

# PMLD LINK

sharing ideas and information

Meaningful Lives

Summer 2018



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## GUEST EDITORIAL

# Meaningful Lives

Welcome to the Summer Issue of PMLD Link focusing on Meaningful Lives. Being able to lead a fulfilling and meaningful life is important to us all. This issue has been wonderful to edit as it has involved reading about the creative work being done to support people with PMLD to lead meaningful lives. The new PMLD Core & Essential Standards show what needs to be in place to support people with PMLD to have a meaningful life and many of the articles demonstrate the standards-in-action.

Some of the Standards are very obviously relevant to this issue of PMLD Link, such as Standard 3: Meaningful/ Quality Relationships, Standard 5: Meaningful Time and also Standard 7: Social, Community and Family Life. But to be able to enjoy life it is vital to get the basics rights – for example, making sure people’s health and communication needs are met - so all the standards are relevant. We can also see how important Standard 1: Leadership is – developing a culture where it is expected that people with PMLD will be supported to have lives full of meaning.

In this issue we are very grateful to Nikki Lancaster for sharing her blog about her son Lennon, and how their family made sure his life was filled with rich experiences.

Marion Messmer reminds us of the basics that need to be in place for people – Changing Places toilets! We challenge you not to want to get involved in the campaign after reading what others have been up to.

On a similar theme, Nancy Beesley highlights the learning opportunities within toileting routines and how they can be made more meaningful.

Mark Bullock and Angela Lydon focus us in on sport, whilst Marie McGovern tells us about the yoga programme she has developed for children and young people with PMLD.

Tracy Barton McClean & Julia Nagy explain how they ensure college learners with PMLD have a meaningful curriculum, and Sarah Parkes gives us a detailed picture of how she teaches Religious Education to pupils with PMLD and the sense of meaning in peoples’ lives that may be created.

The role of meaningful relationships and benefits that Intensive Interaction can bring to people with PMLD in hospital are explored in Dr Julie Calveley’s article, and Janet Gurney explains how people can be supported to embed good practice around Intensive Interaction.

Sarah Townsend’s article focuses on ensuring staff have the skills to support people with PMLD in a person centred way. She discusses a new national qualification around supporting individuals with PMLD.

Professor Peter Oakes describes an evaluation of an innovative community project using music therapy with the aim of encouraging open and honest communication and developing a safer culture.

Through sharing the experiences of Ted, Adrian, Ralph and Lucy, Helene Abbiss shows how their specialist day services support people with PMLD to have a meaningful life by encouraging a sense of purpose and self-worth.

People with profound and multiple learning disabilities deserve a meaningful life. We hope that you find the articles a source of inspiration. Enjoy!

Rachel Hughes, Martin Goodwin and Bella Travis, Guest Editors.

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# Quality not Quantity – Life's Short

Nikki Lancaster  
Mother of Lennon

By the time Lennon turned 2 years old, he had spent the majority of his life in hospital – predominantly in Intensive Care. The short amounts of time we did get to spend at home were fraught with anxiety and worry.

Lennon was oxygen dependent, needed regular suction and was fed into a jejunostomy (a surgical feeding tube placed into his small bowel). His stomach contents drained out into a bag and we needed to calculate these fluid losses in order to replace the lost volumes as Lennon had stage 3 kidney failure.

He required multiple medications throughout the day and night including hormone injections. He regularly stopped breathing and on occasion, needed me to resuscitate him at home. Lennon had also been diagnosed as being deaf blind. Caring for Lennon was an immense responsibility and at times I felt completely out of my depth – my head bobbing continuously above and below the surface of stormy waters. When he stopped breathing, I found my own breath stuck heavy in my chest. The pressure was enormous and all consuming. I love Lennon and I would do anything for him, absolutely anything – nothing was too much. I gave up my life to look after Lennon and keep him alive. I quit my much loved career, hardly saw my friends and rarely left the house or Lennon's hospital bed side.

Lennon was admitted to Intensive Care for the fifth time when he 2 years and 1 month old. He was very poorly. He had a central line infection and bronchiolitis. His bowel had failed on Christmas Eve, just 2 weeks prior, and he was surviving on intravenous nutrition. His existing diagnoses of renal failure and pan-hypopituitarism made providing life support for Lennon complicated. The outlook was bleak and the doctors had asked Lennon's father, Ian, and I to consider turning off Lennon's support and ending his difficult and problematic life. We were both horrified at the very thought of life without our little soldier. I wanted so much more for him. I yearned for him to experience life – joy, excitement and happiness. And I wanted others to experience the elation that came along with Lennon's achievements, and for him to leave a footprint on the lives of others, just as he had on our lives. Of course, we said No – Lennon would be the one to decide when he no longer had the energy to survive. And in the moment the word No left my mouth, I made a vow to Lennon, and myself, that his life would be as rich and fulfilled as possible.

Lennon slowly improved and eventually came home – still with a complex and time consuming medical routine. It was then that we were referred to Palliative Care at our nearest children's hospice, Keech hospice in Luton. Keech's holistic approach enabled us to care for Lennon at home and keep him there. I spent the next 8 years researching, planning and booking the most amazing experiences for Lennon, and memories for our family. Yes, he was life limited, in a wheelchair, was deaf blind and had profound and multiple learning disabilities – but why should that be a reason to stop someone from experiencing a full rainbow of life? Why should he miss out?

We took Lennon swimming at Keech Hospice as much as we possibly could – this was always a mammoth task. Changing Lennon's dressings, keeping an eye on his dropping blood sugars, and keeping him warm was difficult but his excitement and enthusiasm to be in the water made all the stress of the situation melt away. We went Ice skating as a family every year on Lennon's Birthday in December, it became a family tradition. Lennon loved ice skating and the faster the better. One year Ian went so fast he managed to fall over and tip Lennon's wheelchair backwards into the ice – I was totally horrified and I'm sure my heart missed a beat. Lennon on the other hand, thought the whole experience was hilarious and seemed to be asking Ian to repeat the whole scenario! Disney on Ice became a twice yearly event. When it came to Lennon, you couldn't go wrong with ice skating and Disney together in one venue – two of his most favourite things!



We fundraised and purchased a walking frame and a special bike. Lennon spent hours toddling around in his walking frame when he was well, and in the summer, we used to stand his walking frame in a paddling pool and he would splash away with such delight. The bike was incredible – it was a life changer for Lennon. He was a real thrill seeker and was enraptured by speed. Ian would take him for long bike rides, speeding through long, windy country lanes. Lennon flapping his arms and screaming with delight! I found a company who provided ski lessons to people with a disability. This was a little trickier and took a lot of planning. Lennon's pan hypopituitarism meant his body disagreed with cold temperatures. But we found ways to work around that. Skiing became a favourite activity for Lennon – the buzz of sweeping down the slopes enraptured him. His face exuded excitement and happiness. We also took him down the mini slope in a donut ring! Neither Ian nor I have ever skied, yet our disabled son has.



We desperately wanted to take Lennon to Euro Disney – we knew he would love it! But the professionals had forbidden us to leave the country without trained medical support. Year after year we applied to The Caudwell Children's yearly trip to Disney Land, Florida – 'Destination Dreams'. Every year they take 25 children and their families plus a team of 12 doctors and nurses. It solved our problem of needing to travel with medical support. And in 2015 we were selected! Destination Dreams was the trip of a lifetime. It took months of planning and we travelled with almost 50kg of medical supplies, a file jam packed with medical notes, letters from doctors and emergency plans. But it was oh so worth it!

We stayed in Give Kids the World and visited the parks. I was shocked that so many of the rides had adapted carts for wheelchair users and ecstatic that for one week Lennon did not have to be excluded from anything. My little thrill seeker absolutely loved the rides! The faster and higher, the more delighted he was. He adored the characters and was mesmerized when we met Mickey Mouse in Magic Kingdom. I think the Electric Parade at Magic Kingdom was his highlight. His permanent beaming face on that trip will remain imprinted in my memory forever.



Lennon sadly died on 3rd August 2017, in the same Intensive Care Unit that had asked us to turn off his life support eight and a half years earlier. It was Lennon's time – his exhausted little body had run out of fight. We had been lucky enough to have been under palliative care for over 8 years, and therefore we had talked about the final stages of Lennon's life many times. Palliative care gave us the knowledge to enable us to make educated decisions over time and not have to make quick decisions during the hardest time of our lives. We had always wanted Lennon to die at Keech Hospice, but unfortunately it wasn't meant to be. The team at Addenbrookes and the lovely staff at Keech worked hard planning, and Lennon made his final journey to the hospice less than 12 hours after he died. He stayed there until his funeral.

We will be eternally grateful for those extra eight and a half years. Eight and half years packed full of joy, excitement and happiness. And yes, Lennon did make an immeasurable impact on the lives of everyone he came into contact with. He is remembered by many as 'The boy with the Midas touch'. Lennon's fun packed life proves that palliative care is not about giving up, there are always ways to live your life – in the capacity and time that you have – to the maximum.

#### Editors' Note

We are very grateful to Nikki Lancaster who has allowed us to reproduce this wonderful blog post from her blog 'Living with Lennon'. You can contact Nikki via her blog. <https://livingwithlennon.com/2018/05/22/quality-not-quantity-lifes-short/> 3/1 1

# Getting the basics right: The campaign for Changing Places toilets

Marion Messmer

Marion is the Changing Places Development Officer at Muscular Dystrophy UK. Here she gives an update on the Changing Places campaign and explains why, for many people, including people with profound and multiple learning disabilities, Changing Places toilets play a vital role in enabling people to live a meaningful life.

Living a meaningful life comes down to being able to live the kind of life that has meaning for you. What goals do you want to set for yourself? With whom do you want to spend time? What is important to you? In order to find answers to these questions, people with profound and multiple learning disabilities, like anyone else, will need to be able to experiment: try out different hobbies, volunteer for different causes, make new friends. In order to be able to do all of this, you need to know that you are not constrained by something as simple as not having access to the right kind of toilet.

Have you ever been concerned whether a venue you are about to visit has the right kind of toilets for you? Have you ever felt constrained by a lack of toilet provision? Most people don't worry too much about leaving their homes. They may have to think about transport and about what they need to take with them to go about their day but there are certain things about which most people don't worry too much. Toilet access certainly is one of them. If you go to work, you expect your workplace to provide a toilet you can use; if you go out to socialise or to run errands, you can expect bars, gyms, supermarkets and other public facilities to provide toilets for you. However, existing toilet provisions don't cater to everyone. This is where the Changing Places toilets campaign comes in.

Changing Places toilets provide the necessary space and equipment over ¼ million people need to use the toilet in safety and comfort. Seeing the Changing Places logo lets people know there is a toilet that will meet their needs. Co-led by Muscular Dystrophy UK and PAMIS (the Scottish charity which supports people with profound and multiple learning disabilities), the Changing Places Consortium aims to promote awareness of the vital need for Changing Places toilets as well as to effect change to building regulations to ensure that Changing Places toilets will be included as standard practice in new public buildings like shopping centres or transportation hubs, to name just two examples.



Since 2016, the Changing Places campaign has gained much traction. This is largely down to all the passionate campaigners who fight so hard for Changing Places toilets. Recently, our campaigners celebrated some important successes. Zack Kerr has campaigned for Changing Places toilets at motorway service stations. His petition led to an Early Day Motion in Parliament.

In February 2018, Lorna Fillingham submitted her petition for changing building regulations in order to make Changing Places toilets mandatory in large venues to parliament. She had several MPs supporting her petition and gathered over 53,000 signatures. One of the Changing Places campaign's long-term aims is working with parliament to change building regulations so that Changing Places toilets become mandatory.

Zack and Lorna's amazing groundwork allows us to build on their success and to continue the relationships they have started to build with MPs.





Alison Beevers has continued her fantastic work to get more Changing Places toilets into Museums throughout 2018. Thanks to her engagement, the Hepworth Wakefield Gallery in Yorkshire installed a Changing Places toilet. This was the most recent installation in a whole range of Changing Places toilets which happened thanks to Alison's unwavering commitment and enthusiasm.

Following the huge success of her LooAdvent in December, Sarah Brisdion organised the Looathon in May at the Baker Street Bathstore in Central London. It was a fantastic awareness raising event with dozens of campaigners coming together from all across the country to take turns sitting on toilets to start a conversation about the lack of Changing Places toilets.

Changing Places toilets really do change lives. The Changing Places campaign will continue to fight for better accessible toilet access for all around the UK. In order to achieve that, we will focus on continuing to raise awareness, increase the number of Changing Places toilets in key venues, such as transport hubs, and lobby



for legislative change to building regulations.

If you want to volunteer for the campaign or if you have any questions about our campaign activity, you can get in touch at [changingplaces@muscular dystrophyuk.org](mailto:changingplaces@muscular dystrophyuk.org).

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#### For more information

Go to [www.changing-places.org](http://www.changing-places.org)  
Find a Changing Places toilet: [www.changing-places.org/find\\_a\\_toilet.aspx](http://www.changing-places.org/find_a_toilet.aspx)

# Inclusive Sport

Mark Bullock

The benefits of exercise and physical activity are well documented and these principles apply to people with PMLD. However, my impression is that the topics of exercise and physical activity for people with PMLD have not received much attention to date. In my work as an Inclusive Sports Adviser, I aim to work with different groups and individuals to address this. I believe the PMLD Service Standards and Individuals Standards can support this work.

**S**tandard 4 of the Service Standards, which is about the physical environment, suggests that the physical environment should allow people with PMLD to access exercise and physical activity, which play a key role in a person's health and wellbeing (standard 6). Exercise and physical activity enables people with PMLD to interact in community and family life (standard 7 of the Service Standards and standard 4 of the Individual Standards), to develop meaningful and quality relationships and have meaningful time (standards 3 and 5 of the Individual Standards).

Paralympic and disability sport has had significantly increased awareness over recent years and particularly since the hosting of the Paralympic Games in London in 2012. Paralympic athletes are now household names and awareness of sporting opportunities is increasing. Para sport is now shown on television, and has a greater presence in the written press, so great strides have been made.

Whilst there has been significant progress in the awareness of sport for disabled people there is still much work to be done to improve opportunities for disabled people to take part in physical activity and sport. My blog on inclusive physical education published by the Sports Think Tank highlights that there is still much to do in the education sector to improve opportunities: <http://www.sportstinktank.com/blog/2018/01/inclusive-physical-education>

Research from London Sport shows that 21% of non-disabled people are inactive in London, defined by taking part in under 30 minutes of activity per week. For disabled people with one impairment the percentage of those inactive is 35.7%, for those with two impairments it is 37.2% and for three or more impairments it rises to 45.7%. It is worth noting that 73.7% of disabled people

have more than one type of impairment (Sport England Active Lives Survey 2015-16).

Sporting opportunities and pathways are largely provided to athletes with a single impairment. The way disabled sport is structured in the UK through the National Disability Sports Organisations (NDSOs) tends to reinforce this single impairment focus. The eight NDSOs are British Blind Sport, Cerebral Palsy Sport, the Dwarf Sports Association UK, LimbPower, Mencap, Special Olympics Great Britain, UK Deaf Sport and WheelPower. Given the high percentage of people with more than one impairment perhaps a different approach is required. The charity Sense have done some excellent work through a Sport England funded project 'Sporting Sense' which has created and developed opportunities for disabled people with complex communication needs to participate in a range of physical activities and sports. <https://www.sense.org.uk/get-support/arts-sport-and-wellbeing/sense-sport/>

Parallel London and Park Run have successfully provided physical activity for people with multiple impairments. The Super Sensory 1k at Parallel London is a great example of how physical activity can be made more





inclusive and accessible for people with multiple and complex impairments. Fellow ambassador Jo Grace developed the idea of the Super Sensory element of Parallel London. 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. The course is specifically designed to engage all participants to the fullest, including people with profound and multiple learning disabilities, people 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 and people who need sensory support to remember an event. This may include people with late-stage dementia or specific brain damage. I took part in the 2017 Parallel London Super Sensory and learned a lot from the experience and watching people take part in the course and families going round together.

As part of my work as an Inclusive Sports Development Advisor I am exploring ways to develop physical activity and sporting opportunities for people with profound and multiple learning disabilities. If we consider that sport often involves people physically extending themselves to the limits of their abilities this concept can be extended to people with PMLD. I have explored with adapting equipment to encourage people to move, reach out, touch and strike objects. In the picture below is an example where I suspended balls of different sizes colours and textures from a colourful frame that facilitated reaching out to touch or hit. The larger orange ball is also audible when moved. If struck with reasonable force the ball moves around the frame and allows a 'self rally'.



Perhaps people with PMLD can explore the emotions and the camaraderie of taking part in a Park Run, for example, by being pushed by a family member or friend: <http://blog.parkrun.com/uk/2018/02/23/for-us-its-just-normal/>

I am looking forward to embarking on an exciting journey to work with a wide range of people and organizations to get more people with PMLD active. If you have any questions, thoughts or ideas please get in touch.

