheffield: Centre for Welfare Reform.

Ellis, R., Sines, D. and Hogard, E. (2014) *Better Lives*. Sheffield: Centre for Welfare Reform.

Cowen, A. (2010) *Personalised Transition - Innovations in health, education and support*. Sheffield: Centre for Welfare Reform.

Duffy, S. (2006) *Keys to Citizenship: A guide to getting good support for people with learning disabilities*. Second revised edition. Sheffield: Centre for Welfare Reform.

Duffy, S. and Sly, S. (2017) *Progress on Personalised Support (Draft Report)*. Sheffield: Citizen Network.

Fitzpatrick, J. (2010) *Personalised Support: How to provide high quality support to people with complex and challenging needs - learning from Partners for Inclusion*. Sheffield: Centre for Welfare Reform.

Sly, S. and Tindall, B. (2016) *Citizenship: a guide for providers of support*. Sheffield: Centre for Welfare Reform.

If you are interested in getting more involved in Citizen Network please contact the national coordinator for your country.

In England that is Sam Sly: [sam.sly@citizen-network.org](mailto:sam.sly@citizen-network.org)

In Scotland that is John Dalrymple: [john.dalrymple@citizen-network.org](mailto:john.dalrymple@citizen-network.org)

## Articles from PMLD LINK on Adult Life

### Spring 2007, Issue 56 - Adult Years

- Three articles written by families and carers about helping to make the best lifestyle choices for their relatives demonstrate that, with determination, personalized supported living is possible, even for people who have very severe or profound learning disabilities.
- The role of a local area coordinator, working in Scotland, which shows how communities can be made accessible for all.
- Changes in legislation in England and Wales related to consent issues.

### Spring 2008, Issue 59 – Families

- The parent of a young man expresses her concerns about a local authority's proposals to make major changes to day service delivery.
- Another parent talks about seeking suitable supported living arrangements for her son and becoming his Welfare Guardian under Scottish legislation.
- A notification of the Department of Health's New Deal for Carers, an ambitious programme to improve the life chances of family carers.

### Winter 2008, Issue 61 – Money Matters

- A review of Independent Budgets found that Individual Budgets can improve people's quality of life by giving them flexibility and control over their services and therefore their lives.
- Articles discuss the growing empowerment of people with learning disabilities and their families who are increasingly taking control of their services and in doing so improving the lives of all concerned.

# The Impact Sensory Processing Disorder has on Daily Living

Becky Lyddon

“It’s like my senses are on max all the time - lights, background noise, pain, heat, smell & taste”: Tim

**S**ensory processing is a function we rely on for the whole of our lives. It is the way we understand, respond and interact with the world around us. How can we learn to recognise and support sensory processing disorders in people with PMLD to ensure they are comfortably supported through daily living activities?

When we’re talking about sensory processing there are two functions that take place: the first being ‘sensation’ - that’s the physical act of receiving sensation by the sensory organ, and the second part being ‘perception’ - that’s the interpretation of the sensation by our brain and the response to it. This is happening every second of our lives through each of our sensory systems.

“Having a shower is agony. The water against my skin, especially my face feels like daggers.”

Our senses work together for us to take part in everyday activities like brushing our teeth, eating our breakfast, getting dressed, reading a book etc. A sensory processing disorder (SPD) is when our brain finds it difficult to do it’s most important job – organising and responding to the information which it receives. For people with SPD it is not the ‘sensation’ which is impacted, it is the ‘perception’, the sensory organs’ function perfectly well. The brain’s interpretation of the sensations is the difficulty. Therefore you can imagine how living with a SPD could impact on everyday activities like brushing our teeth.

There are 3 main ways a SPD can present.

- Someone can have difficulties modulating sensory information (we may be familiar with the terms as ‘seeking’ and ‘avoiding’ sensations).
- People can have difficulty discriminating sensations (knowing where a sensation has come from) and,
- they can also experience motor based difficulties which are commonly related to people with dyspraxia.

SPD can affect any of the senses at any point throughout someone’s day and some people may fluctuate between being a ‘seeker’ and an ‘avoider’.

In 2015 I met Tim at the Autism show while he was looking in our visual installation Lola’s World. He was explaining to me how SPD impacts his life. “I have difficulties when I shave and brush my teeth. When I look at my face in the mirror I find it difficult to see my face without parts moving.”

Tim told me that this means he is unable to shave independently because of his hyper-visual and vestibular sensitivity. “My friends when I was growing up would always ask why I would move my head around while looking in the mirror and not just stay still. This is because it helps me to piece everything together.” Because we rely on our senses to help us to understand our environment, it means we are able to recognise characteristics of SPD through how people interact and engage with their surroundings. One of the most important points covered during our FEEL IT workshops is an activity which helps us to understand some of these characteristics and what they mean. For example, if someone flickers their fingers in front of their eyes while looking towards a light, it is likely they are seeking visual

“I have difficulties when I shave and brush my teeth. When I look at my face in the mirror I find it difficult to see my face without parts moving.”

information. When your fingers are moving, the light entering your eye stops and starts, giving you the sensation of more visual information being received. If someone is seeking a sensation it is likely they are hypo-sensitive to that sense. By observing which sensory systems someone with PMLD may be seeking or avoiding, we can better support them in their everyday lives.

I worked for 7 years as a support worker in a short-breaks setting, and I became very familiar with how personalised sensory processing can be. Each young person responded in a unique way to their environment: one person may be drawn to a shadow flickering on the floor whereas someone else may find the buzz of the radio uncomfortable to hear.

Once you are able to begin to identify sensory processing difficulties you can then think about some of the daily activities which that person is involved in and how it might impact upon them. For example, everyday tasks like brushing our teeth:

- Visually the room may be bright, have overhead lighting or reflective surfaces. Most bathrooms have mirrors, glass and shiny surfaces, which can be extremely painful for some people with hyper sensitivities.
- Auditory: we create sound when brushing our teeth and different sounds are made as the brush moves around our mouth, depending on whether our mouth is open or closed. There may be other sounds in the room - most lights create a buzz which people may tune in to if they are hyper-sensitive.
- Tactile difficulties may be experienced if people are hyper-sensitive perhaps to the brush itself, or the movement of the brush or texture of the toothpaste.
- Smell and taste might relate to the flavour of the toothpaste. Smell is one of the most common SPDs but is also one of the most difficult to identify. While brushing someone's teeth they may gag at the smell of the toothpaste as it is squeezed out, or as it moves nearer to them or enters their mouth.
- Vestibular sensitivities can mean that a person refuses to let someone help them to brush their teeth. This might be because we support the person's head with one hand or because the movements are unexpected and stimulate their sense of movement (When our head moves we gain vestibular input, which is modulated by movement of fluid in the inner ear).
- For someone who enjoys chewing on the brush this may be because they seek to gain more proprioceptive input through their jaw and inside their mouth.

Brushing teeth is just one part of our daily routine and yet you can see how many ways our senses can be affected! Here are some ways you can initially start to support some of these needs:

- Try wearing a cap to reduce overhead lighting or sunglasses
- Use a soft bristle brush for people sensitive to sounds and textures



- Explore different flavour and texture toothpastes
- Help someone to feel grounded before brushing their teeth if they have vestibular difficulties, with a weighted scarf or a head rest to lean against
- For adults who enjoy chewing for tactile sensations, try using an electric toothbrush. This will provide plenty of stimulation for proprioceptive needs, as could stretching exercises and deep pressure around the jaw and mouth.
- Don't forget it doesn't have to be a regular toothbrush: there are finger brushes, chewable brushes, electric and soft bristle brushes. Try and consider all options!

(For more information about teeth-brushing I have a video dedicated to it on our YouTube channel, and it will also be featured in our new 'Homelife' guide book).

By identifying and being able to implement simple ways to support overriding sensory needs for someone with SPD we can have a positive impact on how they engage in activities. When our senses are integrated we are better able to attend and organise sensations.

Let's think about other ways in which SPD may affect an adult. If you were hearing all the sounds in your environment at the same volume without filtering, it's likely you will find it hard to focus on verbal instructions. You might not like to be in crowded environments and may find unexpected noises frightening. When we receive extreme sensory stimulus our brain triggers our fight/flight primitive mode. This is because the amygdala prevents information from being controlled by our pre-frontal cortex (the area where rational thought and decision making happens), and we respond accordingly, our bodies step in to protect us.

"Lunchtime is too noisy. Hearing everyone chatting while eating, there's too much speech. It makes me angry."



"Bright lights make me feel like I can't breathe. At night I cover the car mirrors with my hand so it doesn't reflect as brightly. During the day I close my blinds to block out the light and wear a baseball cap."

SPD can also be experienced as a severe pain which normally relates to hyper sensitivities. Ways to identify this may be through physical communication (the 'fight' characteristics to protect ourselves) i.e. wanting to reduce any chance of someone making the pain more intense or someone appearing withdrawn. I have met young people who are quiet and dazed due to the extreme pain they are experiencing.

A young man I supported rested his eyes while in daylight due to the intensity of the light. As soon as we were in a dark room or controlled soft lighting in a sensory room he would then open them.

To support adults with sensory difficulties we need to be prepared. I have a drawstring bag with some useful resources which I carry around with me, it includes some headphones (either over-the-head ones or small inner ones), swimmers' wax, a camping torch which can clip onto a desk or lap tray, a vibrating cushion, an electric toothbrush, chewing gum (unflavoured), a hat and sunglasses, a roll of non-slip fabric, a squeeze bottle with

an alerting smell in such as mint or orange, and a few bean bags.

If we can help to support someone with SPD then we are likely to help them engage with their environment, which will help people to build relationships, engage in activities and explore their personality!

If you're looking to learn more about how SPD might feel for you, then the Sensory Spectacle Installations give an opportunity to experience sensations in a similar way to how people with SPD have described them. I work with people with SPD and work with them to help create a better awareness and understanding of SPD to the public. We bring some of these to our workshops and when I speak at conferences and events. Also our bespoke sensory dining room training helps you to experience how mealtimes may feel for someone with SPD. Please see our website for more information and the Sensory Spectacle YouTube channel: I upload a weekly video which helps to explain why some people with SPD may find certain activities difficult or why they may behave in a certain way. Please take a look [www.sensorspectacle.co.uk](http://www.sensorspectacle.co.uk)

#### **Contact Details**

Becky Lyddon  
Sensory Spectacle Founder  
[www.sensorspectacle.co.uk](http://www.sensorspectacle.co.uk)  
Email: [sensorspectacle@gmail.com](mailto:sensorspectacle@gmail.com)

## **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).

# Austerity and Cuts for People with PMLD: Some observations, including the importance of knowing your rights

Bella Travis and Eve Jackson

It is recognised that people with profound and multiple learning disabilities (PMLD) have a high level of need and they require full-time support. However, they are not always getting the support that truly meets their needs. This was highlighted in *Raising our Sights* (2010):

‘Adults with PMLD are a relatively small, easily identified group of people with undeniable needs for care and support. Despite these needs, they and their families have often not been provided with services to adequately meet them.’

(Mansell, 2010, p.36)

**W**e wanted to know what impact the current climate of austerity is having on people with PMLD – where it is increasingly acknowledged there is a social care funding crisis (social care funding has fallen by £4.6 billion, over the last 5 years (ADASS, 2016)) and the NHS is under huge strain (King’s Fund, 2016).

For example, have people with PMLD seen cuts to their support packages? Are they finding it harder to access the support and services they need?

We have spoken to a few people, including family carers, people working at a family carers support centre and service managers supporting people with PMLD, to get their views and experiences on this. At the end of this piece we have said we would like to hear about your experiences, to get a broader picture.

Here are some of the points people made:

## General

- ‘In our area there seems to have been a commitment to protect frontline services as much as possible so I think people with PMLD have largely been protected from cuts so far – probably because the families are so forceful! However, a layer of senior managers with expertise at the council has been removed and not replaced. There are now people at the council doing the job of three people. I’m worried we will soon see the impact of this. We have also been told that council savings will be discussed at our next partnership board meeting.’ (Person working at a family carers support centre)
- ‘It is hard to get a picture of what is happening for

people with PMLD as carers are busy caring. What is happening in individual cases – are their direct payments being cut? People with PMLD are a small group, they are not visible. Families can be struggling at home. It doesn’t help that many areas don’t even know how many people with PMLD there are.’ (Family carer of a woman with PMLD)

- Service managers supporting people with PMLD gave examples where people with PMLD had been affected by cuts in some way. A main area highlighted was that waits for services and reviews were getting longer. There were examples of cuts to funding, transport and equipment services as well as long delays in responding to referrals.
- ‘We are always battling to get the support our loved ones need.’ (Family carer of a woman with PMLD).

## Support packages

- ‘The number of hours of 2:1 support has recently been decreased for one young man with PMLD. This is needed for him to go out into the community and is important for his wellbeing. There has been no proper rationale for this cut. We are supporting the family to challenge it.’ (Person working at a family carers support centre)
- ‘I think they are trying to cut packages that are “more than average”.’ (Family carer of a young woman with PMLD)
- ‘In my area the council have said they want to get money back from direct payments that we are not spending in the month – ‘claw back’. As family carers we are already saving them so much. We need the flexibility. Sometimes I can’t recruit staff and so I am doing many more hours caring myself. I want to save the money in the direct payment so I

can afford 2 weeks' residential respite, when I have managed to recruit staff. We need flexibility, that is what personalisation is about. I am going to challenge this but many family carers are older and won't be able to fight back. It is cuts by the back door.' (Family carer of a woman with PMLD)

- 'A person we support was reassessed last year and his funding was halved as there was 'no evidence of challenging behaviours'. We challenged this as none of his hours had been identified as support for challenging behaviours. The decision went ahead. It has been really difficult to get funding for day services. He has a small amount of money in a trust fund so he is using this to pay for day services one day a week. His quality of life is at risk as he is not able to go out when he wants.' (Service manager supporting people with PMLD)
- 'Cuts to staffing hours is a major problem. We have been in constant communication with both Continuing Healthcare and the LA. We have been fighting hard to get appropriate support hours. We have managed to secure some of the 1:1 hours needed, but there is still a long way to go.' (Service manager supporting people with PMLD)
- 'We're finding more and more that there are ongoing conflicts between health care and social care. Local authorities are increasingly making cuts to hours needed to support with mobility and pushing the costs back to health, who won't always fund the package either. Local authorities don't seem to understand that reduced mobility can have a big impact on people's social inclusion and ultimately their wellbeing.' (Service manager supporting people with PMLD)

#### Day services

- 'For a number of years now people have been getting fewer days at the day centre. I don't know anyone with PMLD who is getting more than 3 days per week at the day service. I don't know what people are doing the rest of the time – and what funding they are getting and whether it is enough to do activities on the other days. I know there are some sensory sessions in our area but I have heard families say they can't afford it. Attending a session, will often involve the cost of a session, 2:1 support to attend the session, transport – it adds up. People need a lot of support to access meaningful activities.' (Family carer of a woman with PMLD)
- 'The day services are not always the best place for some of the people we support so we have been challenging local authorities to provide more 1:1 hours so that we can support them to do meaningful activities instead. This has not happened; we keep chasing them but get nowhere.' (Service manager supporting people with PMLD)

- 'One person lost his placement at a day centre he had attended for 20 years because cuts meant that the centre could no longer take people that were out of borough.' (Service manager supporting people with PMLD)

#### Recruiting staff

- 'It is a real problem recruiting. Staff pay is an issue – staff can get paid the same for doing something much easier. Support workers are not valued– they should be paid more.' (Person working at a family carers support centre)
- 'There is a high turnover. It is important staff understand their specific needs so we explain these but we have to do it all again when they leave. It is crucial so that they support the person properly.' (Family carer of a woman with PMLD)

#### Respite/ short breaks

- 'They tried to cut our respite a number of years ago. We challenged them and they cut fewer nights as a result. There was still a cut.' (Family carer of a young woman with PMLD)

#### Accessing health services

- 'The learning disability population has really risen in our area. This has put pressure on services eg. Physios, OTs, SLTs, psychology and psychiatry. There are now huge waiting lists.' (Person working at a family carers support centre)
- 'You can tell that community teams are under pressure, we have waited a long time for services such as SALT, OT and physio. We have worked hard to build good relationships with these professionals so sometimes they will 'pop in' for half an hour if they know a referral will take a long time and they are in the area. This helps us to keep people safe but means that people don't get a person centred service or the long term support they need.' (Service manager supporting people with PMLD)

#### Wheelchairs

- 'The biggest wait we have faced is for wheelchair services, the predicted time is between 6 – 12 months! One person we support is no longer comfortable in his wheelchair as his health needs have changed and he has gained weight. The process to get a new chair is very lengthy, we have to visit the GP, the GP makes a referral for services and they have to complete an assessment to confirm a new wheelchair is needed. We now have to wait for funding to be confirmed and even then it

will be a wait while the new wheelchair is designed, adapted and made.’ (Service manager supporting people with PMLD)

#### Impact on carers

- ‘There is increasing pressure on families. Families won’t be able to care anymore. They are saving the state a huge amount. It is short-sighted.’ (Family carer of a young woman with PMLD)
- ‘Families are terrified of the future – they are exhausted by caring roles. There are people over 80 caring for their 60 year old son or daughter.’ (Person working at a family carers support centre)

#### Transport

- ‘They completely cut the transport to and from the day service that people attend. We were told we would have to arrange private hire cars for the people we support, this would have cost £60 a day which they couldn’t afford. This put more pressure on us as we had to make changes to the rota and planned activities so that we can use the house vehicle. In services where this isn’t an option people could easily miss out on their services.’ (Service manager supporting people with PMLD)

#### Support for families to challenge, including information and advocacy

- ‘I am concerned that carers of people with PMLD are not being reached. Who is informing them of their rights?’ (Family carer of a woman with PMLD)
- ‘There is less advocacy support available for families. Families need support to challenge.’ (Person working at a family carers support centre).
- ‘Making a complaint or getting legal advice is very stressful. I have heard from other families that the council doesn’t take notice of appeal letters any more, you need to get a lawyer involved. I think the council just hope you will go away. You are caring so much it is hard to challenge and chase’. (Family carer of a young woman with PMLD)
- ‘In line with the Care Act, assessments should not take into account the support provided by carers – to get a full picture of the person’s needs – but this is not always happening.’ (Person working at a family carers support centre)
- ‘It is more important than ever to know your rights. We support families to know their rights, including asking for a carer’s assessment. We equip families so that they take resources like ‘Thinking Ahead’ (FPLD, 2013) to the person’s review and to carers’ assessments. We want families to know

options and know what to ask for.’ (Person working at a family carers support centre)

### Know your rights, how to challenge

In the face of the kind of slow or sudden changes in support or funding listed above, it is understandable that many people feel unsure of what to do next. But there are some tried and tested methods for challenging unfair decisions.

