

PMLD LINK

sharing ideas and information

Health Matters

Summer 2024

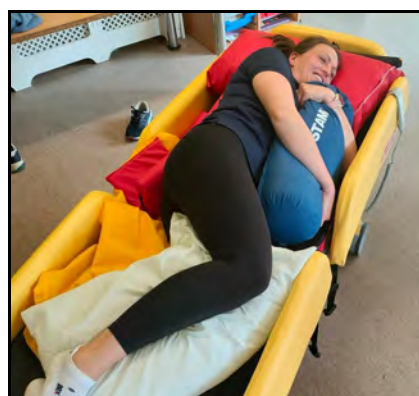


Vol 36 No 2. Issue 108

ISSN 2042-5619

Summer 2024 contents

Page



06 Lung Health
and Chest
Physio



12 Personal
Health
Budgets and



18 A focus on
eye care

- | | | |
|----|--|---|
| 1 | Guest Editorial: Health | Sue Thurman,
Michael Fullerton
and Annie
Fergusson |
| 2 | What does it mean to be a 'person' with
profound and multiple learning disabilities?
Interviews with family members and allies | Ben Simmons and
Stuart Reed |
| 5 | Changing The Narrative | Jenny Miller |
| 6 | Lung Health and Chest Physio:
Essential for Respiratory Wellness in Individuals
with PMLD | Sian Midwinter |
| 8 | The importance of good oral health in relation to
aspiration pneumonia for the learning disability
community | Una Monaghan |
| 10 | Chiropractic Treatment for People with profound
and multiple learning disabilities | Pat Graham |
| 12 | Personal Health Budgets Children with Complex
Health Needs | Helen Leonard |
| 16 | Safe, Efficient and Enjoyable Mealtimes for
children who need mealtime assistance:
– not as easy as it may SEEM | Sally Morgan |
| 18 | A focus on eye care | Lisa Donaldson
and Rachel Pilling |
| 21 | Creating an organisational PMLD Network | John Ockenden
and Alison
Worsfold |
| 22 | Delegated Healthcare Activities: Implementation
in adult social care | Erren Wheatland |
| 25 | The Beauty of Sleep | Michael Fullerton |
| 28 | Hospitals: Panorama and Particulars | Rachel Wright |
| 29 | In the next issue: | Bella Travis, Rob
Ashdown and
Maureen Phillip |
| 30 | Improving Health Outcomes | |
| 37 | Reporting Back | |
| 45 | In the News | |

GUEST EDITORIAL

Health Matters

Welcome to our Summer edition of PMLD LINK - Health Matters! In everyday conversations, it's so common to hear, "As long as you have your health". Good health is of central importance in all of our lives. Here at PMLD LINK we think health is especially important to everyone with profound and multiple learning disabilities (PMLD). So, it's no surprise to hear this Summer 2024 Health journal is our TENTH issue dedicated to health and wellbeing. These journals may date back almost twenty-five years but so much of their content remains very relevant today. It's also quite salutary to reflect on the lack of progress in some areas for people with profound and multiple learning disabilities.

As we edited this journal, the UK experienced a hiatus as a general election was called and a new government elected. Government and other departments went into the pre-election period of sensitivity, which meant some of the articles we expected to include did not materialise. We also received fewer than hoped for personal stories and articles from families and paid carers. The reason for this was simply that those involved in direct caring duties are so busy fighting and advocating for the health needs of the person they love and care for, they often have little time or energy left to write. This strengthens PMLD LINK's motivation to continue to push for change, for people with profound and multiple learning disabilities, not only being acknowledged but their needs fully included in healthcare policy and planning processes. Health inequalities must end!

Despite these challenges we hope you enjoy reading the rich material included in our Summer journal. We open with a thought-provoking article asking important questions about what it means 'to be a person' and the inequities of how people are valued when so many approaches define personhood primarily in terms of cognitive capacities. These same issues underpin so many healthcare decisions or opportunities, so it's vital we acknowledge them.

We have many valuable articles offering information, insights and practical advice relating specifically to people with profound and multiple learning disabilities. These topics include the role of lung health and chest physiotherapy; good oral health in relation to preventing aspiration pneumonia (a frequent risk for people with PMLD); positive health benefits from chiropractic treatments; research into Safe, Efficient and Enjoyable Mealtimes (SEEM); safely and respectfully delivering essential delegated healthcare activities in adult social care settings; accessible eye care and vision checks; a PMLD Network to support social care staff, and the huge topic of sleep!

We're particularly grateful to include two health focused items from families, who share valuable insights from their lived experiences - an article on Personal Health Budgets and another sharing very personal reflections and practical advice (or rather, survival tips!) on hospital stays.

We have also drawn together health-related updates, news and resources for you to browse, which we hope will help support people to have improved healthcare experiences. Ultimately we aim through this issue to capture a rich and diverse range of health issues and creative solutions to improved wellbeing, being respectful of 'personhood' and ensuring people with profound and multiple learning disabilities are treated as equals in relation to health promotion, prevention and planning.

And don't forget to look through some of those older health-themed journals we mentioned at the start of this editorial (see below for health editions). There are some real treasures to be found in there!

Let's not forget, Health Matters ... because it really does!

Guest Editors: Sue Thurman, Michael Fullerton, Maureen Phillip and Annie Fergusson, with help from Amy Nokes, Leigh Wharton

Health-themed back issues: Winter issues 2000, 2004, 2007, 2009, 2011, 2013, 2016, 2018, Spring 2024. Log in as Guest or Subscriber to access journals: <https://www.pmlmlink.org.uk/login/>

PMLD LINK is a registered charity: No 1121085. It publishes the PMLD Link journal three times per year and maintains a website and social media presence. It is run entirely by volunteers.	Contact Us The registered address for PMLD LINK is: Caerludd, Cilgerran, Cardigan, SA43 2SN	Social media Website: www.pmlmlink.org.uk X: @PMLDlink Facebook: @PMLDLink
The journal number is ISSN 2042-5619	To contact the charity editors or trustees: Email: info@pmlmlink.org.uk	Production of the journal is by: Paul Bramble

What does it mean to be a 'person' with profound and multiple learning disabilities? Interviews with family members and allies

Ben Simmons and Stuart Reed

This article presents the findings of a project that explored what it means to be a person. It shares insights drawn from family members and allies of people with profound and multiple learning disabilities (PMLD), and challenges philosophical approaches to personhood that define a person primarily in terms of cognitive capacities.

Introduction

What does it mean to be a 'person'? Is a person simply a human being? Can there be non-human persons, and humans who are non-persons? When does a person begin and end? How should persons be treated, and who gets to decide?

On the surface, questions such as these seem benign and overly abstract – they are found in academic textbooks and debated on university courses by philosophers who rely on 'thought experiments', or hypothetical situations analysed through logic and debate. However, the answers to these questions and their implications are profound. They are linked to religious, medical, and legal discourse and can impact life. These kinds of questions are found in debates about abortions, animal rights, the treatment of prisoners, and a range of other major issues (Read, Simmons and Parfitt 2023).

Questions about what it means to be a person are hugely important for those with PMLD. People with PMLD are sometimes defined in the literature as non-persons. This is because a Western, individualist rational model of personhood still dominates debate. According to this model, being a person requires advanced cognitive ability, communication skills, memory and agency (DeGrazia 2005, McMahan 2010). This model has met with resistance, and some philosophers, most noticeably Eva Kittay (2005), have argued that our social relationships are far more important than our cognitive abilities, and it is these relationships that give us status as a person.

This paper contributes to debates about the meaning of personhood. However, rather than using philosophical reasoning we present the views of family members and allies of people with PMLD. It is our view that family members and allies have a wealth of insight about what it means to be a person with PMLD, but they are rarely consulted in the personhood debate. Our project begins to address this.

Methodology

We interviewed 10 people in July 2023 using an unstructured approach. We interviewed 6 parents, 1 sibling, and 3 allies with significant experience in working with people with PMLD. The interviews were unstructured and lasted between 45 minutes and 2 ½ hours. The participants included artists, academics, a doctor, communication and technology consultants, a support worker, and a charity worker. We analysed the main themes and presented these (and this paper) to interviewees for approval.

Findings: Human genes, hierarchies, and the tricky topic of animals

Family members and allies who participated in our project discussed the relationship between humans and animals. Participants debated whether human beings were a special kind of animal, and the extent to which being a person presupposed being human. The majority of participants felt that genetics played an important part in classifying somebody as a person. Participants used terms such as 'natural hierarchy' or 'evolutionary hierarchy' and stated that human beings occupied the top of the hierarchy, with all other living creatures existing beneath humans. This hierarchy was sometimes linked to moral values – only human beings can be classified as people, and because of this status, humans should be treated better than animals.

Unfortunately, some participants felt that individuals with PMLD were not always recognised as having a higher value than animals. For example, the parents we interviewed described feeling upset, frustrated and offended at people who reduced their children to animals, e.g., by comparing their cognitive abilities and actions to family pets:

So, my in-laws have a dog, and he is a lovely, lovely dog. [...] It drives me nuts that they are comparing their dog to my child. I can see that Harry is a lovely cockapoo...but that comparison really gets to me every time they do it. ... [my daughter's] behaviour sometimes gets compared to the dog.

Furthermore, some parents described their children as being treated worse than animals, such as receiving less attention than pets:

[...] when you're walking down the street, I'm with [my son] and my husband and with my other child and everyone gets a hello, but [my son] doesn't get a hello. I find it so horrible to do that, because he might not answer hello. People say hello to a dog, to a cat, and they don't do that to [my son] and he is very happy to smile back to a person that says hello.

Not everyone agreed on the special nature of being human, and some interviewees suggested moving away from the human-animal distinction towards exploring commonalities:

There is some sort of hierarchy whereby if I equate a person to a dog or, you know, a cat or something that that is monstrously offensive because I've traversed this huge gap that there is supposed to be between us. But if what we're saying is that this cat feels this person, this person feels, and they are equivalent, I don't know what that monstrous gap is made out of other than a, sort of, prejudice against the animal kingdom. I don't know how offensive it is to be equated to an animal.

Similarly, one sibling suggested there was more to being a person than genetics or human morphology, and that relationships should be foregrounded in the debate about what a person is:

[...] you're a person because you take on a human kind of form but actually your interactions may be quite similar to an animal [...] there are people where they would probably relate their relationships with their pets, with their dogs, with their cats as a very similar to a human relationship but they wouldn't say that their dog is a person but is that just because they don't inhabit a person form? If suddenly the dog was a person would that relationship be like that? What they're getting from that is a similar kind of thing isn't it?

Relational Personhood

All participants felt that definitions of personhood should extend beyond the cognitive abilities of an individual to include a social or 'relational' component. Being a person meant being in a relationship with somebody, such as being somebody's parent or sibling, being a student or a teacher, and being a friend. Being a person also meant being part of community such as church community or school community, and it also included being part of a culture:

A person to me is a being who's part of a

community, whether that's a community based on your identity, your locality, even part of a family [...] being part of a collective where you have shared beliefs, values, understandings, traditions, norms [...].

Belonging to a community was seen as transformative – personhood was said to develop and grow in relation to other people, as one parent said: "I like more the idea that no man is an island, that thing that you are a product of your relationships". An individual's personhood is therefore not fixed but dynamic, it is something that grows and develops throughout life:

It's completely dependent on who you interact with, where you interact, what your experiences are, and that develops you throughout your life and that means your personhood, I guess, can change throughout your life. So yeah, it's part of a collective, part of a community and that's what makes you a person and a human being.

Whilst relationships and communities were described as being central to the formation of a person, they were also seen as the means by which personhood could be taken away. Parents recalled a range of negative life events (e.g., their children being mocked in public, not being treated with dignity in hospital, and facing barriers accessing everyday services such as parks, schools and shops). Such events were sometimes described as stripping back the personhood of an individual, or what one parent described as a "willful diminishing of someone's personhood". Conversations around denying personhood included reflections about individuals who are hidden from sight, with limited opportunities to experience the world: "Where does that put someone who has lived and has always lived in an institution and who has PMLD?"

A different way of understanding relational personhood was through discussion of shared needs:

[...] if someone has needs, they are a person. We need love, we need care, we need attention, we need help with things, just some people need more or less of all of that. Different people need different amounts of love to be able to survive, different people need different amounts of help with eating, we all need to eat, we all need to wash, we all need to dress, we all need to communicate, we all need to survive [...]

[...] personhood means for her having all of those things working around her to mean that she can be the best that she is. If she's got good care, good support, good understanding, good guidelines, good structure, good stuff in her life, she's going to have the best life.

Relational personhood was described in terms of ‘impact’ – how one person can transform the lives of others. Participants discussed the myriad of ways that people with PMLD enriched other’s lives, such as spreading happiness and joy, teaching others to “how best to be in the moment and value simple things”, helping others focus on sensory experiences, such as appreciating the light and warmth of the sun, “to see the world differently” and “to laugh at things that I wouldn’t normally laugh at”, to learn about “very individual forms of communication” and ‘learn [...] to care more about other people’.

Finally, social interaction was seen as an important way of discovering the depths of personhood of people with PMLD. Parents were critical of university academics who wrote about personhood without ever meeting people with PMLD. Personhood was said to be revealed through ‘two-way interaction’, through ‘a physical relationship’ that leads to ‘a connection’ and discovery of the depths of an individual’s personhood. Armchair philosophers who write about people with PMLD without meeting people with PMLD were said to write from an uninformed perspective, and questions were raised about the purpose of such philosophy.

“Who” not “What”

As discussed above, philosophers who debate the meaning of ‘personhood’ have attempted to develop criteria which can be used to judge whether somebody can be classified as a ‘person’. In a nutshell, these academic debates are essentially about ‘what’ a person is. The findings presented above describe parents’ views about what constitutes a person, and these views challenge the dominant narrative that reduce personhood to an individual’s cognitive capacity. Being a person means being part of a community, having an impact on others, being treated as a person, and recognising the importance of affect and emotions. These all point toward an affective and relational account of personhood. However, a central theme that emerged during interviews was not about ‘what’ people are, but ‘who’ they are, and this switch in focus raises questions about the value of debating criteria.

The researchers were given a personhood masterclass by participants. Participants created conditions for discussing the lives of people with PMLD, which included sending photographs, video clips, poems, short stories, published literature, interacting with children with PMLD live on camera, and telling evocative stories that resulted in a range of emotions, including laughter and tears. This richness of the lives of people with PMLD is overlooked by the cold logic of philosophy where criteria is developed through detached thought experiments.

Concluding comments

This article presents a rich view of what it means to be a person with PMLD. It suggests that researchers and philosophers must work more closely with people with PMLD, families and allies to co-produce a counter narrative to the dominant cognitivist view, a narrative that is anchored in the lived realities of people with PMLD to ensure that debates are more inclusive of those who are talked about, but rarely consulted.

Acknowledgements

We would like to thank all of the participants who made this research possible.

Contact details

Dr Ben Simmons, Reader in Inclusive Education & Disability Research
Email: b.simmons@bathspa.ac.uk

Dr Stuart Read, Research Fellow, School of Education, Bath Spa University
Email: s.read@bathspa.ac.uk

References

- De Grazia, D. (2005) Human identity and bioethics. Cambridge: Cambridge University Press
- Kittay, E. F. (2005). At the margins of moral personhood. *Ethics*, 116(1), 100-131.
- McMahan, J. (2010). Cognitive disability and cognitive enhancement. In E. F. Kittay & L. Carlson (Eds.), *Cognitive disability and its challenge to moral philosophy* (pp. 345-368). Wiley-Blackwell.
- Read, S, Simmons, B and Parfitt, A (2023) 'Creating authentic and positive stories about personhood for people with profound and multiple learning disabilities: a call for reader expressions of interest.' *PMLD Link*, 35.1 (104). pp. 37-38.

Changing The Narrative

Jenny Miller

In the recent Scottish Government consultation on the Learning Disability, Autism and Neurodivergence (LDAN) Bill, PAMIS provided a response that included their latest strategic focus on combatting the enormous health and human rights inequalities faced by children, young people and adults with a profound and multiple learning disabilities (PMLD). PAMIS highlight that a key contributing factor to the inequalities faced by people with PMLD is the lack of expectation to live into adulthood. PAMIS are leading work to change the narrative. We need to Plan For Life if we are to begin to tackle the rights of people with PMLD. We highlight below some of our contributions in our response to the Bill and hope this will spark some opportunities to collaborate with others reading this journal. Please do get in touch.

PAMIS (promoting a more inclusive society), established in Scotland 32 years ago has worked in partnership with this community to develop research, practice and education that promotes the value and inclusion of this group in the communities in which they live. Led by the family carers on the Board of Governors PAMIS is the lead organisation in Scotland to promote the interests of this group.

Within the PAMIS response to the LDAN Bill is a suggestion that there needs to be a focus on the poorer health outcomes for people with PMLD and an acknowledgement that because this group of people are “not expected to live” health and social care is delivered with this prior assumption. PAMIS suggest that investigations are not undertaken, treatment is withheld or not introduced, and assumptions are made by a medical workforce who were educated to expect someone with PMLD to die at an early age. Until 2 years ago because of this assumption of a child or young person “dying of a profound learning disability” or “dying of cerebral palsy” (evidenced on death certificates) there were no death reviews of this group in Scotland. There were no lessons learnt, no calls for further research into treatment and practice, and this led to the lack of interventions offered and delivered, lack of understanding about effective prevention and treatment and a total lack of planning for a group that could, with the right support, live into adulthood. In October 2021 the Scottish Government introduced the Child Death Review Process and the National Hub for reviewing and learning from the deaths of children and young people was established – <https://rb.gy/po2v2c>

However, for anything to effectively change in the health and wellbeing of people with PMLD, the narrative going forward must change from an expectation of death, to an expectation of life. Families have shared with us over the last 32 years that the repeated messages they are given is of their child/adult child not being well enough to

survive and/or not being expected to live. This mainly comes at the times of diagnosis or of hospital admissions. Weight is placed on the difficulties experienced by the individual, and the joy, happiness, love and laughter that they share with their family is very rarely considered. The lives of people with PMLD are often undervalued, with families being told to take their child/adult home and love them as they won’t survive for long. Healthcare practitioners are guilty of not considering quality of life from the person with PMLD’s perspective, forgetting that someone with PMLD has a different starting point from many of us – often being born with limited vision, limited mobility, seizure activity, developing health concerns at an early age but being incredibly resilient in being able to live their lives with joy despite these deficits or difficulties. PAMIS believe that unless this fundamental shift in narrative is set there will be no change in the outcomes for this group. They are working with other organisations in Scotland to consider how to progress this shift and of course with family carers who have many innovative and creative ideas about next steps. In a future addition of PMLD LINK we would love to share some of these ideas and share progress in this mission.

