

PMLD LINK



sharing ideas and information

Personal Care

Spring 2023



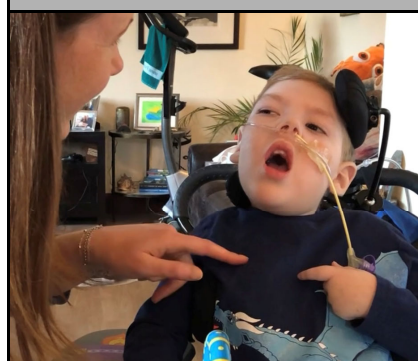
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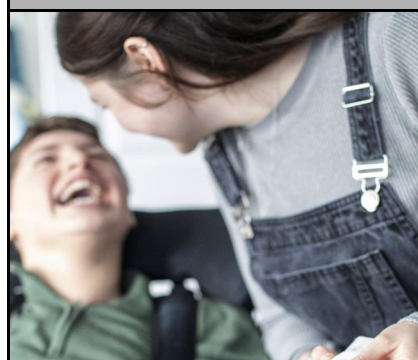
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Cover picture from the article by Lucy Layzell

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GUEST EDITORIAL

Personal Care

This issue has the specific theme of Personal Care and we were not disappointed in the range of contributions that we received from parents and practitioners and researchers. Day-to-day personal care activities, such as bathing, showering, applying creams and lotions, providing medication, dressing, toileting, meal preparation and feeding, may seem mundane and tend not to be talked about much but they are vital to sustaining a consistently good quality of life for people with profound and multiple learning disabilities.

Too often parents and other family members are seen by services providers as the main deliverers of personal care but education, leisure, health and social care services must play their part too, in partnership with each individual with profound and multiple learning disabilities, their family, and those who provide day-to-day support.

The first part of this issue is devoted to articles about how individuals and/or organisations work to ensure that personal care is tailored to meet individuals' specific requirements. Pleasingly, they reflect on the importance of interactions that show dignity and respect for the individual as well as an awareness that personal care activities can offer so many opportunities for developing independence, thinking, communication and social skills.

Many of the articles relate directly to sensitive aspects of personal care. The editors would like to comment that the Mental Capacity Act 2005 (MCA) is designed to protect and empower people who may lack the mental capacity to make their own decisions about their care and treatment. The MCA requires us to presume that everyone over the age of 16 has the capacity to make their own decisions, unless it is proved otherwise. However, where someone has been assessed as lacking capacity, a best interest decision may be made. As laid out in the legislation, it is crucial to encourage the individual's full participation in the decision-making, including their preferences and views as part of the process, and consulting with family members and those close to them. We encourage readers to become familiar with the principles of the MCA, as it relates to every-day decision-making for people with profound and multiple learning disabilities, such as personal care, as well as the bigger issues like moving home, medical treatment, and financial matters.

The second set of articles is an eclectic mix that covers a broad range of equally important aspects of the services that are provided for people with profound and multiple learning disabilities, including different approaches to setting up inclusive activities and their supreme value, the importance of having fun and holidays, seeking the views of individuals about their services, community services provided by charities, supporting professionals in dealing with bereavement, and hospital services.

The Summer issue, due out in July, has the theme of Research. For more details see p.25.

Guest editors: Michael Fullerton, Becky Loney, Maureen Phillip, Rob Ashdown and Annie Fergusson.

We would like to draw your attention to PMLD LINK's appeal for volunteers (see page 2). PMLD LINK needs new volunteers to remain viable. Family members and carers would be especially welcome and PMLD LINK would like to expand its team so that it is more representative of adult social care and health services. The time commitments for volunteers need not be great and there is a buddy system and mentoring for new volunteers. Also, volunteers do not require extraordinary skills; the desirable skills and knowledge are commonplace these days but what is important above all is a commitment to improving the quality of living for people with profound and multiple learning disabilities and their families and supporters. Please consider this appeal and offer your help if you can.

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An appeal for volunteers

Many people in their dealings with PMLD LINK are surprised to find out that it is run entirely by a handful of volunteers – no more than ten at most. PMLD LINK is a small charity and operates on a shoe string budget – its income comes entirely from subscriptions, donations and occasional work for organisations by some of its editorial team. At the end of the day, PMLD LINK just about manages to cover the costs of its operations and this has only been possible because people have given their time and services for free.

PMLD LINK is now in a transitional phase. The trustees of the charity and editorial team hope that PMLD LINK will survive for years to come but there is a capacity issue. As mentioned above, the team is composed of volunteers who also have work and family commitments. Some of them have reached an age where they have to think about retiring. Also, the team could do with having more representatives from the health services and adult social care services and family members. PMLD LINK needs new volunteers to remain viable.

Volunteers don't need to have a professional working background but it is important that they should have an interest in and a commitment to improving services for people with profound and multiple learning disabilities. Family members and carers are especially welcome. Volunteers will not be pitched in at 'the deep end' to do things that they have never done before. The PMLD LINK team will provide a buddy system and mentoring for new volunteers.

Our volunteers have the satisfaction of knowing that their work helps to keep PMLD LINK's activities happening and that their work benefits so many people (parents, siblings, carers, education, health and social care professionals) and enables them in turn to support in various ways many people with profound and multiple learning disabilities. For those interested in career progression, the trustees would be willing to provide references.

Much of the work may be shared between two or more individuals; we think it helps if there is a lead person and a deputy or two for each role.

Volunteers do not have to be technology experts or superb wordsmiths. It is not essential but it does help if they are able to use word processing software and e-mail or online social media to communicate. Similarly, it is not essential but it does help if they have regular access to a PC, laptop or tablet that is internet-ready and supports receiving and sending messages.

We achieve a lot through online meetings and email conversations – there does not have to be much time and effort spent on travelling to face to face meetings. This work may be done at home. The amount of work and scheduling of it will vary according to the role of the volunteer but overall will be the equivalent of on average a few hours per week.

An experienced volunteer will be available to provide practical information and support as required and the editorial team have regular meetings online of the whole team or subgroups as appropriate with a face-to-face meeting at the time of our annual general meeting in May.

Volunteers may make claims for reimbursement of any reasonable expenditure for doing this work.

There are various roles to which interested people might contribute:

- **Editors** – For each issue of the journal a small team of two to four editors works together to edit articles received, develop reviews of news items, resources and books, and detail upcoming courses. They liaise with our knowledgeable production manager to produce the journal to a high standard. The group of editors changes on a rotational basis for each issue.
- **Website assistants** – They ensure that the PMLD LINK website is up to date and add new resources and new electronic copies of the journal and other material as they are produced.
- **Enquiry managers** – They receive all e-mail and other communications to PMLD LINK and respond to them or seek a response from other PMLD LINK team members as appropriate.
- **Production assistants** – They liaise with the editors, production manager and printers on each issue to ensure that printed copies of the journal are mailed to subscribers and other identified persons/agencies.
- **Subscriptions secretaries** – They maintain up to date records of subscribers and act as a main point of contact for subscribers or would-be subscribers seeking help and information.

All of these roles are flexible to suit what volunteers can offer. If you are interested in supporting PMLD LINK, please contact any of the Trustees listed on the Charity Commission website or e-mail info@pmlmlink.org.uk. **Thank You**



Laying the foundations – delivering excellent personal care support

Steve Jones

Reflect provides daytime activities for adults with profound and multiple learning disabilities (PMLD). We now support around 50 people and their families across four bases in Somerset. The delivery of the best quality support with personal care is a key foundation stone of what we do.

So, two questions – one blatantly obvious, the other getting to the heart of what we and all providers should aspire to.

1. Why is excellent personal care so important?
2. What does excellent personal care look like?

Why is excellent personal care so important?

Trust

In the process of setting up one of the Reflect day services, we met with a group of families with sons and

daughters with PMLD. They were asked what a perfect day would look like for their son or daughter. One of the Dads replied immediately, saying, "It'd be wonderful if Jennifer, my daughter, came home from her current day service dry every day instead of soaking wet, with her dry clothes and pads still in her backpack."

Whilst that low level of expectation came as a shock to us, it made it even more crystal clear for us that, if we were to build a relationship of trust and confidence with families, we must first deliver the best possible support with personal care.

If families can't trust us to deliver the best support for their sons and daughters with those essential daily needs, then why should they trust us with anything else? Our commitment to delivering on this continues to be a core Reflect value.

Wellbeing and dignity

Whilst my morning routine isn't particularly extensive by many people's standards, I do like to make sure I'm reasonably presentable before I leave the house. How I look will affect the way I feel, and the way I feel will dictate the course of my day.

The people we support don't just depend on families for a similar morning routine, but on each member of the Reflect team to ensure that we help maintain the same standard throughout the day and until each person is ready to return home.

Ability to engage

We aim to provide a rich, active and varied experience every day for each person we support. We can't expect anyone to participate fully – or at all for that matter - if they're wet, uncomfortable, thirsty, hungry or tired. Hence the need to get support with personal care absolutely right before thinking about anything else.

What does excellent personal care look like?

Who is responsible?

Delivering excellent support with personal care demands collaboration, and is not the responsibility of any one individual person or organisation. We always start by undertaking a comprehensive assessment with the family. They have years of experience, and are invariably happy to share it. The challenge sometimes is that after years of providing support, it has become second nature to them and that they may take for granted the intimate, very detailed knowledge they have built up. Every tiny detail counts, and we make sure that we capture every one of those in developing our support plan.

We also work in close partnership with our specialist health colleagues – occupational therapist, physiotherapist and speech and language therapist - in developing a person-centred plan for each person we support.

Finally, and most importantly for Reflect, we ensure that each member of the team understands our values, standards and expectations – for both the service and each individual.

People and plan

Reflect's support with personal care relies on two central elements: the people who provide the support and the information they have at their disposal in order to do so. So, how does Reflect deliver on these fundamental requirements?

Reflect directors and managers:

- Ensure that we have clear and current support plans based on information from all the relevant people.
- Regularly review support plans in collaboration with families, the team and specialist health colleagues.
- Make sure that feedback from Intensive Interaction informs the way that plans are updated and support is delivered.
- Observe and give feedback to the team on the quality of support delivered.
- Ensure that there is adequate funding to deliver the best quality personal care. To this end, we have been clear from the outset that we would only support people on a one-to-one basis, and two-to-one for personal care. We can then be sure of delivering the quality of support that each person needs and has a right to expect.

Members of the team:

- Develop an intimate knowledge of each person's support needs and the ways these should be delivered.
- Must be prepared to work in partnership with families and other colleagues - no one person knows what best.
- Have a clear understanding of Intensive Interaction and demonstrate evidence through their practice of it being the golden thread that runs through all elements of the support they deliver.
- Are observant – using their own skills and knowledge of the person being supported, supplemented by the skilled use of Intensive Interaction. This enables the early identification of subtle changes that may otherwise go unnoticed and that can then be communicated to others.
- Show a readiness to adapt as and when needed, depending on how the person supported might be on a particular day. Support with personal care may need to be paced differently or delivered in subtly different ways.
- Are passionate about the people they support and the care they provide.
- Demonstrate empathy and patience at all times, shaping support according to the knowledge of each person's needs, overall and on any particular day. (To support this, Reflect is just about to roll out training on empathic handling, helping to ensure that each member of the team understand what it

might be like to on the receiving end of intimate care.)

- Remember that personal care needs to take as long as it takes –no one should ever, ever feel rushed.
- Have great communication skills. They listen to and talk to colleagues, families and other professionals.
- Interaction with the person being supported continues into personal care. When two members of the team are supporting, they talk to the person rather than to each other.
- They let someone know what they're doing and how they're going to do it.
- They use a positive, encouraging tone.

Families

One of our founding principles was that Reflect would always seek to work in partnership with families. This, of course, has to be a two-way thing: through the use of communication books, regular phone calls/messages and an open-door policy enabling families to pop in and see us at any time, we endeavour to make sure that we achieve this goal.

Specialist health colleagues

We're incredibly fortunate to have built very positive relationships with our colleagues.

They are central to our ability to deliver a range of supports, including personal care. In turn, if they make recommendations, they know that Reflect will implement them on a consistent basis to the same high standard.

Postscript

Jennifer has been with Reflect for three years now, and has gone home comfortable and dry every single day.

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Many thanks for supporting PMLD LINK. Every Gift Aid donation makes a big difference.

HOP 6: Musings on interaction and personal care

Sheridan Forster

This edition's theme of Personal Care took me to two memories. Let me share two stories.

In doing my Master's research many years ago, I interviewed support workers who interacted with a woman with profound and multiple learning disabilities (PMLD). One worker told me that for many years they had written in the general service plan "I will independently wash herself with a facewasher". She wryly added, "Well she might suck the facewasher"; a very true statement, as I'd seen the lady suck on cloths many times. Often not thinking a lot before saying something, I responded, "Well imagine if that could go in the service plan: I will have the opportunity to suck the facewasher during bathing".

My mind then skipped to another person. Some of you might remember the "I'm Robbie" film by Kate Burns from the CAN Communicate, in Mencap's Involve Me multimedia package. The film starts with Robbie in the shops, ingredients selected and handed to him to touch and smell, and then moved into the kitchen, where he "participates" in cooking... part of his personal care, shall we say. But it is when he throws the spoons, staff laugh, and sneezes are provoked through too much pepper, that his and the staff's vocalisations of delight share an equal space of joy and shared engagement on his terms.

Both stories prompt me to think about when participation in personal care involves what might be seen as socially devalued behaviour/actions/doings. Sucking a face washer, sneezing on your dinner, wicked yelps with flying spoons. In being with people with PMLD, we are constantly making decisions about what to support and encourage, what to perhaps ignore, what to actively discourage. Sometimes we are making decisions about engagement with behaviours that might involve the person hurting themselves or other people. These can be complex decisions, but might rarely be explored in an open way. Individual staff members or members with greater status may be deciding on censoring based on their own social values, dominant paradigms, or sheer gut feelings of what they see is and isn't acceptable. A form of social restraint can be constantly determining what may or may not be counted as a legitimate way to participate in personal care.

I am reminded of Claire Fraser's call at the Australian National Deafblind Conference to step back and ask with curiosity, "What if we followed that person?". Taking my mind back 25 years, as a disability support worker, I wonder if I stopped and thought "What if we could write

in N's plan, that he could participate in his changing routine by the playful drop of his torso onto his bed that he laughed at every time... Is it something we'll just do behind closed doors"?

Do we... I... need greater bravery to advocate for the idiosyncratic ways that individuals with PMLD may optimally participate in their care routines, in their everyday moments of being?

Contact details

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Sheridan runs a number of communication-focused Facebook groups including one for HOP: Hanging Out Program) <https://www.facebook.com/groups/334617066670161>

Matthew Laurie (<https://www.mattlaurie.com/events>)

Matthew Laurie is a community musician and specialises in supporting children and adults with complex needs and communication difficulties. He offers training online and across the UK. He repeats three Zoom courses each month that are suitable for family members and personal assistants and professionals across all sectors with any level of experience. Places for family members and personal assistants at reduced rate. The courses cover: learn how to lead and support music sessions for children with special needs; Rapport Based Communication - the communication skills needed to build relationships and support the wellbeing; and understanding conflict and distress that give rise to challenging behaviours.

Personal care and shaving

Samantha and Alfie Buck



We use the Phillips One Blade electric rechargeable razor as it has a small blade and comes with graded combs 1-5. And you charge it like a phone once every 6 months or so depending on how often you use it, and the blade is not too bulky.



Alf uses his once a week - he has a shave and then we clip toe nails and fingernails. Alf's beard only gets trimmed when it shows he needs it - he never wants it cut off, just trimmed.