The first and most important thing individuals can do to protect themselves is to understand their rights, as set out in law. Familiarising yourself with the Care Act 2014, for example, can be very helpful. ‘Know your rights’ campaigning guides are available on the Mencap website. The Care Act says that the main priority for councils must be to ensure the wellbeing of those who are eligible for care and support. It also grants citizens the right to a Personal Budget, the right to an advocate if they need one and outlines rights for carers, among many other elements.

Campaigning begins once individuals feel confident with the facts of the case and understand more about which parts of the law can protect them. To challenge an unfair decision that will affect a sizeable group of people, families often group together to write letters to council officers, local councillors and MPs. They might choose to start a petition, contact the local media, or organise a campaign rally or protest. In the case of individuals who have lost support, the most important task is to argue that their level of need has not changed so their previous level of support to be reinstated. Involving a lawyer (funded through Legal Aid where eligible) can be a useful and necessary step to challenge an unfair situation.

Cuts to care and support for people with a learning disability are taking place across the country in many different forms. Please let us know if people with PMLD are experiencing cuts in your area so we can use this to inform our national influencing work and support you to challenge unfair decisions. Please email [campaigns@mencap.org.uk](mailto:campaigns@mencap.org.uk) with ‘PMLD Link’ in the subject line.

#### Contact Details

Bella Travis  
e-mail: [Bella.Travis@mencap.org.uk](mailto:Bella.Travis@mencap.org.uk)  
Eve Jackson:  
e-mail: [eve.jackson@mencap.org.uk](mailto:eve.jackson@mencap.org.uk)

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The 'Know your rights' campaigning guides are available online at: [www.mencap.org.uk/get-involved/campaigning/know-your-rights-guides](http://www.mencap.org.uk/get-involved/campaigning/know-your-rights-guides)

# NEXT ISSUE

Winter Vol. 29 No. 3 Issue 88

## Promoting Inclusion Transforming Lives

Do you have any stories to share?

If so, contact the editor:

Hannah Young  
H.Young@dundee.ac.uk

**Copy date**  
**Monday 23rd October 2017**

## Articles from PMLD LINK on Adult Life

### Winter 2010, Issue 67 – Lifelong Learning

- Notable for an article by the late Professor Jim Mansell highlighting the good practice and the barriers that need to be addressed if adults with profound disabilities and their families are to benefit from personalised support and be able to participate as active and valued members of their community.
- A parent perspective on supporting a daughter to access day time opportunities which are meaningful to her.
- The development of resource bases in Lanarkshire.
- News on the Inclusive Libraries project. /Multi-sensory story telling.

### Spring 2011, Issue 68 – Speaking Up – Being Heard

- Thought provoking and often poignant pieces exploring what is life like for a person with PMLD if no-one talks to them in a way that is meaningful.
- The importance of Human Rights; the shocking lack of attention to meeting the rights of people with learning disabilities and chilling assumptions made about people with PMLD.
- The power of tapping into friendships and positive inclusion in local networks to achieve a sense of real community belonging.
- An overview of Multi Sensory Story Telling to communicate some sensitive issues.

### Summer 2011, Issue 69 - Sharing Perspectives

- Battle against a local authority's proposals to close a small day care centre catering for the needs of young people with PMLD.
- The Involve Me project supports staff and organisations to explore how they can work in a way that upholds the law and respects each individual's human rights.
- The Improving Health and Lives (IHaL) Learning Disability Observatory aims to reduce the health inequalities faced by all people with learning disabilities in England.
- The experience of a family member Family Carer who acts as a Deputy – a person legally appointed to make decisions in someone's best interest when they lack capacity.

# Using Intensive Interaction in the Community

Janet Gurney

This article was originally published in the 'Us in a Bus Newsletter' 20th April 2017 and is reproduced with kind permission from Us in a Bus ([www.usinabus.org.uk](http://www.usinabus.org.uk))

A Speech and Language Therapist (SALT) who I had met at one of my workshops recently raised the thorny question, which she had been asked, of 'should we use Intensive Interaction when in public?'

Thorny, because maybe the question might reveal more about people's comfort zones than it does about what is in the best interests of the person they are supporting. I think this is a really important question; the SALT who raised the issue was spot-on about us ALL being bound by the idea of social normality and fearing judgement. When we are able to step through our own comfort zone, switch our 'self' consciousness into consciousness of the person we are supporting, then we are able to give them the support they need most, when they need it, irrespective of place.

A few of my thoughts:

- We all have public and private ways of communicating (the way I yell at my husband in the supermarket is different from the way I yell at him at home!). This can be reflected in our intensive interactions. My public way of responding to the person's movements or sounds might be more muted in a crowded place than they would be in a private one. But the important thing is that I am still responding in a way that the person recognises/ expects/needs me to. We can encourage carers and families to explore how they can be more muted but still be responsive (e.g. using touch in response to sound or movement).
- In some situations, when our person is becoming stressed, we know that if we do not acknowledge them through Intensive Interaction, then their distress will increase to the point of melt-down. Most of us would prefer that not to happen in public, for our person's sake and for our own! I can't think of a better reason for disregarding our own shyness or discomfort about Intensively Interacting in public – it'll attract a LOT less notice than a full-blown demonstration of distress.
- Having some cards in your pocket, printed with the message – "I see you are watching me using Intensive Interaction to support my friend/son. If you want to know more please call me later or visit [www.intensiveinteraction.co.uk](http://www.intensiveinteraction.co.uk)" – can make a huge difference to how comfortable you feel. You may

never use them, but knowing you can wordlessly offer an explanation to a stranger (who may be genuinely concerned, not just nosey or judgemental) will increase your confidence. And you have just advocated for your person to have the type of support they need exactly when they need it, in order to be part of the community like everyone else. (It's very easy to print your own cards these days).

So, I absolutely agree with the SALT that intensively interacting in public is fine - it gives the person the message that they are worthy of being listened to and that rapport can be maintained wherever they are, even if it is in a slightly different way from when they are at home. Roll on the inclusive and integrated society!

## Contact Details

Janet Gurney  
Director of Training – Us in a Bus  
Email: [info@usinabus.org.uk](mailto:info@usinabus.org.uk)

## Our first joint PMLD LINK conference

24th November

Title: Raising Our Game,  
Raising The Bar  
PMLD Conference

Location: tbc

### Contact:

**[Thomas.Doukas@choicesupport.org.uk](mailto:Thomas.Doukas@choicesupport.org.uk)**

# Are Learning Disability Partnership Boards Still Relevant, Particularly for People with Profound and Multiple Disabilities?

Jeanne Carlin

Learning Disability Partnership Boards were set up under the Valuing People agenda – with the idea of bringing together local professionals and people with learning disabilities and their carers to plan services for people with learning disabilities.

**T**he Partnership Board in Hull, the city in which I live, was set up along these lines and met once a month. It is co-chaired by a senior manager from either health or social care and by a person with a learning disability. I started attending their meetings about 3 years ago. I felt an immense sense of frustration – the Board was trying to meet such divergent needs that it felt like it was not meeting the needs of anyone.

People with learning disabilities are not a homogeneous group and neither are their families and carers. Sitting on our Partnership Board were professionals from learning disability services across all agencies: statutory and third sector, people with learning disabilities who were part of a very active and vocal advocacy group and then a diverse group of carers – mainly caring for individuals who were not able to participate in meetings. The meetings heard from a range of professionals (public health, housing, CCG etc) who came in as guest speakers, did a presentation, answered questions and then left, never to be heard from again. As a carer it felt like watching a moving notice board. There was no real debate of the issues that concerned me as a carer of a daughter with profound and multiple disabilities.

There was a change of management at the most senior level in adult social care and that offered us the space to rethink the role of the Partnership Board. Inclusion North came in and facilitated a meeting. The newly appointed professional co-chair spent time talking to individuals to gain a sense of what people wanted from the Board. As it was always well attended it was assumed everyone was getting something from it, or perhaps we were just hoping that it would fulfil a role because there was not another opportunity to meet across the adult learning disability sector.

We came up with a new model – the Partnership Board would meet every two months and in the alternate month we would have the opportunity to meet in various sub-groups in order to focus on issues of particular concern and in greater depth. One of the sub-groups set

up was a group focussing on the needs of adults with profound and multiple learning disabilities (PMLD). The sub-group is co-chaired by two parent carers with active support from a senior manager in adult social care and from one in health (this support is vital to give the group credibility and ‘clout’). We also receive administrative support from adult social care. The sub-group reports back into the Partnership Board together with the other active sub-groups (advocacy, employment etc). This has meant that the Partnership Board covers a wide range of interests in what feels like a ‘real way’.

As a PMLD subgroup we have focussed on issues brought to the group by both the professionals as well as the family carers. We are trying to remain action-oriented rather than endlessly talking about the issues. As many of you work in PMLD services I will list some of the issues we are working on:

- Written a paper about the need for a specialist doctor in learning disability services with a background in general medicine and palliative care. We are discussing this with the CCG (Clinical Commissioning Group) at the moment.
- The need for training in non-verbal communication for residential care staff across the private, third sector and statutory nursing and care homes. The speech therapist on the sub-group has come up with a model that offers a mix of on-site and course training. We are now costing the resources that will be needed and as a group we will look for ways to fund those.
- Concern about the safeguarding needs of individuals with PMLD who live in nursing and care homes who no longer have families supporting them. One of the local CQC (Care Quality Commission) inspectors attended a meeting and discussed how inspections pay particular attention to individuals in this situation.
- Consumables (include gastrostomy tubes, feeding connectors, gloves, etc) for individuals with PMLD and complex health needs – having clear pathways

as to who is responsible for providing and funding consumables. The CCG has given this task to a 'named' person to resolve.

- Develop a profile of who are the actual adults with profound and multiple learning disabilities living in our city – where do they live; what do they do during the day; who funds their services, age of their carers etc.

Our new model has been operating for just under two years. As a carer of a daughter with PMLD I feel that I am now an active campaigner for better services. I feel that my voice is heard and I do think that I am now working

'with' the professionals who have a stake in making sure that this group of people receive quality services in Hull.

If you are looking to make your Partnership Board more relevant to people with PMLD I would be happy to share ideas via email.

### Contact Details

Jeanne Carlin is a carer of a daughter with profound and multiple disabilities

Email: Jeanne@jcarlin.karoo.co.uk

## Articles from PMLD LINK on Adult Life

### Winter 2011, Issue 70 - Therapies

- One family share their experience of postural care, a twenty-four hour therapy using systems of support.
- Launch of the Postural Care Campaign and the benefits of postural care systems and training for parents and carers.
- The impact of therapists working together as a multi-disciplinary team to provide day services staff with training to improve their practice and achieve important outcomes for the people they support.
- A music therapist's account of using piano and percussion to engage a young man's interest and make him aware that he has a means of communicating.
- A genuine exercise in consultation in Leeds using three communicative approaches to ensure that the voices of people with PMLD have been 'heard' and translated as accurately as possible, when developing services.

### Spring 2012, Issue 71 – Life is for Living

- A range of topics from arts therapies and Intensive Interaction to holidays, enjoying music and wheelchair friendly boats.
- Two articles on wheelchairs and what people do during the day. These are illustrative of new Mencap Guides that have come out of the Jim Mansell Report 'Raising our Sights'. These 'How to Guides' cover different aspects of improving the lives of adults with PMLD; personalisation, support for families, advocacy, training, housing, what people do in the

day, wheelchairs, communication aids, policies and procedures, and planning and commissioning.

- The PAMIS Freestyles DVD which covers examples of adapted sports that can be enjoyed by people with PMLD, whether or not they are wheelchair users.
- Holidays for people with PMLD.
- Articles about music and dance movement therapy.
- The SMILE project in Oxfordshire providing fun activities for people with PMLD based on total communication, particularly Intensive Interaction.

### Summer 2012, Issue 72 – Family and Friends

- A parent's perspective on preparing for the end of life their child, sharing difficult dilemmas as well as some very valuable practical information.
- A sibling's reflections on the life of her brother and her memories as she looks back and considers them growing up together.
- Openstorytellers describe projects to promote friendship and meaningful participation.
- A different perspective on concepts of friendship through some insights gained through research into friendship for people with PMLD.

### Winter 2012, Issue 73 – Technology

- The importance of teamwork and the use of multimedia to enable people to have more control over their lives, improve communication and promote advocacy and empowerment.
- The partnership between a Day Centre and the local library and how technology opened up new opportunities for the people involved.



# Lambeth and Southwark Mencap: PMLD Project Update

Salvador Tedd and Theo Bowstead

The PMLD project (formerly Carousel) was established by Lambeth and Southwark Mencap in 2012, for people with profound and multiple learning disabilities. Professor Jim Mansell's 'Raising our Sights' report in 2010, and the Lambeth PMLD Report (Mencap, 2010) identified a huge lack of resources, support and activities for adults with PMLD in the borough.

The project set out to provide a range of creative activities that would be meaningful, and promote health benefits for this group of people, to improve their lives and also indirectly, to improve the lives of their families. The project has since helped fill some of the gaps in services for people with PMLD, and has been widely praised for its innovative approach and received a hugely positive independent evaluation by the University of Northampton. Five years on, the project provides a service to over 30 adults from Lambeth and surrounding boroughs.

## Activities

The Lambeth and Southwark Mencap PMLD Project runs four main activities every week: Saturday Stories, Dance and Movement, Rebound Therapy and Swimming.

**Saturday Stories:** this is a Sensory Storytelling session offered weekly on Saturdays at Lambeth Walk day centre. Some service users attend the sessions on a weekly basis and others fortnightly.

This project uses theatrical and storytelling elements to engage and entertain, communicating a narrative through the use of objects, sounds, sights, tastes and smells.

*"A fantastic story! She really enjoyed the spinning patterns which engaged with her sight. Amazing!" (PA quote)*

We aim to create a new world to explore every month using music, lighting, props, soundscapes and video projection. After that, there is time for lunch followed by massage stories and relaxation.

## Dance and Movement

We run two Dance and Movement sessions every week in a local community hall, with a newly installed Changing Places toilet. This is a creative movement session which promotes postural care and gives everyone a chance to

spend time out of wheel-chairs.

We begin with a familiar welcome for each individual, singing each person's name (including personal assistants (PAs) and our staff members), asking how everyone is.

*"Really good use of clear, purposeful music and movements."*

*"Great enthusiasm and interaction. Good fun."*

We use parachute games, coloured fabrics, ribbons, balls and sensory items of all kinds, to stimulate and promote purposeful movement. Props are used for reaching, kicking, squeezing or stroking, a great incentive for movement, adapted to best suit the individual in question, for example "Sarah does not like her hands touched directly but will happily reach up for a ball".

We use music throughout the session so people can explore the kinaesthetic relationship between sound and movement, how one can inform the other. We encourage everyone to express themselves through dance and movement and most of all, to have fun. The heart of the session takes place when individuals are able to be out of wheelchairs (lying on exercise mats with pillows, blankets, listening to gentle music).

We have input from the Specialist Physiotherapy team from Guys and St Thomas's NHS Foundation Trust (GSTT): the team attend the weekly sessions, providing therapeutic input, guidance on exercises, and booklets, which detail individual exercises and positioning, enabling support staff and families to follow and keep up the good work.

## Rebound Therapy (Trampolining)

Our Rebound Therapy activity takes place once a week. The many benefits include improved balance, increase or decrease in muscle tone, relaxation, sensory integration, improved fitness and exercise tolerance, improved communication skills and opportunities for facilitated movement.

The list goes on, with a more stimulated digestive system, improved bowel function and internal organ massage (achieved by the rhythmic acceleration and deceleration, and increase and decrease in weight offered by movement on the trampoline), and the clearing of toxins from the body (a process brought about by bouncing on the trampoline causing stretching and contracting of cells in the body).

Bouncing and moving about a metre or so off the ground brings health and safety challenges but the GSTT physio team are highly experienced and work closely with us to ensure we provide safe sessions. Staff complete the Rebound Therapy Level 2 training course before they can take part. We ask for questionnaires to be completed by peoples' G.P's, and just like in the Dance and Movement activity, each person is assessed beforehand by the GSTT specialist physiotherapists to ensure we don't cause injuries. We involve PAs and family members under the close supervision of the trained team.

The team use an award scheme to measure outcomes: the Huddersfield Functional Index used in conjunction with the Winstrada scheme, which allows Rebound Therapy trained staff to measure and record progress of people with profound or complex needs on a week to week basis.

