PMLD LINK
sharing ideas and information

Raising the Bar

Spring 2018

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Cover picture: Photograph taken by Esther Veale

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GUEST EDITORIAL

Raising the Bar

Welcome to the Spring Edition of PMLD Link - a little late to press but so worth the wait! This issue is dedicated to the new Core and Essential Service Standards for Supporting People with Profound and Multiple Learning Disabilities, a document that is rapidly becoming a catalyst for positive change in the care received by people with PMLD.

This issue opens with a clarion call from the editorial team to see standards of care raised for people with PMLD. Every article in this edition of PMLD Link is full of hope for change. The bar set with regards to what best practice looks like will be raised!

Contributions in this issue demonstrate the applicability of the standards across the whole range of provision. Dreenagh Lyle shares her use of the Standards to audit the care provision received by her daughter in their own home; Sam Newton and Launa Randles share their approach to using the Standards as a reflective tool to develop practice within their school and Katie Hobson gives valuable tips on introducing the standards in a youth club setting. Teachers Lou Fraser, Eleanor Gibson, and Jessica Newcombe share their responsive practice to sensitive issues, whilst Elly Chapple talks about the life of Exceptional Learning, Lifeskills and Achievement lived by her daughter Ella. Claire Cocquyt offers insight on how the development of a multi-disciplinary care pathway for people with PMLD in Cornwall reflects the best practice described in the Standards.

We hear from Sarah Giles (Teach Us Too) and Martin Goodwin who both presented at the first Raising the Bar, the conference which launched the standards last year, about their work to ensure that everyone’s voice is heard and listened too.

The development of the PMLD Standards was very much a team effort - one many PMLD Link readers were involved in. Their adoption is similarly a team effort. We want your help in getting the word out there so that families can use the standards to advocate for best opportunities for their loved one and settings can use them to ensure they are delivering best practice care. Our issue ends with an article from Esther Veale describing the adventurous life lived by her sister Mary, and her legacy which will enable others to do the same.

We hope you will join us on our adventure promoting the standards and raising the bar!

Jo Grace, Michael Fullerton, Thomas Doukas and Annie Fergusson, Guest Editors

Raising the Bar II – open for bookings…..See page 5 for more info
https://www.eventbrite.co.uk/e/raising-the-bar-ii-national-pmld-conference-tickets-44284684684

Find out more about the standards via our online platforms!

YouTube: Michael, Thomas, Jo and Annie introduce the standards https://www.youtube.com/watch?v=kMBGKolDz_I&t=3s

Twitter: @PMLDlink to follow our updates
June 5th -join our chat with #WeLDnurses about the PMLD standards. Adding your voice will help Learning Disabilities nurses understand the importance of raising the bar on best practice care for people with PMLD.

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Raising standards ~ a clarion call to meet the challenge!

Annie Fergusson, Joanna Grace,
Michael Fullerton and Thomas Doukas

Regular readers of PMLD LINK will be very familiar with research and official reports demonstrating that children and adults with profound and multiple learning disabilities (PMLD) receive poorer quality services when compared with others (with/without disabilities) and generally, are all too often overlooked. However, by contrast, there are also leading edge examples where people with PMLD really are enabled to lead the healthy, full and meaningful lives they want; the quality and appropriateness of such provision is, similarly, likely to be isolated and to go unnoticed by those who commission services. Anecdotally, we frequently hear that such instances are usually driven by passionate individuals, noteworthy settings or small groups of well-informed people who 'make things happen' despite external constraints (resources, funding) or the shortfall in more strategic support which acknowledges the holistic vulnerability of this group, the isolation of its families and the professional development needs of its workforce.

PMLD LINK will continue to champion positive examples, as evidence that high expectations are, and should be, a very real possibility. Michael Fullerton's article (Summer 2017) is a great testimonial, where one organisation has taken up the baton to drive quality across its provision for people with PMLD who use its services, in part through their responsive programme of training and support for staff. David Standley's article (Winter 2016) shares a proactive, integrated services approach to ensuring improved health status of people with PMLD in its health trust. Their planned respiratory pathway combines active postural care (with training and support for families and supporters) with raising awareness of the potential for common health issues (eg swallowing/ eating/ drinking problems, constipation, reflux, poor oral care, immobility) to quickly escalate into significant respiratory problems – even early death. Penny Lacey (Spring 2011) reflecting on practice in school settings, asks us to 'listen' to challenging behaviour as a means of communication but also, to consciously and actively develop awareness of those who are more passive, making few deliberate demands on those around them.

In the absence of a national framework, such exemplars offer a yardstick for planners on the high quality outcomes that can be achieved. They serve as inspiring role models and support for practitioners and families. Strategic and targeted planning will show results of investment in people and services; higher quality provision will be more effective (and cost efficient) for all, in the longer term.

The way forward

Almost a decade ago Jim Mansell's (2010) Department of Health commissioned review reported that, despite clear government directives, there were clear inequities experienced by people with PMLD in access to appropriate and responsive services. Low expectations were seen as a major obstacle in implementing personalised services for this group. His report set out 33 recommendations for national and local government, health and social services to address these inadequacies. Also that year, Toby Salt reported to the DCSF (education department of that time) on the worrying position of a diminishing workforce of appropriately trained teachers to meet the needs of the growing number of learners with severe or profound and multiple learning difficulties. His report opened with 'this is a sector, and a group of learners that have been out of the limelight for far too long. It needs significant focus, not least because it includes some of the most complex, most vulnerable and indeed expensive learners in our system' (2010:2).

There have been significant developments in the wider sectors of both special education and adult learning disabilities services but there has been no specific focus or investment in, or for, those with Severe and Profound and Multiple Learning Disabilities (Salt, 2010; Mansell, 2010). The predictable consequences for this group show they '...are less likely to have access to various aspects of personalisation (eg personalised care and support plans, personal budgets etc.), less likely to benefit when they do … As personalisation is a core element of current and future health and social care policy and provision, this raises serious concerns'. (Harflett et al 2015: 9) A growing body of evidence has offered much to inform and impel the necessary change for this population, yet little appears to have altered across education, health and social care sectors. Fergusson, noting similarities of research findings to those of Harflett et al (2015), 'This low incidence population are recognised to experience significant inequalities in the services they receive and are amongst the most isolated and marginalised in modern society, and by default so too are their families. They continue to be a group at high risk of experiencing inadequate and non-personalised services, despite this recognition.' (2016:6). Goldbart (2017) cautions however, that changes in context and our political landscape make assessing progress problematic, with limited funding available and unclear lines of responsibility.

A grass roots movement, starting 'from the ground up' offers another approach to change the landscape - and one WE CAN DO! Our models of good practice will offer commissioners and inspector of services, clear evidence and signposting of what high quality, well planned provision should look like. The newly developed PMLD Standards are a start, and a driver, to establishing consistently high quality provision and services across education, health and social care everywhere.

Introducing the standards

The fundamental purpose of the PMLD standards is to respond constructively to the situation. The detail encompassed in the standards endeavours to establish a set of indicative, national benchmarks clarifying 'what Good looks like' for people with profound and multiple learning disabilities (PMLD), to enable commissioners of services and services themselves to evaluate the quality of provision through regular and ongoing self-review.

Using these standards as a benchmark, low expectations will no longer be our baseline; merely meeting someone's basic needs or services viewed as 'good enough' are no longer acceptable. We expect to inspire and challenge services and provision (including our own practices and care) but, most of all, we expect to achieve better outcomes and improved lives for those with PMLD and their families. The intention in developing these standards is to 'up our game' and aim higher; we want better than 'Good'- we want 'Outstanding'! We are raising the bar by setting out ambitious standards as targets for those providing services and care in order to achieve aspirational outcomes and improved Quality of Life for people with PMLD, wherever they live - as a fundamental expectation for this, too long overlooked group.

Soon after the standards launched (November 2017) we received much feedback, particularly through social media, as the document was shared far and wide. One of the challenges received was that some approaches were 'simply included in a list' with others, rather than explored in any depth; the concerns being the approach may be trivialised or even remain unknown. In response however, we need to state that our position on this was very deliberate … and perhaps even courageous? Our vision and how we have intentionally set out these standards takes a very aspirational stance; once such quality and aspiration sets the benchmark, this will become expected, even assumed practice – and therefore specialist and appropriate approaches (such as Intensive Interaction or Postural Care) will be assumed and embedded as an 'everyday practice' - not as a 'bolt on' afterthought or, with the caveats of 'when/if we get the training'. These standards should enable our workforce and unpaid carers to access the appropriate training and ongoing professional development that is crucial to providing the right support! We HAVE consciously set the bar high - working in such a way must be seen as 'core and essential'.

The standards document – a brief overview

Foreword (from Norman Lamb):

- sets the standards in context within the current (political) landscape and in particular the inequities of the health agenda nationally
- endorsements from some professional bodies are included (those available at time of print)

Introduction: Brief section giving detail of the rationale as to why these standards are needed

Towards a working definition of PMLD:

- Addressing the challenges of being clear about who we mean
- gathering factual data on this population (numbers, location, needs)
- discussion around why we need to view this group as distinctive from the general learning disability / SEND population to plan and develop more effective and truly personalised services

Aims of the standards

- includes aspirational indications of what could be achieved with widespread adoption,
- describes who they are for and their tailored use in each role: E, H & SC providers; families and carers ; Commissioners;
- details commitment to collaborative working and a shared responsibility for Quality Assurance ;
- Regulator role (CQC, Ofsted, CIW)

How to use them – some practical suggestions

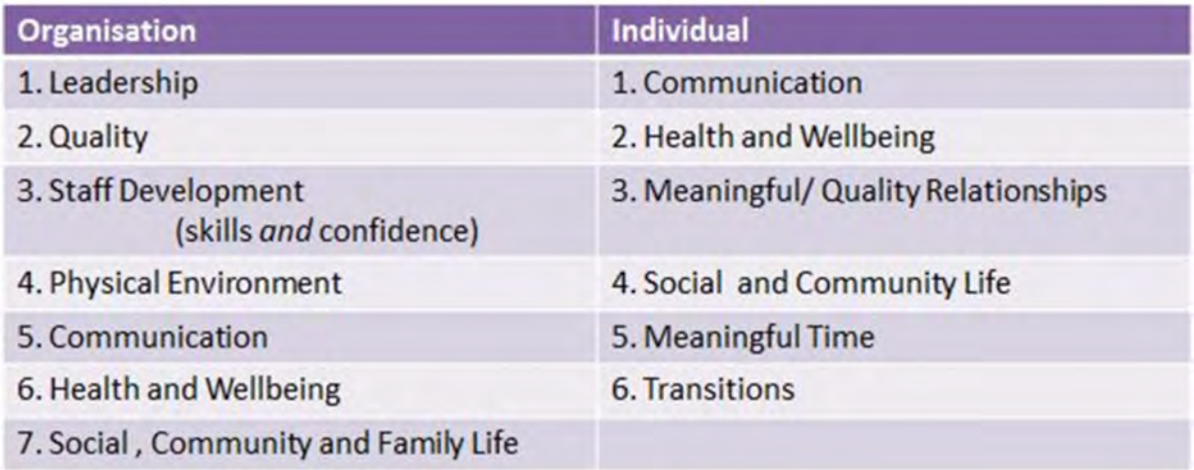
Picture above: Annie signposts examples of good practice in PMLD Link

The Core & Essential Service Standards

- Two sets of inter-related standards - for the Individual and for the Organisation (detailed in table below), to ensure provision to meet individual needs and aspirations are operationalised
- Standards each have a generic title, a brief explanation of the focus and then some practical detail as indicators of evidence

Acknowledgements – the standards were co-produced with volunteer representatives from an incredibly wide range of stakeholders (across all sectors, families and carers) who responded to an open call for involvement.

Further reading and Resources –reference points for anyone engaging with these standards. PMLD LINK plans to develop and share further relevant material via www.pmldlink.org.uk (Resources section).



Organisation	Individual
1. Leadership	1. Communication
2. Quality	2. Health and Wellbeing
3. Staff Development (skills *and* confidence)	3. Meaningful/ Quality Relationships
4. Physical Environment	4. Social and Community Life
5. Communication	5. Meaningful Time
6. Health and Wellbeing	6. Transitions
7. Social , Community and Family Life	

Above table: Core & Essential Service Standards for Organisations and Individuals

Networking and support - a PMLD Community of Practice

PMLD LINK is a forum offering opportunities for such dialogue, mutual support and sharing as a PMLD Community of Practice.

Opportunities to join us currently include:

- PMLD LINK journal – issues this year will explore the new standards - your contributions are needed!
- PMLD Link Facebook page
- twitter (@pmldlink);
- #pmldchat - a new topic and guest hosts each month (facilitated by Michael Fullerton and Jo Grace (Editorial Group members)
- 'Raising the bar - COP for the PMLD care standards' - our online group, is a great place for discussion about the standards and beyond .

Picture above: Celebrating the launch of the standards

Save the date!

In addition to our network we are holding Raising the Bar II, our second national conference, on Friday 2 November 2018. The day will be filled by sharing inspirational practice and challenging low expectations – a focus on the PMLD standards in action. We hope you will join us!

(Tickets for Raising the Bar II conference: Friday 2 November 2018 via Eventbrite: https://www.eventbrite.co.uk/e/raising-the-bar-ii-national-pmld-conference-tickets-44284684684
(or search 'Raising the Bar II')

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Developing the Core and Essential Service Standards for Supporting People with PMLD

Dreenagh Lyle

It was a pleasure to be involved in the development of the Core & Essential Standards for Supporting People with PMLD. Whilst my daughter has always lived at home with me, I have been managing her care-plan for the last ten years via a personal budget from our local authority. The publication of the Standards seemed an ideal opportunity to audit what we do. I included this in my presentation to the Raising the Bar Conference in November 2017. However, these standards would have been so helpful when I was trying to negotiate with previous service providers. Family members and key workers will find these invaluable as a 'go to' source, whether for raising concerns or indeed for evidencing what is working well.

Background

The Lambeth PMLD Report (Mencap, 2010) reported that less than 50% of adults with PMLD on the local Learning Disabilities register had a person-centred plan. Professor Mansell's report 'Raising our Sights' (2010) noted that low expectations were one of the main obstacles to implementing personalisation policies for people with PMLD/PIMD. Slasberg, et al. (2014/15) argue that personalisation is more than just personal budgets; They argue the focus of delivery of the personalisation approach has been on the 'what' rather than the 'how'. I believe these Standards are an excellent tool for unpacking the 'how' of a service.

Introduction

Surely the most important aspect of a person-centred approach to people with PMLD/PIMD is an acknowledgement that their intellectual impairment impacts on their ability to self-report? We can only ever make 'assumptions' or 'presumptions' about somebody's feelings, needs, wishes etc. Ideally, we ought to be aiming for presumptions based on some degree of evidence, as opposed to assumptions, which are not. Unfortunately, in my experience more people use the latter. How often have I heard, 'Oh he understands everything I say.' When I ask how they know, I am told, it is 'in his look' or 'I just know.' No evidence, yet they simply assume the individual understands them. Presumptions however, are evidence based. This means keen observations and a breadth of knowledge of the person are vital, as is an understanding of levels of impairment, different conditions and how they all impact on someone's physical and emotional wellbeing. Finally, we need to recognise it can take 2-5 years to build a meaningful relationship with someone. Often this may not be possible in a climate of high staff turnover, including agency and zero hours contracted staff.