Alf has a beard tidy in the morning with Dad whilst sitting in his commode toilet (hair gets everywhere)



But we also use the razor for other areas of the body that need to be kept trimmed. Sometimes his arm pits are shaved at grade 2, otherwise the rollerball deodorant doesn't touch the skin as it's all in his hair.

We need to see the skin clearly as part of Alf's daily full body check for damage, lesions or pressures sores. This means we can get started with healing creams, dressings, etc. and notifying the community nurses, district nurses, GP or whoever you talk to when things start going wrong.

In our experience I would recommend grade 1 or 2 on other body parts and NOT shave without the comb in the pants area. In the pants area, obviously urine getting into open pores shaved to the skin could cause an infection, so we avoid a shave to the skin without the graded comb on.

We are currently managing a pressure sore and a pile, so shave in that area regularly too.



Alf has a grade 2 on the beard when he starts looking like Grizzly Adams

Contact Details

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They run the Don't Pass the Buck Facebook page
and share everyday living ideas and accessible
places they like to go as a family

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

The text and photos for Alfie and Samantha's piece
was taken from their Facebook post on 5th February
2023

The Coronavirus and People with Learning Disabilities Study

Wave 4 Report

This report is about what the researchers found out the 4th time they sampled the views of people with learning disabilities and their carers about the impact of Coronavirus. The data were collected between September and December 2022 and they included people in all four countries of the UK.

Interestingly, they surveyed 192 family carers or paid supporters of people who couldn't take part in an interview. The research report states: 'In most instances, these individuals were likely to have severe/profound learning disabilities.' (p.10, para 1.2.4.2). 44 per cent of those people were described as having profound multiple learning disabilities (PMLD) (p.72).

The first part of the report covers the methodology and the findings as regards people with learning disabilities in general.

Chapter 4 (p71-98) looks specifically at the impact of Coronavirus on people identified as people with PMLD and their carers. Overall, things seem to have got relatively worse for this group than for other people with learning disabilities. The full report contains much detail about changes in access to services, engagement in community activities and the health and well-being of both the people with PMLD and their carers. It is available at:
https://warwick.ac.uk/fac/soc/cedar/covid19-learningdisability/results/wave4finalreports/coronavirus_and_people_with_learning_disabilities_study_wave_4_full_report_final.pdf

Safe practice during intimate care: safeguarding people with profound and multiple learning disabilities

Martin Goodwin

During their time at school, pupils with profound and multiple learning disabilities (PMLD) receive intimate care as part of their daily routines. As a practitioner I have noticed much variation regarding how schools approach and provide personal care, both from a practice and a service level perspective. Within this article, I discuss some of the key considerations in ensuring safe practice during intimate care.

Despite the need to improve contextualised safeguarding, intimate care can be an overlooked area of school practice. The recent safeguarding issues within Doncaster residential special schools (BBC News, 2022), highlights the need for contextualised safeguarding practices that specifically accord with and address the distinct needs and additional vulnerabilities that pupils with PMLD face.

Intimate Care

Definitions of intimate care are varied; however, they normally describe a process of attending to bodily functions that are normally private and means intensive human contact in private areas. In practice, pupils with PMLD need high levels of support with wiping, cleaning genitals or the bottom. Often a high frequency or level of physical contact is given. Pupils with PMLD are also likely to need a high amount of direction within the intimate care processes and may need a high intensity of physical support and levels of prompting. Additionally, many pupils with PMLD have physical mobility needs which may mean that they need to be hoisted from a wheelchair to toilet or changing bed, often requiring 2-1 support. Other pupils may have additional sensory, medical issues or behaviours that challenge and may have varied individual requirements and preferences that need to be considered.

Increased risk

The process of intimate care raises increased possibility of abuse. Within personal care routines, the vulnerability of the pupil with PMLD is significantly increased due to issues of communication and cognition along with physical and other sensory issues. Pupils with PMLD often require significant support to communicate and they may use communication styles which are considered affective, pre-intentional or use unconventional communication (Rowland 1996). They may (if over the age of 16) be subject to a mental capacity assessment in this regard and may lack sufficient capacity to raise concerns or discuss potential issues of a safeguarding

nature. Physically, pupils with PMLD who are not ambulant face additional vulnerabilities. It is uncomfortable but necessary to assess the additional risks that pupils face within intimate care situations due to being unable to move themselves or indeed, physically, verbally protest within abusive situations.

Within a class, the provision of intimate care can pose challenges in relation to available time, along with considerations of the logistics of staff availability, such as who may be available and the number of staff that leaves in the room to safely attend to others. Classrooms should ensure as much as possible that consistent staffing is in place and pupils should be supported by familiar staff who are aware of their toileting needs. Where two staff are needed to support, at least one person should be familiar to the pupil. Ratios should be sufficient within each class to enable staff to be released to attend to pupils' toileting needs. The familiarity that staff have in providing intimate care to individual pupils is important to consider. Carnaby and Cambridge (2006) discuss that multiple carers do not necessarily reduce the risk to the pupil. Paradoxically, multiple carers can provide a greater level of observation, however by increasing the number of staff providing personal care it can also solicit increased risk.

Recording

Where intimate care is to be given, it is essential that clear information is recorded, and discussions are had that clearly indicate the type and nature of intimate care that needs to be provided. The process for providing intimate care needs to be accurately recorded in a care profile or care plan and signed to confirm that the care provided is an agreed task.

It is important that on an ongoing basis, staff should clarify the way the person requires support or assistance with being toileted especially where the person requires intimate care. Staff should work in accordance with pupils' toileting regimes and toileting programmes, which

may need to be regularly updated. If the pupil's physical or health needs have changed (such as due to an operation), consultation should take place with nurses, physiotherapists and consultants to ensure that the person is not harmed. An individual risk assessment may then need to be completed and the care plan/profile will need to be updated.

It is imperative to have discussions about intimate care with parents as they can greatly contribute to how we meet the pupils' individual requirements. It also ensures a level of checking that the services their child uses are correctly providing intimate care practices. Clarification of differences of understanding regarding how intimate care may need to be carried out within the professional context may be required, as different levels of expectation and differences in carrying out routines may exist between services and the care at home.

Due to the vulnerability of pupils with PMLD it is necessary that supporting staff follow the care profile or plan that is in place. A technique of writing a script, as described by Aitken et al. (2000) for personal care may support the pupil to gradually show increased agency throughout the process through recognition of cues. As the script provides a level of consistency, it also fosters an awareness for the pupil to how they should be supported during intimate care. The script also has a guiding intention, as it supports staff to be aware of how they can support the person during their intimate care and records the process. This ensures that less familiar staff or exceptions to what is usually carried out can be identified.

Ongoing recording and monitoring are an important part of ensuring safe intimate care practice. If a pupil becomes distressed or unhappy within an intimate care routine, it is important that the matter is investigated, and outcomes recorded. For example, if a pupil continues to be upset with a particular carer, an environment or a part of a process, the care should be modified. This relies on staff reporting issues that arise out of providing intimate care to the safeguarding team. Other issues that may arise might include accidentally hurting the person. They might seem unusually sore or tender in the genital area, sexually aroused by your actions, or the pupil misunderstands or misinterprets something, or has a very emotional reaction without apparent cause.

Sexual rights and Freedom

Within an intimate care environment, it is especially important to consider the sexual rights and freedoms of pupils. Signs of sexual arousal may be more apparent and as with all people the arousal may be sexual and exploratory but it also may have a sensory basis. For example, arousal may be stimulated due to the sensation of the pupils' pad being removed or temperature or

conversely exploring own genitals, which is a significant part of human development and normative as a child, or indeed as an adult. Signs of sexual arousal are completely natural, and staff should be supported to feel comfortable and discuss the situations as a team.

If a pupil is regularly showing signs of sexual arousal, whilst providing intimate care, and wanting to further explore their genitals or other deemed sexual areas, it is considered affirmative practice to allow the pupil the freedom to explore their body whilst maintaining their privacy by removing yourself from the area. If you feel that the pupil may be unsafe, it is important to ensure that the most appropriate changing facilities are used so that they can experience sexual freedom. For pupils with PMLD a changing environment may be the only place that they have some freedom of access to their genitals, and therefore careful consideration must be given within schools and within their intimate care policies so that they are not unnecessarily restrictive. Pupils with profound learning disabilities may exhibit sexualised, exploratory or sensory seeking behaviour in public environments. Some pupils are not, despite requests from staff, able to understand or satisfactorily regulate sexual urges and it is important that they should be directed to or provided with a private space. The pupils' dignity should be ensured. Within a professional environment, it is necessary to risk assess levels of sexualised behaviour and consider if they can effectively regulate sexualised urges through temporarily abstaining. Additionally, it is important to risk assess intimate care routines in relation to sexual and non-sexualised behaviour. For example, if a pupil exhibits sexualised behaviour towards other people or if they need support to successfully regulate behaviours towards other people.

Technically within the United Kingdom pursuing sexual arousal or masturbation may be considered a sexual act as it counts as lewd behaviour in a public place (Sexual Offences Act 2003). However, in practice in working with pupils who have limited capacity to understand and sometimes successfully regulate sexual arousal or masturbation, it should be recognised that restrictive practices that inhibit pupils may be considered harmful to the pupil's development and wellbeing, prove problematically challenging for staff who are mediating in such situations, and breach fundamental freedoms protected in legislation such as article 14 of the Human Rights Act. Such practice issues are an ethical conundrum. However, multi-disciplinary decisions, involving learning disability nurses and based on detailed recording, are needed to prioritise the development of a plan that supports the pupil. In addition, policies that protect and safeguard the pupil and staff working in such situations are paramount.

Training and monitoring

Training of staff in relation to intimate care within the professional context of being a school is a necessity. Therefore, all staff undertaking intimate care and supporting with toileting should be trained in relation to the policy and practical care approaches in relation to intimate care. It should not be assumed that, just because staff may have personal care experience, for example with their own children, that this would suitably prepare them for carrying out intimate care with pupils with PMLD.

Manual handling training for staff carrying out personal care is a necessity; however, it is important to also support staff with the postural care of pupils regarding positioning through postural care management. Once initial training is provided regarding the school policy and practices of carrying out intimate care, it is important to ensure that coaching is provided to new or less familiar staff. This could be provided by a lead teaching assistant who can support with manual handling, personal and intimate care.

Policies and Guidance

Within adult social care, care standards regarding intimate care are in place (Care Standards Act 2000, Health and Social Care Act 2012). However, within education similar standards do not exist. Interestingly, Keeping Safe in Education (Department for Education 2022) merely mentions intimate care practice in relation to recruitment of staff; not the issues in relation to intimate care practice and safe management discussed above. Safeguarding is a multifaceted area of practice that stems a myriad of issues. However, effective safeguarding practices need to be in place for vulnerable children who are systemically and culturally at risk within

fundamental routines that occur daily. In view of the complexity of ensuring safe intimate care, statutory guidance regarding the development of safe practice within this area should be provided. Whilst safeguarding issues in relation to the provision of intimate care of pupils with PMLD may not be widespread, it would be prudent that intimate care policies and procedures are audited in relation to the distinct needs and particular vulnerabilities they face.

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Supporting People with Profound and Multiple Learning Disabilities: the Core & Essential Service Standards

The PMLD Standards outline key objectives and principles that ideally should be evident across all education, health, and social care services. The hope is that these standards should be adopted by commissioners and providers of services. Moreover, if they ensure families and other key stakeholders have awareness of these standards, then there should be clarity, from the outset, of what level and type of standards may be expected for the persons with PMLD whom they represent and for whom they act as advocate. PMLD LINK has been pleased with the widespread endorsement of these standards and its annual conferences and the journal have included presentations from people using the Standards to good effect. Do take time to read and reflect on them yourself.

The PMLD Standards are available on the home page of the PMLD Link website:
<https://www.pmlmlink.org.uk/>

An article may be found in PMLD Link, Vol. 30 No. 1, Issue 89 (Spring 2018), pages 2-5.
'Raising standards - a clarion call to meet the challenge'
by Annie Fergusson, Joanna Grace, Michael Fullerton and Thomas Doukas



Sharing experiences, sharing stories

Gill White

Nicola Grove and I recently had the privilege of working with families and carers supported by PAMIS (Promoting A More Inclusive Society), talking about Storysharing and the power of finding stories in the everyday.

On the face of it, there may not seem to be many stories in our everyday lives where routine plays such a significant role. Routine does not traditionally make for a good story.

Does this mean there are none to be found? Far from it. We just need to be mindful of what and more importantly whose story we are telling.

During the workshops, I shared a story to illustrate how a change in perspective can change the story.

My son Leo and I were having one of those truly frustrating days, one of those where everything was taking forever and anything that could go wrong, was going wrong. Time was ticking by and we were running out of daylight. Finally, I had managed to get Leo into his

wheelchair and ready to go. Just as we were about to walk out the door, what happened? Nappy explosion! (Sorry Leo !) So back we went, out of the wheelchair came Leo, through to the bedroom, stripped off, cleaned up and changed. We had a quick cuddle as we were both a bit frustrated by this point, then back into the buggy and finally outside for a much shorter walk than I had intended.

Rather a negative story isn't it? Hearing me relay it, you can certainly tell how fed up I am. But you can also see that, in my story, Leo has become a secondary character.

Now let me share this version, where Leo and I are on a video-call with granny, telling this story together. Thinking about how the person with PMLD is able to contribute here is key. Leo is non-verbal, with some

vocalisations, so we tend to use sensory props to convey story elements or to provoke his natural reactions, which we are then able to respond to.

“Your grandson was a little monkey today! Shall we tell granny? We were finally alllll ready to go out...Leo is in his chair, coat zipped up, good to go...but then...[Leo presses whoopee cushion]

Granny immediately replies “Noooo! Leo!” and laughs.

Immediately Leo’s action provokes a reaction. Even if I relay the majority of the story, Leo is a very active part of this story. Our story. And it changes the tone considerably. From stressful to funny, using only one whoopee cushion!

Picturing how we would relay together the story of what is happening drew Leo into a central role and changed my attitude. Our shared story emphasises that we are a team and that this happened to us, not to me. Something I think is particularly important when you are caring for a non or pre-verbal person.

Not all experiences can be turned into positive or humorous experiences in this way. One instance that comes to mind was when Leo’s food pump broke at dinner time. We had to wait hours for a replacement to be delivered. I was upset and worried, Leo was hungry and couldn’t sleep properly. That was not fun for either of us, but thinking of how we would tell that story together - our shared negative experience - helps validate our feelings and make sense of them, and once again helps to reinforce our bond, that we are a team.

Another way in which this technique is helpful is when we are able to look at what is currently happening from Leo’s perspective and think about how this story would be told by him. If we are able to think about how his story is unfolding while we are in it, this helps us change it to create a better story or outcome for him.

As an example, we had spent a lot of time indoors due to a recent spate of bad weather. I was desperate to get us outside for a walk, as I thought we both needed some fresh air. As soon as we stepped outside, Leo became very cranky as a result of the high winds. Looking at this story from my perspective, the focus could remain more on persevering and achieving my desired goal but, if we look at this from Leo’s perspective, his priorities are entirely different. By seeing this as his story and hearing him, we can change what we do to give him a better outcome, so the story becomes “we zipped up our coats and off we went outside. But... [using a fan provoked a natural “ugh” vocalisation from Leo to which we can respond] ... “UGH! It was windy! We hate the wind. So we gave up and went back home for...[cuddle]... big cuddles! Much better!”



A much better outcome for both of us, driven by Leo and told together.