Contact details

Jenny Miller, CEO at PAMIS
PAMIS (promoting a more inclusive society), are the only charity in Scotland that solely supports and campaigns for children, young people and adults with PMLD and their families to lead healthy, valued and inclusive lives.
Email: jenny.miller@pamis.org.uk
Website: <https://pamis.org.uk/>

References

Scottish Government (2023-24) Learning Disabilities, Autism and Neurodivergence Bill: Consultation. Available at: <https://consult.gov.scot/mental-health-unit/learningdisabilities-autism-neurodivergence-bill/>

Lung Health and Chest Physio: Essential for Respiratory Wellness in Individuals with PMLD

Sian Midwinter

Living with profound and multiple learning disabilities (PMLD) presents unique challenges for both individuals and their families. For adults and children with PMLD, maintaining respiratory health and overall well-being is a complex endeavour that relies heavily on the integration of various health and social care services, including physiotherapy. This article highlights the significance of these therapies and provides practical advice on how families can support their loved ones with PMLD to prevent respiratory illnesses.

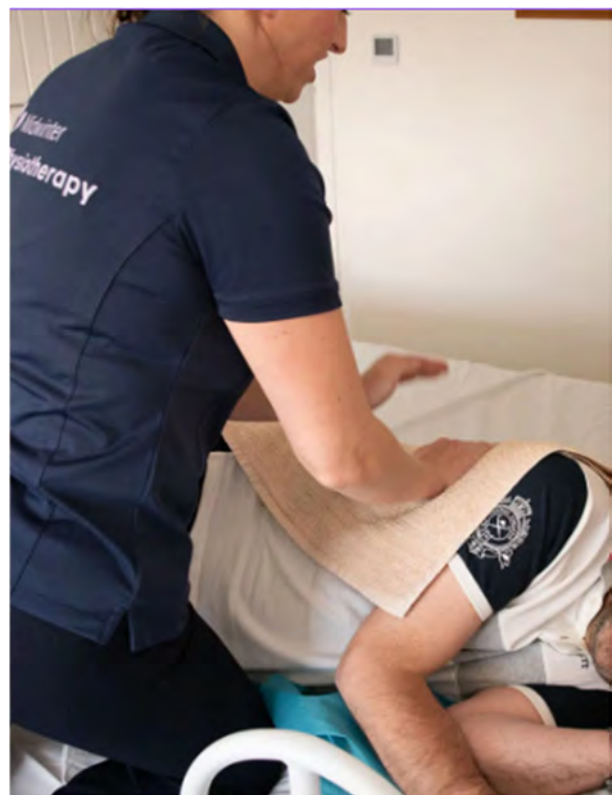
The Importance of Respiratory-Focused Therapies

Therapies play a crucial role in the health management of individuals with PMLD, particularly in maintaining respiratory health. These therapies, which encompass physiotherapy, speech and language therapy, occupational therapy, and sensory integration therapy, are designed to address the complex needs of these individuals.

Respiratory Physiotherapy: A Vital Component

Physiotherapy, especially respiratory physiotherapy, is essential for maintaining lung health and function. For individuals with PMLD, who may have limited movement and muscle control, regular physiotherapy can:

- **Prevent Contractures and Deformities:** Regular movement and stretching exercises help maintain joint flexibility and muscle strength, preventing the development of contractures and deformities that can result from prolonged immobility or lack of purposeful movements.
- **Enhance Respiratory Function:** Physiotherapists use techniques to improve breathing patterns, ventilation, and clear respiratory secretions, which is crucial for preventing respiratory infections and maintaining overall lung health.
- **Increase Physical Activity:** Physiotherapists can help integrate physical activity into daily routines, making movement and exercise a fun part of everyday life while ensuring the lungs get used as designed, to prevent infections and increase ventilation.
- **Improve Quality of Life:** Physiotherapy can enhance an individual's ability to engage with their environment, promoting better interaction and communication, which are essential for emotional and respiratory well-being.



The LeDeR Report and Premature Mortality

The Learning Disabilities Mortality Review (LeDeR) program has highlighted significant health disparities faced by individuals with learning disabilities. One of the critical findings of the LeDeR report is the high rate of premature mortality, particularly due to respiratory illnesses. This alarming trend underscores the need for vigilant health management and preventive care. Respiratory issues are a leading cause of death among people with PMLD. Factors contributing to this vulnerability include:

- **Limited Mobility:** Reduced ability to move independently can lead to weakened respiratory muscles and poor lung function.



- **Difficulty Swallowing (Dysphagia):** Problems with swallowing can cause food or liquids to enter the lungs, leading to infections like pneumonia.

Staying Well and Preventing Respiratory Illness

Preventing respiratory illness in individuals with PMLD requires a proactive and comprehensive approach. Here are some strategies that families can implement:

- **Regular Respiratory Physiotherapy:** Engage in routine physiotherapy sessions to strengthen respiratory muscles, improve posture, and enhance overall mobility. Techniques such as chest physiotherapy can help clear secretions from the lungs. There are not many respiratory physiotherapists out there but routine physiotherapy will help.
- **Effective Positioning:** Ensure that the individual is positioned correctly throughout the day and night to prevent spinal and joint deformities and give the



lungs the best opportunity to ventilate well. Proper positioning can improve breathing and reduce the risk of aspiration. Using supportive seating and sleeping equipment is essential.

- **Nutritional Support:** Work with healthcare providers to manage feeding and swallowing difficulties. A dietitian can offer guidance on nutrition, while a speech and language therapist can provide strategies to improve safe swallowing as well as oral hygiene advice and dental care.
- **Vaccinations:** Stay up-to-date with vaccinations, including the flu vaccine and pneumococcal vaccine, to protect against common respiratory infections.
- **Hydration and Humidity:** Ensure adequate hydration and consider using humidifiers to maintain moisture in the air, which can help in keeping respiratory passages clear.
- **Regular Health Check-ups:** Schedule regular health check-ups with a multidisciplinary team familiar with the needs of individuals with PMLD. This team can monitor health status, adjust care plans, and provide timely interventions.

Conclusion

For families of adults and children with PMLD, integrating therapies, health, and social care (especially physiotherapy focused on respiratory health) into daily routines is crucial for promoting health and well-being. The insights from the LeDeR report serve as a reminder of the importance of proactive health management to prevent premature mortality from respiratory illnesses. By working closely with healthcare professionals and staying informed, families can significantly improve the quality of life for their loved ones with PMLD, ensuring they receive the care and support they need to thrive.

Contact details

Sian Midwinter BSc (Hons) MSc MCSP, is a Specialist Learning Disability and Respiratory Physiotherapist and Director of Midwinter Physiotherapy Ltd

Email: sian@midwinterphysiotherapy.co.uk
Website: midwinterphysiotherapy.co.uk
Socials: @midwinterphysio
LinkedIn: <https://www.linkedin.com/in/midwinterphysio>



The importance of good oral health in relation to aspiration pneumonia for the learning disability community

Una Monaghan

Individuals with learning disabilities, their families and carers are usually all too familiar with the stark health inequalities experienced by their community. Understandably for many people information about these inequalities can seem frightening and overwhelming. However, there is a message of hope that small changes can make a big difference. This paper addresses how changes in oral health can affect a largely preventable disease called aspiration pneumonia. It is hoped that improved toothbrushing and oral hygiene for people with learning disabilities could genuinely start to reduce their health inequalities.

It is acknowledged that the life expectancy of people with a learning disability is lower than the general population with only 37% of adults with learning disability living beyond 65 years of age compared with 85% of the general population. Pneumonia is the most common cause of death among adults with learning disability and is also a common cause of death in children and young people with learning disability. Patients with learning disability experience both bacterial and aspiration pneumonia. The British Thoracic society has highlighted that community acquired pneumonia is a “major contributor to the increased hospitalisation risk that has been described for people with learning disability and results in longer hospital stays than the general population”.

A focus on reducing the incidence and impact of pneumonia is vital as we work to reduce health inequalities associated with the learning disability community. There has been a focus on determining underlying risk factors and causes of the disease and an increased understanding that for many individuals the disease is largely preventable. However, the potential numbers of risk factors is large and there is still limited understanding among the general population and within the learning disability community that pneumonia is largely an avoidable disease.

Common increased risks for the learning disability population include eating, drinking and swallowing difficulties (dysphagia), gastro-oesophageal reflux disease (GORD), sleep disorders such as sleep apnoea, neurological conditions, reduced mobility, smoking, immunodeficiency, long term chronic medical conditions such as uncontrolled epilepsy, diabetes, heart disease, pulmonary disease and renal disease .

The British Thoracic society has stressed within their recent clinical statements that poor oral health is a key

risk factor for pneumonia and, in particular, aspiration pneumonia. There is increasing evidence suggesting that an improvement in oral health could reduce both the incidence and severity of the disease for people with learning disabilities. Consequently, a focus on improving oral health can play a vital role in improving life expectancy and reducing health inequalities.

Aspiration pneumonia is caused by foreign matter entering into the lungs. This is typically saliva, food or stomach acid. Bacteria introduced by this route set up an infection of the lung tissue, resulting in pneumonia. It has been suggested that the oral cavity of people with learning disabilities may serve as a reservoir for bacteria that may be aspirated into the lungs. Food debris is also an issue, especially with underlying neurological dysfunction and/or a dry mouth. For those of us who work in special care dentistry this confirms what we have seen clinically. Patients with learning disabilities struggle to maintain good oral health and often their teeth and mouths are coated with thick layers of dental plaque and rotting food. It is logical to conclude that the numbers of oral bacteria, and in particular more dangerous anaerobic bacteria, will be very high. These bacteria then find an easy route into the individuals’ lungs and can cause pneumonias.

Consequently, it is vitally important that people with learning disabilities have clean and healthy mouths. However brushing teeth well isn’t an easy thing to do. Many people with learning disability will struggle to process information and understand the best way to brush teeth. There can also be issues such as a lack of support, lack of education or lack of skills or dexterity to do this independently. Often they are very anxious in clinical settings and this further prevents their ability to understand professional advice on improving their oral health. Some people rely on others to keep their mouths clean and some patients can exhibit care resistant

behaviour which affects carers and family's ability to provide good oral health care.

It can be easy therefore to stop trying and to accept that poor oral health is an inevitability for this wonderful community. Complacency and/or a feeling of hopelessness can cause individuals, families, and carers to accept poor oral health outcomes with many people not realising the potential risk of associated disease such as aspiration pneumonia.

The dental profession can help by:

- Using personalised care with genuine shared decision making and reasonable adjustments.
- Raising awareness of the importance of oral health and link to aspiration pneumonia.
- Engaging with the learning disability community to improve clinical settings and co-produce learning and information tools such as videos can be especially helpful.
- Improving access to community dental teams who have time and specialist experience in supporting patients with learning disability. Often there is a lack of awareness of the national network of community dentists and that people with learning disabilities can be referred by high street dentists.

Carers and families of those with unsafe swallows can be fearful of toothbrushing. The act of introducing a toothbrush and paste to the oral cavity can be perceived as a high-risk for aspiration. However, we know that an unbrushed or poorly brushed mouth, laden with bacteria is a great contributing factor to a person acquiring aspiration pneumonia, and the benefit of twice daily, effective toothbrushing may vastly outweigh the risk of aspiration during toothbrushing.

Carers, families, and individuals can minimise risk when toothbrushing, and improve oral health by:

- Using fluoride toothpaste (at least 1450ppm) ideally twice a day and spitting out the excess but not rinsing all the toothpaste away. (Spit Not Rinse!) Some people benefit from prescribed higher fluoride toothpastes and some people who experience sensory issues may prefer a different taste to the typical minty toothpastes or prefer a neutral flavoured toothpaste such as Oranurse.
- Trying to avoid sugary drinks and keeping sugary foods to mealtimes.
- Considering which toothbrush to use. Some people cope better with an electric toothbrush or would benefit from a triple headed or suction toothbrush.

Smaller toothbrush heads are easier and more comfortable to use than large.

- Using a non-foaming toothpaste, and not wetting the toothbrush before use can reduce foam and liquid in the mouth.
- Taking breaks and being mindful of the position of the individual when brushing.

Increased awareness of the link with aspiration pneumonia may reduce risk of incidence and severity of the disease. It may help to reduce avoidable deaths and reduce health inequalities. Poor oral health does not have to be an inevitability for people with learning disabilities. It is beholden to all of us to work together and ensure there is ongoing support where needed and that individuals are empowered to improve their health.

Acknowledgement

With thanks to Deirdre Taylor, Senior Dental Nurse and Lead in Oral Health Promotion Hertfordshire Special Care Dental service for her insight and contributions.

Contact details

Una Monaghan BDS, Msc. Clinical Director, Special Care Dental Service, Hertfordshire NHS Community Trust (HCT).

Email: una.monaghan@nhs.net

References

Glover G, Williams R, Oyinlola J. (2020) An observational cohort study of numbers and causes of preventable General Hospital admissions in people with and without intellectual disabilities in England. *Journal of Intellect Disability Research* 2020; 64:331–44

Legg, J. et al. (2023) *BTS Clinical Statement on the prevention and management of community-acquired pneumonia in people with learning disability* Available: <https://pubmed.ncbi.nlm.nih.gov/36863773/>

National Institute for Health and Care Excellence (2020). *Learning disabilities: background information: definition*. Available: <https://cks.nice.org.uk/topics/learningdisabilities/background-information/definition>

Resources within Mouth Care Matters:

<http://mouthcarematters.hee.nhs.uk/wp-content/uploads/sites/6/2020/01/MCM-GUIDE-2019-Final.pdf>
<https://www.gov.uk/government/publications/delivering-better-oral-health-an-evidence-based-toolkit-for-prevention>

Chiropractic Treatment for People with profound and multiple learning disabilities

Pat Graham

Lauren is 35 and lives in a housing support service with 3 others but visits the family home several times a week and I provide ongoing support both to Lauren and to her care provider. Lauren has a profound learning disability and is non-verbal but has always had a full and active life and enjoys lots of different activities. She also has complex epilepsy with focal and tonic seizures for which she takes anti-convulsant medication which partially limits the number and strength of her seizures, although they still often break through.

For some months running up to the start of the first lockdown the number and strength of Lauren's seizures had increased dramatically, and in fact in January 2020 she had 150 seizures, some of which were small, but others were forceful and could throw her off her feet and on to the floor or against walls. She has had quite a number of visits to A&E to check for injuries and concussion. By the time we eventually managed to get an EEG for her it was clear that there was going to have to be a change in medication in the hope of reducing the numbers and effects of the seizures.

So the start of the first lockdown saw Lauren on increased levels of new medication in addition to her existing medication. Gradually over a long period the old medication was withdrawn and as that happened the number and strength of her seizures reduced significantly. As this took place at the start of the Covid lockdown I was not able to visit Lauren for around 3 months and she was not able to visit the family home, and so I could not witness at first hand the changes in Lauren physically, emotionally and cognitively. However, I could tell from conversations with staff and from photographs that they sent me that all was not well with Lauren. She was withdrawn, miserable, tired and lethargic, and didn't want to eat or drink. This could have been because of the trauma of the withdrawal of all of her activities, not being able to visit home or the increase in medication, or most likely a combination of all three.

Once she was able to come home to visit and she was able to get out and about more she did recapture some of her old spark but there was a clear deterioration in her posture that was only getting worse over time rather than better. Her body was tilting over to the right, while at the same time she was leaning forward, and her head was also hanging down most of the time. She was reluctant to move her arms away from her body. Worryingly, she didn't appear to be able to correct her posture despite encouragement.



At that time, it was extremely difficult to find anyone to speak to about Lauren's posture, let alone get anyone who might be able help or to listen to my concerns. We did eventually, after many months of asking, get to see a physiotherapist, but other than giving us a few exercises to try with Lauren, little progress was made. One physiotherapist was heard to say that "this is probably just the way that Lauren's posture is going to be from now on". Might this have been another instance of diagnostic overshadowing? I also tried a private osteopath who also gave us a few exercises to try but again without any apparent improvement.

After one particularly distressing visit home in the spring of 2022 when it became clear that Lauren's posture was worsening, I sat with my laptop and thought, I'm not



moving from here until I find someone who will be able to do something to help her. What I found was a chiropractor. I did some reading to find out what chiropractors did and had no idea whether this would be helpful to Lauren or whether she would even tolerate whatever they might do. I was aware that chiropractic treatment wasn't available on the NHS and that made me a bit sceptical but on the other hand the NHS hadn't come up with anything so far to help Lauren's worsening posture and I was becoming increasingly anxious. I knew that this was treatment that Lauren would have to pay for but as I had exhausted all other options I decided to see what the chiropractor would say.

It was a revelation really. He was able to tell by looking at Lauren and by exploring the parts of her body most affected that she had probably had a historical undiagnosed injury and had tightened her muscles around that injury. His first task was to untighten those muscles using a variety of techniques. Lauren had to have treatments twice a week for the first few weeks, but what a difference that made. She was very responsive to the treatment and really took it in her stride. If Lauren hadn't been happy about what was happening she would have made her views known but she is always relaxed and cooperative at her appointments and it's as if she knows that this is something that is going to make her feel better. Her chiropractor has such a lovely, calm manner with her and is never fazed by anything that Lauren might do.

I had always thought that as long as her posture didn't get any worse then I would be satisfied with that, but what I hadn't anticipated was that her posture, her range of movement and her flexibility would all improve significantly. The chiropractor did say that if she hadn't had treatment then her posture would have continued to deteriorate and might eventually become irreversible. She still tends to revert to her old posture when she is tired or unwell but crucially she is now able to correct it. She has been seeing her chiropractor for two years now

and attends only once every 3 weeks. Although she will probably have to do so indefinitely, I am very happy with that because it is so reassuring to have access to someone who now knows Lauren's body really well and can tell when she is tense or anxious or even when she's had a bigger seizure. We also do exercises with Lauren at home to maintain the improvement and try to make those as fun as possible so that she doesn't even realise that she's doing exercises.

