PMLD LINK

sharing ideas and information

Current issues

Winter 2024

Vol 36 No 3. Issue 109

ISSN 2042-5619

Winter 2024, Vol. 36 No.3 Issue 109

PMLD LINK
sharing ideas and information

Winter 2024 contents

11 When the World Turns

14 My Beautiful Girl

32 What Matters to Me

Page		
1	Guest Editorial: Current issues	Bella Travis, Maureen Phillip and Rob Ashdown with Nicola Grove and Pete Navarra
2	Welcome to the world of Sherborne Developmental Movement!	Amy Fowler and Amanda Turner
5	Veronica Sherborne: an appreciation	Rob Ashdown
8	Silly sessions and the benefits of laughter	Claire Campbell
11	When the World Turns	Flossie Waite
14	My Beautiful Girl	Heather Bailey
18	Always look on the bright side…	Anna Cauvin
20	Working together to influence policy on cost of living and energy costs	Maddy Rose
23	The Power of Stories	Maureen Phillip
26	Two People, Four Hands, No Symbols, Interaction…	Sheridan Forster
27	PAMIS postural care passion providing support for families like Freya's	Carolynne Hunter and Michelle Morrison, illustrated by Kathleen Shearer
32	What Matters to Me: Influencing policy with the experiences, preferences and views of young people with severe or profound and multiple learning disabilities	Taylor Anderson
34	Dear Santa – a festive sensory story	Victoria Navin
39	Point5 Network: an update since 2017!	Liz Baxter
41	Respiratory Community of Practice	Laura Canning
42	Creating a resource that captures the social histories and lived experiences of the PMLD community: which stories should be collected and shared, and how?	Ben Simmons, Becky Churchill and Katie Crouch
43	The PMLD LINK 'Reference group' – Themes that have been raised	PMLD LINK Editors
48	People with profound and multiple learning disabilities in war zones around the world	PMLD LINK editors
50	In the next issue:	Annie Fergusson, Maureen Philip, Michael Fullerton and Rob Ashdown

PMLD LINK
sharing ideas and information

Winter 2024, Vol. 36 No.3 Issue 109

GUEST EDITORIAL
Current Issues

Welcome to the Winter edition of PMLD Link! The theme is 'Current issues' and we hope there is something for everyone to enjoy or be inspired by in this bumper issue for the festive season.

Whether you would like some practical instructions for a 'silly session' or for a sensory festive story; to hear about families' experiences of navigating the system and trying to get the right support for their family member and for themselves, here, and abroad; to be inspired by sensory theatre, story sharing and creative communication; or to read about work going on to influence policy and meaningfully involve people with profound and multiple learning disabilities – you are in the right place.

If you are looking to get involved in something new in 2025 you will find lots of opportunities in these pages! For example, opportunities to help shape research and policy, join communities of practice/ networks and last but not least - join our PMLD Link reference group!

Read on to find out more…

Thank you to all our fantastic contributors and readers over this year!

Wishing you joy, happiness and peace for the festive break and for 2025.

Guest Editors: Rob Ashdown, Maureen Phillip and Bella Travis with Nicola Grove and Pete Navarra

PMLD LINK is a registered charity: No 1121085. It publishes the PMLD LINK journal three times per year and maintains a website and social media presence. It is run entirely by volunteers.

The journal number is ISSN 2042-5619

Contact Us

The registered address for PMLD LINK is:

Caerludd, Cilgerran,
Cardigan, SA43 2SN

To contact the charity editors or trustees:

Email: info@pmldlink.org.uk

Social media

Website: www.pmldlink.org.uk
X: @PMLDlink
Facebook: @PMLDLink

Production of the journal is by:
Paul Bramble

Welcome to the world of Sherborne Developmental Movement!

Amy Fowler and Amanda Turner

Being active and learning to become physically literate are very important for the well-being of both children and adults. Research demonstrates the effects of physical movement on emotional and mental well-being as well as on health and fitness (Mental Health Foundation UK, 2024). It is equally important for people with or without disabilities. Yet a truly inclusive movement programme is often hard to provide.

Sherborne Developmental Movement (SDM) has been created specially as an innovative and inclusive experience which is adaptable, collaborative, challenging and great fun.

In schools, SDM can be used to meet many of the core National Curriculum requirements in all key stages. It enables engaging, creative provision of major aspects of the Early Years curriculum. It is a successful approach for personal, social and emotional learning, and supports teaching and learning of personal and interpersonal communication, language and literacy, including drama. Many mathematical concepts can be taught using SDM and it provides a solid movement education for all Physical Education.

SDM can fit readily into your existing work and provision. It promotes positive learning and personal success. It is relevant, enjoyable and accessible to all. It makes a positive difference.

So what is Sherborne Developmental Movement (SDM)?

SDM was created by Veronica Sherborne and it is a way of developing an awareness of the body and of others. It would be helpful to show how this came about by exploring who Veronica was and the influences and experiences she had that led to her creating movement experiences for the children and adults she worked with that we now call SDM.

Veronica Sherborne was born in 1922, and began her journey into education in the 1940s. She trained as a teacher at Bedford College of Physical Education in the early 1940s. At this time, training to be a teacher at Bedford meant that she was granted recognition as a physiotherapist and a teacher. Her training would have given her all the skills she needed to teach formal PE – which at that time was quite 'military style'.

Bedford College was forward-looking in dance and arranged for visiting lecturers from abroad to share their knowledge and skills. This was when Veronica met Rudolf Laban, during a three day visit to teach the students. His work had a huge impact on Veronica, and later into her career she sought out Laban.

After graduating as a teacher, Veronica taught at Cheltenham Ladies College for 3 years, and it was during this time that she encountered Laban for a second time, during summer time courses that he ran with Lisa Ullman and Veronica attended.

Veronica continued her long teaching career as a lecturer of dance at Bedford College of Physical Education and later she moved to Bath Academy of Art. In 1950 Laban called on Veronica to join him at Withymead Centre in Exeter as a movement therapist. In the mid-1950s, she used some of her ideas gained from Laban's influence, to teach her trainee teachers who then used these techniques with the students they worked with. As she saw great success with her techniques, she then began to develop these techniques with children with special educational needs.

She worked in a variety of settings, developing her ideas with children, adults, parents, teachers, care workers and therapists. Her experiences of movement changed as she used movement with different groups of people, including her own three children.

"The physical bonding she encountered during motherhood and subsequent physical play with her developing children gave her a new and profound insight into the importance of movement, play and relationship in child development" - (Marsden and Sparkes, 2007).

Veronica had a unique and distinctive way of working – focusing on "shared movement experiences". Her work focused on movement experiences for the whole person and their needs, rather than a specific movement technique itself. This is what sets Sherborne Developmental Movement apart from other movement approaches.

Veronica made 6 films between 1965 and 1986, and wrote her book "Developmental Movement for Children" (Sherborne, 1990), after much pressure from others to write it – and thank goodness she did!

She visited and taught her method around the world, including the UK, Canada, Norway, Poland and Australia. Today SDM is still used around the world with Internationally Qualified Course Leaders (IQCLs) in the UK, Norway, Sweden, Belgium, Germany, Greece, the Netherlands and Japan.

She worked with children with severe learning difficulties, and then extended her work to include people of all ages and all needs, and then with adults with dementia. Veronica's work with Laban led her to understand that movement didn't have to follow mechanical approaches. She learned through Laban that movement could be free and be a personal expression.

She was always reluctant to write down her ideas and define exactly what SDM was, she did not want to become a list of prescribed movements or a movement programme.

Sherborne Developmental Movement is a dynamic process between those who use it. It is all about naturally occurring and spontaneous play and movement. Sherborne Developmental Movement can be used with anyone of any age. In the years before and following her death, SDM has been successfully used with babies, children, young people and adults with severe, profound and multiple learning difficulties, trauma, dementia, autism and within mainstream settings. Being able to be present and having good observation skills, allows the practitioner to release their inner child and join in the fun and enjoyment that SDM brings.

Research evidence and SDM

The Sherborne Association UK supported Sunfield Publications to produce an exciting book, "Moving with Research - Evidence -Based Practice in SDM" (Marsden and Edgerton, 2007).

A dive into this book will help you discover some areas of SDM that have evidence based research. Research includes a two year study by Jotham Knodaka focusing on using SDM with children with autism. Research by Dr Liz Marsden focused on improving movement vocabulary and social development of children in early years using SDM. Dr Janice Filer led a study into the bonding potential of developmental movement play. Carrie Weston looked at the influence of SDM on teacher

approach. Dr John Dibbo identifies positive links between SDM and the teaching of gymnastics in primary schools. Marta Bogdanowicz from Poland developed a study to explore her Scale of Observation of Behaviour for Children. Birgitta Althoff from Sweden aimed in her research to find out if it were possible to stimulate movements in people with multiple disabilities through SDM, and give them new opportunities to move, communicate and develop relationships with others.

Who is SDM for?

EVERYONE!! That's the simple answer but in reality we can work with anyone – anyone with or without a physical disability, anyone with health conditions or impairments, young children and their parents, school aged children, students and the elderly.

Do you want to train to use SDM? Here's how!

We use a drawing of a tree to symbolise the structure of the SDM training. The roots symbolise the variety of experiences participants bring to the training programme. The trunk, which is numbered 1 to 12, symbolises the 12 sessions you would need to complete in order to become a SDM qualified practitioner.

Each session is 3 hours long. The branches at the side to the tree (following sessions 4, 6 and 12) indicate where a participant will receive a certificate and can choose to exit the process at that point, or continue to gain further qualifications in SDM.

The branches at the top of the tree represent areas of specialism that the SDM qualified practitioner can choose to pursue. e.g. as a qualified course leader for training, for research or for specific populations.

Sessions 1-6 are based on four aspects that are common to each session;

- learning through movement experience
- learning about the theory of SDM, including Laban's principles of movement
- learning to observe accurately, make assessments and plan ahead
- developing the skills and knowledge required of a reflective practitioner

The training is delivered by an IQCL - an Internationally Qualified Course Leader. They come from a variety of backgrounds including teachers, dancers, therapists and lecturers in education.

The intention in the first six sessions is to give course participants a strong foundation of personal movement experiences. Embedded in these experiences is guided reflection aimed at developing reflective practitioners.

The first 6 sessions focus on body awareness, spatial awareness, relationships, movement qualities and planning.
Having completed session 6 and before returning for session 7, the participants are required to complete the minimum of 12 hours teaching in their own workplace, over a minimum of 12 weeks.

So if you truly want a moving experience for yourself or for those who depend on you, contact us today! We offer training courses throughout the UK provided by our IQCLs.

Please get in touch through our website www.sherbornemovementuk.org or email contactus@sherbornemovementuk.org

We can't wait to start moving with you!

Contact Details

Amanda Turner - Chairperson and IQCL Sherborne Association UK
Amy Fowler - Training Officer, ISCO Rep and IQCL Sherborne Association UK.