### Swimming and Relaxation

The benefits of exercising in warm water for people with PMLD include improved circulation, improved self-esteem, the relief of muscle spasm and pain, strengthening muscles, improved coordination, increased movement, relaxation, and most importantly more fun.

We use a hydrotherapy pool in the Michael Tippett School for these sessions, and this means people can also use a sensory room in which to relax after their swim, an added bonus for many.

The staff team have become skilled at providing a really safe and dynamic session, and have built very trusting relationships with the people they're supporting. The team are able to identify and notice subtle differences in the muscle tone and mood of people and respond accordingly.

Many people attend sessions with their own PAs. These workers are encouraged to support with certain exercises, but the more complex support is carried out by the LS Mencap staff, with a greater depth of expertise and training. Again, the Physio team from GSTT have trained the staff to enable them to safely and effectively support people to exercise in the water, and have also delivered postural care training to raise awareness and understanding of the subject.

We try to capture the progress that people make, and this can be a challenge as the changes can sometimes be very subtle. People tend to acclimatize slowly to the sessions, taking part slowly, increasing the number of exercises over a period of time depending on their response. Warm water, stimulating exercise, freedom of movement - it is no wonder that this is one of the most popular activities we run. We have now reached capacity and are looking for venues in other boroughs to meet the growing demand.

### **Barriers**

Some of the barriers we faced back in 2012 still remain 5 years later, despite the huge efforts of all involved. Two of the big issues have been:

- **Funding:** this project is costly to run due to the need for a high-quality service with safe comfortable and well-equipped venues, highly trained and well-supported staff, and specialist equipment. The project was ambitious in its early days in setting out to be self-funding after three years, but it quickly became apparent that personal budgets could not sustain it, and it has been heavily subsidised through creative means. We're delighted to announce that Lambeth and Southwark Mencap have been successful in three bids in 2017 to help sustain and develop the project (with huge thanks to Garfield Weston, Morrisons Foundation and Bailey Thomas Charitable Trust).
- **Transport:** we haven't been able to offer transport adequately to support the service users and their families. We are still trying to find ways of minimising this problem, but it is a big and expensive challenge.

Other barriers were partly or entirely overcome such as:

- **Venues:** we have now agreements for long term use of all the venues we use. However, this will be a new challenge for the second phase of the project, when we plan to explore neighbouring boroughs.
- **Staffing:** the low turnover of the Lambeth and Southwark Mencap staff has helped to maintain consistency in managing and running the activities. We have also been working with many of the PAs who have been supporting service users for a long time. Sometimes when there is a change in PAs, we are able to give them more support since we already know the person with PMLD well. We can really help when a new P.A starts with little experience, and we've had great feedback about the peer training element of our project, which raises standards and promotes good practice.

- Lack of referrals: this was an issue in the early days but we have almost reached capacity over the past two years. However, we notice that most referrals come through the Community Learning Disability Health team, especially the physiotherapy team, who have played a crucial role in raising awareness with families.
- Recognising progress: this becomes possible especially because of the expertise and consistency of the staff team who, having supported the same people for the past two years or longer, are able to recognise changes - however small. We believe that people attending sessions for some time have become more familiar with the venues and the structure of the sessions, and are therefore more relaxed and confident to progress.

### Future development

Despite all the barriers and concerns, we still see our achievement as a great success. As the University of Northampton evaluation report stated:

"People with PMLD were the main benefactors from involvement in this project. Stakeholders unanimously described a range of improvements in the people with PMLD whom they care for and support. These positive differences ranged from the emergence of very small and subtle changes through to transformative and life changing breakthroughs, where one individual was enabled to meaningfully and enjoyably participate in a group opportunity, for the first time in their life".

We would like to expand this project and continue to respond the needs of the PMLD group, starting with the Southwark borough. We are already looking for possible

venues and are also setting up strategies for fundraising and we hope that our experience will allow us to succeed.

The project, despite being small, has made a great impact on the lives of people with PMLD, and those involved with them. It has offered a little hope and a sign that it is possible to transform lives if we work with determination and embrace peoples' unique differences. People with PMLD are so often overlooked and their gifts are not recognised in a society where competition and production are top of the agenda. We must remember that in giving each person the opportunity to grow and to participate then we can become a more fair and just society.

### Contact Details

Salvador Tedd and Theo Bowstead  
Email: [stedd@ismencap.org.uk](mailto:stedd@ismencap.org.uk)

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## Being Social #PMLDlink



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

<https://twitter.com/pmlmlink>

<https://www.facebook.com/PMLD-Link-777526962325831/timeline/>

# The Very Protective Safeguards

Mark Neary

On 13th March 2017 the Law Commission published a report on their proposals to replace the Deprivation of Liberty Safeguards (DoLS) with 'Liberty Protection Safeguards'. Many adults with PMLD living in England and Wales are currently the subjects of DoLS authorisations and would be affected by these proposals.

## Introductory note by the editors

**D**oLS authorisations make it legal to provide adults with PMLD with forms of care which might be seen as infringing personal liberty. For example, an authorisation may permit an adult with PMLD to be accommodated and receive care in a particular place, or to be accompanied by two people whenever they go out. The DoLS were introduced in 2009 to provide a mechanism for review of detention (and other kinds of restrictions) for people who lack the capacity to consent to their care or treatment but who are not detained under the Mental Health Act. While the need for such a mechanism has been widely accepted, the DoLS legislation has been controversial from the outset. For adults with PMLD, a form of care which is considered a 'deprivation' in legal terms may be seen from another perspective as support which enables them to lead the kinds of lives they wish to lead. It has also become clear that the DoLS process places a significant additional burden on already over-stretched local authorities and courts, resulting in poor experiences of the authorisation process for individuals needing care and their families.

Mark Neary has been a key commentator on DoLS over the past six years. Mark is the father of Steven, a young man with autism and learning disabilities. Steven lived at home with his father with support services funded by Hillingdon Council. In December 2009, the Hillingdon Council arranged for Steven to stay temporarily in a residential unit, as Mark was unwell. Mark wanted Steven to stay for only a few days and expected that he would then return home. In fact, the Hillingdon Council kept Steven at the facility for a year and made plans to move him to a long-term placement in Wales. Mark had to battle with Hillingdon to gain his son's release from care – a battle that went all the way to the High Court. The courts held that Steven had been unlawfully detained and ordered that he must be allowed return home to live with his father. The court noted that the Hillingdon did not properly discuss its concerns or its plans with Mark, did not take Steven's views into account and criticised its decision-making processes. The judge's ruling held that all four Deprivation of Liberty authorisations that had been served on Steven

throughout 2010 had been unlawful. Since this time, Mark has written regularly on the DoLS on his blog 'Love, Belief and Balls'. The following article is reproduced from the blog and contains Mark's thoughts on the Law Commission's new proposals.

## The Very Protective Safeguards

**O**n 13th March 2017 the Law Commission published their new report on their proposals to replace the Deprivation of Liberty Safeguards (DoLS). The full report is accessible online at: <http://www.lawcom.gov.uk/project/mental-capacity-and-deprivation-of-liberty/>

This may sound rather overblown and a trifle pretentious but reading the report brought home again how much Steven and I are embedded in the history of the DoLS legislation. Seven years ago, I didn't know they existed as it was around this time that Steven was served the first urgent authorisation for deprivation of liberty under the DoLS. But seven years on, I'm now a fully paid up, card carrying member of the DoLS Geek Club and on the day of the report's publication my Google alert function went into meltdown!

It's very hard to read the new proposals objectively when you've been so badly burned by the previous scheme. So, pardon me for leaving objectivity at the door, but this is the Neary Acid Test, first thoughts on the new scheme. My acid test is slightly more cynical than Lady Hale's. (Lady Hale is the UK's only female supreme court judge and her acid test provides that the objective element of a deprivation of liberty (DoL) is satisfied if a person is: (1) under continuous supervision and control; and (2) not free to leave). My third eye is always open to searching for the openings that enable the state to manipulate or ignore the new legislation. And from my totally subjective position, I can't help but repeatedly ask the question as I read: Would these new rules have made any difference to Steven back in 2010? That is the lens this post was passed through.

Firstly, there is the name change from Deprivation of Liberty Safeguards. The Law Commission are only suggesting the name as their focus is quite rightly on the



content. However, at the moment, the new scheme is called the Liberty Protection Safeguards (LPS). I'm glad they've ditched the "deprivation" as that word seemed to give a green light to some to detain people without thought for a more constructive care plan. But aren't "Protections" and "Safeguards" the same meaning. It feels rather like wearing two condoms. The report makes repeated reference to the new rules being more compliant with the UN "Convention on the Rights of Persons with Disabilities" (CRPD) and Article 8 of the "European Convention on Human Rights" (ECHR) which protects an individual's right to private and family life – couldn't that have been emphasized in the name? But I don't want to dwell on the name as it may possibly change. I will focus on just a few of the changes here.

The new LPS are meant to kick in BEFORE the person moves to the place where the detention will take place. At present, the person can be detained for ages before the process starts with an urgent 7 day authorisation. The intent behind this change is to force good care planning before the need to move someone. It also forces a human rights based agenda to drive the process as in the LB Bill that we have pressed for MPs to sponsor in the Private Members' Bill Ballot which seeks to change the law for disabled people so that they have more control over what happens in their lives. The State has to make a very strong case from the outset that detention is the most appropriate course of action. This sounds like a very positive move. But I worry about all those cases we heard about during the 7 Days of Action Campaign (<https://www.learningdisabilitytoday.co.uk/7-days-of-action-campaign-launched-to-highlight-plight-of-people-with-learning-disabilities-stuck-in-institutions.aspx>) that echoed Steven's pathway to local authority care – their initial reason for leaving their home was for an agreed period of respite, which quickly turned into something far more sinister. Or the person went to a "holding" place as the care provider pulled out of their package. Would these people fall under the new Safeguards from the beginning? And if they don't, how long before someone notices and acts on the original intention changing.

In a move to cut costs, the role of the Best Interests Assessor (BIA) is drastically changing. There will be a new role called the Approved Mental Capacity Professional (AMCP). At the moment, a BIA is an essential part of the assessment process and can recommend that the DoL isn't authorised or suggest conditions or recommendations to be added to the DoL. Under the new scheme an AMCP will only be appointed in cases of disagreement about the placement or where the LPS is needed to prevent harm to others. In Steven's case, Justice Jackson questioned the independence of the BIAs but the new scheme may compromise that independence even more. The person making the case for the LPS will already be involved in the person's care

planning. Looking at this through our 2010 lens, I know that Whistler's Mother would have signed the LPS like a shot and would have breathed a huge sigh of relief at the lack of external scrutiny.

At the point of the LPS being triggered, the person will be appointed a "representative". More than likely, this will be a family member or carer. So, the detained person will not be totally on their own but most family members will be ignorant of the LPS scheme like I was in 2010 and will need signposting to the rights of the detained person. It puts an awfully huge responsibility on an untrained (in the law) family member to be the main external scrutineer of such a major decision.

Another change that makes me feel very wobbly wobbly is the new role of the "Independent Reviewer". This will be the person who "signs off" the LPS after checking that it is legally sound and that the detention is "necessary and proportionate". This could be anyone from the "Responsible Body" who is not directly involved in the care of the detained person. It could be a colleague sitting across the office from the person who has assessed and written the authorisation. This seems to me to be a huge challenge in maintaining independence. Don't forget, we have got to the final stage of the process – the authorisation of the LPS and only one external pair of eyes may have been involved so far – the representative. It is true that the requirement for an IMCA still stands in the new legislation but we have plenty of evidence at how tricky it is to get an IMCA when the state would rather you didn't have one.

There seems to me to be a rather big contradiction running throughout the narrative for the new scheme. The report talks a lot about the importance of the person's rights. It also nods to the CRPD with repeated mention of the person's wishes and feelings taking priority. This is clearly a very positive move. But then, I wonder if those progressive ideas are diluted by the removal of the "best interests" driver and instead having the replacement, "the necessary and proportionate" rule. I've seen a few commentators state that they see little difference between the two but I'm not so sure. Although, there has been many debates over the years as to what "best interests" mean, it still feels a more encompassing, person centred idea than just "necessary and proportionate". When push comes to shove, it could be argued that something is necessary and proportionate, without being in the person's best interests at all.

The Law Commission have sat on the fence regarding access to court and are leaving it to the government to decide. They flag up a tribunal, similar to a mental health tribunal, as an alternative to a costly Court of Protection hearing. Throughout the 7 Days of Action campaign, I

was shocked to hear the many stories of dudes detained for years and the tribunal system having no effect on their detention whatsoever. I know that if I was faced with the choice between a tribunal and the scrutiny of Justice Peter Jackson, which one I would choose.

The scope of the new scheme is being widened beyond care homes and hospitals to include, amongst others, supported living and the person's own home. I can't get my head around that last one at all. As I watch Steven going about his daily business, it never occurs to me whether he is being deprived of his liberty. He does not live in a cage, gilded or otherwise. I cannot begin to compare his life in his own home and his life in local authority care, with its daily prone restraint, over medication and stopping all his external activities for three months. Sure, he will always need 1:1 support in the home, to support him with the stuff he cannot do and to keep him safe from himself when he gets extremely anxious. But that cannot fall under the scope of this legislation surely? Mind, one man's deprivation of liberty is another man's sensible care planning.

I do like the idea of the law now covering supported living and wonder if it's now the time for honest and brave reasons from the Local Authorities for authorising a LPS. Round my way, the people in supported living are in their pyjamas and in their rooms from 6pm to 7am. Will we see an authorisation that states the deprivation is necessary and proportionate because, "we are not willing to fund any additional hours"? I wrote about the case of

Davey vs Oxfordshire CC who reduced Mr Davey's support by 40% claiming that time alone would encourage his independence. Will the new LPS put a stop to those shameful tactics or at least force the local authority to call a spade, a spade.

If I was a trainer, I would sit the trainees down with a copy of the 2011 Hillingdon v Neary judgment and ask them to analyse how the LPS scheme would prevent such things happening again. Would the "elephant in the room" of Steven's real deprivation of liberty - being kept away from his home - have been revealed sooner? Would the LPS assessments have been more diligent, more fair and scrutinised better than 2010? Would Steven have received the necessary advocacy? Would he have got to court, and therefore, home sooner?

I have to say, I'm not confident of the answer to any of those questions being "Yes".  
But I'm hopeful.

#### **Contact details:**

Mark Neary  
Works as a writer, counsellor and advocate.  
Twitter: @MarkNeary1

The full text of Mark's blog is available online at:  
<https://markneary1dotcom1.wordpress.com/2017/03/14/the-very-protective-safeguards/>

## **Articles from PMLD LINK on Adult Life**

### **Summer 2013, Issue 75 – Human Rights**

- A local Learning Disability Partnership Boards commissioned guidelines to support the commissioners of service, the policy makers and the providers of services on how to gain the views of people with PMLD as they develop services.
- A study that attempts to answer the question 'how do adults with severe and profound learning disabilities experience intimate care provided by paid care staff in residential homes.
- Through his Circle of Support, one young man is able to be seen and to be heard in his locality on the Partnership Board, regionally at meetings and training events and nationally as a representative of people with complex needs on a national forum of people with learning disabilities.

### **Winter 2013, Issue 76 – Well-being**

- A summary of the outcomes of surveys by PAMIS and the training delivered by a 'Well-being Project'.
- An investigation into invasive care procedures in Scotland is published.
- The appropriate development and use of do not resuscitate orders.
- The value of regular health checks by GPs in identifying previously unrecognised health needs.
- The need to develop a more inclusive health care system.
- The need for reasonable adjustments to primary care services from GP practices with support from volunteer 'champions' with learning disabilities and their mentors.
- An integrated sensory assessment service for people with PMLD.
- The absolute necessity for good postural care.
- The value of NHS continuing health care.



## Music, Movement and Intensive Interaction: Access All Areas' Spinning Wheel Project for Adults with PMLD

Alex Covell

Access All Areas is an award-winning theatre company for adults with learning disabilities based in Hackney, London ([www.accessallareastheatre.org](http://www.accessallareastheatre.org)).

**I**t creates professional immersive productions through its Performance Company, delivers the Performance Making Diploma at the Central School of Speech and Drama, and has an industry-first partnership with agency Simon & How to represent seven actors with learning disabilities.

Access All Areas also provides a range of exciting and innovative participatory projects for people with all levels of learning disabilities, including Spinning Wheel.

Access All Areas believes passionately in the importance of including learning disabled artistic voices at all levels of society, to help create an artistic community that is made more vibrant, more varied and more relevant by including a range of voices.

### Spinning Wheel

**S**pinning Wheel is a movement and music project for adults with profound and multiple learning disabilities (PMLD). An innovative project that uses a multi-sensory approach, participants and their support workers experience an interactive and sensory orientated environment that develops their key personal and social development skills.

The tutors are skilled musicians and choreographers who work closely to develop responsive soundscapes and movements that react to the individuals in the room. Participants' communication is celebrated and valued: each sound or movement is recognised and stimulates a simultaneous response or interaction. This encourages

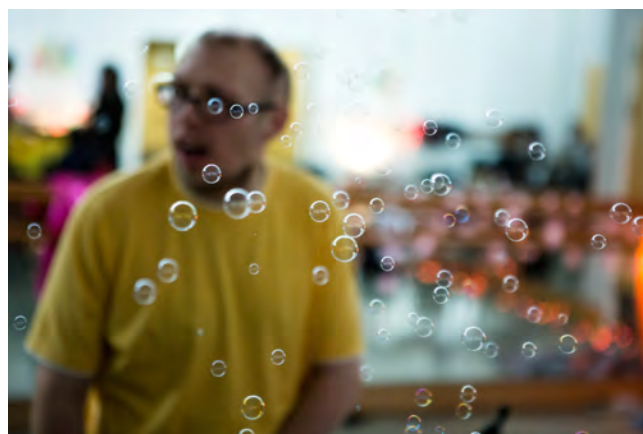
the development of participants' self-awareness, social interaction and creative expression within a sensory environment.