Thinking about how we tell those stories together. Keeping Leo at the centre. With so much emphasis on routine and necessity, it is always good to shift focus away from the feeling that, as a carer, you are doing a job or performing functions. These are shared experiences. We are a team. And that makes personal care a lot more personal.

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Visit: [https:// storysharing.org.uk](https://storysharing.org.uk) for more information about Storysharing.



Smoothie operator

Sarah Walker

A few years ago, Dan went through a difficult time with his digestion. Approaching mealtimes Dan would know that he was hungry but regularly became distressed anticipating the griping pains that eating could bring. It was worrying to see someone who had previously taken such joy from food get so anxious about eating. Dan lost weight; we didn't know exactly how much because, aside from going to A&E, we couldn't find any other way of weighing him. But he dropped from a 32" waist to a 28".

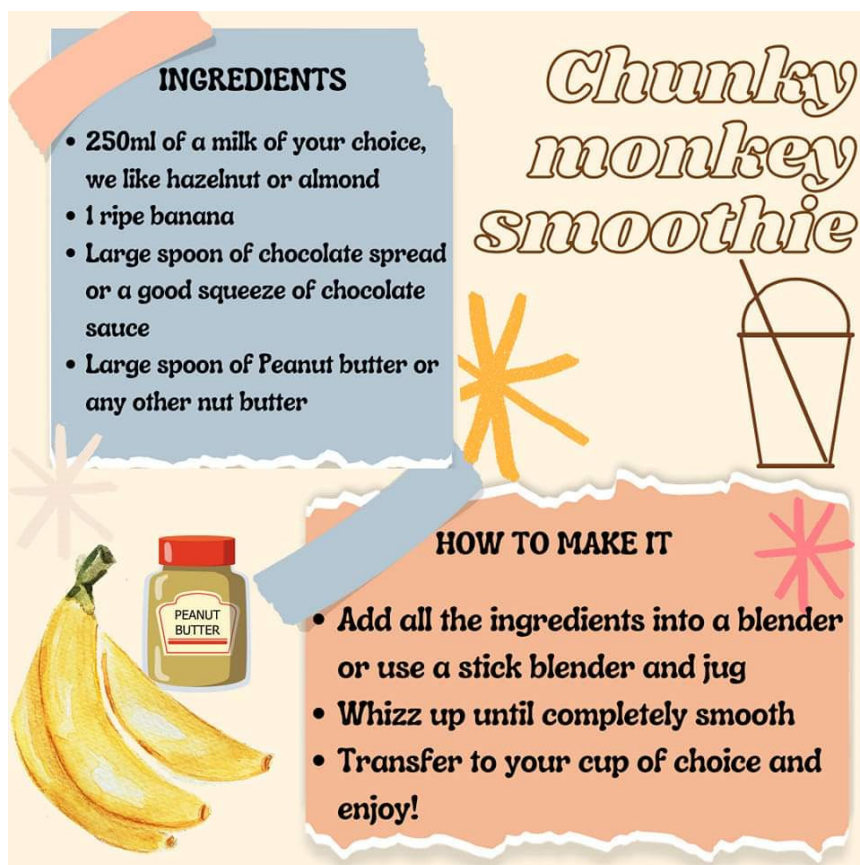
Alongside the changes with diet and medication we searched for a solution to Dan's weight loss and discovered that drinks worked better than having to build up to sitting at the table and concentrating on eating.

Here's one of the recipes that is a favourite of Dan's to get a good nutritional calorie boost, see image 1.

Now Dan's weight has improved and he has introduced his smoothie into his daily routine before heading out for the day. Some days now we'll choose a vegetable and fruit-based smoothie instead. Luckily Dan is very open to trying new flavours and doesn't turn his nose up at any of

the weird and wacky combinations we've tried. When our family all got Covid we were eager to find something to support Dan's recovery and came across this recipe for an immunity boosting smoothie that Dan loves. See image 2.

Making the smoothies has also been a good way for Dan to rediscover his interest in food. We get the blender on the kitchen table and a tray with all of the ingredients so that we can let Dan investigate the taste, scent, texture, colours and temperatures. We support Dan to press the button to start the blender which makes a great loud noise and the vibrations can be felt through the kitchen



We aim to create opportunity for interactions and sensory experiences in many of our tasks. Fe from Dan's team has even written a smoothie song that we sing when Dan's making and drinking it.

Here are the lyrics, you can use your own name and fit it to any tune you fancy!

Chorus

Dan, Dan, Dan loves smoothies (repeat x3)

Verses

- Veggie smoothies are so nice, you can add a bit of spice, Don't forget a pinch of pepper, it makes the turmeric work much better.
- Fruity smoothies quench your thirst with berry goodness fit to burst, You could add a bit of ginger, that's what makes the smoothie zinger!
- Chunky monkeys are the best, they fill you up and give you zest, They're good to have before a swim, they fill your energy to the brim.

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Lyrics by Fiona Nicholls

Dan and Sarah have their own Facebook page
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Blended diets

Lucy Layzell

Meet Alex, a 17-year-old, with the best laugh in the world and a guarantee to have you smiling within a few seconds of meeting him. Alex also has cerebral palsy, epilepsy, visual impairment, and he is gastrostomy fed. Within a year of Alex being born he was discovered to not have a safe swallow and soon a PEG (Percutaneous Endoscopic Gastrostomy) was inserted straight into his stomach to ensure he was fed safely with all the nutrition he needs.



Worsening reflux

Throughout the whole of Alex's life, he was fed artificial milk via a pump which, most of the time, didn't cause any problems. Alex has always suffered from reflux and has a concoction of medication to reduce this, however, as he got older his symptoms started to worsen. Alex would show signs of reflux throughout the day and night, sometimes vomiting up to three times a day. This started to limit his activities and reduce his quality of life as his feed needed to be a much slower rate, increasing the time he needed to be sitting in his wheelchair. Which in turn stopped him doing the things he loved, like swimming, rebound therapy or exploring whilst laying prone.

Eventually his Consultant Gastroenterologist suggested that the way to fix this would be for Alex to have a jejunostomy (like a gastrostomy but with the feeding tube inserted through the abdomen into the midsection of the small intestine), bypassing the stomach (Great Ormond Street Hospital, 2020). This would mean another surgery and meant Alex would be attached to a feeding pump 20 hours of the day, further limiting his access to part of his life which he loves.

The transition to blended diet

Alex's family tried various medicinal ways to improve his reflux until the proposed jejunostomy was the only remaining option, except that was until the option of a blended diet to improve symptoms was suggested. In conversation with other parents and through the wonder of social media, his family thought the added work of blending food for Alex daily would be worth it if it meant avoiding surgery and the huge implication of a jejunostomy.

A blended diet is when food is blended up with liquid to form a liquid-based diet that can be administered through the gastrostomy. This type of feeding is met with caution as some professionals believe it to be unsafe in comparison to artificial feeds (British Dietetic Association, 2019). However, this has largely been attributed to the lack of research and lack of support for families who want to start a blended diet. Alex's local dietetic team were resistant towards using a blended diet. Alex's parents were asked to sign various forms explaining the risks and it was explained that no dietetic support would be given until these were signed. Instead, a private dietician provided much needed guidance on nutrition and tips on where to begin.

Alex started on a blended diet breakfast in June 2021; he had 2 Weetabix, full fat milk, an apple and a handful of prunes. After a couple of weeks, a blended lunch and then dinner were introduced with snacks soon following.



The benefits

After about 6 weeks, Alex was completely off artificial milk and solely fed on a blended diet. His symptoms had dramatically improved. Alex has always suffered with constipation and took daily medication, until he had these natural laxatives introduced into his diet; stopping his need for medication.

Alex had also been struggling to gain weight, however after 6 months of blended diet he gained 10kgs. This massive increase in weight could probably be attributed to the over excitement with the social aspect of cooking, blending and feeds being social once again - the chocolate and cake given may have been a little too much!

As well as his reflux and constipation, Alex has seen an improvement in the condition of his hair and skin, as well as his communication/behaviour and ability to feel hungry or full (which he never showed when he was on artificial milk).

A balanced diet

Initially Alex's family spent time learning calories and nutritional status of ingredients, calculating and measuring food, but after a few months they stopped worrying so much and basically replicate a typical meal (with more vegetables than his siblings!) Quite simply, if he has been swimming, he has more calories just by feeding him chocolate or cake. If he has put on a bit too much weight, they reduce it by feeding him more vegetables and fruit, just like anyone would if they are wanting to lose or gain weight. Over the day or week they make sure he has a balanced diet and eats plenty of fruit and vegetables, carbohydrates, fats and sugars, dairy and protein.

Every 6 months, Alex's dietician reviews his meal plan and assesses whether it is nutritionally balanced. At the last assessment she reported it was better than his artificial milk and he didn't need as much of his regular multivitamins.

The practicalities

Alex's family invested in a Vitamix Ascent blender (£799) which quickly blends up his food to the right consistency. However, there are much cheaper options including Nutri Bullet blender (£70) and Ninja blender (£130). When on holiday, Alex's family take the Nutri Bullet as it is much more compact and easier to carry. They have had their fair share of exploding blenders and squirting food up the wall. At times their kitchen can look like an original Jackson Pollock abstract painting with splatters decorating walls and ceiling.

Many families batch blend meals, where they cook a dinner to excess, then blend it up in batches and freeze



it. This process can save time blending a new meal every day. Alex's family don't batch blend but rather like the idea of him eating the same as the rest of his family and being able to choose what he eats based on his constipation and activities that day, so they blend a meal three times a day. Alex also has around 400-500mls each mealtime which would take up a lot of freezer space.

Trial and error showed that some foods do not blend well and make the consistency too thick and stodgy. These include, pasta (in large amounts), egg, chips/mash (in large amounts) strawberries or fruits with small seeds. Alex's blends are usually made with milk or apple juice (for the calories) although water works well for getting a thin consistency.

Possible disadvantages

Switching to blended diet has many advantages but it is more time consuming and much harder work. Alex has a mic-key button and his family use a straight end bolus extension tube for his blended diet although it does still sometimes cause tube blockages. In addition, the mic-key button needing changed more frequently because it tends to wear away quicker.

It also costs a lot more, the blender is very costly and the weekly food shop has increased because there is another

person in the house eating food (rather than prescribed artificial feed supplied on his prescription).

There are implications for the environment too; although syringes are washed up and reused, they can get quite stiff and need to be discarded. When Alex was on milk feeds, it was simple to connect the pump to his extension and press go. Now, he is on a blended diet it makes leaving the house to go out or mealtimes more stressful.

Blended diet hacks

Now Alex has been on a blended diet for nearly 2 years, we have managed to gain a few hacks to make it easier and less stressful.

To reduce the mess, a white UPPDATERA tray from Ikea (£3) is used to hold his drawn up food in 60ml syringes which have been rinsed before putting in the tray to take to him.



Blended diet won't work for everyone, but it really feels like the most natural way to feed a loved one with complex feeding issues. Maybe it is worth a try; it might just make a huge difference like it did for Alex and his family.

The Blendjet 2 (£44) is a great investment for eating out. Instead of taking out pre-prepared food in syringes, Alex's family order his food at restaurants (request it comes straight away, so it can be blended before everyone else's meal comes) or buy him something from a supermarket and blend it up there and then. The

Blendjet is fairly quiet and it is compact so easy to transport; Alex has a lunch bag which is carried around on his wheelchair containing all his mealtime paraphernalia. The Blendjet is also quite powerful. Although food is blended in smaller quantities, which takes some time, this hasn't posed many problems. Using a Blendjet makes being in a restaurant more of a family experience, as everyone is able to enjoy meals together and give Alex a choice from the menu.



Another hack recently discovered is adding ice or frozen vegetables to meals when they are very hot. When the Sunday roast dinner is plated up, either ice or frozen peas and sweetcorn is used to bring the temperature right down, so it is ready for him to eat with everyone else.

Throughout this process Facebook groups have been invaluable for information of families already using a blended diet (Blended Diet UK and Blending Hope). Born at the Right Time has a podcast, The Skies We're Under, for parents of people with complex needs and which included alternative feeding (Season 1 Episode 9) and blended diet (Season 2 Episode 13 – released May 2023)

Note: The name Alex has been used for the purposes of this article. It is not this young man's real name.



Contact Details

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Useful links

Ikea tray - <https://www.ikea.com/gb/en/p/uppdatera-utensil-tray-white-10460015/>

Vitamix - <https://www.vitamixuk.com/product-category/all-blenders/>

Blendjet - <https://blendjet.com/products/blendjet-2?variant=32478639358018>

Ninja Kitchen - <https://ninjakitchen.co.uk/ninja-catalog/ninja-blenders/>

Nutri Bullet - <https://nutribullet.co.uk/all-blenders/>

The Skies We Are Under Podcast - <https://www.bornattherighttime.com/the-skies-we-are-under-podcast/?layout=grid&occurrence=a3cea91c-56fc-4168-887e-a50cc52e3c36&cadpath=born-at-the-right-time%2Fthe-skies-we-re-under-podcast-live>

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Remember to tag us on social media ~ @PMLDlink

Twitter: @PMLDlink

Facebook: PMLD Link

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

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

The Dentist: helping individuals overcome barriers to their oral hygiene

Victoria Navin

Please see the website to download your free copy of 'The Dentist' resource which includes an introduction to the sensory story, safety guidance/notes, prop suggestions, strategies and extension activities.

Text	Prop	Sensory Experience
We need to look after our teeth and keep them nice and clean So to help we visit the dentist, who will make them gleam.	Dentist Mirror	To sign 'dentist' using Makaton, curl your index finger and tap your front teeth twice. Can the story explorer copy your action and sign 'dentist'? With both you and the sensory explorer looking in the same mirror, model opening your mouth and look at your teeth in the mirror. Would the story explorer like to open their mouth and look at their teeth using the mirror?
The dentist's room is light and bright and smells a little funny You might feel a nervous feeling like a tickle on your tummy.	Alcohol wipe/hand sanitiser Feather or feather duster	Wipe the table or the story explorer's lap-tray with an alcohol wipe? Can the sensory explorer copy your action? Taking their lead, gently tickle the sensory explorer using the feather/feather duster.
The dentist wears a shirt, it may be white, blue or green This protects from the dirt to keep her nice and clean.	Shirt	Present the shirt for sensory exploration (option to offer a choice of colours) Would the story explorer like to try the shirt on? Place shirt over explorer's clothing
She wears gloves and a face mask covers her mouth and nose That is ok, its part of a dentist's clothes.	Gloves Two face masks	Present the gloves for sensory exploration. Model wearing the gloves. Would the sensory explorer like to wear the gloves? Place a face mask over your mouth and nose. Would the sensory explorer like to wear a mask? Present the mirror so they can see their reflection.
I'll take good care', the dentist says as I lie back in the chair. With a big smile she tickles my hand, with a blast of air	Balloon pump or bicycle pump	Present the pump for sensory exploration. If using fake/joke teeth or a dental care teeth model, direct the air at the teeth. Taking the lead of the sensory explorer, very gently and carefully direct the air flow from the pump at the story explorer's hands/cheeks.
Above my head is a light that shines onto my teeth 'I'll use this little mirror so I can look around and underneath'	Battery operated hand held torch, head torch or wind up torch mirror	Present the torch for sensory exploration. Model shining the torch onto your teeth. Would the sensory explorer like to shine the torch on their teeth? Present the mirror so they can see their reflection.
The dentist wears goggles to stop the lights that glare They look like big sunglasses, she offers me a pair.	Goggles/safety or sun glasses Mirror	Offer the story explorer a pair of goggles/safety/sun glasses to wear. Present the mirror. Encourage the story explorer to look at their reflection in the mirror.
The dentist gives me a little bib, it tucks under my chin. She says that when we are ready that we will begin.	Bib/napkin/flannel/paper towel	Present the bib/napkin/flannel/paper towel for sensory exploration. Loosely tuck the bib/napkin/flannel/paper towel into the collar of the story explorer's clothing or lay it over their chest.
The dentist says words like 'relax' and 'open wide' Then gently with her fingers, she takes a peek inside.	Mirror	Encourage the sensory explorer to open their mouth to your cue of 'open wide' whilst they look in the mirror.
There is a special toothbrush used to clean my teeth. It hums and spins around my gums and cleans right underneath.	Electric toothbrush/mini massager	Explore the sensation of the electric toothbrush on the back of the story explorer's hand.
The dentist says I need to rinse my mouth with a mouthwash that is bright pink. I swish it around my teeth and gums then spit it down the sink	Safe/child-friendly mouthwash or water Plastic cup, sink or bowl	Open the lid of the mouthwash and gently waft for the sensory explorer to smell. Model using the mouthwash. Pour a tiny amount of mouthwash into a container. Can the sensory explorer swish the around their mouth then spit it out into a sink? or bowl?