Email: contactus@sherbornemovementuk.org

References

Cullingford-Agnew, S. with Carter, N. , Craddock, A., Rollings, C., Dowson, B. and Brighton, H. (2015) In Lacey, P., Ashdown, R., Jones, P., Lawson, H. and Pipe, M. (eds) *The Routledge companion to severe, profound and multiple learning difficulties.* Abingdon: Routledge

Hill, C. (1998) *Sherborne Developmental Movement: An overview. PMLD LINK,* Issue 32, Vol. 11.1, 16-20

Marsden, E. and Egerton, J. (2007) (eds) *Moving with research : evidence-based practice in Sherborne Developmental Movement* Sunfield, Stourbridge : Sunfield Publications

Sherborne, V. (1990) Developmental *movement for children* 1st edition Cambridge University Press: 2nd edition (2001) Worth Publishing

PMLD LINK
sharing ideas and information

Winter 2024, Vol. 36 No.3 Issue 109

Veronica Sherborne: an appreciation

Rob Ashdown

My clearest memories of Veronica Sherborne are from the early 1980s. When I did teacher training at Bristol Redland College in 1978/9. Veronica was a Senior Lecturer on the specialist course for teaching children who would now be described as having severe or profound learning disabilities. She was a truly inspiring person. She had already developed her unique way of engaging children and adults in interactive learning through movement and I can recall that perhaps 50 per cent of scheduled course activities were spent in a hall at the college practising a range of movement activities on its polished floor. At the time, I was very much into researching and using behaviour modification techniques and the available approaches to teaching were very much teacher-controlled and mechanistic. Veronica's approach was the absolute antithesis and positively encouraged child-led social interactions and enjoyment. I liked the approach but I am not sure that I ever 'found my centre' though. Veronica's approach became known as Sherborne Developmental Movement (SDM), which is described in her book, Developmental Movement for Children (Sherborne, 1990).

My own subsequent teaching experience in special schools showed me that SDM could be made applicable and accessible for all learners, adults and children, including those with profound and multiple learning difficulties if quality training for staff and good resources were made available. It enabled learners to be active and helped them to build relationships and develop their communication skills. The role and behaviour of the adults (teachers, teaching assistants and volunteers) was crucial. The movement of their bodies in close contact with the learner provided security and support, using free-flow activities such as rocking, rolling, sliding, spinning and crawling. The rapport between partners (adult with learner, even learner with learner) and communication between them helped to develop relationships, self-confidence, and self-knowledge and meet social and emotional needs.

Veronica taught that developing the learner's awareness of their body was fundamental. For instance, she created a game called 'Parcels' that involves one learner curling up, then being 'unwrapped' by another learner or an adult. She suggested that spinning on the floor, on bottoms or stomachs, and other whole-body experiences, such as rolling across the floor, would help also to give learners a sense of stability and flexibility and a chance to move with confidence and meaning. Of course, learners with profound learning difficulties needed much physical prompting and encouragement from supporters to participate in these activities. Some activities proved too difficult for some learners with severe physical disabilities but activities, such as side lying and gently turning onto fronts or backs, gentle swinging in blankets or being pulled on their backs across the floor on blankets, were enjoyable and arguably went some way towards developing whole body awareness.

Veronica emphasised the importance of the nature of the floor for body and spatial awareness experiences like sliding, rolling, lying, crawling, spinning and running. She taught that a relatively friction-free floor surface, ideally a polished wooden floor and certainly not a carpeted area, is best for learners to move around and to feel secure and safe in what they are doing.

She stressed that movement activities could be used playfully to develop trust, communication and good relationships; for instance, cradling and supporting, rocking and rolling, swinging and seesaw movements. The guiding partner's calmness, facial expressions, vocalisations, and gentle touches and prompts could help promote engagement and interest from the learner and, hence, promote communication and social awareness. So Veronica valued partnership work: parents or carers with their children, education practitioners with their pupils/students, secondary and primary-aged mainstream school pupils/students with learners with disabilities, and older learners with less severe learning difficulties in partnership with learners with PMLD.

In this kind of relationship play the partners get to feel their body weight against each other. For example, two partners might sit facing each other, touching palms. The guiding partner, perhaps with help from somebody sat behind the learner, supports the learner to slowly raise their hands and do circling and directional movements as mirroring actions. Again with the partners sitting facing each other, with their hands placed on each other's shoulders, they rock gently backwards and forwards together. They might also do a rowing motion, holding each other's hands, with one partner bending backwards, pulling their partner towards them and then reversing the action. Learners might be 'cradled' by an adult sitting

on the floor and gently rocked. This could lead to the learner gradually relaxing and learning to trust their partner. Of course, these activities give opportunities for listening, learning, giving and receiving eye contact, smiling, and gentle touch.

> *"SDM can be seen as a 'conversation' that goes back to the fundamental interactions between people or between a parent /carer and child. Many learners may need additional support to facilitate this conversation, e.g. physical guidance, augmentative communication systems, careful positioning, etc. It is the realisation that movement can be used to develop relationships and communication, in order to feel a sense of wholeness and not to be concerned only about the movement of separate parts of the body, that sets SDM apart from other approaches to PE."*
>
> (Cullingford-Agnew et al, 2015, p.326)

The above only illustrates some of the possible activities. Cyndi Hill provides a good overview of SDM in this very journal (Hill, 1998). Cullingford-Agnew et al. (2015) summarise how Veronica Sherborne sought to develop relationships:

With – Relationships: where partners contain, support and use free-flow and building a rapport.
Shared – Relationships: where partners alternately support each other and demonstrate confidence.
Against – Relationships: to help the learner to focus, channel energy and develop determination.

SDM, done with a partner or within small groups, focused upon the following, among other things:

Awareness of the ground – activities include lying, rolling, creeping, spinning, sliding and pushing.
Awareness of the centre of the body – this includes rocking, being contained by a partner.
Whole body experiences – this includes swinging (in blankets), rocking on backs, sliding, maintaining a stable position against others.
Awareness of hips – includes sitting, rocking on hips, and pushing and pulling.

In the schools where I worked we found that the sessions did not have to take place in a large hall but could also happen in the more familiar environment of classrooms for pairs or small groups of learners. However, there had to be room for wheelchairs, standing frames, hoists and other equipment and furniture to be set aside as well as enough space for the activities. Gym mats could be useful for sitting and lying, and cradling, rocking and rolling activities, though there were real advantages in using a smooth, friction-free floor for many activities.

Sustaining or completing an activity was not insisted upon if a learner's reaction clearly demonstrated dislike of the activity. Most of all we aimed for the movement sessions to be fun for all concerned and always looking for ways of incorporating ideas suggested by the reactions of the learners or adults. Much use was made of visual and auditory cues to signal the start and end of each activity and each session.

Planning by the teacher had to be thorough (but plans had to be as flexible as need be) and communication had to be good within the team of teachers, teaching assistants and volunteers. The team needed to have good knowledge of each learner's likes and dislikes, their particular interests and strengths. For instance, some learners could be tactile-defensive initially in activities; some disliked being contained. There had to be at least one supporter for each child with a few besides so school leadership teams have to be persuaded to make available the human resources and source volunteers. Risk assessment was also necessary; after all some learners were of adult size in our school. For example, rolling a learner might require the strength of two adults or, for cradling, the lead adult might need to have their back against a wall or be supported by another adult at their back.

The involvement in the process of planning and review of the school's physiotherapist and other health service professionals was also essential for some learners on physical development programmes (physiotherapy, hydrotherapy) because we needed to be clear which activities were likely to be most beneficial and which were contraindicated due to a learner's particular physical disabilities or any medical issues (e.g. prescribed body braces and splints, gastrostomy – fed).

In my opinion, the emphasis on relationships and communication and the range of activities means that SDM is more appropriate for learners with profound learning difficulties than other physical education approaches. But they require well-trained, well-organised and well-resourced teams. The value of getting good quality training from specialists (e.g. from the Sherborne Association) and being able to watch and work alongside experienced practitioners cannot be over-emphasised.

SDM has been the subject of several small-scale evaluations: for instance, see the volume edited by Marsden and Egerton (2007). In the all-too-distant past, pieces about SDM and Veronica have appeared in PMLD LINK from time to time. Barry Carpenter wrote a review of her book (Spring 1991 issue, No 9, Vol 3.2). Sadly, Veronica died shortly after the book was published and appreciations of her by Cyndi Hill and Barry Carpenter appeared in the very next issue (Summer 1991, No 10, Vol 3.3) and Cyndi Hill produced two more pieces (Spring 1995, No 21, Vol 7.2; Winter 1998/9 No. 32, Vol. 11.1).

An archive of Veronica's papers and other materials is preserved at the University of Birmingham (https://calmview.bham.ac.uk/GetDocument.ashx?db=Catalog&fname=MS48.pdf). Other books and resources are available on the Sherborne Association's website: www.sherbornemovementuk.org

Contact Details

Rob Ashdown is an editor and trustee for PMLD LINK
Email: info@pmldlink.org.uk

References

Cullingford-Agnew, S. with Carter, N. , Craddock, A., Rollings, C., Dowson, B. and Brighton, H. (2015) In Lacey, P., Ashdown, R., Jones, P., Lawson, H. and Pipe, M. (eds) *The Routledge companion to severe, profound and multiple learning difficulties.* Abingdon: Routledge

Hill, C. (1998) Sherborne Developmental Movement: An overview. *PMLD LINK*, Issue 32, Vol. 11.1, 16-20

Marsden, E. and Egerton, J. (2007) (eds) *Moving with research* : *evidence-based practice in Sherborne Developmental Movement* Sunfield, Stourbridge : Sunfield Publications

Sherborne, V. (1990) *Developmental movement for children* 1st edition Cambridge University Press: 2nd edition (2001) Worth Publishing

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 info@pmldlink.org.uk

PMLD LINK
sharing ideas and information

Silly sessions and the benefits of laughter

Claire Campbell

I would like to share my experiences of creating 'silly session', a session that supports developing interoceptive awareness (see Note 1 at end) and self-regulation through silly, playful interactions that also support a reduction of anxiety and developing close bonds through shared laughter.

I taught in mainstream primary schools and specialist settings for twelve years, leading on music and sensory integration before leaving teaching a year ago. I created this session after listening to a podcast discussing the benefits of laughter for autistic children (White, 2022). The way that laughter reduces anxiety, the way that laughter can skip you to the end of the stress cycle, and the way that your physical health may be benefited from laughing more. The podcast discussion mainly focused on laughter yoga classes and the delivery of these. I loved the idea of something so simple impacting pupil wellbeing so strongly, but I knew this type of formal class would not be accessible to my group of learners at the time, so I went away and created something that was.

There came the birth of 'silly session'. I explored the benefits of dedicating set time to laughter in the classroom and found that I could include communication, self-regulation and concentration skills on the list of things explored and benefited during this session. I gave the session structure, used visuals, picture symbols, songs, communication boards, sensory items and the children's interests to make this session accessible and enjoyable for my learners. I also looked at developing agency and autonomy for the children, giving different options and accepting all communication styles. The children could indicate preferences, make choices and practise consent during this session of shared laughter.

I quickly saw that the children were always very calm at the end of the session (no matter the potentially chaotic route!) and that this could support their understanding of being calm. How often do we say to children 'calm down'? I wonder how many children know how to calm down or what calm feels like. Therefore, I added more explicit reference to feelings during our sessions, using ways appropriate to my learners to model this (some children may be able to identify emotions more easily using colours or photographs). When we were in full on silly mode, I was sure to repeat 'I feel silly' and identify indicators such as ‘my heart is beating fast’. When we then reached our calm state I would reinforce 'I feel calm. My body feels relaxed’. I used a simple accordion style squeeze box toy to demonstrate the tensing and relaxing of our muscles in these different states and to support developing those interoceptive skills. How does my body feel when I'm excited? How does my body feel when I'm calm?

Later on as Sensory Integration lead in a specialist setting, I found I was often asked for support for children who would benefit from accessing sensory circuits (like a gym circuit with three activities designed to energise the senses, organise the senses, and then calm them, leaving the participant regulated and ready to learn) but could not access a typical sensory circuit. Many of the children in school would find it difficult to follow instructions or to engage with resources in a specific way such as throwing bean bags into a hoop. My pupils would want to collect the bean bags, line them up, sort them and at least one would set themselves the task of freeing the beans! So this type of very PE based procedure of a sensory circuit was not accessible to them. It was then that I realised I already had a session that energised and organised the senses before calming and leaving the children relaxed and ready to learn. I had a session that did that without the demand to engage in resources in a certain way but achieved this in a fun and child-led way. And so the silly session grew throughout that school as a way of offering an alternative to a sensory circuit.