### Music methodology and accessible instruments

**H**ackney Learning Trust provided initial funding to purchase specialist instruments and lighting, including sound beams and fibre optics, alongside props, costumes and materials to build a sensory space. Accessible instruments include scrutti boxes, Q chord, ocean drums, xylophones, guitars, a sound beam and an array of percussion instruments. Tuned instruments are open tuned in the same key to allow any user to play in tune through touch or strumming, and instruments are consistently placed in the same part of the room so participants always know where to access music at any point in the session. Through these accessible instruments, participants and carers actively co-create music and soundscapes, interpreting musical direction and collaborating creatively. Carers are encouraged to use the instruments to create an engaging musical dialogue with participants, building their creative care skills and forming a closer bond. Participants' motor neuron skills are developed through the playing of instruments.

### Person-centered planning and evaluation

**E**ach participant has a communication passport that is used to develop a person-centred understanding of the individual's interests, dislikes and preferred means of communication. By ensuring all tutors and volunteers are familiar with these passports, we are able to create a space where participants are able to communicate using their own methods. Maintaining an open, reflective dialogue with all those in the room has been essential in developing best practice and shaping individual sessions and overall projects. Developments include a soft acclimatisation to the room, individual check-ins and one-to-one focussed movement and music. The group then form a circle and start working together to create improvisational movement that responds to the theme of the session.



### Entering the space and acclimatisation

**T**he first hour of the session acts as an acclimatisation period with no set activities or instruction. This allows participants to arrive, orient themselves and anticipate the oncoming workshop. By this time, the space is completely sensory, with materials, instruments and props. Music is played on arrival and participants are encouraged to play and explore the space.

### Approach

**I**nitially Spinning Wheel used songs and music that would be recognised by the participants. This has developed into using a more flow-based interdisciplinary approach, incorporating intensive interaction, Sounds of Intent and the participants' own sounds to create an aural, inclusive soundscape. Each week is led by a theme, with the movement, opening sounds and decorations of the space encouraging a style, feeling or season. Each session's soundscape is unique as it reacts to the needs and creativity of the participants in that moment.

Intensive interaction is an approach to communication skills specifically designed for those who are pre/non-verbal. It requires a series of frequent, often physical communication interactions and exchanges that enable partners to establish person-led and free-flowing fundamentals of communication. Examples include sharing personal space, vocal echoing, behaviour mirroring, exchanging facial expressions, burst-pause sequences and establishing mutual pleasure.

The person-centred approach of intensive interaction allows the creation of a sonic and kinetic dialogue with participants. Tutors and creative enablers open the dialogue by initially mirroring the authentic sounds and/or actions offered by participants. This is developed and extended whilst keeping the integrity of the original sound or action, enabling the participant to recognise their characteristic responses. Extension is repeated and manipulated, giving participants the necessary time to recognise their own part in the dialogue. Some consciously lead this exchange, willingly engaging in communication, extending their own sounds and actions and relishing the control.

### **Creative care work**

Care staff are a vital part of each session. Spinning Wheel encourages care staff to work creatively with participants to develop a positive and enjoyable interaction, developing their communication with and understanding of one another through the use of accessible instruments, props and intensive interaction. This professional development in creative approaches to care work is supported by an informal training session at the beginning of each term that opens up dialogue and ensures all carers understand their role within the session. This also provides quality assurance for participants.

“Over the past year, Spinning Wheel has been a highlight of my week. It has been an exploratory, inspiring journey.”

### **Conclusion**

Spinning Wheel is a unique and person-centred space that responds to the needs and natures of individuals, that values all communication and celebrates this with movement and music.

Access All Areas runs regular term-time sessions in Hackney, as well as bespoke sessions in care-homes and colleges.

To enquire about places on existing projects, to bring Spinning Wheel into your own setting, or for any volunteering enquiries, please contact me.

### **Contact Details:**

Alex Covell  
Email: [alex@accessallareastheatre.org](mailto:alex@accessallareastheatre.org)  
0207 613 6445

## **Articles from PMLD LINK on Adult Life**

### **Spring 2014, Issue 77 – Making Sense of the World**

- Parity for Disability describes guidelines for the staff on recognising the interests of their adult service users and the activities and projects that support their passions and recognise their anxieties.
- The terrible consequences of not recognising when someone is distressed and in pain and an assessment format which will assist in creating a greater understanding and awareness of someone's needs and how they express them.
- Guidelines for staff so that they may confidently use Intensive Interaction.

### **Winter 2014, Issue 79 – Innovations**

- Information about Personal Health Budgets for those living in England.
- New 19-25 College provision for people with PMLD located in Birmingham, on the same site as its partner special school.
- Support for parents in making a guide to young man's care for key workers using multi-media.
- The use of multi-media advocacy to supported a nineteen year old learner coping with PMLD and presenting challenging verbal behaviour.

### **Spring 2015, Issue 80 – The Environment**

- Sisters involved in ensuring through Circles of Support and Person Centred Planning that their sibling has the best possible environment.
- A community music project that has enabled people to have the pleasure to be found in making music with a band in a cafe in Tyne and Wear.
- The Bag Books' Tall Stories project takes multi-sensory storytelling into adult services.

### **Winter 2015, Issue 82 – Arts and Culture**

- Two articles are about making theatre inclusive and appropriate and consider the rights of people with PMLD to be given genuine drama experiences.
- There follow pieces which set out the case for inclusive experiences in art and music and show how people have found creative and innovative ways of giving them people with PMLD opportunity to participate meaningfully and genuinely achieve in different spheres.





## Helping Shane Prepare for Life as An Adult: the Rix Wiki Multi-Media Website and a Focus on Aspirations

Sam Bergin-Goncalves

My son Shane has just turned nineteen. I reflect on his life now as an adult. Shane currently enjoys school, is in good health and spends time with his friends at the weekend. I can honestly say he has a good life and seeing him happy brings me immense joy that words cannot explain. As a family we started to think about Shane's adult life when he was about fourteen. I remember feeling overwhelmed and didn't know where to start. How do you help a child with complex needs prepare for adulthood?

I began by thinking about what was important to me at Shane's age and how I prepared. I was deciding what further education to opt for, to think about where I was going to live, and, of course, meeting up with friends was high up on my list of priorities. My choices were based on my aspirations. So I stopped looking at Shane's disabilities and difficulties but focused on Shane as a person - what was important to him - and explored what was positive and possible and began to dream. These dreams turned into aspirations and a vision of what Shane's future life could look like.

However, for young people like Shane and families like ours to achieve aspirations, we need support and Shane needs support - it's a partnership. Decisions we have made about planning for Shane's future now all stem from our aspirations as a family but how do we include Shane in those conversations?

When you face challenges as a result of a learning disability or communication difficulty getting your message across can be very difficult. This is how I came to develop an easy read multi-media website for Shane called a RIX wiki. It contains information about our

family, Shane's communication, mobility and care needs, the things Shane likes to do, his spiritual life and school life. Shane's brother Daniel helped create the whole wiki. Siblings of disabled children can sometimes feel left out and by involving Daniel in this process he felt very important indeed.

I wanted to share his wiki at his Year Nine Annual review. I knew it was an important review and that new people would be invited. People like the "scary people" from adult services – people who had never met Shane - and I didn't want them to focus on reports which did not always show Shane as the wonderful, happy, affectionate person he is. Previously Shane would stay at his review for up to five minutes and then leave and who could blame him – a room full of professionals talking "about" him and a mountain of paperwork on the table. Shane stayed at his Year Nine review for twenty minutes – an enormous achievement which still brings tears to my eyes when I remember it. With support he shared his life by using his wiki. Everyone focused on Shane and not the mountain of paperwork. The "scary people" from adult services not only got to learn about what was important to Shane but also got to meet him. Shane now attends all meetings about him and uses his wiki to show videos on his achievements. Now we actually celebrate something at reviews instead of skimming over the long term objectives that were set in Shane's Statement when he was three and never met.

We also share our aspirations and we as a family are interested in what can the professionals around the table do to help Shane move one step closer to achieving his aspirations. I remember five years ago we really wanted Shane to be supported to be more independent in the bathroom. Shane had numerous operations at Great Ormond Street in the past to help him become more physically mobile. His last operation was a hip reconstruction when he was eleven so finally he had stable hips and was able to physically sit on the toilet. Our speech and language therapist worked with us to help Shane sign "toilet" and the classroom staff and the school's MOVE programme worked on Shane's pivoting skills. He needed to be able to pivot from the toilet to the hand basin to wash his hands. It took Shane three years to master these skills but that did not matter. Everyone was working together towards an aspiration and step by step was helping Shane become a more independent adult.

Focussing on aspirations has helped us as a family too. Shane used to spend every weekend with us, although we were planning for Shane to have a social life with friends as an adult. Reflecting on this I found the inner strength to allow Shane to attend Saturday club with his friends. Shane was fine - it was me that was the problem. I asked myself, how can Shane have social time

with his friends as an adult if I am not supporting him now to have these experiences?

One of our life long aspirations was to bring Shane to Florida. We all had a role to play. As a family we had to work hard and save up so we could afford the holiday. Shane's hips finally being stable meant he was able to sit in the seat on the aeroplane, being more independent in the toilet meant we did not need a bathroom with a hoist and therefore all the parks were accessible for Shane. Teaching Shane to drink from a cup meant he did not get dehydrated in the humid climate. This was an aspiration we had a few years previous. Shane tended to be nervous around animals. Being severely visually impaired I guess the noises, smells and movements of the animals scared him. Having opportunities to overcome these fears was paramount and visiting zoos and farms at Saturday Club and with us as a family helped Shane become more confident with animals and work towards achieving our ultimate aspiration – to swim with the dolphins.

I'm sure moving forward we will continue to face many challenges but by continuing to focus on our aspirations we can strive (and fight) for the support Shane needs to live the life he wants.

"Focus on the outcomes that children and young people and their families want to achieve, so that all decisions are informed by these aspirations." (Special Education Needs and Children with Disabilities 2014 Code of Practice Chapter 1)

Link to What is a Wiki animation  
<https://www.youtube.com/watch?v=0zaspxuunw>

Link to Shane's story  
<http://youtu.be/wOK84qsB4BA>

### Contact details:

Sam Bergin-Goncalves  
Email: Contact via the editors

# ‘Frozen’ as a Story Massage

Mary Atkinson and Sandra Hooper

This fun hands-on story was kindly submitted by Mary Atkinson and Sandra Hooper from Story Massage. Please see their website for more details about the Story Massage book, resources and training courses. Take a look: [www.storymassage.co.uk](http://www.storymassage.co.uk)



Once upon a time, there lived a princess called Elsa. (Downward fan)



She was called The Snow Queen because she had special powers to freeze things (Bounce)



One day, by accident she froze the whole kingdom so it was in eternal winter. (Calm)



Elsa was so upset and afraid of her icy powers that she ran away to hide. (Walk)



Let it go, let it go, let it go. (Fan)



Her sister, Anna, looked everywhere for her. She was determined to find Elsa. (Circle)



Along came a magical snowman, Olaf, and a mountaineer Kristoff with his reindeer, Sven (Sprinkle)



They searched high and low, over mountains and through forests with magic at every turn. (Wave)



Finally, they found Elsa but she couldn't control her powers and Anna became frozen. (Calm)



Elsa was really sad and hugged her. Their love broke the spell. The kingdom melted and everyone celebrated. (Squeeze)



Let it go, let it go, let it go.... (Fan)



## Contact Details

Mary Atkinson and Sandra Hooper  
Email: [info@storymassage.co.uk](mailto:info@storymassage.co.uk)

# Safe and Positive Touch in the Lives of Adults with PMLD

Thomas Doukas and Leonie Elliott-Graves

In social care, vulnerable people and especially adults with PMLD, are routinely deprived of positive touch. This is because they are either 'touch hungry' which means that they do not receive adequate touch or because they have experienced abusive touch (Green and Day, 2013; Field, 2003).

## Why is touch important?

**P**ositive touch is vital for human development and wellbeing (Field, 2003) and being 'touch hungry' makes some people seek touch inappropriately.

Many organisations have 'no-touch' policies to protect themselves and the staff members from false allegations (Green and Day, 2013; Field, 2003). This makes vulnerable people more deprived of positive touch and can leave them feeling isolated and de-valued (ibid). However, touch can have negative effects especially when it is used to abuse, restrain or control someone. It is important therefore to understand in what ways touch can be used to develop good relationships, trust and empathy and how to protect people with PMLD from negative touch. This is especially important because although touch is a basic human need and is so complex an issue, there is very little research about it.

## What does touch do?

**T**ouch is one of our senses and therefore is one way in which we understand the world around us and our own bodies and identities (Paterson, 2007). Touch is a sense that requires proximity and is inherently reciprocal. This means that you cannot touch someone or something without being touched back and therefore touch brings people closer to others or to objects (Megele, 2015).

Touch is also a method of communication and positive touch can be used to communicate empathy and reassurance (Field 2003; Megele, 2015). Holding someone's hand or placing your hand on someone's shoulder can make them feel comforted and acknowledged. Touch also helps build trust, as people are more likely to trust someone who has touched them than someone who has not (Green and Day, 2013). Massages have been noted to make people calmer and more productive and some studies have shown that it can also help reduce stress and chronic pain. Massage can be as therapeutic for the massage giver as it is for the massage receiver (Field, 2003).

## Differences in touch

**T**here are many different ways to use touch positively and different cultures and individuals have different attitudes to touch. This is important to note as each individual might have a different attitude to touch (touching and being touched) and a personal approach will need to be developed with each. Touch practices can include massage; sensory work and intensive interaction as well as everyday touch gestures.

## Should we use touch?

**T**he research would indicate that touch has many benefits and can develop strong and comforting bonds between individuals and their supporters. Though some people do not tolerate touch as much as others, most people benefit greatly from touching and being touched by others. In addition, the lack of touch can seriously harm people's feelings of comfort, validation and empathy and so the dangers of being avoiding touch completely outweigh the danger of causing accidental discomfort. Moving forward, it is important to ensure that our touch practice is sensitive to cultural and personal difference in attitude and that there is the support there to enable staff to feel comfortable and confident to use touch positively.

This research was conducted in order to explore and develop intensive interaction and safe touch skills and to determine in which circumstances touch is necessary, beneficial and desired or is inappropriate and challenging. A set of guidelines was developed to explore new and creative ways of using touch to foster communication, support care and develop strong relationships and to increase awareness of the benefits of touch.

## Methodology

**T**he research team ran regular sessions with support workers and adults with PMLD to explore touch practically. These sessions involved structured intensive interaction, movement work, role-play, physical work and massage. Through the sessions we were able to

gather rich qualitative and quantitative data that provided examples of successful touch activities and measured the increase in touch initiated by the supporter.

### Findings

Supporters used a range of touch techniques and found that they were successful at increasing alertness among the individuals they worked with.

We measured that without using positive touch activities staff only touched the person they support between 0-3 minutes a week. This excludes personal care where touch is necessary and highly regulated. However, through the use of positive touch, activities such as dance and drama games, intensive interaction and massage, supporters were able to add between 10-60 minutes of positive touch per week for each individual. This increase in touch resulted in improved alertness, eye contact, willingness to communicate, contentment, and calmness and relaxation. In particular, the staff reported that the structure and playfulness of the drama and dance games, allowed individuals to have fun and experience touch in a safe environment. Additionally, the staff reported that massages were an extremely popular activity, enjoyed by the majority of the individuals involved.

As a result of the research project and the process of planning and evaluating positive touch activities, the staff have become more confident in offering opportunities for touch. The staff are comfortable including more body areas in their positive touch activities and what they consider safe-touch zones has significantly increased. All staff involved in this research would strongly recommend the use of positive touch activities because of the benefits these brings to the individual they support. They have established that positive touch activities helps them communicate, connect, and develop trusting relationships with the individuals they support. The adults with PMLD they work with, are showing an increased enthusiasm for touch activities.

The research team has concluded that well planned and documented positive touch activities, are the best way to increase touch experiences and interaction for adults with PMLD. The staff felt that it is important to add touch activities to individuals' care plans routinely, stating the benefits and outcomes for each person they support. Although they found that one or two individuals did not tolerate touch, the majority of people involved thoroughly benefited from an increase in touch once they had become accustomed to the newly introduced activities. It is worthwhile to introduce touch to all people with PMLD and develop activities that promote touch.



### Outcome

This research project developed a guidelines document that can be easily read and used by staff and carers to better support their relationships and interactions with the people they support. This will benefit support workers and adults with PMLD equally and will help establish positive and nurturing relationships as well as increasing the effectiveness of communication between them. However, this document is also of interest to education and leisure facilitators and other professionals who work with adults with PMLD.

### Contact Details

Thomas Doukas, Head of Inclusive Research and Involvement, Choice Support  
Email: [Thomas.Doukas@choicesupport.org.uk](mailto:Thomas.Doukas@choicesupport.org.uk)  
Leonie Elliott-Graves, PhD candidate in Drama and Visiting Lecturer, Theatre and Performance, Goldsmiths, University of London  
Email: [lelli001@gold.ac.uk](mailto:lelli001@gold.ac.uk)

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# Folk Stories: Bringing Folk Music to Everyone – Including People with PMLD

Emmie Ward

I work as a freelance folk practitioner, a college tutor, and storyteller with people with learning disabilities. I've got over 25 years experience of working in a variety of settings with adults with learning disabilities. I did a post-graduate course with Roehampton University on a music assessment system for people with SEN called Sounds of Intent, which I find really useful. The Sounds of Intent system underpins a lot of my work in this field, and aims to promote music development within a framework that covers the whole range of ability, including people with PMLD.