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PMLD LINK articles on personal care

Rob Ashdown

For this article, a trawl was made of articles written in the past decade for the PMLD LINK journal to see what they have to say about the specific theme of Personal Care. For our purposes here, personal care means anything done that carers do which is of an intimate and personal nature. Surprisingly, there has been very little in this journal about the whole range of day-to-day personal care activities required to sustain a consistently good quality of life and living. Perhaps they have been regarded as too mundane to write about.

Getting the basics right

There have been many articles on aspects of health care, including postural care, (see for instance articles in the themed issues of PMLD LINK on health matters and therapies: Issues 70, 76, 85 and 91), which is not surprising since so many people with PMLD have severe physical disabilities and complex health needs. I have chosen to pass over these articles and highlight just two articles on the important themes of nutrition/constipation and respiratory problems that convey important messages.

Louisa Whait (2016) notes that people with PMLD are at a higher risk of having constipation. She argues that this is not surprising when you look at the reasons for constipation which include: inadequate diet and fluid intake, side effects of certain medications, reduced mobility and lack of exercise. She highlights that professionals need to come together with parents and other family members to raise awareness of constipation and the effect it has on quality of life. She further asks them to consider alternative treatments which are less damaging than long term use of laxatives. In the same year, the Government produced online guidance on the recognition of constipation and prompt treatment and the need for appropriate training and education around the issues (Public Health England, 2016). This guidance identifies a booklet by PAMIS (2011) on managing bowels and bladders as a helpful resource.

David Standley (2016) asks us to consider the overwhelming evidence that people with PMLD are among those people at high risk of developing respiratory problems. The risk may have already been identified and specific management plans put in place to be provided by a range of community and specialist healthcare professionals but this is not always the case. Respiratory failure tends to, but not always, follow a pattern of increasingly severe signs and symptoms. As these progress so does the level of medical treatment required which are known as escalations in treatment or care. He provides a guide to the signs of respiratory

distress that can compromise a person's health and makes suggestions about how to access respiratory care. Concerted action can reduce the symptoms and can significantly improve a person's overall health and quality of life.

Dignity and respect

Julie Calveley (2013) discusses how people with PMLD may be affected by the way in which personal care activities are carried out. Intimate and personal care is integral to the care that people with PMLD require. She asks us to consider how we would feel if we were in their place and were wholly dependent on others to carry out such activities on a daily basis. She conducted a study into how adults with severe and profound learning disabilities experienced intimate care provided by staff in residential homes. She found variation in the extent to which dignity was maintained for these people. For example, at times she observed instances of failure to maintain privacy and of staff speaking in ways which could have been interpreted as disrespectful. She compares her findings to those of other studies of dignity in health and social care settings. She argues that people with PMLD are susceptible to experiencing damage to their self-esteem because the self emerges at early stages in the course of development and does not require advanced intellectual functioning. She proceeds to argue that dignity is a right for everyone, and therefore it is a fundamental characteristic and requirement of the 'care' that support staff provide.

Time could be spent quite productively on these activities.

Unfortunately, in my own time as a teacher, personal care activities were often seen by many of my colleagues as the domain of the 'welfare assistant' or 'learning support assistant' or the 'lunchtime supervisor'. They can consume a large chunk of the school day and, although they were perceived as necessary, they were seen as taking away time from actual teaching and reducing opportunities for learning. These days,

hopefully, personal care activities are seen in a different light.

Nancy Beesley (2018) draws our attention to the opportunities that personal care activities offer for learning that should not be overlooked. She points readers to the ideas expressed by Imray and Bond (2015) and Cambridge and Carnaby (2006) who viewed them as providing a context for giving people greater control of their lives and developing relationships, communication skills and self-awareness. It is all too easy to assume that people with PMLD are not capable of making choices about how they prefer activities to be conducted or of being involved in the process. Children consistently having things done to them are at risk of developing 'learned helplessness'. Whereas, Imray and Hinchcliffe (2014) suggest that this may be avoided by careful planning to ensure that these tasks are performed with the pupil, rather than done to them, and according to expressed preferences or choices.

Expectations of services

These articles make plain that well-trained, highly motivated staff are required, yet there remains this nagging feeling that personal care activities may be regarded as unimportant and staff may be ill-prepared for such important work.

PMLD LINK has hosted on its website a document on core and essential service standards (Doukas et al, 2017). As regards the organisation standard on Communication (Standard 3, p. 29), organisations are asked to ensure that they use a 'total communication approach' which is consistent and persistent. They should consider the environment and contexts that promote communication and communication should always be at a pace the person can engage with. This requires patience and time. Staff should use communication strategies, repetition and routine to promote predictability and anticipation, and greater participation.

The organisation standard on Health and Wellbeing (Standard 2, p.30) asks for evidence that all concerns can be responded to in order to prevent chronic or common health problems (e.g. constipation, dehydration, urinary tract infections) escalating. So staff must have good awareness of what is 'usual' for the person in terms of their health and wellbeing, and are able to identify and respond swiftly to indicators of any changes in health status. This means that they must know how each individual communicates their health needs, including indicators of discomfort, pain or distress – and be responsive to these communications. Also, every individual with limited movement requires a 24-hour postural care management plan in place with input from physiotherapy and occupational therapy at all stages.

Organisation standard 2 (p31) also expects that each person should receive respectful and dignified support to do as much as he/she can do for him/herself. As Beesley (2018) points out, people who are always having things done to them are at risk of developing 'learned helplessness'. Whereas, this may be avoided by careful planning to ensure that these tasks are performed with the person and according to their expressed preferences or choices. This may take more time, but will be supportive of good mental health, countering learned helplessness.

Organisation standard 2 also looks for evidence that nutrition, hydration and constipation information is known. Plans need to be personalised for each individual and they must be supported to express their choices for meals.

Organisation Standard 3 looks at relationships. The highlighting of the need for good knowledge and responsiveness to the individual underscores the significance of consistency of staffing and support (p.32). Services should plan rotas to reflect this need. It is impossible to overemphasise the value of, for example, key-working approaches and maintaining consistency of support to enable people to engage in these important daily activities or other events.

Mencap's 'Raising our Sights how-to guide to support for families' (Sunman and Hanrahan (nd) examines the expectations of short breaks services and stresses similar messages that could apply to all services. Among other things, services are expected to:

- listen carefully to the family and recognise that their experience makes them experts, and that they know much about how to best support their family member who has PMLD
- have staff who take time to learn about how the person communicates, and work with the family and others who know them well to develop a communication passport so that all staff know how to communicate with them
- value the people they support and treat them respectfully at all times
- keep up-to-the-minute records of medication or care needs, and view records as living documents that are person-centred and checked constantly
- provide a named key worker who takes time to build a relationship with the individual and their family
- understand the importance of good postural care and ensure that staff are trained to carry out daily physiotherapy exercises if the person needs these
- know how to support a person with their feeding and drinking routines
- ensure staff are skilled in dealing with a wide range

of other technical issues that families cope with daily, such as supporting people who have a catheter, need stoma care, who are tube-fed, or need oxygen

- check with families if they have concerns about changes they see in the person's behaviour as this could be a signal that something is wrong
- offer people with PMLD choices and support them to make choices so that they are involved as much as possible in all decisions being made about their lives
- understand how a multi-sensory approach can help the individual know where they are, and help them cope with the changes
- listen to the family's concerns and act on them in a prompt and professional way

Conclusions

There have been some really informative articles about postural care, therapies and invasive care in the PMLD LINK journal but there has been relatively very little about the particular themes raised by the four articles described above, i.e. dignity and respect, nutrition and bowel management, managing respiratory difficulties and the opportunities for personal and social development and cognitive and communication development in the context of daily activities. These are important matters and should not be neglected. The net impression from this trawl of the journal shows that more could be done to share the personal care strategies and activities adopted by families and services to meet the physical, social, learning and mental health needs of individuals with PMLD. After all, many thousands of people are providing this vital support on a daily basis. PMLD LINK editors would welcome more submissions on this important topic for any future issues.

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Personal care activities can offer so many opportunities

Neil Mullen

Having worked within a variety of settings, both educational and community based, I have had many experiences of being involved in personal care of people with profound and multiple learning disabilities (PMLD). I have been involved in intimate care (toileting/washing), personal care (shaving/putting on clothes) and individual care activities (supporting with transportation). To many that have not had much experience of working closely with people with PMLD, these are just jobs that are part of their daily routines. However, people who have a good deal of experience of providing personal care will know that there are many more opportunities that can be learned, linked, and brought about.

The definition of personal care is providing support appropriate to the needs of people with PMLD. This support can be wide ranging but can include assistance with bathing/showering, feeding/drinking, oral healthcare, changes in/out of equipment, toileting and support in accessing therapeutic services such as physiotherapy, rebound therapy and hydrotherapy. Many people with PMLD will require support with personal care 24hrs a day. These personal care services will be provided by family members, staff from education, health and social care services, personal support teams and close friends.

Providing personal care often leads to people with PMLD developing increased independence and anticipation of events and sequences in their daily routines. Individuals (e.g. staff, family members, carers and friends) and their behaviour (e.g. using objects of reference or sensory cues) become visual/physical reminders that will create the anticipation of a particular personal care activity or next steps in it. This can then also lead to increased independence in their routine, achieved, for instance, by positioning themselves, body movements, and communications with staff on preferences more via a communication device.

Working with people with PMLD in educational, home and community settings has given me years of providing personal care. In all settings, I have found that providing personal care has enabled social relationships to flourish. The closeness, proximity and development of relationships brings about social interactions that may have previously not been developed in differing environments. These social interactions and closeness in personal relationships are strengthened through maintaining respect and dignity within the personal care routines and continued 1:1 communication with one another.

Within this development of social interactions, I have often found that humour between recipient and deliverer of care is developed. This was especially the case when I worked in educational settings where personal care routines were a key part of the day to day activities for students with PMLD. This included changing for hydrotherapy sessions, rebound therapy, positional change in and out of personal equipment, toileting and accessing the school minibus. The students I worked with developed a wicked sense of humour during these activities – examples included laughing uncontrollably when I had made a mistake, eye/body movements (usually at my bad dad jokes!) and finding my singing funny too. I have found this to be an effective and functional way of communicating together and sharing a humorous experience and interacting in a way that might be inhibited within a more formal classroom/learning environment.

The effectiveness of the implementation of personal care can be linked to aspects of PMLD Link's Core and Essential Standards (Doukas et al, 2017) where standards relating to communication, giving meaningful time, and transitions can be further enhanced through personal care work. A key tip is to make sure the environment encourages communication and interaction. Exploring different sensory experiences together, promotes shared communication (e.g. about objects to touch, sounds, things to look at or watch, opportunities for movement, things to taste and or smell).

As far as possible, it is important that people working with people with PMLD promote their ability to exercise choice, control, and independence in self-care, and their ability to avoid, identify and communicate abuse. The importance of the person providing the personal care should not be underestimated in relation to development in other areas besides. This can include empowerment of individuals (e.g. independence,

realisation of potential, ability to say 'no'), promotion of choice, promotion of rights (to dignity and privacy, safety and security) and recognition of preferences. For example, when providing support with eating and drinking, work closely with them to recognise their preferences and what they would like rather than deciding for them.

Personal care is vital in supporting people with PMLD across education, home, and community settings but it is also pivotal in developing and fostering increased communications, anticipation of routines and personal relationships with those providing care. Personal care is not just simply helping to meet their physical needs; it can mean much more to both those receiving and those providing care. I am not currently providing personal care for PMLD individuals and miss the humour, development in personal relationship and development in anticipations and communications. It is always important to remember

this when providing care – the opportunities are endless – yes it is about meeting needs, but it is also about exploring other opportunities that can further enhance their experience wherever that occurs.

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In the Next Issue

The theme of the Summer 2023 issue of PMLD LINK is 'Research'. Whilst most issues often include at least one or two articles that touch on the topic of 'research', we thought a dedicated issue would be an opportunity to focus in various ways on this broad area.

We already have received some articles that are examples of good, small scale research. We would love to receive other submissions on this topic. For example, about research projects relevant to the lives of people with profound and multiple learning disabilities that you are involved in currently or that you have been involved in, or just pieces of research that have had made an impact on you and you would like to share with others.

We would be interested in any reflections you have on research, including what research you think is needed. We would also be very interested to hear about the influences of research – for example, how you have put research into practice in your everyday life or work.

We would love some articles that get across key messages and top tips as 'research' articles can have a bit of reputation for being very academic and dense !

All contributions by Monday 5th June 2023 please.

The Summer 2023 issue editors are Rachel Hughes, Maureen Phillip, Annie Fergusson and Bella Travis.

If you want submit a piece or want further guidance or just want to discuss your ideas, please contact the Editors by e-mail at: info@pmlmlink.org.uk



Personal care: a mother's vision becom(ing) reality

Kate Sainsbury

As Maureen Phillip, of PAMIS, said recently, 'Social care is changing and it has to change to fit a community of people who don't want the old model of care.' My son, Louis, and I are part of that movement towards a new kind of personal care. For the last five years I have pursued a Vision for Louis to live in his own home, cared for by a team of professional carers, with my input and regular visits, surrounded by a wider intentional community who support us and delight in Louis' flourishing. Louis was discharged from hospital eight months ago. Vision has become Implementation.

At the time I developed my Vision, Louis was detained in a psychiatric hospital, through lack of alternative care arrangements, where he protested at his unsuitable surroundings. My Vision was based on claiming Louis as human. My task, driven by love, was to win support for this and to establish lifelong quality personal care and housing, in partnership with statutory agencies.

I found affirmation from Bill Gaventa, whose lifelong experience of spiritual care for people with disabilities, distilled in *Disability and Spirituality* where he observes. 'The act of naming and labelling can thus have great power, a power heightened by the question of who gets to bestow that label and why' (Gaventa, 2018, P.11).

Key components of my vision were these:

- 1) Who is Louis?
- 2) Location - a physical building
- 3) Organisation of personal care

4) Values and goals

5) Development of intentional community

Who is Louis?

Personhood is at the heart of personal care. As a mother, I know Louis as a person, with strengths and gifts, and a history. Relationships are mutual: I love Louis and he loves me. Louis has an excellent memory, relationships are important to him. He remembers friends and likes to plan parties, which gives him hope and resilience. "Balloons! Cake", he says. So the first pillar was that Louis is a person, in relationship with others.