However, an even more valuable benefit of a silly session is the relationship building. It is such a bonding experience. Discovering that pupil X is very ticklish behind the knees, seeing the funny face that pupil Y pulls when they are laughing really hard, hearing that gasp for breath and silent chuckle that pupil Z makes when they can barely breathe because they are laughing so hard (but they're still grabbing your hands and asking for more tickles!). And the ideas behind the session are applicable anywhere. You don't need to have a formal timetabled slot and complete a structured session. It is equally useful to use laughter and silliness ad hoc as and when needed.

On one occasion when working with a child with profound and multiple learning difficulties. I had the challenge of building a relationship with them via video

technology whilst they were shielding during the Covid pandemic. I sang lots of silly songs and one song accompanied an activity where I produced something from my magic bag. Here I used the technology to my advantage, making it look as though all kinds of weird and wonderful things were appearing from my magic bag. This always got lots of smiles and it became a favoured activity that we did most days. Several months later, another practitioner was attempting some feely bag games with this child – activities that they had enjoyed in the past but were now reluctant to take part in. They made attempts to indicate there was something wrong, but the practitioner was unsure what it was. After chatting to the child's parents, who were present for our video sessions, they discovered that the child wanted them to sing the silly song when they got things out of the bag. It is a very small thing but felt significant as we were able to offer that autonomy to the child and give them ways to ask for that song, but also because our silly games had left a mark. They had been impactful, they had been remembered, they had been enjoyed, and the child wanted more.

Since leaving the school setting, I have used silliness and laughter in 1:1 contexts with other children. I am a tutor in alternative provision supporting both children and young people with complex support needs who are unable to access their school provision due to anxiety and/or trauma, and young people with English as a second or other language. At home, my husband and I have used laughter on countless occasions to support parenting our own children.

A valuable outcome of the silly session is that children learn ways to self-regulate and that they can communicate their needs or request these activities independently. This therefore has a positive impact on wellbeing but since leaving my SEN teaching role, I have questioned whether some of the practices in schools are positively impactful on wellbeing. Are they neurodiversity -affirming or are they damaging to autistic and otherwise neurodivergent or disabled pupils? (See Note 2 at end.) The aim of these sessions is not to train compliance or to favour any expected way of communicating. It is to provide such appealing interactions based in such strength of relationship that children are intrinsically motivated to engage. It is for the children to feel their sense of safety in you growing and their anxiety reducing through bonding experiences of shared laughter.

So what do you need to try a silly session? Very little!

Stage 1 - get silly! 5 minutes of silliness. Tickle, chase, force laughter, roll around on the floor together, pull faces, mirror each other (a lovely opportunity to use intensive interaction), and sing silly songs. Give opportunities for the children to choose which silly activity they like best and for them to lead the activities. Use picture symbols, signing, gesture, communication boards to support your understanding of how each induvial chooses to communicate and build the idea that these are activities you can ask for.

Stage 2 - a circuit breaker activity. We 'shake our sillies out' by dancing along to the song. This is nice because it keeps the silly theme whilst using organising skills needed to copy the actions. But you could do any simple activity with an organising function such as throwing coloured quoits onto matching-coloured pins or marching to the 'grand old duke of York' with the simple up and down actions.

Stage 3 - calm time. Choose any preferred calming activity. Sensory play with sand, rice or water; exploring Twiddle resources; massage; reading a book; doing a puzzle. Follow your child's interests.

There is little set up and few resources needed. You by no means need to always follow all the stages to see the benefits of laughter and silliness in your home or other learning setting. A tickle here, a silly song there and we can all be laughing our way to being less anxious and better regulated beings.

Notes

Note 1 - Interoception is an internal sensory system in which the physical and emotional states of the person are consciously or unconsciously noticed and recognised and the person responds appropriately. Interoception skills are required for a range of basic and more advanced functions, such as knowing when to go to the toilet or being aware that you are becoming angry or upset.

Note 2 - Neurodivergence is often used as the term for when someone's brain processes, learns, and/or behaves differently from what is considered "typical." Practitioners no longer regard neurodivergence as an illness or disorder. They instead view them as different methods of learning and processing information which should be recognised and affirmed, that is, publicly supported. However, some of these methods become disabilities in a society which is not genuinely inclusive of all.

Contact Details

Claire Campbell is an autistic music graduate and language lover who taught in mainstream primary schools and specialist settings for twelve years, leading on music and sensory integration. Claire now tutors in a prison, for a trauma-informed alternative provision supporting both children and young people with complex support needs who are unable to access their school provision due to anxiety and/or trauma, and for young people with English as a second or other language.

Email: claire.bartrum@gmail.com

References

White, K. (2022) How Laughter and Playfulness can be used to help reduce Anxiety Link. Podcast on SENDCast. https://www.thesendcast.com/how-laughter-and-playfulness-can-be-used-to-help-reduce-anxiety/

Useful Information

Website for Katie White: https://thebestmedicine.co.uk/

Griffin Occupational Therapy (no date) What are sensory circuits and how can I use them at school?: https://www.griffinot.com/what-are-sensory-circuits-school/ GriffinOT is owned and operated by occupational therapist Kim Griffin.

Information on Intensive Interaction: https://www.intensiveinteraction.org/

Link to the sensory projects YouTube page where sensory engagement and inclusion expert Joanna Grace shares short accessible and practical videos on all things sensory: https://www.youtube.com/@TheSensoryProjects

Shake your Sillies out song: https://www.youtube.com/watch?v=NwT5oX_mqS0

Are you a tax payer?

If you have a personal subscription to PMLD LINK and you pay tax, you can opt for Gift Aid on your subscription at no cost to yourself. By agreeing to Gift Aid, PMLD LINK receives an extra 25p for every £1 of your subscription fee, in a tax refund from the government. This will help PMLD LINK significantly.

You can complete a Gift Aid Declaration form at any time - online or by post. It's quick and simple to do, sharing only your name and address.

If you want to subscribe (or renew your subscription) you can pay online via PayPal, remember to click the Gift Aid button to complete your Declaration form. If you opt to pay by cheque or set up a bank mandate, please complete the Subscription form included at the back of this journal or download a form via the Subscribe tab on PMLD LINK website (www.pmldlink.org.uk). This form includes a Gift Aid Declaration. Post completed forms to the PMLD LINK Treasurer (address on form).

You can cancel this Declaration at any time by notifying PMLD Link. If you pay tax at the higher rate, you can claim further tax relief in your Self-Assessment tax return. If you are unsure whether your donations qualify for Gift Aid tax relief, refer to help sheet IR65 on the HMRC web site (www.hmrc.gov.uk).

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

When the World Turns

Flossie Waite

Pioneers of Sensory Theatre, Oily Cart, invite you to join them in a living, breathing, sensory adventure. When the World Turns, which immerses audiences amongst hundreds of real plants, is touring the UK in February – March 2025. Here, they tell us about their new show, created for and with young people who experience the most barriers to accessing theatre and their families.

The seed of When the World Turns was a conversation between our Artistic Director, Ellie Griffiths, and the parent of a disabled child. The parent shared the barriers their family experience to accessing nature, and being made to feel that they don't belong in natural environments.

That conversation has grown into a sensory show that imagines a new world. In a place that values being rather than doing, listening with all your senses, and leaving words behind, the young audience not only belong, but lead the way.

What is When the World Turns?

Oily Cart uses not just 5 but all 33 senses to create immersive wonderlands for and with disabled children and young people. An Oily Cart show can happen in your local theatre, hydrotherapy pool or school hall; on a trampoline or online; at home or even up in the air.

Our latest show immerses audiences amongst hundreds of real plants, to watch, hear and feel as music, puppets, sounds, scents and shadows come to life all around them. In this living, breathing sensory adventure, the world has decided things need to change. It's shaken and shuffled, tumbled and turned, and now something magical and mischievous has started to grow. Together, we'll create a new world, led by our senses.

When the World Turns has been created for and with disabled children labelled as having profound and multiple learning disabilities. It is accessible, intimate and interactive, with lots of up-close sensory moments, a gentle pace, and plenty of breathing space for processing.

> *"A must-see experience for any family with disabled kids"*
>
> (When the World Turns audience feedback)

An international, sensory collaboration

Creating When the World Turns was a labour of love, spanning across time – it took 4 years to develop - and space – collaborators Polyglot Theatre are based in Melbourne, Australia.

We collaborated with eco-scenographer Dr Tanja Beer to bring art and nature together for the show. Her work is influenced by biophilia, a well-established science that shows how and why connecting with nature improves our wellbeing. Biophilia was central to designing and developing When the World Turns, so we could create an environment that has the maximum positive biophilic impact on the audience. For instance, being surrounded by hundreds of plants, audiences will benefit from the increased oxygen in the air and, studies have shown, will be more likely to feel relaxed and able to decompress.

Just as the idea for the show came from a family's lived experience, we've made sure that disabled children who experience the most barriers to access have been part of the creative process at every stage, both here and in Australia.

Through all the research and development, we asked the question: What would happen if we learned from this community of young people, and followed the atmosphere that they naturally create? Asking this question led us to a gentle, atmospheric show, that leaves space for being with and attuning into the world around us, and all the amazing things that happen when you do. When the World Turns is more than just an accessible experience. It creates an environment that values and responds to each child's way of being in the world. It says you belong here, and this world is listening to you.

Sustainability

When the World Turns is about valuing all forms of life equally, and we knew we needed to live this message backstage as well as to share it in the show. Sustainability was at the centre of all our planning and creative development, asking new questions of Oily Cart's work, which has historically always used lots of 'stuff'.

We have used everything we discovered during our collaboration with Polyglot and Dr Tanja Beer to make sure the show is a 'safe space' for all our creative and touring team – humans and plants. This includes developing a Manifesto of Care (which you can find on our website). The Manifesto was a guide, and commitment, to caring for all the living beings who were part of the first UK tour of specialist schools, and will help us navigate the future tour of public venues.

Offshoots

We love seeing how When the World Turns keeps growing, evolving, and developing different offshoots in the UK and Australia, like its own creative eco-system.

One of these is A World Beneath Us, an At Home version of the show sent to families across the UK in Summer 2024. During the pandemic, when we first started making At Home shows, we learnt that this was the only way that some families can experience an Oily Cart show. So, based on this, we made a long-term commitment to make At Home shows, putting the same level of resource, craft, creativity, and rigour into these formats as the live touring shows. The idea for When the World Turns originally came from a family with a disabled child. To bring the show back to families, in the spaces they feel most comfortable and at home, felt fitting.

"It was wonderful to have something that was so engaging not only for her but also for the rest of the family and lovely to be able to enjoy it together."
(A World Beneath Us audience feedback)

The idea of 'rich inclusion' is at the heart of how we make all our shows. Starting our creative process by considering and working alongside those who experience the most barriers, we have the potential to create structures that can support everyone. It's exciting to us that this means the show can keep rippling out in different forms and to different audiences, both here and in Australia, whilst keeping its essence of 'being' rather than doing, and our relationship to nature.

In Australia, Polyglot Theatre have recently won a PAC Australia Impact Award 2024 for their adaptation of When the World Turns for schools. And in the UK, we are touring Great Big Tiny World, a show for babies, that is inspired by and will tour alongside, When the World Turns in 2025.

> *"As transformative for adults as for babies"*
> (Great Big Tiny World audience feedback)

In each of these shows – When the World Turns, A World Beneath Us, and Great Big Tiny World - we join with audiences to grow a new world: one that values all life, that shows how we're all connected, and that listens.

Further Information

When the World Turns is touring UK venues in February – March 2025. More information, including tour dates, has be added to www.oilycart.org.uk

If you have any questions about the shows and access, please contact our Access + Wellbeing Officer, Maka on access@oilycart.org.uk

When the World Turns is a collaboration between Polyglot Theatre (AUS) and Oily Cart (UK). It was originally commissioned by Arts Centre Melbourne for major arts and disability festival Alter State 2022.

