

PMLD LINK

sharing ideas and information

Wellbeing

Spring 2024



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GUEST EDITORIAL

Wellbeing

Welcome to Spring and to this season's edition of PMLD Link, which focuses on a wide variety of elements relating to the wellbeing of people with profound and multiple learning disabilities (PMLD). As well as sharing practical tips on how we can offer support to improve wellbeing, the articles in this edition highlight the importance of connection, communication opportunities, relationships, personhood and belonging, to name a few. The introductory article by Julie Calverley weaves nicely into Kate Sainsbury's article, as she shares a mother's vision for the wellbeing of her son, who is able to live a purposeful and meaningful life where his wellbeing is supported by his excellent care team. These articles also align with the Five ways to Wellbeing, which we are guided through elsewhere in this issue. We hear about musical hydrotherapy and reflexology as therapeutic tools for relaxation and wellbeing. A range of resources are also highlighted, including gardens, museums and art galleries which can be visited online to support the cultural growth and wellbeing of people with PMLD, their families and support workers.

We are also reminded of the foundational importance of ensuring physical needs are met and how, when someone is comfortable, they are more likely to be able to enjoy external stimuli, which in turn supports their wellbeing. There is also a focus on the mental health and wellbeing of family carers and we hear about a new project which is using creative ways to research this area. The impact of grief and ways in which people with PMLD can be supported throughout the process is also covered in this edition. There are reflections on the impact of the Covid-19 pandemic upon the emotional wellbeing of people with PMLD and there is a piece about remote music, sound and wellbeing sessions which were delivered during the pandemic and continue to run.

We have so many wonderful contributors to this issue of PMLD Link who have been willing to share their thoughts and ideas around supporting the wellbeing of people with PMLD. We hope you enjoy the articles and that you are inspired to try some of the ideas out or indeed send us your thoughts on how you support the wellbeing of people with PMLD.

We are very grateful to three volunteers from the PMLD Link Reference Group who have helped with the editing of this issue. Thank you to Clare Chalaye, Amy Nokes and Pete Navarra for their ideas, time and energy, which was a huge support to our volunteer editorial team.

Sit back, relax and enjoy the Spring Edition.

Guest Editors: Becky Loney, Maureen Phillip, Martin Goodwin, Bella Travis and Annie Fergusson

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Wellbeing - an introduction

Julie Calveley

I was honoured to be invited to write an introductory piece for this special Wellbeing edition of PMLD Link. However, even though I spend much of my life immersed in the study of wellbeing, as I put pen to paper, I quickly realised this task would not be easy. Once I dropped any misguided belief that I needed to present 'all the answers' about what wellbeing is and how to get it, I was much more comfortable with offering what follows.

There is no universal agreement on what wellbeing is. A lack of shared understanding makes discussions and research difficult. My aim in thinking about the meaning and nature of emotional wellbeing is to understand how people with profound and multiple learning disabilities (PMLD) and their families, can live lives that are as free of distress as possible and where they can flourish and thrive.

'Wellbeing is a broad concept' (The Care Act, (England) 2014, and Social Services and Wellbeing Act (Wales) 2014, statutory guidance). This is something many of us recognise - that our 'wellbeing' relates to and is affected by many aspects of life. It is a term we use and hear regularly in day-to-day life and that also appears in policy and legislation, for example, it is a guiding principle in the Care and Wellbeing Acts, and it is a key focus in the 'Supporting people with profound and multiple learning disabilities, Core and Essential Standards' (2017).

It is probably fair to say that 'wellbeing' is important to us all - the wellbeing of those we love, the wellbeing of those we support and our own wellbeing too'.

(PMLD Link Editors, 2023).

Defining wellbeing

According to the NHS, wellbeing 'is generally thought to be made up of things like the experience of positive emotions, people's perceptions that the things they do in their lives are meaningful and worthwhile, and life satisfaction'.

Most definitions and conceptualisations of emotional wellbeing include feeling and functioning components. Wellbeing is generally considered to be, not merely the absence of mental ill-health but, the presence of positive states when things are going well and, the ability to cope and manage when things are not going so well.

The World Health Organisation (WHO) proposes that 'wellbeing exists in two dimensions, subjective and

objective. It comprises an individual's experience of their life as well as a comparison of life circumstances with social norms and values'. Examples of life circumstance include health, education, work, social relationships, built and natural environments, security, civic engagement and governance, housing and work-life balance. Subjective experiences include a person's overall sense of wellbeing, psychological functioning and affective states.

Ideas about wellbeing are affected by cultural and societal values. Variations exist in what is considered important for wellbeing among different groups and individuals.

Cultural and individual differences

The distinctions between Western and Eastern values regarding wellbeing are rooted in cultural, philosophical, and historical differences. Western perspectives often emphasise individualism, personal achievement, and autonomy as key elements of wellbeing. The pursuit of happiness, self-expression, and the fulfilment of personal goals are prominent themes. In contrast, Eastern philosophies often prioritise harmony, interconnectedness, and balance. Wellbeing is frequently viewed through a communal lens, with an emphasis on maintaining harmonious relationships, inner peace, and alignment with the natural order. Concepts like mindfulness and meditation, integral to many Eastern traditions, play a central role in achieving mental and emotional balance. While Western values tend to focus on external accomplishments and self-realisation, Eastern ideals often emphasise inner tranquillity and a harmonious coexistence with the surrounding world. It may be crucial to recognise and respect these variations, understanding that wellbeing is not a one-size-fits-all concept.

Research suggests that priorities may shift across the lifespan. For example, Courtwright et al (2019) carried out a concept analysis of emotional wellbeing in youth and suggested there were particular antecedents, attributes and consequences that were especially important in the teenage years. They found attributes of emotional wellbeing in youth included overall positive emotions, positive self-esteem, and resilience.

Antecedents were safe and stable nurturing relationships; family and social connectedness, hope, and positive body-image. The consequences of emotional wellbeing included self-efficacy, self-actualisation, the presence of positive health behaviours, and the absence of high-risk behaviours. On a personal note, what I think is important for my wellbeing has changed now that I am in my late forties, compared to when I was in my teens and twenties.

Recognising and appreciating diversity in cultural and individual perspectives enriches discussions on wellbeing, potentially offering a more inclusive and nuanced understanding that goes beyond universalising notions of what constitutes a fulfilling and meaningful life.

In an attempt to offer a more inclusive definition Simons and Baldwin (2021) propose that wellbeing is 'a state of positive feelings and meeting full potential in the world.'

Determinants and components

Wellbeing has been conceptualised in terms of needs and feelings, but also in terms of determinants and components. Determinants are the factors that influence those wellbeing experiences and components are the parts that combine to create wellbeing (Simons and Baldwin, 2021).

Might there be differences in the determinants and components of wellbeing for children and adults with PMLD? Or might some priorities be different, as the study by Courtwright et al (2019) found of wellbeing in youth?

The focus of the not-for-profit organisation NAC (Nurturing Affective Care) is emotional wellbeing. We therefore wanted to develop a conceptualisation of emotional wellbeing for people, including those with PMLD / severe and profound intellectual disabilities, to develop a greater understanding of what emotional wellbeing means, what leads to good emotional wellbeing and how we can tell when someone has good emotional wellbeing.

Our aim was to work towards a definition and conceptualisation of emotional wellbeing based on the views of family members and practitioners, together with a literature review. This was to develop a shared language for discussing emotional wellbeing, help point us towards the types of approaches and strategies that promote emotional wellbeing and towards a way of assessing effectiveness of approaches and strategies.

We started to explore the concept of emotional wellbeing by asking family members and professionals two questions:

- 1) What is emotional wellbeing?
- 2) What do you think is important for the emotional wellbeing of people with severe and profound intellectual disabilities?

Question 1: Participants were able to give up to 10 responses.

From the 49 people who took part, 195 different words and phrases were given. A thematic analysis of these responses led us to group these words and phrases into the following themes in Box 1 below.

Box 1: Emotional Wellbeing Themes

- Connection and belonging
- Authentic expression
- Self-awareness
- Autonomy
- Regulation and resilience
- Safety
- Self-value
- Pleasant feelings
- Ease and balance
- Accomplishment

Question 2: Participants were invited to respond with free text. Whilst there was variation in the way that answers were written, broadly speaking most of the answers could be grouped into two themes -authentic expression and relationships.

These ideas come from the perspective of others and therefore the question remains - what does emotional wellbeing mean for someone with PMLD? Are there any specific or unique determinants and components of wellbeing from the perspective of people with PMLD?

Should we consider what we know about the determinants and components of wellbeing expressed by others who are able to use words? Can we take each of the themes and consider 'what does this mean for someone with PMLD and how can we support them with it?' For example, the term functioning may need to be thought about more widely, as by definition, some aspects of functioning are compromised in someone with PMLD.

The best evidence that we have at the current time is that which exists within the general research literature on wellbeing and real time, 'in the moment' evidence from the communication and responses of each individual person.

NAC's approach

NAC has collected, curated and developed guidance and suggestions based on the latest research on wellbeing across all groups and adapted these to be suitable for people who use other means than words to communicate. It gives suggestions for practical ways in which wellbeing can be promoted. This free to access guidance on the NAC website is organised into the following categories:

- Arts and creativity
- Interactions and relationships
- Mindfulness
- Movement
- Music
- Nature
- Senses
- Touch

The criteria for including guidance on the NAC website is that it:

- can be used safely by someone who knows the person well
- is non-invasive
- does not require special or expensive equipment
- is evidence informed

NAC also recognises that individual variation exists and that there is a lack of specific research evidence involving people with PMLD. Therefore, throughout the how to-guides, readers are regularly reminded to be sensitive to all communicative signals and continuously check how the person they are supporting is responding.

The importance of spending time with and getting to know an individual cannot be overstated. Personal values, preferences, and unique modes of expression play a vital role in shaping an individual's wellbeing. What brings joy, comfort, or fulfilment can differ greatly from person to person. For individuals with limited communication abilities or those who rely on others for their daily needs, understanding their specific ways of expressing themselves becomes paramount. Effective support hinges on a deep understanding of preferences, emotions, and non-verbal cues. This personalised approach ensures that care and support align with the individual's values and contribute positively to their overall wellbeing.

Arguably this could provide the necessary evidence as to whether an approach is beneficial. At the same time further, systematic research would clearly be necessary.

Throughout the guidance, users are encouraged to consider outcomes in relation to the emotional wellbeing determinants and components categories listed previously, in Box 1.

The complexity of wellbeing / ups and downs

It is crucial to recognise that living a rich social and emotional life includes experiencing unpleasant feelings, as for example we go through inevitable loss and change. Expressing unpleasant feelings does not necessarily indicate poor wellbeing, because it may be effective in leading to the possibility of receiving emotional support. This challenges a reliance on non-verbal and behavioural signs of pleasant emotions, such as happiness to gauge wellbeing.

We therefore may need to look beyond smiles and laughter and recognise that a rich and healthy social emotional life is inclusive of unpleasant feelings. The expression of such feelings, for example crying or screaming may not necessarily indicate poor wellbeing. Crying or screaming could be valuable ways of expressing feelings, leading to support from others and subsequently a greater sense of wellbeing. This makes it difficult to rely solely on non-verbal and behavioural signs of pleasant emotions such as smiles and laughter as being indicative of wellbeing.

Perhaps wellbeing is not dependent on 'everything being okay' but rather how we respond to life events and are supported through them. It may first appear that good physical health is something that most people could agree is important for wellbeing. However many people (myself included) would say that their own health difficulties have led to a greater appreciation and more compassionate approach to life, giving rise to a greater sense of happiness and connection.

Challenges and problems are inevitable for all of us and whilst they can be minimised, a certain degree of change is largely unavoidable. How you are able to deal or cope with life's ups, downs and external and internal change may be one of the determinants of your emotional wellness.

Wellbeing of others

An individual's wellbeing cannot be considered in isolation of the people they have relationships and interact with. Integral to the wellbeing guidance given by NAC is this recognition and the importance of support for the wellbeing of carers and professionals. It must also be acknowledged that the effect is bi-directional, with the wellbeing of carers affecting that of the person they care for but also that the person being cared for can have a profound impact on the wellbeing of carers.

To end

Wellbeing is likely to encompass a holistic approach to an individual's health and happiness, acknowledging that it is not merely the absence of illness but a state of overall contentment and fulfilment. For individuals with severe and profound intellectual

disabilities, wellbeing may transcend some of the typical measures related to functioning, success and achievement, or these measures need to be thought about differently, embracing a personalised understanding that considers their unique needs, abilities, and challenges.

This may leave us with little in the way of answers and much in the way of questions but I am grateful that we are now, perhaps at the early stages of a journey of exploration that can lead to greater wellbeing and quality of life for people with PMLD and ourselves, whatever wellbeing means for them and us.

In conclusion, acknowledging the diversity in interpretations of wellbeing and recognising the individuality of each person's experience is essential. By appreciating our joint humanity but also our individual differences and tailoring support to the unique needs and expressions of individuals, we can foster a more inclusive and effective approach to promoting wellbeing throughout society.

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Long-term wellbeing - a mother's vision becom(ing) reality

Kate Sainsbury

As Maureen Phillip, of PAMIS, said recently, 'Social care is changing and it has to change to fit a community of people who don't want the old model.' My son, Louis, and I are part of that movement in adult care. We seek care that respects our human rights, supports Louis himself to make decisions, integrates family and professional care, and thereby promotes wellbeing in everybody. I hope learning from our story might help other families pursue their own visions.

We celebrated Christmas Day 2023 with Louis, gathering his family and carers around the table for lunch in his own home. My Vision of a long-term home for him had become reality through years of hard work and collaboration. Louis felt safe, he was loved by us all. I felt a weight lifted from my shoulders and so did my husband and daughters. We felt like one family with the carers and we all felt the privilege of being with Louis.

Louis is thirty-seven, creative, fun, physically active, a people-person. Developmentally his cognitive age is about eighteen months. He depends on others for all his personal care, housekeeping, planning, interactions with the wider world and communication. His chattiness and intelligence are overshadowed by Aphasia and Trauma.

In short, Louis needs a permanent community of care around him. When Louis's previous care suddenly ended in 2017, he had no alternative. This led to four and a half traumatic years, Louis detained in hospital for three and a half; all of our lives turned upside down. In that dark time I conceived a vision. It was to collaborate with funders and a care organisation, to be paid through Self-directed Support, where the organisation would employ and manage carers, assessed on a 2:1 ratio, while I purchased a building through Louis's clinical negligence award - somewhere Louis could put down roots.

I planned to continue to support Louis, continuity for him; enabling me to share my lifelong knowledge of Louis with his team, and for us to continue to enjoy time together. It was to be a permanent solution, Louis's own lifelong home, with a circle of community wrapping around him and his team.

My key goal was for Louis to lead a happy, fulfilled life, to be recognised within his care team, his community, as a feeling, thinking person; a citizen. A parallel goal was to find staff who could bring their own gifts to the care community, to share them with Louis and his team, so they would also find fulfilment and meaning.