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Many thanks for your support.



## Making Safeguarding Musical

Peter Oakes

This article describes an evaluation of an innovative community music therapy project run by Alistair Clarkson and Meta Killick and the care provider Choice Support, as part of the London Borough of Sutton's Making Safeguarding Personal programme.

**A** raft of reports, investigations and allied research have pointed to the importance of culture, climate and leadership in establishing relationships and environments that offer both opportunity and safety for people who remain vulnerable to abuse and exploitation (Francis, 2013; Flynn, 2012; Vincent, 2010). There is also a robust literature on unethical/harmful decisions at work in industrial and other settings (Kish-Gelpart et al, 2010). This has been able to drill down into the individual and organisational factors that lead to unethical choices where culture, climate and leadership have also been identified as critical factors in maintaining ethical standards.

Settings where people with intellectual disabilities receive support might be understood as unusual and

remarkable communities rather than more straightforward organisations (Bronfenbrenner, 1979). There are numerous, often intertwined, relationships involving people with disabilities, families, support staff, managers, local communities, professionals, commissioners, regulators, policy makers and so on. The nature of disability in the context of well documented prejudice, economic hardship and historical injustice means that all of these relationships are fraught with issues of power and inequality. Abuse and exploitation depend on unequal power relationships to survive (Foucault, 1982).

To address the apparently simple need to establish cultures and environments that are both safe and full of opportunity seems not to be so simple after all. Indeed,

some have referred to this issue as a wicked problem – one in which the proposed solutions serve only to worsen the problem (Marsland et al, 2015). Examples of these have been documented elsewhere and might include increased scrutiny, regulation and paperwork. These are factors which can then bring about a culture of fear or at the very least distrust. This can increase levels of occupational stress which in turn increases the propensity of staff to be more controlling in their interactions and so increases the risk of harm. Whilst it seems important to continue to grapple with more traditional approaches to organisational change and leadership, a challenge such as this might also benefit from a more creative approach. This report describes just such an approach where a series of community music sessions were used to establish a culture in which relationships are more open, relaxed, positive, equal and therefore safer. The use of music to achieve this has been well documented in different settings. In the support of people with intellectual disabilities it seems particularly relevant as music affords the opportunity to communicate without words and to engage with other people on an equal footing rather than be immediately disempowered by aspects of a disability and access to important information (Clarkson and Killick, 2016).

**Method**

Whilst it was originally intended that the approach be formally evaluated using different measures before and after the community music therapy sessions,



this was not possible for operational reasons in the organisation at the time. However, it is possible to describe the process and report on the impressions of those involved about the impact of the community music therapy sessions on the life of the community. This will act as a form of pilot study which will enable the development of questions and approaches to measurement that can form the basis of a formal research based evaluation in the future. This pilot evaluation takes the classic form of input, process and outcome (Donabedian, 2002).

**Evaluation - Input**

The setting was a supported living service comprising individual flats with communal areas for 7 people with profound and multiple learning disabilities. Support is provided by staff who work for a wider organisation known as “Choice Support”. Choice Support describes itself as an innovative national social care charity

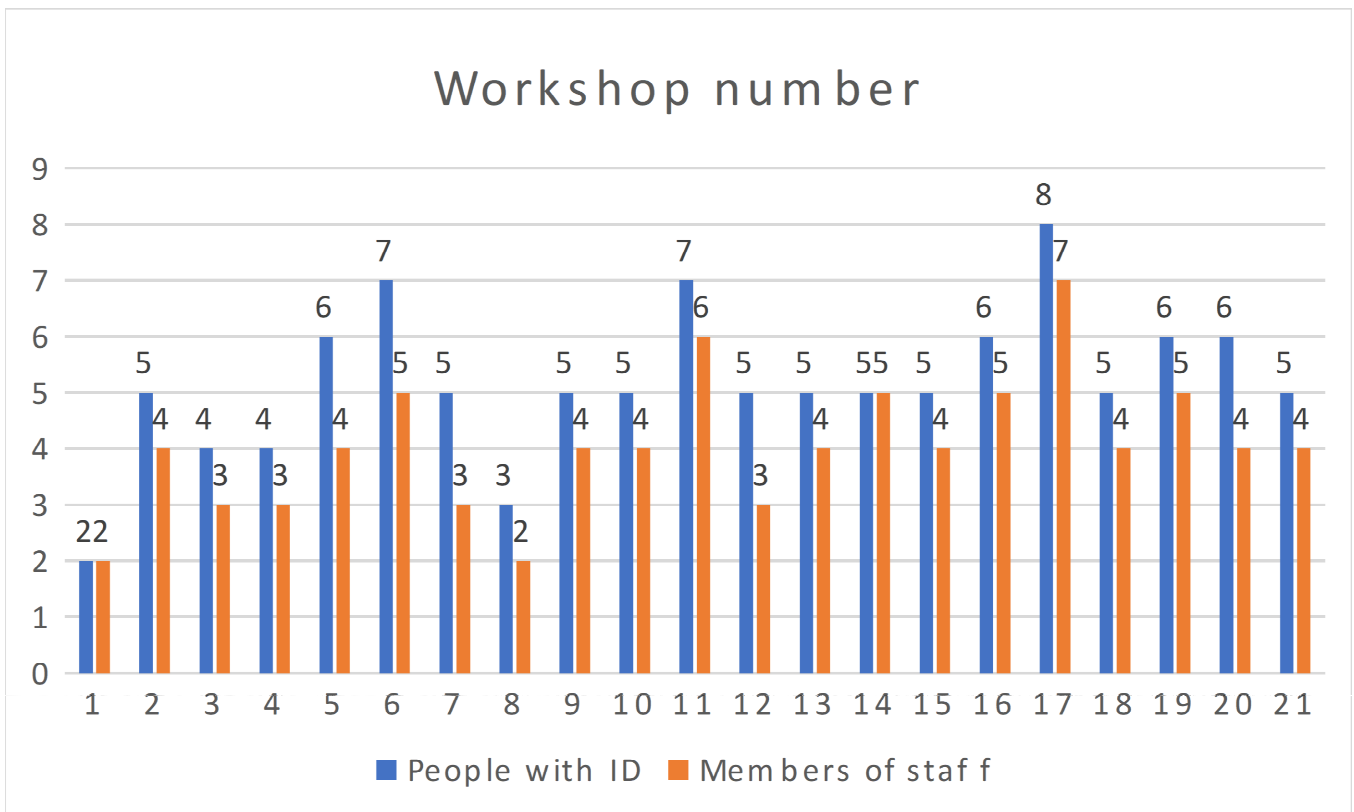


Figure 1: Attendance at each workshop





providing support to people with learning disabilities. It currently employs about 1700 full and part time Choice Support staff who provide services to around 900 people across most of England.

A series of 22 community music therapy sessions were part of the “What Good Looks Like” project provided by an external group of music therapists who were employed and supported by the London Borough of Sutton. The aim was to create space in which ideas could be felt, expressed and thought about as words, actions or sounds.

The community music therapy sessions were open to all the people present on the day of the workshop regardless of whether they lived or worked in the service. Figure 1 shows the attendance at each workshop.

It was important to note that attendance was for anyone who was present and who therefore represented the community at that point in time. It was entirely optional for everyone.

### Process

The community music therapy sessions have two central elements. The first is a model known as “Sounds of Safety” This is developed from the Signs of Safety approach (<http://safegenerations.org/signs-of-safety/what-is-signs-of-safety/>). The Sounds of Safety model has three pictures of Houses; the House of Good things, the House of Worries and the House of Dreams. Participants are asked to think, speak, sing, dance or act their responses to the good; to the worries; and to the dreams of their house, as a community. Those who can are asked to put the ideas down on paper by drawing pictures or most often by writing down the ideas of the group.

The second model is called “What Good Looks Like” which is a development of the Early Indicators of Concern

(Marsland et al, 2007). What Good Looks Like is a unique strengths-based analysis of six areas.

1. **Service Users Wellbeing** - What is our home for?
2. **Staff Skills** - What makes me feel good in this home? (Question to residents)
3. **Service Planning** - What is good about working in this home? (Question to staff)
4. **Management and Leadership** - What's good about our managers?
5. **Quality of Care and the Environment** - What's good about how we are looked after?
6. **External Agencies Involvement** - Who comes to help us? Who do we go to see to help us?



These six areas, as questions, are placed on a simple picture of a house as six rooms. Each of the six areas are used as stimulus for discussion and expression. The Sounds of Safety approach encourages appreciation and valuing of what is positive in the organisation, clarity about any problems and the collective building of a vision for a positive future.

### Outcome

Informal focus groups gave some profound insight into the shared hopes and fears of the people who attended. The members of support staff who attended also provided informal feedback, essentially describing the community music therapy sessions as positive experiences for the whole community and something



that they “looked forward to”. The words used had some expected qualities such as enjoyment, happiness and fun alongside words with a richness to them such as lovely and smiling.

Examples of dreams and the good things about a place to live included things that might be expected about friends, independence and control. Other things mentioned are not perhaps acknowledged sufficiently in the way we offer and evaluate support for people. People appreciated love, belonging and beauty – the garden was particularly special for some people. Likewise, when thinking about worries, there were the things we can all identify with. There were worries about the future, possible changes and the day to day stresses, from transport to paperwork. But there were also the more profound worries about loss: loss of health; loss of happiness and losing the people we love.

In general, these reports suggest a community of people that can understand and accept its history, feels at home with the present and is able to look forward to a positive future. This is also a community of people who are conscious of both the superficial and the profound. It seems possible that the inclusiveness of the approach and the use of music as well as words might enable people to express these more profound hopes and fears.

**Discussion/Conclusion**

This is an informal evaluation pilot that describes the reactions of individuals who live in a service and who work in a service for people with profound and multiple disabilities. They are responding to an inclusive workshop based approach using music to enable communication about the service where people live and work. The aim is to encourage open and honest communication which in turn will facilitate a culture which is safer for everyone. It must be stressed that everyone involved in this evaluation was keen to see it as a positive and worthwhile experience that may have something to contribute to wider discussions about keeping people safe in services that are intended to support them. This report represents a summarising of those ideas set in the

context of current and recent research but it is **not** an independent evaluation.

The results came in the form of feedback on the process and some focus groups about hopes and fears for the service as a whole. Because of the approach that was taken, it has been possible to understand the service as a single community rather than a service that is either received or provided by separate group of people defined. This way of understanding systems of supports may be a helpful model for the future.

The results of the focus groups suggest that recent work on the understanding of well-being might be of assistance to the development of services and supports for people with disabilities.

Five areas of psychological well-being are supported by some robust evidence that is beginning to guide practitioners in various sectors (Kinderman, 2014). These are as follows:

**Be Active**



**Be Connected – to other people**





Keep Learning



Giving (especially time)



Take Notice (be spiritual/mindful)



Interestingly this might be a community that is not “helpless”, “hopeless” or “depressed”. Rather, the process seemed to tap into a community that is positive about itself, the world and the future. This is a community of people who might be said to have survived the experience of being disabled or working as support

staff and who continue to be able to engage with services to express hopes and fears (Gondolph and Fisher, 1988). This might also be understood as a form of reasonable hopefulness (Weingarten, 2010) where we can express confidence that this is a community with the drive and the resources to find solutions to some of the difficulties it faces.

Given the importance of developing and maintaining sustainable supports for people with profound and multiple disabilities that are both safe and full of opportunity, the initial findings of this pilot would suggest that further work on the role of music in opening



relationships and equalising power is worthy of further attention. It might be hoped that a form of participative evaluation would bring to light the possibilities of using music to enhance communication (including the need to challenge each other), reduce general stress and anxiety, and help everyone enjoy life without fear of harm or rejection.

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**Editor’s Note:** Many thanks to Zooming Photography for allowing us to reproduce their photos.



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# Devising and Developing a Curriculum Incorporating Meaningful Time and Transition for College Learners with PMLD

## Reference to Two Key Points of the Core & Essential Service Standards<sup>1</sup>

Tracey Barton McClean and Julia Nagy

This article presents the response to Standard 5. Meaningful Time p.34. and Standard 6. Transition p.34-35. of the new Core and Essential Service Standard for Supporting People with Profound and Multiple Learning Disabilities in a department in an FE college. As an educational setting for 16-21 year old learners with a range of SEND, we are often the last stage of educational provision in their life. Our timetable is planned in a person-centred way to allow learners with PMLD to achieve goals, actively engage and make choices and preferences which will inform a meaningful curriculum and enable a fulfilling life. Throughout the years learners are engaged in study programmes with the college, transition planning is considered for each learner incorporating views of learners, parents, carers, and multi-agency professionals.

**W**e provide and deliver a highly individualised, competency<sup>2</sup> based contents of education whereby the learners' achievements can be transferred and maintained in their adulthood. The acquired competencies of young people with PMLD must always serve to increase their chance of successful inclusion<sup>3</sup> in their respective communities, as their participation in the society is the largest determiner of their quality of life (Chart 1.).

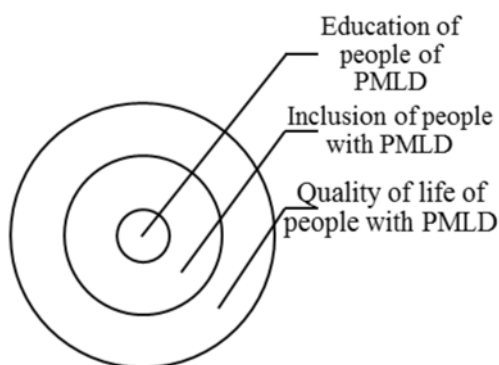


Chart 1. The Purpose of Education for People with PMLD

### Aspirations for learner with PMLD

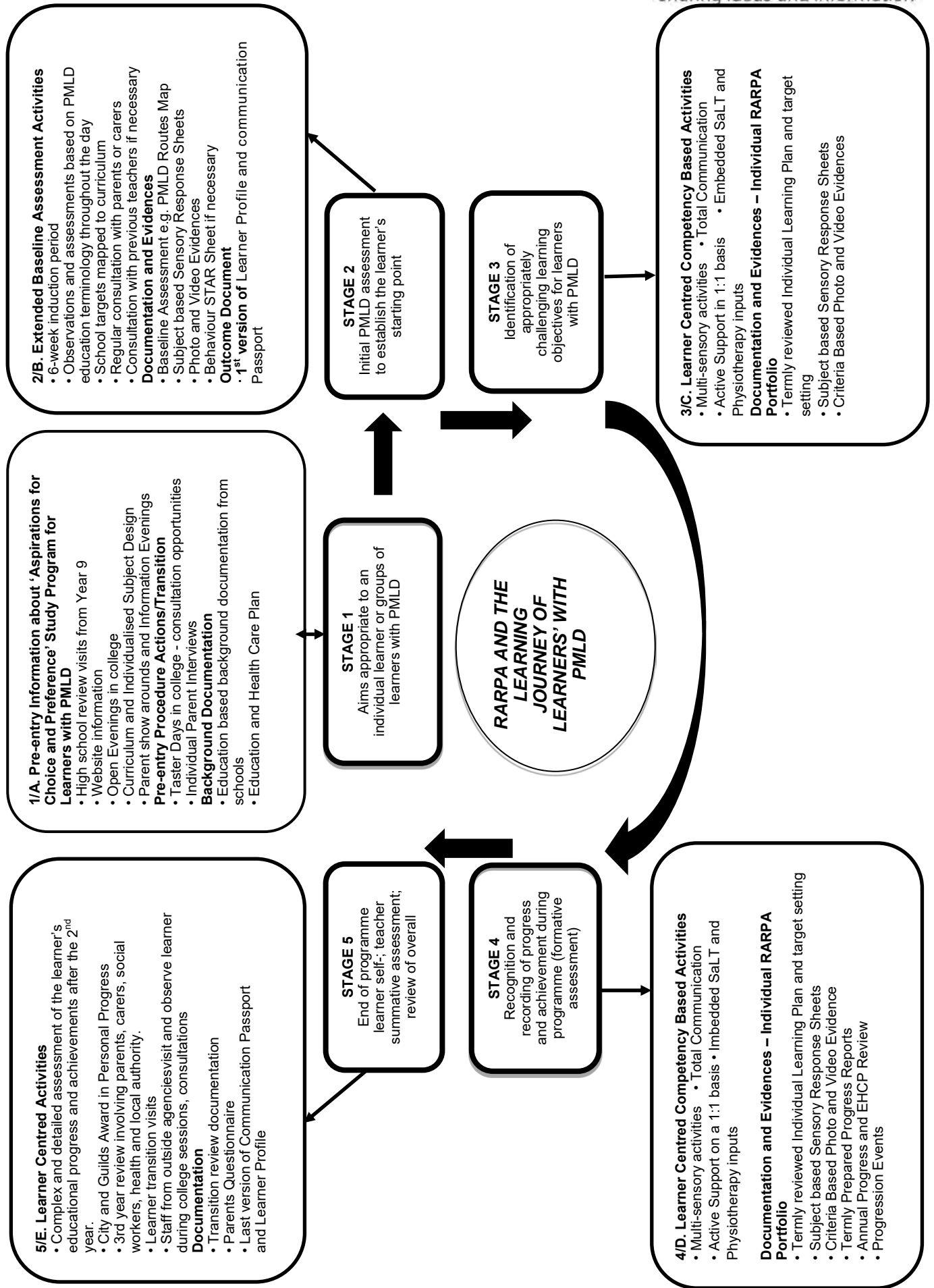
**A**spirations is a department within an FE College in Ashton-under-Lyne, which provides study programmes for learners with a range of SEND, including PMLD and SLD.