Contact Details

Flossie Waite is Communications and Advocacy Officer for Oily Cart.

Email: flossie@oilycart.org.uk

PMLD LINK
sharing ideas and information

My Beautiful Girl

Heather Bailey

My beautiful girl, as you approach your 16th birthday and your National Insurance No. plops through the letterbox, I look back at those years with mixed emotions.

We had a raised triple test in pregnancy and didn't know if you would have Downs Syndrome; we breathed a sigh of relief when all appeared well and we brought you home to your older brother. However, something wasn't quite right. Call it mothers' instinct, but you didn't seem to know how to breathe and suck your milk at the same time. You were difficult to settle and screamed on occasions. Every GP I visited patted me on the head and thought I was anxious.

On August 31st 1996, (a date firmly imprinted on my mind as our lives changed forever) you had your first obvious seizure and went into hospital. It was the day before I was due to return to work as a hospice nurse. Traumatic times and most details are still clear in my mind. Will she live? I asked tentatively. Will I ever see her get married? I remember writing in the hospital chapel book, "Please help our daughter- life will not always be easy for her." How did I know? I should have added a post script- "And God help us!"

I remember returning to the ward one day after a brief visit home – I still had to give time to your toddler brother – I can still see you now, sitting in your bouncy chair, blonde head bowed, drugged eyes and with a slightly dirty bib on. I vowed then never to let you down. I hope I have kept to that, although it has been a rocky road.

I recognise that I have grieved for you all your life. It is a process, and one that never leaves, just fades at times and at others still overwhelms me. I remember hating a total stranger for buying Barbie shoes for her daughter when my daughter didn't even know who Barbie was. I held your hand when you were asleep just to experience it, as you had never slipped your fat little hand into mine and walked beside me. One day I was driving in the car and a big loud voice shouted, "NO!" I realised it was me. How could the world be so beautiful and yet such a beautiful child be so devastated by cruel seizures? All part of the cycle of grief.

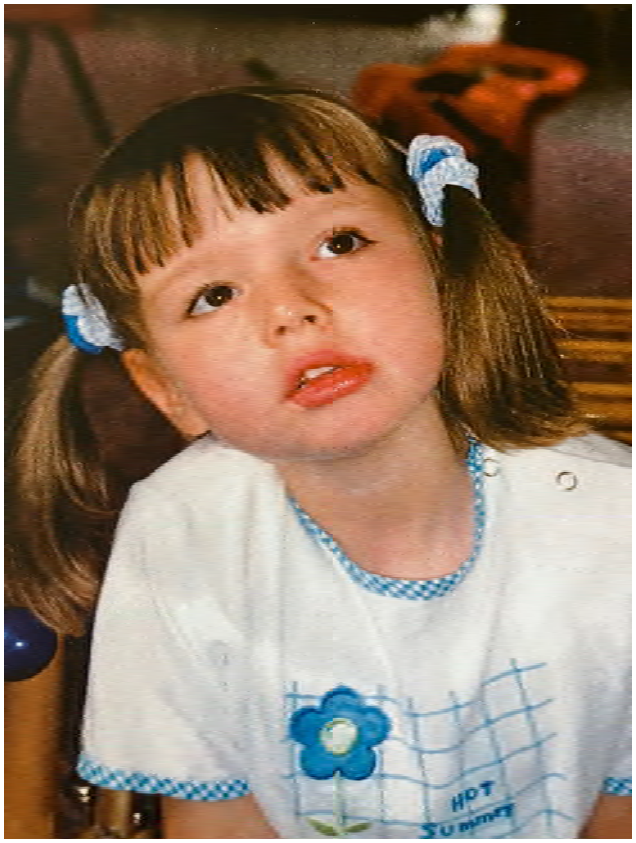
I no longer compare you to others although milestones can still be hurtful. Seizures became a daily part of life, dominating the day as they still do. Just feeding you and changing your nappy used to induce row after row of seizures. Medications came and went. No one else it seemed had the same sense of urgency as me; although now I have learnt to watch and wait. We have tried

different treatments. Everyone needs hope, I recognise it as a way of coping; I defy anyone not to try anything to help their child, particularly when the medical establishment appears to give up on them.

The 'system' has sent us round in many, many circles. Fights, yes fights, for extensions, bath aids, buggies, accessible car, nappies (I could go on), all take their toll and require energy that is often in short supply; I am not asking to swim with dolphins!! There are however, many good individuals within that system and the highest accolade I can give is to say thank you for loving our gorgeous girl. Professionals come and go in our lives, each having an opinion of us, each only seeing a snippet of the life we lead.

Seizures still dominate and are cruel and relentless. The one you had in the bath where I struggled to keep your head above the water as your legs beat against the bath flawed you, and the one where your younger brother asked if you were dead flawed me. Sleep continues to be a problem – certainly the lack of it doesn't help me any; I can write the book on it! When you were little I remember curling up next to you in your cot (we hadn't yet embarked on the 'fight' for a specialized bed!) and

waiting for the next seizure. All I could do was love you. If love alone could fix it you would be up and running by now.
The lack of sleep and seizure activity all serve to make



you irritable and sometimes you shout loudly for hours; it's hard to speak to each other at the table. It would have been fantastic to have you join in the banter with your brothers. The youngest struggles with the amount of time I have to spend with you. It is difficult to get out as a family and we often get left behind. Your Dad and I wonder what kind of teenager you would be. He often says he would give his life to see you well. I expect you would curse us for making you wear pink!

Basic functions can be difficult for you; altered breathing patterns, bowel and bladder management become part of daily routine, not to mention clock watching for the next medication. Nappies often leak and the washing machine is never silent. Physically it is hard to move you now and my body is starting to protest. All this sounds negative, but it's just the way life is.

I love you so much and still want the best for you, but what is the best you can expect from life when you cannot take care of or protect yourself in any way?

You are growing into a beautiful young lady, which to me is fraught with dangers itself. As we approach adult services my heart sinks. How are we to keep you safe and make sure you continue to have the fantastic care you have always had and deserve? No one knows you like me; on the days when you smile and put your arm around me - and it seems like you might almost talk – my heart breaks. You have taught me love, patience and what is important in life. You have brought me to some wonderful people and you are brave beyond belief.

I have found some poignant words to a beautiful song which says – "If you had not fallen, I would not have found you – Angel flying close to the ground."

Well my Angel, I vowed all those years ago not to let you down, and I am not about to start now.

Mum x

The above letter I wrote some 12 years ago now. It became part of my submission to the Julia Samuels, 'Therapy works' podcast. Julia, a renowned psychotherapist and grief specialist had requested applications from people who had an- 'unheard voice'. My episode was aired in Season 5 on April 17th 2024, and is entitled:- 'Heather Bailey, on being a mother of a child with profound disabilities'. It has taken me many years to realise that grief and loss is central to our story. When I look back on the letter I can see now how full of grief it really is. I feel sad for that young mum I was then and all she had to cope with.

No rule book, no timeframe.
No judgment.
Grief is as individual as a fingerprint.
Do what is right for your soul.

I wrote it as we were approaching adult services and I wanted people to know that we had a backstory, that Lizzie was precious and loved and what a responsibility we ALL had in providing a meaningful future for her. To my surprise, it has proved a useful tool! I have used it in support plans, as part of our deputyship application, as a teaching tool and also for each new support worker who comes our way. If they don't bat an eyelid when they read it, then they are not coming on board!

Lizzie is now 28 years old and lives in her own home with 24 hour care provided by a complex care company. The last six years have definitely been the most stressful for us in letting her 'go' and finding the right people to support her. She currently has fantastic carers and thoughtful and enabling complex care nurses who oversee her care. However, it was the journey to this point which was so stressful, coupled with unsuitable carers who disabled rather than enabled her, that almost broke me. It prompted my search for meaning, validation and solace - to really look at, explore and feel my grief journey.

To listen to my quiet inner voice. I read many books and listened to many podcasts on wellbeing, trauma and grief and yet nobody had died! I began to realise that I was living with recurrent grief. Each milestone or challenge takes me back to the beginning when I realised our lives would change forever. Only, each time, 'battles' become harder for the battle-weary. Strange how we use the language of war. I came across research on this entitled:- 'Recurrent grief in mothering a child with an intellectual disability to adulthood - Grieving is the healing', by Judith M Brown (2013). I recognised so much of what was revealed and felt seen and heard. Headings included:

- Initial diagnosis
- Expectation and realisation
- Double mourning
- The personal - reaction and response
- Societal - exclusion and inclusion
- Pivotal point - crisis and coping
- Milestones lost and found
- The future - challenge and change
- Meaning making - identity and agency

Parental chronic sorrow is talked about characterised as periods of wellbeing, alternating with reoccurring sadness of variable intensity, often reactivated at

developmental stages. I have found this to be so. It's been a painful but necessary and beautiful journey to take a look at my humanness. ALL feelings, fear and love, awfulness and awe-fullness, despair and joy, grief and gratitude make us whole. By allowing them in I have become more authentic and my inner voice is heard and my story has been shared.

'There is a crack in everything,
That's how the light gets in'

Leonard Cohen (1968)

I am definitely cracked, but I do look for the light! I appreciate the little things, I love deeply, I am empathetic, I am passionate and want to make a difference, I am an advocate, I can fundraise, manage staff and budgets, and find wonder and joy in the smallest of progress. I can laugh at the absurdity of the system (most of the time!). Lizzie has given me all of these gifts.

Sometimes it is just crap, and courage and honesty is needed at these times. I'm a big fan of Kate Bowler, with her community of people who live in the before and after moments of life, and enjoy her books on - 'Everything happens for a reason and other lies I've loved' and - 'Have a beautiful terrible day'. In the space between hope and despair there is room for movement.

'The best and most beautiful things in the world cannot be seen or even touched. They must be felt with the heart.'

Helen Keller (1905)

There is no flow without ebb and the wonderful Sophie Sabbage (2019) had some wise words in her book on life shocks and how to love them.

- inside our fear we can find what we are willing to fight for
- inside our rage we can find what we stand for
- in our despair we find what we long for.

Profound words. It's taken me years to understand the fear, rage and despair within me but I'm proud that I am willing to stand up and fight for my girl and get our voices heard.

'Special needs parents are the equivalent of Batman, Captain America and the Incredible Hulk combined with a side of Mary Poppins.'

(Anonymous)

Further Information

Julia Samuel offers a series of podcasts at: https://www.juliasamuel.co.uk/podcasts/therapy-works
Julia Samuel has posted a video of the conversation: https://www.youtube.com/watch?v=ygaN9Ed0N00
The podcast can also be accessed on Apple.com: https://podcasts.apple.com/gb/podcast/heather-bailey-on-being-a-mother-of-a/id1646616622?i=1000652672280
(Accessed 15.10.24)

If you do listen to the podcast, stick with it to the final section where Julia's two therapist daughters join her to discuss the themes and issues that were raised. I think they did a good job in their surmising. I was most touched when Julia felt emotional thinking about Lizzie and how they felt her voice was now heard through me.

Affinity Hub signposts to emotional support (including counselling) for parents and carers of children with special needs. This website is managed by Dr Joanna Griffin, a chartered counselling psychologist and mother of a disabled son: https://www.affinityhub.uk

Contact Details

Heather Bailey used to be a hospice nurse. Now she is a volunteer at her local wellness hub and sits on her local partnership board. She has recently lobbied her MP for a minister for learning disabilities. She is a married, proud mum of three. Lizzie is their middle child.