Therefore, staff working with an individual ought to have a clear understanding of someone's communication style, their daily plan including a thorough understanding of professional guidelines and why they are so important. At the very least it is essential that support staff are trained in person centred thinking and intensive interaction approaches, as advocated in the PMLD Standard .

STANDARDS

The standards are clearly laid out on pages 20-27 for 'Organisations' and pages 28-35 for 'Individuals.' Those of us who are family members managing a budget on our daughter or son's behalf may want to use all the standards to some extent. Others may pick 'n' dip. I will outline some of my thoughts from a parent's perspective.

1. Leadership:

As a parent managing a budget, we become the leader. It is our responsibility to see anyone we employ has a clear understanding of what we expect of them. In our team we use clearly written guidelines, daily breakdowns/ diaries and feedback sheets. Recently we started to use an iPad for the feedback. We have additional folders for health related information, various assessments and professional support guidelines. Appropriate training opportunities are offered whenever they arise and budget depending. Most importantly my daughter is always present at recruitment.

2.Quality

I am strongly committed to supporting our team. In my professional work it has always concerned me that there is such a lack of reflective practice generally in the social care sector. Workers feel they have to cope but are often not supported to share their thoughts. Spending all day with someone who uses the word 'salad' as a sensory tool could be fulfilling and rewarding, but could equally be extremely stressful. I came home one day to be told, 'she's been saying "I want to kill you" all day …. But she doesn't mean it …. Does she?' The way this worker asked, I could sense, at some level, she really wasn't sure. Ten minutes spent discussing this allays concerns and helps the worker feel confident in their support style. They feel empowered to speak up instead of, just 'get on with it'.

3. Staff development

Our team are recruited via interviews, inducted via shadowing/reverse shadowing, managed via skills development and reflective practice and developed via training (reading materials and formal assessed work). We constantly review how person-centred we are and all the team understand intensive interaction as an approach we use to attune to my daughter's communication mode rather than an activity we practise at particular times.

4. Physical Environment

There is always a fine balance to be managed. If our sons and daughters are living in a residential setting we want it to be 'homely' and not institutional. We certainly don't want our home to become a micro-institution either. I often joke that our flat is now the Day Centre, although my daughter is out and about most days. She is a well-known presence in our local community. Our flat was purpose built for people with disabilities so is spacious (plenty of room for wild rocking out) and has wide hallways. We adapt to her sensory needs. We have utilised the space for her skills training including using her indoor cane to move about. Slow incremental work, aided by minute task breakdowns has facilitated this. Workers are encouraged to complete these breakdowns if only to demonstrate how complicated seemingly simple tasks can be.

5.Communication

This may be the most important standard of all. There can be so many people involved in the life of an individual with PMLD/PIMD. Family, peers, neighbours, support workers, ancillary staff, doctors, specialists, therapists, social workers … the list is endless. All of these people need to understand each other as well as the person with PMLD/PIMD. Is there an agreed communication plan or passport that everyone uses? Has everyone read it? Do they carry it with them at all times for all appointments and activities? My daughter is totally blind, so PECS style aids are not useful and previous insistence on using Objects of Reference was never helpful. Ockleford (1994) points out that someone who is totally blind with additional intellectual impairments will need the actual object. How can a small rubber cube of a bus help my daughter (who has been totally blind since birth), understand she is about to be taken outside, down the street and onto a bus? It can't. However, sitting in the dentist's with mouth firmly gripped shut, oblivious to all requests; 'Open your mouth. There you go, open up' etc etc.; mouth still firmly gripped closed. Gently lay a toothbrush to her lips and 'voila' straight away, wide open mouth. Once anyone sees a clear exchange like this they are less inclined to the 'she understands everything I say' approach.

6. Health and Wellbeing

When I looked through the indications of evidence for this standard (pp 30-32) the last two points resonated immediately. Nowadays we include hydration, nutrition and constipation information on my daughter Odyssey's daily feedback sheets and these are constantly referred to. Finally, her SLT Food and Eating guidelines are understood and adhered to. Over a five-year period, my daughter's difficulties had progressed to diagnosed anorexia. Strict adherence to her specialist guidelines ensured her recovery. We sat down as a team and tried to envisage what 'food and eating' meant to Odyssey. We arrived at something like this scenario, based on her echolalia and reports from previous support workers. Imagine you are sitting curled up in a ball, tapping your nose rhythmically, lost in your own sensorial inner world, when someone suddenly grabs your hand saying, 'come on, get in the kitchen'. As you are led, possibly resisting, certainly making lots of squawking sounds (which are ignored) you arrive, over a threshold and into another space. The carpet has become vinyl flooring, there is a radio blaring that is not quite tuned in and not on the channel you know and like and then there is a horrible sound that you can't work out (it's the sound of chairs being pulled out from tables). Next is the jarring clattering of cutlery being placed on wooden tables and the sound from the other side of the room (which is an open plan dining room/kitchen) of something noisy and unpleasant and the smell of what else? Food?

Bear in mind, no one has mentioned food yet, just 'get in the kitchen'. Being 'directed' (this can be a euphemism for 'forced' or 'dragged') into a chair could be confusing and scary for someone who does not understand words. The only way they have to tell you they are confused is to resist. Very shortly the situation has deteriorated. And more often than not the resisting is described as 'challenging'. '… was very challenging at mealtime tonight. She refused to eat'.

How difficult this must have been for my daughter and for those staff. Yet there were guidelines written by her speech and language therapist. It's just that no one observed them. No one really believed they would make a difference. They do. Our current team scrupulously observe the guidelines and my previously anorexic daughter now weighs a healthy 53 rather than 35 kilos.

7. Social, Community and Family Life

From the outset we were determined to establish meaningful activities in my daughter's life. We wanted to support her in her daily routine, stretching her boundaries wherever possible. We want her to move with confidence, even if it is only a few steps down the hallway. When she and new workers are confident they progress to short walks outside. To the shop and back, then to the park then as far as? Yoga classes? Who knew this was even possible? Everything is incremental and everything is dependent on her confidence levels. Her team are now so attuned to the various sounds that could sabotage an outing one day they even hear them on days when they can be tolerated. My daughter is well known in our local park, café and tube station. She recently attended a lively 50th birthday party for a friend's daughter and apart from a minor early adjustment had a great day and really enjoyed herself. I believe her new found confidence results from our combined effort to help her to trust us. Now that she does, who knows what's on the horizon?

Conclusion

In a world where seemingly everyone is clamouring to be heard those with no voice are too easily overlooked. Adults with PMLD/PIMD are often living less than fulfilled or meaningful lives. I hope I have demonstrated some ways these standards might be used to enhance their care and support.

Contact details

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Dreenagh is a parent, visiting lecturer and academic researcher. Currently spreading awareness of the PMLD Standards locally, via presentations to LD Assembly and LD Providers Forum. Always keen to share knowledge

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Talking sense (Spring, 2017) 'Focus on staff that care' p27

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Subscription rates for 12 months are: UK Individual £20.00; UK Organisation £30.00; Non UK Individual £27.00; Non-UK Organisation £40.00.

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In order to access the members' page on the PMLD LINK website, you need a Username which is your e-mail address and a Password. You will be sent a link to your personal website account and you can create/reset the password.

We have a limited number of copies of back issues remaining which are available at £5 per copy so may be able to provide you with copies of issues that you may have missed.

If you have any queries about subscriptions or accessing the website, please do not hesitate to contact Rob Ashdown, PMLD LINK Treasurer (e-mail: rob.ashdown@ntlworld.com).

Teach Us Too

Sarah Giles

Being invited to present at the Raising the Bar conference in Manchester back in November 2017 was a real privilege. A room full of like-minded individuals, all intent on improving the lives of those labelled as having Profound & Multiple Learning Difficulties (PMLD). What better audience? Advocates. People who can, and want to, make a real difference!

For this is Jonathan Bryan's mission, his legacy: to make a difference - a difference for children like him.

As a small group, we have established a movement called 'Teach Us Too' spearheaded by 12-year-old Jonathan, who is fast becoming something of a household name. A non-verbal boy with a 'voice' loud enough to make himself heard in all the right places, Jonathan has been applauded for his campaign aimed at ensuring that all children, regardless of their labels, are given the opportunity to be taught to read and write.

With over 230,000 signatures on his initial online campaign, it fast became clear that Jonathan's story had made an impact on many and sadly that it was not unique. A story in which he found himself removed from his Special School in order to be taught to read and write at home. Unfortunately, in wider society it is often the case that labels predetermine opinion and therefore behaviour…such is sometimes the case in terms of education too. Without explicit intent to deny pupils a fulfilling, challenging and progressive education, there is often a level of assumed incompetence for those labelled as having PMLD. This can result in a subconscious 'teaching to the label' and therefore restrict pupil's potential. This is certainly what happened to Jonathan and from what our campaign has heard, he is not alone.

The Teach Us Too campaign received responses from all over the country. From parents and grandparents of children like Jonathan, from professionals and from people with PMLD themselves. It became clear that there is currently no equality of education for children labelled as having PMLD across the country. Experiences differ greatly and it is currently somewhat of a lottery: county to county, city to city and school to school.

The idea that there have thus far been no nationally recognised standards for people labelled as having PMLD is astonishing and it is fabulous that those involved in the Raising the Bar project have taken the time to create such a working document; one that will surely improve the lives of individuals with PMLD. It is a wonderful start to ensuring that there is equality in terms of care and provision for these members of our society across the country. Jonathan would argue that there is an omission of one vital section in these standards though – education. An explicit set of standards aimed at academic educational provision for pupils with PMLD would surely be a significant step in the right direction of ensuring that all children, regardless of their label, are given the opportunity to learn to read, write and fulfil their individual academic potentials.

All of these issues affect people once the label PMLD is assigned. With the label attached, decisions are then made based upon it, including what type of school a child will attend and what type of education they will be afforded. Rewinding to early childhood: the crossroads in a child's life when those labels are being narrowed down, best fit boxes ticked and decisions about their lives made; it is important to understand that young children are being labelled prior to entering the education system. As quoted in the Standards document, 'whilst there is no definitive set of characteristics for PMLD it is widely acknowledged that there are a heterogeneous/diverse group of people with learning disabilities who have a complex range of difficulties (cf. Raising our Sights How To guide for Commissioners, 2013)'. The standards state that while the individual may have a range of disabilities, 'the most significant of which is a profound intellectual disability'.

For Jonathan, being assigned with the label itself is somewhat contentious. He poses a fundamental question: how can one be labelled as having Profound and Multiple Learning Difficulties before anyone has ever attempted to teach them? He argues that, although he does have a complex range of difficulties including (at that time) 'great difficulty communicating' (Standards), he does not have a profound intellectual disability. He would describe himself as having Profound and Multiple Difficulties **with Access to Learning**. Surely, upon entering the education system it is paramount that time be taken to establish each child's individual method of access to the curriculum. The way in which to best support them in learning to communicate and in turn read and write. Classrooms for children with PMLD should be as literacy rich as any other, with exposure to words, age appropriate texts and staff with a mind-set of assumed competence – these are the basic requirements to fulfilling the academic potential of all pupils. As Jonathan stated at the conference, 'it is only in the teaching that professionals will discover whether we have a significant, profound intellectual disability.' Every child has potential, each different of course, but each deserves to be offered the opportunity to fulfill it at the level appropriate to them.

Teach Us Too will continue to represent children like Jonathan, to push for assumed competence over 'teaching to the label' and to engage all professionals with the idea that all children deserve the right to be taught to read and write, regardless of their labels.

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Find out more about Teach Us Too at:
www.teachustoo.com
Read Jonathan's personal blog at: www.eyecantalk.net

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Raising the Bar through a Listening and Responding Approach

Martin Goodwin

This article is a summary of the presentation 'Listening and Responding to People with PMLD' (Raising the Bar Conference Nov 2017) and explores how the process is supported through the PMLD standards'.

About Listening and Responding

The listening and responding approach is a process of observation, documentation, reflection (and) interpretation of people with PMLD's experiences and daily interactions (Goodwin (2013) as cited by Lawson and Fergusson, 2015 p104).

Conceptually, the word 'Listening' was chosen to emphasise the communication partnership that two people, the person with PMLD and a practitioner share. The partnership is one that is communicative, dynamic, relational and interdependent (Bunning in Pawlyn et al. 2009). Among others, Bunning recognises that the communication partner actively listens to a variety of signals that may be intentional or pre-intentional, interprets, supports and through this process they contingently listen and respond (Bunning in Pawlyn et al. 2009) Therefore, the second word within the phrase 'responding' was chosen to emphasise the duality of the communication partner role in what Watson (2016) defines as being characterised by:

> 'firstly, a person's expression of will and preference needs to be acknowledged (noticed and not ignored), then interpreted and finally acted upon'
> (Watson 2016, p356).

The process of listening and responding requires careful and sensitive reflection and interpretation of communicative interactions between the communication partner and the person with PMLD. Through the process of listening and responding meaning is built inter-relationally and over time. Grove and Bunning comment that:

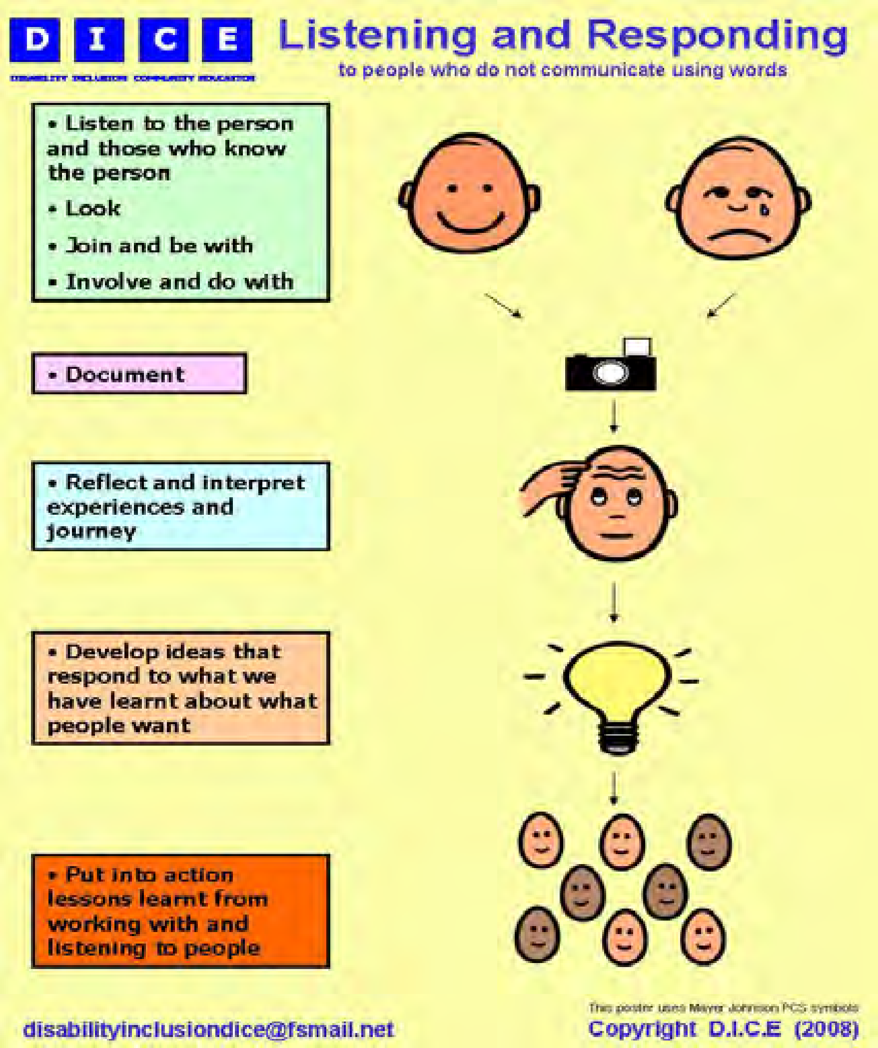
> 'the process of inferencing involves the activation of prior knowledge, as well as feelings and attitudes influenced by the participants and the context in which they operate.'
> (Grove and Bunning 1999; p194).