In July 2016 Sarah Glover and I presented a workshop about bringing folk music to people with PMLD at the efdss conference in July 2016 (English Folk Dance and Song Society): Inclusive Folk: music and dance with disabled young people and adults.

We have been teaching the "Get Your Folk On Plus" classes at Cecil Sharp House since autumn 2015 and I have also taught some workshops for schools' groups. They are fun, friendly, inclusive classes for people with mixed needs and abilities and some of the students have severe learning disabilities and PMLD. I'm going to explain some of the ways we work with people in the group and how we adapt folk songs to make them accessible to everyone..

Recipe for working with Folk songs:

Take the ingredients one at a time:

- Story and words
- The rhythm
- The melody or tune.

Work on each "ingredient"

Mix them all together and enjoy.

"Garnish" with different arrangements and changing the dynamics.

How to work with the song

- Folk music offers a rich world of ideas and images, which are exciting for people to explore with vivid imagery and storylines. We have used songs about highwaymen, sailors work songs and a song about a harvest celebration.
- There are lots of ways to help people to get a sense

of what the story is within a folk song. We use photos, objects, signs, drama and movement to look at the story and words in the song.

- We introduce elements of sensory storytelling: an engaging and highly enjoyable way for students with severe learning disabilities or PMLD to access the story and the music.
- By covering lots of different senses you can reach all of the students in some way.
- It takes the pressure off one to one interaction so it's great for people on the autistic spectrum: the interaction can be with the sensory object rather than with you.
- For some students it helps them focus and enjoy the music to come, as well as being enjoyable in itself. We have found that we can work with students who struggle with concentration by doing some sensory storytelling, then music and returning to the sensory work.

How to work with the rhythm

- Folk music has some beats that can be exciting for people to hear such as slip jigs and polkas. So many of these beats have been designed for people to dance to, they can feel inspiring and uplifting.
- Here are some things we do to help people work with the rhythm in a song:

- Ø Try speaking the words of the song before singing.
- Ø Chanting them in call and response makes it easier for some learners as they don't have to remember the whole thing.
- Ø For example, the folk song 'Byker Hill':

- If people sing or chant in call and response then it's easier to play an instrument at the same time.



- The rhythm can be used as a “massage beat” and tapped out on hands, shoulders and back (if appropriate).

Call: Byker hill	Response: Byker Hill
Call: And walker shore	Response: and walker shore
Call: Collier lads	Response: Collier lads
Call: For ever more	Response: for ever more

- Rhythms can be accompanied with movement as well.
- Accompany with instruments and find ways for people to have as much control as possible to hold an instrument.
- Some people don’t want to play an instrument and it’s ok for them to use their voices or perhaps using their bodies to clap hands or stamp their feet.
- Some people don’t want to play an instrument for long. Its important to find ways to support students to explore and use instruments sensitively.
- One idea we have tried is to make a “jingle belt”: a belt with instruments attached, so the person can touch or hold the instruments on the belt whenever they want and there is no pressure to have to hold it all the time. It’s a good way to start exploring instruments and the sound and feel of them.

#### How to work with the melody

It’s good to have songs that are easier to learn by having simple tunes, but you can also work with more complex melodies. It’s good for people to have the opportunity to hear them, this may be enough for some but others may enjoy different ways to join in.

- The melody can be sung in call and response to make it easier to learn
- It’s usually easier to learn to sing a tune without an instrument, to avoid distraction.
- Find ways for people to join in, with whatever sounds they can make with their own voice. This could be long notes or phrases from the song. Sample these with a Big Mack, to make it easier to hear and tune in.
- Find ways to accompany on tuned instruments so that everyone’s contribution fits the music – making it as meaningful as possible, for example using pentatonic xylophones, tuning strings to an open chord or using apps such as garageband. Some people prefer not to use their voice and only want to play an instrument.



#### Mix it all up

- If the tune is too hard for someone to sing they can improvise sounds or sing long notes/small phrases from the song. These can be added to intros, outros and breaks.
- Change the dynamics to really add to the drama: Fast and slow, quiet and loud, different timbre such as all voice, different instruments: traditional and modern, soft and hard sounds etc
- It’s ok to focus on listening for a while and give people the opportunity to hear something different. Making clear dynamic changes can elicit some good responses from people.
- Encourage playing interactively by building in some 1-1 opportunities for playing in turns, and building in the sounds that people make into a song. Go round to each person and play with them...build their ideas into the song, this could be their own words, sounds, beats, movements etc

The Get Your Folk On Plus sessions will be running again this year on 2nd and 3rd August. We are looking forward to continuing our sound and sensory exploration of folk music with the group. Please get in touch with Cassie Tait in the education team at EFDSS if you are interested in booking a place one on or both of the days: [cassie@efdss.org](mailto:cassie@efdss.org)

<https://www.cecilsharphouse.org/csh-learning/youth/get-your-folk-on-plus>

Please contact Emmie Ward or Sarah Glover if you would like to know more about their music and multi sensory storytelling work.

<https://soundtracks2016.wordpress.com>

### Contact Details

Emmie Ward

Email: [emmie.ward@talktalk.net](mailto:emmie.ward@talktalk.net)

### Links and References

Joanna Grace: Sensory Storytelling

<http://jo.element42.org/>

Keith Park: Interactive Storytelling

<https://mobile.twitter.com/Keithpark1Park?p=s>

Sounds Of Intent assessment system ( Adam Ockelford)

<http://soundsofintent.org/>

Locking the ipad screen: video tutorial

<https://www.youtube.com/watch?v=upp-WYIZFkM>

Emmie Ward, Sarah Glover and Keith Park.  
Soundtracks Multi sensory storytelling

<https://www.facebook.com/Soundtrackscollective/>

Story massage

<http://www.storymassage.co.uk/>

Finding songs online

[www.efdss.org/resourcebank](http://www.efdss.org/resourcebank) has free downloads and resources

<http://www.village-music-project.org.uk> has English social music from C17th onwards

<http://www.vwml.org/search/search-full-english> a fantastic resource with over 50,000 entries

<https://mainlynorfolk.info/folk> Is a great site for getting song lyrics and has lots of YouTube clips

## Articles from PMLD LINK on Adult Life

### Spring 2016, Issue 83 – Its All In The Detail

- A proposal for some national quality standards of care for individuals with PMLD - because the necessary level of awareness and attention to 'detail' are missing currently.
- Evidence underpinning concerns that people with PMLD continue to miss out on true personalisation.
- Exploration of a shift in conventional models of service delivery further offering 'outside the box' thinking.
- A thought-provoking piece about our approaches and perspectives on personal passport and profile.

### Summer 2016, Issue 84 – Leisure and Pleasure

- A parent's account of managing her adult daughter's Individual Budget for almost ten years.
- The Changing Our Lives organisation works 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.
- The Foundation for People with Learning Disabilities have allowed us to reproduce their useful fact sheet on leisure opportunities for children and adults with complex health needs and/or limited mobility.
- The Carousel project aims to build a programme of high quality, meaningful activities for adults with PMLD in Lambeth.
- A sensory art project in Portugal.
- Recent developments at PAMIS with multi-sensory story telling.
- Formation of a collective – Soundtracks - to provide multi-sensory storytelling, poetry, music, song and dance workshops for adults with severe and PMLD.



## In Conversation with Frozen Light: Accessible Theatre for Audiences with Learning Disabilities

Max Adams

Frozen Light Theatre was founded in 2013 with the aim of producing multi-sensory theatre specifically for people with profound and multiple learning disabilities. Co-founders Lucy Garland and Amber Onat Gregory aim not only to increase the amount of accessible theatre on offer in the UK, but also to ensure that more accessible shows are produced in theatres, rather than solely travelling to their audiences by going into care homes or schools. I caught up with Lucy Garland to talk both about the work that Frozen Light have been doing for the past four years, and the on-going national tour of their current show *Home*, which is travelling to theatres all across the UK before finishing with a run at the Edinburgh Fringe in August.

### **How did the idea of staging immersive, multi-sensory theatre for people with severe learning difficulties come about?**

**B**oth Amber (Frozen Light Theatre's co-founder) and I did master's degrees in applied performance at the University of Kent in 2007. During that time we worked in a special needs school with six teenagers who had

profound and multiple learning difficulties and very much developed our work with that initial group. That experience was what helped us develop our mode of multi-sensory storytelling, but we then kind of went separate ways: I carried on doing multi-sensory storytelling on a smaller scale in schools, and Amber was doing similar things all around the world. We eventually got back working together in 2012/13 and we both

thought we wanted to make what we were doing bigger and more theatrical, and specifically we wanted to take it into theatre venues. We were seeing at the time that there was a real push towards access in terms of things like relaxed and more accessible performances and a lot more disabled artists, but what wasn't so present was companies making work that was very much specifically designed for people with the most profound learning disabilities. That was where our passion for making this work comes from.

### **So your essential aim is to make the theatre an accessible space for this new audience?**

**Y**es, and we believe for theatre to be truly accessible for someone with profound and multiple learning difficulties it needs to have sensory elements: it needs to be a lot more enhanced than a mainstream theatre performance. Our audience are on the stage with us – currently with Home we have a floor cloth and they sit around the edge. It's very much about keeping the audiences small, so we perform each show to an audience of six people with profound learning disabilities plus their carer-companions, and then we have a few additional tickets to each show, usually taken by theatre staff or people interested in seeing the format. Myself and Amber both come from a storytelling background and what we're really passionate about within theatre is creating a narrative and telling stories because life is a story and theatre reflects life, so our principal interest is in how we can do that, but make it accessible for our audience. So we always like to tell a story, but we then enhance that story with the multi-sensory side of things: every part of the story has a sensory element within it.

### **So what kind of multi-sensory experiences do you create in the shows, and how do you create them?**

**S**o, in Home, the story is centred in a city that has been destroyed by a dust storm, and the audience experience the dust storm through the use of large fans to create the wind, and they feel the dust which is glitter which flies through the air, and there is also sand mixed with corn flour and cinnamon which they feel. What we've found is it's really important to cover all the senses, so the theatre smells when the audience comes in, and we change the smell of the show half way through. We also try to impregnate every sensory object in the show with a smell in order to try and reach our audience on every sensory level. What's really important about the multi-sensory nature of the shows is that it allows us to interact on a one-to-one level with our audience, and communicate with them non-verbally in a manner that they access and a way that might be more appropriate to their needs. So the multi-sensory aspect allows us to have close interactions with particular

audience members, and as such the performances are very much determined by the way in which we read non-verbal cues and react to what that person needs from us in that specific moment.

### **And how do you find managing audiences with a variety of different disabilities?**

**W**e never know anything about our audience before they come in, and we enjoy not knowing what they like or dislike because it gives us a fresh page to start with. It also does occasionally lead to people discovering new things: for instance it may be that one of our audience members has always hated sand, but when we present it with music and theatre lighting they end up touching sand for the first time. We feel that if we knew beforehand if that person didn't like sand, then we'd be more likely to keep the sand away from that person. Also, for us, theatre is about presenting something to the audience that they might not like. Able audiences go to the theatre and don't like what we see every time, and it is equally important for someone with learning disabilities to have the opportunity to experience things that perhaps they don't like. Both Amber and I have a lot of experience in working with people with learning disabilities, and that's what enables us to manage the space and this experience for our audiences. I was a support worker for adults with learning disabilities for six years, and Amber's assisted in a lot of special schools, so we've built up a lot of years of knowledge through that, and we learn a lot with every Frozen Light show we do.

### **You and Amber wrote a piece for The Guardian in 2015 about staging immersive theatre for people with learning disabilities.**

### **What have you learnt since then and what do you see as your role in helping to expand this form of theatre more generally?**

**W**hen we wrote the Guardian article it felt that they were interested both in what we do and what other artists, even those who don't work with people with learning disabilities, can learn from the way that we work. What we're passionate about is always being audience focused, and so always thinking about our audience's perspective when devising a new piece of theatre. We feel that even if we were to come up with the world's best artistic idea, if it wouldn't work for our audience then there's no point in doing it. In terms of encouraging more people to engage with this form and the audience for whom we perform, we obviously can't put on shows for every person with learning disabilities in this country. There are a handful of other companies doing great work, such as Oily Cart in London and Interplay in Leeds, but our unique edge mainly comes from our commitment to touring theatres. But what that means is that we tour really prolifically and we can't reach every person in each community, and we find that

the more we tour and the more people see us, the more the demand grows. More people catering to this specific audience is definitely needed, as once we've been at a venue we are unlikely to be back for around eighteen months and there's nothing else that they can access. Whereas a theatre company I like may not be back in the same are for a couple of years, that's alright as there'll be another company I like that I can go and see, that isn't the case for our audiences. In November we ran our first artists' residency week in Norwich, where we worked with a group of nine artists to share our practice, and to share what it's like to work with audiences with severe learning disabilities and to teach them ways of adapting or creating work for these audiences. A new company (Collidescape) has started out of that, which is great, and that sort out outreach to other artists is definitely something we plan to do more of. We often have groups of university students come in to speak to us about our work, and we feel that the more people know it exists, the more people will start making this type of work, or the more people who might adapt their own work to make it more accessible for a variety of audiences.

This is an abridged version of an interview undertaken by culturised (an online arts publication founded in January 2017). If you are interested in the full transcript, then it

can be found at <https://www.culturised.co.uk/2017/05/in-conversation-with-frozen-light-accessible-theatre-for-audiences-with-learning-disabilities/>

### Contact Details

Max Adams  
Email: [editors@culturised.co.uk](mailto:editors@culturised.co.uk)

### References and links:

Amber Onat Gregory and Lucy Garland, "Staging theatre for audiences with profound learning disabilities", *The Guardian* 2nd July 2015. <https://www.theguardian.com/culture-professionals-network/2015/jul/02/staging-theatre-audiences-profound-learning-disabilities>  
<http://www.oilycart.org.uk/>  
<http://www.interplaytheatre.co.uk/>

## Articles from PMLD LINK on Adult Life

### Winter 2016, Issue 85 – Health Matters

- An overview of health issues for people with learning disabilities.
- Health checks as an important general reasonable adjustment of benefit to people with PMLD some important questions to ask.
- A call for a national approach to postural care launched at the Changing our Lives 'Got My Back' conference in September 2016.
- Articles on improving postural care.
- Practical tips about getting a good wheelchair assessment.
- Respiratory care and identifying potential risks and symptoms.
- Managing and avoiding constipation.
- Need for a national programme of sight testing and a national pathway of eye care for people with learning disabilities in the community.
- The way in which services are organised and delivered has a huge impact on people with PMLD.
- The impact acute liaison nurses can have when people with PMLD are in hospital.
- The Southern Derbyshire PMLD service and the difference it is making to the lives of people with PMLD.
- Using the Health Equality Framework with someone who has PMLD to demonstrate improved outcomes.
- Personal Health Budgets leading to better outcomes for people with PMLD in West Sussex, Hampshire and Portsmouth.
- How to help people with PMLD manage anxiety.

'Articles from PMLD LINK on Adult Life' were compiled by Robert Ashdown  
e-mail: [rob.ashdown@ntlworld.com](mailto:rob.ashdown@ntlworld.com)





## Supporting people with profound and multiple learning disabilities in social care settings

Michael Fullerton

In this article, I describe some of the key structures which my organisation, the social care provider CMG, has put in place with the aim of supporting adults with profound and multiple learning disabilities to enjoy the best possible quality of life.

**C**MG currently supports ninety-six people with profound and multiple learning disabilities in either supported living or residential services in South-East England and South Wales. These services are ordinary houses which are adapted to meet the physical and mobility needs of the people who live there. In addition we run a small day service in Hove, Sussex, specifically for people with profound and multiple learning disabilities.

### The Direct Support Team

**T**he support of people with profound and multiple learning disabilities in community-based residential or supported living services requires significant expertise and a skilled, competent and stable workforce. One of the ways in which we try to achieve this is by offering staff in our PMLD services the opportunity to undertake a practical qualification that focuses on the needs of people with PMLD (Understanding the Needs of Individuals with Profound and Multiple Learning Disabilities). This is a national Level 3 qualification which

is registered with Ofqual and accredited through OCN (Open College Network). It is facilitated by our Clinical Support Team in partnership with Disability Learning ([www.disabilitylearning.co.uk](http://www.disabilitylearning.co.uk)). As well as skill and competence, the attitude and passion of the direct support team is critical. In my experience, the best teams include a core group who have known the people being supported for a long time. This enables the development of rapport and trust. It also means that the vital early signs that a person is not well are more likely to be recognised, and health interventions swiftly sourced.

### Clinical Specialists' Input

**A**s well as skills in building rapport, the support team need to meet social, communication, sensory, physical and emotional needs and generally be very creative. This, on top of being competent in a range of clinical skills, is a big ask and therefore requires strong and capable support to that team. Local community specialist support is very important, and we try to link in closely with local specialists to ensure a rounded



approach to supporting the individual. In a couple of the regions where we provide services, we are fortunate enough to have enhanced GP contracts in place, which is a really valuable resource, given the complexity of need being supported, and is helpful in ensuring a proactive approach to primary health support.

We also have our own internal clinical team which works to ensure that direct support teams and the people we support are provided with evidence- and research-based support. This team includes a clinical nurse trainer who is a registered adult and children's nurse, a healthcare facilitator, a physiotherapist and a clinical director who is a registered learning disability nurse (myself). We also have access to an occupational therapist on a sessional basis. The team provides training and competency assessment for the direct support teams in a range of areas including postural management, enteral feeding, airway suction, use of BiPAP, epilepsy management, continence care, pressure ulcer prevention and care, infection prevention & control and oral care. The team have developed a 'Principles of Healthcare' Folder which holds current clinical policies, procedures and protocols so that direct support staff have easy access to them.