Our learners benefit from accessing a wide range of facilities within the mainstream college environment serving their integration and connection with their peers e.g. greenhouse, sports hall, gym, and catering.

The 'Aspirations for Choice and Preference' is a tailored study programme for students with PMLD. The study program is based on the international recommendations of inclusive education for people with PMLD<sup>4</sup>. It is both accredited using RAPRA framework<sup>5</sup> (Recognising and Recording Progress and Achievements) and also external accreditation from City and Guilds<sup>6</sup>. The learner journey through 3 year study programme by the RARPA process described in Chart 2. Hereinafter we will use Chart 2 as a reference and will flag any relevant stages in the text.

Following the transition process from high school (Chart 2. 1/A.) the study programme is designed to provide opportunity for learning through a multi-sensory curriculum, for those who are learning between P levels 2 & 6, according to the further education Adult Pre-Entry Curriculum Framework Milestones 1-4<sup>7</sup>. This is a curriculum through which the student can explore, respond to and interpret the world. Sensory based activities can help to decrease self-engagement behaviours, promote communication and social interaction, develop cognitive skills, teach early problem-solving skills, support to make choices and express preferences, strive for acquire self-esteem and confidence and have fun (Chart 2. RARPA Stage 1).

**Chart 2. The Learner Journey Through 3 Year Study Programmes**





The sensory based sessions include – sensory drama, music, art, IT, Sensology, TacPac, Developing Communication and Movements, adapted sport and community based activities.

All learners have a personal, flexible, learner centred timetable designed to meet the needs of the individual, their interests and long-term goals are considered. Timetables are presented in a manner that makes it possible for each learner to understand what the day holds for them using a total communication approach.

The study programme commences with an induction period where the tutor will establish the learner's starting point (Chart 2. RARPA Stage 2.) via PMLD specific observations and assessments which focus on communication, social interaction and cognitive skills<sup>8</sup>. The students work and interact with their tutor and key workers on 1:1 basis throughout the day. Staff records the learner's responses, interactions, preferences, likes or dislikes on a subject relevant Sensory Response Sheets during each session and on the Personal Care and Independence Form throughout their daily routine activities. The observations, assessments and response sheets serve as a basis for creating the first version of the Learner Profile and Communication Passport (Chart 2. RARPA Stage 2. and 2/B.) which are updated as necessary.

After the induction period the learner's personal tutor identifies challenging objectives for the learners with PMLD and designs an Individual Learning Plan which contains a set of targets with a focus on the acquisition, maintenance, rehearsal and development of communication and social skills, cognitive and early problem-solving skills, independence skills, as well as physical development and wellbeing (Chart 2. RARPA Stage 3. and 3/C). Their progress against these targets will be assessed termly during different multi-sensory activities provided by the curriculum. The learner's progress and achievements will be recognised and recorded via criteria based photo and video evidences which will be kept in the learner's Individual RARPA Portfolio.

The tutor prepares a termly report reflecting on the learner's achievements and progress and this will determine the next target or search and design appropriate educational strategies if the learner's target is not achieved. Progression Events are held yearly with a variety of external agencies and community provision in attendance in order that learners and parents can gather information about future options and aid the transition process by making early connections.

Each learner has a yearly person centred annual Education and Health Care Plan review where progress and support is monitored and reviewed with the learner who is assisted to gather photographic and video evidence, alongside parents and multi-agency professionals and transition is discussed from an educational, health and social care perspective. (Chart 2. RARPA Stage 4. and 4/D). The RARPA program terminates after two years with a summative progress and achievement assessment report. At this stage we ask the parents and carers to fill out a questionnaire about their experiences regarding the programme. This feedback helps us to improve and develop the study programme.

Learners work on a City and Guilds Award in Personal Progress qualification during their third year study programme and their criteria based achievements are recorded with photo and video evidence. The 3rd year progress review again involves the learner, parents/ carers, social workers, health professionals and local authorities. According to the learner's educational progress and achievements, next steps into adult life are decided. If educational outcomes to improve his/her quality of life may be achieved they may be presented with the potential opportunity to continue their studies. If the student is transitioning into the local community, the multi-disciplinary committee present at the review will start to work on the learner transition process according to an Action Plan (Chart 2. RARPA Stage 5. and 5/E, in order to provide a smooth transition process.

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# Religious education and pupils with PMLD

Sarah Parkes

A few years ago I was asked to take curriculum lead on the subject Religious Education (RE)...oh how I panicked! RE is the curriculum area I lacked confidence in teaching to pupils with profound and multiple learning disabilities (PMLD) (those pupils working below a P3). Reflecting on my own RE lessons throughout the years, I have focused mainly on celebrating main religious festivals and diving into the 'RE' box at school. Whilst celebrating festivals and exploring religious objects are an important element of RE, I lacked clarity and confidence in what I was trying to achieve through my teaching. This left me with the question; what does RE 'look like' to pupils with PMLD?

**R**E is deemed an essential part of the curriculum (Teach: RE, 2017; All-Party Parliamentary Group, 2013). The legal requirement for special schools is to 'teach RE so far as is practicable', adapting the curriculum where appropriate. I was challenged in how this can be achieved for pupils with PMLD. RE is not only learning about different religions and their values, rituals and beliefs, but also developing pupils' spirituality. For example, responding to the natural world and making meaningful connections with others. In rethinking my approach to RE I had two main considerations. Firstly, how to teach the content of different religions, particularly abstract issues, such as how values link to a religion, and secondly, to provide opportunities for pupils to develop their own spirituality.

## 5 Keys to RE

**T**hrough researching the teaching of RE in special schools, I came across the work of Anne Krisman. Krisman (2008) proposed '5 Keys' from which RE should be based from. These 'keys' focus on the importance of 'shaping RE around the child'. The 5 keys are as follows:

- **Key 1: Connection** – what links can we make with our pupils' lives?
- **Key 2: Knowledge** – what is at the burning core of the faith?
- **Key 3: Senses** – what sensory elements are in the religion?
- **Key 4: Symbols** – what are the symbols that are the most accessible?
- **Key 5: Values** – what are the values in the religion that speak to us?

Krisman proposed that within special schools, RE should:

- 'Link with pupils' developing selves, their unique personalities, and points of connections with the

world outside them

- Use the sensory elements of faiths to engage pupils and develop their understanding of religion as something special to people
- Is powerful, not watered down, and gives an insight into the world of religion and human experience
- Offer opportunities within an RE context to develop communication, a sense of self and a sense of community' (Krisman, 2008: 6)

I trailed this approach within my own classroom and discovered what RE really 'looks like' to pupils with PMLD! I found pupils responding thoughtfully and with insight that I had not seen before. By using the 5 keys approach, opportunities for spiritual development also occurred. RE was exciting to teach which was reflected in pupils' engagement.

Below I have noted some of the responses showed by pupils and also examples of activities we have undertaken:

### Key 1: connection

- Pupils in an Early Years class explored their favourite books. They experienced placing their 'special books' in a box, which was then used to introduce the 'special' books of faith (Topic: special stories)
- In response to listening to the call to prayer, a pupil stilled, widen his eyes and smiled (Topic: How do we live our lives as Muslims?)
- A pupil showed recognition of her Grandmother in a photograph by changing her facial expressions and gestures (Topic 'Who is important to me?')
- During a body mindfulness relaxation, pupils experienced an adult gently squeezing different parts of their body. As the adult squeezed a pupil's arm, his arm became increasingly active (During



collective worship, bodily awareness)

- During collective worship a pupil reached out towards her peer and rested her hand on his hand (Spiritual development displayed through showing a sense of connection and belonging)

**Key 2: knowledge**

- Pupils experienced the Wudhu movements (the Islamic ritual of washing in preparation of worshipping Allah). A Muslim pupil closed his eyes each time the call to prayer was played, and actively cooperative in the movements (Topic: How do we live our lives as Muslims?)
- Pupils explored a range of props relating to the Easter story. A pupil independently moved his fingers over the crucifix and vocalised ‘ahhh’ (Topic: Who is Jesus?)

**Key 3: senses**

- An adult tapped a singing bowl. A pupil stilled at the sound with their eyes wide and made a purposeful movement to touch the singing bowl (During collective worship linked to Buddhism)
- When exploring the outdoor environment, ivy was placed in a pupil’s hands. The pupil slowly and purposefully moved their fingers over the leaves, pausing occasionally. The adult then placed the pupil next to the tree and supported them to touch the trunk covered in ivy. The pupil responded with smiles and vocalisations (Topic: Our Beautiful World. Spiritual development display through a sense of awe and wonder)
- During collective worship, pupils explored a range of natural objects whilst listening to natural sounds. During the week, the pupils used these objects to create art work.



- A ‘spiritual trail’ was created using many different textures during a series of Collective Worship sessions. Pupils explored using either their hands or feet. Gentle music was added with time for pupils to respond to the different textures. A pupil spent over 10 minutes wiggling his feet in grass, occasionally closing his eyes during his time of personal exploration.

- During collective worship, a battery operated candle was placed near a bowl of water. It created a range of reflections on the table (As part of a Buddhism celebration of light)

**Key 4: symbols**

- Pupils experienced a Tibetan Buddhist tradition by creating prayer flags. They made marks using bright colours on flags which were attached to string and placed in the outdoor area. As the flags were blown around in the wind, a pupil stilled and watch them as the flags were moved around by the wind (Topic: Different people, different religions).
- Pupils were provided with boards with raised patterns to represent Labyrinths. Pupils were supported to follow the pattern using their fingers. A pupil intently watched their finger being guided over the pattern. His hand was then placed in a tray of sand. He independently moved his finger, creating a similar action (up and down) (During collective worship to encourage stillness and quietness)

**Key 5: values**

- A pupil showed kindness to a peer after the story of the Good Samaritan by tenderly reaching out and touching the hand of a peer who was upset (Topic: Special Stories. Spiritual Development; making meaningful connections with others)
- A pupil showed an understanding of others feelings by correctly selecting the ‘sad’ symbol to describe how Jesus felt when his friends left in the garden of Gethsemane (Topic: Who is Jesus).

I rewrote the curriculum for pupils from early years to key stage 3 based on the 5 keys. Within each topic I ensured;

- pupils experiences are the starting point for each topic
- a careful selection of what was taught to ensure pupils are not overwhelmed with additional information
- the sensory elements of the religion were capitalised on
- a clear symbol was selected which represented the topic/religion
- a value was selected and a thought out approach of how pupils can explore the value with themselves and each other

An **extract from an Early Years unit plan** is provided on the next page

Subject: RE	Unit title: Who is Jesus?	
Key stage: EYFS/ Key stage 1	Term 4	( Year of LTCM ) 2

**Key Concepts/Aspects of spiritual appreciation: Relationships, self-awareness & reflection**

Keys	Focus	Suggested Activities
Key 1: connection	Whom do I love?	<p>Who do you love? Ask families to send in photos and special objects (e.g. Grandma's blanket) related to their family. Note and observe pupils responses</p> <p>Extend to 'who is special to me in school'. Observe how pupils respond to different people around school (key worker, SMSA, transport guide). Can they recognise familiar people through their voice/smell/other key sense? Allow time for pupils to be in close contact with each other, observe their responses</p> <p>Invite parents in for a workshop. Aim of workshop is to provide an opportunity for parents to explore pupils favourite resources and activities</p> <p>Links can be made to the text 'Guess how much I love you' by Sam McBratney (extend to - who loves me?)</p>
Key 2: knowledge	Christians believe Jesus loves everyone	<p>Link to the Easter story. Create an Easter texture board (e.g. wool for the softness of bread, sharp texture for the crown of thorns, silkness of the curtain torn in two). Additionally, create an Easter sensory experience (six activities) (e.g. 1. Exploring water (Jesus washed disciples feet) 2. Tasting bread/berry juice (Last Supper) 3. Smelling/feeling flowers and grass (Garden of Gethsemane)</p> <p>Use Bible stories of Jesus loving others (e.g. Jesus feeding those who were hungry (Matthew 14), story of the Lost Sheep (Luke 15).</p>
Key 3: senses	All 5 senses	<p>All 5 senses incorporated into Easter sensory experience (see above)</p> <p>Pancakes for Shrove Tuesday</p> <p>Link to emotions (when I see mummy I feel.... happy)</p>
Key 4: symbols	Cross	<p>Explore crosses on a light panel.</p> <p>Use a torch to highlight a brass/silver cross</p> <p>Decorate a cross (individual or class)</p> <p>Hide crosses in messy materials</p> <p>Go into the outdoor environment and use twigs to draw crosses in mud</p> <p>Reflection using candles and crosses (time of calm and relaxing). Add music to create an atmosphere</p>
Key 5: values	Caring for others Loving others	<p>Jesus washed his followers' feet – pupils to explore water in trays using their feet, support pupils to explore water together</p> <p>Making a 'Helping Hands' class picture (handprints). Pupils to experience pressing their hands against another</p> <p>Pupils to sit/lie close to another (either peers or familiar adult) allow time for pupils to respond to another</p> <p>How do we show love to others? Pupils can visit other classrooms to share a story time or bake a cake to share with another class. Link to Bible stories of how Jesus showed his love to others?</p>

### Concluding thought

By embracing the '5 keys to RE' it has provided a way to create a bespoke approach to the teaching and learning of RE, tailored to individual pupils needs. It has created a clear 'sense of purpose' of the subject by providing clarity of what knowledge we are aiming to teach the pupils. This has been evident in pupil responses and their engagement during RE lessons. As RE lead, I continue to be challenged to improve and make deeper connections between RE and pupils lives; ensuring RE content is rooted in context to our pupils and create more opportunities to enhance spiritual development.

For further information, I would greatly encourage you to read the work by Anne.

### Contact Details

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# Time to Care?

Nancy Beesley

If you had told me when I was younger that I would spend my days wiping bottoms I would not have believed you. I now take a contrary pleasure in telling people this is what I do for a living.

In fact I am a teaching assistant at a special school for students aged eleven to nineteen who have severe or profound learning difficulties. I work in a key stage 4 class of eight students with profound and multiple learning difficulties (PMLD). We have one teacher and five teaching assistants. Our staffing ratio is high, but the needs of the class are challenging and complex. In truth my job is multi-faceted, of which bottom wiping is only one aspect, but I do spend a sizeable chunk of my day in the changing room. As a masters student on the Severe and Profound Multiple Learning Difficulties course at the University of Birmingham, I wanted to investigate the impact of personal care within the school day. I knew I was spending a lot of time in the hygiene room and a survey of my school setting showed I am not the only one. Does personal care offer opportunities for learning that are being overlooked?

Fig. 1 How much time is spent toileting in a typical day for your class?



Four people showed their 'working out' and they all spent an average of ten minutes per pupil as a baseline. There is broad agreement in departments about the amount of time taken. Of the nine staff that responded two thirds agreed they spent two hours or more toileting.

Toileting for these staff is time and labour intensive. All sixteen students with PMLD are wheelchair users. All eight pupils in one class and five in the other require hoisting which necessitates two members of staff. From the chart it can be seen that six people estimated two hours or more were spent toileting. The school day is six hours long, therefore two thirds of the staff in the PMLD department believe a third of the day is spent changing students.

Imray and Bond (in Lacey et al., 2015) recognise that, even at school, care plays a considerable part in the life of a person with PMLD. They also observe that care is often seen as necessary, but time wasting. This can be especially the case for teachers who see care giving tasks, such as toilet visits, eating into valuable lesson time, but surely nobody is able to learn if they are uncomfortable, distracted and or distressed? Physiological needs form the foundation of the pyramid in Maslow's 'hierarchy of needs' (Maslow, 2011). Cambridge and Carnaby (2006) argue that care needs should be considered at every level of the hierarchy as they impact on feelings of safety and security and feelings of acceptance. I believe that to be able to make a person with PMLD clean and comfortable is one of the most valuable things I can do of immediate and beneficial effect.

The pinnacle of Maslow's hierarchy is 'self-actualisation' (Maslow 2011), essentially control over your own life. Imray and Bond (in Lacey et al. 2015) believe that giving control to someone with PMLD is the most important thing one can do educationally. It seems logical that to take control of their life would involve exerting control over and actively participating in their own care, including toileting. Cambridge and Carnaby {2006} in their chapter on multidisciplinary coordination recognise that acts of intimate and personal care have many benefits aside from physical health and hygiene outcomes. They identify such tasks as ideal opportunities for relationship building, working on communication skills and teaching self-awareness. In this context 'control' could mean choosing which scented bubble bath is used (Lacey and Ouvry 1998).