A variety of terms are utilised to describe the importance of listening to people who use services. However, the terms used (consultation, involvement, co-production) often leave practitioners questioning how and if people with PMLD can be involved in such processes. The term listening and responding aims to be an inclusive term for potentially empowering processes.

We can listen and respond to people with PMLD within a variety of contexts such as health, education, leisure/day opportunities, residential/supported living and individualised support within the community. So, what might people with PMLD communicate? This list is not endless but presents some communication that may be inferred. For example, within daily routines, I might show: 'I like this activity', 'involve me like this'. During experiences and interactions with a person, I might show: 'I feel sad when', 'I feel happy when', 'I want this more', 'I don't like this', 'stop this!'. Such communication opportunities are essential to promote within daily interactions and experiences and are the beginning of self-efficacy.

On an individual level, it is essential to listen and respond to ensure that we are responsive to people with PMLD. This will hopefully improve the quality of services by them developing the relationship that they have from 'done with' rather than 'done to'. From an ethical standpoint, involvement can actively promote respect for the person while developmentally the process of listening and responding is vital in ensuring the person has increased agency and self-determination. Culturally, such attempts are essential to the person and society as a whole, so that passivity and disablement are reduced. The perspective of the capability approach (developed by Nausbaum) is important in protecting rights, so that people with PMLD are supported 'to be the very best that they can be' (Imray and Colley 2017; p101).

Concerning the structural level, the importance of involving people is mentioned in a range of policies (Valuing people, Valuing people now) and legal documentation (including the UN Convention on the rights of the person with disabilities, UN Convention on Human rights and Children and Families Act 2014).



DICE

Listening and Responding

to people who do not communicate using words

- Listen to the person and those who know the person
- Look
- Join and be with
- Involve and do with

- Document

- Reflect and interpret experiences and journey

- Develop ideas that respond to what we have learnt about what people want

- Put into action lessons learnt from working with and listening to people

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This poster uses Mayer Johnson PCS symbols

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Fig1: Listening and Responding Process (Goodwin, 2013)

The Listening and Responding Process

The listening and responding process involve steps which may be visited and revisited in a cyclical and non-hierarchical fashion. The listening and responding process comprise of:

1. Listening to the person and those who know the person
2. Looking at the person and what they do
3. Joining, being with, involving and doing with the person
4. Documenting with the person what is important to them
5. Reflecting and Interpreting on the person's experiences and journey
6. Developing ideas that respond to what we have learnt about what people want
7. Putting into action lessons learnt from working with and listening to people

Listening and Responding Methods and Approaches

While research and use of tools and approaches to support choice making and involvement in services have received gradual attention, the tools have unhelpfully been conceived as individual components. Conceptually, I have grouped the approaches under the headings of ‘creative approaches’, ‘consultative approaches’ which may offer direct ways of involving people with S/PMLD, while ‘Interactionist’, ‘Documentative’, ‘Person Centred Approaches’, ‘Non-Directive/Non-Instructed Approaches’, ‘Representational approaches’ have an interpretive grounding. (See Fig 2). For ethical, moral and legal reasons, practitioners should always attempt to involve people in choices and decisions directly, but where this is difficult, it is possible to use a combination of approaches to listen and respond. Ultimately, in working with people with PMLD, the approaches involve an interpretive approach where we listen and respond to the person and build understanding accumulatively with the support of others.

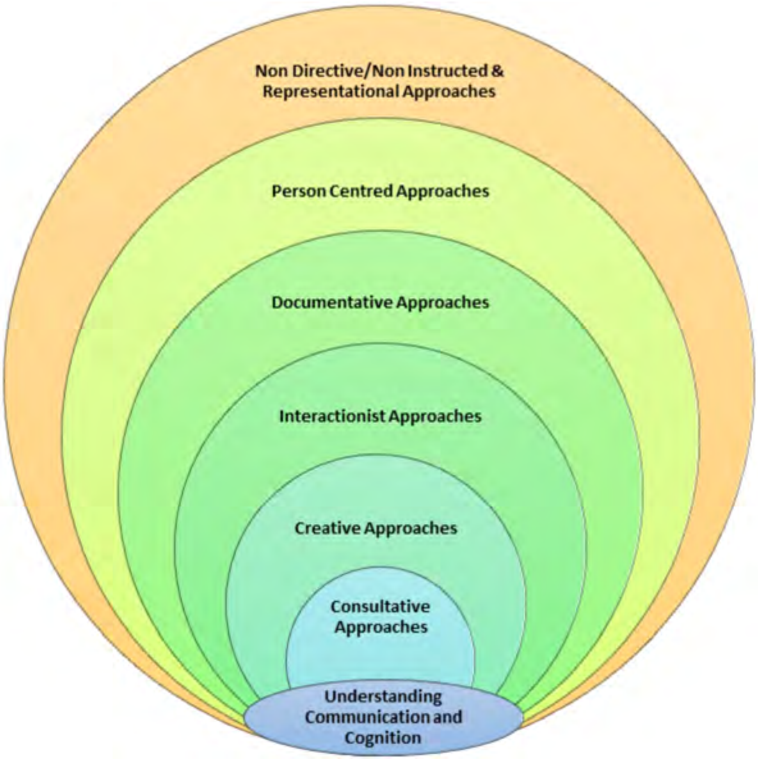

Fig 2: Model of blended approaches that support the process of listening and responding

Similar to the philosophy of the Mosaic approach (an approach utilised to elicit the views of children in the early years of their life - see Clarke et al., 2005), the tools and approaches that can be utilised to listen and respond to a person with PMLD should be viewed as pieces that fit together to help create a picture of what may be important to the person. Akin to the Mosaic approach the methods can be used in conjunction with each other and represent a range of potential ways to involve the person. A combination of the approaches can be utilised, and blended tighter to constitute a 'multi-dimensional' (Clarke et al., 2005) way of listening and responding. Some specifically designed approaches and tools have been designed to attempt to enable people with learning difficulties in choice and decision making and involvement in services. However, research is lacking into the efficacy of the application of the tools and approaches with people with PMLD.

Understanding Communication and Cognition
Understanding how a person communicates and how they learn or think, the strengths and difficulties of the person and the dynamic communication partnership they have with a communication partner is the foundation on which each of the following approaches rest.

Consultative Approaches
Consultative approaches employ tools to support ascertaining preferences and eliciting the views or ideas of people with PMLD who are recognised as beginning to communicate using formal means or conventionally communicating.

Creative Approaches
Creative approaches employ a range of media such as art, music, drama, storytelling. The media offer potential for people with PMLD to be involved in the process of shared exploration in which the reactions, responses and preferences of the person are noticed and shared or independent choices are made. Within creative approaches, a process in which a product is created to share with others can be made and on which interpretations and re-interpretations can be made.

Interactionist Approaches
Interactionist approaches are about joining in with the person and being with the person with PMLD.

Documentative Approaches
Documentative approaches aim to record what is important to the person and express their personality, likes and dislikes and wishes.

Person Centred Tools and Approaches
Person-centred approaches provide a set of tools that centre on decisions and thinking on what is important to the person and what the person wants. The tools help practitioners to reflect and document using person-centred thinking.

Non-directive/Non-instructed and Representational Approaches
Such approaches support practitioners or advocates to help decisions to be made that reflect the person's perceived interests, wishes, lifestyle and personality. Non-directive/Non-instructed and Representational approaches help protect the best interests of the person by challenging services and supporting services to design and deliver provision that reflects the perceived interests, wishes, lifestyle and personality of the people that they support.

Towards Listening and Responding and Raising the Bar

So why should a listening and responding process be prioritised? Through evidencing daily experiences, interactions and routines to build an understanding of what is important to the person, the process of listening and responding aims to enable practitioners and services to make positive changes or continuation of support based on what works well for the person and evidence why we do what we do. As well as maintain, shape or change the circumstances of the individual, themes about what is important to the person can be used to inform and influence decisions at a service and local authority level (Goodwin 2013).

The approach or enabling a process of Listening and Responding is not clear-cut. In practice, the validity of the process is challenging as in reality we may not ever know what a person with PMLD thinks or feels about a situation and as Grove suggests we should not be afraid of admitting that we do not know (Grove et al., 2000). Validity of interpretation may be improved by drawing on the thoughts of significant others. Ultimately this relies on people who will faithfully represent the person with PMLD. With whoever undertakes this role, potential limitations exist from bias, inference, personal values and attitudes, (Ware, 2004) and also the possibility of overestimation (McConkey cited by Porter, 2001). It is therefore important that this is considered and ideally a number of people will be involved (through processes such as Circles of Support or other) so that agreement from different perspectives can be reached.

Enabling choice and decision making and involvement in services has and arguably will always be a particularly challenging area of praxis. In recognition, acknowledgement of this has been provided to promote the rights and ethos central to empowerment are realised and safeguarded through an evidenced approach. Where it has not been possible to ascertain the views of people with PMLD, services should demonstrate how it has attempted to do this and how the service design and delivery reflect the perceived wishes, feelings, preferences of people they support (Goodwin et al., 2015).

The value of listening and responding to people with PMLD requires a culture change within services and society as a whole. Serious commitment must be given to genuine listening and responding to make things the best they can be in partnership with the person and those who know the person well. The process of inferring what is meant when the person communicates and ensuring effective responses from communication partners requires structure within services, provided through policy, training and practice management so that staff are supported. The PMLD standards can help support this process.

The listening and responding process clearly links with the ethos of the Core and Essential Service Standards for supporting people with PMLD, particularly within the area of communication, choice and decision making and involving the person. These core issues are reflected in the standards provide a foundation to promote a route to self-advocacy. The standards rightly advocate that measures such as recognising the range of ways that people communicate, ensuring that their means for communication, preferences and choice making is assessed so that this can guide supported decision-making processes and enable their increased involvement.

Together with people with PMLD, through the daily experiences and interactions that we share and through ensuring an evidenced-based process of listening and responding in partnership with the people who know and care the most about the people they support; it is possible to raise the bar.

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Meaningful Time

Samantha Newton and Launa Randles

The Children's Trust School in Surrey was introduced to the concept of the PMLD Core and Essential Service Standards in early 2017.

As a School we linked with its founders who had already undertaken much work to support drafting, developing and eventually the launch of this tool with a true belief that we could provide a unique view as a specialist provider recognised for delivering high quality education, health and care in one setting. As a School, within a charity Trust providing a range of services for a number of Local Education Authorities (LEAs), Clinical Commissioning Groups (CCGs) and social care providers we absolutely subscribed to the development of a document which evidenced our work and could be used by others to benchmark the services they provide.

Knowing that the final set of standards would be a document which outlined key objectives and principles for providing access to consistent high quality support, which would confront and challenge on behalf of this high risk, low incidence group inspired the multi-disciplinary team at the School to support the ambition that these Standards be adopted nationally wherever relevant.

As a provider we fully endorse that the Standards can evidence effective service delivery alongside regulatory measures for bodies such as OFSTED, CQC and CIW as a benchmark of quality.

At the launch of the Standards in November 2017 and for the purposes of this article The Children's Trust School set out to describe 'Meaningful Time'. As a multi-disciplinary team and with our partner school (Rosewood Free School in Southampton) we identified and agreed that there were 3 core things to meet Standard 5 of the Core and Essential Service Standards for Individuals.

Core 1 ~ Meaningful Multi Disciplinary Team Assessments

We recognise and acknowledge that with this group of individuals there are often a myriad of people and professionals involved outside the families from across education, health and care.

There is often a large and at times unwieldy jigsaw of information from individual assessments undertaken across large multi-disciplinary teams (both clinical and non-clinical) and there is often a danger of silo assessments and working within these teams.
Talking about personalised, child centred approaches is 'common language' to those working with this group of people. However, to truly 'information gather', there must be an identification of and drawing from 'meaningful assessments' where there is a recognised and celebrated culture and ethos that 'time can only be meaningfully planned where information is viewed holistically'. Recognition that a person is never simply viewed in the 'parts' that have been assessed and where there is expectation for full and in-depth shared understanding of the child or young person's needs, their likes, dislikes, motivators, preferred learning styles, optimal learning positions, potential barriers to engagement and learning, and their intended outcomes are clearly identified.

At The Children's Trust School meaningful time is planned following base lining as a multi-disciplinary team, then involving and listening to the family. All clinical and non-clinical assessments then feed into the five key skill areas of the specialised developmental curriculum i.e.

- Communication
- Cognitive skills
- Environmental control technology
- Social and emotional well-being
- Physical skills (gross and fine motor)

To use the words of Penny Lacey (2015, p46) it allows for all parties to 'find out exactly where the child is and what they can do…………..but it doesn't leave them there'

To conclude Core 1:
Meaningful time / learning can be planned for when there are clear assessments, that are viewed holistically and with active and continuous working partnership between all leaders of learning and professionals involved in the education, health and care of the child or young person with complex and profound needs.

Core 2 ~ Meaningful personalised activities

Following quality, meaningful assessments, meaningful time can be achieved by well planned, meaningful personalised daily activities.

At both The Children's Trust School and Rosewood Free School much has been done to embed a strong ethos which recognises the value of repetition and consistent approaches through familiar routines.

Everyday tasks and activities are planned to support all individuals from pre intentional levels who may be developing anticipation through to those operating with intention to engage in a way meaningful to them. Culturally both schools subscribe to actively planning to take account of the 'preparations for learning' required e.g. checks required to support the person to be best prepared to engage and both schools deem this crucial. If we are to present an activity without the young person being 'comfortable, motivated, ready and with us…' how do we expect them to access the activity or support them achieve their goals.

There must be a continued personalised journey of learning recognising strengths and the next challenge. At our schools, across the five curriculum areas the development of activities takes into account the child or young person preferences including time spent actively, passively, socially and in solitude which seeks to support their ability to develop 'self-occupying skills'. In a world where they are generally surrounded by people and professionals this is recognised as key?

Activities are person centred, age-respectful, made accessible, stimulate and excite (whilst being mindful of over stimulation which may hinder learning) and ultimately carefully planned.

To conclude Core 2:
Every child, young person or adult following the Core & Essential Standards requires a planned personalised pathway that meets their own needs, recognises opinions and preferences. The person's actions, levels of engagement underpins what happens and contributes to the proceedings.

Core 3 ~ Meaningful and high quality assessment of engagement and progress

Following quality initial multi-disciplinary assessments, planning meaningful personalised daily activities there must be high quality and ongoing evaluation of engagement and progress.