Louis' freedom to express himself is part of his wellbeing

Collaboration between the care organisation and myself in practice means we recruit together, nurture gifts, build up trust. We agree on values, kindness, commitment, creativity, curiosity, patience; Louis the most patient of all. It takes time to build up such a community. We are now three years along the road to my vision, Appletree.

It was hardest in the early days, while Louis was still in hospital. We needed enough skill capacity in the staff team for Louis to be safely discharged. Yet experiences in hospital were toxic too. I cannot imagine how awful it was for Louis, continuing to be returned to the locked ward after his time out. While he lived in this way, his stress responses were high, which made supporting him harder. Now with those times behind him, there are fewer triggers for trauma, staff and Louis have developed confidence in each other.



Louis was discharged in May 2022. A key turning point was the arrival in Spring 2023 of an insightful, skilled Team Leader. She has modelled good practice, drawn the team together, Louis likes her, and vice versa. She and I are mutually supportive and appreciative. The momentum between us is now drawing in new members, attracted by the positive atmosphere they sense in us and in Appletree when they visit.



They find Louis, relaxed and fulfilled. They find routines, plans for days and weeks ahead. They find the house, a converted set of farm buildings, built around a secure courtyard, with gardens to back and side. It is an attractive, spacious place to work, where timetables for daily activities can be planned, for all seasons and weathers. Louis chose the colours in his home from paint swatches. He decorates his living space with his own art works and balloons, his freedom to express himself is part of his wellbeing.

Visitors find a language community, sharing Louis's words, sounds and phrases with him and each other, celebrating his and our own progress, learning Makaton together.

Communication is such an important aspect of wellbeing. It expresses relationships, trust, fun, confidence in each other as well as information exchange. Louis's language has noticeably grown over the last six months.

We have been supported in all this development by a circle of friends and organisations, (including Maureen Phillip and others from PAMIS). We have volunteers who offer sessions of crafts and story-telling, we have a circle of friends who visit. We hold a weekly online prayer group, which Louis attends with his carers, and weekly sessions of music therapy.

The importance of relationships was noted by researchers Nankoosing and Haydon-Laurelut in *The Relational Basis of Empowerment* (2013). They analysed good and bad practice in personal care. They described people flourishing within a network of positive relationships, shaped by a culture of hope. They highlighted that each of us seeks a life that is 'enjoyable, meaningful, engaging and fulfilling' (Nankoosing et al, 2004).

Louis has a word for feeling safe and experiencing pleasure like this, 'Eeeh!' he says, with shining eyes and soft body language. Louis has taught me, and others, to notice our pleasure 'in the moment', our mutual inter-dependence.

Our example of quality personal care is a model for statutory partners. We worked with the Universities of Portsmouth and Edinburgh Napier, the Aiteal Trust and PAMIS to tell Louis's story and the development of Appletree (www.theaitealtrust.com/research). This will be exhibited in the Scottish Parliament in 2025. This is the model of wellbeing we seek to extend as we go forward. Louis and others with profound and multiple learning disabilities are our best educators, we need to listen and be led by them and in turn this will lead to better trust and understanding which will ultimately improve the wellbeing for everyone involved in care and support.

Contact details

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COVID19, Confusion, Communication and Companionship: Disability support workers' experiences of communicating with people with PMLD through the pandemic

Michelle Murphy and Anne-Marie Martin

People with PMLD tend to use ways of communicating which rely on non-verbal behaviours such as facial expressions, body posture, visual cues, vocalisations and vocal tone. These behaviours are often ambiguous and open to more than one interpretation, so extensive support from a familiar communication partner is required to enable wider social interaction. Consequently, individuals are at risk of becoming socially isolated (Beadle-Brown et al., 2016). Meaningful social interaction and communication are important in fostering positive mental health and are linked to improved quality of life for people with intellectual disabilities (Beadle-Brown et al., 2016; Felce & Perry, 1995; Schalock et al., 2008; Tough et al., 2017).

During Covid-19, social distancing and lock-down restrictions compounded the risk of social isolation for people with PMLD. Service provision was seriously disrupted with many school and day service closures, social event cancellations and visitor bans in residential homes. In disability residential homes, and more widely, support staff were required to wear personal protective equipment (PPE), such as face masks, gowns, aprons and gloves. This meant that communication through facial expressions, gestures, body language, and touch were covered over by the PPE.

This study explored six disability support staff experiences of interacting with people with PMLD, in residential homes, during the Covid-19 pandemic. Through individual, online interviews, they shared their experiences of the opportunities that arose, challenges they encountered, how these were overcome and what new insights they gained.

Their experiences were captured in six themes 1. unwavering commitment, 2. running on empty, 3. being a safe haven, 4. heightened sensitivity, 5. empathic understanding and 6. new insights.

Unwavering commitment

All participants spoke of feeling an increased sense of responsibility toward, and were unwavering in their commitment to, the people they supported through the pandemic. They were aware the person may not understand what was happening and may have difficulty expressing their thoughts and feelings. They were mindful of anxiety, loneliness, confusion and/or distress that persons with PMLD may have felt. Although staff shortages, uncertainty and burnout

created significant demands, participants remained dedicated to the wellbeing of the people they supported, and tried hard to provide reassurance and a sense of safety during what they described as a very challenging time.

'We became their beginning, their middle and their end. That was it. We were all that some people had' (Paula, p. 26)

Knowing the person's usual means of communicating helped them to observe and identify changes in their communicative behaviours. These were taken to be indicators of the person's wellbeing and were monitored continuously.

'[Individuals] were not engaging as well as they would have. They would have been less interactive, less eye contact, more sleepy' (Paula, p. 9)

Participants tried to give time to be present and support the person through the fear and anxiety. They tried to foster some sense of security and structure, by remaining upbeat and using fun, jovial banter to reassure people.

'offering ... more time, to sit with them more, trying to be a present figure with them' (Eily, p. 28)

This commitment and dedication to the wellbeing of individuals with PMLD persisted, despite staff living through the pandemic themselves.

Running on empty

All participants spoke about feeling guilt, uncertainty, increased responsibility, insufficiency and

exhaustion. The unpredictable, unprecedented nature of COVID-19 and frequent restrictions and guideline changes caused participants to feel unsupported, uncertain and anxious. They were fearful of how this may impact on how they communicated with people.

'People were burnt out, staff were burnt out and morale, it did go down ... people were just exhausted' (Ellie, pp. 15/16)

Participants spoke of worrying for the person's physical health, in the earlier stages of the pandemic but as restrictions continued, they were also concerned for their mental health.

'There was also a fear that their mental health would suffer' (Eily, p. 26)

They felt a responsibility to provide a sense of safety, security and reassurance to individuals.

Being a safe haven

Established relationships between participants and persons with PMLD were considered foundational to communication. Knowing each other fostered trust and provided a sense of safety amid all the uncertainty and change. The presence of a familiar person who understood the individual's expressions made communication possible and enabled them to monitor the person's wellbeing.

'I would be doing it the same way all the time so that they can understand, so there's no surprises ... There has to be a trust there ... that's built over time, that's built over familiarity ...' (Karen, pp. 7/8)

Conversely, participants believed residents recognised familiar staff by their personalities and mannerisms, which also provided reassurance and facilitated communication. They observed that, despite wearing full PPE, the person with PMLD recognised and responded to familiar staff or loved ones on hearing their voices. All spoke about this, and acknowledged it as one of the most enabling aspects of communicating through the pandemic.

'as soon as mum is on the phone, they light up, and they'd be smiling, and you know they recognise mum's voice straight away, or dad's voice, just straight away. I found that that kept them going a bit longer' (Ellie, p. 29)

Heightened sensitivity

Participants worried about the individual's reaction to PPE, as masks and visors impacted communication through facial expressions. They experienced a heightened sensitivity to, and became more conscious of communication strategies.

'your facial expression was now halved, so all they had was your eyes' (Eily, p. 7)

They described becoming much more observant of communication behaviours and changes in eye contact, facial expressions, posture, and vocal sounds. Consequently, they discovered and learned more about how the person communicates.

'She is looking into your eyes to see where you are coming from, it's all eye contact with her ... I didn't take much notice of before COVID'.

Empathic understanding

Participants experienced particular difficulty with feeling insufficient at helping the person to understand why all these restrictions and changes were taking place. They wanted to convey to the person that they understood, and they were there for them.

'trying to explain what's going on ..., you don't know how much they comprehend. ... why can't they see their family, why they're not seeing mom and dad, That was difficult. It was actually upsetting'. (Ellie, p. 21)

Staff felt upset and conflicted at having to implement self-isolation guidelines, and spoke of feeling guilt around what the person with PMLD may be experiencing such as the effects of visitor restrictions.

'he had his teddy, he had his radio, he had all those things, but he didn't have human contact' (Eily, p. 25)

Family photo albums were helpful and participants made time to sit with the person, look at their family photos and chat about their loved ones. Window visits had varying impact. For some, it seemed positive and helpful, but for others, it seemed to cause distress.

'They knew they were outside, they could see them, but they weren't coming in' (Eily, p. 14)

'we just wave to ... mum ... and they wave back. That was with the elderly parents, that couldn't work the video calls. They wanted to see them' (Mary, p. 17)

The importance of communication between the person and their family was highlighted. A sense of loss was felt for the person and their families regarding missed time together.

New insights/learning

Social distancing guidelines meant that people could not come together for usual group activities, and the closure of day services and reduction in activities slowed the pace of life. Participants described how some people became bored with decreased outings, day service and

social activities, and would pace up and down or engage in self-stimulating behaviours. However, some seemed happier and more content with less activity, smaller social circles and slower-paced activities.

'their world got smaller, but they were more content' (Eily, p. 21)

The slow-down resulted in more opportunities for participants to spend time with the person and observe how they responded to different experiences. They became more attentive and sensitive to their expressions.

'Covid slowed it down, you got to see more of the person' (Polly, p. 14)

Staff discovered the importance of becoming more aware of communication and of giving time to discover the person's own unique communicative styles, and gave new insights into the person's choices and preferences.

'I think they're wonderful communication partners. If you were going to listen, if you are there, if you are open to listening to the person, you would be surprised how much you learn' (Polly, p. 25).

Conclusion

The COVID-19 pandemic raised new and unprecedented challenges for disability support workers who support people with PMLD. The importance of communication for emotional and social wellbeing was highlighted by the pandemic. Against a backdrop of anxiety, exhaustion and uncertainty, they felt an unwavering commitment to ensuring the wellbeing of people with PMLD. Their commitment also extended beyond the person with PMLD, to their families and loved ones, actively taking steps to nurture and maintain their relationships.

*Full details of this study are published in the British Journal of Learning Disabilities: Murphy, M., & Martin, A. (2023). We became their beginning, their middle and their end. British Journal of Learning Disabilities, <https://doi.org/10.1111/bld.12565A>

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When the jelly wobbles

Sandra Archibald

What is wellbeing for me, my family and Isaac in particular?

His head tilts forward, eyes fixed on the dancing cactus. Isaac's glum expression turns to vexation as he shoves it away with a determined movement of his forearm. The lip of the table luckily, or unluckily, (depending on whose perspective) prevents it crashing to the floor. His support worker chuckles, accustomed to Isaac's decisive dissent.

Leaning his head back in the chair, Isaac scowls and draws his hand across his mouth, once, twice and again - his own peculiar version of the Makaton sign for 'toilet'. The sign accompanied by his guttural vocalisation makes it crystal clear that he is not at all happy - something is bothering him. On the changing bed, his support worker notes his swollen, tight, abdomen and understands that he is in pain and in no mood to be distracted by talking cacti!

Another day is about to form. Lying cocooned under the covers, I groan. "Why so early Isaac! Eyes still closed in the dark of morning, I note the tension in my head and the ache in my lower back. Pushing up onto my arm the sudden stab of pain from my finger, reminds me that I slammed it in the car door these two days past. Isaac's angry screeches increase, louder now with the intervals between each, shorter. I slither off the camp bed moved by guilt, at my sluggish response to his calling. I grab for the dressing gown to block out the cold of the room. An hour or so later Isaac is with his support worker.

And I, am washed, breakfasted, warmly layered against the cold - and in my happy place. Dipping my hand into the thinly frozen pond, I scoop up the fragile ice and admire its evocation of glass. Just a month hence, this sensation will be replaced by the jelly like frogspawn, slithering through my fingers and landing with a plop back in the pond.

I cannot recall the exact words of the author or the title of the book, but an analogy sticks. 'When you poke the jelly, its whole form wobbles' the author writes about the interconnection of mind and body. The mind is not



separate from the body nor the body from the mind. The one affects the other. When one is discomforted or in pain, the other will be affected too.

A couple of days later Isaac is receptive, engaged, communicative and comfortable. The cactus rears its ugly head upon the table with the lip. Isaac makes a sound

and a couple of seconds later, the cactus mimics his sound and dances, then falls still and hushed. Isaac watches, silently waiting for it to move again, to speak. It remains as silent as he is. "Move" Isaac's stare demands – when it still does nothing, he claps his hands rapidly with an impatient complaint. Seconds later the cactus responds in animated mimicry of Isaac's clapping and irate vocals. The cactus completes its action and again falls to silence. Isaac watches, waits, considers; then reaches out to touch the cactus. It remains motionless. Not wanting to interrupt we grin quietly, intrigued, waiting for him to figure it out.

Just as I'm warmly dressed and therefore comfortable enough to want to stop by a frozen pond and scoop up the ice; Isaac, on feeling comfortable and pain-free, is willing to engage with the dancing cactus. His experience

of the world differs somewhat from mine, by the nature of his condition (requiring continuous assistance to meet his basic needs) but we are all still, jelly-like.

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Tired of Spinning Plates? A Project Exploring the Mental Health Experiences of Adult Family Carers of Adults with Learning Disabilities

Martina Smith, Katherine Runswick-Cole, Sara Ryan and Chris Hatton

The Tired of Spinning Plates project is a two-year National Institute of Health Research (NIHR) funded project exploring the mental health experiences of adult and older adult family carers of adults with learning disabilities. This project has come about due to the lack of attention in policy and research about the mental health of this particular group of carers.

The project is managed by a team of university researchers, some of whom are also family carers to people with learning disabilities, and it is also guided by a group of family carers and adults with learning disabilities. This guidance group, called the 'Tea and Cake Group', meets regularly to discuss the project and offer feedback and suggestions that continue to shape the project. We write blogs together about the things we discuss which you can find on the project website.

When we designed the project, we planned to co-design a survey about family carer mental health with family carers. During our meetings with carers, they told us they have had enough of filling out surveys. We agreed as a group to redesign this part of the project and came up with the idea of an online exhibition about the mental health experiences of family carers of adults with learning disabilities. The exhibition has been designed so carers can upload and share what they feel is important

to them and in a format that they choose. This could be a piece of writing, a picture, a news article, a voice recording...the possibilities are vast! We are very excited to learn more about family carers experiences and we plan to use what we learn, to create teaching materials for the professionals and services that matter to carers. We are determined to listen to carers and to not make assumptions about what matters to carers.

Please do follow our social media accounts and/or keep an eye out on our webpage for updates about the exhibition, and PMLD Link's Facebook and social media accounts or please do email us at: carermhspinningplates@sheffield.ac.uk, for more details or if you would like to get involved.