Imray and Hinchcliffe (2014) suggest a focus on process rather than product will give control to the learner so tasks are performed with the student rather than to them. Children consistently in the position of having things done to them will come to accept this as an unchangeable fact (Colley 2013; Imray and Hinchcliffe 2014) often described as 'learned helplessness'; a term first coined by Seligman (1975). Sharing control, however, is hard for the teacher or carer, especially in a goal-oriented setting like a school (Ware 2012). It is all too easy for a dominant care giver to assume a passive recipient is not capable of action. Enabling independence relies on a facilitator who will actively look for ways to

transfer control and will positively and consistently reinforce the action or behaviour, repeatedly over time, Lacey and Ouvry (1998).

This would suggest well trained highly motivated staff are essential as (Cambridge and Carnaby 2006; Ware 2012; Colley 2013; Imray and Hinchcliffe 2014) all agree. Imray and Hinchcliffe (2014) even suggest that the special needs sector could not function without support staff; certainly true in my own setting. However, Imray and Hinchcliffe also observe that a need for specialist knowledge at this level is often overlooked. Cambridge and Carnaby (2006) recorded staff reporting that personal care was a significant part of their job but feeling it was regarded as unimportant or for which they were ill prepared. Cambridge and Carnaby (2006) assert intimate care is regarded as ‘dirty work’ and an aspect of life that is stigmatised in many societies, yet excretion is one of the seven processes of life, fundamental to existence.

Pawlyn and Budd (in Pawlyn and Carnaby 2009) state that the significant cognitive impairment of people with complex needs makes it unlikely that they will achieve continence independently. However, when I asked people about learning opportunities within the care routine I found many answered in terms of learning for personal care. They mentioned independence, managing clothes, hand washing and transitioning to the bathroom.

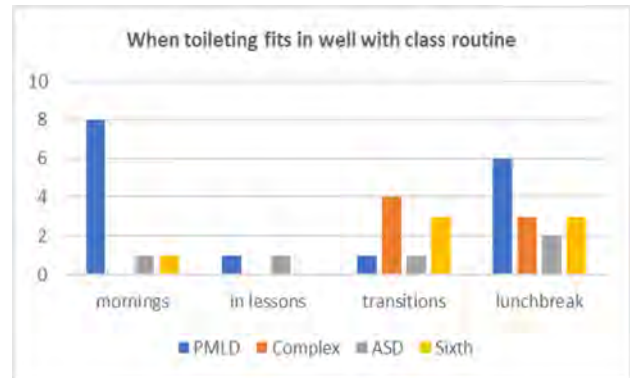
Fig. 2 Are there currently learning opportunities within toileting routines? Could there be future opportunities? Do any students have targets related to personal care?

Learning opportunities	PMLD	Teacher
	Support staff	Teacher
Present opportunities	3	1
Future opportunities	6	2
Current targets	0	0

One teaching assistant agreed that there are current opportunities for her students, but felt they are not consistently utilised. Another Teaching Assistant felt learning opportunities are restricted by time while another felt lack of time restricted learning completely.

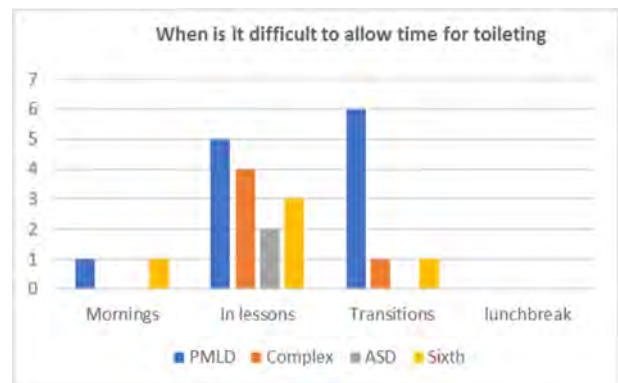
The teaching assistant who felt lack of time stopped current learning opportunities said future learning was possible if more time was allowed.

Fig. 3 When do you feel toileting fits in well with other class routines?



There are specific times allocated for changing during the school day. These are in the mornings following registration and, after eating, during the lunch break. The majority of staff felt these slots were the easiest times to accommodate toileting.

Fig. 4 When is it more difficult to allow time for toileting?



Fourteen people felt it was difficult to toilet within lesson time. One teaching assistant commented that:

“Single lesson, means student miss a lot if they go out”

Five people mentioned staffing as a contributing factor to their choice. Stating that either leaving a lesson to toilet would mean there were not enough staff to deliver the lesson or that at certain transitions, when staff took their breaks, there were not enough people to toilet. As figs. 3 & 4 show, lessons are the most difficult time to toilet and specified changing times the easiest; with transitions also presenting challenge for the PMLD department. Many people cited time and staffing issues. I would posit that time and staffing are the main considerations when deciding whether or not a pupil is changed. Odour or distress may have some bearing, but any other indication by a student would probably not be acknowledged.

Colley (2013) points out that within the National Curriculum Guidance for England and Wales (QCA 2009) it is recognised that ‘out-of-class time’ can offer learning



experience for pupils with cognitive difficulties. If this is the case, why are these valuable opportunities not being tapped? Staff need to stop thinking functionally narrowly when toileting people who will never gain continence. A broad-minded approach would recognise a myriad of learning opportunities within the process of toileting: interaction, communication, physical development, to name but a few.

Teachers need not regard the bathroom as draining time out of the curriculum, but as an extension of the classroom. All staff must think innovatively about how lessons are delivered and targets framed. Teachers should be involved in changing, at least occasionally, both to fully appreciate the amount of time and physical effort required, but also to remind themselves of each student's potential to be able to assess and plan for their needs.

An approach that embraces the potential of care for learning requires good quality training for the staff delivering care. This training must spell out the benefits of the process with clear examples of what a student's active participation would look like. I agree with Cambridge and Carnaby (2006) that it is important support staff have some 'theoretical background' for the tasks they perform. Often, we are told what to do, but not why it is being done. This knowledge would both ensure better quality of care and raise the status of the

task by imbuing value. Improvements to the changing environment would also add value for both students and staff. The changing room should be a nice place to be.

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# Understanding the needs of individuals with PMLD – A bespoke qualification

Sarah Townsend

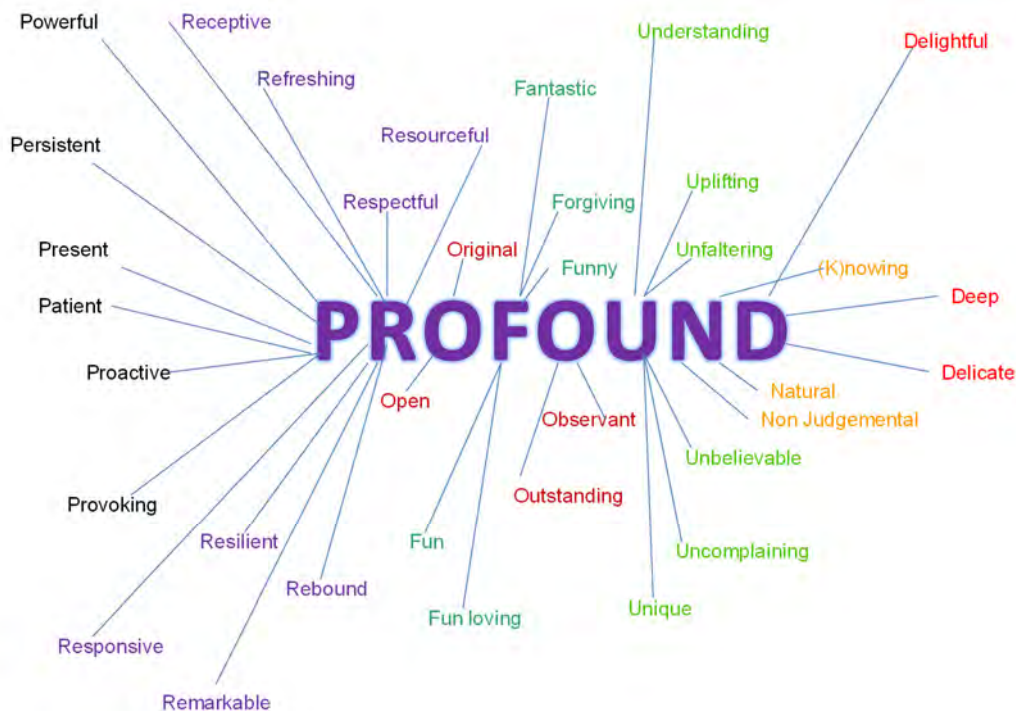
This article discusses a new national qualification focusing on the support of individuals with PMLD: the OCN London Award in Understanding the Needs of Individuals with PMLD.

Reports commissioned by the government (Bercow, 2008; Lamb, 2009; Salt, 2010; Mansell, 2010) indicate that there is a necessity for improvements in the quality of training for staff to meet the requirements of those with the most complex needs. Training opportunities are improving and there are some inspiring people delivering quality training. However, there is very little in the way of practical short courses which lead to a nationally recognised qualification focussing purely on those with PMLD. In fact this is the only qualification listed in the Learning Disabilities Core Skills Education and Training Framework for supporting people (children, young people and adults) with PMLD (Subject 11). It is true training can be effective with or without accreditation but by creating a course that is registered with Ofqual and regulated by an awarding body it means there are set standards that need to be met. This validates the skills and knowledge learnt and makes them transferrable to other organisations and roles. It also encourages reflection on practice and helps staff to apply theory to practice.

This course focuses on core skills needed to support individuals with PMLD who have complex needs which are unique to them; these core skills are reflected in many of the Core and Essential Service Standards (Doukas, Fullerton, Fergusson and Grace, 2017). The ability for staff to communicate with a person at the early stages of development, using the person’s preferred method of communication and working in a person centred way is paramount if support is to be effective.

### Working towards a definition

The first outcome for this course is to explore the complexity of PMLD; we ask participants to come up with their own definitions. Whilst many of the definitions we have explored tend to focus on a person’s disability, the course focuses on a person’s ability and encourages staff to come up with positive words that match the personalities of people they support. Here is what we have come up with so far - can you help add to the list? Please send us your suggestions, we want to make the list much bigger!



### Experience and impact of the qualification

**R**eflection on action (Schön 1991) is a key element of this course and has been highlighted by the majority of people attending as one of the main advantages. (PMLD Standards - Organisation 1.3 & 3)

A senior teaching assistant said the following

“Completing this qualification makes me realise how much I already know and how much there is still to learn. It has helped me reflect on what I do that is good and where I need to develop. Most training I attend is usually a one day course with little time to reflect, it has been great to have time to look at what we do and why and consider how far we have come and how far we still need to go”.

Others have reported that it has helped to develop their confidence and gives them credibility in their role.

“I have not studied since I left school so was very nervous about doing a qualification, but once I started I was fascinated by the content and the relevance to my role which made it meaningful and gives value to my role. I am inspired to continue my studies”.

“I am more confident to try out different activities as I have a better understanding of what to do and why. This course has helped me to relate theory to practice and to feel more confident. For example I now feel I don't need to fill silences I can just sit with a person and feel connected and share a rare moment of silence”

Health and Wellbeing is another area explored on the course. Many participants feel they are better at supporting the physical health needs of individuals with PMLD, as mental health and wellbeing is harder to identify. During one course involving Day Service staff there was a discussion about a young girl who appears to display anxiety at certain points of the day. Staff were unsure why this was and her behaviours were sometimes misinterpreted. Staff observations had been recorded but had not been taken further. An outcome of the training was that an anxiety profile was to be developed so all staff were clear about what to look for and a tracking sheet was to be set up so it was easy at a glance to see a pattern and explore strategies to use in those situations. The use of Intensive Interaction and yoga as well as a quiet environment and spending more time on preparing for transition from one place to another were also discussed. The overall impact was that staff were better informed and could support the young girl in a more meaningful way (PMLD Standards – Organisation 6, Individuals 2, 3, 5, 6).

Communication is a strand woven through both the standards and the content of this qualification as communication is fundamental to inclusion and meaningful time. Things that often come to light on the course are those times when the people we support are excluded from the conversation not intentionally but maybe at handover or in the corridor. How can we make sure they are included in all conversations?

One participant, a support worker in supported living setting said she found it difficult when other staff approached her to ask her about her forthcoming wedding. Despite trying to include the person she was supporting in conversation she felt it had very little relevance to them and was conscious that they were not part of conversation. The outcome of this was that the group developed a sensory story about the wedding that could be shared with the resident so they could be included in the conversation. This helped to promote inclusive communication and develop a meaningful activity for all those involved (PMLD Standards – Organisation 5, Individuals 1, 3, 5).

Communication barriers for people with PMLD are widely evidenced (Mc Conkey, Morris and Purcell, 2001; Healy & Noona-Walsh, 2007; Hostyn & Meas 2009; Martin, O' Connor-Fenelon, and Lyons 2012) so, as part of this course, participants explore case studies to see how these barriers can be overcome; they are then encouraged to write their own case study. This has helped participants to identify all barriers and come up with solutions.

One participant on the course said

“Using real life case studies really brought it home to me how important we are as communicating partners, we can either be the barrier to communication or the key to opening up meaningful communication. We have to be observant and not allow anything or anyone to distract us. We have made signs saying 'please do not distract my communication partner' this has led to a decrease in the amount of time communication is interrupted”.

Meaningful time is vital for all of us, it contributes to our mental health and well being as well as developing our sense of value amongst other things and this is no different for people with PMLD. So as part of this qualification participants explore new activities, different sensory resources and create a sensory story in order to develop and adapt meaningful activities to use with the individuals they support. (PMLD Standards – Individuals 2.6, 3.3, 5).

There is lots of feedback from this part of the course and below is just one comment:

“The sensory engagement part of the course was the most fun, we played with lots of resources that could be created quite cheaply. I have gone away with lots of ideas. I am definitely going to make the jelly fish”.

A group of staff from The Children’s Trust School attending one of the latest courses wanted to adapt a David Walliams short story into a sensory story. Bertha the Blubberer was written and resources were made, careful consideration was given to the meaning of the story and the experiences that could communicate that meaning. This story has been delivered to the children. Below are pictures of Bertha!



Yoga is another activity that has been discussed on recent courses as a beneficial way of promoting health and well being. Some participants are now exploring different training courses to develop yoga in their service. At The Children’s Trust School, yoga is now a regular activity offered to children and young people with PMLD. The benefits for this have been noted as:

- Stilling to rhythmic sounds
- Become more engaged in the session
- Become more familiar with routine – anticipates
- Increased eye contact
- Positional changes
- Breath more audible at times and frequency
- Tolerates foot and hand massage for longer periods
- Body language more relaxed

These examples illustrate the impact this training has had on individuals with PMLD and the people that support, albeit from a small sample.

Experience indicates the importance and direct impact of professional development on staff retention; staff that are more accomplished, competent and appropriately qualified are more likely to enjoy their work. It therefore stands to reason that if both the person with PMLD and carers or support staff alike enjoy an improved quality of experience and well-being then support will be more effective.

The PMLD Standards have now become a working document on this course, which individuals will be able draw on whilst reflecting on their own values and the values of their services with the intention to continually improve services for all people with PMLD.

#### How to access the course

More information on the OCN London Award in Understanding the needs of Individuals with PMLD level 2/3 is available from the Disability Learning website (<http://disabilitylearning.co.uk/courses/accredited-courses>). Unfortunately, it is not possible to draw down funding for this course so it has to be self-financing. However, we have lots of ways in which we can try to make it more affordable, especially for families who employ their own staff. Please do contact me if you would like to explore different options. Organisations with large staff teams who want to run the qualification with their own trainers can become a registered centre with OCN London (although there are costs involved in this). Alternatively you could run the qualification through our centre which, for small numbers of staff, is more viable.

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## **PMLD LINK is 30 years old in 2018!**

### **How would you like us to mark this significant milestone?**

In our next decade we want to find new and more creative ways to offer support and share information and ideas. We need suggestions and ideas from YOU ~ please get in touch!

email: [info@pmldlink.org.uk](mailto:info@pmldlink.org.uk) twitter: @pmldlink Facebook: PMLD Link Plans are underway ... so watch this space!!

# Yoga for children and young people with PMLD

Marie McGovern

I completed my two-year training to become a Yoga teacher in 2006. I was working at The Redway School during that time as a Teaching Assistant, and was given the opportunity to teach yoga by the head teacher Ruth Sylvester and the deputy head Diane Walker. I studied for my qualification with the Inner Healing School of Yoga. After qualifying I attended a basic certification program with Yoga for the Special Child (Calm for Kids Module 1 and Module 2). I also attended a course led by Graham Nolan on Yoga, Body work and Multisensory Impairment and a six-month (90 hours) course on “Healing Space” Yoga for People Living with Cancer. In 2016 I completed an online Yoga Nidra course through the yoga nidra network, led by Uma Dinsmore-Tuli & Nirlipta Tuli.