### Health and Wellbeing

Each person with PMLD has a health assessment and a health action plan, a hospital passport and a DisDAT assessment (St Oswald's Hospice and Northumberland Tyne & Wear NHS Trust) for discomfort/distress recognition. Twenty-four hour postural support plans, based on appropriate multi-professional assessment, are in place to maintain and protect body shape. These plans set out the individualised equipment and the staff skills development needed. We seek regular specialist equipment reviews from external local wheelchair services and orthotics (for spinal jackets and specialist footwear). Such support also focuses on proactive pressure area care to prevent pressure damage. We recognise the benefits of hydrotherapy and in Essex, Brighton and Norfolk, people we support have access to this. Hydrotherapy programmes developed in partnership with local physiotherapists complement daily movement plans.

Our healthcare facilitator works closely with speech and language therapists, dieticians and other health professionals to ensure people have detailed assessment of eating/drinking and swallowing difficulties. Our clinical nurse trainer also provides training in dysphagia to support teams, which is complemented by competency assessment. Support and training also focuses on respiratory health and the risk of aspiration and includes suctioning training when this is relevant. Those of our services which support people with PMLD have an especially strong focus on infection control, given the risks that are posed to people should they be exposed to infection.



Picture above: Smoothie-making

### Creative Thinking

A key challenge is in ensuring a team can do it all, i.e. be good not only at the healthcare support but also at the social, sensory and emotional aspects. Managers are considered as 'Practice Leaders', and the clinical team work closely with managers to ensure they are skilled in leading the team, with competence, confidence and with a clear vision of what can be achieved. Key staff have been provided with sensory-focused training by a specialist in this area, who is due to train further staff soon on 'Developing your sensory lexiconary' and 'Sensory Engagement for Mental Wellbeing'. Sensory activities do not come naturally to all support staff, and sometimes a 'scaffolding' approach is required whereby the skilled and creative staff take a lead and other staff come on board over time as they observe and gain confidence.

### Inspiring Events

One of the highlights of our calendar is the Supportive Therapy Day. The aim is to offer a range of supportive therapies and sensory activities to create effective communication between individuals, enhance greater social interaction and provide great benefits on an individual's overall physical health. The range of opportunities available on the day include sensory stories, massage, hydrotherapy, art classes, music and drama sessions (including the ever popular limbo dancing), and using assistive technology to communicate and maintain control over the environment. The day ends with a sensory disco and the infamous 'Pimp my Chair' (inspired by the TV programme 'Pimp my Ride'). This fun competition gives people the opportunity to get creative, pimp up their wheelchairs and showcase their ride! However, the aim is not simply that people will

have a great day out. What we hope is integral to the day is providing people with PMLD with opportunities they may not have experienced before and inspiring staff teams to ensure people have access to such opportunities during the rest of the year, not simply as a one-off event.

Another key event is our Athletics Championship when people with PMLD join other people CMG support to compete in a range of track, field and sports hall events. This is focused on gaining a range of sporting and sensory experiences. There is always a lot of competition among the supporting staff and families!

### Total Communication Approaches

Staff need to be skilled and creative when communicating with, and listening to people with PMLD. Communication assessments are sought from speech and language therapists and we have a range of communication tools and resources to ensure support is individually tailored to maximise expressive and receptive communication, with emphasis on the Royal College of Speech and Language Therapists' Five Good Communication Standards (RCSLT, 2013). Teams use intensive and sensory interaction and hi and lo tech communication technology to support a person's ability to communicate and gain control over their environment. Switch technology is used a lot to support people to engage in everyday activities such as baking, cooking, housework and playing music. As mentioned above, we also use the DisDAT (St Oswald's Hospice and Northumberland Tyne & Wear NHS Trust) to help supporting staff to recognise those sometimes discreet and subtle signs that someone is in discomfort, pain or distress.

### Emotional and Psychological Wellbeing

We want staff to focus strongly on the emotional wellbeing of people with PMLD. Factors that impact upon emotional wellbeing including loss and change, physical health and communication barriers. We emphasise the importance of staff being able to 'tune' in to non-verbal cues as to what the person is feeling and wanting. All training includes a focus on working in a person-centred manner, and really appreciating the individual and what he/she may be experiencing at any given time.

### Ensuring Quality

Ensuring each staff team is providing excellent health, social and emotional support at any given time is a challenge. Therefore we need to closely monitor each service to check that the team is delivering as anticipated. We have systems in place to audit services, using standard organisational auditing tools, as well as a specific 'Postural Care & Wellbeing Audit'. We complete an annual 'Driving Up Quality' self-assessment. We also measure ourselves against nationally agreed service

standards including the 5 Good Communication Standards mentioned above (Royal College of Speech & Language Therapists, 2013), Seeability's Eye Care and Vision Charter and Public Health England's Health Charter for Social Care Providers. We are currently working with a number of organisations and professionals to develop new service standards specifically for social care providers supporting adults with PMLD.

To check actual quality, however, requires continual listening to stakeholders and responding to concerns. We have a monthly Safeguarding Forum, which is chaired by an independent chair who is an ex-Director of Social Services, and provides an important mechanism for responding to concerns. Our 'PMLD Forum' provides the inspiration and sets the tone for the vision that we have for PMLD services. The forum, which is facilitated by members of the internal clinical team, aims to provide an opportunity to share best practice and ensure awareness of current research and thinking in relation to this group of people. Frequently the Forum will have guest speakers to provide variety to the range of discussions. The Forum has looked at health care needs, postural management, communication, community participation, social inclusion, engaging in meaningful activities, assistive technology, pain and distress recognition and management. Ultimately the Forum is about bringing people together to develop new initiatives and advocate for people we support. We want to ensure that we are always working hard to provide the best possible support to people who present with some of the most complex needs and whose health can be so vulnerable.

### Contact Details

Michael Fullerton  
Clinical Director at CMG  
Email: [michael.fullerton@cmg.co.uk](mailto:michael.fullerton@cmg.co.uk)

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## Touch Trust Health and Well-being through Movement

Karen Woodley

The Touch Trust is a Dance Organisation based in Cardiff, Wales whose work is specialised to those with Profound and Multiple Learning Difficulties (PMLD) as well as with autism and other complex needs. We deliver a sensory programme that encourages self-development and active lifelong learning within a social, creative and nurturing environment. We promote inclusive communities through the provision of creative movement opportunities for those often denied access to the arts.

**B**ased on over forty years of practice and research in Special Schools, Day Centres, Hospitals and in Higher Education, Dilys Price OBE, the founder of the Charity, took the best points from educational pioneers such as Conductive Education and the philosophies of Steiner as well as Pedagogy, Piaget and Maslow to create a movement based sensory programme for people with PMLD.

A high level of support is needed for people with PMLD due to the person's physical disability as well as the sensory impairment and needs of each person. In order to teach and reach our friends, things need to be broken

down into simple steps. In the arena of health and wellbeing, elements such as movement, music, touch, dance and positive praise are essential for development because they are all directly linked to our creativity, our emotional world and physical expressions and working with the body is important as it is here that we feel and come to know the world.

Through rigorous and passionate daily practice, teaching and research, Dilys interweaved 'what works' together with the modern dance ideas of Rudolf Laban to create this uniquely successful program and it is Laban's analysis of movement which is the basis of all the movement



work at Touch Trust. Below are some examples of methods used in order to support specifically movement and posture development for people with PMLD:

### A: Body Image and Sensory Integration

Aims:

- Awareness of body zones, joints and limbs (achieved through touch and action – passive or active)
- Increased general body sensation (achieved through touch, friction, massage and action – passive or active)

Methods:

- Touch, rub, pat, massage, limbs and trunk (hands, feet, back and head)
- Body parts: rotated, raised and lowered, moved inward and outward
- Work on the periphery or centre of the body and gradually work inward or outwards as partner relaxes.
- Use rhythmical activities (as of heartbeat and breathing)
- Use patterned phrases, having a beginning and an end (i.e. Folk dance)

### B: Dynamic (Effort and Rhythm) Area

Aims:

- Reinforcement of two basic rhythms, i.e. heartbeat and breathing rhythms
- Experiences of difference between firm and fine pressure (Passive)
- Experiences of difference between lively and slow rhythms
- To eventually get a response from partner or firm pressure, light touch, slow and lively play (Active)

Methods:

- Use slower rhythm to do repetitive activities, i.e. raising and lowering arms with deep breathing (Passive or Active)
- Use a more enlivening upbeat rhythm and through touch gently pat the rhythm of the music on your partners body (Passive)
- Later try to get partner to push against you – to make some slight resistance against pressure (Playful Activity – Active)
- Later try to get partner to respond with light touch to your touch (Playful Activity – Active)

### C: Communication

Aims:

- To encourage participation in action

Methods:

- One must always be a dancing partner ( In this relationship one is not in the role of nurse, mother/ father or physiotherapist)
- One will always initiate phrased movements and lead the movement pattern, but one will be sensitive to any beginning or purposeful movement of your partner, and allow him/her to initiate movement leading this into constructive play or patterned situation. At first this purposeful movement of partner will probably fade or disintegrate, becoming even seemingly destructive or chaotic (purposeless) after a few moments. Then one must firmly take the lead again.

(Dilys Price OBE, 2012)



Picture above: Touch Trust - Sian

The Touch Trust Programme addresses the health and wellbeing needs of each Guest (everyone who comes for sessions) through individual or group relaxation and movement expressions, taking care of the physical and emotional needs in a warm, friendly and social environment. Individuals with PMLD may not achieve in the ways that we are fortunate to and may be very aware of this so 'Achieving' and 'Success' is something we constantly stress. Throughout each session the facilitator praises the Guest, showering them with a bombardment

of positive Eco Factors if you like, that lets them know and understand their worth, beauty and achievements. This is what gives people the root to continue to 'achieve, succeed; grow, create and feel their contributing to the whole'. Because our work is holistic and focuses on individual differences and appreciation of each person's unique action and expression while being rooted firmly in the discipline of creative movement, the result is positive energy, connection and development.

The methods that we use to achieve health and wellbeing for each Guest are:

- Constant praising even when they appear to be engaging in less positive activities and try to move them into a more positive activity
- Use voice and sound as a way to engage the guest
- Mirror the guest and develop trust (enter their world)
- Do not be too intense; learn to step back and allow the guest to come to you
- Do not make the guest the focus of the session but invite them to be part of your group
- Respect the individuals space

The outcomes on health and well-being for our guests are:

- Endorphins are activated through our work with dancing and enjoyment which in turn lessens the effect of any of the stress hormones within the organism.
- Oxytocin, critical to human emotional connection is released through our work with touch in the form of massage for relaxation, energy stroking and shiatsu holds.
- Movement changes from being shut off to expressive and full of life.  
*"Naomi (person with PMLD), her achievements include – happiness and interest in others and her environment; her self-harming has stopped. Her mother says Naomi is no longer clinically depressed. She enjoys creating expressive movement and voice activities and she is regaining here walking ability. Her mother says:  
"For the first time ever I can cuddle her, she is learning that the world can be a beautiful place"*

*Naomi can enjoy the group creative movement activities now (after having to be in a one to one situation only)" (Dilys Price OBE, 2012, p. 66)*

- Confidence and self-esteem flower
- Social development and friendship
- Physical and Emotional development
- Joy!

People come to us stressed and tired from life and they leave transformed and feeling uplifted because they have

been celebrated for their uniqueness: the guests, support workers and families too! If you are interested in visiting us for a taster session, in our training course to become a session leader or in our one day workshop for parents and carers please do not hesitate in contacting [info@touchtrust.co.uk](mailto:info@touchtrust.co.uk) or calling: 02920 635 660.

### Contact Details

Karen Woodley  
A registered Dance Movement Psychotherapist and the Training and Membership Coordinator for the Touch Trust

Email: [karen.woodley@touchtrust.co.uk](mailto:karen.woodley@touchtrust.co.uk)

Photographs: Martin Sotelano

### References

Dilys Price (2012). Handbook for the Touch Trust Certificate. Cardiff: Touch Trust.

## NEXT ISSUE

Winter Vol. 29 No. 3 Issue 88

## Promoting Inclusion Transforming Lives

Do you have any stories to share?

If so, contact the editor:

Hannah Young  
[H.Young@dundee.ac.uk](mailto:H.Young@dundee.ac.uk)

**Copy date**  
**Monday 23rd October 2017**

# Sea Shanties with Keith Park and Quartz class, Bedelsford School

Keith Park and Andrea Williams

For many weeks, Keith Park visited Bedelsford School and led Quartz class through a range of lively, funny and melodic call and response songs to which the students listened, gestured and vocalised. These sessions were based around the rhythm of sea shanties, and as the students, who all have profound and multiple learning difficulties and their keyworkers sat in a circle, they were mesmerised by the frolic and pace of Keith's voice and his accompanying accordion.

**N**ow the day had finally arrived for our long-awaited trip to perform at the Museum of London Docklands, which sits alongside the meandering River Thames in the East End of London. As we were guided to the atmospheric third floor of the museum by Noel Hayden, it seemed like the sounds of the sea still silently echoed around us from the eclectic collection of artefacts.

The use of sea shanties, substituting the student's names instead of the usual response lines such as 'haul away Joe' is a fun way of developing interactive communication skills, based on the continuous reception of the student's names. Sea shanties were deliberately interactive, as working songs on board sailing ships in the 19th century, so they are very easy to adapt to many educational settings.

The communication skills include awareness, attending, turn taking, anticipation, and engagement. Here are two examples:

A Yankee ship came down the river  
Daniel!  
A Yankee ship with a Yankee skipper  
Daniel!  
And who do you think was master of her  
Daniel!  
And what do you think they had for dinner  
Daniel!  
A parrot's tail and a monkey liver  
Daniel!  
And a big cheer for.....  
Daniel!!!!!!

Last night I was in Ireland  
Spud!  
Digging turf and tatties  
Spud!  
But now I'm on lime juice ship  
Spud!  
Hauling on the braces

Spud!  
King Louis was the King of France  
Spud!  
Before the revolution  
Spud!  
But then he got his head cut off  
Spud!  
Which spoiled his constitution  
Spud!  
Saint Patrick was a gentleman  
Spud!  
He came from decent people  
Spud!  
He built a church in Dublin town  
Spud!  
And on it put a Steeple  
Spud!  
And a big cheer for.....  
Spud!

It was a magical experience and when our performance ended, the audience which comprised of museum staff and visitors expressed their delight with a wonderful applause. We thoroughly enjoyed ourselves, and many thanks to Keith Park, Noel Hayden, and all the wonderful staff at the Museum of London Docklands for making this memorable day possible for the students of Bedelsford school.

## Contact Details

Andrea Williams, Class Teacher, Bedelsford School,  
Grange Road, Kingston Upon  
Thames, Surrey, KT1 2QZ.  
Email: [bds@bedelsford.rbksch.org](mailto:bds@bedelsford.rbksch.org)

Museum of London Docklands No1 Warehouse,  
West India Quay, London E14 4AL  
Tel: 020 7001 9844



# Point 5 Network for Teachers

Sue Hogan

Point 5 is a network of teachers of pupils with PMLD, MSI (multi-sensory impairment) and Complex Needs based in and around London. The name is derived from the percentage (0.5%) of school-age pupils defined as having PMLD in 2012.

The group was formed in December 2013 by Gail Weir and Lucy Wijsveld, then Head and Deputy respectively at Greenmead School in Wandsworth. Both Gail and Lucy have since moved on: Gail is now Head at Waverley School in Enfield and Lucy is Head at Clifton Hall in Croydon, but they continue to co-ordinate the group.

Point 5 is just entering its fourth year and in that time it has evolved and grown and will continue to do so as it responds to the needs and interests of the group members and as special education for this group of unique learners changes.

The concept came from Gail and Lucy, who recognised the need to train and support teachers new to working with PMLD pupils in a way that sustained and developed them over time. There are a number of inspiring courses available as 'one-off' days but the Point 5 network is designed to provide an opportunity for teachers to develop their practice, to learn from each other and reflect on their own practice both as individuals and within the group. Crucially it allows teachers to discuss their own pupils with other practitioners. It is designed to impact practice immediately.

Initially there were five schools involved: Greenmead, Waverley, Swiss Cottage, Cherry Garden and St Nicholas in Canterbury, each of them sending two teachers. These are schools with which Gail has had links with through her working career. The group now comprises 12 schools and subdivides into North, South and Central London to facilitate the visits. Teachers typically are part of the group for one or two years, after which the process becomes flexible with some perhaps dropping out for a year or two before returning. It is flexible depending on the ability of schools to release staff and to allow other teachers of PMLD classes to participate.

The format has changed but some features remain constant:

- There is an inaugural meeting early in the Autumn term and then three further meetings;
- All participants bring two pieces of video to each meeting, each featuring a pupil with PMLD and

focusing on a particular area which has been decided in advance – e.g. expressing 'more' or 'call and response'. This is shared with the group, giving the presenting teacher an opportunity to explain and interpret the footage, and then open it up to discussion. It is a really valuable tool, leading to some interesting discussions and highlighting our crucial responsibility as teachers of pupils with PMLD to be accurate, open minded and questioning in our interpretations of responses.

The key aspect that has changed is in lesson observation. In the network's first two years, part of the day involved the host teachers showcasing a lesson around the chosen theme – e.g. sensory stories, or ICT. Two years ago, however, it was decided that the showcasing role be taken on instead by lead professionals experienced in working with this group of learners, with the aim of developing practice, demonstrating strategies, troubleshooting and mentoring individuals.