With thanks to Dan Goodley from the University of Sheffield for this drawing on the previous page. A drawing of three sticks each holding a spinning plate. One plate is yellow, one is blue and the other is red.

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You can find us on X (formally Twitter): @SpinPlatesCare or Instagram: @spinplatescare
This project is funded by the NIHR [Project reference 135080]. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

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Use the hashtags #pmlid and #pmlidchat to join conversations about making a positive difference to the lives of people with PMLD. See you online!

Multisensory Wellbeing, loss, and grief

Sarah Helton

This article discusses the importance of supporting people with profound and multiple learning disabilities (PMLD) with the issues of loss, bereavement, and grief and provides guidance on how to do this.

“Anything that’s human is mentionable, and anything that is mentionable can be more manageable. When we can talk about our feelings, they become less overwhelming, less upsetting, and less scary. The people we trust with that important talk can help us know that we are not alone.”

Fred Rogers, American television host and author

During our lives, we will experience a wide range of losses that can affect our wellbeing. These include daily losses, such as losing our car keys, which can frustrate or anger us, but that we generally navigate quite easily. However, more significant long-term losses, such as the death of a loved one, require us to manage the complex emotions of grief.

People with PMLD are no different; they experience daily and long-term losses, such as a favourite piece of music being turned off, the bubble tube no longer working, their taxi driver being ill and unable to take them to college, their carer moving to a new job or their grandfather dying.

- What do these losses look like for people with PMLD?
- Are these losses recognised, acknowledged and supported by those around them?

The complex physical and medical needs of people with PMLD mean that their emotional needs can be overlooked. When we detect something troubling them, we tend to go through a mental checklist assessing whether they are unwell, hungry, thirsty, need a postural change, etc. How far down this list is their ‘emotional wellbeing’? Positive wellbeing is achieved when the various elements of a person’s life are balanced – their physical, social, and emotional needs.

Observation

Look out for changes in body language, facial expression, posture, movement, behaviour and vocalisations. Having a strong connection with those we support allows us to observe changes from their usual ‘contented’ state. These differences can be very small, including changes in breathing patterns or facial skin tone, and we need to use all of our senses and intuition to ‘see’ what is going on.

Tip: Consider having a personal emotions chart with photographs showing the person in different emotional states and a description of how the emotion is presented. Include their ‘usual’ contented state as well as: happy, sad, excited, tired, unwell, etc.

Acknowledgement

Having observed a change in their emotional state, acknowledge it. This applies to all types of emotions as it will help the individual develop their understanding of emotions, how they feel in their body, and what causes these feelings. ‘I can see you’re happy. Your lips are smiling, and you’re swinging your legs. Are you happy because your Dad will be here soon?’ Or, ‘I think you might be feeling sad. Your head is down and you’re looking at the floor. Are you sad because we can’t go swimming today?’

Acknowledging and supporting the losses and associated grief experienced by people with PMLD is an integral part of supporting their overall wellbeing.

Mirroring

Another way to acknowledge a person’s emotions is by mirroring them. Use intensive interaction to mirror the person’s movements and sounds. This shows them that you have seen how they are feeling and that this is important to you. You are taking the time to have a ‘conversation’ with them about their feelings.

Tip: When appropriate during the intensive interaction exchange, ask about the cause of their feelings, e.g., ‘are you feeling sad about Holly (a friend who has died)? Would you like to look at some photos of Holly and listen to her favourite music?’

Support loss and grief

Work with the person to better understand their loss and grief. Talk about what has happened and explore it using their modes of communication and multisensory resources.

Tip: Create a sensory story about the person’s loss. For example, if they are grieving due to the death of their dog, as well as talking about their pet and looking at photographs of the dog, develop a sensory story about the dog. Include a toy dog for them to hold and groom, a

switch to press (with recordings of dog sounds), a 'woodland/grass' scent to smell to replicate the walks they went on etc.

Modelling: Be a good grief role model

Finally, endeavour to be a good grief role model. Share your own experiences of loss and bereavement. Talk about situations that caused you grief and the emotions that you experienced. Including what these emotions felt like in your body and how you managed the feelings. The children and adults with PMLD with whom we work can learn a great deal from seeing and hearing about our losses. It will help them feel less isolated with their grief and to realise that loss, bereavement and grief are things that affect us all.

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Sarah has worked in the Special Educational Needs/Disabilities (SEND) field for 25 years in a diverse range of roles. She now works as BackPocketTeacher in the field of child bereavement, specialising in the (sadly often overlooked) needs of bereaved children with SEND/Learning Disabilities. Sarah also facilitates training for the national charities Winston's Wish and Child Bereavement UK.

Sarah recently finished a PhD researching how children with SLD and PMLD communicate grief. She hopes to share her findings in future editions of PMLD Link.

For further support and resources:
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Art and Wellness with Musical Hydrotherapy

Joel Cahen

This article focuses on the practice of Musical Hydrotherapy, the synergy created between art and wellness, and how it applies to working with people with profound disabilities. Musical Hydrotherapy is a practice pioneered by the charity Liquid Listening which I co-founded in 2010, with Adele Drake, founder of Drake Music. The practice generally involves the aquatic body work support (a variation of Watsu, a form of Aquatic Body Work) of a recipient floating on their back in a hydrotherapy pool as they listen to music played beneath the water surface.

The practice began as an extension of my Wet Sounds art project that transforms swimming pools into artistic experiences with light and sound above and below the water surface (<https://www.wetsounds.co.uk/>). The two ways art manifests in our lives are by creating it or by encountering it.

Creating art

The process of creating art has garnered considerable acknowledgment for its role in fostering wellbeing and positively affecting mental and emotional health. This journey of exploration, occasionally cathartic, and imbued with emotional or soulful expression, is

facilitated by the production and presentation of artwork. It enhances focus, coordination, a sense of planning, and a feeling of achievement.

These are all positive steps towards developing self-esteem and improving wellness. The communication that is involved in art and craft making can help the artist deal with conflict and unresolved issues as well as opening a channel of communication with their surroundings. These are just some of the benefits of art-making that go towards enhancing one's wellbeing.

The encounter with art

The encounter with good art does not by definition improve our health or wellbeing but the experience of good art or music can be a profound and nurturing encounter. It can launch one into an introspective reverie, it can excite and inspire ideas, and illuminate different perspectives on the person's perception of their world. The artistic encounter contributes to innovation in culture and helps forge our sense of social and personal identity.

Music has a strong association with wellness. Research shows how particular frequencies or chord progression, and even music from particular composers can enhance wellbeing, (a claim which I find too steeped in cultural biases to be universally true). However generally speaking,

“Music impacts the brain by... reducing stress, pain and symptoms of depression as well as improving cognitive and motor skills, spatial-temporal learning and neurogenesis, which is the brain's ability to produce neurons.”

University of Central Florida (nd)

The music I create for Musical Hydrotherapy includes a variety of sound textures, not fixed by particular set rhythms or harmonies. It invites the listener to creatively engage with the music through stimulating the imagination. I also include sound that mimics the effect of brainwave frequencies, particularly Theta waves. Theta activity has a frequency of 3.5 to 7.5 Hz and is classed as “slow” activity. It is seen in connection with creativity, intuition, daydreaming, and is a repository for memories, emotions, sensations. These run in the background of the mix with the intention of subliminally entraining the listener's brainwaves to this relaxed “slow” state.

I also curate a playlist made up of my own compositions and those of other musicians, selected for their creative merit and ability to create, guide and accompany the journey of relaxation and introspection, bringing the listener close to the transitional state between being awake and being asleep (<https://www.liquidlistening.org/playlist>). This invites the listeners to relinquish the need to control the situation and allow for the water and the aquatic body work to do the rest.

Musical Hydrotherapy; spaces through sound and in water

There is an overlap between spaces for art and spaces for healing. Perhaps it traces back to tribal societies where the shaman was the storyteller and the healer of the tribe. In art presentations, the environment determines the way the audience will approach it.

Similarly, for a treatment to be effective, the recipient of the treatment has to be receptive and welcoming. The environment of the treatment is very much part of the remedial effect.

Our experience shows that unifying the space for art and the space for treatment through Musical Hydrotherapy in such a relaxed environment can have a very positive effect on the recipient's wellbeing. This is based on research we conducted with The University of Roehampton in 2015 (led by Adam Ockelford) and on dozens of filmed and anecdotal testimonials from school staff.

Since 2010, we have been delivering this artistic experience to children and staff in hydrotherapy pools at a number of special needs schools across the UK. The practice is carried out in a warm pool heated to 34c, with the standard white lights turned down. A trained staff member receives the child in the water, after being changed to swimwear in the changing room, and delivers a very calm 30-45min session in the water. Some children are more reluctant to be taken into a floating position straightaway but the music playing underwater offers an invitation to lie back and listen. Gradually, sometimes after several sessions, even the more agitated and reluctant children can experience calm and uncharacteristic relaxation that lasts throughout the day.

The staff member supporting the child is guided to ‘listen’ to the recipient. The practitioner develops a sensitivity to be able to follow their movement or lack of movement in the water with little intervention. The focus is on ‘being’ not ‘doing’. Liquid Listening's aquatic bodywork trainer Steph Hodgson's writes :

“This is particularly relevant to the children with complex disabilities, particularly those with limited mobility outside the water, who much of Liquid Listening's work focuses on. Often children arrive in the water “wheelchair-shaped” as well as full of tension. Being in the warm water in a hydrotherapy pool is a huge release and freedom in itself for them, but the real impact happens when the child is “met” and held by the practitioner, the vibrations from the underwater sound travelling into their bodies. The practitioner feels the child's nervous system letting go and entering a state of deep release, which in turn allows their bodies to release muscle spasms, release suppressed emotions, overwhelm or trauma, reduce agitation and enter a state of deep calm”. (<https://www.liquidlistening.org/who-we-are/meet-steph-hodgson-blog>)

Underwater, listening becomes a personal inquisitive journey. Underwater, the directional sound, that gives us a sense of space above the water, disappears and collapses inwards. Sound is perceived through bone

conduction, it is heard as if resounding from an inner voice. There is not a more personal and intimate experience of sound.

Floating buoyant in liquid evokes sub-conscious memories of our first 9 months of pre-natal existence, when sound and vibration were our first indication of something other than ourselves, when we were receptive and listening.

The hydrotherapy pool transforms into what only can be called a sacred sensory space; a space for treatment as well as a space for the reception of art in the form of music. The success of the practice hangs on the great care taken to maintain and hold the space as such.

Impact

It is difficult to obtain direct feedback from most of the children we work with due to their limited ability to express themselves verbally, so it is not clear what their impression is of the music or the support they receive. Nearly all of them relax and their behaviour transforms during their session. The teachers who know them well, remark on the changes they witness and note that they have found the experience to increase the pupil's self-regulation.

The impact is also noticeable among the teachers trained in Musical Hydrotherapy who attune to the pupils they are working with. Within many learning environments, the space to interact and simply spend quality time with pupils is missing. Some teachers who experienced Musical Hydrotherapy commented on how they felt they were taken on a journey, others found it incredibly emotional and were deeply touched by it. They were also touched by the, at times immediate, effect they see on the children's behaviour and their abilities to self-regulate.

Conclusion

Just as a well-designed environment can enhance the reception of art, creating a conducive space for treatment can maximize its effectiveness. By optimizing the surroundings to promote comfort, tranquillity, and accessibility, individuals undergoing treatment can better engage with the process, leading to improved outcomes and overall wellbeing. Incorporating elements of artistic expression, and sound in particular, into treatment spaces not only enriches the sensory experience but also cultivates an atmosphere conducive to relaxation, introspection, and emotional expression. As a result, individuals undergoing treatment are better positioned to connect with their inner selves, engage more deeply with the healing process, and ultimately achieve more favourable outcomes.

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Joel Cahen is a sound designer, composer and curator. He is also the co-founder and artistic director of the charity Liquid Listening. His award winning, internationally acclaimed project Wet Sounds has transformed swimming pools worldwide into art spaces. More on his work on www.newtoy.org

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HOP 9 – When HOP takes a little tumble...

Sheridan Forster

In the previous edition of PMLD Link (Winter 2023), I wrote about the “ingredients” for making a Hanging Out Café. The event, held in October 2024, with a dozen people with multiple disability felt like a resounding success.

Then I received this feedback: “Feedback my staff gave me was that they felt the session was silly and it made them feel insecure in their abilities as support workers (SW) and uncomfortable.” Strangely, I could not be more grateful and humble for the feedback. Let me share a little context; a couple of minutes during the Hanging Out Café.

A man and I were seated by each other, both in our wheelchairs, within arms reach of a table with papers on it. He was hunched forward, perhaps had been for decades, with his vision marked by his lap and perhaps a few inches ahead of him.

At some point, I don’t know why, I handed him the HOP booklet – this meant, I picked up the book, and placed it under his fingers, and waited for him to grasp it. Slowly, gracefully, he lifted his hand and the book, took it to his side, then dropped it over the edge. His face belied no meaning, or maybe there was a tiny eyebrow rise. My mind said “he can grasp and drop, let’s see if this can be our moment”. I slowly handed another sheet of paper. Again, the delicate grasp, wave out, and drop (I wish the words caught the beauty). For me, it was a conversation as deep and warm as any with words.

“We gotta go now,” said his support worker, grasping the wheelchair handles.

“Wait a second, we’re having a chat”, I interceded, and then continued the conversation without words between the man and I.

In the situation I was absorbed in the moment. Sitting back now, I see the situation differently. Through the support workers eyes I can see that this strange performance would have looked silly, baffling, bordering on a behaviour... I can see how this odd woman “talking back” at him, undermining his authority and oversight of duty of care could have led to insecurity.

I can see that the workplace culture and education of the support worker would have left him disrupted by my behaviour and the behaviour that I was engaging in with his charge.



It is valuable for me to step back. To pause. To understand the situation for those who are differently engaged beside people with profound intellectual and multiple disability.

The challenge now is to work out how to step forward... I must work forward in a way that understands the reality for those who view interaction differently from me. A way that does not view them as empty vessels in need to be filled with my wisdom... perhaps softly owning my story, listening to theirs, and exploring a new one together.