**T**hese courses were beneficial in giving me a starting point and the confidence to develop the yoga programme we use at The Redway School for children and young people with Profound and Multiple Learning Disabilities (PMLD). I believe that yoga is for all, and that we are all unique and no label should define or limit our own potential. I do not teach a particular style of yoga.

In the sessions I do not physically place the pupils' bodies into different positions (Asanas/body postures). Rather, I use an approach that allows the pupils the opportunity to experience the essence of yoga through their senses. It is important to let the pupils set the pace as it can take a lot of concentration for anyone with PMLD to communicate.

Yoga also gives the pupils tools and techniques (such as time) to explore the silence and freedom in their own space, to experience a sense of well-being; it's only when we are calm and relaxed that we can truly experience real happiness.

In yogic philosophy there are five elements of creation - earth, water, fire, air and ether - giving us our five senses – smell, taste, sight, touch and hearing.

- The Earth element is associated with our physical body, and sense of smell.
- The Water element is our energetic body (the breath) associated with the sense of taste.
- The Fire element is our emotional body associated with the sense of sight.
- The Air element is associated with our sense of touch, and
- The Ether element associated with the sense of hearing

Below is an **outline of a session within the yoga programme at Redway.**

#### **The aim of the session:**

To allow the students time to investigate and experience the world around them through their senses.

#### **General learning outcomes:**

- Pupils to lead the pace of the session
- To enjoy space and silence to hear themselves
- To learn that it's worth making the effort to communicate
- To engage with staff and peers
- To find ease and comfort in their bodies

#### **Objectives:**

- To understand there is a beginning and end to the yoga session
- To explore and show curiosity in activities
- To show responsiveness to sensory stimuli
- To deepen relationships through shared activities
- To listen and respond

#### **Activities:**

- The space is set up before pupils arrive. A calm environment is created, with use of subtle lighting and scented oil burning in a diffuser. Distractions are kept to a minimum to allow pupils the silence to engage.
- The session begins by engaging our sense of smell, offering each pupil in turn a tissue infused with scented oil. This is the clue (the object of reference) that it is time for yoga. The sense of smell is the most primitive of senses. It is sometimes referred to as the distance sense, and can connect us with memories, emotions and instincts.
- Positioning and comfort is important. The pupils are

individually hoisted out of their wheelchairs; beanbags etc. are used to create physical security, with adequate support to allow them to feel comfortable.

- To explore the sense of hearing, chimes, music, and chanting are used. Rhythm and music are powerful links to the memory. I offer each pupil in turn the chimes to feel to explore the texture. Then I ring them, and we sing a yoga song especially recorded for us by a school staff member.
- Touch is the first of our senses to develop in the womb, and gives us strong emotional experiences. Touch can sometimes help someone to feel better, or reduce stress and can provide comfort. We feel with every part of our body that contains nerves. It's the brain that 'feels', so tactile stimulation is brain stimulation.
- The body awareness routine is a method to offer the pupils an opportunity to practice mindfulness, as the body does not live in the past but in the here and now.

If physical touch is uncomfortable the use of the facilitator's breath on the pupil's skin can be used, to allow pupils to experience the air as it touches skin. Anyone with visual or hearing impairment may be restricted in experiencing what is happening around them. They may not realise the wider world exists or they may find it so confusing and threatening that they ignore it as far as possible. Touch may give them the security they need to explore. The use of touch is mentioned in an article on Yoga Nidra for the hearing impaired by the yoga writer Swami Nirmalaratna Saraswati (<http://www.yogamag.net/archives/1990/cmay90>)

The body awareness routine follows a particular route, with a facilitator offering a firm but gentle touch to each area of the body as it is mentioned. It is kept the same each time it is practised, beginning with the right hand thumb, first finger, second finger, third finger, fourth finger, palm of the hand, back of the hand, wrist, elbow, right shoulder, right side of chest, right side of waist, right hip, right thigh, right knee, right ankle, sole of the foot, top of the foot, big toe, second toe, third toe, fourth toe, fifth toe. There is then a pause and the same routine is begun slowly on the left side. Another pause follows before the facilitator moves to the top of the head and offers each pupil a massage to the head. There is a final pause when the facilitator waits for any responses from the pupil.

This practice offers bilateral motor integration with the effective use of both the right and left sides of the body. It can calm the nervous system, which may help support the brain in processing sensory information more effectively.



To explore breath, we use various methods since the muscles of respiration are not as obvious and it can be confusing for children especially those with cognitive and processing issues:

- A balloon and pump is used to explore how balloons expand as air is pumped, just as our lungs expand when we inhale and contract when exhaling.
- A hand fan is used to experience coolness of the air on skin, to represent the coolness of inhalation as it touches our nostrils.
- We use bubbles to experience the moisture that our breath contains.

The breathing practices can help to take a deeper intake of oxygen, which may take the individual to a state of deep relaxation, and consequently help the function of the digestion and elimination system and can boost the immune system. Deep relaxation releases neurotransmitters that profoundly influence both mood and behaviour.

To explore the sense of sight, we use hand torches to shine onto coloured foil card, supporting pupils to focus and relax eye muscles. We also provide a blanket placed over each pupil to encourage the feeling of warmth as the sense of sight is associated with the element of fire. The yoga session ends by ringing the chimes and a gentle



rub on the palms of the hands or the soles of feet, to reconnect with the space we are in. Then we sing the yoga song and thank each pupil and member of staff. I feel privileged to teach yoga to the students at The Redway School. I have learnt so much from them. They have taught me how to listen and observe and to wait patiently for their responses. No two sessions are the same: some run effortlessly, and then other times certain challenges occur, but yoga is about flowing with life and letting life flow through you. I have very supportive staff and they are open to what we are offering the pupils through yoga. It is very rewarding when the pupils begin to engage with the activities: some of them are beginning to show preferences by smiling, happy sounding vocalisation, reaching out to touch staff as they approach them, or reaching for more of an activity when it has ended, and sustaining eye contact for longer periods. One pupil is using her own sound which we incorporated into her yoga practice as her object of reference, to help her to relax her body to make it safer as she is hoisted

out of her wheelchair and positioned on her wedge. Other members of staff have commented that she is using this method in different situations during her school day. Some of the sessions vary depending on the well-being of the pupils on that day, but as the yoga sessions are led by the pupils, for the pupils, then it is down to us as staff to be aware of any additional needs (tiredness, discomfort, feeling unwell) on any particular day.

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## Raising the Bar II

Friday 2nd November, Birmingham



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## How-to guide 11 commissioning

For people with profound and multiple learning disabilities

**Raising  
our Sights**



# What makes a good life?

## Guest Editors

Thinking about what a 'good' or 'meaningful' life looks like for someone should be an important starting point when thinking how best to support them.

**T**he Raising our Sights Commissioning guide (2012) invites commissioners and providers to think about what makes a good life for someone with PMLD – and how services can support people to achieve this. They suggest that this is one way to make sure commissioners and providers are delivering a 'good' service for people with PMLD.

Here we share an **extract from the Raising our Sights Commissioning guide**, which focuses on what a good life is, and measuring quality of life and satisfaction:

'Another way to find out what a good service for people with PMLD looks like is to think about what makes a good life for someone with PMLD, and how services can support people to achieve this. The notion of a good life is explored more in the book *People with Intellectual Disabilities: Towards a Good Life?*, which identifies a number of themes for a good life, including personal relationships, rights, education in the wider sense of

learning though experiences, communities and belonging, duty and commitment to others. For a service to support someone with PMLD to have a good life, the service needs to be able to find out what is important to that person, and ensure the person can have those things in their life. This can be achieved by using a person-centred/personalised approach and focusing on the wellbeing and satisfaction of the individual.

The quality of services can also be measured using quality of life indicators. The Life Satisfaction Matrix, developed by Lyons, is discussed more below. The capabilities approach is another approach to this, developed as a measurement of the minimum entitlements that every person should have. It was originally used within international development, and Martha Nussbaum, an American philosopher, has used a capabilities approach to focus on disabled people in society.

**Nussbaum identified the following ten capabilities that everyone should be entitled to, regardless of disability:**

**1. Life**

Being able to live to the end of a human life of normal length; not dying prematurely, or before one's life is so reduced as to be not worth living.

**2. Bodily health**

Being able to have good health, including reproductive health; to be adequately nourished; to have adequate shelter.

**3. Bodily integrity**

Being able to move freely from place to place; to be secure against violent assault, including sexual assault and domestic violence; having opportunities for sexual satisfaction and for choice in relation to having children.

**4. Senses, imagination, and thought**

Being able to use the senses, to imagine, think, and reason—and to do these things in a “truly human” way, a way informed and cultivated by an adequate education. Being able to use one's mind in ways protected by guarantees of freedom of expression with respect to both political and artistic speech, and freedom of religious exercise. Being able to have pleasurable experiences and to avoid nonbeneficial pain.

**5. Emotions**

Being able to love and care for others, and to experience love and care in return; to love, to grieve, to experience longing, gratitude, and justified anger. That human emotions are recognised and support given to foster them.

**6. Practical reason**

Being able to form a conception of what is good, and planning and reflecting on one's life. Nussbaum identified that emotions such as like and dislike are a form of reason about what is good. This entails protection for the liberty of conscience and religious observance.

**7. Affiliation**

- a. Being able to live with and toward others, to recognise and show concern for other humans, to engage in various forms of social interaction.
- b. Having the social bases of self-respect and non-humiliation; being able to be treated as a dignified being whose worth is equal to that of others.

**8. Other species**

Being able to live with concern for and in relation to animals, plants, and the world of nature.

**9. Play**

Being able to laugh, to play, to enjoy recreational activities.

**10. Control over one's environment**

- a. Political. Being able to participate in political decisions that are relevant to one's life; having protections of free speech and association.
- b. Material. Being able to own and use property on an equal basis with others; having the right to seek employment on an equal basis with others.

(Nussbaum, 2000)

The capability approach provides an interesting and insightful way to consider the lives of people with PMLD, and a framework to consider the aims and outcomes of services for people with PMLD. How does the service you provide enable people with PMLD to obtain these capabilities?

**Measuring satisfaction and quality of life**

It is difficult to measure how satisfied someone with PMLD is with a service, or with their life, as they cannot readily communicate their level of satisfaction. Nussbaum's Capability Framework can be used to measure quality of life, through evaluating which capabilities apply to an individual with PMLD. The issues around measuring quality of life for someone with PMLD is explored in an article about measuring wellbeing of students with PMLD that is available online. One of the authors of this article, Gordon Lyons says that wellbeing for a person with PMLD is primarily about doing enjoyable things. **Lyons developed the Life Satisfaction Matrix**, an instrument to measure quality of life for a child with PMLD, which contains one central theme, four main categories and 14 subcategories

**Central category**

Doing enjoyable things. Quality of life for a person with PMLD is primarily about doing enjoyable things. It's about being engaged with people who, and in activities that, are needed, wanted, liked and/or preferred.

**Main category 1: Just like other children but personal**

Subcategories:

- Wellbeing discourses. Subjective wellbeing does not make sense for these children, but quality of life and happiness do.
- Disability discourses. Disability is understood in different ways. People who are unfamiliar with PMLD often only see a disability in these children, and not how they are feeling, learning and growing.
- Childhood and adulthood. These children are developing. They have a future, but they live in the here and now.

- Individuality. These children are individuals, and have their own characters and expressions.

**Main category 2: Happiness and contentment**

Life satisfaction is about feeling both happiness and contentment.

Subcategories:

- Day-by-day. Happiness and contentment should be experienced daily, and life lived one day at a time.
- Just taking it all in. Contentment can be just taking it all in.
- Balance. Happiness and contentment is about personal balance.

**Main category 3: Comfort and wellbeing**

Life satisfaction is about feeling both comfort and wellbeing.

Subcategories:

- Physical health. Relief from acute/chronic pain is a prerequisite.
- Daily wellbeing. Just having a good day is valued.
- Belonging. Relationships are central.

**Main category 4: Favourite things**

Life satisfaction is doing and having favourite things.

Subcategories:

- Being with others, caring and sharing.
- Special things. Doing special things with special people.
- Water play. Playing with water expresses freedom, fun and belonging.
- Fun. Having a wicked sense of humour!

The Department for Education has developed a resource for teachers working with pupils with PMLD about quality of life, based on Lyons' work. This includes tools to help schools measure the quality of life of pupils with PMLD and their families. These resources can be accessed at [www.education.gov.uk/complexneeds/modules/Module-1.4-Quality-of-life/All/m04p010a.html](http://www.education.gov.uk/complexneeds/modules/Module-1.4-Quality-of-life/All/m04p010a.html)

Quality of life can also be measured and used to evaluate the effectiveness of services. One tool to measure the quality of life of families is the Beach Center Family Quality of Life Scale. This is available at [www.beachcenter.org/resource\\_library/beach\\_resource\\_detail\\_page.aspx?intResourceID=2391&Type=Tool&JScript=1](http://www.beachcenter.org/resource_library/beach_resource_detail_page.aspx?intResourceID=2391&Type=Tool&JScript=1)

Social return on investment (SROI) analyses and measures the value of changes brought about across a triple bottom line of social, environmental and economic outcomes.

At this time we are not aware of any social return on investment analysis specifically around services for people with PMLD, although there are a number of areas where this type of analysis is likely to show large benefits. E.g. postural care services or health facilitation. Future contracts and tenders for services for people with PMLD may start to specify a level of social return on investment. It may also be a way for the service provider to demonstrate the value of their service, particularly to commissioners who do not have specialist knowledge regarding people with PMLD. More information about social return on investment can be found at [www.sroiuk.org/publications-uk/doc\\_details/241-aguide-to-social-return-on-investment-2012](http://www.sroiuk.org/publications-uk/doc_details/241-aguide-to-social-return-on-investment-2012)

'It is important that the people responsible for measuring outcomes, evaluating services and planning new ones have the right skills to do this, including knowledge of the needs and possible outcomes for people with PMLD. It is also crucial they involve people with PMLD and their families in this'.

**(Raising our Sights Commissioning guide (2012), Pg 10-11, 36-37)**

We hope this extract encourages you to read or re-read the Raising our Sights Commissioning guide which has a number of useful tools to help commissioners and providers develop good services for people with PMLD.

Read the full guide here: [www.mencap.org.uk/sites/default/files/2016-06/Raising-our-sights-Commissioning%20guide.pdf](http://www.mencap.org.uk/sites/default/files/2016-06/Raising-our-sights-Commissioning%20guide.pdf)

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**Editor note:**

All the Raising our Sights guides can be downloaded from PMLD Link website.



# Encouraging a sense of purpose and self-worth

Helene Abbiss

This article describes the approach used by Parity for Disability's specialist day services to create meaningful activities for students with PMLD.

## Ted

When Ted, a 40-year-old man with PMLD, suffered a stroke and became critically ill, doctors in the intensive care unit said that due to catastrophic injury to his brain, everyone should expect the worst. Ted spent several months in hospital, where family watched over him, and friends visited him regularly. Thankfully, Ted recovered enough to leave hospital. He's now back home and leading his life again.

Ted's enthusiasm for life prior to going into hospital, and his continuing get-up-and-go after a debilitating illness, indicates that Ted's life is meaningful not only to his family, and to his friends, but also to Ted. Though he's lost some mobility and some of his basic living skills, he hasn't given up. Ted maintains a social life, revels in activities and is rebuilding his skills.

We know Ted well, as like many of the people (called students) who use Parity for Disability's services, he's attended for years. We see Ted experiencing joy, affection, entertainment and adventure. Throughout his adult years, Ted has continued to grow and achieve, learning to recognise symbols and objects of reference, truly bonding with close friends, and building more independence in the everyday things he needs to do.

## Developing our approach

In setting up Parity's specialist day services in the early 90s, we had to consider what gave life meaning for someone with profound and multiple learning disabilities. No such services existed in our region (or in the country, as far as we knew), and we had to develop our approach from scratch. We took a holistic view of what our students (most of whom have PMLD) would need in order to enjoy a good quality of life. This resulted in a philosophy of care and support that went beyond addressing people's immediate physical and social requirements.



We drew from Maslow's hierarchy of needs, a widely-accepted motivational theory in psychology. In brief, at the bottom of the hierarchy are the basic requirements of physical survival, followed by psychological needs around self-esteem and belonging. At the top is self-fulfilment - achieving potential. Maslow's theory suggests that, for someone with PMLD and their accompanying challenges, a meaningful life would be one where the person feels motivated to keep moving up this hierarchy.