This change came about for a number of reasons. Results of the end-of-year questionnaire in that early period indicated problems with the model in terms of developing practice. It was seen that the group's aim of encouraging critical analysis could be daunting especially to those new to the field of PMLD. The introduction of lead practitioners made it easier for those teachers to absorb and explore without the stress of being observed while they were still developing their skills. It also provided challenge to the lead professionals in terms of reflecting on practice, rationale and examination of approaches and methods.

When Gail and Lucy first conceived of the group, they were influenced by aspects of teacher training in Finland, where all teachers typically take a five-year Master's course and then continue with research-based teaching throughout their careers. One aspect of the training is being able to watch experienced practitioners and take part in detailed discussion about the teaching and learning. Professional discourse and critical evaluation of teaching practice is the norm and highly valued by all teachers regardless of experience and position. This challenge and exploration is to the mutual benefit of the student teacher and the experienced teacher.

In the Spring term, teachers are invited to see lessons run by lead professionals in a particular area – e.g. drama, intensive interaction, or sensory stories. In academic year 2015-16, there were four lead practitioners; this year there are five. Lead practitioners offer a number of dates, and other teachers in the network sign up to watch the lessons, discussing the work they have seen and how they might be able to apply ideas to their own work. In the Summer term there is 'Outreach' work by the lead professionals, supporting individual teachers with issues that they have identified or that have emerged throughout the year.

The group meets four times per year. In the Autumn term there is an inaugural meeting with introductions, topics of discussion (e.g. this Autumn term the Rochford report and assessment for learning tools), and the logistics and focus for the further meetings are decided. The group is democratic in terms of agenda setting and focus, responding to the interests of the group. Previous discussion topics have included: Penny Lacey's work, curriculum development, age appropriateness, TaSSEls (Tactile signing for sensory learners), use of technology, especially eye gaze. The group decides together on the theme of the video of pupils – play, expressing 'more', independent learning, showing progress are all previous examples.

Swiss Cottage Teaching School has supported the group, giving meeting space for the large meetings and allocating a section on its hub for research and information sharing.

Education for this group of very complex learners is still young, technology is reducing barriers to learning and is enabling learners with PMLD to explore and participate in their world, but the most crucial factor remains skilled, perceptive teachers with open minds who strive to understand how people with PMLD see, understand and think about the world.

If you are interested in finding out more about setting up a similar group please contact:

Gail Weir  
Waverley School  
105 The Ride  
Enfield  
EN3 7DL  
Gail.weir@waverley-sch.co.uk

#### **Contact details**

Sue Hogan  
Assistant Head at Waverley School and takes the lead on teaching and learning for pupils with PMLD.  
Email: s.hogan@waverley-sch.co.uk

## **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.

**mail: [info@pmlmlink.org.uk](mailto:info@pmlmlink.org.uk)**

# In the Next Issue

## Promoting Inclusion Transforming Lives

Hello all.

PAMIS and TCELT (University of Dundee) are partnering to organise the first Promoting Inclusion Transforming Lives Conference, to be held in June 2017. The conference will attract more than 200 national and international delegates for two days. Part of the conference will focus specifically on profound and multiple learning disabilities, and we are keen to capture some of the presentations, discussions and outcomes from that focus in the Winter Issue of PMLD Link.

More widely, we would also be delighted to receive submissions from those who cannot attend the conference, but may like to contribute an article relating to one of the following themes:

#### Inclusive life transitions

Work that has or is supporting inclusive educational transitions and wellbeing; and inclusive life transitions and well being; What is the evidence? What is best practice? What innovation is required?

#### Inclusive Spaces

Work that has or is supporting inclusive communities and

spaces. Consider the physical, environmental, cognitive, cultural, emotional, creative and social space. What is the evidence? What is best practice? What innovation is required?

Contributions can be any length up to 2000 words. Short or long! Please send your contributions by Monday 23rd October to Hannah Young who is Guest Editor of the Winter issue.

e-mail: [H.Young@dundee.ac.uk](mailto:H.Young@dundee.ac.uk)

PAMIS – Promoting a More Inclusive Society - is the only organisation in Scotland that works solely with people with profound and multiple learning disabilities and their families for a better life. PAMIS celebrates its 25th anniversary this year! In these twenty-five years it has grown from a small charity to a well-established and valued part of the voluntary sector. (<http://pamis.org.uk>)

TCELT is The Centre for Transformative Change: Educational and Life Transitions. It is an inter-disciplinary and cross-university research centre at the University of Dundee (<https://www.dundee.ac.uk/tcelt>).

## 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)

## IN THE NEWS



### A Big Thank You to Beverley Dawkins

**B**everley Dawkins, a long standing and effective member of PMLD LINK's editorial team and trustee of the charity, has recently tendered her resignation so that she could have more time to focus on her other work as Chief Executive Officer of Generate. The editors and trustees would like to thank Beverley for her outstanding work for PMLD LINK.

Beverley has now worked with children and adults with a learning disability and their families for almost 40 years. She initially qualified as a qualified Speech and Language Therapist, with a huge caseload and spending much of her time in training other professionals. Then to everyone's good fortune, she was appointed as Mencap's national officer for profound and multiple learning disabilities and became a leading light in campaigns for the rights of people with PMLD. In this Mencap role Beverley became indelibly associated with the Death by Indifference report, which she wrote, about preventable deaths of people with a learning disability and follow-up campaigning; she also helped set up the PMLD Network; she was a key leader in the national Changing Places campaign for fully accessible toilets; and she was instrumental in the production by Mencap and the PMLD Network of the hugely informative series of Raising our Sights how-to guides and films aimed at helping those involved in supporting people with PMLD, both service providers and commissioners of services, to better meet their needs.

Beverley, as ever, is keen to help families and key workers realise what is possible in terms of services and support and provide them with the practical information will equip them to ask for this. This has been evident in her varied contributions to the PMLD LINK journal as editor and author and is just as visible in her work for Generate which is a charity that aims 'to create better days and better lives for people with a learning disability by working together with them and the people who know them well.'

In December 2010 she received a well-deserved OBE for 'service to people with special needs' from the Queen's birthday. At the time Beverley said to PMLD LINK "I feel incredibly lucky to have been a part of the work campaigning to improve services for people with a learning disability. You don't often get chances to actually change something real and I feel honoured to have worked alongside the families who have fought so hard for justice and change." How typical of her to applaud others like that. We wish her well for the future and thank her for her invaluable support.

### Independent Support can be Invaluable to Young People with SEND and their Parents

**I**ndependent Support (IS) is a national government initiative launched in January 2014 and designed to help parents and young people navigate through the Education, Health and Care (EHC) planning process.

In January, the National Development Team for Inclusion (NDTi) published a report called 'What Works in the Delivery of Independent Support'. If you have not read it yet, it is worth doing so to see how highly valued IS has become by young people with special educational needs and disabilities (SEND) and their parents, and also by the range of professionals involved in the care and support of disabled children and young people across the education, health and social care system. The Council for Disabled Children deliver and manage the IS Programme on behalf of the Department for Education (<https://councilfordisabledchildren.org.uk/independent-support>).

IS is particularly valued when it is responsive and proactive throughout the journey of education, health and care planning and decision-making regarding levels and type of funded support. The report states: 'When it works well IS is a catalyst for change and leads to transformation in people's lives and their experience of

local services; when these things don't happen there doesn't appear to be much difference to the previous system of support (pre IS and the wider SEND reforms).'

Significant numbers of people are accessing and benefiting from IS through a variety of means although this varies around the country and by IS provider. The report notes that most parents and families value the support they receive from Independent Supporters, particularly the sense that someone is there for them who really listens and is truly on their side, is impartial and has integrity. IS can be particularly crucial during periods of perceived inaction by others such as when waiting for draft plans to be agreed and signed off. A high value is placed on IS being "arm's length" from local authority or other statutory services and the NDTi did find that there are different degrees of separation from statutory services – from full independence as a result of provision by a third sector organisation to provision by an Information Advice and Support Service (IASS – previously known as Parent Partnership Support or PPS) that sits within a local authority.

The full report is available online at: <https://www.ndti.org.uk/resources/publications/independent-support-final-report-findings>

## Best Milky Wishes

A lovely piece of news comes from Flo Longhorn who tells us that the photo below is of the cow and calf bought from donations in Penny Lacey's memory at the Best of British Special Education conference on 2-3 March 2017 at the Swiss Cottage School Conference Centre, London. The animals went to Muniguda, India for Namaste House for very special children. Flo says she does not have a picture of the 120 hens as they would not fit in the lens of the camera! The two-day Forum was organised by Flo and was dedicated to the memory of Penny.



## Calls for a new cross-government strategy for learning disability in England

On 24th April 2017 the House of Commons Committee of Public Accounts published 'Local support for people with a learning disability'. Two years ago, this same Committee reported on the Department of Health's (DoH) efforts to move people with a learning disability out of mental health hospitals and into the community. At that time, the Committee found that progress had been poor but was promised improvements. The recent Committee report notes that the DoH and NHS England have since made progress, developing the Transforming Care programme and moving some people out of hospital. However, the Committee states that more needs to be done to address known barriers: money is not moving with the individual to pay for his or her support in the community, too many people are not having care and treatment reviews and the uncertainty caused by the proposed changes to local housing allowance risks hampering the provision of accommodation in the community.

The report notes that central and local government combined spend approximately £8 billion supporting people with a learning disability. Local authorities spend £4.61 billion on social care services for people with a learning disability. While local authority spending on adult social care has decreased (by a mind-boggling 8.4% from 2010–11 to 2013–14), spending on learning disability services has been increasing. 39% of spending on adult social care services is on adults (aged 18–64) who have a learning disability. The Committee expresses concerns that there is currently no cross government strategy for the learning disability population and that support for people with a learning disability who live in the community is patchy with significant local variations. The report recommends that there should be a greater focus on measuring outcomes and improvements to the quality of life from the billions spent each year on this support.

It is hard to escape the overall impression that learning disability policy receives little attention from Government and this Report argues the case for more improvements. It is available online at:

[https://www.publications.parliament.uk/pa/cm201617/cmselect/cmpubacc/1038/103803.htm#\\_idTextAnchor004](https://www.publications.parliament.uk/pa/cm201617/cmselect/cmpubacc/1038/103803.htm#_idTextAnchor004)



## Parallel London



**P**arallel London is a fully accessible fun run and free family festival at Queen Elizabeth Olympic Park on Sunday, 3 September 2017. There's a 10km, 5km, 1km, 100m and the Super Sensory 1km.

The Super Sensory 1km supports memory by getting participants to complete a course full of multi-sensory experiences, from sound and smell to textures and colour.

This course has been specifically designed to engage all participants to the fullest, including:  
Individuals with profound and multiple learning disabilities

Individuals on the autistic spectrum who engage with the world in a primarily sensory way and welcome the opportunity to rehearse a situation before entering it  
Individuals who need sensory support to remember an event. This may include people with late-stage dementia or specific brain damage

The sensory world is a lot of fun and sensory stimulation can be used to support everyone's memory. So, if you are wondering if this event is for you, yes, it is. Everybody is welcome.

<http://www.parallellondon.com/>

## Community Led Support

**C**ommunity Led Support (CLS) is another programme from the National Development Team for Inclusion (NDTi) delivered in partnership with participating Health and Social Care Partnerships and local authorities across, England Wales and Scotland. The CLS has the stated aim of changing the culture and practice of community health and social work delivery so that it becomes more clearly values-driven, community-focused in achieving outcomes, empowering of staff and a true partnership with local people.

CLS assists organisations to work collaboratively with their communities and their staff teams to redesign a service that works for everyone, that evolves and is continually refined based on learning. NDTi is delivering a programme of support tailored to each area but with some common principles that govern the work.

Des McCart of Healthcare Improvement Scotland is quoted as saying that "....the solution lies in working with communities and their existing assets. Community Led Support brings together the key building blocks of Social Care in a way that starts from the original ethos of social care set out in legislation in 1968. In returning to basic principles and working with communities very much in their lives now, great things can and have been achieved. People and communities of people are able to exercise choice and control and to live lives that are much closer to those that they would wish for."

On 16th March 2017 in Edinburgh, the three partnerships (East Renfrewshire, South Ayrshire and Scottish Borders) gave updates on their early experience of adopting the Community-led Support model. The event was co-hosted by Healthcare Improvement Scotland, NDTi and the Guardian Newspaper. For more details go to:

<https://www.ndti.org.uk/our-work/our-projects/community-led-support/cls-in-scotland>



## Frozen Light's Next Show

**F**rozen Light theatre company, which creates exciting and original multi-sensory theatre for audiences with Profound and Multiple Learning Disabilities (PMLD) will be at the Pleasance Beyond venue in Edinburgh 21st to 24th and 26th to 28th August, as part of the British Council's Edinburgh Showcase.  
<https://edinburghshowcase.britishcouncil.org/directory/artist/frozen-light/2017>

## Management of chronic constipation of adults within the community

**N**DTi have published the updated guideline 'Management of chronic constipation of adults within the community' on their website. This guideline can help staff to identify the likely causes of constipation and the possible solutions.

It can support clinical decision-making by giving staff the strength of the evidence on which those recommendations are based. Used correctly, the clinical guideline should help to reduce the unpleasant symptoms of constipation, improve well-being for the individual who has constipation, and avoid the serious and sometimes tragic consequences of mismanagement.

## NDTi Housing Choices Discussion Series

**T**he National Development Team for Inclusion (NDTi) has criticised a continuing over-reliance on traditional forms of housing and support such as residential or nursing care for people with support needs

In order to 'stimulate debate' and to encourage more 'serious exploration and consideration of alternative options', between January and June of this year NDTi published a series of 4 discussion papers entitled 'Housing Choices: Exploring and comparing the characteristics of housing and support arrangements for people with care and support needs'.

They are available at:  
<https://www.ndti.org.uk/resources/publications/housing-choices-discussion-paper-4>

## Social History of Learning Disability Annual Conference

**T**he next Social History of Learning Disability Conference will be held at the Open University in Milton Keynes on 20th and 21st July 2017. The theme of the conference is 'Doing research on the social history of learning disability: Learning Lessons'. The keynote speaker is Associate Professor Iva Strnadová from the University of New South Wales. Iva is widely acknowledged as an international expert in learning disability, particularly in areas of transition across the life course.

Details of the programme and how to register for the conference can be found here: <http://www.open.ac.uk/health-and-social-care/main/research/research-events/conferences-seminars/social-history-learning-disability-shld-conference7>

Please register by 10th July 2017.

If you have any queries, please contact Amanda Hilton at [shld-conference@open.ac.uk](mailto:shld-conference@open.ac.uk)

## The LeDeR Programme

**T**he Learning Disabilities Mortality Review (LeDeR) Programme is delivered by the University of Bristol. It is commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England. The LeDeR programme has just published its latest newsletter (June 2017).

A key part of the LeDeR Programme is to support local areas to review the deaths of people with learning disabilities. The Programme is developing and rolling out a review process for the deaths of people with learning disabilities. Other parts of the LeDeR programme relate to a series of additional projects:

- Finding out about the age and cause of death of people with learning disabilities in England
- Finding out about the provision of 'reasonable adjustments' for people with learning disabilities
- Providing guidance on writing death certificates of people with learning disabilities
- Collating reports about people with learning disabilities to identify commonly occurring problems.

For more details go to: <http://www.bristol.ac.uk/sps/leder>

## Erin Keogh Exhibition – the first of many!



**E**rin Keogh recently enjoyed the very successful launch of her first exhibition. A fabulous collection of Erin's paintings and her other artworks took centre stage at the official opening ceremony of the Pamis 'Promoting Inclusion, Transforming Lives' Conference, in Dundee in June. Her work was admired by international delegates throughout the three day conference and she even sold her first painting - to Jenny Miller, CEO of Pamis. (Erin and Jenny pictured above).

Erin (20) attends Project Ability, a local arts centre in Glasgow, to enjoy her creative talents. She already has plans to hold her second exhibition there in the coming months. Watch this space for more news of this wonderful artist!

<http://www.project-ability.co.uk/programmes/aspire/intro>

## Hold the Date! Friday 24th November 2017 'Raising Our Game, Raising the Bar'

**A** National Conference to enhance support and service standards for people with PMLD. This unique and inspirational conference is aimed at all stakeholders involved in supporting children and adults with a profound and multiple learning disability.

This includes families, advocates, health/social/education professionals, commissioners and service providers. New

Core Essential Service Standards for education, health and social care settings will be launched at this event. These Standards will be instrumental in ensuring people receive consistently good support nationwide, and throughout their lifespan.

Dedicated solely to focus on celebrating and sharing excellent practice in supporting people with profound and multiple learning disabilities, a fantastic range of key nationally and internationally renowned speakers will inspire, provoke thought and debate with one vision in mind - each of us 'Raising Our Game'.

Hold the date and keep a look out on twitter and Facebook for more information – coming soon!

Michael Fullerton, Thomas Doukas, Jo Grace and Annie Fergusson

## “Our 1000th shopper has just walked through the door!”

**N**ina Martinez, Storytelling Manager at Bag Books, says:

“Hello from Bag Books and I would like to introduce you to our latest title, ‘He’s a Winner’. This multi-sensory story is dynamic and such a joy to tell to our listeners. The story tells of that very routine trip to the supermarket that we all enjoy but when Jim walks through those automatic doors little does he know what is in store for him. Although we are not all as lucky as Jim, this story does bring the combined sensory elements of a trip to the supermarket and the cheese smell will stay with you forever!”