Email: heatherbailey03@gmail.com

References

Bowler, K. (2018) *Everything Happens for a Reason (And Other Lies I've Loved).* New York ; Random House

Bowler, K. (2020) *Have A Beautiful, Terrible Day! Daily Meditations for the Ups, Downs & In-Betweens*. New York: Convergent Books

Brown, J (2013) Recurrent grief in mothering a child with an intellectual disability to adulthood: grieving is the healing. *Child & Family Social Work*, 21 (1), 113-122. https://onlinelibrary.wiley.com/doi/pdf/10.1111/cfs.12116?msockid=16a25c044649610b2e814f5147726018

Cohen, L (1968) Anthem, In *Selected Poems, 1956-1968* New York: Viking Press.

Keller, H. (1905) *The Story of my life.* New York: Doubleday, Page and Company. (The quotation evolved from a statement in a letter from Helen Keller dated 1891 that appears in the book. Helen Keller originally credited the saying to her teacher Anne Sullivan.)

Sabbage, S. (2019) *Lifeshocks: and how to love them*. London: Coronet Books

Access to Recent Back Issues on the PMLD LINK Website

Subscribers can log on as a members of the PMLD LINK on its website (http://www.pmldlink.org.uk/login) and access downloadable pdfs of the most recent ten issues from the last three years. Only subscribers can access these. We do ask that you use these downloadable pdfs for your purposes only and that you do not share them widely online.

Many organisations that are subscribers (typically universities, schools, colleges, NHS services, charities and some other groups). We recognise that each organisation has paid for a higher subscription so that all members of their community (e.g. students, teaching assistants, nurses, therapists, family members of people with PMLD) to be able to access these recent issues. We want these organisations to be able to share recent issues within their community.

We ask that organisations make plain to their members that downloaded copies should not be shared online with others outside their community.

In order to access the members' area of the PMLD LINK website, it is essential to log in with a username which is an e-mail address and a password. Our website managers, can set up a generic username and password for any organisation to share with their community. If any organisations want this facility and if users experience any difficulties with logging on, please let us know by contacting info@pmldlink.org.uk

All issues dating back more than three years are in the public domain of the website and may be accessed for free by 'guest subscribers'. Go to: http://www.pmldlink.org.uk/subscribe/, click on Free Subscription and follow the instructions.

PMLD LINK
sharing ideas and information

Always look on the bright side…

Anna Cauvin

Any parent will surely agree that coming to terms with the disability of their child is no easy task. It is often a long, winding path heavily laden with worry, doubt and anxiety.

Our first child, Simon, was born in 2008 and despite a long difficult labour, he seemed perfectly fine at birth. It was only in the coming weeks and months that things became more complicated. He had low tone and struggled to feed. At three months, a problem with his vision was first detected. At ten months, he still wasn't able to roll or sit or use his hands. The bad news just kept coming at every new appointment with a health professional. Simon turned sixteen in June of this year. No formal diagnosis has been found so he is labelled as having a profound intellectual disability.

When I look back at photos of Simon as a baby and as a young child, I often feel a strange mixture of emotions; on the one hand, a memory of his adorable cheeky grin and tremendously cute way of babbling, but, on the other hand, a memory of the overwhelming anxiety of trying to come to terms with his evident neurodevelopmental delay.

I particularly remember a feeling of never quite doing enough; that I needed to do more exercises with him to increase his muscle tone and that I needed to be more disciplined in how I spoke to him to enable him to learn to speak (we're a bilingual family living in France and I was told by several speech and language therapists that I was hindering his ability to learn to speak by maintaining two languages in the home). It felt as if everything had to be scripted and planned to ensure his development, or rather to ensure that we didn't hold back his development. Where was the room for us just being his parents? When was the time to just enjoy being with him without an agenda, without the need to achieve? Why the constant feeling of not being good enough at parenting?

After a particularly stressful summer when Simon was about five years old, I happened across an article about Intensive Interaction on the Internet. Little did I know then what a life changing moment this would become.

Fast forward a few months and I'd got in touch with the Intensive Interaction Institute in the UK and was starting an online course being mentored by another parent who had already gained extensive experience of the approach. The aim was to help me get to grips with the principles of the approach. For each mentoring session, I prepared and sent over a short video clip of an interaction between Simon and I.

I don't think I'll ever forget one of the very first pieces of feedback given to me: "Oh, what a beautiful way you have of interacting with him, how lovely to see how you spend time with him" or words to that effect.

It struck me that, to that day, I had not heard many positive things said about our relationship with Simon, about our way of playing with him. That is not to say that people might not have thought such things but everything was so focused on trying to reduce the gap of his developmental delay that time was "wasted" on looking at the way that we could spend time just being together.

As time went on, Intensive Interaction gained more and more meaning for me both in terms of my understanding of it and my experience of it. And, as I delved further into it and felt its positive influence over me and over our mutual development with Simon, I began to notice that I was healing. I was gaining confidence in my parenting skills – after all, Intensive Interaction has always been based on research into parent-infant interactions and motherese – and I was even finding my voice to advocate

better for his needs which did not always correspond to the needs that some professionals put forward for him. Intensive Interaction allows us to get to know a person so much more deeply, we learn to tune-in and use and trust our senses to know how to adapt our own behaviours. As a consequence, I began to trust in the feeling that even at times of more intense challenging behaviours on his part, I would be able to work out a way to behave in order to ease whatever difficulty he was expressing through his behaviours. And what is more, I also now had an incredibly supportive, understanding and engaged community to turn to.

In 2020, together with a friend whose daughter has profound and multiple learning disabilities, we decided to set up a non-profit organisation in our local area in France to provide support and information for other families living with children with neurodevelopmental disabilities. Our motivation was both to contribute in our small way to raising awareness of disability and thus ensure a more open, positive outlook for our children in the future. We also wanted to offer the kind of support to families that we felt we had been sorely bereft of as new parents.

Although France is still struggling in many ways to respect the rights and lives of people living with disability, I am pleased and relieved to say that change is slowly happening. One of the major reasons for this delay is that disability has largely been hidden in French society; disabled people are kept at a distance from society in enclosed specialised spaces (hospitals and institutions, as disability until recently was seen as a medical issue only). But things are changing and I remain convinced that very often it's parents and families who initiate those changes. And in order to do that, parents have to feel they have the courage and confidence to say that they know what is best for their loved ones.

Recently, the High Health Authority (Haute Autorité Sanitaire) set out the "positive approach" in its latest recommendations for best practice. This outlines the need to think very carefully about how our own behaviours as communication partners, impact and influence the emotional state and the overall development of people with intellectual disability. There is an implicit understanding that unless professionals learn to regulate and question their own behaviours, it will be difficult to respond to the needs of the people with whom they work. Alongside these recommendations, there is also a greater interest being taken in the experiential knowledge and skills of parents. The idea is that it might be time to reconsider the model whereby professionals explain to parents how to parent and instead they learn to listen to parents more and work alongside parents to meet the child's needs.

Although this is changing, there is still a lot of work to be done. And particularly in terms of supporting parents who are still at the early stage of their journey. They might not yet have so much experiential knowledge but they do already have a strong parental instinct and might well hold a number of key elements of understanding about their child that must be taken into account in planning for that child's future.

In our organisation we now have a large core group of parents who have become members but they all still remain parents of older children and we're trying to think of ways to reach out to newer parents so that they can benefit from the support network that we're trying to grow.

I'd very much love to hear from anyone in the UK who's had experience in the field and might be able to give us some tips and ideas as to ways to respond to the needs of new parents.

Contact Details

Anna Cauvin is a parent-carer

Email: annacauvin@gmail.com

Working together to influence policy on cost of living and energy costs

Maddy Rose

Disabled people have been disproportionately impacted by the cost-of-living crisis: 42% of families that include a disabled person receiving benefits in poverty (Social Market Foundation, 2021) and 75% of people referred to food banks in the Trussell Trust network reported that they, or a member of their household are disabled (Trussell Trust, 2023). This has been compounded by the extra costs that disabled households face; on average disabled households require an additional £1010 a month to have the same standard of living as households without somebody with a disability (Scope, 2024).

Cost of living crisis for people with a learning disability and their families.

People with a learning disability have been particularly affected by recent surges in utility bills, due to their increased energy needs: mobility and hygiene needs can require increased consumption of electricity, for example, to run electric wheelchairs, whilst some people with a learning disability have additional health barriers, requiring medical equipment like oxygen concentrators and ventilators. Many also have important non-medical sensory needs that might involve significantly increased use of electrical devices, or they may need their homes to be heated to a high temperature for longer because they are supported by 24-hour carers.

Despite these vital energy needs, many are still forced to go without essentials: over a third (38%) of 1050 respondents to a Mencap survey who had a learning disability had not turned their heating on despite being cold (Mencap, 2022/23) and Joseph Rowntree Foundation analysis showed that 67% of low-income households with a person who has a learning disability were in arrears with at least one bill this year with many forced to disconnect or ration their energy supply (Joseph Rowntree Foundation, 2024). This is particularly concerning, given the clear link between learning disability and health conditions that are exacerbated by living in a cold home and which make the supply of affordable heating vital (LeDeR, 2020).

Proposed energy reforms

This year, Labour's manifesto committed to reducing energy bills by reforming standing charges which have more than doubled in the past four years to over £300 a year. Standing charges are one of two core components of energy bills; they represent a static daily charge on bills and energy customers are currently charged a daily fixed amount regardless of how much energy they use.

Ofgem proposed shifting standing charges in energy bills from a daily flat rate to one based on the volume of energy a household consumes; this would mean the more energy a customer uses, the more they would pay in standing charges. However, Mencap and sector partners were concerned that Ofgem's proposals would adversely impact vulnerable customers with high energy needs, like people with profound and multiple learning disabilities who may rely on medical equipment or need higher heating. Low-income high energy users would have seen an increase in their energy bills by twice as much as beneficiaries of this policy, even though their high energy use is often necessary for them to live happy and healthy lives.

Insights from families of people with profound and multiple learning disabilities

PMLD LINK, PAMIS and Riverside School connected Mencap with families of people with profound and multiple learning disabilities, including high-profile energy costs campaigner Carolynne Hunter, to learn more about the energy needs of their households and to explore the likely impact of Ofgem's planned standing charge volumetric reforms. The key issues families reported were: anxiety over how higher bills would impact wider household finances that are already stretched; the myriad essential energy needs of loved ones with profound and multiple learning disabilities; the legacy of energy debt over the past 3 years; and a feeling of not being recognised by decision-makers or energy suppliers.

> '*Because of my daughter's medical needs, we need to power an air-con unit in the Summer 24/7 and in winter, she needs to have the heating on all day and night to stop recurrent infections. We need to power a secondary fridge for her supplements and her pureed diet. We power a bed monitor for her epilepsy. She needs to use an inflatable bath chair which can take up to two days to charge. Other households can cut back but we can't without endangering her.'*
>
> *'Government aren't properly seeing families like mine and really vulnerable children like my daughter. I feel like we don't matter and we're not taken seriously. There is no alternative for her and her energy needs'.*

We were able to give feedback on these energy needs to Ofgem officials and they shared that these detailed examples were vital in helping them understand the nature of the likely impact of their standing charge reforms.

In their subsequent paper, Ofgem reflected some of our concerns, directly citing the need to account for low-income high energy-usage households. As a result, they proposed reducing the scale of the standing charge reforms they had planned, meaning that the impact on households of people with a learning disability with high energy usage will be lower than expected.

Further involvement

We will continue to argue that decision-makers need to consider the high energy needs of people with a learning disability, particularly those with and multiple learning disabilities. We are also encouraging Government to restart efforts to introduce an energy social tariff to address long-term energy affordability and debt for disabled people. This would provide targeted price support through a fixed cash or percentage discount on the unit rate of gas and electricity for low-income and disabled households and would lift as many as 1.4 million disabled households out of fuel poverty (Age UK, 2024).