Even with access to good services, people with PMLD encounter daily challenges to their physical comfort and safety, and to satisfactory engagement and interaction. Their climb towards achieving potential involves more setbacks than for the average person without PMLD. Yet visitors to Parity's services see smiling faces, and describe positive experiences of engaging with students who show a sense of purpose and of their own self-worth.

It seems that fostering and encouraging both of these qualities in students with PMLD is key, and provides access to a meaningful life.

The activities at Parity are intended, in particular, to generate a sense of purpose in each individual. We get to know each new student and set goals, in collaboration with the person, and people who know them best. This is done with a view to long-term achievement that will enable the student to experience a better quality of life. The goals are built into the person's activities.

A student can be working towards more than one goal within an activity. While painting, they might have a communication aim of using their 'yes' and 'no', and also have a physio aim of stretching one arm to maintain or improve on the flexibility they have. Each student is encouraged to challenge boundaries and work towards something, however long it may take.

**How do we know we're succeeding in creating meaningful activities for the student?**

The person shows they're stimulated, encouraged, inspired, curious, interested, excited, and enjoying themselves. Their family tells us the person is looking out each morning for the transport that will bring them to Parity. They're demonstrating verbally or in other ways that they have positive memories of the people they engage with, and the things that they do.

**Adrian**

Another of our students with PMLD, Adrian, loves anything on wheels. He spent several weeks on a project on transport with built-in aims including using his mobility, following steps to plan an outing, making decisions and connecting with others in the community. The project revolved around gathering relevant photographs and experiences, with staff keeping an eye out for opportunities. When they spotted a police car parked at the back of the day service, Adrian and his keyworker Tarne went over and met the officer. When a mobile library appeared opposite the day service, they caught it before it moved away.

"We were stopping anyone and everyone saying, 'Excuse me, do you have a minute?' We just flew across to the mobile library to stop it driving off," said Tarne.

As a choice-making exercise, Adrian led a 'magical mystery tour' in a Parity minibus using two Big Mac switches, one instructing Tarne who was driving to turn 'left' when he pressed it and one saying 'right'. They circled the estate, passing Parity several times to the great amusement of Adrian, and his fellow students and staff watching out of the windows, before finally exiting for the open road. They travelled four miles to a nearby village, going in and out of several car parks on the way!

The project created great memories for Adrian, also shared with his family, while providing plenty of means for Adrian to use his skills and mobility, engage with others and experience more of the world.

By valuing each student for who they are, we aim to foster what seems to be another key ingredient of a

meaningful life, a sense of the person's own significance. Someone with PMLD may have great difficulty viewing their achievements and their value in a tangible way, but there are still ways that they know they have worth, value, and importance.

Students interact with others on their own terms, responding positively to appreciation from others through touch, affectionate words and sounds. Mutual understanding and shared experiences lead to further validation, such as laughter at a joke, or the results of turn-taking using music, physical activity or vocal sounds. When supported to connect with others on the level that works for them, many students increase the ways that they interact. Some changes happen quickly, others gradually over a period of years. Adrian recently started reaching out to new students, something he would never do before.

Staff listen to the students however they communicate, acknowledging their wishes, ideas and needs. Once staff learn about each person's likes, dislikes and interests, they encourage them to express or share these with others. Ted's day service organised a day where all the activities were themed around Ted, celebrating his personality and interests. Ted's Irish heritage and his love of hugging and time spent with friends were incorporated into games and a trip to a pottery-painting cafe.

We also see giving to others as an opportunity for students to experience their worth and value to others. We support students with PMLD to give friendship, comfort, or sympathy, which they do constantly, without being prompted. We support students to offer and make drinks. Students act as ambassadors for the charity, meeting guests and helping guide them round the service, or attending public events.

**Ralph**

Ralph is a bit of a daredevil and loves to participate in anything which makes his friends and family nervous! Ralph's friend had been indoor skydiving and when he was looking at the pictures, Ralph indicated with the biggest smile that he would like to have a go. Ralph was free to fly high up into the tunnel with minimal assistance from the staff at Basingstoke I Fly, who were attuned to the person-centred approach. Ralph has indicated that he wants to go again, and we're hoping that his experience will give others the incentive to try something a bit different and daring.

**Together we can raise the bar**

Local authority day service provision for most people with PMLD in our region seems to aim only to tick the

### Lucy

Lucy has brought a lot to the group since joining recently. She has lived successfully with a local family since 1999 as part of the council's Shared Lives programme. But despite a good home life, Lucy experienced two years when she risked spiralling into crisis while using a 'new model' community-based day service.

"Monday to Friday, she would arrive at the library in a taxi, then leave again in a minibus to go out," her main Shared Lives carer, Gillian explained. "It seemed like most people had to leave the building."

Gillian said activities involved going round the shops, or going to the library or garden centre. Lucy experienced continence issues due to the 'on the move' nature of the service. At one point, during the winter, she joined a walking group. Lucy doesn't use a wheelchair but cannot sit, stand or walk for long periods of time without experiencing pain in her legs. Lucy, who doesn't use speech to communicate, also lacked consistent relationships and social connections, something she'd valued at the previous day service she went to. Lucy would often come home in tears.

Gillian was able to convince Lucy's care manager of the urgency of the situation, and Lucy started attending Parity. Lucy certainly seems motivated now. She seems to know that she matters to the staff, and to others at the service. She's formed close friendships with two other students with PMLD. Her trips out are meaningful, not just a way to pass the time.

"She wouldn't go out on the minibus," says Sarah, Lucy's keyworker. "Gillian explained to us that Lucy might be worried that she was being taken to a library or garden centre again. So we started planning short trips with a student Lucy was fond of. She now knows we're not just taking her somewhere that she doesn't want to be. We show Lucy pictures, look on the internet together so she's clear where she's going. She goes to the other day services to socialise. She's been on a canal boat trip, to Runways End Activity Centre, on shopping trips to buy food." Gillian reports that Lucy is ready and waiting each morning for her taxi to Parity.

Lucy's experience with the community-based service demonstrates the catastrophic results when we ignore the worth and significance of someone with PMLD. Lucy's consultant from the Community Team for People with Learning Disabilities said she noticed a dramatic change in Lucy's demeanour.

'good safeguarding' and 'out in the community' boxes. Twenty-seven years after Parity's services began, we see that people with PMLD still have difficulty accessing a meaningful life, because few services have developed to support them in managing their very individual daily requirements. In an environment where local authority decision-makers continue to overlook the most basic needs of people with profound disabilities, the concepts of fostering a sense of purpose and promoting a feeling of self-worth remain largely disregarded.

We've been called a 'Rolls Royce' service, accused of providing too much (i.e. too many staff). We've been told that people with PMLD can successfully participate and have their needs met on a six-client-to-one-staff basis. Yet as far as we're concerned, we are simply meeting needs in line with the requirements of the Care Act, with the same concept of wellbeing incorporated into our approach as that defined in the Act.

We hope the new Service Standards will lead to a better understanding of what constitutes appropriate provision and how best to meet the needs of people with multiple disabilities. We're sharing the Standards in our region and with MPs, councillors and all other influencers, wherever possible.

One of the first activities that staff organised for Ted upon his return to Parity following his illness was the chance to spend time with two of his best friends. We saw great joy as they all reconnected. Ted couldn't sit up by himself at first, but now can. His current goals include learning to eat again independently, a skill he lost, and regular physio to improve his hand function. Ted still has aims related to fulfilling his potential, like developing his understanding of cause and effect. We'll be doing all we can to support Ted to keep climbing.

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### Editors' reflections:

Some suggestions of how Parity for Disability's care and support for Ted, Adrian, Ralph and Lucy might demonstrate aspects of the PMLD Standards:

- Adrian led a magical mystery tour in a Parity minibus using two Big Mac switches, which shows 'The person is empowered and enabled to do things; not 'done to' the person.' Standard 3: Meaningful/ Quality Relationships
- All the stories show how 'the person is supported to have high aspirations and to achieve goals meaningful to them to promote and enable a fulfilling life.' Standard 5: Meaningful Time.



## Intensive Interaction and complex health needs Tuning-in: The cornerstone of effective practice

Julie Calveley

Humans are social beings and social interaction is essential to living a meaningful life (Adler and Rodman, 2009) and underpins many of the Core and Essential Service Standards (Doukas et al, 2017). This article describes the Intensive Interaction approach and how it can be used with people who spend a lot of time receiving physical, nursing and medical care and treatment. The focus is on the crucial importance of tuning-in as a cornerstone for good Intensive Interaction practice that enhances quality of life. Some ideas are presented for how Intensive Interaction can most effectively be provided for people with complex health needs and within a hospital or care setting.

### **The Intensive Interaction Approach**

Intensive Interaction enables communication and social interactivity (Firth and McKim, 2018). The approach is based on natural communication development as seen in parent-infant interactions and is used to help people learn and rehearse the 'fundamentals of communication'. It is used with people who have communication difficulties arising from autistic spectrum disorders, severe learning disabilities, profound and multiple learning disabilities (PMLD), brain injury and dementia.

This is a summary of the techniques used in Intensive Interaction:

- Enjoyment
- Tuning-in
- Observing and waiting
- Allowing the person to lead
- Being responsive
- Being relaxed and unhurried
- Pausing
- Timing responses
- Positioning and available look



**Box 1 The fundamentals of communication:**

- Enjoying being with another person
- Developing the ability to attend to that person
- Concentration and attention span
- Learning to do sequences of activity with a person
- Taking turns in exchanges of behaviour
- Sharing personal space
- Learning to regulate and control arousal levels
- Using and understanding eye contacts, facial expressions, other non-verbal communications and physical contacts
- Vocalising and using vocalisations meaningfully, including speech

(Hewett, 2018)

Intensive Interaction is a non-directive teaching approach through which communication attainments are made (Hewett, 2012). It also provides a way for people who are socially isolated to engage with and feel connected to others and contributes to emotional development and general health and well-being (Nind, 2012, Calveley, 2018), as summarised in Box 2.

**Box 2 The fundamentals of communication 2: Emotional learning and outcomes**

- Knowing that others care, learning to care
- Enjoying being with another person – connecting, bonding etc
- Attachment, attunement
- Self-security, to feel safe, secure, calm
- Self esteem, sense of self
- To identify own feelings & see same in others
- Gradually to understand feelings
- Trust stuff etc
- Empathy, knowing/caring about how somebody else feels
- Right- hemisphere brain development

(Hewett 2018, based on various: Bowlby, 1953, Lamb et al 2002, Schore, 2003)

Intensive Interaction can be misunderstood when it is simply seen as imitation of what the other person does. This has been damaging to the reputation and effective use of Intensive Interaction, which can be more accurately described as an approach carried out by a person who sensitively 'tunes-in' and chooses when and how to respond based on the signals they receive. One way of responding is with copying, joining-in or imitation, but this is not the only way and everything that is done, should be based on 'tuning-in'. The use of imitation in Intensive Interaction is discussed in more depth elsewhere (Calveley, 2018 in progress).

Intensive Interaction is more than a pedagogical method,

it is a practice and an ethos with a clear rationale and vision of personhood. It is underpinned by psychology, philosophy and ethics and encompasses particular values about humanity, which are fully recognised, made explicit and aspired to. Intensive Interaction cannot be reduced to a set of techniques. It is not just something that you do, it cannot be acted, but rather involves full engagement of mind, body and heart. Through training people can be equipped with the behavioural techniques of Intensive Interaction but there is something more that is required from the practitioner; their presence, acceptance, compassion and desire to be with, 'listen' to and truly understand the person.

**Tuning-in**

It is this presence that allows a practitioner to 'tune-in'. Tuning-in means reading a person's emotional, psychological, cognitive and physiological signals and sensitively responding in ways that are meaningful and convey understanding. It is the ability to hear, see, sense, interpret, and respond to verbal and nonverbal cues and communicate to the person that they have been genuinely seen, felt, and understood. Intensive Interaction practitioners tune-in in order to be aware and reactive to emotional needs and internal states and thereby attempts to achieve 'attunement'.

Siegel (1999) described the process of attunement as an 'interpersonal dance' between two biological and psychological systems. Through attunement the person can feel that they have been 'met with empathy' (Stern, 1987). Attuned responses give stability, security and help the person to feel safely supported. Such responses can validate a person's behaviours and their internal state of being and state of mind. Understanding tuning-in as the foundation of Intensive Interaction can generate an appreciation of the wider application and benefits of the approach, for teachers, therapeutic professionals, carers and family.

**Intensive Interaction in care and hospital settings**

By definition, people with PMLD have physical difficulties often requiring much health and medical care and intervention. It is not uncommon for people with PMLD to receive nursing care on a daily basis or to spend regular and prolonged periods in hospital. Meaningful and effective education programmes or support therefore must take account of and be provided within and around physical, health and medical needs. Through tuning-in an Intensive Interaction practitioner takes account of the physical, emotional and psychological state of the person at all times, which makes a customised, synchronised and fully sensitised experience possible (Swinton, 2012). Intensive Interaction can therefore be beneficial at times of poor health and contributes to the provision of holistic care, support and education.

Intensive Interaction practitioners develop strong

observational skills and learn to read a person's intentional and non-intentional signals which can help to identify indicators of pain, anxiety, tiredness, hunger and boredom as well as enjoyment, contentment and relaxation. Such signals might be hard to spot and decipher because a person with physical disabilities and complex needs may have difficulty exhibiting outward behaviour and their movements, sounds and expressions may be extremely subtle. The ability to observe for the tiniest behaviours, signs and signals and clues over time and the cultivation to finely 'micro-tune' to pick up on cues is therefore highly beneficial for a person who has limited capacity to express their internal state and intentions.

Learning and performance is optimum when a person is alert, comfortable, free of pain and hunger and has adequate mental energy. Brain activity and alertness fluctuate throughout the day and can depend on, often unpredictable factors such as tiredness, pain, discomfort, hunger and body temperature, seizure activity and respiratory problems. Tuning-in ensures that there is a good 'fit' between the practitioners input and the person's needs (Hewett and Nind, 1998). By looking for 'teachable moments' a practitioner can enable a young person to receive education even during periods of poor health.

Intensive Interaction is arguably one of the few ways a person with PMLD can take the lead and fully and actively participate in an interaction or activity. Although fun and enjoyable, and sometimes exciting, this requires a degree of energy and therefore can be demanding and tiring, especially for a person who is experiencing poor physical health. An Intensive Interaction practitioner uses their ability to tune-in to help make judgements about what the person needs and wants throughout the day. They will look for signs that indicate a readiness and ability for active participation or when something different is needed such as comfort, entertainment, distraction, stimulation, movement or time to rest.

The critical issue of timing also applies to the pace of an interaction and the timing of responses. Cognition is impaired in people with PMLD and information processing is slow and inefficient (Lacey, 2009; 2012). Tuning-in, holding back, allowing for pauses and waiting are vital for getting the timing and tempo of interactions and activities right, and also for knowing when the interaction or activity needs to end and something else to be offered.

Being an in-patient in hospital can be busy with frequent medical and nursing visits and interventions. This can take up much time, and due to many factors, be unpredictable. The environment can also be noisy and the atmosphere feel charged and tense. Intensive Interaction can create a 'safe bubble' helping to block out

potentially stressful surroundings. The support of nurses, therapists and doctors who understand what a 'good bedside manner' looks like for someone with PMLD (i.e. tuned-in and responsive), and who can identify an interaction and consider whether it is possible, subject to medical priorities, not to interrupt is key to enabling Intensive Interaction in hospital.

When supporting people in hospital, timetabling and planning of activities needs not to be rigid but to remain flexible and responsive to the changing needs of the person and the availability, work loads and routines of staff. Scheduling Intensive Interaction 'sessions' provided by visiting therapists or teachers can therefore be problematic. It may be more effective for those who care for the person on a daily basis to be trained in the approach, as this could make it available as possibilities arise. Furthermore, training health and medical care staff would enable them to integrate Intensive Interaction within the provision of other aspects of care, thereby maximising opportunities for interactions and for potential communicative initiations to be responded to.

A person with PMLD is highly dependent on those around them to meet most, if not all of their needs. However, it is important to remember that whilst there are many tasks to carry out to meet those needs, there is also value in just being present for companionship, care and comfort. The connection that can be felt through the attunement achieved with Intensive Interaction can be profound and intense and arguably, is an essential outcome itself. The mere presence of a relaxed, calm, supportive person can make a person feel more relaxed and less anxious and this can be enhanced by positive physical contact (Sunderland, 2007).

Touch can signal safety and trust, soothe, calm, regulate emotions and improve health (Keltner, 2010). Whilst a person with complex health needs may be on the receiving end of a lot of functional touch, Intensive Interaction provides a way of offering appropriate social and 'nurturing touch', which is a primary channel of communication and crucial for the psychological and emotional experience and development of people with PMLD (Barnes and Hewett, 2015, Doukas et al, 2017). Positioning and medical equipment can be barriers to social, nurturing and affectionate touch, and the collaborative support of a multi-disciplinary team may be needed to allow for such touch to be offered effectively and safely.