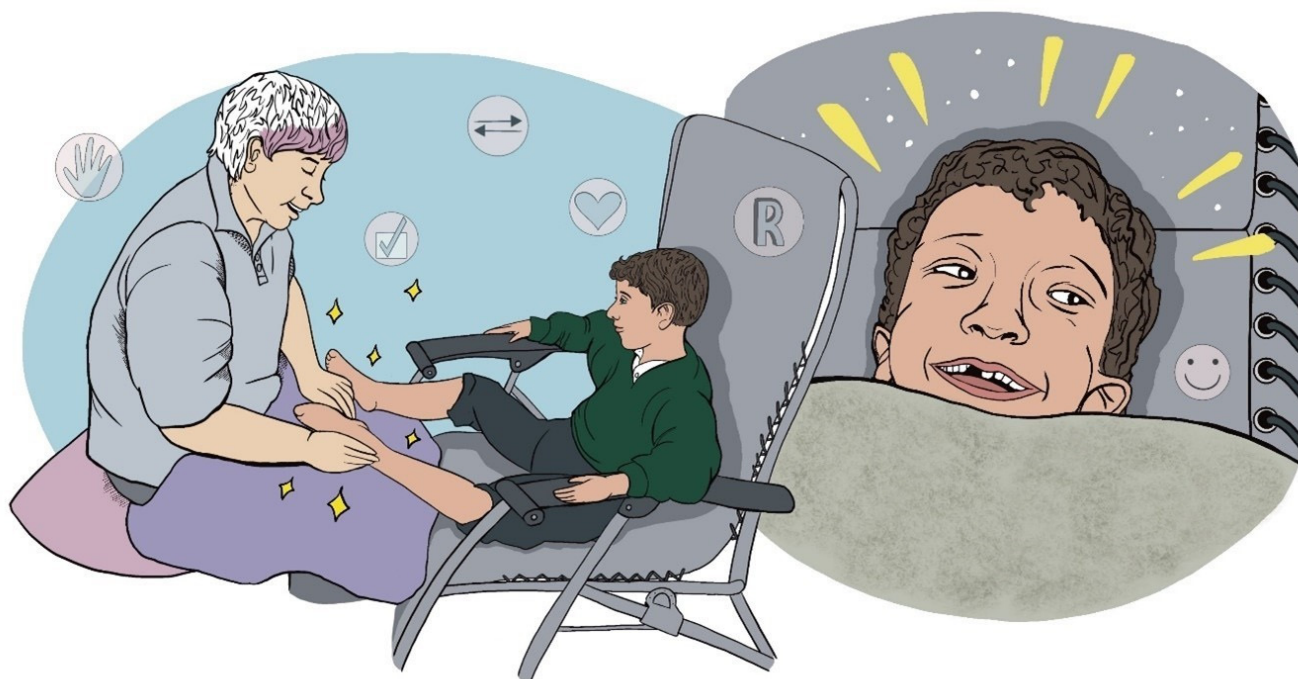
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A reflexology perspective on wellbeing

Lorraine Senior

Reflexology is an ancient touch therapy practiced and cherished in many parts of the globe but only more recently introduced to the western world. The Association of Reflexologists (AoR) refer to Reflexology as a non-invasive complementary therapy which is based on the theory that different points on the feet, lower leg, hands, face, or ears correspond with different parts of the body. Reflexologists, guided by these principles, passionately believe that applying pressure and movements to reflex points within these areas encourage relaxation and enhance overall wellbeing.

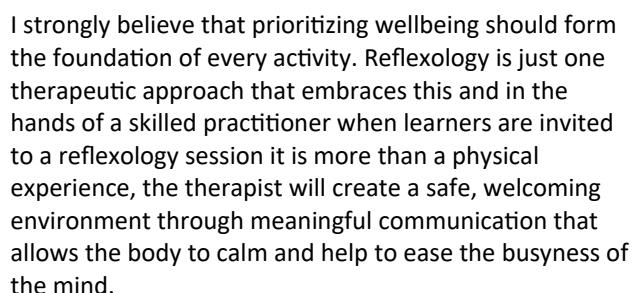
There are many different methods, techniques, and approaches under the huge umbrella of reflexology. Functional Reflex Therapy (FRT) is just one approach with a unique framework that offers support to the reflexologist. It brings a specific intention and purpose to the session, draws a clarity, and focus and where appropriate includes the use of the FRT tool kit which may help with building and establishing the therapist client relationship, encouraging engagement, interaction, understanding and having a little fun. The overall framework raises awareness of the time that may be required for a person to gather, process, and respond to information.

While this therapeutic support is beneficial in a variety of settings, my primary focus has been enhancing emotional wellbeing during the school day. Give a moment to envision the potential of making this valuable therapy accessible in every school throughout the world embracing the diverse needs of all young people, helping them to be in a better frame of mind to cope, to manage

and to thrive. Then take a further moment to recognise that this approach is not only for schools, but it is relevant to a much wider audience and inclusive for all ages.

There is no intent to diagnose conditions, to prescribe or cure, reflexologists respect the uniqueness of every individual. Although we cannot truly say how the body will respond to receiving this positive touch therapy, most people who have received reflexology often feel relaxed and may notice a feeling of improved mood and general wellbeing.

When I think about the word and concept of 'wellbeing' many things run through my mind – comfort, contentment, acknowledgement, respect, active listening, time, choices, fun, connections, having a purpose and effective strategies to cope with stress and tension. The essence of wellbeing is surely a merging of all these, leading to satisfaction for the best quality of life and I'm sure you can find many more to add.



In the quiet surroundings of the reflexology therapy room, emotions can find a gentle outlet and tears may flow, becoming quite a powerful prompt for releasing tension, contributing to a profound sense of wellbeing. While not a common occurrence, I am familiar with these moments of emotional release, and I recognise their significant impact on both physical and mental health. One young person's reflexology story stands out, where the end of the session occasionally brought a release of emotions through tears (Senior, 2024). Bringing the session to an end, simply being respectful, sitting quietly together, holding hands, provided a valuable and sufficient connection, allowing time to re-balance, regulate and then eventually a smile. And back in the classroom the opportunity to share if he wanted to through his eye gaze to tell me how he felt and what he thought! Along with answering the important question would you like to go for reflexology next week.

expand their skills and develop their business within this field. FRT support has additional pathways where the qualified Reflexologist may share simple techniques using the principles of reflexology to empower parents and carers with the FRT Rainbow Relaxation routine to use within the comfort of their own home, and the FRT Rainbow Relaxation Programme with positive touch relaxation skills to use within the classroom is available with myself and supports the wellbeing of young people and staff.

Contact details

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Oracy and Wellbeing

Rebekah Clee

Oracy is all about talk and how we communicate. It is the opportunity to interact and develop language. Oracy is key to developing and building the relationships around us. It is the way we express and share our needs and wants with others.

Wellbeing and Oracy are interlinked. Communication is a means through which we can enjoy being together and the way that we can share this with others. Therefore, always taking time to communicate with others is essential. A large element of wellbeing starts with placing Communication at the heart of learning. Communication in education starts from the moment a young person comes into the school environment. Everyone has a responsibility to support and build on empowering all pupils to use their own communication methods. Communication, in its simplest form, includes the welcome we give, the gestures in passing, the time to say hello. It is about building pupil inclusion and a sense of belonging with the world around them.

We all need to take time to value every communication, ensuring we don't miss any opportunities to communicate and to always show that we are supporting wellbeing. I am passionate that we need to really understand and develop Oracy opportunities and build expectations. "On average, oral language approaches have a high impact on pupil outcomes" (EEF, 2021:pg1).

As a Literacy Lead in a school for learners with profound and multiple learning disabilities (PMLD), I wanted to explore and understand what opportunities enabled the pupils to make progress in their communication journey. I took time to look at how Oracy and wellbeing are supported in the school and what this looks like.



Why is Oracy so important?

Oracy is giving every person a voice – spoken words or other ways to express themselves. That voice is individualistic, and may be a smile, a gesture, an eye movement or a simple interaction. Oracy is the time and the space to be able to talk, express and grow from these opportunities.

Every day all our pupils will use their own unique voice but it is our responsibility to value the voices around us. When we are truly listened to, we are indeed truly valued. This value is how the communication spark grows. It encourages pupils to further speak or communicate, starting to build a real depth of learning. These are the foundations of Wellbeing, for what is more valuable than knowing you are heard?



"Oracy refers both to the development of speaking and listening skills, and the effective use of spoken language in teaching and learning" (APPG, 2021). This may be through Makaton, eye gaze, communication devices and many more assisted ways to help build and share how we express ourselves.

Communication for pupils with PMLD can be seen in many ways. Each pupil has their own unique and amazing way to be understood and to communicate. We have a responsibility to take time to develop these pathways of communication to understand and find a person's chosen communication approach or system - and to utilise it. In school we often talk about a total communication approach. This includes the opportunity for developing and understanding how we can start the journey of building a person's preferred communication method.



There are many different approaches and some build and develop as they are used, extending and creating new learning. The most important factor is that communication approaches are bespoke to the person using them, knowing we are the bridge to finding the best ways, each and everyday to open up communication.

Intensive Interaction is one opportunity to really stop and say we value the way you communicate. Intensive Interaction is a beautiful and intensive approach to working together. It is a communication based on acknowledging and using a person's own communication techniques, movements and responses. It provides the opportunity to empower interaction, with the pupil leading and choosing how they wish to communicate.



The importance of providing literacy for all, can be powerful. Most recently I witnessed a non-verbal pupil with PMLD show they can recognise whole words. This

was seen whilst providing words, symbols and pictures used together within a sensory story which engaged and captivated their attention. Reading, stories and interactions with songs and rhymes can be key in building this learning further.



Oracy develops social opportunities, demonstrating the importance of time together and the joy of friends and social play. These social times can often be a barrier for those with communication needs and PMLD. In schools, simple changes can start to remove the barriers. For example, ensuring pupils are near or facing each other to create the beginnings of social interactions and taking the time to build and support blossoming friendships, though fun and interactive group sessions.



I found that simply being aware of the barriers became the starting point of change and we enjoyed seeing the interactions and fun as they grew.

Always working in a person-centred way enables the best opportunities to create wellbeing. What do I enjoy? How do I communicate? What are my goals and aspirations? In school we found that pupils grew from sharing their amazing skills. A pupil who loved reading was encouraged to sit with the younger children to share a book. A pupil who was learning to use their communication device joined a social group where 3 other pupils were chatting on their devices. These are just some unique ways to create Oracy opportunities.

Irresistible invitations to play has to be another way to open up Oracy and build wellbeing. Taking time to see what others enjoy and then extending or building on this. Taking time to absorb new environments and explore how we see the world around us, can create chances to open new language opportunities through excitement and pleasure.

Language and communication can be complex and often, as we aim to support a person with PMLD, we may struggle to navigate the correct approaches. Oracy is a journey that we undertake with each pupil that we work with, support and care for.



Every interaction has power and enables a deeper connection in building communication and value, increasing a sense of belonging and wellbeing.

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Five Ways to Wellbeing; towards a framework

Pete Navarra

The term 'wellbeing' has a range of meanings and definitions. The Oxford English Dictionary's definition for wellbeing is a person's state of being healthy, happy or prosperous. It is a term widely used across many sectors of society including hospitals, schools and workplaces. Research has found that there is a link between wellbeing, physical and mental-health, and the accomplishment of goals and academic achievements. But how do we think about wellbeing in terms of people with profound and multiple learning disabilities (PMLD)?

Five Ways to Wellbeing (Aked et al., 2008) are a set of evidence-based steps or actions developed to promote healthy wellbeing:

- Connect
- Be active
- Take notice
- Keep learning
- Give

Over time this framework has been adopted by many organisations (e.g. NHS, 2022).

This article aims to give some starting points and ideas that could be used to address each of these steps, making them relevant and accessible to someone with PMLD. Of course, these ideas will need to be adapted and made relevant to each individual. A creative approach will be essential to ensure people with PMLD have new and exciting opportunities to improve their wellbeing, as well as supportive, positive relationships with others in their lives.

Five practical steps to mental wellbeing for people with profound and multiple learning disabilities

1. Connect with other people

The focus for this part of the strategy is the building and the maintenance of positive relationships:

- Take time to coactively explore and play with an object/material the person seems to like. Take turns in exploring the item, demonstrating a shared interest and thus opportunities for connection; positive sounds, words and facial expressions can be used to communicate this. This process can be repeated so that over time the sequence of the game will become familiar, allowing anticipation and a sense of security to develop.
- Intensive Interaction is an approach to communication for people at an early stage of communication development. The approach supports individuals to enjoy interactions with others, and to learn the fundamentals of

communication, such as turn-taking, and the use and understanding of eye contact. This often intuitive, communicative approach can support people to connect and to take part in conversations and interactions, with or without any need for the use of words.

2. Be physically active

Being physically active improves fitness and evidence shows it also improves mental health and wellbeing:

- Place an item of interest where the person can see it, preferably within their mid-line and within arms-reach so that it can be retrieved. Once achieved, allow this item to be explored before placing it slightly further away so that an increase in movement is required to reach it again (making sure this is a playful exercise and not likely to cause any frustration). The item can also be placed at different angles from the mid-line thus encouraging a range of different movements.
- Coactive supported movements can be in different ways e.g. in hydrotherapy, used in the form of dance or by re-enacting the movements of different sports like basketball, tennis or cricket.

3. Learn new skills

Learning new skills can enrich an individual's sense of self by improving understanding and allowing them to gain the positive response success can bring:

- Set up a range of cause and effect activities so that the person's actions can quickly receive feedback. A pyramid of plastic cups can be stacked so that they can be easily knocked down, creating a visual and audible impact. Switches can be connected to lights, a radio or a fan so when pressure is applied a clear cause and effect result is evident.
- Use a range of foods/ingredients that have varied textures and smells; explore them individually before adding to a plastic mixing bowl. Repeat this process until all the ingredients are in the bowl. Mix them together using hands, feet or any utensil that is appropriate: a sensory dish has been created, explore the results together.

4. Give to others

Acts of kindness and giving can improve mental wellbeing.

- Explore an item with the person, maybe something you use frequently or even something you wear (a hat, a scarf?). Allow it to be explored and manipulated. Support the person to return it to you, and respond with positive facial expressions and sounds/words to communicate your thanks. Repeat as a game, involving anticipation and developing the idea of 'giving'.
- Play a game with a ball that involves passing it back and forth to each other, ensuring everyone can access the game. Celebrate and show your appreciation each time you receive the ball.

5. Pay attention to the present moment (mindfulness)

- Being aware of the present moment, of thoughts, feelings, or the world around us can have a positive impact on our wellbeing. Try sitting in silence, facing each other for an extended period of time or maybe next to one another whilst looking out of a window. If a sound or movement is initiated interpret this as the start of a conversation and reply using the strategies of Intensive Interaction, as described above.
- Position a warm foot spa so that it can be comfortably accessed. Consider the use of essential oils to stimulate the olfactory senses, and lights to support a calming ambiance. This multisensory approach may support relaxation and offer an opportunity to de-stress (but remember that a person's preferred smells and lighting may be different from yours: talk to those who know the person well and observe responses to find their preferred options).

Ideas to develop opportunities for wellbeing are potentially limitless and definitely individual to everyone, with or without a profound learning disability. Keep a note of people's experiences and reactions to ensure accurate records are in place about individual likes and dislikes, and make sure records are updated when necessary. A positive sense of wellbeing is important for everyone, so use the above ideas to get started.

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Here is where hope begins

Jo Grace

The training days that I offer take years to build, and in them is collected and curated wisdom from hundreds of lives. When I began working on the Sensory Engagement for Mental Wellbeing day, I was motivated by having read so many articles about the poor mental health of people with profound and multiple learning disabilities and the lack of support for them in this regard. Once it was developed I offered it to people and no one booked on it. I ran it twice as a ticketed event and a handful of super-dedicated people attended. Fast forward ten or so years (counting accurately would make me feel old) and it is my most booked training day, and the online version has been studied by people all around the world. When I was setting it up I felt very alone, but now we have organisations like NAC wellbeing and an all-round growing awareness of the importance of maintaining mental health alongside physical health for everyone.