We are eager to hear from more families of people with profound and multiple learning disabilities. If you are keen to get involved in Mencap's work on policy issues affecting people with profound and multiple learning disabilities and their families, sign up here to be a Policy Shaper www.mencap.org.uk/get-involved/campaign-mencap/our-work-parliament/become-policy-shaper or if you are interested in sharing your story, please contact stories@mencap.org.uk

Contact Details

Maddy Rose is a Policy Specialist at Mencap, leading its work on cost of living, fuel poverty, PIP and financial inclusion. She also supports Mencap's Policy Shaper group.
Email: maddy.rose@mencap.org.uk

References

Age UK (2024) *New Age UK analysis shows an energy social tariff would have lifted 2.2 million households out of fuel poverty this winter*. Available online at: https://www.ageuk.org.uk/latest-press/articles/2024/new-age-uk-analysis-shows-an-energy-social-tariff-would-have-lifted-2.2-million-households-out-of-fuel-poverty-this-winter/#:~:text=Around%20one%20in%20seven%20(15,a%20reduction%20of%20around%2066%25

Desouza, D (2023) 'Mother of disabled teenager to fundraise for others following Winslet donation', Independent, 10.11. Available online at: https://www.independent.co.uk/news/uk/mother-gofundme-kate-winslet-scotland-money-b2445119.html

Joseph Rowntree Foundation (2024) *The scale of the challenge: JRF's pre-election cost of living tracker*. https://www.jrf.org.uk/cost-of-living/jrfs-pre-election-cost-of-living-tracker

LeDeR (Learning Disabilities Mortality Review Programme) (2020) *Annual Report 2020*. University of Bristol. Available online at: https://www.england.nhs.uk/wp-content/uploads/2021/06/LeDeR-bristol-annual-report-2020.pdf

Mencap (2022) *Cost of living website survey, November 2022/3* (There is no live link to the Mencap website survey findings but contact Maddy Rose for information)

Scope (2024) *Disability Price Tag*. Available online at: https://www.scope.org.uk/campaigns/disability-price-tag

Social Market Foundation (2021) *Time to think again: disability benefits and support after Covid-19*. Available online at: https://www.smf.co.uk/publications/time-to-think-again/

Together for Short Lives (2023) 'Carolynne shares her story in exclusive video diary', 15.05. Available online at: https://www.togetherforshortlives.org.uk/carolynne-shares-her-story-in-exclusive-video-diary/

Trussell Trust (2023) *Hunger in the UK*. Available online at: https://www.trussell.org.uk/publications/hunger-in-the-uk

SUBSCRIPTIONS 2025

Subscription rates

UK Individual £25.00
UK Organisation £35.00
Non UK Individual £32.00
Non-UK Organisation £45.00

Subscriptions are for 12 months from the point of subscribing. Subscribers receive 3 issues of the PMLD LINK journal. During this period they have access to the members' area of the PMLD LINK website (www.pmldlink.org.uk) which allows them to access downloadable versions of back issues from the last three years. Subscribers only can access these. Organisations can share their membership privileges with employees and volunteers. Libraries may do so with researchers and students and other users.

Other older issues are in the public domain of the website.

To set up a subscription you can pay by cheque or by BACS direct to PMLD LINK's bank account or via Paypal.

If you pay by cheque, this should be payable to PMLD LINK and should be sent to PMLD LINK Treasurer, Caerludd, Cilgerran, Cardigan, SA43 2SN.

If you pay by BACS, the account details are:

HSBC Bank
Account name: PMLD LINK
Account No 81156284
SORT 40-39-06

If you wish to use Paypal, click on the relevant button on the subscribe page of the PMLD LINK website (www.pmldlink.org.uk).

If you have any queries about subscriptions or accessing the website, please do not hesitate to contact us (email: info@pmldlink.org.uk).

PMLD LINK
sharing ideas and information

Winter 2024, Vol. 36 No.3 Issue 109

The Power of Stories

Maureen Phillip

Stories are all around us; everywhere we go, everything we do is a story. We all access and tell stories every day. We laugh at stories, we cry at stories, we share and collect these stories. This article shares a little of how PAMIS works with stories to enable people with profound and multiple learning disabilities (PMLD) to teach communities how to "be" with them.

I would like to start this piece by remembering the role that stories play in our lives. Stories are us and we are stories. Stories are who we are and what we become. If we think of the river as a metaphor for life; it begins at the source and travels through the landscape winding its way over and around obstacles on route to the sea. The river's journey is not always easy. In an everchanging landscape the river has obstacles to overcome on its journey from source to sea, just as we have obstacles to overcome on our journey from birth to death. As the river winds its way on that journey, other tributaries and rivers might join it and in turn impact the journey at various points as it progresses to the sea. We too are impacted by the stories of others we meet on life's journey. These stories shape and change our lives, sometimes positively and sometimes negatively but they change and develop who we are.

We all have stories that we tell ourselves and we live our lives according to these stories, but we do have the power to change these narratives as we make our way through life. For people with profound and multiple learning disabilities it is not so easy for them to shape or change the narrative of their lives as their lives are very much influenced by the stories of others they encounter along their journey through life. The list is endless, and the river of their lives have many tributaries; education, social care, and health to mention a few. So how can stories contribute, support and offer something that makes navigating life a little easier?

Stories can connect individuals, they can engage, educate, connect communities and offer fun and enjoyment along the way. The world tales of Anansi, the trickster god who could shapeshift into a spider and who became famous for his insight, wisdom and intelligence is a classic example of how collective understanding can grow from shared experiences. In the folktale 'Anansi and the Box of Stories', the trickster Anansi has to go on a quest before his father, the god of the sky, would give him the box that holds all the worlds stories. Once his quest is completed, he receives the box of stories and decides to release them to be spread in the wind to be available to everyone. This way the knowledge of all the

stories reaches the far corners of the world and means that these stories provide a collective insight available to everyone.

It is this collective insight that stories can provide to support people with PMLD to feel they have a place in their community and that they too can feel a sense of belonging within it. PAMIS works with stories to do this in many ways, with individuals and groups, through music, art, books, nature, festivals to name a few. We have stories for every occasion, but it is the stories we work with alongside communities that support a collective understanding of people with PMLD. Working with communities through story helps dissolve the myth that it is too difficult for someone who has no experience with this group to create a meaningful experience for them. PAMIS works with communities through story to dispel this myth and this journey has been one of the most rewarding experiences.

For a number of years people with PMLD and their families have said that they would love a great day out just like everyone else. A day where they could arrive at a time that suits them, to an event that wasn't necessarily an organised event. What they wanted was to go to gardens, museums, libraries etc and places in their community where there were activities that were accessible to them and where the person with PMLD could join in with everyone else, or be by themselves. Over the years PAMIS has provided many such opportunities and worked with the National Galleries of Scotland, particularly the Children and Families team at the Modern Art Gallery (Modern One) which now have an inclusive programme they offer everyone.

Edinburgh's International Book Festival, Wigtown Book Festival, Wildhood festival and others also provide great days out. Then there are the stories of The Japanese Garden at Cowden and The Alloa Hub that offer opportunities for people with PMLD and their families to engage with cultural heritage and history through the

creation of multi-sensory stories. Both those venues had no experience of people with PMLD visiting and there were no Changing Places in either of the venues, but they were keen to ensure people with PMLD felt they could enjoy what was offered. Through our ongoing work supporting the staff at these venues to develop some multi-sensory stories, everyone involved gained a greater understanding of people with PMLD.

In The Hub, the Clackmannanshire Tapestry holds a wealth of local stories that provides endless opportunities for story development and enjoyment. PAMIS also worked with a local author and helped create a multi-sensory immersive experience of her book that we shared together at the PAMIS friendship club. Supporting the community through story removes any anxiety people may have about engaging with people with PMLD. The enthusiasm and enjoyment the community gained from creating stories for the PAMIS families was immense and wonderful to see.
The creation of these stories in community venues means that people with PMLD and their families know there are resources there for them to access. When introducing these stories to families at the Japanese Garden, you could see the joy on everyone's faces as they enjoyed time together. These community stories are like tributaries that flow into the lives of people with PMLD and contribute to changes in their story on several levels. Through the stories people begin to be connected with their community and slowly understanding builds. They are more visible in the community, they can relax

knowing that there will be people who understand them and resources there that they can engage with. Stories also expand the learning experiences for people with PMLD and provide access to lifelong learning opportunities.

Through the stories at the Hub people with PMLD can learn about local history and the anecdotal stories of people from the area. Families can also get involved in telling their own stories, if they wish to, and people with PMLD can also be involved in that process.

There are future plans in this community for story walks and again working with the community means that the walks will be inclusive of people with PMLD, not only in terms of physical access but in the design of the stimuli used to tell the story, i.e. the sounds of the train, the smell of the engines and much more. By being involved in this way people with PMLD will be able to join the walks and be meaningfully involved in them alongside everyone else. The Japanese Garden stories also facilitate learning through story. The initial four stories range from the story of the history of the garden, the gardener's story, a story about the Zen Garden and a Japanese folktale. Having these resources available to families means that everyone can have fun exploring not only the garden, but also learn more deeply about its creation. As the river of stories flows onwards and the stories of the community joins the stories of people with PMLD, there is a learning together that takes place between the two and through this connection everyone's lives are enriched. People with PMLD teach the community how to connect with them and the community offers their stories as a way for people with PMLD to connect with local heritage, nature or wherever their interest lies. Soon people begin to notice what is around them and over time this engagement fosters a connection and a sense of belonging. This is the power of story.

Contact Details

Maureen Phillip is the Creative Director for the Scottish charity PAMIS. She is also an Editor for PMLD LINK.
Email: maureen.phillip@pamis.org.uk

PMLD LINK
sharing ideas and information

Two People, Four Hands, No Symbols, Interaction…

Sheridan Forster

Some people who we interact with might not understand Key Word Signs, but touch can still be an important form of interaction.

Sometimes these people might be called pre-intentional or intentional informal communicators.

Think about the sign FINISH – an extended thumb wiggling. If you did not know that it was a symbol to represent 'finish', what do you think it would mean? For some people a thumb means 'grab me and keep going'.

Hands can convey lots of things between two people.

Many people know about 'touch cues' – the use of touch to alert the other person to something, such as sitting up or reaching a cup. Sometimes I call these CUEmmunication, where there is a one-way message being perceived.

Touch can also be used interactively; I like to call this TWOmmunication. This sort of communication involves two people expressing, understanding, and expressing again…

Holding your hands palm up and jiggling them can be a way of inviting another person to reach out to them. Placing your hand on someone else's and pausing can sometimes mean 'what next?'.

Touching a body part that someone just touched or is moving can be a way of saying 'I see that this is what you are doing'.

I started this abstract with 'finish', so it is fitting to end it with 'hello'. Some people do not perceive or understand a spoken hello. They may not understand the sign HELLO. But everybody should be greeted…What sort of 'hello' might be TWOmmunication for people that you know?

Contact Details

Sheridan Forster is a practising speech pathologist and researcher with an interest in adults with profound intellectual and multiple disabilities.
Email: sheri@sheridanforster.com.au
Website: www.sheridanforster.com.au

Note: The sign for FINISH mentioned in the article is a sign from Australia (https://auslan.org.au/). Signs differ depending on the language. The equivalent BSL/Makaton sign can be found here https://www.signbsl.com/sign/finish. Check for the relevant sign language from your own country.

PMLD LINK
sharing ideas and information

Winter 2024, Vol. 36 No.3 Issue 109

PAMIS postural care passion providing support for families like Freya's

Carolynne Hunter and Michelle Morrison,
illustrated by Kathleen Shearer

PAMIS ('Promoting a More Inclusive Society') believes everyone deserves to live a life included, full of dignity, comfort, and quality. For individuals with profound and multiple learning disabilities, being included often requires their posture and positioning being managed 24 hours a day, 7 days a week. With over 30 years of experience rooted in the lives and stories of family carers and the individuals they care for, we have developed a unique approach to helping families understand the impact of gentle, kind, supportive positioning (postural care), including through education delivery aiming to empower practitioners and family members.