At The Children's Trust levels of engagement are recorded throughout the day against a RAG rated system.

- R = a red mark indicates 'no focus' or 'emerging fleeting' engagement
- A = an amber mark indicates 'partly engaged' or 'mostly engaged'
- G = a green mark indicates 'fully engaged'

Individual engagement books entitled 'Evidence, Achievement and Progress' track engagement against ten identified targets.

To gauge the levels of engagement, to aid consistency and fine tune all leaders of learning judgements, multi disciplinary discussion is expected.

Patterns should be identified, discussed and challenged through internal and external validation and moderation. The school collates this meaningful evidence, highlights progress and alerts the whole multidisciplinary team to achievement and any potential or early signs of regression.

Should low levels of engagement be prevalent or recorded, class teams are expected to discuss appropriate interventions that can be put in place in order for the child or young person to participate and raise levels of engagement.

Where high levels of engagement are recorded discussions take place on how to maximise opportunities to develop skills across contexts and environments. It enables the child or young person a fulfilling life.
To demonstrate meaningful ongoing assessment case studies have been produced to celebrate the child or young person engagement in tasks in a way that is meaningful to them.

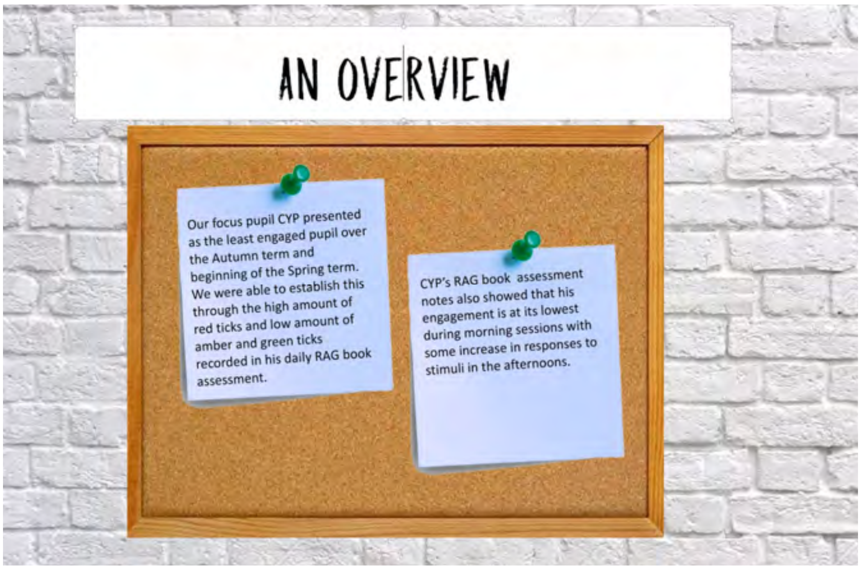
Again, the school has developed a cultural expectation about the importance of and the impact of quality ongoing assessment by demonstrating their evidence to all staff, governors, trustees and Ofsted. They are a powerful means to deliver the message of positive engagement.

As a School we have chosen to draw information from the RAG system and analyse across what it was telling us across the board. As a result we were able to identify that one of the biggest influencing factors in raising levels of engagement across the whole school was in the use of music.

Thought was given to this known motivator and how we could increase its use with the general aim of creating an empowering motivating environment in which the child or young person were stimulated into actively participating in activities. We have therefore invested in a larger number of lunchtime clubs such as the 'vinyl' and 'sound and vision'.

We have invested in specialist provisions such as Drake Music and are supporting staff to undertake training in specialist programmes such as The Sounds Of Intent which will result in all young people having clearly identified sounds and music preferences that motivate them to engage.

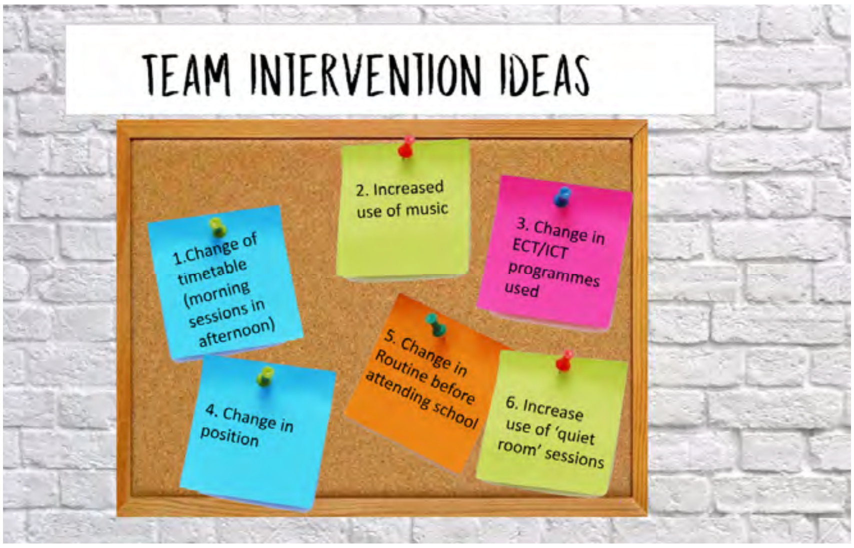
Case study – Increasing Engagement for a pupil in purple class at The Children's Trust School



AN OVERVIEW

Our focus pupil CYP presented as the least engaged pupil over the Autumn term and beginning of the Spring term. We were able to establish this through the high amount of red ticks and low amount of amber and green ticks recorded in his daily RAG book assessment.

CYP's RAG book assessment notes also showed that his engagement is at its lowest during morning sessions with some increase in responses to stimuli in the afternoons.



TEAM INTERVENTION IDEAS

1. Change of timetable (morning sessions in afternoon)

2. Increased use of music

3. Change in ECT/ICT programmes used

4. Change in position

5. Change in Routine before attending school

6. Increase use of 'quiet room' sessions

EVIDENCE

SPRING 1 RAG ASSESSMENT SUMMARY

SPRING 2 RAG ASSESSMENT SUMMARY

To conclude Core 3:

All need to be involved in questioning how we can better enable our very complex pupils to engage, learn and progress.

Even the most hard to reach have motivators and interests, whether at school or beyond. These are aspects that capture their attention and it is therefore our collective jobs to discover them and share the knowledge of them to be applied across contexts.

It is crucial that educators have a grasp of what engages, why and explore how this can be used to increase learning impact
Engagement is very much in the gift of the 'educator'.

Ongoing evaluation of engagement and progress is crucial to continued planning for 'meaningful time'…………….

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Sounds of Intent - http://soundsofintent.org/

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Vol. 30 No. 1 Issue 89

Development of a Multi-Disciplinary Care Pathway for People with Profound and Multiple Learning Disabilities (PMLD) within an Adult Community Learning Disabilities Service

Claire Cocquyt

People with PMLD have greater health needs than the general population and other individuals with learning disabilities. They are more likely to have respiratory disease, epilepsy, gastrointestinal reflux, helicobacter pylori and osteoporosis (NHS England, 2013). Despite being a relatively small population group, these individuals continue to be at high risk of experiencing inadequate and non-personalised services (Doukas et al, 2017).

What did we do?

Following a team away day in 2013, the Adult Learning Disability Team in East Cornwall made a commitment to improve the quality and consistency of care for people with PMLD. Work began with the formation of a multi-disciplinary pathway working party (nurses including epilepsy specialists, physiotherapists, occupational therapists, speech and language therapists and a dietician) that set about completing an audit to evaluate how their service compared with best practice guidance.

The questions were developed by the working party and focussed on recommendations from a number of government papers and reports that drive high quality care for people with PMLD (Heslop et al, 2014; NHS England, 2013; Mansell, 2010; Michael, 2008) .

What did the audit show?

Areas > 50% compliance	Areas < 50% compliance
Named care co-ordinator	Pain Monitoring
Feeding regime	Occupation / Sensory Assessment
Communication with the GP	Holistic Health Needs Assessment
Eating and Drinking Assessment	Communication Assessment
Recorded Weight	Postural Assessment

Table 1: Summary of audit results 2014

Results from the 2014 audit are shown in Table 1. Individual's specialist health needs were not being identified and assessments and interventions were carried out in isolation with little multi-disciplinary working. Most of those open to the service received input from one or two clinicians at a time but rarely had up to date assessments in all recommended areas of care. For individuals who were not funded by Continuing Healthcare (CHC), there was no robust review. The audit also flagged a number of improvements that could be made to the electronic note system to make information easier to record and find.

What did we do?

The outcome of the audit was to develop a county wide multi-disciplinary care pathway within the Cornwall Adult Community Learning Disabilities Service. The multi-disciplinary working party was broadened (to include the West Cornwall Learning Disability Team) and they set out to drive clinical change through training and the development of an electronic database to identify people with PMLD and track their progress through the pathway.

The Pathway

Figure 1 summarises the pathway. Once the priority clinical need has been addressed by the appropriate clinician(s), the person with a profound and multiple learning disabilities is expected to receive assessments and intervention from other professionals within the learning disabilities team as below:

Figure 1: The PMLD care pathway

Health needs requiring other specialist advice and intervention are referred to the appropriate primary and secondary health care services. The individual will have a named care co-ordinator from the learning disabilities team during the time that they are open to the team. The care co-ordinator is the named person of contact who helps to ensure the person ‘follows’ the pathway. Those who are eligible for Continuing Healthcare (CHC) remain open to the team at all times and maintain a care co-ordinator from the team.

Impact of the pathway

The audit is repeated each year and was widened to include individuals also open to the West Learning Disabilities Team. In between audits, the working party linked closely with team managers and the rest of the clinical community team to achieve their annual audit action plans and develop services to compliment and embed the pathway into daily work. Examples of ‘projects’ which have happened between audits are shown in Figure 2.

- Training to all staff within the service
- Development of an annual review process
- Robust administration process to ensure return of signed mealtime plans
- Increased links with GP’s
- Improvements to the electronic record system
- Routine recording of height at postural assessments and rebound therapy
- Embedding the pathway into everyday work
- Project with Primary Care Liaison to evaluate the quality of Annual Health Checks for people with PMLD

Figure 2: Working party projects alongside the pathway

Results from the 2017 audit (Table 2) illustrate the positive impact of the pathway on clinical care. Of the 20 questions that were repeated from 2016, 13 showed an increase in numbers of people with PMLD having received assessment and advice.

Areas where doing well	
Communication with the GP	91%
Review by Community Team	89%
Health Assessment	88%
Documenting PMLD	84%
Posture / Mobility Assessment	84%
Eating and Drinking Assessment	83%
Posture / Mobility Plan	81%
Signed Mealtime Plan	77%
Up to date feeding regime (PEG)	75%

Areas to work on	
Pain Monitoring	16%
Hospital Passport	18%
Annual Health Check Date	21%
Health Action Plan	33%
Occupation / Sensory Assessment	39%

Table 2: Summary of audit results 2017

How does the pathway meet the Core and Essential Service Standards?

- Assessment of communication
- Communication Profile
- Timely access to Speech & Language Therapy including training around communication and dysphagia
- Clear advice & guidance from Speech and Language Therapy to keep people safe when eating and drinking
- Routine monitoring of health needs
- 24 hour postural management plan
- Postural management care plans and training
- Personalised nutrition and hydration information

Future Plans

Areas for further development:

- Improving compliance with Health Action Plans,

Hospital Passports and Pain Profiles
- Developing an outcome measure for the pathway
- Service user and carer feedback
- Weight monitoring
- Ongoing improvement to our records system
- Improving transition into adult services for young people with PMLD
- External training

Conclusion

This work has demonstrated the benefits of a multi-disciplinary team effort within a Community Learning Disability Service to better understand and proactively meet the needs of people with PMLD. Prior to this, there was not even a clear understanding of who this population were in Cornwall. The efforts of the multidisciplinary team have highlighted the complexities of the biopsychosocial needs of people with PMLD and that change can only be brought about by collaborative team effort. It is hoped that the national drivers for change will only strengthen with the recent publication of Core and Essential Service Standards (Doukas et al, 2017). In Cornwall we continue to be committed to improving the service we provide to people with PMLD and hope that our work will inspire others.

Acknowledgements must go to the pathway working party as without their continued commitment and enthusiasm, this work would not have been possible.

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Tips for implementing the PMLD Core and Essential Service Standards in Youth Club settings

Katie Hobson

I am a student at the University of Hull, studying Education Studies with Social Inclusion and Special Needs. I have worked in residential care homes for adults with learning and physical disabilities and profound and multiple learning disabilities, and in a College for students with autism. I currently work for a national charity helping to run Youth Clubs for young people with PMLD and other disabilities. I work at two clubs within East Yorkshire that have 10 to 15 children and young people in attendance each week during term time. All young people in attendance have varying special needs and are between the ages of 11 and 19. The activities offered include a themed craft activity around various current events and calendar festivals, various games and quizzes are engaged in each week according to the theme and the young people have the opportunity to socialise with their friends, develop social skills and make choices.

I know it is not always easy to implement new standards and practices so here are some tips for how to promote good practice and how I have helped implement the standards in my workplace.

Tip 1- Speak to management about the standards. I spoke to the group leader at the youth club I work at and they were aware of the standards. We arranged a team meeting and considered how we could promote and embed the standards by being consistent in promoting children's leadership through turn taking and group activities. As a result of this team meeting the staff team had resulting team reflection sessions to consider how things were working and whether the way we engaged with the standards could be improved in the future. Most staff thought we could improve communication with some young people with profound and multiple learning disabilities, and considered how best to do this. As a team we need to continue reviewing this to best meet the needs of new and existing young people who join the youth club.

Tip 2- Promote leadership and the children's voice through provision of activities. We arranged a feedback session with the young people, giving them the opportunity to communicate what they wanted to get out of the youth club, ensuring that it is person centred and empowers the young people to have a voice. In the future, to ensure good practice staff could complete the feedback session again on a regular basis to ensure that changing needs and wishes are being considered and influence activity choices. Staff could also reflect on activities, the room layout and communication taking place to ensure children's needs continue to be met (Gibbs, 1988).

Tip 3- Children's communication can be considered in line with the standards. In the youth club staff consider how young people best communicate on an individual basis and adapt communication, social activities planned and the physical environment of the club based on how to enable the young people to get the most out of the youth club. For example, we talk to the parents and communicate with young people themselves to find out what they want from the youth club, consulting in regular group meetings with all attendees to establish rules for everyone and what games, activities and snacks children want from their youth club. By taking ownership of the youth club this promotes respect and creates a happier, more inclusive social environment. Staff do consider if current communication strategies are appropriate for the child and this may result in further multi-disciplinary input from professionals such as the Speech and Language or Occupational Therapist. Communication with staff and children are reviewed and this may result in adaptations to communication strategies used in the youth club such as PECS symbols and IPads used to communicate, empowering children and giving them a voice (Cross, 2011).

Tip 4- Ensure wellbeing and community is a priority. Children can be encouraged to think of the youth club as a place to recharge and engage in what they want to do. This could involve planning a pamper session where children give each other hand massages or receive them from the staff and paint their nails etc. Children can be involved in planning these sessions and staff can reinforce the importance of relaxing and promote a group activity simultaneously. The youth club plans and implements trips for children and this can reinforce a community belonging by becoming involved in buying ingredients for what they will cook, learning life skills along the way. This can be applied to adults and young people as they can benefit from volunteering and being involved in the community, fostering a sense of belonging which is important in ensuring people lead a full and active life.