People with profound and multiple learning disabilities are highly vulnerable to mental ill health but their access to support is limited. Knowing how to promote the mental health of people with profound and multiple learning disabilities can empower those who love and care for them. As with physical health small strategies used often can have a powerful impact. (It is like always eating an apple instead of a packet of crisps). In this article I'm going to share a couple of these little strategies that you can use regularly to promote mental health for people with profound and multiple learning disabilities.

Hope

People in a depressed mindset feel that things are bad and will always be bad, central to this experience is the belief that things will not change. We could consider hope to be the opposite of this feeling, people who are hopeful believe that things might change, and might change for the better. Hope is quite an abstract concept to be thinking about in relation to people with profound intellectual and multiple disabilities but if we find a way of sharing this idea of things changing, and changing for the better we are on an experiential level, talking about hope.

The person with profound and multiple learning disabilities that you know likely has an item they love, a sensory toy perhaps in which they delight. For one of my friends, it is a pink rubber toy that squeaks when it is waved. She is given this toy often. Her experience of the world is either one with this toy in it, or one without that toy. In the world without the toy she is okay. But in the world with the toy she is overjoyed. Those around her all know how much she loves it so they give it to her often. Here is my little mental health tweak to that: take her the toy, but take it hidden inside the box or bag it is kept in. Like many people with profound and multiple learning

disabilities she has a zone of engagement that is very close to her body. My advice is to bring the box containing the toy into that zone of engagement and then reveal the toy.

What happens when you share a reveal like this, is that the person experiences the dull everyday world where the toy is not, CHANGING into the bright and joyous world where the toy is. Multiple experiences of a reveal like this can develop the sense in a person with profound and multiple learning disabilities that the world as they know it can change into a world where great things happen. It is hope at an experiential level!

Agency

I have a shed full of sensory resources and I can often be found digging through boxes in search of the thing I've just realised is exactly right for the story I want to tell but unable to find it anywhere. When evaluating sensory resources, I am looking for something that draws the attention of a sensory system. I want interest in it to begin with sensation, so that it includes as many people as possible, I do not want it to be reliant on understanding, just for understanding to be a bonus. To give an example: a cuddly toy might be interesting to look at for someone who understands the toy represents a character in the story, but without that understanding why would you look? Does it light up? Is it a neon colour? Or is it brown fluff? I want a sensory reason for you to look. Sometimes I look for things that will fill a whole sensory system – for example looking through coloured cellophane. Imagine me digging through my shed, picking things up and evaluating them in this way. If I were to evaluate the resources in accord to their benefit to the mental health of people with profound and multiple learning disabilities (PMLD) top of my audit list would be agency.

Agency within sensation is found in any sensory experience that contains within it an “I did that” or an “I am”. To explain this I’ll give you some with and without examples, so for example: You could have the most amazing projection wheel spinning above a person – it would fill their visual field, it would draw the attention of their senses without their needing to understand, it would be a glorious sensory experience, but – it happens whether they are there or not, whether they shout or not, there is no “I” in that experience. In contrast a foil space blanket (always so popular in the sensory world) might attract the attention of someone’s vision because of the way it sparkles in the light, and if they move it will change, the light will bounce in a different way, there is “I” in that experience.

When people with profound and multiple learning disabilities encounter experiences in which they can have agency, even at a very simple level, they learn that they are people who can effect change in the world. Feeling like you can effect change sits opposite feeling helpless.

People can feel ill-equipped and out of their depth when it comes to supporting the mental health of people with

profound and multiple learning disabilities. I hope that the simplicity of small tips like these encourages people. Ultimately whilst the physical health care needs of people with profound and multiple learning disabilities may be dramatically different to our own, their mental health care needs are surprisingly similar.

Contact details

Joanna Grace is a doctoral researcher studying identity and belonging for people with profound intellectual and multiple disabilities and the Founder of The Sensory Projects.

Through The Sensory Projects Joanna provides in person and online training aimed at those who support people with profound and multiple learning disabilities. She is active on social media and always welcomes new connections.

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Songs, Signs & Sounds: Online Music and Wellbeing Sessions for Young People with Complex Needs

Georgie Lockett and Karen Nicholson

We launched Songs, Signs and Sounds two years ago as a disruptive social enterprise that offers high-quality musical experiences for young people with additional and complex needs. We deliver weekly online music sessions 52 weeks of the year, free for 12 hours or available via subscription. These pre-recorded, interactive sessions are aimed at people with special educational needs and complex disabilities (SEND), and are a mixture of music making activities, wellbeing techniques and sounds.

When the world moved online during the pandemic, it became very clear that online resources were needed by SEND families. We noticed that these remote, yet accessible sessions became a vital support, not only in providing high-quality music making opportunities, but also in creating a real sense of community. We realised that many families were being isolated from accessible music resources, and that wider provision was really lacking. And so, Songs, Signs & Sounds was created! We want to change this lack of access by creating fun, interactive and affordable music sessions that reach as many people with additional needs as possible. We also wanted them to be convenient and flexible enough to fit in with individual routines.

Each week a brand new session is released and follows a clear and familiar structure of:

- Welcome song
- Hello song
- Exploration of a song (in a variety of genres)
- Shake break
- Sound Journey (based on theories of sound healing and sound therapy)
- Goodbye song

We (Georgie and Karen) both have a huge interest in music and wellbeing and are certified sound therapists. It's important for us to incorporate these skills into our sessions to provide accessible sound healing techniques to those with additional needs. After receiving videos and feedback from parents on our weekly music sessions, it soon became apparent that the 'Sound Journey' section of our sessions was a firm favourite with many of the participants. After this revelation, and as a result of wanting to provide additional content for our paid subscribers, we decided it was time to create live sessions, once a month, purely devoted to music and wellbeing.

We wanted to create a session with a calmer environment; a safe space for our young people to feel heard, seen and validated. They already live in a world where many things are made inaccessible to them, and music and wellbeing should not be one of them. Everybody deserves opportunities to relax, de-stress and access opportunities which are good for the mind, body and soul.

So, this marked the start of our newly created Music and Wellbeing sessions. In the sessions we welcome all participants calmly and gently through music and singing. After this, we provide a feelings 'check-in' using both auditory and visual cues. The session then begins with the sound of the singing bowl; it also ends with this sound to give a clear auditory cue for participants, signalling the beginning and end of the music.

We each select a sound maker which we play individually, and then to a specially created backing track of calming sounds and music to encourage listening and reactive responses. We also encourage intoning, vocalisations and movement through the music – allowing our participants to be present in the moment and allowing as much time and space as is needed; watch our short video to see what this looks like! (link to video <https://www.songssignssounds.co.uk/music-wellbeing>) One parent wrote this feedback: "Thank you so much for last night's session. We slept like a log after taking part, he was so vocal and engaged in the session it was lovely to see. Watching him close his eyes and fall asleep while being sang good night was such a special moment."

Another sent a photo annotated with this feedback:

"Thank you for making her smile . Her chest has flared up again and she's feeling pretty rubbish, so was lovely to see her just listening and enjoying the session. Can never thank you enough for providing these sessions for us to access whenever we need xx"



These sessions are so important for the health and wellbeing of our young people; they allow them to just simply be and go where the sound or music takes them. Sometimes, this is a change in breathing, a smile, or sessions can provoke a sound or movement. Whatever it may be for the individual, it's important to us because we are saying – we see you, we hear you, you are safe, and we are holding this space for you right now in the way that you need it.

One of these sessions was recently used by a parent to calmly bring round their child after a hospital procedure. They wrote: "As per usual we were refusing to wake up after surgery. Nurse just came in to wriggle her about and I could see her eyes flickering and I said she just doesn't feel safe here. She's ok, we just need to get her

home, but to get her home she needs to wake up, so it was over to you. First attempt we managed to get eyes open immediately!"

These sessions are a firm favourite for us too; through the slower and calmer pace of the sessions we learn a lot about our own practice, both through the music and our young people. It gives us time to reflect. It slows down our busy minds and allows us to be present in that moment with them. It's a magical experience that allows wordless conversations to happen on a much deeper level of understanding.

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Songs, Signs & Sounds Music and Wellbeing sessions are free for our SS&S Patreon subscribers or £20 for non-subscribers.

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The importance of promoting relationships for learners with PMLD

Aimee Prentice

When thinking about wellbeing, it is difficult to separate this from relationships with the people around me, my support network of family, friends, and colleagues. Meaningful relationships are an important part of life, and this is something that I am very mindful of when I think about our learner's time with us at school. This is also outlined in the Core and Essential Service Standards (Doukas et al, 2017) which state that a sense of belonging is a vital element of an individual's quality of life. Therefore, an important question that I often ask myself is, how are we ensuring that our learners can form these relationships that so often shape who we are as people?

Within the Engagement for Life Curriculum we have a dedicated strand called Making Relationships. The thread acknowledges the importance of supporting the development of relationships to promote wellbeing. It also sets out a series of skills and experiences designed to enable learners to engage in activities that promote active participation and the formation of nurturing relationships.

When the curriculum was written in 2017, social interaction was covered in the communication aspect of the curriculum. During trialling of the curriculum, it became apparent that for this area of the learner's development social opportunities and real-life application are more important than functional skills development. It is not just the act of being able to expressively communicate but the intention behind the interaction which is important. Learners should be encouraged to seek out interactions to gain the attention of others. Approaches such as Intensive Interaction encourage a learner to develop social communication skills such as turn-taking, shared attention and engagement.

The intention of the Making Relationships strand is for learners to develop their interpersonal skills, enjoy the company of others and form special friendships. Hughes (2011) proposes that friendship is especially important for people with the most profound learning needs but acknowledges the challenges in facilitating this. Amongst these challenges are sensory impairments, communication difficulties, differences in interests and abilities. Robertson et al. (2001) previously identified that learners with profound and multiple learning disabilities (PMLD) typically have highly restricted social networks. Therefore, the Making Relationships strand intends to bridge the gap by championing these relationships and empowering both learners and the staff that support them to develop their skill sets.

Learners with PMLD are reliant on others and therefore need the skills to develop trusting relationships with the people around them so that they are active participants within a given partnership, rather than passive bystanders. But more than this, if we are to say that relationships are integral to a good quality of life, and we acknowledge that people with PMLD are more likely to miss out on these relationships, then a successful curriculum must meet this need.

Making Relationships is taught through the lessons of Social and Emotional Wellbeing which occur four times per week. There are discrete activities that can be taught such as Intensive Interaction, 'ready, steady, go!' type activities, and turn-taking games. Importantly there is an understanding that due to the nature of our learners a cross-curricular approach is also required, with practitioners looking for opportunities for skill development throughout the day.

Every learner has a designated key worker who will get to know them well, documenting their likes and dislikes through a wellbeing communication passport. This is constructed on the idea that learners will be most successful with an adult that they are close to and who understands them. This enables staff not only to facilitate choice-making but also to introduce opportunities and new experiences for the learners. It is these relationships that are also essential in all other areas of communication when working closely with learners with PMLD. The first step within Making Relationships is concerned with creating these relationships with key workers at school. Key workers play a vital role in enhancing the quality of life for learners with PMLD by providing personalised support, advocacy and encouragement tailored to their unique needs and abilities. This reflects the early developmental attachment need of the learner. However, it is also important that learners do not get too attached to one person at school because when that person is absent,

this break in a relationship can be detrimental to wellbeing and learning.

Playfulness should be encouraged at every turn because it is important in enabling the development of emotional, cognitive, and social aspects. Playful activities offer learners an opportunity to become actively engaged and interactive. Within Making Relationships we look at how the learner is responding to both adults and peers and how they respond to the actions of their peers so that they are supported to form a special friendship with these peers.

The concern is then how to encourage playful behaviour with learners who may not play naturally or have some measure of difficulty with the challenges involved in social interaction. It could be seen that there is potential for the notion of playfulness to become a secondary or forgotten consideration in the day-to-day routine of the classroom, with positional needs, personal care routines, and mobility aids taking precedence. One way to overcome this could be training around the value of playfulness so that practitioners appreciate the significance of this and how it can be incorporated into these necessary routines. Further training around Intensive Interaction could also be a useful technique in promoting playfulness.

For friendships to be meaningful, there is a need to maximise the time for this to happen. By creating a school culture where playfulness is embedded into daily routines as well as in play activities this could be beneficial in supporting the further development of playful relationships. Watson (2014) argues that children with PMLD are playful and that promoting playfulness could have important benefits both for the children and for those around them. These include increasing stimulation, communication skills, and responsiveness. It is further suggested that the close connection developed through playfulness can boost self-worth. While there is an historic absence of PMLD specific focus within academic and professional-level discussions regarding curriculum policy and practice guidance, documents such as the Core and Essential Service Standards (Doukas et al 2017) evidence the development of wider conversations concerning research into bettering the lives of people with PMLD.

I feel that we have been able to develop a curriculum that attempts to empower learners and champion their right to make meaningful connections with people around them.

Contact details

Aimiee Prentice is a teacher who has worked with learners with PMLD for over a decade. She currently leads the Engagement for Life Pathway at a large special needs school in the UK, working with learners aged from 2-19. Aimiee is also a master's student on the PMLD/SLD pathway at the University of Birmingham.

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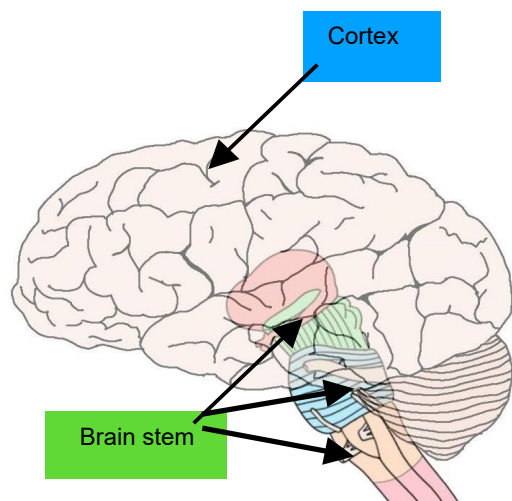
Neuroscience, Narrative and PMLD

Nicola Grove

In 2021 Mark Solms published a landmark text which asked what consciousness means for an anencephalic child. Anencephaly is a birth defect whereby the neural tube fails to close, and the foetus lacks the largest part of the brain. This includes the neocortex, which is responsible for cognition and thinking. As learning and intellectual disabilities are associated with cognitive impairment by definition, understanding how different parts of the brain work together is important for all of us who live and work with individuals with profound and multiple learning disabilities (PMLD).

Mark suggests that the seat of consciousness lies not in the cortex (the higher levels of thinking and reflection), but in the brainstem with basic emotions. By restoring feelings to the centre of what it means to be human, we are led to re-evaluate the way we think about identity, selfhood and learning. This provides exciting opportunities for exploring how we live and work with individuals who have PMLD.

In April 2022, Mark gave a webinar presentation organised by PAMIS. What follows is my attempt to put the key aspects of the theory from *The Hidden Spring* (Solms, 2021) into the context of my narrative work with children and adults who have severe and profound intellectual impairments¹ (<https://pamis.org.uk>).