The benefits of chiropractic treatment were brought home to me recently when as a result of an accident in her day service bus Lauren ended up with a fractured clavicle and concussion and was probably traumatised too. I was able to take her to the chiropractor who saw her more frequently for the next few weeks. He was able to identify where she was stiff and sore and to give her appropriate treatment to relax her muscles around the injury. As a result, she has now recovered a full range of movement really quickly.

Anyone with a family member who has profound and multiple learning disabilities (PMLD) who might benefit from chiropractic treatment will, I'm sure, have concerns about their vulnerability and even bone density, as I did. I have discussed these matters with Lauren's chiropractic team and have been reassured that they are very aware of these issues. If you also have these concerns I would recommend having a full discussion with a chiropractor if you are contemplating treatment. If a hoist is used to lift your family member then that is something that you would also need to discuss.

As a result of attending the clinic with Lauren on so many occasions, I decided to have treatment myself after suffering chronic back pain for many years, probably because of being a carer for so long, and it has also made an enormous difference to my quality of life too. As it is so challenging for people with PMLD to express how they are feeling, especially when they are in pain, it has been such a relief to know that it has been possible to alleviate some of that pain and discomfort for Lauren. Indeed, by having treatment myself, I know what it will feel like for her and that it isn't frightening or painful.

Contact details

Pat Graham is Lauren's mother and also Chair of the Pamis Board

Email: patgraham@gmail.com



Personal Health Budgets Children with Complex Health Needs

Helen Leonard

Personal Health Budgets (PHB) are poorly understood by many professionals and families alike even though they have been in existence for some years now. I will try to explain and demystify them for you!

Origin of Personal Health Budgets

Personal Health Budgets trace their roots to Disability Rights and Independent Living movements, when disabled people campaigned for a right to exercise choice in their own lives by having control over the support they need to live independently. It was gradually acknowledged that allowing people to purchase the specific services they need promoted autonomy and independence, rather than creating dependency on inflexible state-provided or purchased services.

Direct Payments for Social Care support started in the 1990s. The pilot for Personal Budgets for health-related

support began in 2009. Independent evaluation of this Personal Health Budget pilot demonstrated benefit in terms of quality of life and psychological wellbeing. Perhaps surprisingly it also showed significant cost savings, especially for high value packages, so they are particularly effective for people with most complex health difficulties (Jones et al, 2017)

Why Personal Health Budgets help

If you have even a passing familiarity of people with complex disabilities (including those with profound and multiple learning disabilities), you will have come across scenarios where there is a service on offer locally but

this does not offer support tailored to specific individual needs or include the supply of equipment or something else that would greatly benefit and improve someone's quality of life, however there is some administrative barrier. Perhaps the service is not from a pre-approved provider the local authority or health service already has contracts with, or the request is unusual, or there may be disagreement about whether health, social care or education should pay.

Sometimes one service will not pay for something even when it will have clear benefits and save another service significant costs. Dylan's story is a good example of this. Dylan has cerebral palsy and wanted to adapt his wheelchair to enable him to go to university independently and live without carers. This involved 2 simple things; a powered footplate to allow him to transfer independently without a carer moving the footplate and assisting him, and moving the charging point to an accessible position that he could reach to plug it in. Local wheelchair services would not normally cover these £2k costs even though it would save £13k in ongoing social care costs for carers and allow independent living. (<https://www.england.nhs.uk/blog/there-are-wheels-within-wheels/>)

An important feature of Personal Health Budgets different from previous initiatives, is that they allow recipients to define their own needs and desired outcomes (like Dylan's request to adapt his chair to allow independent living), coproducing a care plan which identifies how to achieve those outcomes; a 'What Matters to Me' approach (NHS, 2020).

Who can receive a Personal Health Budget?

Anyone can be given a Personal Health Budget (PHB) by their Integrated Care Board (ICB), if the ICB choose to spend their funds in this way, so in theory anyone entitled to NHS care can have a discretionary PHB. Funding can vary from small one-off payments to large ongoing packages for people requiring high levels of care support. Some people have a legal entitlement to a Personal Health Budget including disabled children with high levels of health need, which mean they are eligible for Children's Continuing Care (CCC) funding or, at 18, adult Continuing Health Care (CHC). More about CCC and CHC below.

Children's Continuing Care funding

Where children have a very high level of health need, needing support beyond that which would typically be funded by social care, they may be entitled to support through Children's Continuing Care (CCC). Continuing Care eligibility is assessed across 10 domains of need: breathing, eating and drinking, mobility, continence or elimination, skin and tissue viability, communication, drug therapy and medicines, psychological and emotional needs, seizures and



challenging behaviour. Children do not need to have problems in all of these domains and a very high level of need in just one area can be enough to qualify. A child is likely to be eligible for Continuing Care funding needs if they are assessed as having a severe or priority level of need in at least one domain of care, or a high level of need in three domains of care, but this is not prescriptive and informs a wider professional assessment of needs. More information about CCC including the scoring of each of the domains can be found in the National Framework for Children and Young People's Continuing Care. (DoH, 2016)

Examples of children who would qualify due to a need on just one area are those with a tracheostomy tube that requires frequent essential interventions (additional to routine care) by a fully trained carer to maintain an airway; children requiring ventilation at night for very poor respiratory function; children on IV nutrition and children with seizures that often do not respond to rescue medication and the child or young person needs hospital treatment on a regular basis. Disabled children may qualify with a combination of high needs across 3 or more domains.

Transition and Adult Continuing Health Care (CHC)

Some teenagers in transition may not meet children's criteria but may meet adult continuing healthcare (CHC) criteria once they turn 18, as this carries two additional domains of 'cognition' (important for young people with a learning disability, which is not taken into account in children's criteria) and 'other significant health care needs'. (DHSC, 2022)

Receiving funding through health for young disabled adults has huge financial implications as well. Adult Continuing Health Care is not means tested and the person is not expected to contribute to the costs of care. If a disabled young adult is assessed as needing support by social care only, they are expected to contribute a significant amount towards paying for their care out of their disability benefits.

Why I am so passionate about Personal Health Budgets

My son, Matthew, received a Personal Health Budget and it was life changing. He is now 23 and was born with complex disabilities. I was a paediatrician before he was born and I chose to specialise in Paediatric Neurodisability when he was 2. We struggled for 17 years to get things we needed = like a suitable wheelchair, adaptations to the house and, most of all, support with his 24 hour a day care needs. Because of the complexity of his health needs, he easily met eligibility for children's and adult Continuing Care. We initially used the additional health funding to increase his stays in respite / short break care, but the quality of this care deteriorated significantly with management changes, and I withdrew him as I felt he was unsafe. There also was no good local option for his post-18 care. He was already struggling with the busy environment of school. The education department questioned the value of an educational placement post 18 due to his profound learning disability and, at best would only fund 3 days a week, term time only. The suggestion was that care at other times would be delivered by the family and a social care agency. Our past experience of agency care was that it was unreliable and of poor quality. During his time in school, upward of 30 people were involved in his care at any one time between classroom, transport and respite care and there was also high staff turnover and poor communication. I knew we needed a small team of people that understood Matthew and were trained to meet his unique needs. I also wanted some choice about who came through my front door and looked after my son. I met resistance to this from social care, who did not understand Personal Health Budgets and declined our request to manage our own care, despite our legal entitlement. After a formal complaint and escalation to NHS England, we received our budget more than 6 years ago.

We have since used this budget to employ our own care team at home, who help Matthew to access activities that he loves, like hydrotherapy and being outside in the fresh air for hours every day, especially in wind, rain and snow, which rarely happened at school. We employ people who share our values and will be happy delivering this. We purchased a wheelchair with a back that adjusts to his growth and evolving scoliosis (having previously waited more than 10 months for this to be approved, despite the old chair being outgrown and broken).



Supported by people who know him well, spending a lot of time outdoors and enjoying home cooked food prepared by people who have the time and skills to feed him, Matthew is much calmer, infinitely happier, sleeps better and his seizure control has improved. His weight was previously well below 0.4th centile. He gained 18 kg in the first 18 months at home, ending discussions around other interventions.

The most surprising thing to me, apart from his reduced agitation, has been the cost saving. In the process of battling with social care, I had costed out their suggestion for adult life including escorted transport at £99 per day, a specialist educational place and agency care. Our current package saves at least £50k a year and probably nearer £100k a year in direct costs. The indirect costs such as avoidance of gastrostomy for example, would add a lot more. I do not miss the endless MDT meetings, which again are expensive (add up everyone's hourly rate next time you are in big meeting) and often did not help us.

The other indirect benefits are immeasurable; Matthew's happiness, the effect on me and his sisters and their relationship with him. They can be part of his care team (trained and paid) if they choose during holidays from university, rather than unrecognised young carers. One of our care team is now training to be a Learning Disability nurse, having come to us from school unsure about what she wanted to do 5 years ago. We supported her on an access to healthcare course and changed her hours to accommodate her training. Another has lost weight, and her health has improved as a result because the care team are outside with Matthew so much, (rather

than driving between short 'time and task' home visits in her old care job).

Professional perception of Personal Health Budgets and local implementation

Implementation is very patchy. In some ICBs, individual professionals seem to have 'got it' and can see the potential benefits. They are proactive with how they may be used and support professionals and recipients to do so. Elsewhere suspicion and resistance to Personal Health Budgets remains, which is understandable in an under resourced system struggling to meet competing demands.

Families' experiences of Personal Health Budgets

Our story of the difficulties we encountered to secure a PHB is common. Once we received our budget, we have had little support to run our care package, when we should have been offered the option of a third party to become an employer on our behalf. Many families would struggle to take on the responsibility of employing and running a care team and I have made mistakes along the way. We get some support through our employer's insurance and their helpline, but the day-to-day running is left to us. I often describe that I have just been promoted - from a carer, to managing a care agency. There is still a lot of work there, but it is different.

Telling our stories

I am now connected to many people across England with Personal Health Budgets who have similar stories to tell about better health and wellbeing outcomes, reduced use of health services and more fulfilled lives.
<https://www.peoplehub.org.uk/our-stories/charlotte-and-toms-story/>
<https://www.peoplehub.org.uk/our-stories/robyns-story/>

You will generally find that people rapidly lose interest or glaze over if you tell them you want to talk about a piece of health policy (which is essentially what Personal Health Budgets are) but when I explain them through my own experience (or Dylan's, Charlotte and Tom's, Robyn's or other published stories) they make sense and usually generate interest and questions, so I am open to talking about our experiences.

How you can help and further sources of support
Please, please, please let families know about Personal Health Budgets. The majority of eligible people, as we did, find out about Personal Health Budgets for themselves, with only 27% finding out about them through a health professional. NHS Digital (2022)

Let families who may want to use their budget to employ

carers, know that they do not have to become employers and a number of third-party organisations exist to do this for them, whilst the family can still be in control of the care they receive and who delivers it. Where families are left without this third-party support or choose to take on responsibility themselves, we have set up an online resource to assist families like ours, called MyCareBudget which now has over 5,000 users. (https://mycarebudget.org/mediawiki/index.php/Main_Page)

There is a wealth of resources about Personal Health Budgets on the Future NHS collaborative platform and you can sign up for this with an NHS email address. (<https://future.nhs.uk/PCCN/view?objectID=14302864>)

This article is adapted from another article, originally written for the British Academy of Childhood Disability Newsletter in 2023

Contact details

Dr Helen Leonard is a Consultant in Paediatric Neurodisability and manages a PHB for her son Matthew. She has been Chair of the National PHB Quality Framework Advisory Group, Regional Clinical Lead for Personalised Care for North East and Yorkshire. She is also a Trustee of In Control, a national charity, who work towards everyone having the support they need to live a good life.
Email: helenclairel@icloud.com

References

- Dept of Health (2016) National Framework for Children and Young People's Continuing Care. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/499611/children_s_continuing_care_Fe_16.pdf (2022 Accessed 16 January 2023)
- Dept of Health and Social Care (2022) National Framework for NHS Continuing Healthcare and NHS funded Nursing Care. (https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1170290/National-Framework-for-NHS-Continuing-Healthcare-and-NHS-funded-Nursing-Care_July-2022-revised_corrected-July-2023.pdf)
- Jones K, Forder J, Welch E, et al. (2017) Personal Health Budgets: Process and context following the national pilot programme. Canterbury, UK. (<https://www.pssru.ac.uk/pub/5331.pdf>)
- NHS (2020) *What is a Personal health Budget*. <https://www.nhs.uk/nhs-services/help-with-health-costs/what-is-a-personal-health-budget/> (2020 Accessed 16 January 2023)
- What is a Personal health Budget* NHS Digital (2022) <https://digital.nhs.uk/data-and-information/publications/statistical/personal-health-budgets> Accessed 16 January 2023)

Safe, Efficient and Enjoyable Mealtimes for children who need mealtime assistance: – not as easy as it may SEEM

Sally Morgan

Respiratory health has been highlighted as a cause of premature deaths of people with learning disabilities for some time. There are many reasons for respiratory health problems, but some of them are related to eating, drinking and swallowing e.g., choking on food, or food or drink entering the lungs and causing a chest infection.

Respiratory Health & Eating, Drinking and Swallowing Difficulties

Many people with profound and multiple learning disabilities (PMLD) can experience difficulties with eating, drinking and swallowing. They may be given the diagnosis of 'paediatric/(developmental) feeding disorder' (Goday et al, 2019). This means they will eat and drink less than they need to grow and thrive. It impacts four areas; nutrition (calories and nutrients), feeding skills e.g. using a spoon or biting skills, medical needs e.g. reflux or health interventions e.g. tracheostomy, and relationship between the person and their carers e.g. stress during mealtimes.

Many people with PMLD often have particular difficulties with the sensation and coordination of the movements of their lips, tongue, mouth and swallowing muscles e.g. biting the food, sensing the feel of the food to move it back through the mouth or swallowing the food smoothly. This is called 'oropharyngeal dysphagia'. All children who have oropharyngeal dysphagia will also have paediatric feeding disorder. However, a person can have paediatric feeding disorder without having oropharyngeal dysphagia e.g. a person who has a very restricted diet due to allergies or who cannot feed themselves, but can chew, bite and swallow with no difficulties.

The consequences of oropharyngeal dysphagia can affect health and wellbeing of the person with PMLD and their family and other carers. e.g. they may cough and choke during mealtimes, with an immediate risk to life or the food and drink may 'silently' go into the windpipe (aspiration), with risks of slower long-term lung damage. Family carers who offer full or partial mealtime assistance can find mealtimes both a joyful time for interaction and a place of stress. e.g. they may be concerned if the person they are assist is eating safely or eating and drinking enough, or whether mealtimes are enjoyable for them both at home and when out and about.

Oropharyngeal dysphagia in people with PMLD has been little researched and there are minimal guidelines for this group. The research sometimes focusses on specific diagnoses; Cerebral Palsy, Down Syndrome and within the adult field the wider term 'Learning Disabilities'. NICE guidelines for children and young people with Cerebral Palsy ((National Institute for Health and Care Excellence (NICE), 2017), some of whom will have PMLD, suggest that there should be a focus on three areas: Safety, Efficiency and Enjoyment. There is some current research exploring interventions to improve people's eating and drinking and swallowing skills. However, families need to assist several mealtimes a day balancing these three priorities now, not waiting for new findings. Speech and Language Therapists (SLT) are usually the lead professionals working with families to provide recommendations for the meal. There are many aspects (targets) that could be changed within a meal. One target recommendation could be a smoother texture for meals, which is a compensatory strategy. This may improve safety (coughing and choking risk less), efficiency (faster meal eaten) and enjoyment (reduced family-carer stress as they are not anticipating a choke). However, there are potential negative consequences to any mealtime change. Providing smoother textures could reduce safety long-term (person not learning to eat more textured food and increasing risk if they are given any lumps), reduce enjoyment (a single-texture meal), and could lead to reduced efficiency (less consumed). SLTs often recommend multiple mealtime recommendations and family-carers are known to not always follow them for multiple reasons (Charpentier et al, 2020 and Chadwick et al, 2006).

The SEEM project

My PhD research project aims to create a toolkit to guide this complex decision making between the family-carer and SLT. The focus is on children with neurodisability who have oropharyngeal dysphagia with a particular level of need, rather than diagnosis. The focus is on children that require mealtime changes e.g. different position, pacing and/or food texture, and

mealtime assistance (described as 'Requires Assistance' or 'Totally dependent' (Sellers et al, 2014). Many of these children will have PMLD, though not all. This project focuses on school-aged children, as previous studies have mainly focused on pre-school, younger children or adults.

My project is using an evidence-based practice model. Evidence-based practice has three aspects.

1. **Best research-evidence: Systematic Literature Review.**

I am looking at all the research papers I can identify to find out what might work to support family-carers and their children. I have only found 25 papers so far and the information is very varied.

2. **Clinical expertise: Survey of current clinical practice.**

I have surveyed SLTs about their practice when working with school-aged children. I am still analysing this information, including the written resources SLTs use to provide recommendations e.g. mealtime mats. SLTs described much greater use of many different mealtime changes/targets when compared with the wider multidisciplinary team participants of a previous survey (Parr et al, 2021).

3. **Patient and/or carer values and preferences: Qualitative observational study of mealtimes of family-carers and children.**

I am currently out meeting some wonderful children and family-carers for this ethically approved study in the North Thames region. I am exploring family-carers and children's experiences of an assisted mealtime. My small 'Parent Expert Group (PEG)' has been essential in planning this study. I worked as a SLT with children and families for 19 years before starting a teaching role and this research, but I continue to learn so much from them. My project is also guided and supported by PhD supervisors, Professor Katerina Hilari, Dr Kathleen Mulligan and Dr Kelly Weir, alongside a SLT stakeholder group and specialist SLT advisors.

The final part of my study is to bring all the information I gather to co-create a prototype discussion toolkit together with family-carers and SLTs. I will be sharing my results further as the project progresses. If you want to read more and access my current conference abstracts and future journal articles for free, they are/will be on my University profile: <https://www.city.ac.uk/about/people/academics/sally-morgan#publications-link> or email to join my project's mailing list.