Tip 5- Promoting meaningful and quality relationships is considered in line with the standards. We do this by offering games such as interactive quizzes that link to the theme of the week that encourages team work and develops tolerance and appropriate interaction with each other to develop appropriate relationships with peers. Staff also provide positive, encouraging role models for students which helps in learning how to socialise and interact appropriately and ensuring young people have an adult to come to and ask questions and receive guidance from.

Tip 6- It is important to ensure that time young people spend at the club is meaningful for them. Staff do this by ensuring people have a chance during meetings to have their voice heard and contribute to the running of their club, taking ownership of it and this contributes to them feeling valued and supported by staff and parents. Staff and parents work in partnership with young people to promote meaningful, useful and fun opportunities when accessing the youth club. When planning activities the staff attempt to raise the young people's aspirations by exploring traditions and festivals around the world which may increase their practical knowledge of cultures and traditions. In addition, during half term and school holidays regular trips with all the youth clubs are organised and implemented around the region which may include sports days, theatre trips and museum tours which promotes aspirations and experiences which may otherwise not have been gained, contributing to young people spending meaningful time with the youth club and meeting the standards.

Tip 7- Staff support families and young people with PMLD to transition successfully to and from the youth club by ensuring that each staff member gets to know the parents/carers well in an informal manner through pick up and drop offs at the door.

When a young person first starts at the club we ascertain their needs and review this over time to ensure that their transition strategy remains relevant to their needs. We also ensure that parents and carers attend regular meetings with the staff at the charity who run the youth club to ensure that current needs are being met.
This article summarises how to implement some of the Core and Essential Service Standards with children with PMLD and other disabilities by considering the case study of a youth club. The tips can be applied to adults and services to promote good practice in all settings and services.

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There are so many things going on that are relevant to children and adults with PMLD and their families and the people who support them. We want to make sure that you can keep hearing about anything that matters to you.

Obviously, we need to keep the names and addresses of all paying subscribers (personal subscribers and contact persons in organisations) so that we can continue to send you the PMLD LINK journal. Also, we need your e-mail address because this is used as a user name to access the website and to send occasional reminders about subscription renewal and other information.

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Vol. 30 No. 1 Issue 89

Sex Education – support to learn about puberty

Louise Fraser

I have been a teacher for ten years. My career began in mainstream but now I am firmly at home in a special school setting. Our school caters for children from 2 to 11 with a range of special educational needs and disabilities, where I am the PSHE (Personal Social and Health Education) lead for the school. When I took on this role I became interested in how the topics we deal with within PSHE were addressed for our students with PMLD and began looking for resources, and examples of best practice.

I noticed that for most other subjects, teachers might go to extraordinary creative lengths to translate something into the sensory world and make it interesting and meaningful. When it came to some 'tricky subjects' in PSHE, there was a tendency to deliver the material briskly and the resources used to support teaching were not always accessible. This meant we were not meeting Individual Standard 2: Health and Wellbeing from the Core and Essential Service Standards for Supporting People with PMLD. The health and wellbeing of our learners was not actively and effectively being promoted – we were glossing over the topic.

Schools are experiencing more freedom in how they deliver and adapt the curriculum for their learners. One of the positive developments of the Rochford Review (REF)into how we assess students in special schools could be that we are no longer tasked with teaching Tudor Kings and Queens, for example, to students to with PMLD who would benefit far more from spending that time doing rebound therapy or joining in with a musical activity. I can see that in the future some of the curriculum content considered irrelevant will be binned and we will be able to focus all our efforts on what those children most need. So will we bin talk of periods? Talk of masturbation? Talk about sex, gender and sexuality?

When I began looking at how we address puberty education for learners with PMLD I assumed my own lack of knowledge in this area was due to a lack of experience. But the more I looked for information the more I realised it is just not available. Usually a little bit of skilful Googling here and there has been enough to pull up amazing resource banks to top up my knowledge for other topics. I have found people who are experts in their subject area to guide me with my teaching and have drawn from a wealth of knowledge held by the community as a whole. But for meaningful PSHE for those with PMLD it wasn't just a lack of knowledge within me, there was a lack of knowledge within the field itself. Reflecting on this situation within the framework of the PMLD standards, it was difficult for Organisational Standards 3, 5 and 7 to be achieved – for example because there was no training for staff (Standard 3), little in the way of ensuring effective communication (Standard 5) or for enabling staff to promote individuals rights to health and wellbeing (Standard 6).

After a reasonable amount of further research – and I am not claiming to have turned every stone—one of the results I hope for from writing this article is that other people will come forward and share what they know .I had come across only three resources to support my teaching:

- Paul Bray's article for NASEN: 'Learning about Sex'
  This article backed up what I believed about the rationale for teaching all of our students about puberty (from which they were not immune from experiencing). With statistics as well as ideas about how to approach practice for young people with learning needs in general.
- Flo Longhorn's book: 'Sex Education and Sexuality for very Special People – A Sensory approach'
  This resource had a fantastic overview specifically for PMLD students and advocates using a sensory holistic approach to learning. Within it I found ideas for resources that could be used to address: sex, bodily experience, gender and puberty. It has a specific section on Menstruation and pre-menstrual tension which gave some great therapeutic ideas for dealing with these specific issues.
- PAMIS, the organisation (http://pamis.org.uk)
  I came across the work of this group through a conversation with Jo Grace. The resources they offer around sensitive issues and their story telling sessions are great but, alas, not all of us are in Scotland.

What these resources reminded me of again and again was that people with PMLD are not excluded from puberty by their disability. Indeed many of the medications our students take can have a significant impact on how they experience their bodies; their care routines and lack of personal mobility can mean their access to their own bodies is limited compared to non-disabled peers.

Puberty happens to people with PMLD, so we should be equipping them to understand and cope with it just as we would any other child (Individual Standards – 2: Health & Wellbeing and 6: Transitions). You do not have to go back many generations to find women who were never spoken to about menstruation for whom their first period would have been a frightening and strange experience. We have learned as a society that hiding that information from people is cruel. We are better at talking to young people about the changes their bodies go through. No one finds it easy, these are sensitive conversations to have, but we have them because we recognise their value and because we care about the individuals with whom we have them.

Imagine being that young woman experiencing menstruation for the first time, or the young man experiencing a wet dream for the first time, and not knowing what it is, not knowing why your body feels different, smells different. It would be scary. It would be scary for someone who is able to go and ask their friends, for someone who can look things up in books, for someone with a means to solve the mystery themselves. But what if you couldn't do those things, and not only did this thing happen to you but all sorts of other strange sensory sensations and things started taking place. Panty liners smell a certain way, they have a certain feel, and someone will shove one between your legs, your underwear will hold it against sensitive areas of your body, and sometimes it will be there and sometimes it won't.

Imagine not being provided with the information you need to understand what is going on as your body hits puberty. And imagine not being able to seek it out. And even if you could seek it there are no resources that refer to you and certainly none that show people like you within them which doesn't exactly support the idea of quality relationships (Individual Standard:3 Meaningful / Quality Relationships) with a sense of belonging and empowerment.

All of these challenges are further complicated by the fact that there seems to be a general assumption that people with PMLD don't experience what everyone else does anyway. I myself am raising an eyebrow at this and emitting a deep sigh. Flo Longhorn (who refers to people with PMLD as "very special") thankfully puts it quite succinctly "Most women, including very special women, spend 6.2 years of their life menstruating." She goes on to point out that a 1988 Mencap project "reported nearly identical symptoms in a survey on menstruation and very special women. They found that very special women, both teenagers and adults, showed: signs of increased levels of anxiety, physical aggression, increased self-mutilation and increased epileptic fits. Their outwards symptoms were the same as for ordinary women, but they had no means of verbalising their distress or alleviating their own discomfort" and she goes on to mention that this has an impact on their mental health, dependent on how the effects are managed.

This does not need to happen. These things are predictable! Girls have periods! We know that it can cause people to feel unprepared, confused, scared. We don't talk to them about it because we don't know how and this predictably potentially leads to further social, emotional and mental health issues. If we were to risk assess this we would be saying we why on Earth haven't we approached this before. After all it was already being talked about as a priority 30 years ago!

The 'issue' sometimes people come up with is "But they don't understand it, so why approach it?" Beginning from an assumption of inability is never a good sign. The idea that we won't attempt to help because our efforts would ultimately be pointless, isn't a great start point. Similar arguments have been used historically to restrict people's access to other aspects of life, art, culture, religion, even to communication itself. We no longer see these things as pointless for people with PMLD and as a result we are seeing more realisation of the skills and experiences that all sections of society have to offer, some notable examples of these are: Jo Grace's Sensory Art Project, Flo Longhorn's Spirituality training, and Keith Park's interactive story telling adventures. These advances started with people pioneering new ideas which may have been difficult for some. Perseverance and people pushing for rights for all has helped to burst through any barriers and the Standards are part of this for the future. A quote from the Standards furthers this and puts a new perspective on the issue raised at the beginning of the paragraph. "A person's ability to communicate is not dependent on their being able to master certain skills, it is dependent on our ability to listen and communicate responsively" (Jo Grace, p6 of the Standards). Puberty talk is not excluded from this.
I understand, from the perspective of both parent and teacher, that these conversations are difficult at ANY level. They are difficult with mainstream children, they could be difficult here, but that still doesn't mean we shouldn't have them. There is a lot of taboo still attached to talk about puberty, particularly periods and, as a result, people are often reluctant to talk about the subject and find it difficult to broach. I don't have the answers, but I do think we should talk about it openly; families and professionals also need to talk to each other.

As a professional I have always found that having open, but sensitive, conversations with parents allows for a rapport to develop, just as it is with any topic. We should consider that there are a myriad of different things which influence families reactions to discussions regarding this area. For instance, some families may take a long time to adjust to where a person is, and then being asked to take on board physiological age verses chronological age is another challenge. As a parent myself I can also understand the feeling that my child will always be my child and it is a natural instinct to want to protect them from anything which might be scary or uncomfortable. It also means accepting that they are growing up, and a young person's life moves on so quickly this can be difficult too. But it is important that we all understand, and sensitively approach, the fact that talking about puberty and bodily changes doesn't change them as a person. These things will happen to them anyway, and what we want is for no person to be left without good quality support through teaching and appropriate resources available to them. We need to develop an ability to open a discourse with each other to get the best outcomes for our young people's understanding and experience during puberty.

However you want to approach the topic of puberty having resources to support the adults involved as well as the young people is incredibly important. I am aware of the other students within my school who would benefit alongside their PMLD peers from more open, more sensory, conversations around puberty and sexuality. In fact we already have a range of sensory resources which relate to specific aspects of puberty for both our male and female students (e.g. bras, deodorant, and panty liners) with the aim to engage the senses appropriately. There are a wide range of general resources on puberty out there already, some of which we have been able to adapt for our learners. For instance we have social stories and booklets which some of our more able learners can access but even in these there is a lack of frankness within the pictures: for example we have no images of people wearing pads (whether they use a panty liner or not), or people in wheelchairs. I am lucky enough to have a member of my team who is a great artist and is working with me to create resources which have specific representation of these issues, but it seems that these resources should already be out there.

We must aspire to be more open. It is only by being honest, and opening conversations in teams, and between professionals and parents and with our young people that we begin to break down the taboos which exist. By doing this we can begin to make progress in getting good quality education, resources and training out there that matches and meets the needs of everyone, just as the Standards advocate. We need to aspire for more to ensure that equality and inclusion are the given standard in talking about puberty, because the current state of affairs isn't just unfair, it's disrespectful and inhumane.

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References

Flo Longhorn training - http://flopublications.com/index.php/training

Keith Park – keithpark1@onetel.com

Jo Grace's Sensory Art project - http://www.thesensoryprojects.co.uk/the-structured-sensory-art-project

PMLD LINK is 30 years old in 2018!

How would you like us to mark this significant milestone?

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

email: info@pmldlink.org.uk twitter: @pmldlink Facebook: PMLD Link
Plans are underway … so watch this space!!

Exceptional Learning Lifeskills and Achievement (ELLA)

Elly Chapple

I'm grateful for the invitation to write for PMLD Link, to share our story and the journey we have been drawn to for one particularly exceptional person – our eldest daughter Ella. We hope that over the next few years we will be able to develop and share our experiences further so that the positives we have uncovered and developed can be used in wider contexts for others.

When I became a mother for the first time in 2006, to an exceptional and 'out of the box' little girl, my own expectations were thrown all but out of the window in one fell swoop. There was no manual, no list and no 'how to' guide. There were a lot of good suggestions, books offered and endless appointments. There were early intervention services that were lifelines – I don't think my daughter or I will ever forget Linda Barker at the Portage service which once a week was the only thing that made sense at times, such vital necessary services which get little voice. But the string with which to tie everything together to make sense of what to do and how with regards to my daughter, my unique new little being, was missing. For a while I felt inadequate in my ability to look after her, that she was constantly being framed as beyond the scope of prescriptive normal. With hindsight I realise that a lot of the 'experts' with lots of qualifications, had no real idea either because everything was looked at in boxes of their specialism rather than as a whole individual. To try and make sense of things and keep my own sanity, like many parents of exceptional children, I became an avid research investigator, reading all manner of things, and questioning everything that didn't somehow 'fit' with what my daughter was trying to say. I'm grateful that I had a strong family around me and a mother who always taught me to go out of the box and seek my own answers in life. Without that support, I'm not sure I would have quite managed to wrestle back the rightful feeling that my gut instinct was rarely wrong. What I didn't know then and am so grateful for now, is that the tiny little 4lb 12oz exceptional bundle - my daughter - was about to become my greatest teacher and my own strong interests in and passion about human communication and difference would be thrown into stark focus, mapping a route that I had to follow and decipher in her wake.

Ella, like many other children, has a collection of labels. Or she did have. Some we have lost along the way, some we have since gained. Some I feel are relevant to her as a person and some have added less understanding or empathy and more of a 'we're not too sure' but 'we think you belong over there' and 'you'll achieve X to this point because of….' approach. She did carry the PMLD label as a younger child around the age of 4. In hindsight I think this was more to do with the fact that she hadn't yet been diagnosed as a Deafblind/MSI child — despite being congenitally Deafblind/MSI (from birth) and so it was a case of a complex presentation of combinations that didn't really fit a specific anything. However conversely now I think that it just wasn't so complex to work out. I feel the lack of her diagnosis hindered the perception of her ability, and created a preconception of what she could/couldn't achieve according to her labels, which reduced the belief and value placed upon her as a person. And I am convinced she would have felt that too because of her naturally higher level of senseability. She was finally diagnosed as Deafblind/MSI in 2013, aged seven, after I persistently sought out the 'key' to unlock her and the ability that we saw in her daily. The term originally to me was confusing as she had some vision and some hearing, until explained by our strong advocate and expert Nicola Brotherdale at Sensory Linq. Her belief in Ella and her consistent support to bring us to where we are was, and is, invaluable. A loss in both vision and hearing , your key learning senses, can have a phenomenal impact on your understanding of the world as 85% of our learning comes through our eyes and ears. 'It's not about the amount of sight and hearing you have; it's about the combined impact of having more than one sensory impairment' (SENSE, 2017).