Furthermore, Louis is a particular person. He is extrovert, feels at home in nature, loves walking and swimming, enjoys food, is creative, is sensitive, feels ashamed after difficult incidents. Louis loves me, wants to see as much

of me as possible, wants to be part of a circle of familiar people and places from his youth. Louis thrives with structure to his days and weeks, enjoys meaningful activities, regular exercise, social time. Louis needs to be understood as a person, with hopes and fears, needing security, understanding.

Louis has PMLD but that is not who he is. Medical, deficit models do not define him, nor behaviours triggered by underlying trauma, trauma caused to him by poor personal care in hospitals and care settings.

I, in my sixties, growing older, need long-term arrangements for both our futures. As his Welfare Guardian and Deputy, I had power and skills to make long-term care arrangements. All these aspects of Louis would shape the other components of the vision, on which I worked in parallel processes.

Location - the building

Louis had funds from a medical negligence award, available to buy a property. It needed to be close enough to our family home, far enough away to help Louis understand his home as separate. It would be rural, on a bus route, accessible in times of snow, near to population centres, for recruitment and support for carers.

The care partner

Compassionate, skilled caring was key to long-term support for Louis. I wanted to support those who cared for Louis to build relationships, develop communication, wanted to show them they were valued. My vision was to work with a care organisation rather than managing carers myself. An organisation was identified that cared for people with complex needs. Senior managers in the multi-disciplinary team (MDT) and the care organisation

supported my vision, and my collaboration as active, expert partner.

Collaboration

This collaboration between stakeholders and me was core, part of the innovative nature of the project. I am the person who has known Louis longest. I speak his language, I can express his voice, and I exercise multiple roles as Mother, Welfare Guardian, Deputy and Householder (technically owning Louis' house on his behalf). Collaboration was facilitated by PAMIS, the Scottish charity for people with PMLD, whose staff introduced me to policy makers, helped me build trust and relationship with professionals. Collaboration was underpinned by policies for people with PMLD, Self-Directed Support legislation, and the Human Rights framework.

Collaboration is embedded in the care outcomes in the contract between the local authority, the care provider and myself. Collaboration is how I work with Louis and with his care team.

Goals and values

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

Intentional community

My Vision was to surround Louis and his team within relationships with local communities and wider virtual groups, for affirmation, companionship, long-term stability, practical help.





History

As we moved from vision to implementation, different aspects of the vision overlapped. Louis was assessed as needing 2:1 care at all times, funding was agreed. I obtained Court approval to buy property and got agreement from all stakeholders before making an offer. The purchase gave us all confidence. It also gave us location, and visibility in community.

The house was a set of converted farm-buildings, built around a secure courtyard with gardens to back and side. It was large, with potential for future growth and development, the right distance from home. The spaciousness in the house and the garden is an asset for staff, where timetables for daily activities can be planned, for all seasons and weathers.

The care organisation and I recruited staff members. They learnt about Louis from me, we valued each other. The organisation gave them mandatory training, I shared my knowledge about Louis. Helpfully there was a long transition out of hospital.

Recently, we revisited the core value of seeing Louis as a person, not defining him by deficits. I called on regulatory organisations, expressing Louis's voice for reinforcement of this, and the care organisation responded favourably. We also recognised the importance of describing roles and responsibilities for future working practice.

Community

We now have volunteers who offer sessions of crafts and story-telling, and we have a circle of friends who visit. We hold a weekly online prayer group, which Louis attends with his carers, a chance for his spiritual needs to be met and for him to be part of a wider circle of friends.

Relationships within personal care

The importance of relationships was affirmed by researchers Nunkoosing and Haydon-Laurelut (2013) in *The Relational Basis of Empowerment* where they examined good and bad practice in personal care. They described people flourishing within a network of positive relationships, the importance of hope for those cared-for and those caring, to shape a culture. They cite Diener and Seligman (2004, p2) to highlight that each of us seeks a life that is 'enjoyable, meaningful, engaging and fulfilling'.

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

Structural influences

Camphill, L'Arche and Louis' boarding school communities shaped my vision of Louis' care community, with rhythms for days, weeks, seasons, their ethos of





lifelong learning, their emphasis on relationships, acknowledgement of spiritual realities, and living well in nature.

Benefits to Louis and others of personal care

The benefit for Louis receiving personal care in his own home, is the security he gets through familiarity and predictability. He now has stable relationships with a team of carers, and regular contact with me. Louis' language has developed, staff recognise words and share their understanding with Louis and each other. Louis is less frustrated and there is delight in conversation. Enabling Louis towards greater autonomy is giving him greater self-esteem. Self-esteem gives him self-belief and hope. The happier Louis is, the better experience everyone has.

With a stable core staff group, team relationships are growing, they increasingly feel valued.

Our example of quality personal care is a model for statutory partners.

These are early days, Louis was discharged from hospital only eight months ago, but slowly this is starting to work, for Louis and his care-givers.

Learning

My learning is that relationships within personal care are key, collaboration and trust take time to develop. Setbacks are part of life. I've learned to persist, and to

hold on to the vision. I have learned to trust my understanding of Louis, when to express his concerns, when to seek help. I've learned that quality personal care depends on collaboration, communication, seeking happiness, mutual fulfilment, living 'now', telling stories both about the future and the past.

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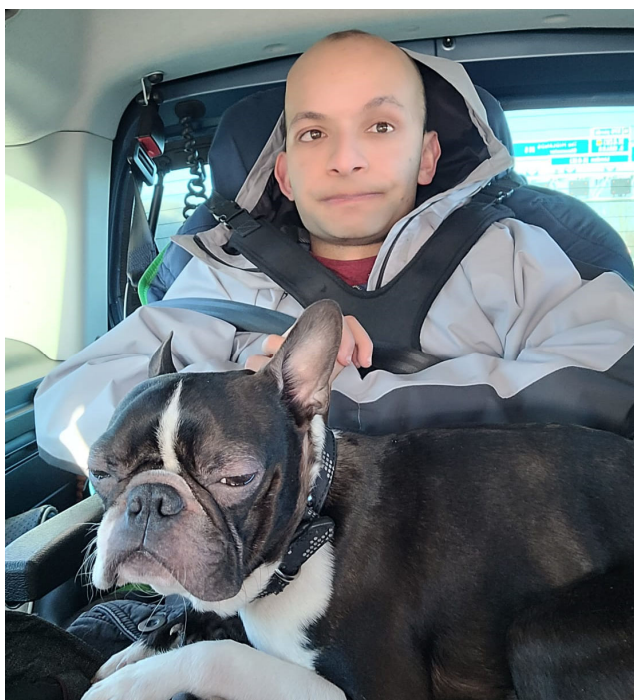
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A holiday of necessity

Sandra Archibald and Becky Downey

This February Isaac headed to Weston for a holiday of necessity whilst his room was revamped. Not for aesthetic purposes of course, but rather to make it more suitable for Isaac's family and the endless stream of carers and professionals who pass in and out of it, completing his many daily care tasks!



The car was packed to the brim with supplies that most of us never need to consider; slings, bulky sleep system, including a mattress, splints, medicines, personal care, creams, pads, etc. All must fit in a car that can hold barely anything other than Isaac, in his wheelchair! Then add to that 4 people, 3 dogs and a deep abiding belief that this car can be turned into the Tardis. Ha! 'Ye of little faith.' I shoved, kicked, squeezed and slammed the door shut on the last bag. Two dogs on one lap are a squash even when they are small. Niles (a support worker's dog) and Isaac meet each other for the first time and both are unperturbed. Niles eyes the empty space that is Isaac's lap and edges onto it one limb at a time. Isaac, known for pushing people off his lap should they prove annoying or too heavy, is peaceful throughout the 2-hour journey (as pictured). Even as we tumbled from the car and threw the bags to the ground so we could extricate Isaac, he is peaceful and glowing. We arrived on the top of a hill to an accessible bungalow, 'The Crescent Hideaway'.

Isaac liked the place immediately and he loved being in the middle of activity. He had a genuinely brilliant time away, remaining happy and content throughout. Isaac is a sociable person, who loves to share his pleasure with

others. He'll frequently reach out to draw you in, but he gets bored, irritated, and angry too. With this trip came the realisation – he needs to go on holiday, to experience something new, to be somewhere different! It has been nearly 8 years since he's been on a holiday, his busy social life was sharply curtailed by Covid and his staff team have changed too. It has been warming for us to observe Isaac's pleasure in being away and to slow down, take things at his pace. There is a tinge of guilt too, for not considering that he also needs a break from the everyday. Hearing his deep chuckles - as he sat in the middle of the bungalow watching us, as we went to and fro, playing noisily with the dogs, making food, just doing - and returning to him. Catching his gaze across the room he smiles a reply. He is interested. We sat with him, enjoying the sun, warm through the wall of windows, on the veranda, splashed grinning in the hot tub. And yes, we visited the beach and a pub where Isaac scoffed pasties and people watched.

Worth the stress of packing? Undoubtedly!

Will we do it again? Absolutely! Isaac needs a holiday too.

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Putting the FUN into a bit of me time

Lindsey Price

In today's busy lifestyles we see a need to try and make time for ourselves. To take time out for our own self care and mental well-being. And even for the most able of us to try and fit in some dedicated well-being time is difficult. Yet imagine how hard it must be to find that little bit of "me time" for those that care and for those we are caring for in our lives.

Families, parents and carers can find it difficult to access outside experiences because of many barriers. These can range from accessibility, self-confidence, location, time, venue, etc.; even assessing whether there is the correct accessible bathroom available can put a stop to daily activities.

A local charity based in Warrington, Families United (FUN), has been in existence for twenty years this June. It provides support and events for families and carers looking after children with disabilities. Their aim is to ensure that they offer external events, trips, residential and activities to families caring for a child with a disability.

Chair of the charity Dr. Lisa Edwards explains: "When we think about personal care it isn't just looking after ourselves physically and ensuring we are healthy; a big part, is looking after our mental health too. We find that a lot of our families feel isolated and cut off from day to day living whether it be because of lack of suitable activities or having the confidence to venture out. We want to ensure that those caring for a child with a disability have somewhere they can go to meet other

families and make new friends. We also want to have lots of fun, experience different activities and new places too."

Families United run a regular FUN session every month that has many families joining in with activities such as crafts, sensory fun and even visits from Animal Therapy groups and entertainers.

Over the past couple of years FUN has joined forces with The Puddle Project, a self-sustaining social enterprise in a beautiful rural setting that aims to bring physical and mental well-being to those with special needs. Most recently FUN members enjoyed a pancake making extravaganza at the Puddle Project whilst using the time to mentally unwind in the peaceful surroundings.

Families United member Michelle, explains what it means to her visiting the Puddle Project: "First time we visited was a Mother's day event and they were amazing with my boys. I am a very isolated mum, I have ADHD, chronic health issues and anxiety, I also care for three children, two of whom have additional needs. The director of the Puddle Project, Phil took my boys under



his wing and let them be kids from the very first session. They have grown in confidence and each time have been gently encouraged out of their comfort zone. It's an amazing place, with amazing staff; the Christmas session they ran brought me to tears (happy ones though). Here, it's not only my children that are supported but myself too. I can't wait for this year's adventures."

Often sport and exercise can be difficult to participate in and finding places that accommodate all needs can be elusive. Families United understand the value of sport



participation and team work and as part of their regular monthly activities they offer a number of sessions at Sport Works. The activities are fully supported with staff members and include an hour of wet sport in the pool and an hour dry sport session.

Families United member Gill Connor, said: 'My daughter Emily, has been supported by Families United for the past sixteen years. At the moment they are supporting her with swimming. Emily could swim when younger but mobility problems and operations meant that she lost all confidence in the water. FUN are supporting her with activities in the water and sport to increase her confidence. I don't know what I would have done without the friendship and care from Families United.'

This year Families United has a packed calendar of fun planned including visits to The Catalyst Museum, Lucem Cinema, Children's Adventure Farm Trust and Chester Zoo. Plus with their big birthday coming up they will be holding a super 20th birthday party for their FUN members. In terms of personal care both physically and mentally FUN will always be making sure their families are number one.

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Lyndsey Price is a trustee of Families United

If you would like further information or wish to support Families United please email familiesunitedwarrington@gmail.com or visit <https://familiesunited.org.uk>
Facebook: Families United
Instagram: Families United Warrington

Including individuals with profound and multiple learning disabilities in a national survey: promoting inclusiveness and understanding

Tanya Evans and Leigh Wharton

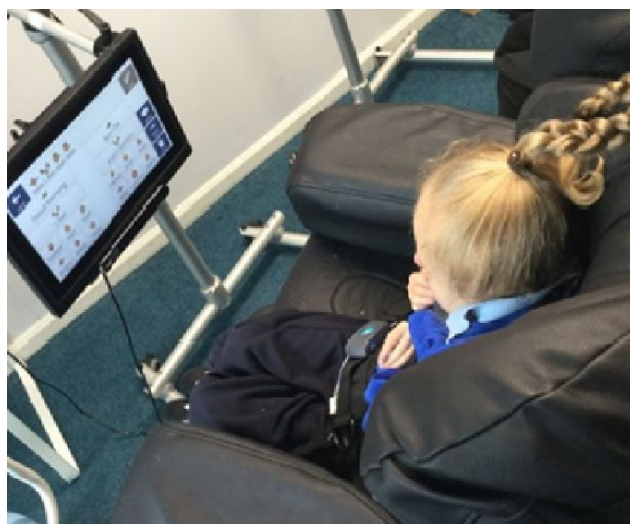
Ysgol Ty Coch School, in Pontypridd, was approached by Jordan Doherty, a Participation Officer for the Children's Commissioner for Wales, who was building a toolkit to support local authorities to think about the Additional Learning Needs Code for Wales 2021 and the participation of all children and young people. During the initial stages of the project, Jordan and her team realised that many children were at risk of not being heard, as adaptations were not being made to gather their opinions. Jordan needed some input from teachers "on the ground" to understand how we ensure all voices can be heard.

Tanya Evans, a teacher from Ysgol Ty Coch, met with professionals from Health and Social Care to explore as professionals how they could include children with ALN (additional learning needs) to help fulfil the Children's Rights Approach principles of Empowerment and Participation (Children's Commissioner for Wales, 2017), as part of the United Nations Convention on the Rights of the Child (UNCRC).

After the initial draft toolkit was composed, Jordan visited Ysgol Ty Coch to gather knowledge and insight from teachers in the school, developing the toolkit with the information provided with a focus on ensuring the voices of young people with profound and multiple learning disabilities (PMLD) could be included.

The first step in ensuring that Welsh young people with PMLD were included in the Ambitions for Wales survey was to make the survey accessible. In October 2022 the Children's Commissioner for Wales, Rocio Cifuentes, launched this Wales-wide survey of children, young people, professionals who work with them, parents and carers, to find out what key areas of work she should focus on. The closing date for completing the survey was in November 2022 and its outcomes will be published this year.

Making the survey accessible was accomplished by providing alternative formats, such as widget symbols, and sensory exploration through a series of planned lessons, and by designing the survey in a way that is simple to understand and navigate when using assistive technologies (using Grid 3 software: <https://thinksmartbox.com/product/grid-3/>). When designing the survey, it was very important to use clear and concise language that is easy to understand. This involved using simple words and avoiding jargon or technical terms.



The survey was opened to all young people, professionals, and their families to gain knowledge and understanding to act upon "What Matters" to them so it could inform the strategic direction of the work carried out by the Children's commissioner for Wales.

By ensuring that Welsh young people with PMLD are included in the Ambitions for Wales survey, the Children's commissioner for Wales could gain valuable insights into the needs and preferences of young people with PMLD, which can help inform policy decisions that affect their lives.