If you are a parent or family carer of a child or young adult with PMLD and oropharyngeal dysphagia who needs mealtime assistance, and you might be interested in either taking part in the co-creation project and/or

increasing the diversity of my 'parent expert group' then I'd love to hear from you.

Contact details

Sally Morgan (Senior Lecturer in SLT/ Clinical Doctoral Research Fellow, City University of London) sally.morgan.2@city.ac.uk

References

- Goday PS, Huh SY, Silverman A, Lukens CT, Dorrill P, Cohen SS, et al. Pediatric Feeding Disorder: Consensus Definition and Conceptual Framework. *Journal of Pediatric Gastroenterology & Nutrition*. 2019;68(1):124-9.
- National Institute for Health and Care Excellence (NICE). Cerebral palsy in under 25s: assessment and management. 2017. Report No.: [NG62].
- Charpentier A, Morgan S, Harding C. A service evaluation of parent adherence with dysphagia management therapy guidelines: reports from family carers supporting children with complex needs in Greece. *Disability and Rehabilitation*. 2020;42(3):426-33.
- Chadwick DD, Jolliffe J, Goldbart J, Burton MH. Barriers to caregiver compliance with eating and drinking recommendations for adults with intellectual disabilities and dysphagia. *Journal of applied research in Intellectual Disabilities*. 2006;19(2):153-62.
- Sellers D, Mandy A, Pennington L, Hankins M, Morris C. Development and reliability of a system to classify the eating and drinking ability of people with cerebral palsy. *Developmental Medicine & Child Neurology*. 2014;56(3):245-51.
- Parr J, Pennington L, Taylor H, Craig D, Morris C, McConachie H, et al. Parent-delivered interventions used at home to improve eating, drinking and swallowing in children with neurodisability: the FEEDS mixed-methods study. *Health technology assessment (Winchester, England)*. 2021;25(22):1-208.

A focus on eye care

Lisa Donaldson and Rachel Pilling

Our two writers are passionate about improving an area of health for people with learning disabilities that we can all often overlook – vision and eye care. Many of us don't go for sight tests until we notice changes in our vision, and yet vision problems are often insidious and may be hard to communicate. Eye clinics are now one of the busiest areas of the NHS in terms of outpatient waiting lists as the number of people with sight problems increases.

For people with profound and multiple learning disabilities (PMLD) the risks are all the more heightened as sight problems are often 'silent' in their development or presentation, and so very easy to diagnostically overshadow, by making the assumption when someone may not be using their vision effectively, it is simply part of the overall disability. However, with your support eye care professionals are able to assess and diagnose what someone with PMLD can see and suggest ways to help people make the best use of the vision they have.

Here, Lisa (an optometrist) and Rachel (an ophthalmologist) describe what each of their professions do and take you through some of the ways in which to access better eye care and the strategies that can be put in place to help someone with PMLD with their vision.

Sight tests are for everyone

Lisa writes:

"As an optometrist, we know that regular sight tests are a really important health check to have. They are a gateway to getting the right prescription glasses, through to spotting serious sight threatening conditions or signs of other underlying health problems, like diabetes or high blood pressure.

What is less well known is that vision issues are the most common co-existing condition that people with learning disabilities experience, with a rising prevalence amongst people with PMLD. There is even research that says everyone with a severe or profound and multiple learning disability "should be considered visually impaired unless proven otherwise". For many people with learning disabilities the problem with vision stems not from the eye but from the brain, which Rachel will explain more of later.



Symptoms such as eye rubbing, discomfort with bright lights, being hesitant in poorly lit environments, losing interest in social activities, bumping into furniture, being alarmed at an unfamiliar noise or when approached, and significant changes in general behaviour, may also be triggered by changes in vision, or the need for glasses.



From my work in special schools, I know half of the children will have a problem with their vision, but we also know over 4 in 10 have never had a sight test or eye care. This extends to adults too – we know half of these individuals won't have had a sight test in the recommended period of 2 years.

As with other aspects of healthcare, the familiar barriers experienced by people with profound and multiple learning disabilities exist. As optometrists we can use so many different techniques to help overcome those barriers. I can reassure all readers that you do not have to be able to speak, to read, sit still or tolerate a dark room to have a sight test. I can tell a huge amount from quietly observing how someone is using their vision, for example if they can track a moving object, distinguish a colour or a picture, or notice things in their peripheral vision. I'll check to see if their eye movement is well controlled, or restricted.

I can still understand if a person needs glasses and measure the required strength through techniques at a distance using a special instrument (a retinoscope) and lenses, all performed from a distance if a person does not want me in their personal space.

Helping someone feel comfortable and at ease is vital, so for people with PMLD talking to them and their supporters helps me get to know what works best for the person and how they communicate. I demonstrate and explain everything I am going to do before I try to do it, and having someone present who is familiar with the

person helps as we can show how the tests work on them.

Getting used to glasses is another common concern. I work alongside dispensing opticians, registered and trained professionals who are expert in supporting people not just with glasses but other aids for their vision. If you have always lived your life in a blur because you are very short sighted, suddenly seeing all these people and objects around you can be too much. Sometimes it is a case of gradually building up the use of glasses, introducing a weaker prescription initially, or really engaging in a favoured activity with the glasses first.

And we shouldn't forget the sensory feel of wearing those frames. There are many different types of glasses frames we use at SeeAbility that are softer and more pliable, as well as frames that can be adapted for different facial characteristics or hearing aids and wheelchair head rests, for example.

SeeAbility keeps a list of optometrists who have told the charity that they can offer more support to people with learning disabilities. We also have a suite of resources all about eye care including 'easy read' versions, and forms that you can take to an optician to help them put in the adjustments that a person with PMLD might need.

Our eye care champions have lived experience and are happy to present about their work to improve and promote eye care for people with learning disabilities who have PMLD. So please do get in touch with us if you need any more information about eye care (see further reading listings below)."

Understanding vision

'Rachel says':

"As Lisa writes, vision is key for everyone with a learning disability, not least because people with profound and multiple learning disabilities (PMLD) are surviving and thriving into middle and older age, a time when everyone begins to develop a vision issue of some shape or form.

By your 40s most people start to notice they need reading glasses, and there are many common eye conditions related to ageing, such as cataract, that can present at an earlier age in people with learning disabilities.

I have a particular interest in cerebral visual impairment (CVI), also known as brain based visual impairment. For people with CVI, the eye examination may look entirely normal, but the brain has difficulty making sense of the information it receives. For someone with reduced processing capacity, vision is 'tuned down' especially in



busy, noisy or new environments. This has an impact on learning independence skills, recognition of faces and places, and communication.

CVI is now the most common cause of visual impairment in children, and of children with a visual impairment, 72% will have an additional disability - most commonly a neurodevelopmental one. So for children and adults with PMLD, having more information on CVI can be really helpful.

It can actually be really tiring for a person with PMLD to use their vision, especially when there are lots of things to look at. How a person uses their vision might fluctuate minute by minute because of this – put simply the brain may 'switch off' from using vision just to allow for a bit of rest.

As we learn more about CVI, we know more about what can really help a someone adapt and also develop their seeing world. In the same way minimising background noise can help someone with hearing impairment, with CVI the aim is to minimise clutter and visual distractions. I would advise anyone who has CVI or suspected CVI to create an environment which minimises the effort of seeing (plain walls, high contrast marking, minimal clutter, keeping things still, or making things big and bold and bright).

As an example, I have been involved in using 'colour tents' which can help soothe someone's vision by reducing visual clutter and movement but also through the use of bright colours stimulate visual attention and awareness so a person feels able to keep their vision 'switched on'."

The CVI Society has some excellent resources on this (see further reading).

As readers of this journal will be supporting people with PMLD but have perhaps not yet been able to meaningfully access eye care for them, it can be helpful just to start the process by making a note of how the person is 'functionally' using their vision. It can be useful to use the CLIMB framework to think about what that is telling you.

Communication – using AAC, symbols, signing or even recognising faces and facial gestures

Learning – how they interact with their world and discover new things

Independence - including things like finding food on a plate, locating clothes, shoes

Mobilising – getting about and understanding the environment they are in

Behaviour - recognising that sensory overwhelm can show itself in behaviours that challenge or through withdrawal

There are also the helpful tools that SeeAbility has highlighted, which include a 'functional vision assessment' form for supporters and carers to use (see further reading).

As Lisa has reiterated, once someone is on their eye care journey, there are lots of adaptations that can be put in place, from getting an accessible sight test through to the treatment they need in a surgical setting. I am pleased to say the Royal College of Ophthalmologists has guidance for all hospital eye clinics on how to make the changes needed by people with learning disabilities (see further reading)."

Hope for the future

Lisa concludes:

"What has been missing in eye care is a real focus on the targeted and failsafe schemes that people with learning disabilities need (particularly people with PMLD) but this is starting to change. With Rachel and many others, including PMLD LINK, we have been championing not just the case for a national programme of eye care in special schools but better optical care pathways.

In England, a special schools eye care scheme is about to commence after ten years of campaigning and we hope that this will begin to deliver a more equal right to sight, but it is just the start.

We've worked with local eye care services to improve access for people with learning disabilities and autistic people. These areas now offer an Easy Eye Care pathway, which means longer appointments through opticians who have had additional training on supporting people with learning disabilities. The new Easy Eye Care pathway

is currently only set up in a few areas of the country, but we would like to see this service in every local Integrated Care System so people with learning disabilities, including those with PMLD, can go to an accredited opticians, or ask for a home visit, where they know everything will be geared to their needs.

We would also like to see more alignment to the GP learning disability Annual Health Check, so everyone with a learning disability would be offered an annual NHS sight test (and there's no question as to whether you have to pay or not). This means a change to NHS regulations which we'll keep campaigning on.

To stay in touch about our campaigns and other news in eye care please do use our contact details below.

Contact details

Lisa Donaldson, optometrist and Head of Eye Health and Vision at SeeAbility.

Professor Rachel Pilling, consultant paediatric ophthalmologist and Professor of Special Needs and Learning Disability Eye Care, University of Bradford.

Email: eyecare@seeability.org

Website: www.seeability.org/eye-care

X/Twitter: @SeeAbility

Facebook: www.facebook.com/RSB.SeeAbility

LinkedIn: www.linkedin.com/company/seeability-eye-care/

Further reading and resources:

Eye care resources and easy read materials:
<https://www.seeability.org/eye-care>

Functional visual assessment tools - to help you understand how someone is using their vision:
<https://www.seeability.org/resources/functional-vision-assessment-fva> <https://www.seeability.org/resources/bradford-visual-function-box>

Royal College of Ophthalmologists Eye Care for People with Learning Disabilities
<https://www.rcophth.ac.uk/resources-listing/eye-care-for-adults-with-learning-disabilities-2015/>

Cerebral Visual Impairment (CVI) resources
<https://makeiteasiertosee.co.uk/>
<https://cvisociety.org.uk/>

Creating an organisational PMLD Network

John Ockenden and Alison Worsfold

About 5% of the people supported by United Response would be described as having profound and multiple learning disabilities (PMLD). The organisation works in local communities across the country so people with PMLD and the staff who support them are dispersed widely; very often they are the only such people supported by the organisation in their locality. These factors, combined with the particular challenges of caring for and supporting people with PMLD, mean that staff can feel isolated, and disconnected from their local colleagues and the wider organisation.

Two developments in the last decade have supplied the means to overcome this. Firstly, The PMLD Standards (Doukas et al, 2017) offer a framework for collaborative discussion of best practice, celebration of existing successes and identification of areas for improvement, both at individual and organisational levels. Secondly, video conferencing has become familiar and reasonably comfortable for most people; it's now possible for people from across the country to meet and share their experiences without travel and accommodation costs, and within a reasonable time-commitment.

Empowered by these developments, our PMLD network meetings launched this Spring, with representatives from fifteen different teams sharing good practice and identifying areas that require improvement. Initial feedback from participants emphasised the positive benefits of meeting with colleagues who share the same privileges and challenges involved in supporting people with PMLD.

We plan to focus initially on the standards that relate to health, before moving on to address standards of broader support, in quarterly meetings, culminating in an exploration of the issues relating to transitions. As much as possible we'll use the standards within the context of the "Foundations of Good Support" (United Response, 2019), as this is how support is framed across the wider organisation.

In addition, the network will develop proposals both for increasing the visibility of people with a PMLD in the organisation's internal and external descriptions of its work, and recognising and celebrating the work of those who support them.

We expect the network to evolve, determining its own structure and purpose as we learn more about what its members need. Already we can see the potential for the network. For example, we are more likely to access high quality staff training in the particular health needs of people with PMLD (we discussed PMLD organisation

standard 6:2 in our first network meeting) together than we would be alone.

We're interested in hearing from others treading a similar path, and we hope to be involved in the further development of the PMLD standards; they're a rich and much-needed source of wisdom and guidance, for everyone involved in caring for and supporting people with PMLD.

Contact Details

John Ockenden, Practice Development Coordinator, United Response
john.ockenden@unitedresponse.org.uk
Alison Worsfold, Head of Health, United Response
alison.worsfold@unitedresponse.org.uk
United Response <https://www.unitedresponse.org.uk/>

References

Doukas, T., Fergusson, A., Fullerton, M. and Grace, J. (2017) *Supporting People with Profound and Multiple Learning Disabilities*. Core and Essential Service Standards, 1st Edition. [Available at: <http://www.pmlmlink.org.uk/wp-content/uploads/2022/01/Standards-PMLD-h-web-6-Jan-2021.pdf>]

United Response (2019) Foundations of Good Support (<https://www.unitedresponse.org.uk/resource/foundations-of-good-support/>)



Delegated Healthcare Activities: Implementation in adult social care

Erren Wheatland

Many adults with profound and multiple learning disabilities continue to live in their family home in adulthood, where the family have access to appropriate support and the family home can meet the person's needs. There are adults with profound and multiple learning disabilities however who may choose to move out of the family home, or need to for a variety of reasons e.g. the family have insufficient support, the family home environment cannot meet the person's needs. In circumstances in which people need to live in supported accommodation they are often restricted in where they may live, having a choice of who may support them, and with whom they live by virtue of a lack of skilled, community-based staff to meet their complex health needs. Healthcare activities they may require include, for example, gastrostomy care and enteral nutrition, catheter care, CPAP/BiPAP (both are types of non-invasive ventilation devices to support breathing), administering suppositories, insulin administration, oral suction, stoma care, and managing complex epilepsy.

It is vital that we seek to avoid situations in which adults with profound and multiple learning disabilities live in clinical, remote accommodation because of their health and/or postural needs, when with the right structures in place they could be supported within their local community, by appropriately skilled social care staff – ensuring that their holistic needs are met as ordinarily as possible. That is where 'delegated healthcare activities', and the collaboration between local health teams and social care can integrate to ensure people can continue to live in and be an active part of their local community.

A delegated healthcare activity is an activity that a regulated healthcare professional, such as a nurse, nursing associate, occupational therapist or speech and language therapist, delegates to a care worker or personal assistant (<https://www.skillsforcare.org.uk/Support-for-leaders-and-managers/Managing-a-service/Delegated-healthcare-activities/Delegated-healthcare-activities.aspx>).

Delegation of any healthcare activity must be person focused, with the person supported at the centre of all discussions and decisions. It requires close collaboration with the person, their family, health and social care professionals to ensure all work towards shared goals and outcomes. Where a person is unable to make the decision for themselves, the principles of the Mental Capacity Act apply, and decisions must be made in the person's best interest. Collaboration and co-production can have a positive impact on a person's physical and emotional wellbeing, by ensuring support is inclusive, personalised and responsive, enabling them to live their life in the way they choose. This article describes how one social care provider organisation strives to achieve all this.

Skills for Care – Delegated Healthcare Activity Guiding Principles

Skills for Care, the Department of Health and Social Care (DHSC) and partners have co-developed voluntary guiding principles to support person-centred, safe and effective delegation of healthcare activities. The principles are designed to be adapted locally to complement existing best practice and local protocols. In line with the Skills for Care "Delegated healthcare activity guiding principles" we have a robust governance framework in place which is led by our Director of Quality and Specialist Service Delivery, and supported by a nurse-led health and wellbeing team. For each healthcare activity we have an evidence-based policy and procedure following best practice. Membership of professional bodies and networks', together with subscriptions to update alerts from NICE and Department for Health and Social Care, ensures we remain up to date.

Safe Delegation

Critical to safe delegation is developing a skilled, confident and knowledgeable team. Training relevant to the needs of the person bridges the gap between theory and practice. It is important to delegate healthcare activities that are within the team member's scope of competence and ensure they fully understand the policy, procedure, guidelines and protocols. Our policy states that team members must complete their mandatory training and care certificate prior to moving onto healthcare activities; it is essential that team members have an understanding of the fundamentals of care and support, and feel comfortable to take on the healthcare activity. Everyone's delegated healthcare activities should be adequately supervised and supported so they can provide safe, effective, compassionate care and support.

Assessing competence and confidence

Learning doesn't just happen during training; there needs to be a focus on practice leadership, supervised practices and competency assessing. Adopting coaching and mentoring techniques enable theory to be embedded into practice. If we consider gastrostomy training, for example, the home enteral nutrition nurses will train the support team but don't support with competency assessing. We provide a minimum of 3 observed supervisions by the manager or deputy manager (who must have at least 2 years experience of that healthcare procedure). We proactively share expertise and guide team members to develop good practice and build their confidence. Critically we need to ensure practice is consistently good, with a team that communicates well together, and is equipped with the skill, knowledge and confidence to support each delegated health activity safely and well.

We have standard competency assessment tools with a set of both standard and person focused assessment criteria. For example, for gastrostomy care and enteral feeding, one of the criteria is asking why the person they are supporting has the gastrostomy, implications on their health and wellbeing, if they can consume anything orally etc. This means we are focusing not just on the healthcare activity, but the holistic health needs of the person.

Challenging the knowledge and attitudes of team members is an important element of assessing competence. This includes being positive and proactive to instill knowledge and confidence, and encouraging the team member to self-reflect. Ongoing assessment of competence is essential, with periodic observational supervisions to observe interactions, practices, coach and mentor team members, and be alert to indicators of poor or inconsistent practice. This is key to safe and effective outcomes.