Hospital passports are used in some health authorities, and are intended to improve care and patient and family in-patient experiences. Intensive Interaction can be included in such documentation and in care plans with an explanation of how the approach is integral to maximising the person's health and well-being. Intensive Interaction can also be included in Education and Health

Care Plans (EHCPs), Person Centred Plans and support plans detailing what resources, training and recording systems are necessary in order ensure that adequate provision is made.

### Conclusion

Intensive Interaction can be beneficial to people during periods of ill health and whilst needing medical intervention. Effective practice relies on the ability to tune-in in order to take account of the person's physiological, psychological and cognitive state, moment by moment. Ideally, all people who provide care, support, companionship and education would be trained in Intensive Interaction so that for the majority of time the person has someone available to be alert for interaction opportunities throughout the day and within other activities and tasks that take place. Intensive Interaction is a teaching approach that can continue to be used during periods of poor health and because no equipment is needed it can be used within hospitals. It is also be a therapeutic approach that can have a positive impact on the person's physiological, psychological and emotional health and therefore contribute towards recovery to optimum well-being.

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# The Leeds Motor Activity Training Programme

Angela Lydon

The West SILC (Specialist Inclusive Learning Centre) is a large 5 site special school in the west of Leeds. The school is divided up into departments including a complex and multiple learning needs department for primary and secondary students with Profound and Multiple Learning Difficulties (PMLD). Sarah Riley, the complex needs department lead, first heard about Special Olympics 14 years ago when the Special Olympics World Summer Games were held in Ireland. At that time the West SILC hadn't been formed and what is now the West SILC main site was a standalone special school called Milestone.

In September 2012 I took up my post at the West SILC at our primary partnership site and the following February our new complex needs department opened at our Farnley Academy Partnership. Initially our secondary students moved, and then myself and the remaining complex needs students moved in September 2014. Once I had established my class Sarah asked me to take the lead on Special Olympics, a project she hadn't been able to work on and that is where our journey began.

There is little if anything written about Students with PMLD and PE but as a PE subject lead and class teacher for students with PMLD I believe passionately that these students have as much right to high quality PE as any other. This can mean very different things for students with PMLD but that doesn't mean PE lessons don't have a place in their curriculum. Often it is felt that PE for Students with PMLD is covered by Hydrotherapy, Rebound Therapy or Physiotherapy but these are therapies and therapy is not PE. PE promotes physical activity: it includes whole class work and a high percentage of activity throughout the session. A class Hydrotherapy session may take an hour but changing and

then waiting for their 20mins in the pool does not constitute a quality PE session.

I began considering developing Special Olympics as a PE project for our Students with PMLD. I began the process of becoming an associate club with the Motor Activities Training Programme as our sport. A representative of Special Olympics came out to deliver an introductory workshop and we felt we had discovered a programme that slotted perfectly into our timetable as a PE provision for our students.







The Motor Activities Training Programme is a Special Olympics programme specifically for athletes with PMLD. MATP runs in 8 to 12 week training periods which culminate in an MATP Challenge Event. During the training periods athletes work on motor skills that are pertinent to the individual and their overall motor development.

This fitted perfectly into our ethos of a personalised curriculum. All our students have Personalised Learning Plans (PLPs) linked to their Education and Health Care Plan Outcomes. In line with our status as a MOVE centre of excellence, every student has physical targets as part of their plan. These targets fitted perfectly into our MATP session plans. Soon each class was delivering MATP within their timetable for an hour a week as our PE provision.



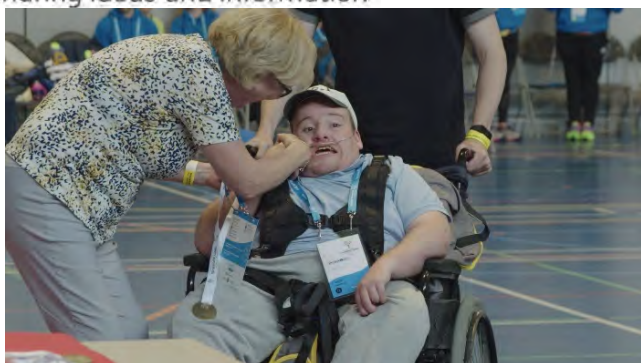
Once the weekly sessions were embedded in the timetables of all for classes my next job was to organise our Challenge Events. The Challenge Day is an event unique to MATP - it has a specific structure that provides the athletes with an opportunity to represent their school and showcase the skills that they have developed over the training period. Each event includes an athlete parade, the reading of the Special Olympics Oath and a warm-up. The main content of the event is each athlete coming out in front of their audience of supporters to demonstrate the level of skill they have achieved. This is followed by a whole group cool down and then closing ceremony that includes medal presentations for all participating athletes. This format provided an amazing opportunity to celebrate our students in a way that they

had never been celebrated before. It also provided an opportunity for parents to come to an event to celebrate their children and see others also celebrating their children for their genuine achievements.

We got off to slow start with our challenge events at school. They initially started out as Come and Try sessions. I would set up a range of activities and the students would come and participate and enjoy the activities provided for them. We invited other special schools from around Leeds to a couple of these events to show them what we were doing and what they too could do with their students. It was around this time that my youngest daughter started school and as I worked four days a week I found myself with a day a week to fill. I mentioned this in a discussion with the MATP Development Manager Niamh Reilly and she suggested I use that day to work with her as a Development Officer developing MATP nationally for Special Olympics.

I took the role as it seemed a natural progression and at the same time became an MATP tutor. This really moved things on with our club. I began training teachers and support staff at other schools in Leeds. The club name changed to MATP Leeds and we started holding MATP Leeds Challenge events. By this stage I had mastered the planning and delivery of a Challenge Event and we were able to hold what has become termly MATP Leeds Challenge Events, including up to 30 athletes from 4 special schools. The events have been attended by parents, who have loved the atmosphere, and the celebration of their children and they have also provided a fantastic forum for the development of relationships across schools. I secured a development grant from Special Olympics for the development of MATP Leeds. It provided equipment to deliver the Challenge Events this included a PA system to save my voice, medals to award at the events, a case for our portable mobile hoist so it could go with us for events where the hall we used wasn't equipped with tracking and I was able to issue small equipment grants to the other member schools.

In 2015 we became aware of an amazing opportunity for our students and MATP. The Special Olympics National Summer Games was due to be held in Sheffield in August 2017 and MATP athletes were going to be fully included for the first time. MATP had been featured at the previous games in Bath but this time the athletes were to be fully included in the opening ceremony at Bramall Lane, have the opportunity to stay overnight in a hotel next to the ground and then represent their region in a Challenge Event at the English Institute of Sport in Sheffield. The planning began. I had two major roles in the planning process: I was a Development Officer directly involved in the planning and execution of the event and all that involved and also the Head Coach of MATP Leeds. After I attended a test event in Sheffield in



August 2015, we were determined that our students would get to the games.

MATP Leeds were assigned 10 places for the games. The other schools engaged in the club felt they would not be able to attend so it fell to us at the West SILC. Sarah was determined that we would get as many students as possible to the games. We identified nine students to attend and began the planning for fundraising. We held a sponsored Slam Dunk at school. Where Students were sponsored for the number of baskets they scored. The response was amazing, and we raised over £1000 which was a massive chunk of the costs for the Games entry and the accommodation. I held regular coffee mornings with the parents of the students attending. They were all so excited about the games one parents described them as a “shining light” for them, something they were so looking forward to.

We planned, we fundraised, we put in the application, we ordered the regional tracksuits and organised their delivery and we made sure all information was sent through with regards to the needs of the students for the accommodation. I worked with the other clubs nationwide in my Special Olympics role to support all the other MATP athletes and their application and attendance to the games. When August 2017 came round the support from school staff was outstanding. Every class teacher from the complex needs department attended as well as two support staff. Sarah organised the MATP Leeds delegation with her usual incredible attention to detail and dedication. She took all the large equipment down the day before the event and then drove back to Leeds to return the next day in the school people carrier with a student, staff and more equipment. I was already in Sheffield attending briefings.

The day of the Opening Ceremony arrived. I spent the morning running a Come and Try Event for local participants with PMLD at the EIS then I returned to the hotel. The atmosphere in the foyer and bar and restaurant was amazing. The West SILC delegation had all arrived and settled in and were buzzing, it was fantastic to see everyone. There were a couple of late arrivals, last minute tickets to sort and many plastic ponchos to

distribute against the rain. I went across to the holding room with our students and then left them to go into the stands. It was strange not lining up with them, I was there as a Special Olympics Development Officer not a class teacher. The rain was pouring down but this didn't seem to dampen anyone's spirits. Then the parade began and it was time for the Yorkshire and Humber Delegation to enter. There right at the front leading their regional delegation into the stadium were the West SILC students from MATP Leeds. It was a proud and emotional moment. My colleague and MATP Development Manager Helen was in the stand next to me, and she leaned over and said “That's what it's all about”!

The following day was the Challenge Event. We had nearly 30 athletes from four regions attending the event. MATP Leeds led the athlete parade into the sports hall and they all did us proud. Our athletes showcased what they could do with determination, hard work and humour. The atmosphere in the viewing area with the friends and family was incredible. I had the privilege to stand and watch a student from my class represent his club, school, city and region as a Special Olympics athlete at National Games, I cried! Jim Carter (Carson from Downton Abbey) as a patron of Special Olympics came to see our event as part of his tour of the EIS and VIPs from sponsors and Special Olympics Europe Eurasia presented the athletes with their presentation medals. It was a fantastic day.



It has been an incredible journey from the first discovery of MATP to representing our region at the National Summer Games. We have established high quality PE for our students and other students with PMLD in Leeds and we have provided an incredible experience for our students and their family and friends that they will never forget. Changing lives through sport can apply to everyone!

### Contact details

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Angela.lydon@westsilc.org

# Intensive Interaction: The challenge and reward of embedding good practice

Janet Gurney

Pretty much everyone I know who is in the position to use Intensive Interaction, regularly, consistently and respectfully to support someone they care for will tell you what a difference it can make - not just to the person they are interacting with, but to themselves. It is a tried and tested way of building bridges of meaningful connection and engagement, with people who often struggle with the fundamental steps of communication because of their profound learning disability, or a complex need such as autism.

Over the last 18 years, I estimate that well over 15,000 people have attended my Introduction to Intensive Interaction workshops – and the feedback at the end of the day is always positive. But - and this is a significant but - we know that not all of those people will be adequately supported in their workplaces to use what they have learnt ‘regularly, consistently and respectfully’. Now, crumbs are better than no bread at all, so some Intensive Interaction might be better than none, but wouldn’t it be great if more people were encouraged to try out what they have learnt, to reflect on their practice, to keep trying and to make the difference they really want to? Connection, engagement and communication is at the heart of what makes everybody’s life meaningful; what a goal to work towards.

To work towards that goal, for the last 10 years, Us in a Bus has added ‘Coaching and Mentoring’ (C&M) to the ways we offer Intensive Interaction services. It sprung from requests to ‘Come and show us’, from teams who had enjoyed the Introduction to Intensive Interaction workshop but who were worried about ‘getting it right’. Of course, the main way we know if we’ve ‘got it wrong’ with Intensive Interaction is that the person we are interacting with will let us know! They may ignore us, not notice us, move away or respond in a way that leaves us in no doubt. It may be that we have chosen the ‘wrong’ action or sound to respond to; we may be too close; we may not have considered the way they are processing sensory data (maybe they cannot focus on our sound whilst they need to process the sound of the fridge humming) etc.. In nearly 30 years of using this approach I would say that I have often ‘got it wrong’ and will probably continue to do so, but I don’t think I have ever caused harm to my interactive partner in doing so. They may have been uninterested or irritated, but not hurt. I need to constantly step outside my comfort zone (rather than expecting them to) and stretch myself into thinking ‘How else can I let this person know I have noticed the internal signals they are creating, and use those signals to let them know I am responding?’ And it is this ‘How else’ that our coaching and mentoring (C&M) is aimed at addressing.



At the core of our C&M is demonstration. But we very soon learnt that demonstration alone is not that useful a tool when it comes to enabling someone to find their own way to turn the theory they have learnt into their own practice. Demonstration can be overwhelming (‘I’ll never be able to do it like that’) or down-right scary (‘They don’t want me to sing, surely?’). So our job soon became a more gentle balance of observation, feedback, reflection, as well as demonstration. We developed another workshop, Next Steps in Intensive Interaction, to provide a forum for facilitated reflection, un-picking, trouble-shooting, leading into planning the next steps that the practitioner wanted to explore with the person they supported. We added to and adapted the C&M to meet the needs of the teams and the people they were supporting. And we have never stopped learning ourselves from the experience of delivering C&M. We have been privileged to witness people with complex needs or PMLD patiently encouraging and guiding the person who is trying to notice their body language – sometimes the raising of an eyebrow or the lift of a shoulder has been an eloquent ‘Come on, I’m making it easy – haven’t you noticed yet!’ nudge in the right direction. We have met members of support teams who are convinced they ‘can’t do it’ but who, when we hold up the mirror of feedback to them, realise that they have been ‘getting it right’ for years. Seeing people become confident that their own practice of Intensive Interaction is effective, and seeing relationships blossom with the people they support is a joy. That confidence then gets



transferred to their colleagues, as the members of the team who have been involved in the C&M in turn encourage their colleagues to observe, explore and take more steps towards meaningful engagement. So what was the experience like for someone who was involved in C&M input earlier this year...

Charlotte Turner is a Deputy Manager at a new service in Surrey provided by Care Management Group Ltd. Before the service opened last year, she and some colleagues attended our Introduction to Intensive Interaction workshop, but it was clear to the staff team when a young man, Christopher, with complex autism moved in, that they wanted more help in working out how best to use the approach to lower his anxiety and establish a relaxed relationship that would best support him. Over a period of 10 weeks, 2 experienced Interaction Practitioners from Us in a Bus visited weekly, working closely with 4 members of the team, observing, demonstrating, reflecting, staying in touch between visits, attending meetings, setting 'homework' etc. Here is Charlotte's response, 4 months after our input ended:

- What influence did taking part in Coaching and Mentoring have on the way you connect and communicate with the people you support?**

It gave me confidence! I was very nervous about supporting individuals who did not communicate verbally, as it was new to me, but the coaching and mentoring sessions gave me skills in how to communicate in their own style. It opens up many different communication pathways, and has helped create a great bond with the people we support, and helps me understand their needs more. The coaching and mentoring side has also helped me in my role as Deputy Manager, as I now feel more able and confident in guiding my team to use intensive interaction in their support.
- What did it add to the one-day training workshop on Intensive Interaction you had previously attended?**

It made it more real; in the sense that you could see the effect it had on individuals, and the worth it holds! It also becomes easier to understand when seeing the interaction in motion, and again helps with the confidence as you get the chance to work with the practitioners, seek guidance and ask questions as they occur.
- What difference has it made to the people you support?**

Massive difference! The people we support seem more confident, more trusting of staff and are more open to trying new things! Individuals seem happier and are doing things that they have never done before, or haven't done in a long period of time. It's also a great amount of fun for staff and the people

we support alike! Our service is a new service, and this training and the skills we've gained have been a great part in transitioning these people into their new home. It has helped our new journey together be smooth, happy and successful!

- What would you say to people who are thinking about doing it?**

DO IT! DO IT! DO IT! There's never anything to lose, and you will never understand the impact and difference that intensive interaction can have on an individual until you try it. The sense of satisfaction you get personally as well, is amazing.

We wouldn't want to sound too positive! Things go wrong and we have to re-evaluate and re-plan. We have found that the biggest factor to nail in place from the start is management support. If that isn't there, we pretty soon run into rota problems – the members of staff involved are not there on the day we visit, as something else 'more important' has cropped up. Involving management at some level in the training and C&M process is an important factor in ensuring that changes in practice are supported after the Us in a Bus team withdraw; senior members of staff need to be confident in supervising and encouraging the on-going development of good intensive interaction. To help that process, we offer to facilitate 'trouble-shooting' meetings at the end of the C&M, returning every six weeks or so until we are confident that these meetings have successfully turned into peer-support meetings that don't need us anymore. We offer a visit after a year, having requested video of interactions first, so we can come and give feedback – not quite an inspection, but something to help teams focus. And sometimes, turnover of staff is so fast that when we call to arrange that visit, few of the trainees are still working there. However, given what Charlotte so clearly says, when your sense of personal satisfaction in your job deepens, and you are witnessing the changes the people you support are making in their lives, the incentive to stay and do more is high. Even if it is sometimes three steps forward and one step back, we would say that every step has been worth the effort.

The last words go to Christopher's mother who says: "C&M means staff are part of the Intensive Interaction experience, bringing the principles to life. It is both inspiring and motivating, creating new ways of thinking, working and being together. I've seen the staff and my son evolve and grow in confidence forming trusting relationships. The foundation for other wonderful things to happen. Simply life changing."