Traditionally the cortex is thought of as the seat of conscious action and thinking. Mark's theory turns this around; he shows that cortical activity is unconscious, and the seat of consciousness is actually a tiny area in the brainstem. Mark claims that children born without a cortex are emotionally conscious, and that means that they are a) aware and b) can learn from experience. So what is the purpose of consciousness, and what is the process by which consciousness occurs?

Consciousness, Memories and Emotions

To successfully process stimuli within the environment, the brain needs to be able to predict what is going to happen, and ideally this is automatic, learned behaviour that enables us to return to a settled state from an aroused state. However, not all environments are predictable. There are always novel, unpredictable situations that we encounter. The disruption of encountering uncertainty leads to arousal of emotions which are consciously felt. These feelings help the person to evaluate whether the uncertain event/experience is positive or negative. This in turn stimulates perceptual arousal in the cortex and supports the person to evaluate e.g. "I feel THIS (emotional consciousness) about THAT (perceptual consciousness)". This is how we learn from experience.

Over time, these experiences may form memories. Memories are generated from images of sensory perceptions, which come together through an emotional memory trace (cf. *Bodily Emotional Traces*, Janssen & Rodbroe, 2007). The perceptual images provide the context for the emotional evaluation (I feel THIS about THAT). The process results in a virtual representation of the world at cortical level - both the sensory impressions, and what we feel about them. This memory is preserved and consolidated at an unconscious level (so that when you encounter the same situation, you can predict how to act) - but if the consequence is NOT what you expect, the memory trace is re-activated, becoming "live" or unstable, so that a new prediction can be made. Feelings are THE most important aspects of our existence. They are not just reactive, they are what enable consciousness and prediction. Emotions can be experienced without self-awareness, and they are not a precondition for the experience of emotions, only the recognition and labelling of them. This is why non-human mammals who lack a sense of self are nevertheless capable of experiencing emotions. Emotional arousal enables voluntary behaviour (i.e. intentional, willed activity; making choices of how to act in the here and now) and learning. Interestingly, the higher levels of emotions inscribe more deeply in the channels of our

brains (p131). It follows that uncertainty is the key driver of learning.

Key Reflections

It's important to bear in mind that Mark Solms chose extreme cases of brain damage to illustrate his theory. But hydrancephaly (lack of cortex) is extremely rare. Hence we can hazard a guess that most of the individuals described as having profound and multiple learning disabilities, with whom we live and work, will have some level of cortical functioning.

Our starting point is that the way we respond to individuals is absolutely critical. Nurturing environments and loving relationships are fundamental. We need to:

1. Recognise that people who have cognitive impairments affecting cortical (higher level) brain functioning, are emotionally conscious, and aware and possess selfhood. They may not be able to consciously reflect on what the feeling is, or what it means, but they do experience a range of emotional reactions. Mark suggests that we tend to think of meaning as language based, whereas it is affective meaning we need to explore. Affective meaning is conveyed through behaviours and tone of voice more than the words themselves.
2. Recognise and make room for, the expression of the basic emotions. In practice this may mean recognising and helping someone to manage FEAR; giving them opportunities to CARE for others or for animals or plants; ensuring they have opportunities for SEEKING - exploring and being curious. We mustn't forget the interoceptive (e.g. calm) and sensory effects as well.
3. Recognise that a degree of uncertainty is essential to enable us to learn from experience. It is the management of that uncertainty that is critical (because however hard you try as a service provider or family member, you can't eliminate uncertainty altogether. Uncertainty stimulates cortical function ("Consciousness is felt uncertainty").
4. Recognise how memory works; stimulating, consolidating and reconsolidating memories is the basic process underpinning learning from experience. We must recognise that people with PMLD do remember. They may not be able to think about their memories, but they have them - emotional, sensory and procedural. Memories can develop, change and disappear.
5. Recognise that the process of encountering uncertainty leads to emotional arousal, and activated memory traces, stimulates voluntary action, cortical awareness, and conscious perception. It is up to us to help individuals to manage and use it as a learning experience where possible.

Narrative

What does this have to do with story?

Mark refers to personal co-constructed narratives as one of the main ways of activating and working with memory. Within stories an emotional arc operates through non-verbal means (exclamations, body movements, facial expressions, and vocal patterned intonation, rhythm), all of which are ways that people with PMLD can often respond to, and use to express themselves.

Storysharing® is an approach that uses co-constructed narratives built around the emotional impact of an experience. This fits very well with the theory of emotional consciousness. Through activating memories we can strengthen, alter, and even erase them and help the person to think through: I feel THIS about THAT.

In Storysharing® we focus on the small stories we tell about things that have happened to us personally - not big life stories but the tiny anecdotes which seem to take up 60-70% of social conversation - and which externalise and make explicit our learning from experience.

To have significance Storysharing® needs to focus on an event that is unusual enough to be noticed and attended to.... That's the "uncertainty" element and an emotional dimension - the story is driven by affect. Storying personal experiences support people to manage uncertainty, especially when they are events that are worth paying attention to through stimulating the differentiation of emotions. Through telling a story, the memory and the sensory perception of the event is updated and reformed, therefore storytelling needs to be active – they need to be active and aware of their own telling.

Mark's theory recognises that these "activated memories" can be - and often are – something that people create together in social situations. As storysharers, we believe that people with very profound disabilities can have a voice, can take part in society, can advocate for themselves and others, can reminisce and build relationships and have a strong sense of who they are. Mark Solms' theories provide a framework within which to explore and develop our values and our practice.

Contact details

Nicola Grove is a retired speech and language therapist, who has specialised in augmentative communication, multisensory storytelling, and access to authentic literature for persons with severe and profound disabilities. She is Professor for Profound and Multiple Learning Disabilities at the Rix Inclusive Research Centre, University of East London. She also facilitates workshops on theory for self advocates and co-researchers, with Jan Walmsley for the Open University.
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Storysharing® information at <https://storysharing.org.uk> Two free introductory courses in Storysharing are available here <https://storysharing.thinkific.com>
Further training in Storysharing is available from PAMIS - info@pamis.org.

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In the Next Issue

The theme for the Summer 2024 issue is of PMLD LINK journal 'Health'

The NHS Long Term Plan, first issued in 2019, made a commitment to improve the health and wellbeing of people with a learning disability. Since then we have had the annual LeDeR review reports which have provided information about the deaths of people with a learning disability, with the aim of improving care and preventing premature mortality. And yet we only have to watch our TV news to see that all is not well with NHS provision for any of us, let alone those with learning disabilities. Health of people with profound and multiple learning disabilities is closely tied to the health of their carers and we know that lack of support to families can compromise this.

Despite such a gloomy picture, we remain passionate that the health needs of people with profound and multiple learning disabilities and their experiences of health inequalities should not be ignored. Our next Issue is devoted to this topic. We are keen to hear about the health issues that matter to you. Why not share the positive steps and initiatives being taken at local or national level by key individuals or groups to promote the health of people with profound and multiple learning disabilities. This may be physical health, mental health or anything encouraging healthy lifestyles. If you have a good news story to share, we'd love to hear from you – whether in an article or short news item. We would also like to hear of some of the challenges that you are facing in ensuring the physical and mental health of the people with profound and multiple learning disabilities with whom you live or work with.

We encourage you to send us your health-related articles, personal stories or reflections (up to 1500 words). We also love to include photos (with consent) and simple photo stories, to keep people central to what we do. News items, reviews of events and signposting to relevant blogs, website and resources are also welcomed.

All contributions by 27 May 2024 to: info@pmlmlink.org.uk

Summer 2024 issue editors are: Sue Thurman, Michael Fullerton and Annie Fergusson.

If we can help or to discuss your ideas, please reach out to us on info@pmlmlink.org.uk

See the Get Involved section on our website for further guidance and Photo Consent Forms <https://www.pmlmlink.org.uk/get-involved/>

Sensory Wellbeing: Collar & Cuffs Co's Inclusive & Wellbeing-led Approach to Arts, Culture, and Heritage

Julia Collar

In the realm of arts, culture, and heritage, the pursuit of wellbeing is a shared objective, but the path to achieving it is not always universal. Collar & Cuffs sensory theatre and arts company is a passionate voice and force in this space. Specialising in exploring emotional development, mental health, and overall wellbeing, the company's unique approach revolves around inclusive whole-family approaches through sensory engagement. This article delves into Collar & Cuffs Co's commitment to fostering wellbeing, particularly for individuals with profound and multiple learning disabilities (PMLD) and their families.

The Inclusive Sensory Approach

Collar & Cuffs Co's commitment to inclusivity is reflected in its team of artists, all of whom are neurodivergent and/or disabled, and through co-production with young people and adults with a wide range of complex needs. Their projects, especially since the onset of the pandemic, have expanded to collaborate with various museums, cultural institutions, heritage sites, and horticultural organizations. The primary goal is to create inclusive sensory tours, trails, and resources that provide not only sensory-rich experiences to widen access but that also foster calm, connection, and co-regulation.

Beyond the individual with PMLD, the company recognises the importance of involving parents, caregivers, and siblings in these sensory journeys. By broadening the sensory dimension, Collar & Cuffs Co ensures that families and groups can participate in truly shared activities, creating meaningful connections, making memories, and being together in-the-moment and in response to each other.

Projects in Focus

1. **Sensory Exploration of Constable's 'The Cornfield'**
Not all sensory tours take place in art galleries, they can happen almost anywhere! Last year, Collar & Cuffs Co created a sensory story and accompanying physical resources for Constable's 'The Cornfield,' commissioned by South Shields Museums and Art Gallery in association with the National Gallery. By capturing the ambiance of the painting, the project aims to recreate a languid, late summer afternoon, fostering a multi-sensory engagement with art that is specifically designed to help regulate and soothe. The sensory story, sound effects, and resources are available online for free download. (Available from: <https://southshieldsmuseum.org.uk/learning/sensory-journeys>).

2. **Self-Led Sensory Trail at the British Museum**

In collaboration with Mencap, Collar & Cuffs Co has been working through the Wolfson Project to co-produce a self-led sensory trail at the British Museum. Set to launch in March 2024, the trail explores quieter areas of the museum, taking participants on a journey through Japan, ancient Korea, China, and India. Mindfulness, deep breathing techniques, and sensory tools are seamlessly integrated into the experience, making it accessible and enjoyable for all. The audio component, featuring narrators from Mencap, adds a personal touch with original haikus and songs.

3. **Sensory Tours at Kew Gardens**

Collar & Cuffs Co's Makaton-signed sensory tours at Kew Gardens have been running successfully for over a year. The story-led tour of the Mediterranean Garden, adapted for the Temperate House in winter or inclement weather, invites participants on a quest to gather natural gifts from the land. Signed in Makaton, these tours provide carefully curated sensory tools, allowing participants to engage safely with the botanical surroundings. The post-tour sensory kit enables further exploration of different areas within Kew Gardens, promoting independent sensory investigations. (Tours can be booked online: <https://www.kew.org/kew-gardens/whats-on/send-family-sensory-tours>).

4. **Sensory Exhibition Tours at MK Gallery**

In alignment with each exhibition, Collar & Cuffs Co conducts sensory exhibition tours at MK Gallery, Milton Keynes. These tours cater to both group experiences and individual families, with 'Bitesize' sessions offering a more tailored and condensed version for anyone who needs it, including due to anxiety levels. The tours prioritise establishing calm, connection, and regulation before introducing elements that may be more stimulating. Including a variety of sensory stimuli such as costumes, music,

objects, dance, and sensory stories, these Makaton-signed tours provide a comprehensive and engaging exploration of art. (For more information see: <https://mkgallery.org/whats-on/>)

Philosophy of Wellbeing

Collar & Cuffs Co's overarching philosophy centres around the belief that feelings of safety and calm are fundamental to creating lasting connections between individuals and cultural institutions. Recognising the importance of repeat visits for heritage and arts organizations, the company emphasises the role of wellbeing as a core value in their sensory accessibility and interpretation work. Alongside this, it's essential that facilitators, whether staff or volunteers, have a sufficient level of skill and knowledge to be able to differentiate and adapt immediately in response to individual and family access needs.

The company also tries to use low-cost/no-cost resources wherever possible, and not just to model sustainability. When someone connects with a resource in a really meaningful way, and when repetition will almost certainly build on that response, being able to let families know where they can source or make their own from junk, and that it will not cost more than a few pounds or may even be free, opens up the possibility of future adventures, as well as ensuring experiences initiated by accessing culture and heritage become embedded.

The Impact on Families with PMLD Members

The company knows that for families caring for someone with PMLD, establishing a sense of safety and wellbeing must also be supported with practical resources such as Changing Places toilets, suitable parking, helpful and responsive staff, and adequate pre-event information, so the company tries very hard to hold everyone's needs in mind, including the wellbeing needs of parents/carers and of siblings. The effort and stress of getting a whole family through the day to reach the start of a sensory tour can be considerable, but knowing that once on site all basic needs can be met, everyone will be warmly welcomed, and everyone will have a tailored, relevant, and accessible experience enables carers to finally relax, trust, and feel able to enjoy themselves too – the most golden moment being when every member of a family is giggling together, or are sharing in the same moment of awe. By creating work that prioritises safety, calm, and connection, Collar & Cuffs Co endeavours to make cultural and heritage spaces more accessible and welcoming for everyone, regardless of their abilities, disabilities, family role, and mental health needs.

Contact details

Julia Collar, Creative Director, Collar & Cuffs Co. Collar & Cuffs Co, is a multi-award-winning inclusive sensory theatre and arts company, founded in 2016. Wherever possible, Collar & Cuffs Co aims to provide supporting resources for tours and trails, including sensory stories, by free download, so these can be used to prepare for visits or to continue the adventure afterwards.

Resources are either housed at/signposted from www.collarandcuffs.org
Email: info@juliacollar.com

For more information:
Website: www.collarandcuffs.org
Facebook / X : @CollarandCuffsCo



REPORT BACK

Frozen Light and their Sensory Studio Artists - finalists for a National Award

By Emma Venier

Frozen Light is the only theatre company exclusively and extensively touring sensory work for audiences with profound and multiple learning disabilities (PMLD) to mainstream theatres, heritage and arts venues across the UK. We were thrilled to be nominated, and shortlisted as a finalist, for the [Offies Awards](#) 2024. We were nominated for our latest multi-sensory theatre production, *'The Bar at the Edge of Time'*, after performing this show at the Tramshed, Woolwich in November 2023. The Offies Awards celebrate the best of independent theatre across Greater London, and we were delighted to be nominated in the Access Category.

We were especially thrilled to be nominated for *'The Bar at The Edge of Time'* as this is Frozen Light's first show created **by** artists with PMLD **for** audiences with PMLD. Two years ago we began collaborating with our artists Lydia, Rosey, Olivia and Lucy, four young women with profound and multiple learning disabilities, in a purpose built Sensory Studio. These four Sensory Artists are paid for their pioneering work through monthly sessions facilitated by our Co-Artistic Directors.