Documentation and Record Keeping

In addition to training and competency assessing, robust documentation and record keeping is needed for delegated healthcare activities. These need to be person-centred, produced collaboratively and verified by a health professional.

The photo of Samir El-Ziftawy is a reminder to #MindYourLanguage; to use respectful language when supporting people but also when documenting and record keeping. Hence we would avoid language like "Samir is PEG fed"!

For all delegated healthcare activities there needs to be a clear protocol/guideline and risk management plan for support teams to follow e.g. with gastrostomy care and enteral nutrition that might include risk of aspiration,



infection, complications and mitigation measures to minimise identified risks. Each protocol or guideline should include an escalation plan, including being watchful for sign/symptoms and/or complications, knowing what to do, who to contact and how to seek immediate medical advice and support if necessary.

We have specific health monitoring forms to record, for example, oral suctioning, bowel monitoring, catheter-associated urinary tract infection (CAUTI) monitoring etc, to ensure consistency of monitoring and recording. We have also embedded use of the Restore2mini across the organisation. The [Restore2mini](#) is a tool to support early identification (Soft Signs) of deteriorating health. It also aids improved communication with health services, by aligning to the 'situation, background, assessment, recommendation and decision' (SBARD) tool that is used widely in healthcare settings. (see: <https://rb.gy/1zyuww> for further information).

Monitoring and Review

Delegation of a healthcare activity is reviewed regularly. This includes a review of the protocol or guideline with the relevant Healthcare Professional/s and update of policies and procedures in line with evidence-based best practices. We have refresher training, which is generally two yearly, but with an annual assessment of competence structure in place.

Reviewing and monitoring of risks and incidents related to delegation is completed using our internal governance system, overseen by the Head of Health and Clinical Governance. Any untoward event related to a healthcare activity is documented, which promotes reflection and lessons learned. This is monitored centrally via the Governance and/or Quality Board meetings and can be shared with the relevant health professional. A good quality Annual Health Check provides an additional layer of monitoring and review of the healthcare activity for the person.

Challenges and Barriers for Social Care

Providers

Delegating healthcare activities can create challenges for providers; balancing diminishing resources with providing safe and effective support. For example, we see reduced access to allied health professionals due to stretched resources and budgets, and increased difficulties accessing training for healthcare activities. A recent example of a situation we had to address was when a health professional advocated what we consider unsafe practice. They had suggested they train one team member how to orally suction and that person could then cascade the learning. This is against our policy, raising questions of accountability and responsibility, and is unsafe for the person. Shared values and shared responsibility between provider, commissioners and health and social care professionals will enable barriers to be overcome, and enhance people's lives and outcomes.

Conclusion

With the right training, practice observations, governance and monitoring, social care providers can provide healthcare support that is effective, efficient and safe for people with multiple health issues. It is possible to offer health/clinical support for people away from health/clinical settings and balance the meeting of complex health needs whilst ensuring we are maximising positive life experiences. This does require open, proactive collaboration between health and social care working together with the person at the centre of the support and their families to ensure people can live well, in their local community.

Contact Details

Erren Wheatland, RN (Adult & Child), BSc, PGCert. (Epilepsy),
Head of Health and Clinical Governance, Achieve together
Email: erren.wheatland@achievetogether.co.uk

Achieve together are a social care provider organisation supporting adults with learning disabilities, including adults with profound and multiple learning disabilities.

We offer health/clinical support for people away from health/clinical settings – balancing meeting the complex and multiple health needs of people with profound and multiple learning disabilities, whilst ensuring we are maximising positive life experiences within local communities. We support a number of people in England and Wales with healthcare procedures/activities, by and large this is within registered homes or supported living, supporting people with profound and multiple learning disabilities, but not exclusively. Being flexible and creative with evidence/research based support, led by a nursing team means we can offer support to people who may otherwise be living in more clinical settings.



Get Involved

All contributions to our journal PMLD Link are welcomed. Share your ideas about future topics for the journal or make suggestions of authors we might approach. If you want to write for us yourself, it's easier to get your experiences and thoughts into print than you might think. We also welcome shorter items about new resources, books, websites, events, courses or news in general.

PMLD Link readers include family members, carers and professionals working across child and adult services for people with PMLD. To see typical contributions, look at some recent back issues. You can download a free copy of PMLD Link from www.pmlmlink.org.uk or sign up as a 'Guest' to view back issues of our journal.

Our Editors are keen to support new writers. We will provide support at every stage - from the germ of an idea through to the finished piece in print. Articles are usually between 1- 4 pages of A4 (about 350-1500 words). They can be very practical in nature or have a more research /academic approach. We are very flexible in our requirements! To see our Guidelines for Writers visit the 'Get Involved' pages on our website www.pmlmlink.org.uk.

For more information contact info@pmlmlink.org.uk

The Beauty of Sleep

Michael Fullerton

How often do we check in with others in the morning, “Did you sleep alright?” Just like talking about the weather, we talk a lot about whether we slept well or not. We have a natural concern if someone close to us hasn’t slept well, as we know this can have a negative effect on their day.

For many years I was proud of the fact I didn’t need much sleep, going to sleep about midnight and up at 5am. I am now regretting that, aware that insufficient sleep quality and quantity can have a significant impact on mood, concentration and increase the risk of health issues such as stroke, heart disease and Alzheimer’s. I’m now trying to retrain my body and brain to sleep for longer!

When it comes to people with learning disabilities, how much or how little do we consider, or know what a person’s sleep quality and quantity is like? It will be straightforward if the person is able to tell us, but what about those people who can’t say, can’t tell us?

Benefits of sleep

We spend hours every night with little or no awareness of what is happening around us or within our body. In fact, if we gain enough sleep and we live to be 75 years of age, we will have been asleep for 25 years of that lifetime. To take up that amount of time sleeping we would hope to expect there to be multiple benefits - and there are.

The benefits of good quality sleep include keeping our mental functions working well, such as remembering, learning, making decisions and solving problems. If we don’t get enough sleep the opposite is true in that our memory and ability to concentrate and learn is affected, as is our ability to make sensible and safe decisions or solve problems. If we have poor mental health, we can struggle to gain good sleep, but if we have poor sleep this will also create worse mental health.

If we are sleeping well, this means we are restoring our body and mind, and this generally makes us feel better. Some of the key benefits of sleep include restoring our immune system in order to prevent or fight infection. During sleep the body produces hormones to repair tissues and cells and in children and young people, the growth hormones they need to develop. Sleep is also good for cardiac health, helping to lower blood pressure, slowing our heart rate down which allows the heart and vascular system to rest. Good quality sleep helps to regulate our appetite and maintain a healthy weight with the production of a hormone called leptin, which ‘tells us

when we are full’ and reducing ghrelin which is our ‘hunger’ hormone. It also helps regulate our blood sugars, reducing our risk of Type 2 diabetes.

Disordered Sleep

If sleep is disturbed or deprived it can have significant impact on day-to-day life, moods, behaviour and overall health. If we have an existing health issue, poor sleep can affect the ability to rest and recover and may perhaps make the condition worse. Inadequate sleep can both be caused by anxiety or depression or, cause us to experience anxiety or depression. It may be difficult to determine which came first, especially for people who cannot easily self-report issues that are affecting them.

If we don’t get good sleep, we can feel lethargic, struggle to get motivated, lacking energy and drive during the day. We might have difficulties with concentration and remembering what we are supposed to be doing. When we have not had enough sleep, we can become less patient and more irritable with others. If we don’t have a learning disability, and are not supported in social care, we might just be seen as ‘a bit off’. For someone with a learning disability, they might well be seen as being ‘challenging.’ Instead of being given the space and support they need, extra pressure may be put on them, leading to greater irritability and possibly being prescribed psychotropic medicines as a result. People with profound and multiple learning disabilities who are unable to self-report their difficulties are reliant on those close to them to assess and identify in a holistic and complete manner. If disrupted or disordered sleep is not even a consideration, the person’s difficulties with sleep or quality of sleep, can go unnoticed for a significant amount of time.

There are specific classifications of sleep disorders with which people may be diagnosed if they have chronic sleep problems that impact on their lifestyle, health and wellbeing. The main categories are -

Insomnia disorders, where a person has difficulty getting off to sleep or staying asleep and this interferes significantly with daily life. So even with a good sleep environment, the person struggles to sleep, causing sleepiness and difficulty concentrating during the day.

Sleep related breathing disorders could include issues such as chronic snoring, and obstructive or central sleep apnoea. Obstructive sleep apnoea is the most common and serious sleep related breathing disorder, and requires specialist clinical support and treatment to reduce symptoms and minimise risk.

Central disorders of hypersomnolence – this is excessive sleepiness and a serious problem in which the person is chronically sleep deprived. It covers conditions such as hypersomnia, where a person has a strong desire to sleep or nap during the day, such as when at work, school, or socialising with people. It could include narcolepsy which is a specific neurological disorder.

There are different circadian rhythm sleep wake disorders, which are quite common and can have impacts on functioning. These can include jet lag, and also shift work disorders which can affect people who work variable shifts. This may be something to consider for family carers who are having to provide 'round the clock' support, having no alternative but to be alert and responsive overnight and try to function well during daytime hours as well.

Parasomnia covers a wide range of behaviours while asleep including sleepwalking, having night terrors and sleep paralysis.

Sleep related movement disorders are repetitive movements that impact upon sleep quality and could include restless leg syndrome, or teeth grinding.

There may be a number of additional reasons why people with profound and multiple learning disabilities experience sleep difficulties or disorders.

- Posture/Body shape. A good quality assessment with a 24 hour postural care plan, which often includes the use of sleep systems, can maximise sleep quality and quantity.
- Health and neurological issues, may include respiratory conditions with aspiration risk (such as reflux) or pressure injuries. Epileptic seizures, (nocturnal or others) can impact on the person's overall wellbeing and of course cause sleep disturbances.
- Sensory impairments may impact on sleep in a number of ways including a disrupted circadian rhythm and difficulty establishing night-time cues. Referrals to specialist sleep clinic may be appropriate, and establishing clearly defined routines and a sleep-inducing environment are essential.
- Pain/Discomfort may result in disturbed sleep. In order to preventatively/proactively seek to alleviate or minimise this, intimate knowledge of a person

with profound and multiple learning disabilities is needed to identify when they may be experiencing pain, discomfort or distress.

- Incontinence. Strategies should be in place to maximise comfort during sleep and minimise sleep disturbances with continence.
- Impact of medicines. Many medicines can adversely impact on sleep quality and quantity. Close dialogue with prescribers should consider impact of medicines on sleep. Also take account of complementary and alternative therapies.
- Lifestyle. People with profound and multiple learning disabilities will be reliant on others to support exposure to daylight/sunlight and good physical, mental and spiritual wellbeing.
- The sleep environment - essential equipment (eg enteral feed pumps), designed to support the person may pose a risk of noise or vibration disturbance. Technology advances reduce these risks but should be considered when assessing the sleep environment, along with temperature, light levels etc.
- Reliance on family/carer support. This creates added risk of disrupting sleep while repositioning, supporting, or simply checking on the person while they are asleep. We need to minimise this impact as much as possible -lower lighting, soft footwear, and even assistive technology for monitoring perhaps.

Disordered Sleep Research – people with profound and multiple learning disabilities

There is limited research into sleep quality for people with learning disabilities generally, and even less focused on people with profound and multiple learning disabilities. Shanahan et al (2023) completed a systematic review focused on the prevalence of sleep disorders in adults with learning disabilities. They found significant variable prevalence of disordered sleep for people with learning disabilities, and challenges with measuring sleep quality and quantity. The type of sleep disorders and difficulties experienced by people within this research included difficulties falling asleep; limited amount of sleep; night waking; daytime napping and sleepiness. The main sleep disorder featured across studies was sleep related breathing disorders in specific syndromes. Korb et al (2021) considered 'Sleep: the neglected life factor in adults with intellectual disabilities.' Further research is certainly required more specifically in relation to people with profound and multiple learning disabilities. Within this, ensuring clarity of what constitutes disordered sleep within the profound and multiple learning disability population and identification of the key short/long term health impacts can help to ensure proactive strategies are put in place to enhance sleep quality and quantity and improve quality of life for people.

Sleep related breathing disorders such as sleep apnoea are often not adequately detected and treated. It is important for all clinicians involved in the support of people with profound and multiple learning disabilities to be aware of the person's sleep and sleep quality in GP visits, Annual Health Checks and Health Action Plans. Any concerns or doubts can then be monitored closely, referred on to sleep specialists, investigated and at the very least, a sleep hygiene plan introduced.

Understanding and Assessing Sleep Difficulties

As a family member, or support worker, you may wish to consider some or all of the following when assessing potential sleep issues for the person with profound and multiple learning disabilities:

- Make sure sleep issues are considered within the person's Annual Health Check (for those aged 14 years onwards) and Health Action Plan
- Health Checks should combine with regular medication reviews and should take account of any complementary or alternative therapies.
- Pain, discomfort or distress.
- The potential impact sensory loss may have on the person.
- The nighttime routine together with detailed recording of nighttime observations, including time prior to the person going to bed. Record any daytime sleepiness and naps.
- The sleep environment including lighting, temperature, bedding, mattress, noise etc.
- Sleep positioning, the 24-Hour Postural Management Plan and presence or absence of sleep systems and overnight position changes.
- Managing continence and comfort overnight.
- Impact of respiratory diseases, and/or epilepsy.
- Presence of any trauma or PTSD.
- Impact of your own behaviour as carer.

Considering our own behaviour

As part of my role in adult social care, I have spoken to a number of waking night staff about their role in promoting good quality sleep. Team members were careful to seek to minimise the risk of sleep disruption, by wearing soft shoes, lowering the lights, opening and closing doors quietly, limiting noise, maintaining temperature to suit the person sleeping etc. The use of assistive technology allows us to avoid physical checks on people at night but equally there may be good reason where physical checks are essential. A challenge in social care is the fact that the person may be supported at night-time by multiple people. With change of staff, the consistency of routine for the person is critical, so an awareness and continuity of adhering to a clear sleep hygiene routine is so important. This includes familiarity and predictability of the routine which helps prepare the person for bedtime and sleep. The plan must be clear on

how we communicate that - bedtime is soon, it is bedtime now, and finally... time for sleep. Sometimes a person may be supported overnight by 'sleep-in' staff. That worker is paid to sleep during the night but responds to the needs of a person if required. 'Sleep-in' staff may not be as immediately responsive meaning the person with profound and multiple learning disabilities is awake and alert for longer, impacting negatively on their ability to return to sleep as easily.

Maintaining Good Sleep Hygiene

There are many useful tips to maintain good sleep hygiene. I would recommend the Sleep Charity and Sleep Foundation for excellent tips on improving sleep quality and quantity. If you are concerned about a person's sleep, do maintain a sleep diary, speak to the person's GP and seek a referral to a Sleep Clinic if you continue to be concerned and the issues are not resolving. Ensure the person has a clear Sleep Hygiene Plan which covers all the things that are important to them, to get the best possible sleep, as consistently as possible – and aim for us all to sleep well!

Contact Details

Michael Fullerton, Director of Wellbeing, Achieve together

Email: michael.fullerton@achievetogether.co.uk

Socials: @MichaelFullert3

Website: www.achievetogether.co.uk

References

- Korb, L., O'Regan, D., Conley, J., Dillon, E., Briggs, R., Courtenay, K., Perera, B. (2021). Sleep: the neglected life factor in adults with intellectual disabilities. *BJPsych Bulletin*. 2023;47 (3):139-145, doi:10.1192/bjb.2021.122
- Shanahan, P., Ahmad, S., Smith, K., Palod, S., Fife-Shaw, C. (2023). The prevalence of sleep disorders in adults with learning disabilities. A systematic review. *British Journal of Learning Disabilities*, 51, 344-367.



Hospitals: Panorama and Particulars

Rachel Wright

There is a panoramic view of any hospital admission for families of children with complex needs. But step closer and the days are riddled with particular incidences creating a uniquely, stomach churning rollercoaster. It might be that the text messages going out to family and friends saying, “He’s getting better”, “Doing well,” “It’s been a success.” These statements are all true. They are honest, broad strokes of the panoramic view of this current chapter of one family’s story.

But step closer to the scene. A little nearer, a bit more, just one more step so you can smell the hospital soap mixed with bleach and stale, crisp linen. There. That’s it.

Look close enough and between the lines of sweeping statements lies particular details; vomiting, agitation, thumbs up from the consultant, concerned looks from the nurse, sitting up, sitting out, alarms.

Small steps, occasional smiles, glimmers of hope, sodden bed clothes, waiting, mouth care, alarms.

Pressure area care, stained pillow cases, postural care, positioning, opinions, tests, alarms.

Attentive care, real connection, hours of crying in discomfort, moments of delight, beeping, buzzing, alarms, alarms and oh so many alarms.

The complexity of care grows as more and more professionals build their own web. Families start juggling treatments, complications and medications. Before long, prescriptions are written to tackle the side effects of the pain medication. Then at two in the morning, in the fog of fatigue, the puzzle becomes too complicated as they try to understand the new side effects requiring another kind of treatment prescribed for the medicine given for the ramifications of the first pain medication set up for the mammoth consequences of the original monstrous surgery.

Each bump and dip on the daily rollercoaster is fizzing and tingling with every kind of emotion. Breath holding where incidences of kindness pierce loneliness like a knife. Fear and anxiety about the unpredictable future (or next hour) ripple constantly under the surface, only drowned by the ebb and flow of the hospital’s rhythmical 24-hour clock.



In **How to survive Hospital Admissions** (The Skies We're Under podcast, season 3, episode 11) Rachel Wright, Sarah Clayton and Lucy Parr share top tips for hospital stays because, as they say "parents like us are more likely to be packing a bag for A&E or a hospital stay than a weekend getaway."

In this episode they chat about:

- The best parent hospital beds and getting enough sleep.
- The queue for the shower holding a hospital towel which feels like sandpaper - like we're all on the worst possible camping holiday.
- Advocating for your child with the healthcare team
- How to show what your child is typically like.
- Hospital Apocalypse grab bag.
- Hospital Passports.
- And importantly looking after your bowels; "there is one thing guaranteed to make a hospital stay even worse – constipation."