The Children's Commissioner has made available a participation plan to help adults who support children with additional learning needs (Children's Commissioner for Wales, 2002). It is a useful tool for policymakers and organisations in understanding the needs and aspirations of people with PMLD and working to create a more inclusive and supportive society for all.

Young people with PMLD can be included in decision-making processes, have their voices heard, and have their needs and preferences considered by using the appropriate communication techniques such as using communication devices, switches, e-tran frames and gestural communication. As a result, it is our responsibility as educational professionals to pay attention to and try to understand each young person's ideas and points of view.

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Editors' note

Readers may have seen a piece by Gary Owen on BBC Wales from 12 October 2022 that shows a pupil using eye gaze technology to access the survey. Although the video does not show the whole range of activities detailed in the participation plan, it is well worth a look. It is available at:
<https://www.bbc.co.uk/news/uk-wales-63215347>

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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



Losing Oliver: a case study in professional grief

Delyth Williams

Those of us who work with and/or care for those with profound and multiple learning difficulties know what an absolute privilege it is and when you put us in a room together, we all love to share stories and ideas. But what is talked about less is when we encounter the loss of one of these young people. To start this story I want to begin by telling you about a very special young man named Oliver.

I first met Oliver in 2016 when I was hired as maternity cover for his 1:1 carer. I remember so clearly, on the first day that I met him, I was so impressed by his determination and the use of his voice as staff who knew him skillfully offered him choices and he made them with a turn of his head. I knew then and there that we would become great friends. My favourite memory of this time is when his mum Sandra would drop him off after school holidays and I'd say good morning. He would turn his head away in defiance and Sandra informed me he wasn't speaking to me as he hadn't seen me for a week. Over the two terms I supported him I got to know him

and his family well and was sad when my contract was up. Luckily this didn't last long, as the school called me in as a supply teacher one day and I never left again. I eventually became his teacher and was lucky enough to work with him until the pandemic hit. He joined his classmates and their families on video calls and, as we all became vaccinated, I was able to pay him visits at home. Then one day Sandra contacted me to say that his condition had deteriorated and they (with Oliver of course) had made the decision to end his care. I was able to visit one last time and say goodbye, which I will always be grateful for, and in the coming days held my breath

until we got the news that he had passed in October 2022.

On reflection, what initially felt like grief in the coming days was actually “busyness”. Passing on pieces of information to relevant parties, sharing photos with his parents and checking in with colleagues became a way to feel like I was doing some good. His funeral service was beautiful and afterwards we sat together as colleagues and reminisced on all our memories of this exceptional young man. We all agreed that to have known Oliver was to have truly been in the presence of greatness.

Then the “busyness” began to fade and I had to try to make sense of the grief. We spend a lot of time with our young people, observing them and caring for them and getting to know them so well that we can interpret even the slightest twitch of an eye or raise of an eyebrow. However, as a professional it is important to maintain professional boundaries and not ‘over-step’. I began to do the only thing I know how to do when I don’t understand something, I researched it.

I started my research by speaking to colleagues. As teachers we are very used to putting our own feelings to the “back of the queue” so I anticipated this might lead to some difficult conversations but in reality I found the opposite. Other staff, even ones I didn’t know very well, were keen to talk about their own experiences with grief as a professional. Every one of them had that one pupil (or at least one), that had touched their lives so deeply that their grief was easily pulled from the filing cabinet of their minds with just one or two questions. In these conversations what came up every time was “It’s part of the job”. I’ve thought about this statement a lot, a statement which I myself have made time and time again. What I realised is that we are so used to putting our own feelings aside that this has become a default setting, even in times of grief. And then a colleague led me onto my next phase of research by saying “I just don’t know what’s out there to support us”. Like a dog with a bone, I hit Google.

My initial search led me to a webpage called [educationsupport.org.uk](https://www.educationsupport.org.uk). Here they acknowledge that as leaders in school settings we are “often characterised as being very strong” and that it is “easier to carry on managing the current situation than reflecting on loss”. I called the helpline number as “research” and within about 5 minutes the very skillful and kind operator had led me down the path of reflecting and sharing with her. I explained that as a professional who also cared for a young person, it’s quite tricky to allow yourself to feel grief and not overstep any boundaries. She was patient and listened and reassured me it’s OK to feel sad.

Once I’d pulled myself together, I continued my research

and I’m sorry to report, there was little else to be found. There were a few blog posts, one of which was [joincake.com](https://www.joincake.com) and really highlights one of the problems with grieving as a professional - “teachers give so much to their students, and they often don’t want to be in the limelight.”

Another poignant quote, contributed to a blog on [Quora.com](https://www.quora.com), that I think sums up the reason we feel such loss when we lose when of our young people, “These kids did contribute a lot to the world in their short lives: they brought love and friendship to their friends and family”.

Grief by nature is messy. It’s complicated and it’s very easy to put ourselves last and not allow ourselves to have processing time. But on this journey, I have learnt that this step is an important one. Be kind to yourself.

In loving memory of Oliver

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Sources

<https://www.educationsupport.org.uk/resources/for-individuals/videos/coping-with-bereavement/>
Helpline: 08000 562 561.

<https://www.joincake.com/blog/how-to-help-a-grieving-teacher/>

<https://www.quora.com/Teachers-how-did-the-death-of-your-student-affect-you>

Creating authentic and positive stories about personhood for people with profound and multiple learning disabilities: a call for reader expressions of interest

Stuart Read, Ben Simmons and Anne Parfitt

This paper introduces the controversial concept of 'personhood' as it relates to people with profound and multiple learning disabilities (PMLD). Traditional narratives of 'PMLD', combined with dominant accounts of what it means to be a person, can lead to people with PMLD being identified as 'non-persons'. We are concerned that framing people with PMLD as non-persons contributes to the perpetuation of existing inequalities that this group experiences. We are interested in changing this narrative in ways that allow authentic and positive stories of personhood for people with PMLD to be generated and shared. In closing this paper, we introduce our new research in this field, and welcome readers to contact us if they are interested in getting involved.

What is personhood?

The terms 'person' and 'human' are sometimes used synonymously in everyday discourse. However, in legal, medical, theological, and philosophical texts, the terms can have different meanings. For example, the term 'human' is sometimes used as a biological designation and refers to those who belong to the species 'Homo sapiens' (University of Missouri, School of Medicine, 2023). By contrast, the term 'person' is sometimes used to refer to individuals who are deemed to meet certain measures of conscious awareness and cognition (e.g. being a person presupposes an individual's ability to move with intent, communicate and make moral decisions) (DeGrazia 2005). In fields as diverse as artificial intelligence and zoology there are debates about whether personhood is something that is solely the preserve of living, conscious and cognitively-competent human beings, or whether other mammals such as primates, or non-biological machines, such as sophisticated computers, can also be considered 'people'. Similarly, there are ongoing debates about when personhood begins and ends. For example, people who are professionally medically trained are likely to have different answers than religious leaders about what happens before birth and after death.

How does the personhood debate relate to individuals with PMLD?

Debates about personhood sometimes focus on individuals with neurological impairments, particularly if those impairments are persistent and severe. These debates can upset people as they involve questioning the status of loved ones. Such debates

extend to a consideration of who should be protected in our society, and how and when such protection should be introduced or taken away. High profile examples of personhood debates include campaigns around abortion laws, and court cases about when children should be taken off life support machines.

In our review of the personhood literature, we have identified problems with narrow definitions of both 'personhood' and 'PMLD', which leads to a difficult suggestion that individuals with PMLD may lack personhood (Simmons and Watson 2014a). To be specific, dominant accounts of personhood in Western philosophy require individuals to display a set of cognitive competencies in order to be classed as fully-fledged people (e.g. Kittay, 2009). Whilst the exact mix of competencies is contested, philosophers have suggested that personhood requires rationality, agency, linguistic communication skills, and a sense of self over time (DeGrazia 2005). However, children with PMLD are described in psychological and educational literature as experiencing congenital neurodevelopmental impairments and are said to 'function' at the earliest, preverbal stages of development. For example, children with PMLD are described as being pre-agentic, pre-linguistic and pre-intersubjective (Simmons and Watson 2014b). The dominant individualistic, competence-based view of personhood, combined with developmental descriptors of 'PMLD', precludes children with PMLD from being classed as 'people' (Kittay, 2009). It is this tension that we want to examine and challenge through our work.

Why are personhood debates important for people with PMLD?

Discussions regarding what constitutes personhood are important, as interpretations determine who is and is not viewed as a complete person. While discussion of personhood in relation to people with PMLD may seem contentious and extreme, we have previously argued that denial of personhood contributes to the disadvantage and discrimination that people with PMLD and their families experience (Simmons and Watson, 2014a). For instance, the Coronavirus pandemic has revealed the stark inequalities experienced in myriad ways by disabled people due to this population being perceived as 'less than human' (Read et al., 2023, p. 40). Considering people with learning disabilities, evidence has revealed how this group are much more likely to experience mortality due to COVID-19 (Williamson et al., 2021), and how people with learning disabilities have been given 'do not resuscitate' orders despite not requiring end of life care (Care Quality Commission, 2021). These findings add to the existing body of literature which documents health inequalities that people with learning disabilities may face, which may in turn impact on perceptions of personhood. For instance, Tuffrey-Wijne et al. (2013) explored the barriers that people with learning disabilities may face when accessing healthcare, such as delays in receiving treatment. Research has also demonstrated how such barriers may contribute to people with learning disabilities experiencing premature mortality (Heslop et al., 2013, 2014).

What can we do about it? Expressions of interest for our proposed project

Throughout spring and summer 2023 we will be running a project with parents/carers of people with PMLD, as well as allies/professionals who support people with PMLD. For this project, we plan on hosting a series of focus group-style workshops and/or individual interviews in which participants will be asked to discuss what personhood means for people with PMLD. Participants will also be asked to share their thoughts on how authentic narratives of personhood for people with PMLD can be shared with policy makers and professionals. We would welcome anyone who is potentially interested in being part of this research to contact us.

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Working with students with PMLD on the hospital wards: an explorer's advice

Pete Navarra

Will they make the Pole? A challenge against the physical and the solidity of mind, a challenge requiring simultaneous control. Explorer Sir Ranulph Fiennes selects his team noting the unobserved - an individual's motivation: "I selected the best people, by going for their motivational factor. With many of these expeditions in harsh climates, there can be a variety of setbacks and disappointments, which mentally must be overcome by the person's own motivation in order to keep going" (Fiennes, 2018).

The harsh climate here is the hospital ward, the Pole is meaningful engagement, and the team are the teacher and student with Profound and Multiple Learning Difficulties (PMLD).

The hospital ward is unfamiliar territory for many children and a sensory storm for those with PMLD; the frequent movement of people, the sounding of monitors, the absence of routine and the dimness of illness can shackle wellbeing and negatively affect an individual's sense of purpose. So why strive for the Pole? The reward of success is the feeling of having purpose in life (Uusiautti, 2013) which, in turn, can bring happiness and have a positive impact on an individual's admission to hospital. However, individuals with PMLD have complex needs and are at high risk of developing complications (MENCAP, 2019) which can extend admissions and bring disappointment; so to get to the Pole motivation must be found.

Extensions to admissions can be many weeks or months and being confined to a ward/bed as part of an individual's recuperation can affect the retention of skills. However, their loss can be minimised and new skills gathered, if hospital school teachers initially focus on an individual's motivations and use these as a vehicle to the Pole. Motivations can vary greatly between individuals and be discreet on first meeting. However, this information can be gathered from parents or carers and their home school will also provide supporting information. The most propelling motivations are those that instigate responses which can range from relaxing and coactively engaging to initiating interaction. Length of engagement can also be a measure of motivational factor which can vary from fleeting to extended periods. These markers are greatly varied but can be used as a base to conduct observations and give structure to information gathering questions/activities.

After being diagnosed with Crohn's disease Tara (not her name), a primary aged student with PMLD, faced a number of weeks on the ward. The pain she'd been experiencing and the unfamiliarity of her surroundings

had, her mum informed, made her once smiley daughter withdrawn and now a blank facial expression shadowed the joy she'd often communicated. Talking with mum it was revealed that Tara liked music and her favourite song was 'Can't Stop the Feeling!' from the film Trolls; this was her motivation. During our first session Tara coactively explored a warm heat pad before coactively moving her hand towards her mid-line to touch a sensitive switch (connected to a music source) which started her favourite song. This seemed to make her fleetingly widen her eyes; this response was minimal but confirmed her motivation. The same switch and music were used over the coming weeks and with each session more obstacles were added and required to be overcome in order to access the switch; starting with changing the direction her arm had to move, then reducing the support given to make these movements, next increasing the switch's distance, and finally placing a variety of sensory items in front of the switch that had to be explored/experienced before it could be activated. Each time she activated the music celebrations acknowledging her successes were ignited: first with the teacher raising his arms and moving whilst vocally congratulating her, to teacher and student smiling and coactively dancing. The pole had been reached and Tara's flag firmly planted. The journey had encountered storms and lulls in its progress but the team (teacher and student) had developed an understanding that 'set up the starting blocks' in the eyes of the storm.

Exploring and venturing forwards is hard but not impossible, even in the harshest of climates, if we remember that with each step the destination gets closer and that the first step is to find an individual's motivation. Once found, keep going until the Pole is reached.

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Advice About Legal Issues

PMLD LINK is run by only a handful of volunteers working in their spare time to produce the journal and maintain the website. We are parents, carers, teachers and workers in services and have a good range of collective experience and knowledge. However, none of us have legal expertise and only one or two, mainly through family experiences, have had to deal with service commissioners and providers.

As a result, PMLD LINK, as currently organised, does not have a campaigning role and has no capacity to support individuals in their dealings with organisations. PMLD Link can really only offer its journal and its Facebook page and twitter account as a means of sharing information.

If you ever need advice and support for dealing with a particular issue relating to someone with PMLD for whom you have a concern, we would advise that the obvious start is your MP. There will be some entitlements to support for you and/or the person with PMLD as constituents.

Next, you might contact Mencap's national learning disability helpline. Go to the website where there are details about making contact via phone, webform or email: <https://www.mencap.org.uk/advice-and-support/our-services/learning-disability-helpline>

All unpaid or family carers can contact their local carers organisation in their local authority area for information, advice, and for emotional support'.

As regards legal advice, there are some other potential sources for general legal advice:

- 1) Access Social Care: Legal Network. This service (previously called the Legal Coalition Network, then hosted by Mencap), is now on an independent footing. They work with families to find solutions to situations. For referrals go to: www.accesscharity.org.uk/need-help. Complete online form to start the process or phone 02476978903.
- 2) Another organisation is CASCAIDr - <https://www.cascaidr.org.uk/> run by Belinda Schwer who offers regular webinars, templates & other free resources to respond to issues where the Care Act is not being upheld.
- 3) Some areas have local law centres which offer legal advice, casework and representation to individuals and groups. Specialising in social welfare law, the staff will have an in-depth knowledge of the issues that communities face, and in some cases can support people to access legal aid'.

As regards NHS complaints, you can make a formal complaint to the service provider and/or commissioner. If you do this and are not happy with the way your complaint has been dealt with and would like to take the matter further, you can contact the Parliamentary and Health Service Ombudsman (PHSO) which makes final decisions on unresolved complaints (<https://www.ombudsman.org.uk/making-complaint>) or phone 0345 015 4033.

Anyone making a complaint about an NHS service is entitled to support from an independent advocate. The advocate can support people to complain about the treatment or care that they or a friend or family member have received from an NHS service. This support is available at every stage of the complaints process, and the advocates are independent professionals who are not employed by the hospital or the NHS'.