Last spring our artists with PMLD focused on the research and development (R&D) of our sixth national touring production, *'The Bar at The Edge of Time'*. During this process, we were astonished by the way in which the Sensory artists shaped the show, from the choice of musical instruments to devising props. The artists participated in our biggest and most inclusive audition process to date. Lydia, Rosey, Olivia, and Lucy are credited as members of the show's Creative Team and rightly named as artists in The Stage's five-star review of our show.

We were overjoyed that all four artists attended last month's Offies Awards Ceremony in London, with their families and carers. The journey from Norwich to Woolwich was joyful and full of anticipation. We booked a fully accessible coach which could accommodate up to five wheelchair users and an additional 33 seated passengers from [Sanders Coaches](#). They provided wheelchair restraints and wheelchair compatible seat belts and provided guidance on suitable pick up and drop off points to allow adequate space for operating the wheelchair lift. Our driver Dave was kind and helpful, ensuring everyone felt safe and comfortable throughout the drive.

In the week leading up to our trip Amber, one of Frozen Light's Co-Artistic Directors, visited Woolwich Works - the Offies Awards venue - and the Premier Inn where we would be staying, to ensure all our access needs and adjustments were addressed. Amber was able to create a video tour of both the hotel and venue, including important details such as the location of Changing Places toilets and a quiet space. These videos helped to build everyone's confidence ahead of the trip away and the day itself.

The Offies Awards ceremony was full of sparkle and glamour, and we were treated to live music and a glass of

fizz on arrival. Frozen Light didn't win the category we were nominated for, but instead we had a game changing two days with our team - learning firsthand what it takes to enable an artist with complex needs to make the journey to London. For one family it was their first visit in 20 years. We are so excited to be establishing a budget that can support our artists with profound and multiple learning disabilities to go and experience other theatre - to inform their own creative work.

"What a fantastic experience. None of us had been on an overnight trip together and everything ran smoothly, I'd do it again in a heartbeat. Our young ladies were treated like artists, and the fact that they did something other young ladies would do was just amazing and we're truly grateful for this wonderful experience."

Parent of Sensory Studio Artist

Contact details

Emma Venier, Audience Development Officer. Frozen Light. Email: info@frozenlighttheatre.com

For more about Frozen Light's Sensory Studio ,UK Tour dates, free resources and much more visit:

www.frozenlighttheatre.com

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IN THE NEWS



News from Professor Nicola Grove

I have the enormous privilege of an appointment at Rix Inclusive Research Centre, University of East London as Professor for Profound and Multiple Learning Disabilities. The focus is on building connections with people and their families and allies, and developing citizenship and employment opportunities. I'm so lucky to be working with an inspiring team, including our co-researchers - in an environment that is fun, challenging, exciting and imaginative. Check out our website <https://www.rixinclusiveresearch.org> and the work of Purple Stars with museums and spaces. <https://purplestars.org.uk>

At the moment I am working on three projects: a survey to look at how young people with PMLDs are involved in consultations, locally and nationally; a collection of personal stories with the great teachers and kids at Charlton Park School in Greenwich; collecting information from families about the feelings expressed by individuals with PMLDs, with Dr Julie Calvey of NAC Wellbeing <https://www.nacwellbeing.org>.

Do contact us with your ideas and questions to help us develop our work.

Nicola Grove PhD
Professor of Profound and Multiple Disabilities, Rix Inclusive Research, University of East London, Honorary Fellow, Royal College of Speech & Language Therapists

New report from Nuffield Trust: Preventing people with a learning disability from dying too young

Around 1.3 million people in England have a learning disability and may need more support to stay in good health. But are they able to get access to the services they are entitled to in order to prevent illness or keep well? This new report looks at a set of five key preventive health care services and functions to understand whether they are working as they should for people with a learning disability.

They recommend that:

- NHS England should conduct a national review of the quality of annual health checks for people with a learning disability.
- Integrated care boards should use local data to review the number of people on GP learning disability registers and organise targeted information campaigns to encourage people to join the register.
- The number of health and social care staff working in care coordination roles should be increased to improve care coordination for people with a learning disability.
- All providers of NHS and publicly funded social care should deliver training to staff in the use of the 'Reasonable Adjustment Digital Flag'.
- All local authorities should provide weight management programmes specifically designed for people with a learning disability.

Read the full report or easy-read summary here: <https://bit.ly/3IEBnEY>

Scottish Learning Disability Week 2024

Scottish Learning Disability Week 2024 runs from 6th-10th May. This year's theme is 'Digital Inclusion'. There are lots of downloadable resources to help you to take part on the Scottish Commission for Learning Disability website. Find out more: www.sclcd.org.uk/learning-disability-week/

Key messages from research

by Catherine de Haas

I am one of four authors who have written two articles which encourage researchers to include people with profound and multiple learning disabilities (PMLD) into research. The four of us have had decades of involvement with people with PMLD. We currently work as researchers but have previously worked as teachers, as a speech therapist, and as an assistant clinical psychologist. Melanie Nind and Jo Hope are experienced researchers and are supervising Jo Grace and I through our PhD journeys. I am the mother of Johanna who lived with PMLD until she died in 2019.

Our first article '*Doing research Inclusively: Understanding what it means to do research with and alongside people with profound intellectual disabilities*' was published in 2022 (de Haas et al, 2022). It argued that research should be 'with' and not 'on' people like my daughter Johanna and start with deep knowledge of them. We are pleased to announce that our second article, '*Expanding possibilities for inclusive research: Learning from people with profound and multiple intellectual disabilities and decolonising research*' has just been published (Grace et al, 2024). This newer article embraces 'deep knowledge' of people with disabilities like Johanna. It shows how, through 'being with' them, that they can be included in the research process. It includes them in knowledge-making, by opening up possibilities about what is acceptable knowledge. We take inspiration from research done by First Nation people. We are indebted to the contributions of Becky, Felicity and Seren who all live with disabilities similar to Johanna's and who worked together with Jo Grace exploring ways of understanding identity. Knowledge making is an uncertain business in these circumstances. We write about leaning into felt embodied forms of meaning. This can feel strange if you're used to learning in more traditional ways and is difficult to explain in words. The articles are illustrated with photographs to help the reader with these potential difficulties. They are freely available online. We hope that you will or have enjoyed reading them.

Contact details

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Research around growing older in people with learning disabilities

The University of Dundee, Liverpool John Moores University, the University of Edinburgh, and the University of Hertfordshire are running the IncludeAge project. This project aims to find out about the community spaces that older people with learning disabilities (including those who are LGBTQ+) use in their everyday lives. This includes the offline and the online places that people use. Researchers are looking for middle-aged to older (40+) people who have a learning disability and / or who are LGBTQ+, to take part in a study exploring their experiences of inclusion, belonging, and community throughout their lives.

They hope that this research will be able to help develop policy and other practical suggestions for change to enable middle-to-older aged people with learning disabilities and LGBTQ+ people to feel more included, wherever they are. To find out what taking part would involve <https://www.ndti.org.uk/assets/files/Expression-of-Interest-Form.pdf>

Anyone interested can return the completed form with their details so they can find out more. This does not mean they have agreed to take part. The research is funded by the UK Economic and Social Research Council (ESRC) and is running from 2022-2026, and has received university ethical approval [UOD-SREC-SHSC-2023-20].

If you have any questions, please feel free to contact Jacqui Lovell by email (J.M.Lovell@ljmu.ac.uk) or phone (07505221036).

Why We Care campaign

Mencap's Why We Care report, examines the social care system in England and Wales through the experiences of those who work in it. It explores the challenges of the sector and celebrates the dedication of frontline staff supporting people with a learning disability, looking at what motivates them, what they do and the value they bring to people's lives. Support workers and others working in social care are crucial to ensure people with a learning disability get the support they need to stay happy, healthy and fulfil their ambitions.

Read the report & sign the petition calling for the Government to increase funding for social care, to enable better pay and recognition for support workers:
www.mencap.org.uk/whywecare

Voices of people with PMLD and their family carers must be heard

PAMIS, Promoting A More Inclusive Society, a Scottish based charity that solely supports people with a profound learning and multiple disabilities (PMLD) and their families to lead healthy, valued and inclusive lives, are core participants of the Scottish COVID Inquiry. They feel that the voices of people with PMLD and their family carers must be heard in this Inquiry. They are currently providing evidence for the Health and Social Care Impact portfolio and on the morning of Wednesday 13th March 2024 Chair of PAMIS Board, Pat Graham, and PAMIS CEO, Jenny Miller, gave oral evidence.

“abandoned, forgotten, invisible” were key themes and their experiences were shared explicitly across an intense, emotion evoking hearing. PAMIS were keen that the Inquiry understood who this invisible group were and were assured that their film <https://rb.gy/6vd1r1> would be watched by the Inquiry team and made available to others. The hearing is available here <https://www.youtube.com/live/p-CxcOVDITM> and was subsequently picked up by the media both in Scotland and across the UK.

News from Scotland

A very significant piece of Scottish policy is currently out for consultation - The Learning Disabilities Autism and Neurodivergence (LDAN) Bill <https://rb.gy/76exhm> aims to “better protect, respect and champion the rights of people with learning disabilities, autistic and neurodivergent people”. PAMIS, the Scottish third sector organisation that solely supports children, young people and adults with a profound learning and multiple disabilities and their families to lead healthy, valued and inclusive lives, is working with families to ensure that people with PMLD are visible within all aspects of the Bill.

A weighty consultation that has been co-designed with people with lived experience, practitioners and third sector organisations. There are 5 overarching themes and 14 specific themes and also the consideration of establishing a Commissioner to protect people's rights in practice. This Bill will be prepared by the Scottish Government and then considered by the Scottish Parliament. When a Bill has been passed by the Scottish Parliament, it becomes a part of Scots law as an Act. The consultation closes at 10pm on Sunday 21st April 2024. A range of formats for responses are accepted and there are a number of resources available to support engagement. <https://www.scld.org.uk/learning-disability-autism-and-neurodivergence-ldan-bill-consultation->

[information/](https://consult.gov.scot/mental-health-unit/learning-disabilities-autism-neurodivergence-bill-consultation/). The online responses can be completed here <https://consult.gov.scot/mental-health-unit/learning-disabilities-autism-neurodivergence-bill-consultation/>

RIX is 20 Celebration

On 1st May 2024, The RIX Centre for Inclusive Research at The University of East London is holding a 20-year celebration. The RIX Centre is a Research and Development Centre with a mission to improve the lives of people with learning disabilities through effective use of digital and multi-media technologies. The event on 1st May will feature guest speakers Amanda Broderick, Andy Minnion, Beverley Dawkins and Jonty Rix, and include workshops from Access All Areas and Sensory Storyteller Nicola Grove plus a pop-up museum and spoken word activities. The event will take place at the Royal Docks Centre for Sustainability in London Docklands, with a Changing Places Toilet on site. Booking is essential. Contact: Kanchan Kerai K.Kerai@uel.ac.uk for more details.

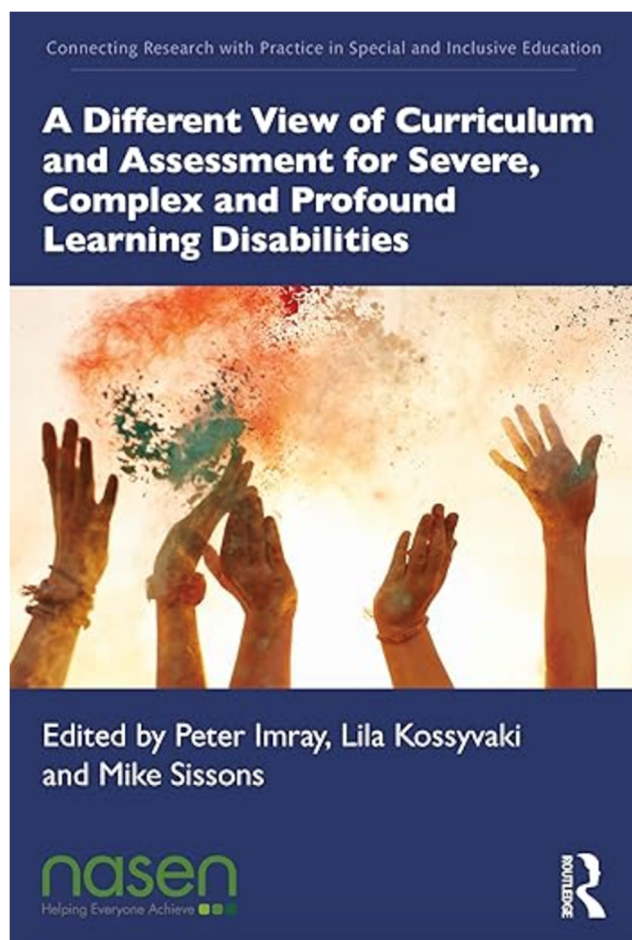
Learning Disability Week 2024 for England, Wales and Northern Ireland

Learning Disability Week 2024 for England, Wales and Northern Ireland runs from 17th-23rd June. This year's theme is 'Do you see me?'. It is about being seen, heard and valued. Resources will be available on Mencap's website from early May. Find out more: www.mencap.org.uk/learningdisabilityweek

Welsh National Opera's multi-sensory concert

Opera Tutti, is now on tour across the country, in Wales, the Southwest and the West Midlands. Since its inception at Mayfield School, in 2020, Opera Tutti has visited over 20 special schools, bringing the world of opera to life through puppets, props, lights, scents and costumes for young people with PMLD. The concert has been enjoyed by students and teaching staff alike. WNO is now developing Opera Tutti II, with new repertoire, follow on one-to-one musical interactions for those that attend the show, plus an adapted version for Studio Theatres to meet a broader SEN group. For further information contact: sandra.taylor@wno.org.uk

NEW RESOURCES



A Different View of Curriculum and Assessment for Severe, Complex and Profound Learning Disabilities (published by Routledge in January 2024) seeks to explore the notion that any sound pedagogy must understand the unique talents and needs of its learners who must be at the centre and not the periphery of our considerations. A curriculum which prioritises mathematics, technology and science at the expense of other learning will frustrate and marginalise those pupils whose abilities and passions lie in the field of art, or dance, or music, or literature, or practical and physical activity. Their needs will be overlooked, for in order to get the curriculum right for any group of learners those learners must be at the centre and not the periphery of our considerations.

A Different View of Curriculum and Assessment recognises that learners with different learning needs demand and deserve a different approach to teaching. They, and not the curriculum, must be our starting point. The content of the curriculum is not determined in

advance but is derived from a consideration of what has value for them, the learners. Throughout this book the individual learner appears not as an object - a passive consumer of knowledge - but as a free agent, actively engaged with others in realising their own possibilities. Paying attention to the learner in this way means that in shaping pedagogy we must not only answer the question of what learning should take place, but crucially we must also pay the closest attention to the questions of how it should happen and, even more importantly, why it should happen.