The Skies We're Under podcast is created by and for parents of people with disabilities and the many practitioners who support them. It's for everyone trying to get from one end of the week to the other, whilst bridging the gap between the life we expected and the one they're actually living. You can find the podcast at <https://www.bornattherighttime.com/the-skies-we-are-under-podcast/> and listen to it wherever you access your podcasts.

Contact details

Rachel Wright, Qualified nurse, unqualified parent and author.

Rachel is the Founder and Director of Born at the Right Time

Website: www.bornattherighttime.com

Twitter/Facebook: @BornatRighttime

In the Next Issue

The Winter issue of the PMLD LINK journal will be one of our 'general' issues, without any theme and so we welcome contributions on any topics that are important or of interest to you. We know how popular the 'Wellbeing' theme has been, so new items on that subject would be welcomed too.

Don't forget to think about photos! We love to include photos and photo stories - they really help bring things to life. So, please do think about sharing photos – whether it is to accompany a written piece or just to submit with a caption or couple of lines of description. You can find our consent form and photo guidelines on our website (<https://www.pmlmlink.org.uk/get-involved/>).

We welcome contributions from anyone, whether you've written before or not! The Editors are keen to support new writers and are happy to offer help to those who want it. (Find out more: <https://www.pmlmlink.org.uk/get-involved/#guidelines>)

Articles should be no longer than 1500 words, please. We would be pleased to receive shorter items sharing ideas or useful information. We also welcome brief items of news or reviews, about resources, blogs, books, websites, forthcoming events and courses - so please let us know about these too.

All contributions by Monday 7th October to: info@pmlmlink.org.uk please.

For further guidance or to discuss your ideas, please feel free to contact the editors.

Many thanks in advance!

The Winter issue editors are Bella Travis, Maureen Phillip and Rob Ashdown.

Improving Health Outcomes

The following are a selection of approaches and relevant resources that can support improved healthcare experiences and lead to better health outcomes. This list is by no means exhaustive as we find new and more successful ways to promote and support positive health and longer lives for everyone with profound and multiple learning disabilities. Hopefully this information and signposting is helpful to readers of PMLD LINK.

Annual Health Checks a UK overview

The challenges faced by people with learning disabilities, in terms of physical and mental health is well documented and backed by numerous reports and research papers. Indeed, for people with profound and multiple learning disabilities, multiple health conditions and vulnerabilities will often be present, requiring support from a variety of health specialists. Integral to health investigations and support, for people with learning disabilities are Annual Health Checks, to seek to ensure thorough health checking by GP Practices to work proactively and preventatively.

Annual Health Checks commenced in 2003 in Wales, and then 2008 in England despite being proposed back in 2001 by Valuing People. Since then, Annual Health Checks have been implemented in Scotland and Northern Ireland.

An Annual Health Check should be offered to every person with a learning disability and obviously a person could choose to decline. This thorough check allows local GP practices to get to know the person well, seeking early intervention to health concerns, and avoiding premature and avoidable deaths. While Annual Health Checks are available across the UK to people with learning disabilities, there are slight variations between the four nations of who can access these checks and at what age and of how they are accessed/delivered.

Annual Health Checks – England

This is available to anyone aged 14 years or over who is on their GP's learning disability register, which should obviously include everyone with a profound and multiple learning disability. If you are not sure if your family member or person you care for is on the register, please check with their GP Practice. The person should receive an annual health check appointment and one outcome of this consultation should be a personalised Health Action Plan.

More information: <https://rb.gy/pr5mzm>

Annual Health Checks – Wales

As is the case in England, Annual Health Checks in Wales are recommended for people with learning disabilities over the age of 14 years. A recent introduction in Wales is the 'Once for Wales Health Profile' introduced collaboratively between health and social care and is designed to aid a personalised focus on each person's unique needs and challenges.

More information: <https://rb.gy/wfhu5u>

Annual Health Checks – Scotland

A directive to all Scottish Health Boards in 2022 was issued by the Scottish Government to ensure Annual Health Checks are offered to people with learning disabilities aged 16 years and over. These checks are completed by a registered nurse or GP using the Scottish Annual Health Check for Adults with Learning Disabilities.

More information: <https://rb.gy/80zfom>

Annual Health Checks – Northern Ireland

In Northern Ireland Annual Health Checks are offered to adults with learning disabilities, through health facilitators, who are learning disability nurses whose role it is to liaise with the person's GP, encouraging uptake and following up on actions.

More information: <https://www.disabilityaction.org/news/annual-health-checks-for-people-with-a-learning-disability>

The Annual Health Check process

Across the four countries, the Annual Health Checks but will cover a broad view of the person's physical health, mental health and lifestyle; it is an opportunity to raise any concerns and queries you may have. The comprehensive list topics addressed may vary but in general include asking about things that can be more common if you have a learning disability, such as epilepsy, constipation, problems with swallowing (dysphagia), or with your eyesight or hearing. Most checks will also include, for example, a thorough physical examination, review of medicines, vaccinations and cancer screenings (where eligible), blood and urine testing, blood pressure, height and weight checks, review of dental checks. Some appointments may include other things such as an ECG, physical checks of breasts or

testicles, referrals or signposting for further specialist support, investigations and treatments.

Every Annual Health Check should result in a person-centred Health Action Plan from the GP or health professional, detailing actions to ensure the person remains in the best health.

The importance of reasonable adjustments and the new Reasonable Adjustment Digital Flag

The NHS says that if people have a disability, there should be a flag on their health record to say if they need reasonable adjustments to access their care. A flag is an alert on someone's health records asking staff to look at the record for more information about the reasonable adjustments someone needs. This is not just good practice; it is the law. Healthcare staff have a legal duty to make reasonable adjustments under the Equality Act 2010 and the Accessible Information Standard.

A reasonable adjustment is a change that a service can make, to help disabled people to access good, person-centred health and care. Person-centred means making sure things are put in place to meet your unique individual needs, wherever possible. It is likely you will need different reasonable adjustments in different places or for different procedures.

In the future, a Reasonable Adjustment Digital Flag will be used across all health and social care services, which are funded by NHS or local councils. Information will only be added to the digital flag, or shared, if you agree. You may need services like a hospital, the doctors, a pharmacy, or physiotherapy. In all these places, staff will be able to see what your reasonable adjustments are, if you agree.

Reasonable adjustments can support your communication, physical and sensory needs but also ensure your emotional needs are considered too. For example, extra time for appointments, a quiet place with dimmed lights to wait or appointments at less busy times. You might need some common procedures done differently, like having blood taken from a different part of your body that's easier for you to manage. Perhaps you need a hoist to move from a wheelchair to an examination couch, or a Changing Places style toilet with adult size, adjustable changing bed and space for carers – or disabled parking close by. One really important reasonable adjustment to have noted, for anyone with profound and multiple learning disabilities, is that all

health professionals involve and work in partnership with families or support staff who know that person best.

It's important to tell health professionals about your lived experiences and what works best. Ask them to add information about reasonable adjustments to your health records. You can add or update this information at any time.

Health and Care Passports

Personalised Health and Care passports (previously called Hospital Passports) are another approach to reduce inequalities and improve the health outcomes experienced by people with learning disabilities and autistic people. Hospital passports have been in use across the UK for a number of years. Hospitals, care providers and other services commonly produce their own or local versions of the Hospital Passport, which vary in structure, content and the level of detail.

In general, all hospital passports provide basic key information about an individual, their disabilities and their health needs. They share significant details about the health conditions a person has (eg cerebral palsy, epilepsy, dysphagia), the ways they communicate (including how to tell if they are unwell, showing discomfort, pain or distress), current medications, known allergies and any emergency protocols in place to manage their health issues effectively.

Specific information about essential healthcare interventions are noted (eg nutrition via PEG, use of nebulisers or suction). If a person need help to eat or drink safely, they may include a mealtime plan or advice from your Speech and Language Therapist. Similarly, they may include guidance from a physiotherapist, if they need support to move or to protect their body shape.

Passports will have a record of key people involved in their care and support – from next of kin, GP, care manager and any other professionals.

Recently NHS issued new guidance and a generic template for Health and Care passports (NHS June 2024) to be used across Integrated Care Systems in NHS and local authority funded services. The concept of a shared passport template aims to provide a more consistent approach nationally. It offers a common structure and predictable content for health professionals to become familiar and navigate more easily, for improved healthcare outcomes and experiences.

<https://www.england.nhs.uk/publication/health-and-care-passports/>

Learning Disability Acute Liaison Nursing

The introduction of the role of Acute Liaison Nurses, as far back as 1999 was to reduce health inequalities for people with learning disabilities when in contact with acute health services such as hospitals. We know from a number of Learning from Lives and Deaths – people with a learning disability and autistic people (LeDeR) Reports that people with learning disabilities die earlier and have poorer health outcomes than non-learning-disabled people.

While there is disparity across the UK in the numbers and roles of Acute Liaison Nurses, generally where they are in place within acute settings, they play a vital role in advocating for the person with a learning disability, ensuring effective reasonable adjustments and compliance with the Mental Capacity Act and Equality Act.

The role of the Acute Liaison Nurse and essentially the focus is on ensuring that a person's journey through acute health services is person-centred, the person and their family and/or carers are listened to, treated with compassion and respected throughout.

The Acute Liaison Nurse can play a pivotal role in many ways such as:

Health Facilitation

- Supporting pre-admission processes, and clinical assessment
- Assessing that services are appropriate and accessible
- Ensuring safe and timely discharge/follow up and further referrals
- Make recommendations about appropriate levels of care
- Advocate for the person, and advise on reasonable adjustments

Consultancy

- Guiding on capacity and risk assessment, and care planning for people with complex needs
- Supporting with complaints and incidents
- Support with Discharge Planning and further community support

Education

- Educating people with learning disabilities, their families and carers
- Raising awareness of learning disabilities and autism among hospital staff
- Providing information necessary to facilitate referrals and subsequent admissions

Health Promotion

- Serving as a contact person for community teams, internal hospital teams, admission and discharge teams, people with learning disabilities, their families and other professionals

Service Development

- Writing organisation policies
- Ongoing service development and quality assurance
- Making information accessible
- Completing audits
- Leading on health projects

Work is underway to seek to create a framework for these critical roles, to enhance consistency in how the role is applied. Ultimately, the roles are designed to ensure health inequalities are reduced and we enhance the life expectancy of people with learning disabilities across the UK.

Hospital Guide

The 'Meeting the needs of people with profound and multiple learning disabilities (PMLD) in hospital' guide was co-produced by PMLD LINK, Mencap and families, to help healthcare professionals and support staff to understand how to give people with profound and multiple learning disabilities the best possible care in hospital.

The guide explains some of the common barriers this group of people experience to getting the right healthcare eg recognition and treatment of pain, potential complications from common health conditions, unique and non-typical ways to show deteriorating health, negative assumptions about quality of life. It details suggestions to help prepare someone for going into hospital (where this is planned) and how to prepare for emergencies (eg hospital 'grab bag', medications list (or MAR sheet)).

The guide has a lot of very practical information, for example, about a person's unique but essential reasonable adjustments and how these may be more extensive for hospital stays (for example the need for enteral nutrition or a SAFE bed or use of a sleep system to manage postural care). The key role of the hospital learning disability Acute Liaison Nurses is highlighted, to help navigate the hospital systems and ensure holistic needs are met. In addition it includes further helpful information, including guidance on partnership working between hospital staff and families/support workers and clarification about the Mental Capacity Act and best interests decision-making.



The clear information and examples of good practice in this booklet are just relevant to people with profound and multiple learning disabilities, but for a far wider audience.

“If hospital staff get things right for people with PMLD, whose combined needs are very complex, they should be able to get it right for everyone” (Mencap/PMLD LINK, 2019: page 3).

<https://www.pmldlink.org.uk/wp-content/uploads/2020/02/Treat-Me-Well-Guide.pdf>

PMLD Standards

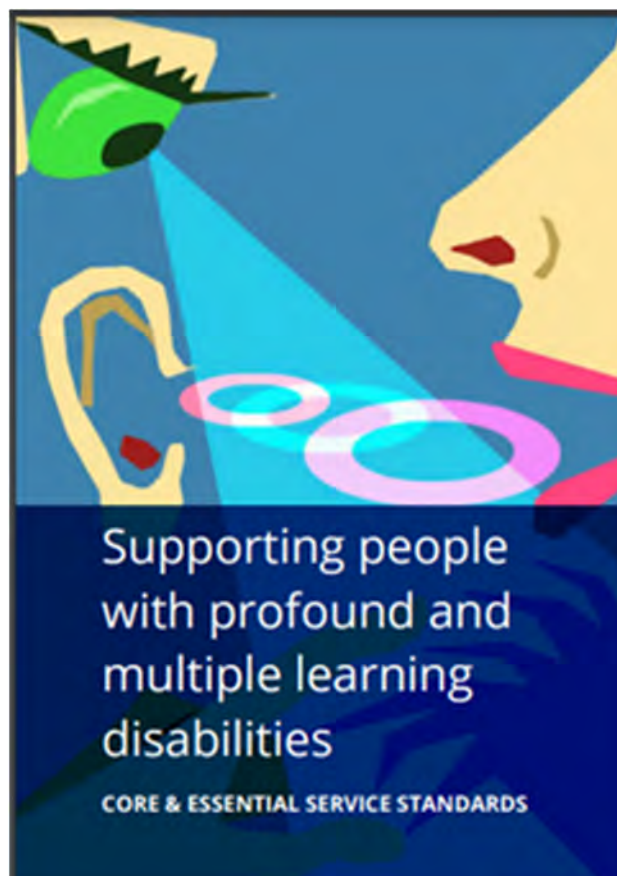
Supporting people with profound and multiple learning disabilities: Core and Essential Service Standards – mostly known as the PMLD Standards - were designed to improve the lives and experiences of everyone with profound and multiple learning disabilities, including their health status. They were co-produced by a diverse group of family members, education/health/social care professionals and academics who shared a passionate desire to ensure this population, regardless of their age or circumstances, consistently receive excellent support and services. This publication comprises two sets of inter-related standards. The Standards for Individuals offer benchmarks for personal outcomes, challenging low

expectations by offering more appropriate high quality, aspirational and meaningful benchmarks. The Standards for Organisations offer detail to indicate the actions and evidence services need in place to enact or operationalise and meet these standards in the services and provision.

Health and Wellbeing are a very important element within these standards. Their relevance, value and influence is emphasised in the way a person’s health underpins and is embedded to the success of ‘achieving’ each and every standard.

The standards were originally designed as a tool for self-review by services and to aid for commissioners in ensuring the provision they were funding was appropriate and of the highest quality. They are also frequently used by families to challenge inadequate, inappropriate and poor quality services to ensure a person receives the best care and support.

Download the standards : <https://www.pmldlink.org.uk/resources/>



Raising our sights – for better health

In 2010, Professor Jim Mansell published an important report called Raising Our Sights, which looked at services and support for people with profound and multiple learning disabilities (PMLD.) In response to recommendations in this report, ten 'how-to guides' (some with accompanying videos) and an eleventh, Guide for Commissioners were developed (2013). Although they were written so long ago, they continue to provide helpful advice on how to recognise good services and support for people with PMLD, how to challenge and campaign where people with PMLD are not getting the right support and how to make these changes happen (including checklists for commissioners.) There are three guides that specially address health issues:



Guide 2 – Clinical procedures



Guide 4 – Health



Guide 10 - Wheelchairs.

These and other helpful health resources can be located on the PMLD Link website

<https://www.pmlmlink.org.uk/resources/#health>

Distress and Discomfort Assessment Tool (DisDAT)

DisDAT Distress and Discomfort Assessment Tool		
Individual's name: _____		
DOB: _____	Gender: _____	
NHS No: _____		
Your name: _____		
Date completed: _____		
Names of others who helped complete this form: _____		
THE DISTRESS PASSPORT Summary of signs and behaviours when content and when distressed		
	When CONTENT	When DISTRESSED
Face Jaw & tongue Eyes		
Vocal sounds Speech		
Habits & mannerisms Comfortable distance		
Body posture Body observations		
Known triggers of distress: (write here any actions or situations that usually cause or worsen distress)		

DisDAT v22 © St Oswald's Hospice and Northumberland Tyne & Wear NHS Trust

In the late 1990s staff from learning disability and palliative care teams at Northgate Hospital in Northumberland noticed that pain score tools were not helpful for people with severe cognitive and communication impairments. In 2001 and 2003, they piloted the use of a distress and discomfort assessment tool (DisDAT.) This tool identifies distress (rather than pain specifically), documents signs and behaviours when somebody is content and also when they are distressed, and attempts to put any distress into context with a checklist of possible causes. Northumbria University carried out a validation study of DisDAT which was published in 2006. This concluded that:

- Distress signs and behaviours are not specific to any one cause.

- Each person has their own 'vocabulary' of distress signs and behaviours.
- Teams collectively pick up more signs and behaviours than any one individual.
- DisDAT documents identify distress accurately and carers find it easy to use.

Since then, many services have adopted the use of DisDAT which continues to be developed, refined and updated, based on research and feedback from users. More about DisDAT and the most updated version of the tool itself can be found on St Oswald's hospice website.

<https://www.stoswaldsuk.org/how-we-help/we-educate/education/resources/distress-and-discomfort-assessment-tool-disdat/>

NHS Midlands and East Top Tips

Another 'oldie but goodie' resource is this 'Top Tips' document produced by NHS Midlands and East. The document contains a wealth of useful information and explains that "these Top Ten Tips have been developed to support everyone, professionals and carers alike to help the person with PMLD live a fulfilling, happy and healthy life."



<https://www.mencap.org.uk/sites/default/files/2016-06/NHS%20EM%20-%20PMLD.pdf>

Sensitive Stories

For people with profound and multiple learning disabilities (PMLD) connecting with the world around them using their senses is their way of navigating their everyday experiences. Multi-sensory storytelling offers so many opportunities for people to engage, anticipate and become more familiar with all sorts of situations – including those related to health and growing older. The Scottish charity Pamis, explored this sensory storytelling approach to tackle important sensitive topics, such as sexual development, transitions or health interventions, like preparing for a visit to the hospital or the dentist. Originally, they created a number of Sensitive Stories as part of a research project, following Chris Fuller's model for Bag Books stories (<https://www.bagbooks.org/>), and making them specifically for individuals. This set of Sensitive Stories continue to be regularly on loan to families from Pamis' resource library. However, Pamis' basic story templates can be easily adapted to focus on other topics and help support others.