REPORT BACK

Fire Songs by Frozen Light

by Sarah Walker

I was privileged to experience the latest show from Frozen Light Theatre as both performer and audience member. My brother Dan and I are on the audience panel of the sensory theatre group Frozen Light and last year I was excited to hear that they were bringing their new show to the Lowry Theatre in Salford. Fire Songs has the additional element of a choir performing in the round and I was even more thrilled to learn that as they were low on numbers for sopranos I was welcome to join them.

I'd been in a mixed voice adult choir since 2007 but we shielded Dan through the worst of Covid and when choirs went back to in person rehearsal I hadn't felt safe to return. Frozen Light provided me with rehearsal tracks and sheet music and I learnt the songs and familiarised Dan with the music by listening to the tracks together on repeat. I attended several rehearsals with the Manchester Choirs, the Sunday Boys and She Choir; it was so fantastic to be in a room filled with fun and harmony. The choirs were both excited at performing together and in learning about sensory theatre and Frozen Light's audience. Emma (Frozen Light Audience Development Officer) did an amazing job at explaining what would be happening in the show during each song and the choirs were offered a session on disability awareness over Zoom. I was able to share my experience of other Frozen Light shows and to talk a little more about the audience of people with PMLD their shows are created with and for.



It was wonderful to perform in the two shows on the Friday and I loved covering myself in all things gold for my costume; my gold jumpsuit not quite enough so I even snuck in a go with the light up wings the cast wear!



It was a new experience for me to not be directly supporting someone but to be able to take it all in for myself. Each Frozen Light show has a Name Song where the cast sing directly to each audience member at a time using their name. It is always my favourite part of their shows, the connection that is created is indescribable. Fire Songs did not disappoint, and the pure joy shared in the audience during the name song brought me at times to tears along with other members of the choir. What an incredible opportunity for choirs to connect with members of their local communities in this way. An audience group that is highly unlikely to get the chance to see them in concert in any other way, who in turn can show the choirs a fresh way to experience music.

Saturday brought me back into more familiar territory as I was there supporting Dan alongside his personal assistant, Fe. We had made a campfire box using paintings we'd done, a battery tealight and some cellophane. Dan was really interested in the box on our journey to the theatre whilst we listened to the music from the show.

For Dan to manage in an unfamiliar place with masses of sensory input would always be a huge ask. He'd surprised



me with how well he had been able to tolerate these challenges to enjoy previous Frozen Light shows. This time it was all a bit too much for him to be able to stay in the room for the whole performance, but the beauty of this show is that it's entirely acceptable to move around in the space and to go out and come back in as needed. We listened and joined in with the singing from the corridor and interacted with lots of the props that were brought out to us.

When the show had finished and the space was calmer, we were able to go back in and check out the set in more detail. A particular hit for Dan was the mirrored gold floor.



We used the show as inspiration for further sensory activities in the weeks that followed. We created a sensory tray with a log, some pine cones, battery candles and fairy lights and listened to audio of a crackling fire.



We created a tasting experience of campfire s'mores using a jar of marshmallow Fluff, a bowl of melted chocolate and some gluten free biscuits. Dan enjoyed crushing the biscuits in a sandwich bag by tapping it with a rolling pin and then tasting the three components both separately and mixed together.



If you ever get the opportunity to experience a Frozen Light show I really cannot recommend it highly enough.

Sarah Walker

If you're interested in seeing what Dan and Sarah are up to then please follow them on their Facebook page @makeachangecheshire

IN THE NEWS

Diagnosis and management of pneumonia

In England, data from 2020 showed the most deprived populations have a pneumonia mortality of 48.9 per 100 000 population compared with 24.4 in the least deprived. In individuals with learning disability and autism the annual Learning from Deaths Review shows a consistent high mortality with deaths from bacterial pneumonia being in the order of 24% and deaths due to aspiration being 16%, based on 9110 deaths, of which 622 were children, between 2018 and 2020. The journal, Thorax, has recently published two comprehensive British Thoracic Society (BTS) Clinical Statements with evidence-based practice points on community-acquired pneumonia and aspiration pneumonia in individuals with learning disability.

The clinical statement on the diagnosis and management of community acquired pneumonia for people with learning disability addresses the risk assessment, prevention and management of community-acquired pneumonia in people with a learning disability of all ages. Each section is summarised with key clinical practice points. The recommendations made are based on a review of the published evidence, where available and pertinent, but are predominantly based on expert opinion.

The statement provides useful pragmatic guidance for specialists providing community level respiratory management to people with a learning disability.

The BTS has also published a clinical statement on aspiration pneumonia which seeks to provide practical clinical guidance through sections covering the relevant epidemiology, pathogenesis, prevention, diagnosis and management (including palliative care considerations where appropriate).

Note that these statements contain much important detail but lay people will need support from specialists to fully understand the implications for practice.

Both statements in the journal Thorax are downloadable for free as pdfs at: https://thorax.bmj.com/content/78/Suppl_1

Equality and Human Rights Commission report

Decisions about the care and support that individuals and unpaid carers receive from their local authority can have a huge impact on their lives, as well as those of their carers and families. Therefore, the right to challenge decisions about the type and extent of care provided (or not provided) is fundamental if individuals feel they are not receiving the right care or support.



In February the EHRC (Equality and Human Rights Commission) released a report called 'Challenging adult social care decisions in England and Wales'. The EHRC had carried out an inquiry to understand people's experiences of challenging, or trying to challenge, local council decisions about adult social care or support. Note that there is nothing specifically about people with PMLD and their families and carers but the findings are relevant.

The EHRC lists the main findings as follows:

- local authorities make daily decisions about people's access to social care
- people have a right to challenge these decisions but the system for challenging decisions is confusing and subject to long delays
- local authority complaints processes are time-consuming, complicated and stressful
- people are not given crucial information about how to challenge decisions
- people fear that, if they challenge decisions, they will face negative consequences and lose access to care
- some users are concerned at a lack of independence from the person making the decision
- data collection and analysis is not good enough, so patterns and trends are being missed

The net result, according to the EHRC, is that the system is failing those who need it. People are deterred from seeking help and feel ignored and disempowered. Some

people are in crisis and desperate for help. The report does not just give findings but also make related recommendations for change.

This publication and related resources are available from the EHRC website:

<https://www.equalityhumanrights.com/en/challenging-adult-social-care-decisions-england-and-wales>

New research project to examine the effectiveness of Intensive Interaction

The National Institute for Health and Care Research has awarded researchers £1.8M to examine the effectiveness of Intensive Interaction with people with profound and multiple learning disabilities (PMLD). Despite the wide use of Intensive Interaction, there is limited evidence on if and how it works. The funding for the 'INTERACT trial' will enable researchers to conduct a large scale randomised controlled trial (RCT) with children and young people with PMLD in educational settings.

Participants in the trial will include family carers and practitioners who support children and young people with PMLD. They will be trained to deliver Intensive Interaction. The team will identify their experiences of using Intensive Interaction and the impact it has on the young people's communication, education and their quality of life. The trial will be managed and delivered by a multidisciplinary team of researchers from across the country, including academics from the University of Kent's Tizard Centre.

Dr Jill Bradshaw, Principal Investigator and Co-Head of the Tizard Centre, University of Kent said "People with profound and multiple learning disabilities and those who care for and support them can be invisible in our society. They can feel excluded. This funding is a great opportunity for us to work together and find out more about the impact of using Intensive Interaction with people with PMLD".

Jenny Miller, Chief Executive of PAMIS, an organisation that solely supports children, young people and adults with PMLD and their families to lead healthy, inclusive and valued lives, stated "this research for such a marginalised group of people is very welcome. The commitment from the research team to get such a major piece of funding is highly commendable especially as we know how difficult it is to obtain research grants for this group. Intensive interaction has been used for many years as a key intervention, being able to examine the

process and impact will provide much needed insights not only into the approach but on the children and young people themselves. We are delighted to be a part of this and will be supporting the involvement of parents/family carers". The project has just started and will run until July 2027.

Research Team:

- Dr Jill Bradshaw, Joint Lead (Intervention), Nick Gore, Tizard Centre, University of Kent
- Professor Catherine Hewitt, Joint Lead (Trial), Alison Booth, Kerry Bell, Arabella Scantlebury, Clinical Trials Unit, University of York
- Professor Judy Clegg, University of Sheffield
- Professor Lindsay Pennington, Newcastle University
- Dr Fliss Kyffin, Bangor University
- Professor Lucy Zeigler, Public and Patient Involvement and Engagement member
- Jenny Miller, Chief Executive, PAMIS
- Amanda Allard/ Marie Hunt, Council for Disabled Children

Oily Cart is celebrating 40 years of making theatre

This year Oily Cart, the theatre company, is celebrating 40 years of making theatre for and with young people. The company's founders started working together in Wandsworth in 1981. They were among the first performers to take on the challenge of making inclusive shows for disabled children of all ages. They continue to share their particular brand of sensory theatre practice across the UK and not just in theatres but at home, online, on the street too. They have shown that there is no limit to what theatre can be.

Oily Cart has done much to make theatre more accessible. They have created highly interactive, sensory shows in which their performances integrate sounds, smells, touch, light and shadow, close-up choreography, live music and movement. In their articles in PMLD LINK and in their work they have demonstrated their belief that all children have the right to experience first class theatre and that their shows should be close up, responsive and led by their young audiences.

To find out more, go to: <https://oilycart.org.uk/>

Frozen Light celebrates its tenth birthday

To celebrate its tenth birthday, Frozen Light, is organising a Sensory Sharing Symposium on Thursday 25th May 2023 at The Garage, Norwich. The symposium will provide opportunities to explore the future of sensory theatre and find out more about Frozen Light's creative collaboration with artists with profound and multiple learning disabilities (PMLD).

Frozen Light invites sensory and other theatre makers and programmers, family members, carers and support workers of adults with PMLD, academics and others working in the field of learning disability research, to join them for this day of sensory theatre in the company's home city, Norwich.

The event will be accessible for people with PMLD with sensory activities on offer throughout the day. There will be a chill out space and Mobiloo available.

For more details go to: <https://www.frozenlighttheatre.com/sensorysymposium>

Storysharer courses

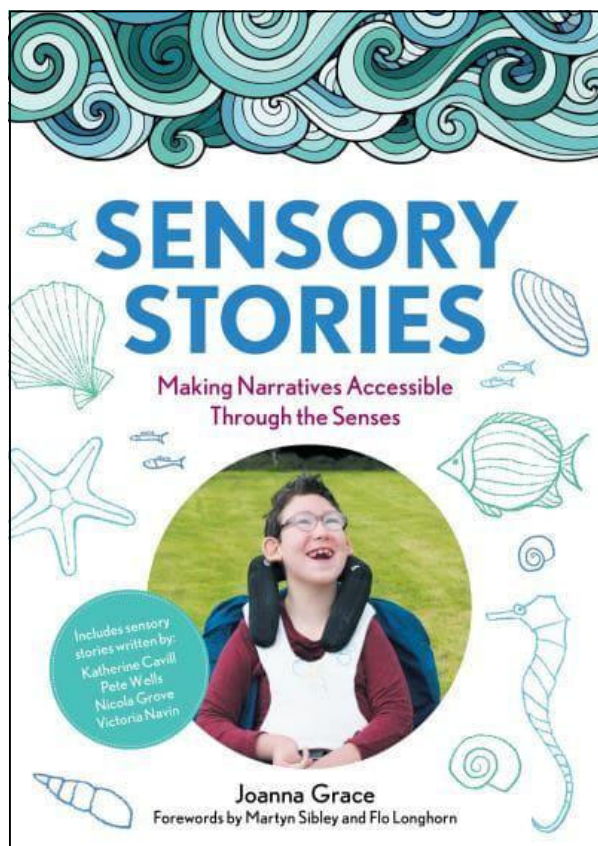
PAMIS (Promoting a more inclusive society) are about to launch a suite of Storysharer courses facilitated by Dr Nicola Grove. The Storysharing programme enables children and adults with severe and profound communication difficulties and complex needs to share their experiences in the form of short co-told stories.

Initial courses will include Introducing Storysharers, Storysharer Advocate Partner training and Becoming a Storysharing Licensed Practitioner.

Participants will have the opportunity to build on their understanding of the importance of sharing experiences and the fundamental principles of the Storysharing approach. The Storysharer Advocate Partner training pairs up verbal and nonverbal communicators to advocate for themselves and their friends. The programme is inclusive of advocates who have learning disabilities and want to extend their skills, and has been successfully piloted. The Licensed Practitioner training will develop your understanding where you will learn knowledge and skills to use with the individuals and groups you support.

Courses will be available virtually and in person. If you would like more information about any of these courses, including pricing, please contact fiona.harper@pamis.org.uk.

RESOURCES AND BOOK REVIEWS



Title: Sensory stories to support additional needs: making narratives accessible through the senses (2nd edition)

Author: Joanna Grace.

Pages: 208 pages

Publisher: Jessica Kingsley Publishers

Publication Date: October 2022

ISBN: 9781839971471

Price: Paperback £22.99

Sensory stories to support additional needs: making narratives accessible through the senses is the second reinvigorated updated edition of this book. It is written by Joanna Grace, who many of you would know as the founder of the Sensory Projects, is a sensory engagement inclusion specialist, trainer, and PMLD guru. Joanna is currently studying for her PhD.

The book is broken up into five parts, background, sharing sensory stories, using sensory stories as a basis for engaging and interacting sessions, sensory strategies activities, and finally guest stories.

Each chapter shares a lot of theory, and real-life

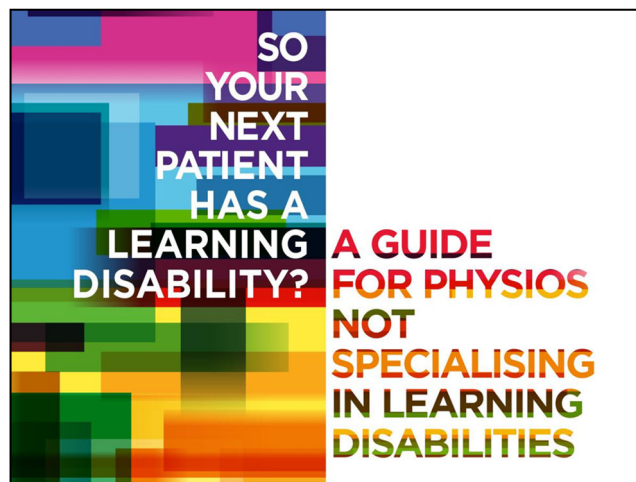
experiences and it is underpinned by Joanna's experiences in delivering high-quality and engaging stories for people who have profound and multiple disabilities. This book raises the bar on what a high quality, inclusive, engaging sensory story should be.

Highlights of this book include Joanna's valuable advice, such as using 10 lines for each story, and the props and how to use them to engage the senses. Part 5 contains the guest stories from many knowledgeable and formidable guest authors including Victoria Navin from Rhyming Multisensory Stories, Katherine Cavill, Nicola Grove, and Pete Wells who is the founder of the Sensory Stories Podcast.

I have delivered a few of the sensory stories that are included in this book, and I have found the advice on facilitating the stimuli extremely useful. Once you have finished the book it may inspire you (like me) to develop your own sensory stories and ensure that stories are accessible to all.

Book review by Leigh Wharton; e-mail:
leighwharton21@hotmail.com

ACPPLD launch animated guide on reasonable adjustments for physiotherapists



In February, the ACPPLD (the Association of Chartered Physiotherapists for People with Learning Disabilities) launched a 3-minute animation to support physiotherapists to make reasonable adjustments when people with a learning disability access their services. This builds on a 2020 'So your next patient has a learning disability – A guide for physiotherapists' campaign and aims to present the messages in a new innovative and

engaging way.