### Contact details

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## In the Next Issue Health and Wellbeing

The theme for the next issue is health and wellbeing. Health is an area of life that has a profound impact on the quality of life and wellbeing of a person with profound and multiple learning disabilities (PMLD). Many children and adults with PMLD will face multiple health issues which can either be dealt with in a way that ensures a good quality of life or be neglected and lead to premature death - a factor highlighted in the recent LeDeR report.

Many of the standards contained in the Core and Essential Service Standards in Supporting people with profound and multiple learning disabilities focus on health and well-being. For individuals this means 'each person's health and wellbeing are actively promoted and supported to enjoy a full and long life.' This requires that organisations supporting these individuals 'ensure effective support to promote the health and wellbeing of each person, including any specialist health care needs that increase the vulnerability of the person.'

The Winter issue will include articles from a variety of health professionals, focussing on promoting good practice to ensure a good quality of life for people with profound and multiple learning disabilities. We would welcome any further contributions and articles that reflect positive practice enhancing quality of life for people with PMLD in all areas of physical, emotional, mental and spiritual wellbeing.

Please send any contributions for this important next issue by 22nd October to the lead editors Jeanne Carlin [jeanne@jcarlin.karoo.co.uk](mailto:jeanne@jcarlin.karoo.co.uk) or Sue Thurman [sue@thurmancc.co.uk](mailto:sue@thurmancc.co.uk)

## IN THE NEWS

### Early Day Motion on health inequalities tabled by Norman Lamb MP

Norman Lamb MP has tabled an Early Day Motion (EDM) about health inequalities for people with learning disabilities and autism. It urges the Government to introduce mandatory learning disability and autism training for all primary healthcare professionals led by the experts, people with learning disabilities and autism themselves, to reduce health inequalities. Please ask your MP to support it. Find out more: [www.parliament.uk/edm/2017-19/1365](http://www.parliament.uk/edm/2017-19/1365)

Find out who your MP is and how to contact them: [www.parliament.uk/mps-lords-and-offices/mps/](http://www.parliament.uk/mps-lords-and-offices/mps/)

### Latest on Nascot Lawn Respite Services

It was open to Hertfordshire County Council to refer the decision by Herts Valleys CCG - to cease funding Nascot Lawn Respite Services for disabled children - to the Secretary of State for Health and Social Care, but they have decided against doing so.

Stephen Kingdom, campaign manager for the Disabled Children's Partnership says: "Members of the Disabled Children's Partnership, alongside the families who have fought so hard to keep Nascot Lawn open, are utterly baffled by the county council's decision not take more decisive action over the CCG's decision to withdraw funding for the centre and refer the matter to the Secretary of State for a final decision – an option open to the council under local authority regulations.

"The CCG's decision to stop funding Nascot Lawn needn't have been the end of the matter if the council considered that this would not be in the interests of the local health service. It seems self-evident to us – and to parents – that closing Nascot Lawn is not in the interests of the health service in Hertfordshire, given the impact it will have on children with complex health needs and their families."

Read the full news item and quote from the Disabled Children's Partnership, here: [www.disabledchildrenspartnership.org.uk/news/](http://www.disabledchildrenspartnership.org.uk/news/)

## An 'influential advocate' in the field of learning disability nursing is awarded MBE

**M**any congratulations to Helen Laverty, who has been awarded an MBE. The following is taken from the University of Nottingham's press release: 'The achievements of a University of Nottingham nursing lead have been recognised in the Queen's Birthday Honours list.

Helen Laverty has been appointed a Member of the Order of the British Empire (MBE) for her expertise in learning disability nursing and her pioneering work in shaping Government policy on health and social care. Helen, who has been influential in the education and development of more than 700 learning disability nurses at Nottingham, is a passionate advocate and supporter for those living with a learning disability.

Alongside her academic responsibilities she founded Positive Choices -the only national network of learning disability students, academics, employers, people with a learning disability and families in the UK.

Professor Shearer West, Vice Chancellor of the University of Nottingham said: "Helen has been an academic educator of learning disability nursing students for over 20 years, influencing the profession at its very roots.

"Her firm belief in equality and inclusion for all and her passion for nursing has led to her becoming an influential advocate in this field- shaping national policy and championing the rights of those with learning disabilities. This recognition is richly deserved."

Read the full University of Nottingham press release, here:  
[www.nottingham.ac.uk/news/pressreleases/2018/june/champion-of-learning-disability-nursing-awarded-mbe.aspx](http://www.nottingham.ac.uk/news/pressreleases/2018/june/champion-of-learning-disability-nursing-awarded-mbe.aspx)

## #MyGPandMe

**T**he charity Dimensions UK has launched a new campaign #MyGPandMe – a campaign that is providing training for all GP surgery staff, sharing information and resources with patients and support teams and calling on policymakers to reduce health inequality. This has been developed following research by the charity which found that almost a third of people with learning disabilities or autism feel less likely to be treated with care and concern at the doctors, and two thirds said their GP did not make reasonable adjustments for them. You can find lots of resources and information on the following webpage:

<https://www.dimensions-uk.org/get-involved/campaigns/make-gps-accessible-mygpandme>

## Petition to make autism and learning disability training mandatory

**P**aula McGowan has launched a petition to prevent avoidable deaths by making autism and learning disability training mandatory. Paula's son Oliver, who had autism and a mild learning disability, died in hospital aged only 18 on 11th November 2016. Paula believes that his death could have been prevented if doctors and nurses had received mandatory training and had understood what reasonable adjustments they should put in place. You can sign Paula's petition here: <https://petition.parliament.uk/petitions/221033>. Read the blog Paula wrote for Learning Disability Week here: [www.mencap.org.uk/blog/learning-disability-week-2018-paulas-story](http://www.mencap.org.uk/blog/learning-disability-week-2018-paulas-story).

## Rightful Lives – Human Rights & People with learning disabilities

**A**n event focusing on the human rights of people with autism and/or learning disabilities is taking place in September. It will be an online exhibition running for a week from Monday 24th September and will be called "Rightful Lives". Follow the progress of the exhibition on Twitter at @RightfulLives or the hashtag #RightfulLives or on Facebook at #RightfulLives.

Find out more here: <https://markneary1dotcom1.wordpress.com/2018/06/03/rightful-lives-an-update/>

## RESOURCES

### Accessible booklet on Learning Disability, Autism and Human Rights

The British Institute of Human Rights has produced an accessible booklet to support individuals with learning disability and/or autism to use human rights when accessing care and support. It has been produced with the support of a range of organisations, using the views and feedback of people with learning disability and/or autism.

The booklet is free to download from the British Institute of Human Rights' website:  
<https://www.bihhr.org.uk/learning-disability-and-autism?platform=hootsuite>

### Care and Support of People Growing Older with Learning Disabilities

NICE has published a new guideline on the care and support of people growing older with learning disabilities. The guideline covers care and support for adults with learning disabilities as they grow older. It covers identifying changing needs, planning for the future, and delivering services including health, social care and housing. It aims to support people to access the services they need as they get older. An EasyRead version and a video is available. See <https://www.nice.org.uk/guidance/ng96> for more information.

### Disability Rights Handbook

A new version of the Disability Rights Handbook has just been published. This contains in-depth information and guidance on the benefits system and social care services. It's available from Disability Rights UK to purchase and should also be available in local libraries.

<https://www.disabilityrightsuk.org>

## Reasonable Adjustments Guides

The Government has published a number of guides to making reasonable adjustments for people with learning disabilities. These cover the following areas:

- Blood tests
- Cancer Screening
- Constipation
- Health Checks
- Obesity and weight management
- Substance misuse
- Dysphagia
- Pharmaceutical services

For more information see: <https://www.gov.uk/government/publications/reasonable-adjustments-for-people-with-learning-disabilities>

## Guides for adult siblings

Sibs is the UK charity for brothers and sisters of disabled children and adults. Sibs has released guides for adult siblings, to support them with key issues they may be experiencing as an adult sibling, or may do in the future.

- Decision-making and the law: When your brother or sister can't make a decision, who does?
- Looking after money: When your disabled brother or sister needs support to manage their benefits and funding
- Keeping savings safe: When your disabled brother or sister can't manage a large amount of money, who can?
- What to do if your disabled brother or sister doesn't receive the care that they should
- The impact of challenging behaviour on you: When your disabled brother or sister's behaviour is harmful or aggressive.

For more information see <http://www.sibs.org.uk>

# SHORT COURSES & CONFERENCES

## September

Title:	An Introduction to Intensive Interaction
Date:	3rd September
Location:	London
Provider:	Us in Bus
Contact:	info@usinabus.org.uk

Title:	Intensive Interaction – Building relationships with people who have profound learning disabilities and complex needs
Date:	12th September
Location:	Glasgow
Provider:	Concept Training
Contact:	www.concept-training.co.uk/courses/categories/pmld-courses

Title:	Recognising and Responding to Maltreatment Experienced by Disabled Children
Date:	28th September
Location:	Glasgow
Contact:	BASPCAN <a href="http://www.baspcan.org.uk/events">http://www.baspcan.org.uk/events</a>

## October

Title:	FEEL IT workshop – a unique insight and immersive understanding of Sensory Processing Disorder
Date:	3rd October
Location:	Newton Abbot, Devon
Provider:	Sensory Spectacle
Contact:	www.sensoryspectacle.co.uk hello@sensoryspectacle.co.uk

Title:	INTERACT 2018 – a hands on day where parents, professionals and students can learn practical skills to support children and adults with additional needs
Date:	4th October
Location:	Devon
Provider:	Sensory Spectacle
Contact:	www.sensoryspectacle.co.uk hello@Sensoryspectacle.co.uk

Title:	Five Day Course for Intervenors
Date:	8th to 12th October
Location:	Coventry
Provider:	RNIB Pears Centre in association with Natsip and SENSE
Contact:	receptionpearscentre@rnib.org.uk (Joanne Jones)

Title:	INTERACT 2018 – a hands on day where parents, professionals and students can learn practical skills to support children and adults with additional needs
Date:	18th October
Location:	Newcastle
Provider:	Sensory Spectacle
Contact:	www.sensoryspectacle.co.uk hello@Sensoryspectacle.co.uk

Title:	FEEL IT workshop – a unique insight and immersive understanding of Sensory Processing Disorder
Date:	10th October
Location:	Cambridge
Provider:	Sensory Spectacle
Contact:	www.sensoryspectacle.co.uk hello@sensoryspectacle.co.uk

Title:	INTERACT 2018 – a hands on day where parents, professionals and students can learn practical skills to support children and adults with additional needs
Date:	11th October
Location:	Cambridge
Provider:	Sensory Spectacle
Contact:	www.sensoryspectacle.co.uk hello@Sensoryspectacle.co.uk

Title:	FEEL IT workshop – a unique insight and immersive understanding of Sensory Processing Disorder
Date:	17th October
Location:	Newcastle
Provider:	Sensory Spectacle
Contact:	www.sensoryspectacle.co.uk hello@sensoryspectacle.co.uk

Title:	PMLD – Profound and Multiple Learning Difficulties
Date:	23rd October
Location:	Glasgow
Provider:	Concept Training
Contact:	www.concept-training.co.uk/courses/categories/pmld-courses

Title:	Intensive Interaction – Building relationships with people who have profound learning disabilities and complex needs
Date:	23rd October
Location:	Glasgow
Provider:	Concept Training



<p>Title: FEEL IT workshop – a unique insight and immersive understanding of Sensory Processing Disorder</p> <p>Date: 31st October</p> <p>Location: Reading</p> <p>Provider: Sensory Spectacle</p> <p>Contact: <a href="http://www.sensoryspectacle.co.uk">www.sensoryspectacle.co.uk</a> <a href="mailto:hello@sensoryspectacle.co.uk">hello@sensoryspectacle.co.uk</a></p>	<p>Title: Beginners' Makaton course – for parents and carers</p> <p>Date: 27th &amp; 28th September</p> <p>Location: Tiverton, Devon</p> <p>Provider: Becky Lyddon</p> <p>Contact: <a href="mailto:beckymakatontutor@gmail.com">beckymakatontutor@gmail.com</a></p>	
<b>November</b>		
<p>Title: Raising the Bar II National PMLD Conference</p> <p>Date: 2nd November</p> <p>Location: Birmingham</p> <p>Provider: PMLD Link</p> <p>Contact: <a href="mailto:info@pmldlink.org.uk">info@pmldlink.org.uk</a></p>	<p>Title: Foundation Makaton course</p> <p>Date: 26th &amp; 27th November</p> <p>Location: Islington, London</p> <p>Provider: Becky Lyddon</p> <p>Contact: <a href="mailto:beckymakatontutor@gmail.com">beckymakatontutor@gmail.com</a></p>	
<p>Title: How are you feeling? – A conference exploring INTEROCEPTION merging research with professional practice.</p> <p>Date: 6th November</p> <p>Location: London</p> <p>Provider: Sensory Spectacle</p> <p>Contact: <a href="http://www.sensoryspectacle.co.uk">www.sensoryspectacle.co.uk</a> <a href="mailto:hello@sensoryspectacle.co.uk">hello@sensoryspectacle.co.uk</a></p>	<p>Title: Follow Up Makaton course – after completing the Beginners' course</p> <p>Date: 28th &amp; 29th November</p> <p>Location: Islington, London</p> <p>Provider: Becky Lyddon</p> <p>Contact: <a href="mailto:beckymakatontutor@gmail.com">beckymakatontutor@gmail.com</a></p>	
<p>Title: An Introduction to Intensive Interaction</p> <p>Date: 9th November</p> <p>Location: Redhill</p> <p>Provider: Us in a Bus</p> <p>Contact: <a href="mailto:info@usinabus.org.uk">info@usinabus.org.uk</a></p>	<p>Title: Learning Disability Today Exhibition and Learning Day</p> <p>Date: 28th November 2018</p> <p>Location: London</p> <p>Contact: Pavilion</p>	
<p>Title: The Curriculum Conundrum: post-Rochford</p> <p>Date: 9th November</p> <p>Location: Manchester</p> <p>Provider: Contact: 01524 426 395 or <a href="http://www.hirstwood.com">http://www.hirstwood.com</a></p>	<p>Title: Best of British / European Special Education Forum</p> <p>Date: 29th and 30th November</p> <p>Location: London</p> <p>Provider: <a href="mailto:florencealonghorn@gmail.com">florencealonghorn@gmail.com</a></p>	
<p>Title: Beginners' Makaton course – for parents and carers</p> <p>Date: 17th &amp; 18th September</p> <p>Location: Islington, London</p> <p>Provider: Becky Lyddon</p> <p>Contact: <a href="mailto:beckymakatontutor@gmail.com">beckymakatontutor@gmail.com</a></p>	<b>December</b>	
<p>Title: The Curriculum Conundrum: post-Rochford</p> <p>Date: 23rd November</p> <p>Location: London</p> <p>Provider: Contact: 01524 426 395 or <a href="http://www.hirstwood.com">http://www.hirstwood.com</a></p>	<p>Title: Enhanced Makaton course – after completing the Foundation course</p> <p>Date: 11th &amp; 13th December</p> <p>Location: Islington, London</p> <p>Provider: Becky Lyddon</p> <p>Contact: <a href="mailto:beckymakatontutor@gmail.com">beckymakatontutor@gmail.com</a></p>	
	<p>Title: Recognising and Responding to Maltreatment Experienced by Disabled Children</p> <p>Date: 28th September</p> <p>Location: Glasgow</p> <p>Contact: BASPCAN <a href="http://www.baspcan.org.uk/events">http://www.baspcan.org.uk/events</a></p>	

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## About Us

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

- Rob Ashdown** Former teacher of pupils with severe and profound and multiple learning difficulties and special school Headteacher.
- Jeanne Carlin** Retired Disability Consultant and a parent of a young woman with PMLD.
- Helen Daly** Mum to a young Adult with PMLD, previous career in Further Education for 20 years - including Curriculum Team Manager for Inclusive Learning and Developing an Improving Choice Programme for people with Complex Needs. Currently involved in carers groups in the Eastern Region, Learning Disability Partnership Board and associated projects.
- Ann Fergusson** 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.
- Michael Fullerton** 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.
- Martin Goodwin** 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.
- Joanna Grace** 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.
- Rachel Parry Hughes** Lecturer in Social Work, Goldsmiths, University of London, researcher in the field of profound and multiple learning disabilities
- Becky Loney** 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.
- Wendy Newby** Deputy Headteacher at The Shrubberies School, Stonehouse, Gloucestershire. This is a school for students with Severe and Profound Learning Difficulties
- Sue Thurman** Former NHS Speech and Language Therapist for adults with learning disabilities with a particular interest in PMLD. Now writes and trains about communication and is a Registered Intermediary assisting vulnerable witnesses to communicate at police stations and courts.
- Bella Travis** Policy Lead, Mencap
- Hannah Young** 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.

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

# PMLD LINK

sharing ideas and information

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

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