To explain the experience of this dual sensory loss, imagine if you will - a set of traffic lights on not one but both of the main motorways to a key destination, constantly stopping and starting the flow of traffic. Imagine the driver reactions. You can probably envisage which one would be you. As queues form and progress slows, eventually drivers are likely to:

a) Turn back (give up)
b) Daydream, patiently wait or occupy themselves with something
c) Become outwardly communicative about their growing frustration and maybe even resort to aggression
d) Something else!

This simple analogy hopefully aids understanding of some of the differing responses and frustrations when you are at odds with what is being presented to you. If this happens most days, or every day, it would create stress on unimaginable levels, you would be fuelled with adrenaline and in a very high, fight or flight state. So imagine how a child with loss in both senses will feel and why life can be so very challenging.

Although severely sight and hearing impaired Ella had useful vision until, tragically at the age of 7, she went blind - a horrific period in her life. At this point, she was traumatised and incredibly stressed with severe, high risk anxiety levels. How her blindness came about is for another article but suffice to say the impact of this event caused her to stop, in every sense, entirely. She retreated to the safety of our home, she refused contact and she fought everyone and everything with aggression. She didn't sleep, wouldn't leave the house and wouldn't stop rocking, all day Her fight or flight response impacted every second of her day; she didn't trust anyone and her zest for learning and life literally ground to a halt. This changed all of our lives forever. We had to start all over again , from the beginning.

Over the next 4 years we pieced back together our daughter; like a smashed vase we had to find every last part and glue them back into place. This has taken us on the most unbelievable journey; the last 2 years in particular has awoken a daughter I grieved for, who was all but lost in the chaos of her life created by others. The real Ella, the little 4lb 12oz bundle, who knew what she needed to do from day one, came back. I'll never forget the day she really started laughing again, our first sign that she was healing.

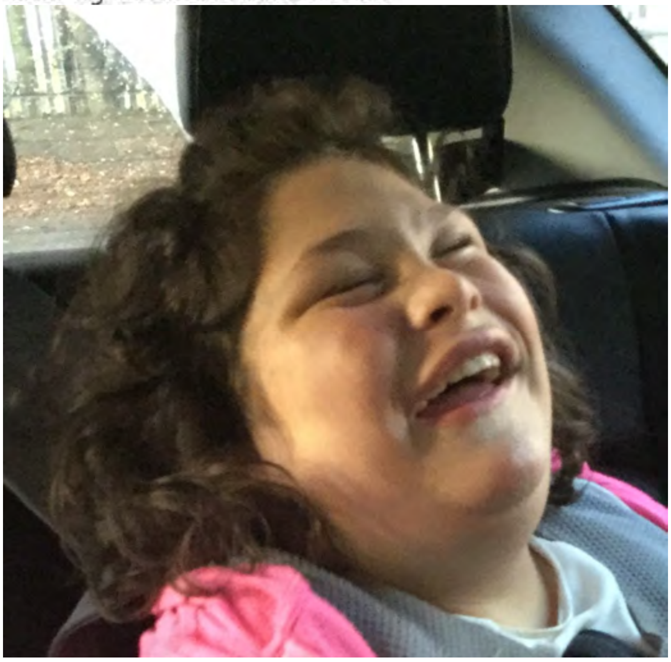
So what did we do? We started at the beginning. We looked at the whole child, the whole life and the all of her needs - together, not separately. We took control of the situation and grew confident in our own research and knowledge base, that as experts by experience we could make it work for Ella. We worked as a team, around the clock to find the puzzle pieces we needed. The first essential to address baffled some professionals, but seemed simple to us - if Ella was going to achieve in life as she wanted to, we needed to restore her trust in people and life, to rekindle the zest for learning again. How could we do that? One key approach was to focus on Ella's own individual learning process developed through trusted relationships, based on genuine observation, growing emotional understanding and supporting communication in varying forms. We also learned … to … slow ... down!

Dr Jan Van Dijk, the late and much missed expert in Deafblindness, developed and advocated an approach for Deafblind/MSI children he simply termed Child-Guided Assessment. He deemed that any standard assessment was based on children having typical experiences and that if you did not experience the world in this typical manner then most assessments would be fairly irrelevant with actual responses misunderstood or not valued. Van Dijk highlighted the importance of limbic resonance, often referred to as emotional intelligence. Parents reflect this with their children all the time – your intuitive state, your gut instinct and why you consciously or unconsciously form an integral part of their learning and development. With Ella, this was key to 'unlocking' her before learning could really begin.

The limbic brain (reptilian brain or the emotional brain) is where the 'fight or flight' response derives from - we had seen this fully active in the extreme in Ella when she lost her vision. For many exceptional children, this raised anxiety can dominate throughout their daily life as they try to interact within a 'typical' world that potentially does not respond and interact with them in a state of mutual accordance. We have learned that the relationship between a trusted support and a child is the foundation of success. It is absolutely the key part of first steps towards unlocking potential; understanding the 'why' and then the 'how' so that learning can be facilitated for individual success. We have learned that the environment and culture in which learning takes place must echo the values of authenticity, belief, high/great expectations, mutual respect and dignity for all involved.

When there is a high state of limbic resonance between the child and the trusted support, there is genuine connectedness and understanding; this alignment facilitates progress. Why? Research shows that the limbic system learns best through motivation, extended practice, and feedback (Goleman, 2004). Because the emotional responses are attuned, the relationship is in harmony and the fight or flight state is reduced, allowing learning pathways to be enjoyable and motivating, not fearful. When the child is consistently supported with this approach, adaptation and interaction evolve naturally with the relationship growth and thus the learning and achievement. The child's self-value and confidence increase and the desire to participate improves as they develop positive, enjoyable learning experiences, growing their ownership of learning and metacognition.

We have seen this progress, experienced it and developed it further following our teacher and guide – Ella. Her drive and desire to be part of this world and have a rightful place is inspiring and amazing daily. She has quite literally come back from the darkest of places imaginable and begun again with faith anew. We have a phenomenal team of committed and driven Intervenors



who support her daily, and we are on a quest to find out more. Her resilience, strength and passion for life, despite all it threw at her, have inspired hope, faith and a path to achievement and we are truly humble and engaged participants in her journey to becoming herself and show the world what Ella can do.

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SENSE: https://www.sense.org.uk/

Sensory Linq: http://sensorylinq.co.uk

Editors' reflections:

- Some suggestions of how Elly Chapple's care and support for her daughter Ella might demonstrate aspects of the PMLD Standards. Ella's health & wellbeing are promoted and supported by others actively developing strategies to ensure good mental wellbeing [Individual: Standard 2, see page 30; Organisation Standard:6 p20].
- The approaches used with Ella were evidence-based and developed by experts in the deaf/blind field. Practice recognised and responded to her 'holistic vulnerability …[to] ensure the quality of [her] physical and mental health status' [Organisation Standard:1 (page 20)].
- lly's article emphasises the central premise of developing trust, reciprocal communication and shared meaning through quality relationships [Individual: Standards 2, 3 and 4], demonstrating '…life is about thriving and not just surviving' (p33)

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.pmldlink.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.pmldlink.org.uk.

For more information contact Rob Ashdown (rob.ashdown@ntlworld.com).

Butterfly Day

Eleanor Gibson and Jessica Newcombe

The seed for Butterfly day was sown on a training day with Flo Longhorn, thinking about spiritualist (see details below). In a special school there are often difficult times for pupils, families and staff: sometimes children die and whether this is expected or not it is always a time for grief and sadness. In addition there are all the ‘normal’ griefs of loss and change we experience in everyday life – of families undergoing separation or bereavement, people moving away or other changes.

For any of us, these life events can present extreme challenges; it is not easy to understand or articulate what happens, and what we feel, when someone leaves our lives. How much more difficult is this for someone with severe learning disabilities? Although as a school community we respond as best we can, we wanted to begin to be more proactive in creating an environment where loss could be addressed safely and with sensitivity.

We decided to provide an opportunity for remembering those who have left us, and took away some ideas from Flo’s course. We named the day Butterfly Day and hoped the ‘what’ and ‘how’ of it would come to us.

For inspiration we drew on personal experience: for one of us, as a bereaved child in the 1960s, there was little understanding at the time of what I might be feeling or what might help me. Since that time, awareness has grown regarding the impact of loss on the lives of everyone concerned, and the needs of children have been addressed with care and creativity within the mainstream population. However, loss, death, grief, transition are subjects that we tend to shy away from with the people who are most vulnerable to them.
The new ‘Core and Essential Service Standards: Supporting people with profound and multiple learning disabilities’ are a very welcome step along the journey towards better provision and understanding. Butterfly Day links strongly with the Organisation Standard 7:

Social, Community and Family Life. People tend to focus more on the happy aspects of these things: the getting out and seeing friends, being able to access the community for example, but the more difficult and sadder times are as much a part of being meaningfully included as the joyous times and bereavement is something we share with those closest to us. Through this day other topics highlighted in the Standards are addressed: communication, health and wellbeing (especially mental health), transitions and meaningful relationships.

Butterfly Day promotes health and wellbeing by providing opportunities for us all to come together to process difficult experiences and to find the positive in loss. The day was structured to be as inclusive as possible, with activities that were meaningful and open to be interpreted on different levels, facilitated by adults who already have positive relationships with and a depth of knowledge about the young people they were accompanying. We also hope to promote a sense of belonging: grief shared is usually easier to bear; there is the possibility of comfort, shared strength and moving on.

We created a framework of 'activity stations' where students and adults could take their time to create and enact small rituals of letting go. Our responses to loss are very individual, and it felt important that the opportunities offered were not prescriptive, but were open ended to create genuine choices in the expression [or not] of each individual's thoughts and feelings. Families were notified about Butterfly Day, giving the opportunity children and young people to bring photos to school of anyone they particularly wished to remember. Although we make every effort to get to know the families and the young people we work with, inevitably we won't always know about family absences, or perhaps of significant people that the young person has been especially close to.

Despite times moving on since the 60s, death and loss are still life events that we prefer not to think or talk about in our culture. But wherever there is grief there will be feelings which, whether expressed or not, will be felt by everyone. We can only imagine how that might feel for a child or person with PMLD. The sense of interoception, through which we sense what is happening inside us, may not be fully developed, or may, conversely, be over sensitive. The feelings and sensations may be there but there may be difficulty in differentiating, naming, filtering and interpreting feelings. The sense that there are strong feelings around, that there is sadness or anger or grief, to feel those sensations and emotions yet have limited capacity to understand or express them, can be a difficult and damaging experience. People with PMLD may not have access to any of the outlets that most people would use such as talking about feelings or physical activity. They may not be able to choose to be alone, or to choose who they would like to be with. They may not be able to contribute to the rituals and remembering that goes on, either formally or informally. They may not understand who those feelings belong to, or may assume that whatever is going on is their fault.

The activities offered in Butterfly Day are based around personal perception of what might be helpful, rather than any accepted model of grieving. Whilst grieving is in some sense a process, it is essentially non-linear and the trajectory for each person is individual and idiosyncratic. Also in our mind was the knowledge that this was just one day in the year, just a beginning, a way to open a conversation. We wanted the children and young people to feel safe and held within that conversation, knowing that at the end of the day they would be going home to their families.

So the activities were designed to be symbolic, 'read' at whatever level was appropriate to the child or young person's level of understanding. Adults who were accompanying and facilitating the process could choose to talk, or not, in terms that were general or more personal, literal or more metaphorical. This would depend on how well they knew the young person, both their circumstances and their modes of communication. We are well versed in the use of functional communication in school, but communication involving emotions may be more subtle: how can we help children and young people to be aware of, differentiate and process complex emotion?

Accompanying someone on this journey involves paying attention firstly to them, and to their nuances of gesture and behaviour, and paying attention to our own feelings and responses: we are often able to sense what another person is feeling by noticing shifts within ourselves. Being able to talk about our own losses may provide an opening for someone else to safely begin to grieve. Whilst some of us may choose to do some of our grieving alone, we need to know that others have walked that path before us.

The activities we chose were:

- Letting go: bubbles to blow, dropping a stone down a chute, butterflies to make or play with and real flowers that could be placed on the 'river of remembrance' [a blue sari] or taken or pulled apart. Many people [children and adults] enjoyed choosing a flower and placing onto the sari.
- What remains: Choose a special stone: if you wish decorate your special stone and place on the river of remembrance. At the end of the day, some

stones remained in their natural state, others were simply decorated or beautifully inscribed.
Light a candle, place as desired, write or draw a message, leave a photo plant a seed in a pot. Many people planted a sunflower seed in a small biopot, and took it away with them as a sign of the future to come.

- Comfort station: Hugs freely given on request. Teddies and Emoji cushions to cuddle. This was very popular! We expected staff to be a little nervous of this, and made sure that staff posted here were comfortable with giving lots of hugs, but staff and pupils alike were delighted! Care was taken that the emoji cushions included an angry and an ambivalent face, as well as a simple happy and sad. Young people could talk about what they were feeling, or not, as they wished or were able to indicate.

Picture above: This corner was also used for the Hanging Out Progamme time (Forster,2008) - time to just 'be.'

- Express: create a memory tree or remembrance wall – space and resources to write, draw or choose stickers to express a memory, thought, or feeling. This was intended to be a very open activity, an invitation, and many enjoyed taking time to express themselves through drawing or writing, choosing colours or stickers. There were heart stickers, emoji style stickers, stars and butterflies, to echo some of the images we sometimes use to talk about people who have passed
- Inner reflection: space to sit and reflect, alone or with others. Origami flowers to open in water. The flowers were intended as a representation of the impermanence of life: that things change for the better as well as worse, that renewal is possible. They are also just visually absorbing, encouraging a sense of calm and peace

At the end of the day we staged a butterfly release - as a symbol of transformation, hope and possibility. This proved to be a magical way to finish, invoking awe and wonder in the most sceptical of us! It was a day that was appreciated by pupils and staff: families were informed ahead of time so that they would be prepared for unexpected moods or responses at home; quiet activities and relaxed opportunities for talking created a calm atmosphere of acceptance in classrooms. We all need time, space and the depth of relationship to express and process our feelings. To open to grief takes courage, requires companionship; with an openness and acceptance of whatever comes. In the words of Jeanette Winterson: 'The missing part, the missing past, can be an opening, not a void. It can be an entry as well as an exit.'

Butterfly Day is now firmly on our annual school calendar: it will change and grow as we become more experienced in supporting our ordinary and extraordinary losses. It is the beginning of the conversation. In the future we hope to draw on the practices of other cultures who have tried and tested ways of regularly remembering the lives of those who have gone before us to develop our Butterfly Day further. We know that it will remain a valuable opportunity to celebrate lives as well as mourn them.

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References

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Forster, Sheridan (2008) HOP: Hanging Out Program : Interaction for People at Risk of Isolation. Free to download from : https://sheridanforster.com.au/passions/hanging-out-program-hop/

Flo Longhorn training events: http://flopublications.com/index.php/training/12-fpl-special-events

Read our blog on our adventures
creating sensory experiences with heart and soul -
https://sensorysoul.wordpress.com/

Championing Positive Risk

Esther Veale

There is freedom waiting for you,
On the breezes of the sky,
And you ask "What if I fall?"
Oh but my darling,
What if you fly?"
- Erin Hanson -

Positive Risk is often discussed as a vital element of person centered planning for people with learning disabilities and for those with dementia, and quite rightly so. It is widely accepted that we have a duty to enable people to make and enact choices about their own lives even if those choices don't work out and that equally, we have a parallel duty to ensure that those risks are measured, managed and that people are kept as safe as possible whilst taking them.