Most people with a learning disability can access mainstream physiotherapy services with reasonable adjustments and healthcare services have a legal obligation to make reasonable adjustments to help people achieve positive outcomes. Specialist learning disability physiotherapists would be available if more support is needed after making reasonable adjustments. The animation offers up some simple but practical advice and suggestions on how to improve the physiotherapy outcomes for people with a learning disability.

The ACPPLD describe this guidance as 'critically important within the current climate due to the recruitment problems of specialist learning disability physiotherapists across the UK'.

The YouTube Animation is available at: https://youtu.be/mzK_q5rg6TI

The ACPPLD's campaign also includes a booklet and poster which are available at: <https://acppld.csp.org.uk/documents/so-your-next-patient-has-learning-disability-useful-leaflet-poster>

Although designed specifically for physiotherapists, the materials will also be of use to other health and social care professionals.

The Right Way: a children's rights approach

The Children's Commissioner for Wales has posted documents which set out how people may support a children and young people with Additional Learning Needs to take part in decision making about how to make a service better.

The framework is intended to support local authorities and health bodies (Local Health Boards and NHS Trusts) to develop a children's human rights approach to their duties under the Welsh Government's Additional Learning Needs and Education Tribunal Act (2018). Indeed, all professionals delivering services for children with Additional Learning Needs can adopt this approach to ensure the children with Additional Learning Needs are appropriately supported through the services they receive.

All the documents are available at: <https://www.childcomwales.org.uk/resources/the-right-way-a-childrens-rights-approach/a-childrens-rights-approach-to-additional-learning-needs/>

As described by Tanya Evans and Leigh Wharton in their article for this issue of PMLD LINK, there is a participation

toolkit which can help people to involve children with PMLD in making decisions about the services they receive. This is available online at: https://www.childcomwales.org.uk/wp-content/uploads/2022/06/ALP-toolkit-final_English_060622.pdf



Nutrition and Hydration Week

Nutrition and Hydration Week has taken place every year since 2012, usually in March. This year it was the week of the 13th to 19th March. The aims include promoting good nutrition and hydration care, as characterised by NHS England, and sharing examples of good practice.

Around 3 million people are at risk of malnutrition in the UK. So, events like this provide opportunities to raise the awareness of the risks and promote the good practices that can help prevent malnutrition and dehydration. The ideas and resources shared by various organisations can save lives and generally improve people's health and well-being. The various resources, useful links and newsletters with more suggestions are available for free on the website: <https://nutritionandhydrationweek.co.uk/>

COURSES, CONFERENCES AND EVENTS IN 2023

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

April		May 2023	
Title: Date: Location: Provider: Contact:	The River Performances 17– 28 April Bespoke by arrangement Bamboozle Theatre Company To register interest: jade@bamboozletheatre.co.uk	Title: Date: Location: Provider: Contact:	Developing the PMLD curriculum for learners aged 16-25 2 May 09:30 - 12:30 and 23 rd May, 09.30 – 12.30 Online NATSPEC https://natspec.org.uk/events/developing-the-pml-d-curriculum-for-learners-aged-16-25-session-one-4/ Ensure you book both sessions.
Title: Date: Location: Provider: Contact:	Parenting a Child with Complex Needs Workshop Wed, 19th April 10.00-12.00 and 26th April 10.00-12.00 Online Born-at-the-right-time admin@bornattherighttime.com	Title: Date: Location: Provider: Contact:	Understanding distress and behaviour that is difficult to support Thur 11 May, 13.00 – 15.30 Online Matthew Laurie https://www.mattlaurie.com/events
Title: Date: Location: Provider: Contact:	Rapport-Based Communication to build relationships and support wellbeing Wed, April 19, 13.30 – 15.30 Online Matthew Laurie https://www.mattlaurie.com/events	Title: Date: Location: Provider: Contact:	Kidz to Adults South Tuesday 16th May 2023, 09.30 - 16.30 Farnborough International Exhibition & Conference Centre Kidz to Adultz Tel: 0161 214 4592. Email: kidzteam@disabledliving.co.uk
Title: Date: Location: Provider: Contact:	Preformal PMLD Curriculum 20 April, 15:45 - 19:15 Online Peter Imray, EQUALS admin@equalsoffice.co.uk	Title: Date: Location: Provider: Contact:	Rapport-Based Communication to build relationships and support wellbeing Thur, 18 May, 13.30 – 15.30 Online via Zoom Matthew Laurie https://www.mattlaurie.com/events
Title: Date: Location: Provider: Contact:	The Skies We're Under Podcast Live (April) Fri, 21st Apr, 10:00 - 11:00 Online Born-at-the-right-time admin@bornattherighttime.com	Title: Date: Location: Provider: Contact:	The Skies We're Under Podcast Live (May) Thurs, 18 th May, 20:00 → 21:00 Online Born-at-the-right-time admin@bornattherighttime.com
Title: Date: Location: Provider: Contact:	24-hour postural care from cradle to grave 27th April, 12.00 – 8 th June, 18.00 Online Born at the Right Time/Simple Stuff Works Email: admin@bornattherighttime.com	Title: Date: Location: Provider: Contact:	The importance of messy play 19 th May Online Hirstwood Training Email: lois@hirstwood.com or https://hirstwood.com/
Title: Date: Location: Provider: Contact:	Fire Songs Performances 25-26 April The Civic Theatre, Barnsley FROZEN LIGHT Theatre Co. Civic: 01226 327000	Title: Date: Location: Provider: Contact:	Sensory Sharing Symposium Thursday 25th May The Garage, Norwich Frozen Light Email: info@frozenlighttheatre.com or https://www.frozenlighttheatre.com/sensorsymposium

Title: The Engagement Model Date: 23 May, 15.45 - 17:15 Location: Online Provider: James Waller, EQUALS Contact: Email: admin@equalsoffice.co.uk	Title: Technology to support learning Date: 21st June Location: Online Provider: Hirstwood Training Contact: Email: lois@hirstwood.com or https://hirstwood.com/
Title: Rapport-Based Musical Interaction Date: Thur 25 May, 13.30 – 15.30 Location: Online Provider: Matthew Laurie Contact: https://www.mattlaurie.com/events	Title: Sensory Topic Planning Date: 22nd and 29th June Location: Online Provider: Hirstwood Training Contact: Email: lois@hirstwood.com or https://hirstwood.com/
Title: Fire Songs Date: Norfolk & Norwich Festival Location: Performances 27-28 May Provider: The Garage Theatre, Norwich Contact: FROZEN LIGHT Theatre Co. Festival Box Office: 01603 531800	Title: EQUALS National Conference - Different not Differentiated? Date: 23 June, All Day Location: Friends House, 173-177 Euston Road, Central London, NW1 2BJ. Provider: EQUALS Contact: admin@equalsoffice.co.uk
Title: The Lost Feather: A Sensory Storytelling Session Date: 29 May – 16 July Location: Touring Provider: Oily Cart Contact: To express interest: alison@oilycart.org.uk	Title: Rapport-Based Musical Interaction Date: Thur 29 June, 10.00 – 12.00 Location: Online via Zoom Provider: Matthew Laurie Contact: https://www.mattlaurie.com/events
June 2023	Title: Intensive Interaction Date: 30 June Location: Online by zoom Provider: Janet Gurney, Us in a Bus Contact: info@usinabus.org.uk £75 per person; £25 for parents/family carers/students; 2 free bursary places available
Title: Parenting a Child with Complex Needs Workshop Date: 5th June 19.30 and 12th June 21.30 Location: Online Provider: Born-at-the-right-time Contact: admin@bornattherighttime.com	Title: Sensory learning: a practical approach for support staff Date: 30th June Location: Online Provider: Hirstwood Training Contact: Email: lois@hirstwood.com or https://hirstwood.com/
Title: Understanding distress and behaviour that is difficult to support Date: Thur 8 June, 13.00 – 15.30 Location: Online via Zoom Provider: Matthew Laurie Contact: https://www.mattlaurie.com/events	July
Title: Natspec National Conference 2023 Date: 13th and 14th June Location: Crowne Plaza, Stratford-upon-Avon Provider: NATSPEC Contact: https://natspec.org.uk/events/natspec-national-conference-2023/	Title: Making Complaints, Working Together and Not Losing Your S**t Date: Tues, 4th July, 19.30 – 21.00 Location: Online Provider: Born-at-the-right-time Contact: admin@bornattherighttime.com
Title: Myth Busting Multisensory Rooms Date: 14 June, 15:45 - 17:15 Location: Online Provider: Joanna Grace, EQUALS Contact: admin@equalsoffice.co.uk	Title: The 2023 Super Sensory Lexiconary! Date: 13-14 July Location: Birmingham Provider: The Sensory projects Contact: https://www.eventbrite.co.uk/o/the-sensory-projects-9788075245
Title: Rapport-Based Communication to build relationships and support wellbeing Date: Thur, 15 June, 13.30 – 15.30 Location: Online via Zoom Provider: Matthew Laurie Contact: https://www.mattlaurie.com/events	

Title:	Understanding distress and behaviour that is difficult to support
Date:	Thur 20 July, 10.00 – 12.30
Location:	Online
Provider:	Matthew Laurie
Contact:	https://www.mattlaurie.com/events
Title:	Rapport-Based Communication to build relationships and support wellbeing
Date:	Thur, 20 July, 13.30 – 15.30
Location:	Online via Zoom
Provider:	Matthew Laurie
Contact:	https://www.mattlaurie.com/events
Title:	Rapport-Based Musical Interaction
Date:	Thur 27 July, 10.00 – 12.00
Location:	Online via Zoom
Provider:	Matthew Laurie
Contact:	https://www.mattlaurie.com/events
September	
Title:	Intensive Interaction
Date:	1st September
Location:	Online by zoom
Provider:	Janet Gurney, Us in a Bus
Contact:	info@usinabus.org.uk
	£75 per person; £25 for parents/family carers/students; 2 free bursary places available
Title:	Parenting a Child with Complex Needs Workshop
Date:	6th Sept, 13.00 and 18th Oct, 16.30
Location:	Online
Provider:	Born-at-the-right-time
Contact:	admin@bornattherighttime.com
Title:	Kidz to Adultz Wales
Date:	Thur, 21st Sept, 09.30 - 16.30
Location:	International Conference Centre, Newport, S.Wales
Provider:	Kidz to Adultz
Contact:	Tel: 0161 214 4592. Email: kidzteam@disabledliving.co.uk

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

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

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

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

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

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

For online study opportunities visit The Sensory Projects Online College.

NAC (www.nacwellbeing.org)

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

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

New course starts 3 January 2023, weekly over 5 months

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

Contact: julie@nacwellbeing.org

Story Massage Programme (www.storymassage.co.uk) Story Massage offers online training courses and easy to access resources. These are for those wishing to use the Story Massage Programme at home or work. You can study at your own pace. You have full access to the online course materials for 6 months. Contact: 07899813659 or info@storymassage.co.uk
Pamis (https://pamis.org.uk/services/training) Pamis offers face to face courses, events and other training and development opportunities for family, paid carers and practitioners. Contact: fiona.harper@pamis.org.uk to book or make enquiries
Postural Care – Simple Stuff Works & Born at the right time (https://www.simplestuffworks.com/training) A range of opportunities and CPD accredited modules, including: Introduction to 24-hour postural care (half day workshop) 24-hour postural care: Hands-on training for the workforce 24-Hour Postural Care: Getting to the Core of the Problem Contact: admin@simplestuffworks.co.uk
Born at the Right Time (www.bornattherighttime.com) For 2023, a host of new courses are being launched, from entirely on-line courses to be completed at your own pace to in-person advance practitioner events. See website for more details
Hirstwood Training (https://hirstwood.com) Range of online, on demand opportunities including: Creating inspiring sensory classrooms Sensory Impairment and Sensory Loss Sensory Resources Contact: lois@hirstwood.com
<u>Learning Disabilities Speech and Language Therapy-HWHCT</u> Speech and Language Therapists in the Community Learning Disability Teams across the Herefordshire and Worcestershire NHS Health and Care Trust have developed some new, free training, in line with the RCSLT 'Eating, Drinking, Swallowing Competency Framework'. Level 1 and 2 eating and drinking training is available to the general public through their FREE online e-learning - https://www.hacw.nhs.uk/mealtime-matters For updates follow https://www.facebook.com/LDSLT.HW/
EQUALS (https://equals.co.uk/training-from-equals/) EQUALS provides FREE Online Training for Members covering a range of topics including: the Engagement Model of assessment, teaching learners with Profound & Multiple Learning Difficulties, and EQUALS Pre-Formal PMLD Curriculum For further information please contact Paul Buskin at paul@equalsoffice.co.uk
PCPLD Network (palliative care for people with learning disabilities) (https://www.pcpld.org/events and conferences/) PCPLD makes available free webinars as well as making past webinars available as recordings. They also offer podcasts.

Subscription Rates:

UK:	Personal	£25.00	Organisation/Group:	£35.00
EU/Overseas:	Personal	£32.00	Organisation/Group:	£45.00

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About Us

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

Rob Ashdown	Former teacher of pupils with severe and profound and multiple learning difficulties and special school Headteacher.
Annie Fergusson	Annie has been the main advocate for her brother (with profound and multiple learning disabilities) for over 20 years. Retired from a long career as a practitioner and university lecturer in the special education and learning disability field. She is a member of Advisory Groups for the national Learning Disabilities Mortality Review (LeDeR) programme and NHS England Seldom Heard Voices project and has a role as a family associate with Dimensions, a social care provider. Annie was one of the team who developed the PMLD Standards.
Michael Fullerton	Michael is Director of Health & Wellbeing with Achieve Together, a social care provider supporting adults with profound and multiple learning disabilities. Michael is a registered learning disability nurse and leads a health team focused on the quality of life of people with profound and multiple learning disabilities. Michael was one of the team who developed the PMLD Standards.
Martin Goodwin	Martin is a teacher of pupils with PMLD and a Regional Tutor/Visiting Lecturer for the Severe and Profound Multiple Learning Disabilities course at the University of Birmingham. Martin has specialised in approaches to improve interaction, communication and participation of people with severe and profound learning disabilities. He has experience of working in the fields of play and leisure, education, residential and advocacy.
Rachel Parry Hughes	Lecturer in Social Work, Goldsmiths, University of London and a Senior Social Worker at Buckinghamshire Council. Rachel has a long-standing interest in the support of people with profound and multiple learning disabilities.
Becky Loney	Becky has supported people with profound and multiple learning disabilities and their families for over 30 years. She currently works as an independent advocate and an involvement worker and uses creative communication approaches and sensory storytelling throughout her different roles.
Wendy Newby	Headteacher at The Shrubberies School, Stonehouse, Gloucestershire. This is a school for students with Severe and Profound and Multiple Learning Difficulties.
Maureen Phillip	Maureen Phillip is the Creative Director for the Scottish charity PAMIS (promoting a more inclusive society). This wide and varied position means she 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.
Sue Thurman	Sue worked for many years in the NHS as a Speech and Language Therapist for adults with learning disabilities with a particular interest in PMLD. She now spends most of her time as a Registered Intermediary assisting vulnerable witnesses to communicate at police stations and courts. Sue is also a governor at a local special school.
Bella Travis	Now a policy manager at Mencap, Bella was part of Mencap's former national PMLD Team. She was involved in campaigns and developing key publications and resources including the 'Raising Our Sights' How-to guide series. More recently she worked with Ann Fergusson on a joint-produced hospital resource for people with profound and multiple learning disabilities. Bella helped co-produce the PMLD Standards.

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sharing ideas and information

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Visit www.pmlmlink.org.uk

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