For fifteen years, PAMIS has strived to share knowledge of postural care to help minimise occurrence of body distortion in people living with profound and multiple learning disabilities . Our journey has seen us be influenced by family carers, connect with inspirational educators and collaborate with practitioners across Scotland and beyond. Our role is one of determination – to build a knowledgeable community working to ensure people with profound and multiple learning disabilities don't face the associated difficulties body shape distortion can bring and end the needless premature deaths they can cause.

One of these needless premature deaths influenced PAMIS' journey. Jenny, a PAMIS mum, was told her son was in respiratory failure. Facing the end of his life, she sought to find something that could make him more comfortable with whatever time they had left. Little did she appreciate the impact helping Craig to sit and lie in a supported position would have on pain reduction and his respiratory function, his oxygen levels increasing in front of her eyes – an experience she will forever be indebted to John and Liz Goldsmith for enabling. While sadly, Craig passed in the comfort of being surrounded by his family, Jenny's fight had only just begun – helping others recognise the power of postural care in maximising the life of people living with profound and multiple learning disabilities .

Jenny's motivation and passion, believing in Craig's legacy, has driven PAMIS' belief in supporting other families caring for someone with profound and multiple learning disabilities in providing opportunities to increase their own knowledge.

Sharing knowledge

Twenty-four-hour postural care is crucial for someone living with profound and multiple learning disabilities . Without early intervention, many individuals are at risk of developing body distortions leading to pain, physical and mental health issues and a reduced quality of life. Understanding postural care is essential for practitioners, family carers and care providers.

With the help of Jenny's motivation and passion, our education model has progressed from a 2 day in-person session to a convenient online programme. Our education partners Born at the Right Time and Simple Stuff Works, support delivery of this online programme. The unique aspect of our education draws from our history of valuing family carers. We recognise knowledge is not just scientific, it's also personal - family carers' stories are integral to our delivery.

We've supported the growth of family carers' knowledge, skills and confidence to co-deliver our education. Participants engage in online discussions facilitated by family carers like Jenny who share their personal stories of working co-productively with practitioners to implement postural care. A collaborative learning environment is created with support from an experienced physiotherapist or occupational therapist. Learning is brought to life through theory combined with real-life scenarios helping participants gain deeper understanding not only of why postural care is important but emotional connections experienced by families themselves. Our aim is to provide a supportive community for all participants, ensuring they feel heard, empowered and informed while recognising their commitment to improving the lives of those they care for.

Our education feedback shows lasting impact. One parent shared,

> *"Off the back of the training, we now have a sleep system at home. My son is getting a full postural assessment for seating to keep him from slumping."*

A practitioner shared,

> *"I benefitted greatly from hearing about families' experiences. It balanced technical information with the human side of addressing postural needs."*

Craig's legacy lives on in our education. It's never too late to learn why protecting body shape is crucial to the comfort, well-being and quality of life of the person you are caring for.

The power of postural care – one family's experience

Freya is my beautiful wee girl who faces numerous challenges due to her severe complex health issues and disabilities. Freya's life is marked by resilience, love and her inner happiness, despite the serious health challenges that surround her daily life. Freya is blind, non -verbal and completely immobile. "Freya will always require constant nursing support by means of specialist 2:1 nursing care, including BIPAP ventilation, oxygen, frequent suction, being gastrostomy fed and constant monitoring of her heart rate and 02 saturation levels, providing her with proactive medical care to keep her comfortable and alive.

Freya's journey of life has been fully laden with health difficulties. At just two years-old, she was in and out of hospitals, battling seizures and chest infections, leaving me anxious and desperate for answers. My struggles intensified when I met the spinal surgeon regarding Freya's scoliosis. The news was devastating! The surgeon informed me that due to her complex respiratory condition, as she grew into her teens, Freya was unlikely to survive an operation to correct her spine. Her spine would most likely curve, leading to a prognosis of a short, painful life. The words echoed in my mind, filling me with a sense of despair that was overwhelming.
Reflecting on the initial trauma of receiving the surgeon's diagnosis, I felt consumed by complete darkness. It seemed there was no light at the end of the tunnel, and I was left struggling with a profound sense of loss. As a mother, I was determined to give my daughter the love and care she needed, but the prognosis weighed heavily on my heart.

In the wake of the surgeon's appointment, I initially rejected suggestions of supportive equipment from our physiotherapist, unable to accept Freya's needs marked her as "different." I didn't want Freya to be seen in a wheelchair! She was my baby, and I couldn't bear the thought of her being labelled. This denial was a natural response to the overwhelming reality I faced, one that many parents in similar situations can relate to.
A critical conversation with our physiotherapist created a turning point. Continually expressing my reluctance towards any supportive equipment, the physiotherapist

eventually respected my wishes and said she'd take everything away - but she planted a seed of possibility. It struck me that maybe her persistence meant hope. I will never forget that conversation.

In that moment the journey towards acceptance of postural care to protect Freya's body shape truly began. My open mind and curiosity enabled a new chapter in our lives! A chapter filled with practitioners working together with me to give Freya the best quality of life possible.

As postural care became the normality of Freya's care plan, her life gradually transformed. I learned to embrace the equipment I once saw as clumsy, restrictive and uncomfortable, understanding these tools were integral to Freya's health and happiness. The standing frames, adapted wheelchairs and splints became instruments of empowerment rather than symbols of difference. I even cried at the loss of Freya's standing frame which she could no longer use because of leg contractures. I'd lost the only time I would see my girl stand and she lost seeing the world from a different position.

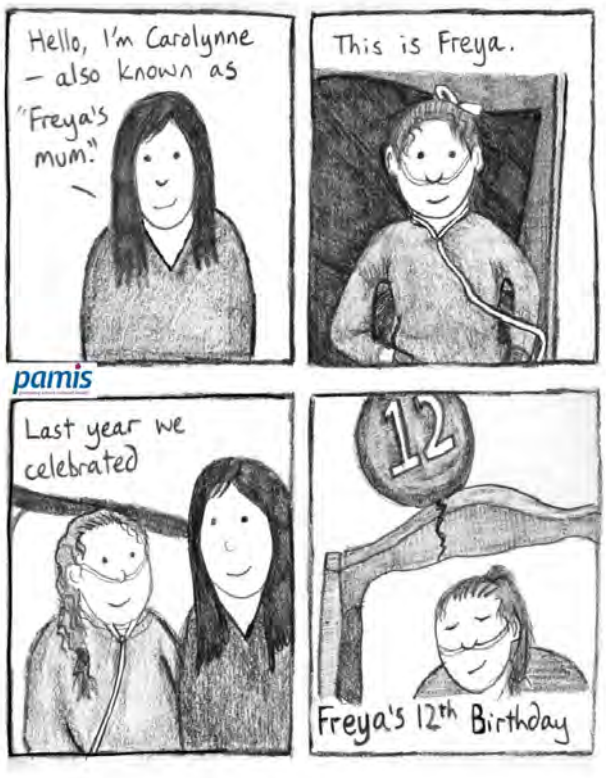
Freya, almost 15, has blossomed into a vibrant teenager who loves engaging with the world around her. Her journey, during which she has faced numerous obstacles with courage and resilience, exemplifies the importance of hope, adaptation, community support all made possible with postural care.

Influencing others

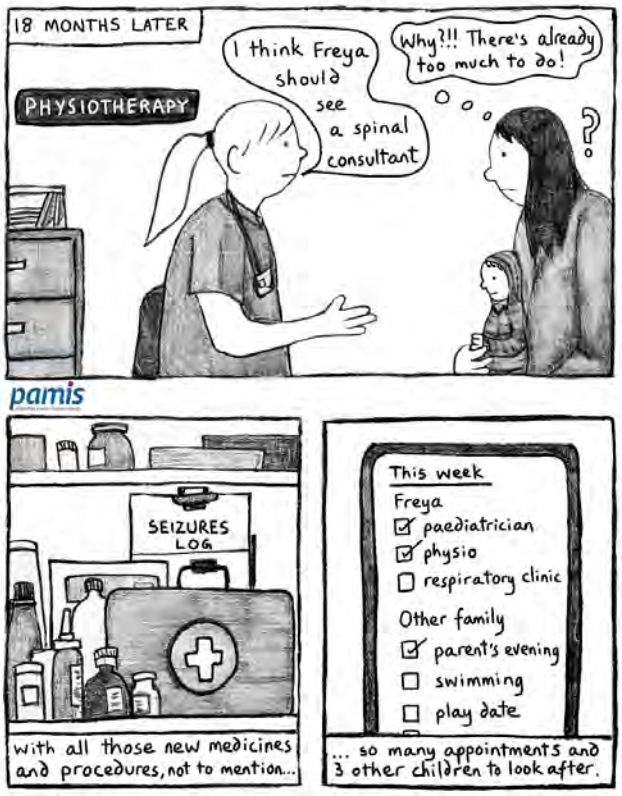
PAMIS has long believed partnership is often the only way forward, recognising the strength of learning with and from others. As we grew in our knowledge around postural care, supporting our families to know more, we became aware of how many people are vulnerable to body shape distortion. We connected with others working across the country, sharing our passion and motivations to end postural distortions related to destructive positioning. These collective desires drove a recognition by Scottish government and NHS Education for Scotland of the importance in creating a postural care strategy for Scotland. And, on a wet day in Edinburgh, our collective came together to share our hopes and dreams for change. What followed was a truly collaboratively co-designed strategy, Your Posture Matters, created by practitioners from a range of professions, third sector organisations, individuals living with movement difficulties and family carers, including Jenny; our shared passion to end body shape distortion being driven by three strong ambitions. Craig's legacy runs strong throughout the document, opening with his story of a time when it was thought it was inevitable his body would distort, inevitable he would die prematurely and then, giving hope to all who have followed, like Freya's family, that posture and positioning for people with profound and multiple learning disabilities can be supported; postural care can be life enhancing and life sustaining.