Lee's visit to the dentist.



Beth is growing up

Pamis together with Mencap, produced some simple guidance on creating your own sensory Sensitive Stories, enabling you to personalise them to an individual and the situation you want to focus on (eg preparing for a hospital appointment) or learn about (eg menstruation). Download the Sensitive Story guidelines: <https://www.pmlmlink.org.uk/wp-content/uploads/2020/02/Treat-Me-Well-Sensitive-Stories.pdf>

For further information about Pamis' sensitive topics contact: maureen.phillip@pamis.org.uk

PAMIS Health information leaflets

In the early days of PAMIS there was a fantastic programme of workshops that focused on developing the knowledge and skills of family carers of people with profound and multiple learning disabilities (PMLD). These were developed with leading health practitioners and as a consequence a series of health information leaflets were developed.

Sadly, the years have passed with no further funding or resource to update them. Families have relied on the progressive up to date information on the world wide web. Although informative and useful PAMIS recognise that life is challenging enough without navigating a thousand different links so they are keen to develop a resource that enables family carers to very rapidly access relevant and appropriate resources and information.

PAMIS are keen to test out an approach and will in the coming months be hosting a round table on epilepsy, drawing research and evidence into a discussion about practice relating to people with PMLD. They then hope to develop a resource based on these discussions. If this approach works, to then develop a programme to capture specific health conditions that impact on the lives of people with PMLD.

They are of course keen to collaborate with anyone else interested in this programme especially if you have some ideas of funding!! Please do get in touch with PAMIS with thoughts, ideas, resources and evidence.
<https://pamis.org.uk/contact/>

Health Resources from Oxfordshire Family Support Network

Interactive health website: This organisation has created an interactive website of accessible health resources and signposting. One feature is an interactive body map. You select an area of the body to find relevant information. This site also covers other topics including common illnesses, cancer, undiagnosed conditions, pain and medications, sleep, mobility and adaptations, therapies, fitness, accidents & emergencies and end of life care & palliative care.

See: <https://allaboutthehealth.oxfsn.org.uk/>

Webinar - Top Tips on teeth cleaning: This network hosted a valuable webinar for carers who struggle to clean the teeth of the people they look after. The practical advice and support including a Q & A session was presented by their local Community Dental Clinic.

A recording of this webinar is available on OxFSN YouTube channel: <https://www.youtube.com/channel/UCOvqbs2WU16XFi19pBJ874w>

Connect with us on social media

Remember to tag us on social media ~ @PMLDlink

X : @PMLDlink

Facebook: PMLD Link

Facebook: Raising the bar - CoP for the PMLD care standards

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



REPORTING BACK

Elements of Us in a Bus A celebration event with invited guests

By Anne Laney

The decision to celebrate the 30th Anniversary of Us in a Bus in a variety of ways in 2020 was dramatically prevented by circumstances we have no need to mention. One of the greatest disappointments was the cancellation of the Sensory Event we had worked hard to prepare. For invited guests only (that selection process is turbulent and difficult, more on that later) it was to be an exciting sensory exploration of the ethos and underlying principles of Us in a Bus and aspects of how we work, especially, but not exclusively, showcasing Intensive Interaction.

Initial discussions quickly highlighted the fact that the purpose, and nature of delivery of our work, could be broken down and categorised in such a way that the “elements” of Us in a Bus really rather neatly fit into groupings that could be represented by Fire, Water, Earth and Air. The Elements. How thoroughly pleasing and exciting to have a concept within which to plan. The diagrams attached illustrate our thinking regarding this and some of our thoughts about content, so I’d like to focus here on other aspects of planning and delivery. Having held a fabulous Colours of Us in a Bus event in 2015 for our 25th Anniversary, we initially thought about re-creating the completely immersive experience of this. It was an amazing experience, but during our reflection immediately afterwards we had noted that the huge demands on time and money were possibly not

proportionate to the level of enjoyment our guests actually obtained from coming. I say possibly because clearly many enjoyed the spectacle of an indoor poly tunnel decked out as a jungle (for example)! Completely changing environments, turning them into sensory mini worlds, is hugely time consuming and potentially expensive, and, we decided, not worth it for a one-day event.

So, we decided Elements would be streamlined to minimise set up and take down (our venue was time restricted) and we would try not to purchase any further equipment.

With our thoughts regarding what might be part of each Element’s sensory exploration agreed, the creative

business of planning structure and content began. The restrictions on venue availability dictated that we would have four run-throughs of an hour long “session/ experience”, with plenty of time for guests to arrive and the scene to be re-set between repeats. The arithmetic was pretty easy (thank goodness) and the 15 minutes per Element seemed about right.

The question of structure verses spontaneity was a big one. And how to transition from one element to the next creating a “whole” rather than 4 separate sections. This felt important. It is the blend of elements that makes Us in a Bus, and we endeavour to give each equal weight. This needed to be represented in the content of the experience in some way. The structure needed to be such that it supported the timeliness of the day but allowed for as much spontaneity as the guests needed within it. This is, after all, the basis of Intensive Interaction. Showcasing how to combine guest led engagement with pre-decided sensory ideas had to be at the centre of the day.

We’re fortunate to have several theatrically experienced team members and one absolute technical whizz on our team, so we confidently came up with the concept of having a pre-recorded backing track. Within this there would be; sound effects representing Fire, Earth, Water and Air; spoken affirmations; auditory cues to tell practitioners when to move through the structure and spoken poetry to transition between Elements.

We recorded each practitioner speaking the affirmations and Anna designed and produced the most magnificent, space holding, gently prompting backing track to be volume adjusted in the moment in order to take account of guest needs.



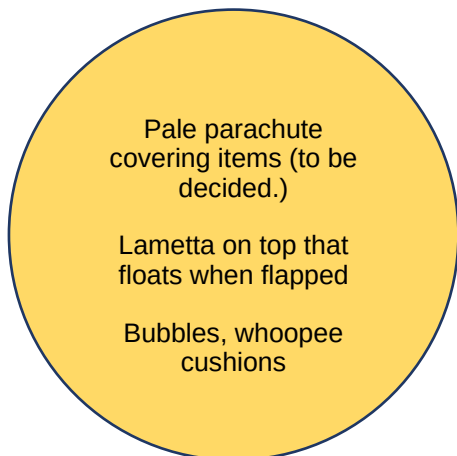
To minimise the set-up/take-down we designed a circle experience around a layered “cake” of parachutes (see photos). With careful positioning of available sensory items and having a stage manager using each parachute to gather up the outgoing element and reveal the next, we managed to choreograph a smoothly managed “performance” that meant that everyone else could remain engaged and available to our guests.



Which brings us neatly onto our guests. The most important aspect. The decision regarding who to invite is arduous, long and emotionally charged. Carefully discussing each person and considering their own individual sensory and social needs is time consuming, but necessary. Whilst we always want to explore sociability and create new connections whenever we can in sessions, this is not a session. There is no time to work through the complexities of navigating personalities new to each other. As a one-off experience we decided it was relevant and acceptable to invite those we were confident would enjoy the new place/new people/new things aspects. Inclusivity is, of course, always prominent in our work, but the reality of acknowledging the anxiety “newness” creates in some is important. List agreed, we then created a second “back-up” invitation group. Previous experience had highlighted that although carers always have the intention of ensuring the guests attend, logistics of drivers/shifts/long journeys/taxis/meal times/ medical conditions mean there will be no-shows.

Air

“ I am Me....I know who I am....I breathe....I am the only me ”
(centred, mindful, calm, breath of life)



Recorded sounds of wind
Live playing bass flute
Ips hum tune fade out recording so singing obvious. Turn into quiet hello song
Explore items.
Note, respond, share

Fire

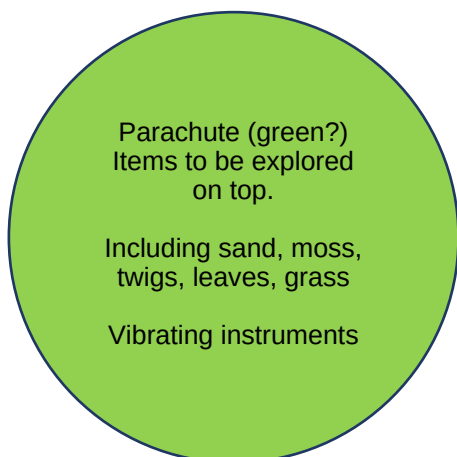
“ I know you're there....See me reach for you....I want to be with you ”
(Having a sense of others, warmth, friendship, desire)



Recorded sounds of crackling fire
Song. All ips “campfires burning/draw nearer/ all together/we see each other
Extend song exploration of items in parachute
Special focus on facilitating links and sharing
Note, respond, share

Earth

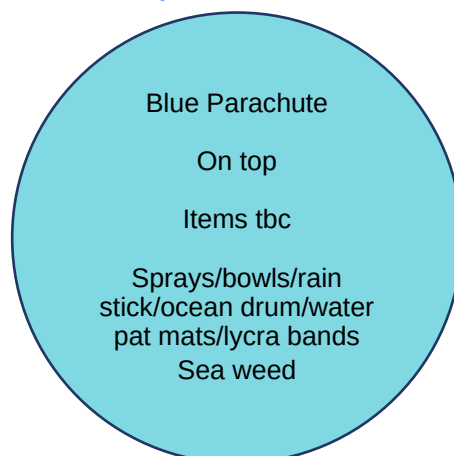
“ I know where I am....I am safe....I am listened to.... I can grow ”
(being safe, secure, grounded)



Recorded sounds of low pitched drumming
Song “and Phil put his finger in the sand and we all did too”(eg)
Keyboard? ‘New’ song?
Gradually explore contents of parachute.
Individually mostly as next stage (fire) is the largest sharing section.

Water

“ I am brave....I am open to possibilities....My life is my own....I am Me ”
(Having a sense of adventure, ebb and flow, new experiences, turn taking)



Recorded sounds of gentle sea
Song. All ips. To tune of My Bonnie. E.g. “oh Terry he splashed in the water, Oh Terry he splashed yippee! Oh Terry he splashed in the water, and now it has passed to me”
Explore items from parachute. Continue song. Have fun. Get wet.
Goodbye Song



So there we had it. Venue booked. Invite list drawn up. Content created. Previous Us in a Bus practitioners attendance confirmed. Trustee and volunteer support for catering and car parking duties sorted. Equipment gathered.....and with virtually no outlay on this.

We had made a decision early on that although the event would be as economic as possible in terms of content, we would invest in hiring a Mobiloo mobile Changing Places unit and what an absolutely fabulous bit of kit that is! The fact that we managed to book for a single day was fortuitous. The company have so many festival bookings during the summer that normally single day requests are apparently blocked!

The Elements of Us in a Bus event finally took place on Wednesday 26th June 2024 at Christ Church in South Nutfield, Surrey. Five no-shows meant that guests at one of the repeats received input from three people each, which resulted in extreme fun! Late comers arrived 10 minutes before the end of the final session, and the seamless way the Us in a Bus team extended the content (including the tweaking of the soundtrack and changing rooms so departing guests could bid farewell) to enable the new arrivals to experience a significant section of what they had missed, was just a joy. Communicating the “plans” and “directions” to the practitioners via the medium of song (using the same tune as was currently being sung) in an attempt to hold on to the atmosphere for everyone, was both hilarious and remarkably successful!

So, on the hottest day of the year, I think we created a valid, worthwhile, enjoyable event that gave opportunities to some of the people we see regularly to meet with each other for the first time. The moments the event took off were (and I don’t know why I should be surprised by this) the moments when the team immersed themselves in the Intensive Interaction aspects of facilitating connections between people. Who was looking at who? Who was doing something that needed sharing? We forget I think that we are pretty skilled at doing this automatically. It is something we promote as a hugely successful and valuable way of using Intensive Interaction and is not necessarily as widely practiced as it should be.

We have yet to sort through our guest photo consent, so the photos here are of us only; some from the day and some from our exploratory run through the previous day. Please note our CEO Victoria Goody offering herself as guinea pig for the afternoon!

If you would like to chat about this aspect of Intensive Interaction, please get in touch. For now...we’re all in recovery and deciding if the 35th anniversary (which is in 2025) is too soon to “go again”!!

Contact details

Anne Laney, Practice Manager at Us in a Bus.
Email: Anne.laney@usinabus.org.uk

Us in a Bus is a registered charity who supports people who are often isolated and who find communicating with the world (and the people in it) a massive challenge. The people we support have profound and multiple learning disabilities, complex needs and sensory processing differences, requiring specialist assistance to build meaningful engagement with others. Us in a Bus are based in Redhill, Surrey.

Email: info@usinabus.org.uk
Website: <https://usinabus.org.uk/>
X @UsInABus
Facebook/ Instagram @UsinaBus





REPORTING BACK

Sensory adventures in Sweden: BIBU Biennial 2024

By Zoë Lally

At Oily Cart, we make shows that use all of our senses to open up theatre to all children, whoever they are, whatever barriers they face, and wherever they are from in the world.

Sensory Theatre offers a universal language, communicating through our senses rather than speech. With language barriers reduced, we're curious to find out how different international perspectives can open us up to new possibilities. BIBU, the international children's theatre festival that happened in Sweden this May, was an exciting opportunity to find out.

We were delighted that this year, BIBU continued to put access front and centre, making sure that disabled children with the most barriers to access were considered and welcomed. Kollaborativet's show *Mellan os emellan* was an incredibly beautiful and accessible

show that created a world of sensory play. Audiences could control their own experience, guided by expert performers and gentle shifts in the atmospheric lighting, as the piece unfolded. Some children were drawn to the spiky and soft sculptural elements; others enjoyed the amplified twangs of the stretchy bands entwining the set. Some found joy in crawling through reflective tubes or being wheeled around the space, while others enjoyed crashing into a giant inflatable wall - the choice was theirs. As the show went on, even the adults in the room seemed to relax and enjoy their own sensory exploration.



There were fantastic sensory moments across the festival, from the mesmerizing soundtrack of Katja Seitajoki / Arena Baubo's Skymningsfåglar (Dusk birds), which was enhanced by the eery movements in a low dusk-light, to the intimate binaural and ASMR-triggering performance in Skuggteatern's Lyssnaren (The Listener), and the audience's excited yelps of anticipation at the kinetic circus of Kompani Giraff.

The seminar programme also brought together some great thinking around arts access for disabled children. Dr Gill Brigg and the Scen:se project shared their work embedding emotion in sensory storytelling within the classroom, and artist and choreographer Dalija Acin Thelander's session on sensory performance for neurodivergent audiences was both thought-provoking and practically useful.

Finally, we co-delivered a seminar on access, choice and collaboration alongside Scen:se, Folkteatern Gävleborg and Estrad Norr, which was also a wonderful moment to announce our new international collaboration. Together, we'll be further exploring how we can create more choice for families through different types of shows - from intimate 'at home' experiences to touring venue shows and interactive durational exhibitions (watch this space!)

BIBU was a glorious reminder that there is no singular way to create sensory theatre -the possibilities are limitless! Together, and collaborating across countries, we can fight for a world where all children have access to theatre.

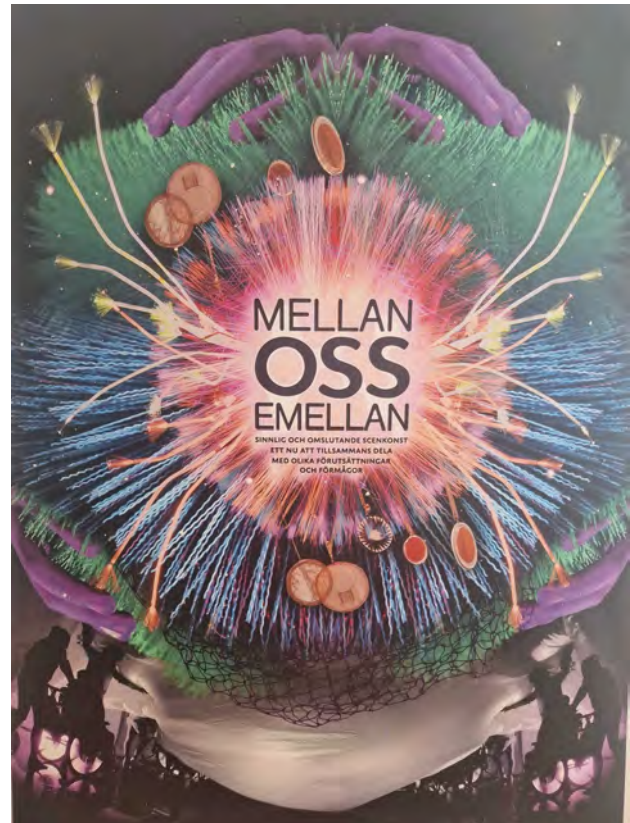
Zoë Lally, Executive Director / Co-CEO of Oily Cart

Oily Cart imagines the impossible and rips up the rule book of theatre to make it more accessible.

E-mail : oilies@oilycart.org.uk

Website: <https://oilycart.org.uk/>

Socials x @Oilycart Facebook / Instagram @Oilycart



REPORTING BACK

Celebrating Sensory Heritage: A new project for people with profound and multiple learning disabilities in Bedfordshire and Luton

By Julia Collar

Hello, I'm Julia, the director of Collar & Cuffs Co. I'm thrilled to share some wonderful news with you. We've recently been awarded nearly £15,000 from the Heritage Horizons project at the University of Bedfordshire, funded by the National Lottery Heritage Fund. This generous grant will support a new and exciting initiative that's very close to my heart: exploring the sensory heritage of people with profound and multiple learning disabilities (PMLD) in Bedfordshire and Luton. This project will run from September 2024 to April 2025, and I'd love to tell you more about our plans.

What is Sensory Heritage?

Sensory heritage is a way of capturing and preserving the lived experiences of people with PMLD. It involves recording their sensory interactions with the world around them and transforming these into formats that everyone can access and appreciate. By valuing and preserving sensory perspectives, we ensure that people with PMLD are included in our social history, often for the first time. This project is also a celebration of the family and community support networks that play such a vital role in the lives of people with PMLD, highlighting particularly how research and technology have led to longer, healthier lives, improved mobility and access, new ways to communicate, and new ways to learn and play.