A Different View of Curriculum and Assessment for Severe, Complex and Profound Learning Disabilities. Edited By Peter Imray, Lila Kossovaki, Michael Sissons

PAMIS Bereavement and Loss Learning Resource Pack

The PAMIS Bereavement and Loss Learning Resource Pack is for those supporting bereaved people with profound learning and multiple disabilities and their parents and carers. This resource emerged from world leading research carried out by PAMIS, on the shared experiences of people with profound learning and multiple disabilities and those caring for them. It is relevant to anyone involved in the lives of people with complex disabilities, including parents, paid carers, teachers, speech and language therapists and psychologists. The resource explores the following issues:

Unit I: Supporting bereaved people with profound and multiple learning disabilities

- understanding how bereavement affects us
- supporting people with profound learning disabilities
- supporting spirituality

Unit II: Supporting bereaved parents and carers who have cared for someone with profound and multiple learning disabilities

- caring for someone with complex healthcare needs
- experience of bereavement for families who cared for someone with complex healthcare needs

The Pack also includes a DVD with two 20 minute video clips of parents sharing their own experiences and those of their sons and daughters. Further details: <https://pamis.org.uk/resources/bereavement-and-loss/>



Count Me In! is an innovative and practical multi-media resource for making music inclusively with learners across the spectrum of neurodiversity, including those with profound learning difficulties. It was developed by the University of Roehampton and the education charity Services For Education in Birmingham. It was launched in July, 2023.

Count Me In! comprises a book and a free online resource <https://soundsofintent.app/count-me-in/> that is underpinned by the Sounds of Intent framework of musical development. There are twelve projects that can be used by music-specialists and non-specialists alike – no musical training is needed. They are great fun and have lots of ideas for activities with sensory learners. There are freely available audio files of interesting sounds – everything from the wind whispering through the leaves on trees to a motorbike revving up its engine!

The core of Count Me In! is the book, of 176 pages with 591 colour and 75 b/w illustrations. Soft-back: £24.99, eBook: £22.49. Publishers: Routledge, part of the Taylor & Francis Group

The Hanging Out Programme

The Hanging Out Program (HOP) was developed by speech pathologist Dr Sheridan Forster in 2007, with people with profound and multiple learning disabilities in mind. The approach focuses on prioritising interactions and connections, with an achievable and effective premise: spend 10 minutes every day interacting with a person, giving them 100% of your attention, and afterwards keep a note of what happened. Reflect, explore, develop – and mostly give the person 100% attention and quality time, to prioritise communication in a way that is meaningful to them.

Sheridan's website gives more information about this simple approach. <https://sheridanforster.com.au/passions/hanging-out-program-hop/>

PCPLD Palliative Care Network for People with Learning Disabilities

The PCPLD Network is a charity bringing together service providers, people with a learning disability and carers working for the benefit of individuals with learning disabilities who have palliative care needs. The ethos of the charity is that people with a learning disability should receive the coordinated support needed in living their lives to the full, until the end of their life.

The PCPLD website has a huge range of resources including webinars, podcasts, guidance and stories of individuals and how they have been supported with end-of-life care. These include a webinar that was made in collaboration with Kingston University, launching the 'Victoria and Stuart Project', a 2-year study into end-of-life care planning. This event for 'Dying Matters Awareness Week 2023' focused on involving people with learning disabilities and people with profound learning disabilities in end-of-life care planning. Jean Willson shares the life of her daughter Victoria, and how Victoria was supported by her family, her circle of friends, her support staff and the palliative care team, to live a good life and to have a good death. "Her family look back now with peace and pride in being part of the team that enabled Victoria to live happily and die majestically." Jean Willson (mother).
X: @PCPLDNetwork @VictStuProjec
Website: <https://www.pcpld.org>

COURSES, CONFERENCES AND EVENTS IN 2024

Many training providers are still not running face-to-face or in-house training courses, but there are some excellent online training opportunities available. It is suggested that you visit the websites of regular and relevant providers as listed in this issue.

May		Title:	Developing the Curriculum (to support bereavement and grief)
Title:	Europe in Action conference	Date:	15 May (9.30am-12.30pm)
Date:	7 to 9 May	Location:	Online
Location:	Glasgow	Provider:	Sarah Helton, Back Pocket Teacher
Provider:	Inclusion Europe	Contact:	www.backpocketteacher.co.uk
Contact:	https://www.inclusion-europe.eu/conference-europe-in-action-2024-glasgow/	Title:	The Loses of Life (how to support individuals with SLD/PMLD with the losses of life, big & small)
Title:	The Bar at the Edge of Time – Frozen Light	Date:	21 May (9.30am-12.30pm)
Date:	Dates & Venues vary	Location:	Online
Location:	(see below) 2 shows daily	Provider:	Sarah Helton
Provider:	Frozen Light Theatre Co.	Contact:	Back Pocket Teacher
Contact:	https://www.frozenlighttheatre.com/tour-dates-the-bar		www.backpocketteacher.co.uk
Date:	7-12	June	
Location:	The Lowry, Salford	Title:	Difficult Conversations, Conflict and Relationship Building with Parents/ Carers
Date:	15/16	Date:	3 and 10 June (9.30-1.00pm)
Location:	Platform, Glasgow	Location:	Online
Date:	17/18	Provider:	Born at the Right Time
Location:	Macrobert, Stirling	Contact:	admin@bornattherighttime.com
Date:	22/23	Title:	Bereavement and Grief (developing plans for individuals with PMLD)
Location:	Beacon Arts, Greenock	Date:	3 June (9.30-12.30)
Date:	24/25	Location:	Online
Location:	Roths Hall, Glenrothes	Provider:	Sarah Helton
Date:	27/28	Contact:,,,,;	Back Pocket Teacher
Location:	Lemon Tree, Aberdeen		www.backpocketteacher.co.uk
Date:	31 May / 1 June	Title:	International Masterclass in Paediatric 24-hour Postural Care
Location:	Eden Court, Inverness	Date:	4 - 6 June
Title:	A Special Kind of Grief (introduction to supporting individuals with SLD or PMLD with grief)	Location:	Lichfield, UK
Date:	10 May (9.30am-3.30pm)	Provider:	Born at the Right Time
Location:	Online	Contact:	admin@bornattherighttime.com
Provider:	Sarah Helton	Title:	Super Sensory Lexiconary
Contact:	Back Pocket Teacher	Date:	6 – 7 June
	www.backpocketteacher.co.uk	Location:	Brighton
Title:	Essentials in Communication and Co-production with Parents and Carers	Provider:	The Sensory Projects
Date:	14 May (9am-1pm)	Contact:	thesupersensorylexiconary2024.eventbrite.co.uk
Location:	Online	Title:	Rebound Therapy practitioner training
Provider:	Born at the Right Time	Date:	6-7 June
Contact:	admin@bornattherighttime.com	Location:	London
		Provider:	Reboundtherapy.org
		Contact:	info@reboundtherapy.org

Title:	MSI Intervenor Course (5 days)
Date:	10-14 June
Location:	Worcester
Provider:	Jenny Fletcher
Contact:	Office@regency.worcs.schs.uk
Title:	Rebound Therapy practitioner training
Date:	13 - 14 June
Location:	Luton
Provider:	Reboundtherapy.org
Contact:	info@reboundtherapy.org
Title:	Surviving to thriving: sequenced learning in a PMLD classroom
Date:	21 June
Location:	Online
Provider:	Hirstwood Training
Contact:	https://hirstwood.com/events/thriving-pmld-24/
Title:	Introduction to Intensive Interaction
Date:	26 June
Location:	Online
Provider:	Us in a Bus
Contact:	https://usinabus.org.uk/training-dates/
Title:	From Research to Reality (putting bereavement & grief research into practice for individuals with SLD/PMLD)
Date:	28 June (9.30-12.30)
Location:	Online
Provider:	Sarah Helton
Contact:	Back Pocket Teacher www.backpocketteacher.co.uk
July	
Title:	Grief and SLD/PMLD (supporting grieving individuals with SLD/PMLD)
Date:	2 July (9.30-12.30)
Location:	Online
Provider:	Sarah Helton
Contact:	Back Pocket Teacher www.backpocketteacher.co.uk
Title:	MSI Intervenor Course (5 days)
Date:	9-10, 15-17 July
Location:	Cheltenham
Provider:	Jenny Fletcher
Contact:	bsargent@nationalstar.org
August	
Title:	Reimagining Connections:
Date:	17th IASSIDD World Congress
Location:	5-8 August
Provider:	Chicago, USA
Contact:	IASSIDD https://iassidd2024.org/

ONLINE TRAINING AND WORKSHOPS (REPEATED, ON-DEMAND OR BESPOKE)

Us in a Bus (<https://usinabus.org.uk/what-we-do/#training>)

Us in a Bus offers workshops on 'Intensive Interaction' run by Janet Gurney. For more information, including costs, please contact admin@usinabus.org.uk or telephone 01737 823310.

Make Intensive Interaction part of people's daily lives. To discuss your specific needs contact Anne Laney: anne.laney@usinabus.org.uk.

The Sensory Projects (www.thesensoryprojects.co.uk/conferences-training)

The Sensory Projects offer:
In person training days, workshops and conference presentations.
Online study courses and workshops.
Live online training days, workshops and conference presentations.
Consultancy services are also available.

For online study opportunities visit The Sensory Projects Online College.

NAC (www.nacwellbeing.org)

NAC provides online and in person courses and consultancy to support the emotional wellbeing of children and adults with severe and profound intellectual disabilities.

Including: Trauma Promoting Emotional Wellbeing Emotional Regulation Depression and Low Mood Bereavement, Loss and Grief

New course starts 3 January 2023, weekly over 5 months

Mindfulness Through the Breath and Body for People with Profound Disabilities
<https://learning.nacwellbeing.org/mindfulness/>

Contact: julie@nacwellbeing.org

Story Massage Programme (www.storymassage.co.uk)

Story Massage offers online training courses and easy to access resources. These are for those wishing to use the Story Massage Programme at home or work. You can study at your own pace. You have full access to the online course materials for 6 months.

Contact: 07899813659 or info@storymassage.co.uk

Pamis (<https://pamis.org.uk/services/training>)

Pamis offers face to face courses, events and other training and development opportunities for family, paid carers and practitioners.

Contact: fiona.harper@pamis.org.uk to book or make enquiries

Postural Care – Simple Stuff Works & Born at the right time
(<https://www.simplestuffworks.com/training>)

A range of opportunities and CPD accredited modules, including:
Introduction to 24-hour postural care (half day workshop)
24-hour postural care: Hands-on training for the workforce
24-Hour Postural Care: Getting to the Core of the Problem

Contact: admin@simplestuffworks.co.uk

Born at the Right Time (www.bornattherighttime.com)

For 2023, a host of new courses are being launched, from entirely on-line courses to be completed at your own pace to in-person advance practitioner events.
See website for more details

Hirstwood Training (<https://hirstwood.com>)

Range of online, on demand opportunities including:
Creating inspiring sensory classrooms
Sensory Impairment and Sensory Loss
Sensory Resources
Contact: lois@hirstwood.com

Learning Disabilities Speech and Language Therapy-HWHCT– Mealtime Matters

Speech and Language Therapists in the Community Learning Disability Teams across the Herefordshire and Worcestershire NHS Health and Care Trust have developed some new, free training, in line with the RCSLT 'Eating, Drinking, Swallowing Competency Framework'.

Level 1 and 2 eating and drinking training is available to the general public through their FREE online e-learning - <https://www.hacw.nhs.uk/mealtime-matters>

For updates follow <https://www.facebook.com/LDSLTHW/>

EQUALS (<https://equals.co.uk/training-from-equals/>)

EQUALS provides FREE Online Training for Members covering a range of topics including: the Engagement Model of assessment, teaching learners with Profound & Multiple Learning Difficulties, and EQUALS Pre-Formal PMLD Curriculum

For further information please contact Paul Buskin at paul@equalsoffice.co.uk

PCPLD Network (palliative care for people with learning disabilities) (<https://www.pcpld.org/events> and conferences/)

PCPLD makes available free webinars as well as making past webinars available as recordings. They also offer podcasts.

PMLD LINK was established to make a difference to the lives of children and adults with profound and multiple learning disabilities (PMLD). People with PMLD have profound intellectual and multiple disabilities, very severe communication difficulties, often extreme physical and/or sensory disabilities, and complex health needs. Their needs are frequently overlooked by more general support organisations for people with learning disabilities. PMLD LINK maintains a clear focus on this small and often hard to reach group.

Since 2007 PMLD LINK has been a registered 'not for profit' charity and its affairs are managed by volunteer trustees who have in-depth knowledge and are relatives of people with PMLD and/or are academics and professionals with relevant backgrounds in health, education or social care services, and other community and voluntary services.

Revenue from subscriptions to PMLD LINK and all grants and donations are used to maintain the production and dissemination of the journal, the development of the PMLD LINK website and the management of social media platforms for networking and information sharing.

Currently the trustees are:

Rob Ashdown (Treasurer): Former teacher of pupils with severe and profound and multiple learning difficulties and special school Headteacher.

Annie Fergusson (Chair): Family carer for her brother with profound and multiple learning disabilities, retired professional and academic in the learning disability/special education field and a member of several national advisory groups and of the Families Team at Dimensions, a social care provider. Annie was one of the team who developed the PMLD Standards.

Michael Fullerton: Director of Health & Wellbeing with Achieve Together and leads a health team focused on the quality of life of people with profound and multiple learning disabilities. Michael was one of the team who developed the PMLD Standards.

Martin Goodwin: Head of department and teacher of pupils with PMLD and specialist in approaches to improve interaction, communication and participation of people with severe and profound learning disabilities

Becky Loney: (Vice-Chair) Independent advocate and has supported people with profound and multiple learning disabilities for over 30 years.

Sue Thurman: Former speech and language therapist who has worked in statutory and voluntary services for both children and adults with profound and multiple learning disabilities for many years and remains passionate about promoting their value and inclusion in society.

Maureen Phillip: Creative Director for the Scottish charity PAMIS (promoting a more inclusive society) and works in partnership with people with profound and multiple learning disabilities to support communities to recognise that people with profound and multiple learning disabilities are the best educators, as they teach us what it is to be human.

PMLD LINK would not function without its wider team of marvellous volunteers who have an interest in and a commitment to improving awareness, services and opportunities for people with PMLD. Our volunteers maintain PMLD LINK's activities and influence and this work benefits so many people, enabling them in turn to support many more people with PMLD, in various ways.

Each of the wide-ranging tasks are shared between two or more individuals who share practical information and give support as required through meetings online or occasionally in face-to-face meetings. Volunteers fulfil various roles. Most obviously, they edit issues of the journal – commissioning and editing articles, researching for and developing news items, reviews of resources and books, and providing details about courses, events and other relevant opportunities. The team of editors changes on a rotational basis for each journal issue.

There is other important, behind-the-scenes work that volunteers do besides:

- Ensuring that the PMLD LINK website is up to date and adding new resources and new electronic copies of the journal and other material as they are produced.
- Maintaining an active social media presence to keep people informed about news, events, opportunities and resources.
- Receiving and responding promptly to e-mails and other communications to PMLD LINK.
- Ensuring that printed copies of the journal are mailed to subscribers and others.
- Contributing to a reference group that identifies current and relevant topics which provides direction for PMLD LINK's developments and the content of journal issues

If you are interested in supporting PMLD LINK in any way, please contact any of the trustees listed on the Charity Commission website or e-mail info@pmlmlink.org.uk.

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sharing ideas and information

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

Visit www.pmlmlink.org.uk

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