For a long time it has been acknowledged that positive risk taking is an essential aspect of achieving full and meaningful life experiences that create opportunities for development and growth. What is less often considered is what positive risk taking looks like for people with PMLD, where there is greater onus on family, support staff, teachers and carers to drive this agenda. Here, positive risk taking has no less importance and it still plays a role in individuals having agency, power and control over their lives. For these reasons, the notion of positive risk taking is embedded within the Core and Essential Standards; as part of strong leadership, as part of having meaningful life experiences and as part of playing a visible and active part in the local community. This article briefly unpicks what this could look like for people with PMLD and what it looked like for one person in particular; my sister Mary.

Mary was certainly a champion for positive risk taking; a true adventurer and 'adrenaline junkie'. She discovered on her many adventures that 'there is usually a way'. The combination of a Rough Rider wheelchair to tackle tough terrain, a vacuum posture cushion and a bevy of strong friends equipped with will and a keen sense of adventure to lift her over styles meant she could join in on cross country walks. She adored cycling in a Duet; a wheelchair tandem bicycle and feeling the full force of the breeze in her face. She enjoyed the contrast in speed from the acceleration of Devon's many steep downhills to the slow and steady huffing and puffing of her fellow cyclist as they then pedalled up the other side. She would consistently giggle at the bumps of the potholes and cobbles under wheel. She canoed, she camped, she would gleefully be bounced and buffeted by the surf in a dinghy on the North Devon coast. She stayed up late into the night at music festivals relishing the hubbub and revelry and making connections with her fellow festival goers.

Mary did all of these things and more until her death in March 2017 at the age of 33. She far outlived any life expectations placed upon her and astounded medical professionals with her resilience time and time again. Mary's longevity and her richness of life experiences were down to her own desire to push boundaries, to strive for more, to take positive risks and also to the willingness of those close to her and caring for her to interpret this desire for adventure and create opportunities for these adventures to happen. Mary lived fully and triumphantly within a framework of positive risk taking.

What is positive risk?

The word 'risk' invites a sharp intake of breath. The tension around the concept is palpable, even its utterance sounds like a highly venomous, hissing snake! Risk itself is merely about managing uncertainty, it is only about what might happen. Often the perception is that risk means a harmful outcome will certainly occur. In some social care settings there is the tendency to avoid all 'risks.' But much of the time the negative impact of avoiding all risks is far greater than the potential negative impact of taking some. Life is inherently full of risk, there is no escaping the fact that living is a risky business, especially so if you are a person with complex needs and medical conditions. Positive risk taking therefore is an acknowledgment of this. It is about striking a balance between safeguarding individuals and providing opportunities for individuals to expand their experiences; to grow and develop. There is a big difference between taking dangerous and hasty action in the hope that it will pay off and taking a considered approach where benefits and dangers are weighed up and steps are taken to reduce the likelihood and severity of these dangers. In essence, positive risk taking is about considering all of the 'what ifs' including those on the flip side. And in considering all the 'what ifs', as well as 'what if this could cause harm' we also include 'what if the outcome of this activity is triumph and joy' - and perhaps most importantly we consider the reality that will certainly be faced if we do not even try.

Why is positive risk taking so important for people with PMLD?

For parents and others charged with maintaining the wellbeing and safety of people with PMLD the desire to maintain a low risk existence is understandable when comfort, health and even life itself are already on a tipping point. In many respects, underneath an outward fragility of people with PMLD is a high degree of robustness. In most cases this is founded in a survival against the odds and as warriors of painful experiences and discomfort. In many ways we must ask ourselves how much more can be achieved by our hardy warriors! There is undeniably vulnerability to be considered and respected but alongside this is tremendous physical resilience and we have a duty to acknowledge this too and to set high expectations of the kinds of lives people with PMLD could and should live.

In setting these high expectations we must also accept the duty of advocacy in all aspects of life. As communities of care around people with PMLD, we are their extended means of accessing all the excitement the world has to

offer. Most people have the opportunity to take their own positive risks, to make considered judgement and to open up their own worlds. From the relative simplicity of choosing something new on a menu to decisions over whether to take up a potentially dangerous new hobby, it is all too easy to be overly cautious with the risks we take when these implications are for someone else. There is a danger of playing it too safe in case they don't like it or it doesn't work out for them. Instead it is our duty to accurately interpret long standing preferences that have been communicated and enable increasing exposure to opportunities that are based on these preferences. Perhaps if someone fleetingly smiles at moving fast in their wheelchair they should have more opportunities to do this in other ways, for example, on an adapted bike or swing. Positive risk taking is about acknowledging these communicated choices and having the bravery to act upon them.

Positive risk taking in the form of embarking on outdoor adventures, is important for many reasons but for my sister it was most powerful in its ability to connect her deeply to her immediate surroundings and, most importantly, to people sharing the experience with her. Through intrinsic enjoyment of having the wind in her hair, the sound of sea birds screeching and feel of sea spray on her face the most profound channels of communication were opened through a shared mindful acknowledgment of immediacy and of a moment lived together: "Did you feel that lurch in your stomach as we went over that humpback bridge on our bike? Me too!" This visceral enjoyment and connection with immediate sensations are often the most powerful arena for authentic connection with others when your capacity to imagine future and recall details of past events are limited.

What might positive risk taking look like for people with PMLD?

Risk is inherent in the sphere of outdoor adventures. This is what my sister lived for, what enlivened her and what, it can be argued, contributed to her longevity and quality of life.

One story of legendary significance in our family is that Mary once had a cup of tea mid abseil. Admittedly, a cup of tea mid-abseil is not everyone's 'cup of tea' and indeed positive risk taking need not be a literal interpretation of Erin Hanson's 'breezes of the sky'. For some people, those with PMLD and those without, the breezes of the sky offer no joy, indeed, the very idea of climbing or zip lining would be torture! Instead, positive risk taking means that there is will and action to take up safe and carefully planned opportunities to try new things and to gain new experiences or to gently and considerately increase tolerance and push boundaries through careful planning, judgement, reconnaissance and evaluation It is a step by step process of expanding comfort zones in an effort to create a positive outcome. Expanding comfort zones can also be about the wider community in which people with PMLD live too; by showing greater presence and participation in local community events it is possible to expand comfort zones of people with limited experience of meeting and communicating with people with PMLD. Positive risk is also about embracing and exploring the seemingly mundane, the everyday; perhaps going out in the snow or wind or rain for brief periods and allowing people to feel the wind and rain on their faces. Keeping warm by employing the insulating properties of a space blanket and creating an instant tent to listen to the rain falling from inside a warm cocoon. All before returning inside and enjoying the contrast of a warm footspa.

Ways of including positive risks in people lives will be different for different people at different times. These outdoor adventures weren't always a preference for Mary. On her first holiday as a tiny baby the wind, rain and change of environment was too much to bear. They were built up bit by bit until being out in the elements was a joyful experience. Later in Mary's life, when it was less appropriate to drink tea mid abseil, positive risk was about delaying the fitting of a gastrostomy feeding device so that she could continue to enjoy those cups of tea for as long as possible until the real risks of aspiration was greater than the sensory benefits of enjoyment from food. Later still, towards the end of Mary's life, positive risk taking was no longer about cycling and staying up all night, meeting new people and dancing the night away. It was about having high expectations for her care and

sadly about making brave decisions about where she should be in the last few days of her life.
Fundamentally positive risk taking for people with PMLD is important because there are very real risks of not taking positive risks. By not taking risks we deny opportunities for development, for growth and for happiness. Without positive risk taking we restrict people with less learning and less adventure. Embedding positive risk taking can be the difference between existing and living, between surviving and thriving. In making space for positive risk taking we must see the essence of the people we wish to plan for; Who are they? What would they do without limits? What makes them tick? What floats their boat? What brings them joy? What makes them sparkle? Can we enable them to sparkle brighter? Can we find more joy?

Mary's Beat

In memory of Mary a small fund has been set for others with learning disabilities living in Devon and Somerset who would like to apply for a small grant to fund some musical or outdoor adventures of their own. For more information and an application form, please visit http://www.somersetcf.org.uk/marysbeat

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In the Next Issue

Meaningful Lives

The theme of the next issue of PMLD Link (Summer issue) is 'Meaningful Lives'. We would like this issue to illustrate the many different 'meaningful lives' lived by children and adults with PMLD and their families and friends. We are also interested in the more general questions 'what is a meaningful life?' and 'what are the sources of meaning in the lives of children and adults with PMLD and their families?' In what ways do you support people to lead a meaningful life? Do you believe people with PMLD have access to a meaningful life? If not, what barriers present challenges and how can the issues be improved?

Can you contribute an article to help us? Or perhaps you can send us a photo or image which shows 'meaningful life' as experienced by a person with profound and multiple learning disabilities?

Articles can be anything between 300 and 2000 words. We would be delighted to hear from anyone with an idea for an article, however provisional, and stand ready to assist you to develop your idea. If sending us a photo or image, please tell us who is in it and your reason for sending it.

The deadline for submission of completed articles and photos is 11th June. We look forward to receiving your contributions!

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Twitter: the world of the banal or something more?

Jo Grace

Twitter is a social media platform where you get 280 characters to say anything you like. Comedian Shaun Lock points out that where once people would have walked along grumbling to themselves now they are able to share these grumblings with a global audience. I understand the point of view and the Twitter eye roll is one I receive a lot. But like any communication tool its value is in the way that you use it.

When you consider Twitter as a place where you can talk to anyone, without having to go to a physical location, and where conversations are necessarily concise (no time wasting waffling here), then you begin to see how well it matches the needs of someone who is time poor who wants to connect with someone else who shares an interest or expertise on a subject that those in their local pub or shop might not be able to help them with.

Through the wonders of Twitter I have been able to connect with research teams around the world and ask them direct questions about their research. To do that in real life I would have to travel hundred of miles and pay hundreds of pounds in expenses and tickets, to even stand a chance of having my question selected during a Q&A. Like I say: it’s how you use it that counts! And here at PMLD Link we are using twitter to generate conversations around topics important to the lives of people with PMLD. Not only do our #PMLDchat Twitter chats help to connect us and enable us to explore these topics but they have the wonderful side effect of awareness raising as by holding the conversations in the public space of the Twittersphere we place them somewhere where others might notice them and have cause to stop and think.

A whistle stop guide to joining our #PMLDchat Twitter chat.

- First you will need a Twitter account, you sign up with an email address, upload a profile picture (if you stay as an egg – this is the image that is displayed until you upload a photo of your choosing – some people may suspect you of being a robot not a real person). Come and find me: @jo3grace Click follow on my account and tweet me a hello (Do this by clicking the button that says Tweet and including my twitter handle: @jo3grace in what you write). I will be happy to show you around! Make sure you also follow @PMLDlink. When you follow an account the things they tweet will show up in your newsfeed.

- A Twitter chat is a way for a group of people who do not necessarily know each other to share a conversation about something they are collectively interested in. Imagine a public meeting hall with an advert inviting people to stop by to talk about a particular topic – you might pop in if the topic was of interest to you. Some chats are at specific times on specific days, others are slow chats which people drop into over the course of a few weeks or even a month. Our #PMLDchat is a slow chat which focuses on a different topic each month – we are always on the look out for new ideas so feel free to tweet us suggestions.

- To find what is being said in the current #PMLDchat simply put that hashtag into the search bar at the top of your Twitter screen. You can then choose whether to display the tweets chronologically or in order of the most popular, either will give you a flavour of things but chronologically is more useful when joining in the conversation. When you do this it is as if you are listening outside the door of the meeting hall, deciding whether to go in.

- You may see a particular tweet you want to respond to. Simply click ‘reply’ on that tweet and type your reply. When you type your reply make sure you add #PMLDchat into your tweet, this allows anyone searching the #PMLDchat hashtag to see your response. Using the hashtag is like stepping inside the room. If you tweet your reply without using the hashtag you are shouting from outside the room: you can hear what is being inside and you can hear your own shout, but the people inside can’t hear you. It’s like shouting at the television.

It really is that simple. Once you find chats you are interested in Twitter becomes a frenetic place full of fascinating conversations. We know from the current state of politics globally that it can be a horrifically powerful tool – use it for good!

Our most recent #PMLDchats at the time of writing have been about Puberty and about Assessment. Both proved to be very hot topics.

During the puberty chat we discussed how to address the challenges of becoming a teenager with individuals with PMLD, we recognised that this can be a point of weakness in schools and some tweeters shared their own ideas about how to tackle the situation. People advocated having open frank discussions between carers, parents and staff. One setting shared their use of sensory baskets that allowed their students to experience some of the sensations that would be associated with puberty before it was actually happening to them, for example being able to touch sanitary towels and get used to the feeling before having them placed against one’s body in intimate areas.

The assessment topic took place in the shadow of education's Rochford review which has questioned how students in special schools are assessed. What stuck out to me personally from this chat was the gulf in knowledge between staff working in schools and parents with children who attend those schools. In special school teaching circles Rochford has been much discussed but many of the parents attending our chat had not even heard of it, their question was “If this affects our children why weren’t we consulted?” A very good question indeed.

Our next chat will be about the use of the term Profound and Multiple Learning Disabilities. We will consider what other terms are used to describe this population and also question whether people who do not have Learning Disabilities, but instead experience great barriers to their learning because of their physical disabilities, are being given the label PMLD and what the implications of this are for them and for people with profound disabilities who also have multiple learning disabilities. Do join us, new voices are always welcome – remember the hashtag! #PMLDchat

IN THE NEWS

People with learning disabilities are dying early because of health inequalities.

The Learning Disabilities Mortality Review (LeDeR) Programme

University of Bristol Norah Fry Centre for Disability Studies

This information can be made available in formats such as easy read or large print, and may be available in alternative languages, upon request

Annual Report
December 2017

University of BRISTOL

NHS England

The latest report from the Learning Disability Mortality Review Programme (LeDeR) presents some harsh facts about the premature death rates of people with learning disabilities. From their findings 1 in 8 died from health inequalities and failings in care. People with Learning disabilities die on average 15-20 years sooner than the general population disabilities, 28% dying before the age of 50 – not because of their health conditions but due to the inadequate health care they received ; neglect or abuse, organisational dysfunction, delays in care or treatment and gaps in service provision were identified in the report

Of reviews completed so far (13% of deaths) findings highlight three areas for learning: 1.Inter-agency collaboration and communication. 2.Awareness of the needs of people with learning disabilities. 3.The understanding and application of the Mental Capacity Act (MCA).
Read the full report or the Easy read version http://www.bristol.ac.uk/sps/news/2018/leder-report.html

Information request about dental care

The aim of the report, as with previous 'reasonable adjustments 'reports from PHE, is to share information, knowledge and best practice throughout the country to support people in improving services and care. They hope to include as many good practice case studies as possible in this report so that other people can benefit and use this information to support people with learning disabilities in relation to their dental needs and oral health care. They want to signpost people to resources they can access free of charge. Please send your stories, examples of your work and resources that relate to dentistry services and oral health care for people with learning disabilities to anna.marriott@ndti.org.uk

New report on sight problems of children and young people

Looking back on four years of their 'Children in Focus' project, SeeAbility has supported over 1,200 special school children across England, providing adjusted eye tests and collecting data. This is the biggest global study actively reporting on the eye care needs of children with learning disabilities. SeeAbility states 'of the children using our service over a four year period we have found, with help from Dr Maggie Woodhouse in analysing our data that:

- Nearly half (47.5%) had a problem with their vision.
- A third (31.7%) needed glasses.
- Over four in ten (43.7%) had no history of any eye care
- Only 7% had ever used a community optician.
- Of those children with a sight problem more than a quarter (28%) had a problem that was previously unknown to school or their parents'.