Bag Books have published several new titles recently; have a look at their bookshop.  
<http://www.bagbooks.org/bookshop>

Bag Books will be holding an open multi-sensory story training day on Monday 25th September 2017 at Marlborough School, Sidcup, Kent. The school is walking distance from Sidcup Station which has links to many major London stations. Also nearby is a Premier Inn for those that require accommodation.

Places cost £100 per person inclusive of lunch. Participants can also buy a copy of Bag Book's DVD training pack for a further £100 – a saving of £50.

Please contact [nina@bagbooks.org](mailto:nina@bagbooks.org) to book a place.

# RESOURCES

## Annual health checks for people with learning disabilities - step by step toolkit

**W**e know that people with learning disabilities tend to have poorer physical and mental health than other people and die younger. Many of these deaths are avoidable and not inevitable. Annual Health Checks can identify undetected health conditions early, ensure the appropriateness of ongoing treatments and establish continuity of care. GPs and practice nurses can help people with learning disabilities to get timely access to increasingly complex health systems. To this end, the Royal College of General Practitioners has published a toolkit of guidance and resources to enable health service professionals to organise and perform quality Annual Health Checks.

For details about the toolkit go to: <http://www.rcgp.org.uk/clinical-and-research/toolkits/health-check-toolkit.aspx>

## Hft PIP “quick tips” guide for family carers

**H**ft is a national charity providing services for people with learning disabilities throughout England. The charity produces a range of helpful resources. Last year, Hft’s Family and Carer Support Service (FCSS) created four Personal Independence Payment (PIP) videos which give information about:

- \* How people are assessed
- \* Completing the forms
- \* Going to a face to face assessment
- \* Decisions and appeals

The FCSS has created a user-friendly PIP “quick tips” guide for family carers. The tips are intended to make the process of completing the form as straightforward as possible, and help family carers complete it in a way that will give the assessors an accurate picture of their relative’s situation. For more details go to:

[http://www.hft.org.uk/Supporting-people/Family-carers/Resources/DLA\\_to\\_PIP/](http://www.hft.org.uk/Supporting-people/Family-carers/Resources/DLA_to_PIP/)

The FCSS urges that, if you are struggling to complete the assessment on your own, ask social services to provide you with contact details for local benefits support groups and charities. They also invite you to contact FCSS for more information.

Tel: Freephone 0808 801 0448. FCS takes calls Tuesday to Thursday from 9:15am to 4pm, but if you call outside of these hours, leave a voicemail and FCSS promise to return your call within seven working days.

Email: [familycarersupport@hft.org.uk](mailto:familycarersupport@hft.org.uk)

## Launch of Loretto Lambe’s story telling resources at PAMIS Conference

**T**he PAMIS Conference, ‘Promoting Inclusion, Transforming Lives’, was held in Dundee on 14th to 16th June 2017. One event of significance at the conference was the launch of the new multisensory story telling resource that was created and developed in memory of Loretto Lambe.

Julie Taylor has a blog on the PAMIS website ([www.pamis.org.uk](http://www.pamis.org.uk)) where she gives examples of how Pamis works with family carers and people with profound and multiple learning disabilities and volunteers to use personal stories to help transform practice and train nurses, doctors, teachers and social workers. The contribution of personal stories in helping people understand the lives of people with PMLD and their families is regarded as key to helping services deliver appropriate education, care and support. Loretto and Hannah Young contributed an informative article on multi-sensory story telling to PMLD LINK (see Vol. 23 No. 1 Issue 68, pp 29-31)

## Full Facts

The organisation 'Full Facts' checks statistics and information which is presented in the public domain as 'fact'. This may be a useful resource for anyone wishing to engage in campaigning. Some recent examples of the organisation's fact-checking can be found below:

The adult social care spending gap (17th May 2017)  
<https://fullfact.org>

Where does councils' money come from to pay for adult social care? (11th April 2017)  
<https://fullfact.org>

Are the most significant council budget cuts in deprived areas? (19th May 2017)  
<https://fullfact.org/economy/are-most-significant-council-budget-cuts-deprived-areas/>

## So Your Next Patient Has A Learning Disability - Useful leaflet and poster

The Association of Chartered Physiotherapists for People with a Learning Disability (ACCPLD) has designed a leaflet and poster to support Physiotherapists and other NHS colleagues who do not specialise in working with people with learning disabilities. The intent is to help people with a learning disability to access mainstream physiotherapy services by making reasonable adjustments.

The 'So Your Next Patient Has A Learning Disability' leaflet aims to give some simple but practical advice/suggestions to mainstream physiotherapists on how to manage their appointments for people with learning disabilities. The ACCPLD believes that it will also be of use to other health and social care professionals

The 'Making reasonable adjustments' poster compliments the leaflet. The ACCPLD hopes it will be displayed in wards and departments across the UK and will serve as a prompt to make sure reasonable adjustments are in the forefront of people's minds.

Both resources are available online at:  
<http://acppld.csp.org.uk/documents/so-your-next-patient-has-learning-disability-useful-leaflet-poster>

## Raising our sights guides and films

In 2010, Professor Jim Mansell published a report called Raising our sights, which looked at services and support for people with PMLD. In the report, Professor Mansell outlined what needed to change to improve the lives of people with PMLD. These how-to guides focus on his key recommendations. We thought this issue would be a good opportunity to remind readers of the guides. The eleven guides below cover different topics and show you how to:

- recognise good services and support for people with PMLD
- challenge and campaign where people with PMLD are not getting the right support
- make these changes happen if you're a commissioner, including checklists for commissioners on each topic

The topics covered are: advocacy; clinical procedures; communication; health; housing; personalisation; support for families; training the workforce; what people do in the day; wheelchairs and commissioning.

The six films accompany some of the guides and illustrate the importance of making these changes. They also highlight the impact that the right support can have on the lives of people with PMLD and their families.  
<https://www.mencap.org.uk/advice-and-support/pmld/raising-our-sights-guides>

As well as these guides, family members and service providers may find Mencap's 'Know your Rights' guides helpful. Separate guides address day services, eligibility for care and support, short breaks, the Care Act, being assessed for social care and responding to consultations.  
<https://www.mencap.org.uk/get-involved/campaigning/know-your-rights-guides>

## Preparing for Adulthood: Demonstration Site Evaluation Report

**N**DTi's Preparing for Adulthood programme brings together a wide range of expertise and experience of working with young people and families, at a local and national level and across government, to support young people into adulthood with paid employment, good health, independent living options and friends, relationships and community inclusion.

The purpose of the demonstration site project is to show what is possible in delivering the PfA agenda and to develop exemplar practice so that all authorities can learn from and replicate them.

As part of the demonstration site programme, an evaluation of the programme was conducted to:

- identify outcomes achieved
- understand how and why demonstration sites have made progress towards outcomes
- identify lessons and key learning, and their transferability to other local areas.

This evaluation report describes some of the outcomes achieved, and importantly identifies the key factors in supporting this change.

[https://www.ndti.org.uk/uploads/files/Demonstration\\_sites\\_evaluation\\_report\\_-\\_final.pdf](https://www.ndti.org.uk/uploads/files/Demonstration_sites_evaluation_report_-_final.pdf)

## TCPix Multicultural Image bank

**T**otal Communication have been working on making the whole of TCPPix Multicultural Image bank available to everyone. To access the whole image bank and download all or any images you wish to use, please visit the Total Communication website and click on the 'downloads' tab and then on the 'TCPix button'.

TC Pix is a free resource which may be downloaded, copied and freely distributed as required but it is asked that Total Communication Services CIC is acknowledged as the source. Total Communication welcome suggestions for vocabulary/ categories for future development of the Image bank and their graphic artist is able to provide bespoke images, specialist resources and teaching packs. For further Information about TC Pix and how it was created read the blogs on the website.

Total Communication can be contacted via the website (<http://www.totalcommunication.org/>), Facebook (Total Communication Services CIC) or Twitter (@TotalCommOrg).

## Useful Top Tips from Sibs

‘Sibs’ exists to support people who grow up with or have grown up with a disabled brother or sister. It provides support for both child and adult siblings. As child siblings become adults they often have to take on more and greater responsibilities and may feel isolated and in need of support. Use the Sibs website to get information on sibling issues and to get mutual support from the UK adult sibling community. Sibs provides information on coping with feelings, bereavement, safeguarding concerns, and support groups. There is also a moderated online support and discussion forum for adult siblings.

As a starter try out its Top Tips for adult siblings. Go to: <https://www.sibs.org.uk/support-for-adult-siblings/top-tips-for-adult-siblings/>

# Raising Our Game, Raising The Bar PMLD Conference

Our first joint PMLD LINK conference

24th November

A National Conference to enhance support and service standards for people with PMLD. This unique and inspirational conference is aimed at all stakeholders involved in supporting children and adults with a profound and multiple learning disability.

Location: tbc

**Contact: Thomas.Doukas@choicesupport.org.uk**

## Being Social #PMLDlink



We use Twitter and Facebook to keep followers up to date with news and development regarding the journal, and also to share relevant news and information. We welcome your engagement and hope that you will share items too.

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

<https://twitter.com/pmlmlink>

<https://www.facebook.com/PMLD-Link-777526962325831/timeline/>



# SHORT COURSES & CONFERENCES

## August

Title: Dementia and the Senses - Exploration Weekend  
Date: 18-20th August  
Location: Woodbrooke, Birmingham  
Provider: Joanna Grace  
Contact: <http://jo.element42.org/training>

## September

Title: Introduction to Intensive Interaction  
Date: 8th September  
Location: Redhill, Surrey  
Provider: Us in a Bus  
Contact: [www.usinabus.org.uk/events/training-dates](http://www.usinabus.org.uk/events/training-dates)

Title: Story Massage Training  
Date: 19th September  
Location: Birmingham  
Provider: Story Massage  
Contact: [www.storymassage.co.uk/training/course-dates](http://www.storymassage.co.uk/training/course-dates)

Title: FEEL IT – sensory processing difficulties  
Date: 25th September  
Location: Glasgow  
Provider: Sensory Spectacle  
Contact: [www.sensoryspectacle.co.uk](http://www.sensoryspectacle.co.uk)

Title: Multi-sensory Story Training Day  
Date: 25th September  
Location: Sidcup, Kent  
Provider: Bag Books  
Contact: [nina@bagbooks.org](mailto:nina@bagbooks.org)

Title: Story Massage Training  
Date: 27th September  
Location: Manchester  
Provider: Story Massage  
Contact: [www.storymassage.co.uk/training/course-dates](http://www.storymassage.co.uk/training/course-dates)

Title: FEEL IT – sensory processing difficulties  
Date: 28th September  
Location: Newcastle  
Provider: Sensory Spectacle  
Contact: [www.sensoryspectacle.co.uk](http://www.sensoryspectacle.co.uk)

Title: Intensive Interaction for people with autism'  
Date: 29th September  
Location: London  
Provider: Intensive Interaction Institute  
Contact: [sarahinteract@hotmail.com](mailto:sarahinteract@hotmail.com)

## October

Title: Story Massage Training  
Date: 4th October  
Location: Cambridge  
Provider: Story Massage  
Contact: [www.storymassage.co.uk/training/course-dates](http://www.storymassage.co.uk/training/course-dates)

Title: INTERACT – skills to support interaction  
Date: 5th October  
Location: Preston  
Provider: Sensory Spectacle  
Contact: [www.sensoryspectacle.co.uk](http://www.sensoryspectacle.co.uk)

Title: Delivering a SENSory curriculum  
Date: 6th October  
Location: Belfast  
Provider: Hirstwood Training  
Contact: [www.hirstwood.com](http://www.hirstwood.com)

Title: Intensive Interaction Introduction'  
Date: 6th October  
Location: Birmingham  
Provider: Intensive Interaction Institute  
Contact: [sarahinteract@hotmail.com](mailto:sarahinteract@hotmail.com)

Title: INTERACT – the latest skills to support interaction  
Date: 12th October  
Location: London  
Provider: Sensory Spectacle  
Contact: [www.sensoryspectacle.co.uk](http://www.sensoryspectacle.co.uk)

Title: FEEL IT – sensory processing difficulties  
Date: 18th October  
Location: Bristol  
Provider: Sensory Spectacle  
Contact: [www.sensoryspectacle.co.uk](http://www.sensoryspectacle.co.uk)

Title: INTERACT – the latest skills to support interaction  
Date: 19th October  
Location: Bristol  
Provider: Sensory Spectacle  
Contact: [www.sensoryspectacle.co.uk](http://www.sensoryspectacle.co.uk)

Title: Building a sensory curriculum  
Date: 20th October  
Location: Bradford  
Provider: Joanna Grace and Flo Longhorn  
Contact: <http://jo.element42.org/training>

Title: Date: Location: Provider: Contact:	Sensory approaches for challenging behaviour 25th October Glasgow Hirstwood Training <a href="http://www.hirstwood.com">www.hirstwood.com</a>	Title: Date: Location: Provider: Contact:	Intensive Interaction Conference Thursday 9th November Leeds Intensive Interaction Institute/ Leeds and York Partnership NHS Foundation Trust Learning Disability Services <a href="http://www.intensiveinteraction.org/whats-on/conferences/conference-uk-2017">http://www.intensiveinteraction.org/whats-on/conferences/conference-uk-2017</a>
Title: Date: Location: Provider: Contact:	Delivering a SENSory curriculum 26th October Glasgow Hirstwood Training <a href="http://www.hirstwood.com">www.hirstwood.com</a>	Title: Date: Location: Provider: Contact:	Massage in the special school 14th November York Equals <a href="http://www.equals.co.uk">www.equals.co.uk</a>
Title: Date: Location: Provider: Contact:	FEEL IT – sensory processing difficulties 30th October Plymouth Sensory Spectacle <a href="http://www.sensoryspectacle.co.uk">www.sensoryspectacle.co.uk</a>	Title: Date: Location: Provider: Contact:	Sensory stories for mainstream settings 15th November Cardiff Joanna Grace <a href="http://jo.element42.org/training">http://jo.element42.org/training</a>
<b>November</b>			
Title: Date: Location: Provider: Contact:	Intensive Interaction Co-ordinators Course 15 month course starts late November 2017 Worcestershire (21 study days) Intensive Interaction Institute <a href="mailto:sarahinteract@hotmail.com">sarahinteract@hotmail.com</a>	Title: Date: Location: Provider: Contact:	Raising Our Game, Raising The Bar—PMLD Conference 24th November TBC ChoiceSupport /CMG with PMLD Link <a href="mailto:Thomas.doukas@choicesupport.org.uk">Thomas.doukas@choicesupport.org.uk</a>
Title: Date: Location: Provider: Contact:	Next Steps – Intensive Interaction 1st November Redhill, Surrey Us in a Bus <a href="http://www.usinabus.org.uk/events/training-dates/">www.usinabus.org.uk/events/training-dates/</a>	<b>December</b>	
Title: Date: Location: Provider: Contact:	FEEL IT – sensory processing difficulties 1st November Cardiff Sensory Spectacle <a href="http://www.sensoryspectacle.co.uk">www.sensoryspectacle.co.uk</a>	Title: Date: Location: Provider: Contact:	Addressing the Mental Health Issues for Learners with Complex Needs and Autism 1st December London Hirstwood Training <a href="http://www.hirstwood.com">www.hirstwood.com</a>
Title: Date: Location: Provider: Contact:	A creative day with EQUALS 2nd November University of Manchester Equals <a href="http://www.equals.co.uk">www.equals.co.uk</a>	Title: Date: Location: Provider: Contact:	Introduction to Intensive Interaction 4th December Redhill, Surrey Us in a Bus <a href="http://www.usinabus.org.uk/events/training-dates/">www.usinabus.org.uk/events/training-dates/</a>
Title: Date: Location: Provider: Contact:	Story Massage Training 9th November Glasgow Story Massage <a href="http://www.storymassage.co.uk/training/course-dates">www.storymassage.co.uk/training/course-dates</a>	Title: Date: Location: Provider: Contact:	Story Massage Training 6th December Brighton Story Massage <a href="http://www.storymassage.co.uk/training/course-dates">www.storymassage.co.uk/training/course-dates</a>

**Subscription prices are:**

<b>UK:</b>	Personal	£20.00	Organisation:£30.00
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## 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>	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>	Jill Davies currently works for Oxleas NHS Foundation Trust as a community nurse specialising in mental health in people with learning disabilities.
<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>Michael Fullerton</b>	Michael the Director of Quality and Clinical Care with CMG, a social care provider supporting adults with profound and multiple learning disabilities. Michael is a registered learning disability nurse and leads a health team focused on the quality of life of people with PMLD. Michael co-hosts the @PMLDChat Twitter chats.
<b>Martin Goodwin</b>	Martin is a teacher of pupils with PMLD and a Regional Tutor/Visiting Lecturer for the Severe and Profound Multiple Learning Disabilities course at the University of Birmingham. Martin has specialised in approaches to improve interaction, communication and participation of people with severe and profound learning disabilities. Martin has experience of working in play and leisure, education, residential and advocacy.
<b>Joanna Grace</b>	Joanna Grace is a sensory engagement and inclusion specialist. She is the founder of The Sensory Projects which are run on the principle that with the right knowledge and a little creativity inexpensive items can become effective sensory tools for inclusion. Joanna co-hosts the #PMLDChat Twitter chats.
<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
<b>Hannah Young</b>	Hannah completed her PhD studies on the loss experiences of people with PMLD. She is Researcher for PAMIS, a Scotland-based charity supporting families of people with PMLD, and has led a number of projects that aim to enhance quality of life for this group. Her experience also includes teaching, training and digital developments. Hannah acts as Welfare Guardian for her brother.



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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