The Project's Highlights

One of the most exciting aspects of this project is the invitation extended to Sensory Pathway learners from The Chiltern School in Houghton Regis to co-curate a touring, interactive, and playful sensory exhibition with us. This exhibition will not only share their stories, perspectives, and values but will also delve into the history of Hillcrest Special School, which served our community from 1979 until its closure in 2012; Hillcrest then merged into The Chiltern School. The exhibition will travel to various locations in Luton and Bedfordshire, offering a unique opportunity for everyone to engage with and learn from these sensory experiences and to foster improved understanding of people with PMLD. In addition, we'll be organising evaluation visits to heritage sites across Bedfordshire and Luton. These visits will give people with PMLD and their families a chance to explore accessibility and sensory experiences at these sites. This will help us improve inclusivity and make heritage more accessible for everyone with insights from these visits shared with host organisations to help them engage with audiences with PMLD, and to look towards shared creative possibilities for the future.



How Can You Get Involved?

Share a local story

There are many ways for you to get involved in our project. If you are a parent, carer, teacher, teaching assistant, nursery nurse, or play worker based in Bedfordshire or Luton then we would love to hear your stories and experiences. Sharing a sensory life story of someone with PMLD from Bedfordshire or Luton can help us create a richer and more inclusive local narrative.

Be a volunteer at the exhibition

We are also looking for volunteers to help create and install the final exhibition and to support visitors as they explore and play. We will provide training in Makaton signing, sensory storytelling, and ways to support and facilitate sensory play. This is a fantastic opportunity for anyone aged 18+, particularly for anyone looking to develop experience in inclusive and participative arts and heritage, or for any retired colleagues from the SEND sector who would enjoy dusting off their skills.

Share your memories of Hillcrest

If you have a personal connection to Hillcrest Special School or Hillcrest Post-16 in Dunstable, please contact us. Whether you worked there or have a family member who was a pupil, your stories and memories will help bring the history of Hillcrest to life.

Connect across the miles through sensory sharing

Even if you're not based in Bedfordshire or Luton, your input is still very much needed. We welcome contributions from people with PMLD across the UK, shared through their parents, carers, day centres, schools, or residential homes. By contributing your sensory experiences, you can help us create a map that showcases the diverse and unique ways people with PMLD interact with the world. This will foster greater understanding and connection across the country and may enable us to expand the project in the future to create an even bigger archive and exhibition. Use our online form to contribute at www.collarandcuffs.org.

Remembering Hillcrest Special School

Hillcrest Special School holds a special place in my heart. It was established in 1979, nearly a decade after the law changed to ensure that children and young people with learning disabilities had the right to an education. My own mother, Liz Collar, taught at Hillcrest for many years, from the 1980s until her retirement in the early 2000s. My sister and I were fortunate enough to volunteer at the school over many years, where we witnessed innovative teaching methods that made complex subjects accessible to students with severe learning disabilities and PMLD.

We have fond memories of the students we grew up with, shared experiences with, and who continue to inspire us today in our work with people with complex needs. When Hillcrest closed in 2012, much of its rich

history and creativity was lost. However, The Chiltern School, which took its place, has continued the legacy of curiosity and creativity.

Through this project, we aim to capture the story of Hillcrest and celebrate the lives and contributions of former staff, students, and their families. We hope to honour those who are no longer with us, recognising the profound impact they had on so many lives, much like ripples on a pond.

Profound & Multiple: A New Vision for Heritage

So this is why our project is named "Profound & Multiple." The contribution of people with PMLD to the community, their families, schools, and care networks, is profound, and it is multiple. What are those who have never met or communicated with someone with PMLD missing out on? What contribution to our local history is being missed if these lives are not included in the record? The Wigit symbol for 'profound' is a pair of exclamation marks – a shout, an alert, a visual and visible call to attention – and so this has become the symbol for the project.

We want to increase the visibility of people with PMLD in Bedfordshire and Luton and to encourage local heritage organisations to include people with PMLD in their planning, development, and programming. The final interactive exhibition will engage the local community, expanding their knowledge and perceptions of people with PMLD through immersive and insightful experiences, and will be a multi-sensory call to attention.

We hope this project will foster greater confidence in the community when they meet and communicate with people with PMLD. We also hope it will encourage people to ask important questions about why people with PMLD are often absent from local history and why they are not frequent visitors to local arts, culture, heritage, and conservation sites. By including the experiences and life stories of people with PMLD for the first time, this project seeks to make a meaningful contribution to the local history of Bedfordshire and Luton. Through this inclusive approach, we hope to create a richer, more diverse, and more representative narrative for future generations.

Join Us in Celebrating Sensory Heritage

We look forward to sharing updates from the project and creating Profound and Multiple!! with you. You can keep up to date with developments via our social media channels:

Facebook: /CollarandCuffsCo

Instagram: @CollarCuffsCo

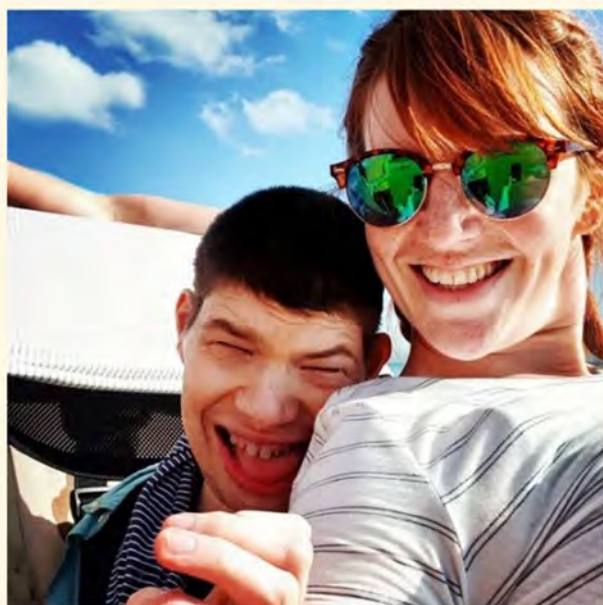
www.collarandcuffs.org

sensoryheritage@gmail.com



IN THE NEWS

PMLD LINK's webinar and new video for Learning Disability Week 2024



This year Learning Disability Week 2024 asked - 'Do you see us?' 'Do you hear us?' 'Do you include us?' During that week Annie and Michael from PMLD LINK delivered a webinar for Learning Disability England inviting the audience to really think about these questions, in relation to people with profound and multiple learning disabilities.

Our presentation used inspiring stories of people living their best lives to challenge perceptions. We were thrilled to showcase a number of great examples of individuals and organisations from the PMLD LINK community, leading the way to include and raise the profile of people in meaningful ways. One of these was presented through a short video we made with Dan Walker and his family. Using some wonderful images and film clips we created a fantastic visual story, showing just what a full and meaningful life Dan enjoys and the

valuable connections and contributions he makes in his local community.

We make the webinar recording and this video available soon – but in the meantime, you can enjoy our video story on our Facebook page (@PMLDLink). Our special thanks to Dan and his family for so generously working with us and sharing such wonderful images. Thanks too, to Victoria Wright at Mencap for her technical wizardry. Follow Dan Walker at <https://www.facebook.com/makeachangecheshire>

Scottish Covid Inquiry Health and Social Care Impact Hearings

PAMIS, Scotland were designated as Core Participants in the Scottish Covid 19 Inquiry in 2023 and since then have committed a considerable amount of time to ensure that the voices of people with a profound learning and multiple disabilities (PMLD) and their families in Scotland, who were so adversely impacted, were heard. We have also highlighted that for many the pandemic is still impacting, not least in the lack of support, interventions and day services.

The Scottish Covid 19 Inquiry is a public inquiry to investigate the pandemic, how the Scottish Government responded to it, and how both affected people in Scotland. It is an independent institution chaired by Lord Brailsford, a senior judge, and has just completed the evidence gathering for the Impact on Health and Social Care Portfolio.

The role of PAMIS, as core participants, has meant that our group can play a significant role in the Inquiry's investigation. As Core Participants we have particular rights and powers – including the right to make opening and closing statements through our legal representatives. We have provided a broad range of evidence through written statements, reports and oral evidence giving. PAMIS has been represented by Thompsons Solicitors and they have supported many witnesses to provide evidence.

PAMIS are grateful to all those who have given their time to provide this evidence, at times a harrowing experience, but one that we believe will make a valuable contribution to the lessons learnt and the future inclusion and visibility of our community. Particular thanks to Pat Graham who has not only contributed as part of the PAMIS Board but has also provided a huge amount of personal family caring evidence, information and insights that help all families with a relative with

profound and multiple learning disabilities (PMLD). Her pioneering and persistent work in establishing an acute hospital pathway that enables known and paid carers to provide support while in an acute hospital is specifically mentioned and recognised within the closing statements. Highlighted below are the links to the closing statements which took place on 27th June 2024. These include the closing statement on behalf of PAMIS, alongside a number of other organisations. We had highlighted the invisibility of people with PMLD and their carers, the lack of consideration within decision making and the disproportionate impact on the health and wellbeing of our community. This was reflected on within the closing statement from the Scottish Ministers with specific reference to PAMIS/people with PMLD, leaving us with a sense of hope that lessons will not only be learnt but that change will happen.

All of the evidence and information about the Scottish Inquiry can be found on the Scottish Covid Inquiry website <https://www.covid19inquiry.scot/>
Closing statements from the morning including PAMIS: <https://www.youtube.com/watch?v=F23yTlePmxM&t=35s>
Closing statements in the afternoon including the Scottish Ministers: <https://www.youtube.com/watch?v=DP8AqahiP7Q>

Report from Jenny Miller, CEO PAMIS (promoting a more inclusive society), Scotland

Hospital VIP Red Bags project

Our recent work at Choice Support includes the VIP Red Bag scheme which was developed in a bid to tackle health inequalities faced by people with learning disabilities. Many people with a learning disability die over 20 years younger than the general population and often from preventable causes. The scheme aims to highlight to hospital staff that the person with the Red Bag has a personalised Hospital Passport. This is because they may require additional support and may need reasonable adjustments during their appointment or hospital admission. The scheme was launched in Wakefield in 2022 and is available free to autistic people and anyone in Wakefield with a diagnosis of a learning disability.

There have been positive changes for people who have used the VIP Red Bags. Hospital staff have known where to access people's hospital passport, been prompted to follow best interest routes and made reasonable adjustments to enhance the care and support received. A hospital passport is an important document detailing

how best to support someone in hospital.

The project has been moving from strength-to-strength and so far, over 1500 bags have been distributed. This has been achieved through support from the local Complex Needs team, care co-ordinators, other service providers and through various events. Funding for the VIP Red Bags scheme was secured through several sources, including Mencap Treat Me Well campaign, Morrisons Community Fund and Wakefield CCG/NHS England. This funding has enabled everyone in Wakefield on the learning disability register, to have a bag for free. We would like to roll out Red Bags nationwide. This would share the benefits of the scheme and the work we have been doing on annual health checks and hospital passports to allow for more continuity of care across neighbouring hospitals.

Find out more here: <https://www.choicesupport.org.uk/the-vip-red-bag-project>



Choice Support is a national charity, formed in 1984, supporting autistic people, and people with learning disabilities or mental health needs. Our values haven't changed over the years. We are ambitious, continuing to take bold steps forward to promote the rights of people we support. We value people for who they are, and we expect everyone we support to be respected in society.

Contact details:

Sarah Gapper, The VIP Red Bag scheme, Choice Support.
Email: sarah.gapper@choicesupport.org.uk
Facebook: The VIP Red Bag
X/twitter: @vipredbag
YouTube: @thevipredbag

Improving uptake of Annual Health Checks

Building upon their research into health inequalities, the Race Equality Foundation and Learning Disability England have been working with people with lived experience from Black, Asian and minoritised ethnic communities to raise awareness of and improve the uptake of Annual Health Checks. These checks are a preventative measure to detect and address health conditions, reduce early and avoidable deaths annual health checks.

Get your Annual Health Check

? What is an Annual Health Check?

14+ Annual Health Checks are for people with a learning disability over 14 years old.

An Annual Health Check is usually done by your doctor or a nurse once a year. You can ask them about anything that is hurting or worrying you.

The check is done to help you stay healthy. You don't need to be ill to get a health check.

? Why is it good to have an Annual Health Check?

You can get to know your doctor. They can give you ideas about how to stay healthy.

You can talk to a doctor or nurse about anything you might be worried about.

If there is anything wrong then the doctor can sort it out before it gets worse.

To continue to raise awareness they have co-produced a video and easy read leaflet - an important set of resources to help improve uptake of Annual Health Checks from these groups.

<https://raceequalityfoundation.org.uk/health-care/annual-health-checks-ahcs-for-people-with-a-learning-disability/>

Transition from child to adult health and social care services

Jillian Pawlyn, a doctoral researcher at The Open University, is carrying out research with parent carers of young people with profound and multiple learning disabilities/profound intellectual and multiple disabilities (PMLD/PIMD) in England to explore their experiences during their child's transition from child to adult health and social care services. She hopes this research will give insight into the parent carer's transition experience to reduce the knowledge gap surrounding this life experience.

Jillian is looking for parent carers of young adults (18 to 25 years) with PMLD/PIMD in England, whose transition occurred between 2014 and 2024. If you are interested in taking part or want more information, please email jillian.pawlyn1@open.ac.uk

On Raising a child with disabilities - podcast episode

Heather Bailey was a guest on the Therapy Works podcast with Julia Samuels, which aired earlier this year. In the episode, Heather talks about life with her daughter Lizzie who is 28 years old and who has profound and multiple learning disabilities.

From the podcast webpage: 'Heather's story is one of love, loss, resilience, and the constant navigation of a life profoundly different from what she once envisioned. Heather's insights offer invaluable perspectives for anyone seeking to understand the nuances of caring for a loved one with profound disabilities.'

Listen to or watch the podcast episode here: <https://www.youtube.com/watch?v=ygaN9Ed0N00>

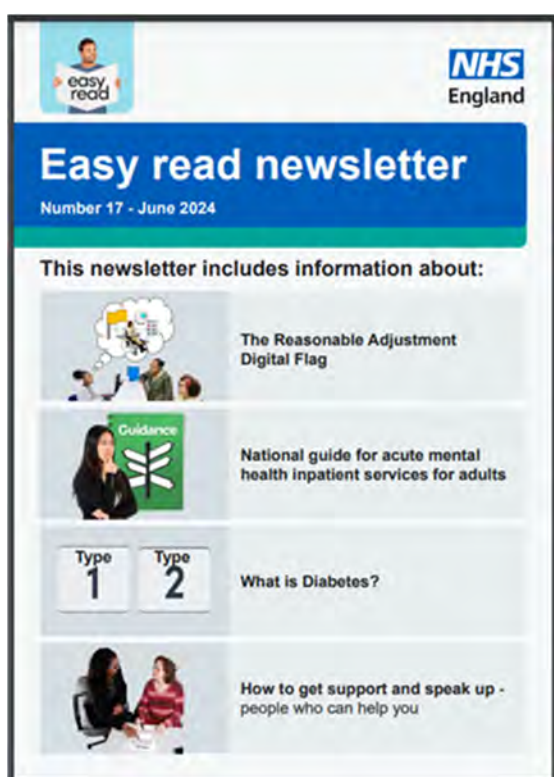
Community of Practice conference announced

Kent, Surrey & Sussex Learning Disability Community of Practice will be holding their annual conference on 4th December. It will take place at Canterbury Christ Church University's Medway campus. Programme details to follow in due course. Information at: https://ldcop.org.uk/community-of-practice-annual-conference-2024?mc_cid=63db359355&mc_eid=f2be835f48

NHS newsletters

The latest newsletter from the Learning Disability and Autism programme team is now out. This issue includes information about, the Reasonable Adjustment Digital Flag, national guide for acute mental health inpatient services for adults and important information about diabetes.

These updates are published three times a year in easy read and plain English. You can view them online: <https://www.england.nhs.uk/learning-disabilities/about/get-involved/newsletters/> Or subscribe to newsletters by email by contacting LDEngage@nhs.net to be added to the mailing list.



Calling learning disability an illness harms people

The latest issue of Community Living magazine features a valuable opinion piece from Chris Hatton, highlighting the potential harm when professionals view a learning disability to be a health condition. One consequence of this diagnostic overshadowing, is that the genuine, and often, multiple health conditions many learning disabled people live with go undiagnosed and untreated. Read more at: <https://communitylivingmagazine.com/chris-hatton-calling-learning-disability-an-illness-harms-people/>

Coping with trauma guide

Due to the nature of their roles, there is unlikely to be a carer who doesn't have some degree of trauma. Trauma massively impacts our ability to cope with day-to-day life, and we might not even know it's there. Because taking care of someone we love can be so emotionally and physically consuming, even if we are aware there is an issue, it can feel impossible to find the time or energy to work on it. Mobiliseonline.co.uk have created a new guide for carers, offering some simple explanations about types of trauma, alongside helpful practical actions and signposts to expert advice. View here: <https://rb.gy/xjm705>

Victoria and Stuart project toolkit launched



As the concluding activity of this research project, an end of life care planning toolkit was created with people with learning disabilities, families, learning disability support staff, and healthcare professionals. The toolkit includes resources and approaches to support staff with end-of-life care planning with people with learning disabilities. <https://www.victoriaandstuart.com/end-of-life-care-planning-toolkit>

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: Independent advocate and has supported people with profound and multiple learning disabilities for over 30 years.

Sue Thurman: (Secretary) 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 people with profound and multiple learning disabilities. 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.

The content in this journal is the intellectual property of PMLD Link. You may not reuse, republish, or reprint such content without our written consent. All information given is merely for educational and informational purposes. It is not intended as a substitute for professional advice. Should you decide to act upon any information in this journal, you do so at your own risk. While the information in this journal has been verified to the best of the editors' abilities, this is not a guarantee that there are no mistakes or errors. The opinions expressed by contributors to the journal are not necessarily the opinions of PMLD Link.



sharing ideas and information

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

Visit www.pmlmlink.org.uk

Vol 36 No 2. Issue 108

ISSN 2042-5619