SeeAbility are calling on NHS England to make wide reforms to community eye care for children and adults with learning disabilities and introduce adjusted eye tests in special schools. Failure to target these high-risk children with eye care they are able to access, is causing unnecessary vision impairment and putting their eye sight at risk. SeeAbility are using the hashtag #EqualRightToSight on social media platforms.
They have a 'top tips' bit on the website too to help direct people on getting better eye care information.
www.seeability.org/equalrighttosight

Parents win latest stage of legal battle

Parents whose children attend a respite centre for disabled children have won their latest legal challenge to keep it open. Herts Valleys Clinical Commissioning Group (CCG) said it would cease funding Nascot Lawn Respite Services in Watford due to "financial challenges". The High Court has ruled the CCG must now consult with Hertfordshire County Council over the proposed closure. Funding is now in place until August.
http://www.bbc.co.uk/news/uk-england-beds-bucks-herts-43142053

RESOURCES

'Healthy Eyes' Training Pack for adults with learning disabilities

The RNIB UK Adult Social Care Practice and Development Team 34 has developed a new training pack for adults with learning disabilities, to raise awareness of the importance of eye health.

This training pack will help adults with learning disabilities recognise possible signs of sight loss in family, friends and themselves, which they may not have been aware of before. It will also explain what to do if an individual thinks their sight is getting worse or they have a problem with their eyes. It has been developed to help increase the individual's confidence when attending an eye examination and to be aware of what is good and bad for eye health.

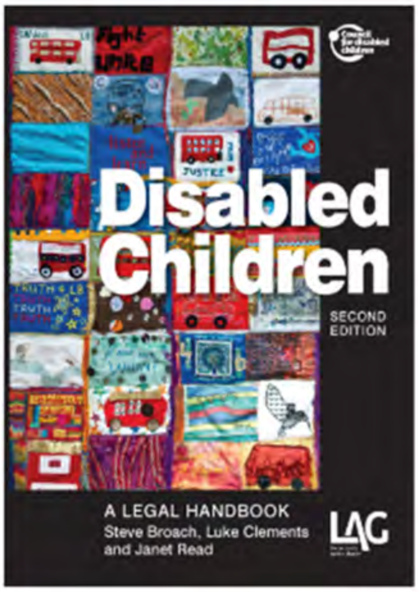
The training pack can be used within a group setting for adults with learning disabilities and would require a facilitator of the group to lead the training session. It includes video clips of scenes acted by The Good Life Group who are a group of adults with learning disabilities. The training pack will be available on a USB. This USB will include the training guide for the trainer and the video clips of the scenes.

If you facilitate a group and would like more information about the 'Healthy Eyes' training pack and how to receive one, please contact RNIB UK Adult Social Care Practice and Development Team by emailing UKPDT.Training@rnib.org.uk or phoning 0141 772 5588.

Holiday information guide

Hft's annual Holiday information guide for 2018 is out now! It is packed with information to help people with learning disabilities and those closest to them choose an accessible, disability-friendly holiday. It includes 5 pages of information about funding funding and grants to enable people to have the holiday they need.

https://www.hft.org.uk/our-services/family-carer-support-service/fcss-updates/holiday-information-guide/



Disabled Children: A Legal Handbook 2nd edition - free PDF version

Disabled children: a legal handbook is an authoritative yet accessible guide to the legal rights of disabled children and their families in England and Wales. The authors navigate the many, often overlapping, sources of law, explaining the difference between what public bodies must do to support disabled children and that which they may do.

Each chapter can be downloaded as a PDF file free of charge here: https://councilfordisabledchildren.org.uk/help-resources/resources/disabled-children-legal-handbook-2nd-edition26

The handbook aims to empower disabled children and their families through a greater understanding of their rights and entitlements. It is essential reading for the families of disabled children, their advocates and lawyers, voluntary and statutory sector advisers, commissioners, managers and lawyers working for public authorities, education, social and health care professionals, students and academics.

The handbook is also available to purchase in hard copy at £50 http://www.lag.org.uk/bookshop/children/2015/disabled-children-a-legal-handbook.aspx and for kindle at amazon.co.uk.

Tackling constipation

Constipation can be dangerous, even fatal, if not managed effectively but not everyone is comfortable talking about bowel movements. Dimensions have created a short film for guidance on regarding constipation, as it is estimated that more than 50% of people with a learning disability experience this at some point in their life

https://www.youtube.com/watch?v=OGF2ilywoiU

Learning Disability Statistics Scotland - 2017 report Resources

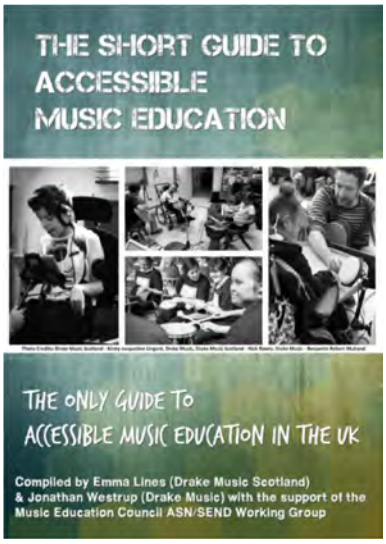
The Scottish Commission for Learning Disability (SCLD) publishes statistics about adults with learning disabilities who are known to local authorities in Scotland every year. The report for 2017 has now been published and is available for free download on the SCLD website: https://www.scld.org.uk/what-we-do/population-statistics/2017-report/

When I'm Gone—Toolkit and report

A recent report by Sense states that 75% of disabled people and their families have no long term support plan. Families need help to plan for the future. Sense offer insight into this issue from their recent research together with a set of practical tools to aid planning for the future. https://www.sense.org.uk/support-us/campaign/when-im-gone/

move item below to follow straight after item above onto page 44

Accessible music education



THE SHORT GUIDE TO ACCESSIBLE MUSIC EDUCATION

THE ONLY GUIDE TO ACCESSIBLE MUSIC EDUCATION IN THE UK

Compiled by Emma Lines (Drake Music Scotland) & Jonathan Westrup (Drake Music) with the support of the Music Education Council ASN/SEND Working Group

The free guide to accessible music education in the UK is now ready to download!

Drake Music & Drake Music Scotland have collaborated together with the Music Education Council's working group for Additional Support Needs to create The Short Guide To Accessible Music Education. The aim is to create a simple 'one stop shop' for organisations, resources, venues, assistive music technology and instruments for inclusive approaches to music education.

https://theshortguidetoaccessiblemusiceducation.wordpress.com/

Film for family carers "What happens when I'm no longer around"

HfT's Family Carer Support Service has launched a new film for family carers. "What happens when I'm no longer around" is a planning guide for families who have a relative with a learning disability, autism, or both. See the film at https://www.hft.org.uk/our-services/family-carersupport-service/fcss-updates/what-happens-when-im-no-longer-around/

Siblings – from Contact – For families with disabled children

This guide is about supporting the brothers and sisters of children who have a disability or long-term illness. It is written for parents and for those working with families who have a disabled child.

https://contact.org.uk/media/1174847/siblings.pdf


Families
contact For families with disabled children
Siblings
Information for parents of disabled children in England, Northern Ireland, Scotland and Wales

New guidance on making reasonable adjustments for Postural Care services

Public Health England have issued new information on the importance of postural care support and meeting the needs of people with postural care needs and learning disabilities. Download the resources from https://www.gov.uk/government/publications/postural-care-services-making-reasonable-adjustments

Connect with us on social media

@PMLDlink on twitter

Facebook pages:
PMLD Link
Raising the bar - COP for the PMLD care standards

Join in with the #pmldchat conversation focused on making a positive difference to the lives of people with PMLD.

See you online

SHORT COURSES & CONFERENCES

June

Title:	Intensive Interaction and Sensory-based Approaches: using Responsive Communication to support autistic people
Date:	8th
Location:	Aberystwyth
Provider:	The Caldwell Autism Foundation
Contact:	rorie@thecaldwellautismfoundation.org.uk
Title:	Five Day Course for Intervenors
Date:	11th-15th
Location:	London
Provider:	Jenny Fletcher, in partnership with Sense and NatSIP
Contact:	msi@jennyfletcher.co.uk
Title:	Excellence in Palliative Care Provision for People with Learning Disabilities
Date:	13th
Location:	London
Provider:	Palliative Care for People with Learning Disabilities Network
Contact:	https://www.pcpld.org/
Title:	Intensive Interaction and Sensory-based Approaches: using Responsive Communication to support autistic people
Date:	14th
Location:	Narberth
Provider:	The Caldwell Autism Foundation
Contact:	rorie@thecaldwellautismfoundation.org.uk
Title:	Promoting engagement in a sensory curriculum
Date:	18th
Location:	London
Provider:	Hirstwood Training
Contact:	www.hirstwood.com
Title:	Promoting engagement in a sensory curriculum
Date:	20th
Location:	Manchester
Provider:	Hirstwood Training
Contact:	www.hirstwood.com
Title:	Promoting engagement in a sensory curriculum
Date:	22nd
Location:	Newcastle
Provider:	Hirstwood Training
Contact:	www.hirstwood.com
Title:	Develop your Sensory Lexiconary
Date:	22nd
Location:	Cambridge
Provider:	Joanna Grace
Contact:	www.thesensoryprojects.co.uk
Title:	Intensive Interaction and Sensory-based Approaches: using Responsive Communication to support autistic people
Date:	22nd
Location:	Lampeter
Provider:	The Caldwell Autism Foundation
Contact:	rorie@thecaldwellautismfoundation.org.uk
Title:	Intensive Interaction and Sensory-based Approaches: using Responsive Communication to support autistic people
Date:	29th
Location:	Ammanford
Provider:	The Caldwell Autism Foundation
Contact:	rorie@thecaldwellautismfoundation.org.uk
Title:	Develop your Sensory Lexiconary
Date:	29th
Location:	Manchester
Provider:	Joanna Grace
Contact:	www.thesensoryprojects.co.uk

July

Title:	Equals summer conference
Date:	6th
Location:	London
Provider:	Equals
Contact:	http://equals.co.uk/
Title:	The Super Sensory Lexiconary
Date:	6th and 7th
Location:	London
Provider:	Joanna Grace
Contact:	www.thesensoryprojects.co.uk
Title:	Social History of Learning Disability Conference
Date:	10th & 11th
Location:	Milton Keynes
Provider:	The Open University
Contact:	Shld-conference@open.ac.uk
	Advanced notice!
Title:	Flo's Forum – Creative Curriculum Creative Teaching
Date:	29th and 30th November
Location:	London
Provider:	Flo Longhorn
Contact:	florencelonghorn@gmail.com

Raising the Bar II

Friday 2nd November, Birmingham

A day filled with inspiration ~ hear about innovative ideas & great practice of the PMLD standards in action!

Join us to celebrate PMLD Link's 30 years of sharing information and ideas that help improve the lives of people with PMLD

Tickets
https://www.eventbrite.co.uk/e/raising-the-bar-ii-national-pmld-conference-tickets-44284684684

PMLD LINK
sharing ideas and information

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	Non UK:	Personal	£27.00	Organisation:£40.00

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Date …………/……………../……………..

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Please pay:	HSBC Bank plc, Ross-on-Wye branch
For the Credit of:	PMLD-Link
Account No:	81156284
Sort Code:	40-39-06

The sum of: £………………

Commencing: ……………………………………...

Account to be debited: ………………………………………………………………………………………

Account No. ……………………………………….

Signature(s): ……………………………………………………………………………………………………

Date: ……………………………………………

About Us

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

Rob Ashdown	Former teacher of pupils with severe and profound and multiple learning difficulties and special school Headteacher.
Jeanne Carlin	Retired Disability Consultant and a parent of a young woman with PMLD.
Helen Daly	Mum to a young Adult with PMLD, previous career in Further Education for 20 years - including Curriculum Team Manager for Inclusive Learning and Developing an Improving Choice Programme for people with Complex Needs. Currently involved in carers groups in the Eastern Region, Learning Disability Partnership Board and associated projects.
Ann Fergusson	Annie is a senior lecturer in the SEN & Inclusion team at the University of Northampton, teaching on undergraduate and postgraduate courses relating to severe, profound and multiple learning disabilities. Her research interests relate to person-centred working, meaningful participation and the voice of the individual in promoting positive mental health and wellbeing. She works one day a week in a special school with a role for training and looking at impact. Annie has a brother with a learning disability. She is a family member of the Learning Disabilities Mortality Review Programme Advisory Group.
Michael Fullerton	Michael the Director of Quality and Clinical Care with CMG, a social care provider supporting adults with profound and multiple learning disabilities. Michael is a registered learning disability nurse and leads a health team focused on the quality of life of people with PMLD. Michael co-hosts the @PMLDChat Twitter chats.
Martin Goodwin	Martin is a teacher of pupils with PMLD and a Regional Tutor/Visiting Lecturer for the Severe and Profound Multiple Learning Disabilities course at the University of Birmingham. Martin has specialised in approaches to improve interaction, communication and participation of people with severe and profound learning disabilities. Martin has experience of working in play and leisure, education, residential and advocacy.
Joanna Grace	Joanna Grace is a sensory engagement and inclusion specialist. She is the founder of The Sensory Projects which are run on the principle that with the right knowledge and a little creativity inexpensive items can become effective sensory tools for inclusion. Joanna co-hosts the #PMLDChat Twitter chats.
Rachel Parry Hughes	Lecturer in Social Work, Goldsmiths, University of London, researcher in the field of profound and multiple learning disabilities
Becky Loney	Becky has a background in running creative services for adults with PMLD within the voluntary and statutory sector and she established the Lambeth Mencap Carousel project. Becky is passionate about intensive interaction and sensory storytelling, and spreads the word by training staff teams in high quality activities and creative approaches.
Wendy Newby	Deputy Headteacher at The Shrubberies School, Stonehouse, Gloucestershire. This is a school for students with Severe and Profound Learning Difficulties
Sue Thurman	Former NHS Speech and Language Therapist for adults with learning disabilities with a particular interest in PMLD. Now writes and trains about communication and is a Registered Intermediary assisting vulnerable witnesses to communicate at police stations and courts.
Bella Travis	Policy Lead, Mencap
Hannah Young	Hannah completed her PhD studies on the loss experiences of people with PMLD. She is Researcher for PAMIS, a Scotland-based charity supporting families of people with PMLD, and has led a number of projects that aim to enhance quality of life for this group. Her experience also includes teaching, training and digital developments. Hannah acts as Welfare Guardian for her brother.

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

PMLD LINK

sharing ideas and information

PMLD Link is a journal for everyone supporting people with profound and multiple learning disabilities.
Visit www.pmldlink.org.uk

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