2 **Illustrations**

1



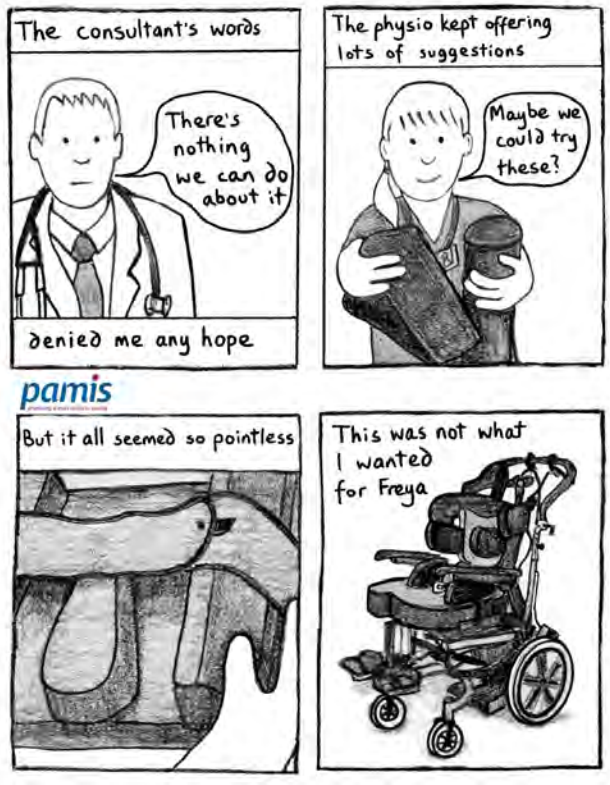
3



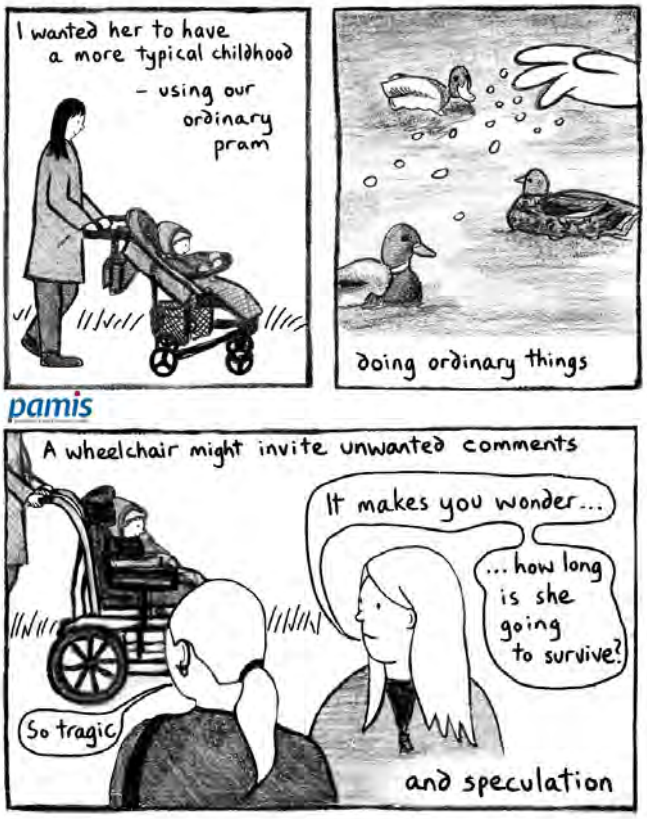
4


WHEN FREYA WAS 2 YEARS OLD
We seen a spinal consultant
Freya will get a scoliosis. She probably won't survive past 12 years old.
Her body shape will cause her a lot of pain. There's nothing We can do about it.
Try to make the best of the time you have.
CURVITURE OF THE SPINE
pamis
I was devastated
I worried about Freya's future
She didn't seem to have one.

5


The consultant's words
There's nothing we can do about it
denied me any hope
The physio kept offering lots of suggestions
Maybe we could try these?
pamis
But it all seemed so pointless
This was not what I wanted for Freya

6

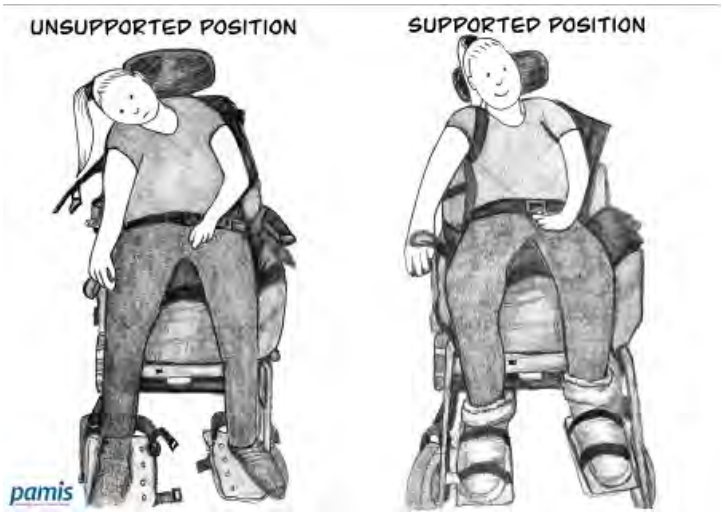

I wanted her to have a more typical childhood - using our ordinary pram
doing ordinary things
pamis
A wheelchair might invite unwanted comments
It makes you wonder...
... how long is she going to survive?
So tragic
and speculation

7


I wanted normality
Have you thought about equipment at home?
It could make life a bit easier for both of you
pamis
I didn't want our home looking like a hospital
So I refused the help we were offered

8

9



Contact Details

Carolynne Hunter is the Postural Care Education Lead at PAMIS and Freya's mum.
Email: carolynne.hunter@pamis.org.uk

Michelle Morrison is the National Development Director at PAMIS.
Email: michelle.morrison@pamis.org.uk

The Illustrator is PAMIS Family Carer, Kathleen Shearer.

Further Reading

PAMIS/ Promoting a more inclusive society: https://pamis.org.uk/
Your Posture Matters/ Turas/ Learn (nhs.scot): https://learn.nes.nhs.scot/60811
Born at the Right Time: https://www.bornattherighttime.com/
Simple Stuff Works – Passionate about Posture: https://www.simplestuffworks.com/

What Matters to Me: Influencing policy with the experiences, preferences and views of young people with severe or profound and multiple learning disabilities

Taylor Anderson

We all want to have our say and influence the things that affect us and are important to us, this is no different for young people with complex needs, however more often than not, it is considered “too difficult” to find ways for their views to be sought. What Matters to Me is an innovative project that has been working with 11 young people with severe or profound and multiple learning disabilities, and their support circles, to explore creative engagement methods that we can use to develop an understanding of things that are important, both to them, and for them. This project had a specific focus on capturing what was important for a positive transition into adulthood, and using the information to influence policy.

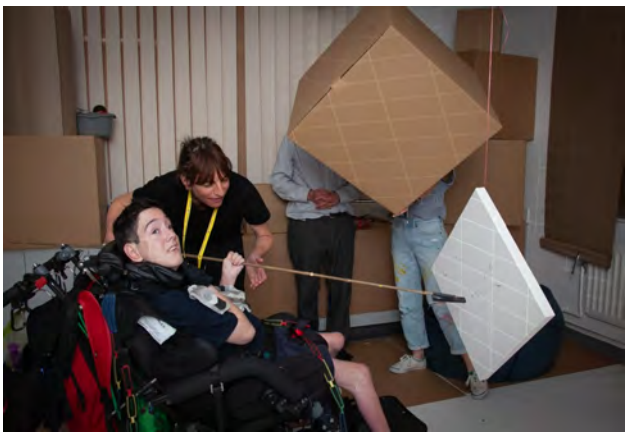
What we are trying to highlight is quite simple – what matters to young people with severe or profound and multiple learning disabilities is likely the same as what matters to you or me!

Young people with severe or profound and multiple learning disabilities have the same rights as everyone else and should be included in decision-making processes. Creative methods can be utilised to access their experiences, preferences and views. In turn, these can be applied to influence and shape the support and services they receive. Meaningful engagement requires dedication and investment in time and patience, developing familiarity and flexibility in our approaches. With the correct principles in place, meaningful engagement can enhance the lives of those with complex needs, and in turn we can learn about what matters to them and provide a platform for this to positively influence and drive the changes we want to see at service delivery and strategic levels.

> *“I don't generally feel that people particularly see or hear my son. I think if I didn't shout and spit and stomp like I have to a lot of the time, he would probably just get lost.” -*
>
> Family Carer

The foundations of the project were established through a relationship-building stage, ensuring time was spent with each young person, their families and support staff in a range of settings. These observations provided us with the knowledge and background of communication needs, likes and dislikes. From this, we were able to plan engagement activities that were individualised and meaningful. Over the past year we have carried out individual and group sessions, including parents, carers, siblings and grandparents in activities, which have provided us with invaluable insights into what is important to and for these young people. One session was delivered with Project Artworks: https://projectartworks.org/

> *“It's about all those relationships that build a picture about someone, what they need in their life and what works and what doesn't work and how to give someone a voice and how to shape their life in the future, which is constantly changing.” -*
>
> Project Artworks worker.



'To see their faces and the way they were interacting and laughing and smiling and actually just being normal youngsters without all the weight of every other day in life that they have round them it was just… it was magical, their faces were just priceless' -

Family Carer

In the later stages of the project, we will be documenting and sharing our learning through the launch of a co-produced multi-media manifesto to highlight the importance and value of engaging with young people with severe or profound and multiple learning disabilities. Family carers have had a paid role in being part of a working group to shape the manifesto development. As well as sharing pictures and video clips and revisiting previous activities through multimedia during our engagement sessions with the young people, we have held focus groups with family carers to gather their input into shaping the manifesto content and development.

Our manifesto will show the journey of the project. We will focus on highlighting the following:

1. Principles of meaningful engagement
2. From engagement to influence
3. Our project learning – Transition – what is important to/for young people with severe or profound and multiple learning disabilities as they transition into adult services

The What Matters to Me manifesto will be launched in March 2025, as well as an in-person launch to raise the profile of the work and to bring this to the forefront of the minds of key decision and policy makers we will be holding an online launch webinar.

You can find out more about the project, and sign up to the network forum here: https://www.challengingbehaviour.org.uk/what-we-do/projects-and-research/what-matters-to-me-project/

Contact Details

Taylor Anderson is the project lead for the What Matters to Me project at the Challenging Behaviour Foundation. If you would like to speak to the project team about What Matters to Me, please contact: whatmatterstome@thecbf.org.uk

Author Note: We have followed a stringent best interest process and carefully considered throughout the whole project process, the use of photographs and film clips of the young people. All the young people participating in this project are over 16 and in line with the Mental Capacity Act 2005 we have followed a mental capacity assessment, and subsequent Best Interest assessment for each individual. These assessments have been conducted with family carers and support circles and have been independently scrutinised before a decision on best interest has been made. We continually review this and share at every opportunity the photographs and film clips taken with the young people to gauge reactions. We ensure with key members of their support circles that the material is dignified and positive and that they believe it is in the individual's best interest to be used to raise awareness of the issues faced by young people with severe or profound and multiple learning disabilities and have a positive impact.

PMLD LINK
sharing ideas and information

Dear Santa – a festive sensory story

Victoria Navin

This sensory story has been adapted by me for this issue of PMLD LINK. This sensory story is one of 35 story packs available from Rhyming Multisensory Stories. 'Dear Santa' is based on a poem written by my dear late Dad, and after he passed, I thought it would be a fitting tribute to adapt the poem into a sensory story, changing some of the items in the original poem to items a person with additional needs would like to receive in their Christmas stocking.

The Benefits of Multisensory Storytelling

There are many benefits to multisensory storytelling: the stories promote communication skills, are an opportunity for individuals to explore and express their likes, dislikes and sensory preferences, to make choices and rejections. Within an educational setting, the stories connect learners to literature, culture, history and topic through the senses, and form a foundation on which to scaffold learning.

For me, the best part of sensory storytelling is the bond created between the storyteller and story explorer as they share their adventures.

I would like to invite you to join our story's character as they explore their wish list to Santa with this festive sensory story that can be enjoyed by sensory explorers of all ages.

The Story Props

The story props are everyday items found around the home/classroom. You do not need to use all the items listed and may wish to swap some out with props of your own. Suggested story props are:

Santa hat, cotton wool, large envelope, Play-Doh/ homemade dough, pot of bubbles, bell, toy car, paint, cardboard tube, toy boat, water spray bottle, washing up bowl, fan, dried rice, Tupperware® box, shaker, tambourine, drum, physio ball, cycling helmet, chocolate coins, Koosh®, torch, lights, doll, shape sorter, kaleidoscope, shaker bells, apples or apple sauce, orange zest, raisins, currants, sultanas, spices: cinnamon, nutmeg, clove powder, allspice, ticking clock.

I have written the story with the list of story props highlighted in bold, with notes on activities to engage the senses written underneath each line.

How to tell a Multisensory Story

1. Place your resources into zip wallets, one wallet for each part of the story that uses a prop.
2. Write or print the line(s) of the text and sellotape onto the outside of the wallet.
3. Place the wallets into a large box in the order in which they appear in the story.
4. Read the line(s) of the story presenting the prop when the corresponding word (in bold) appears in the story.
5. Allow the story explorer (the learner) plenty of time to engage their senses exploring the items and to process the experience. This is an opportunity for people to explore and express sensory likes, dislikes, and preferences, make choices and rejections.
6. Focus on working on communication skills, building anticipation, cause and effect and if working as part of a group, social skills such as waiting, sharing and turn-taking.
7. Be allergy aware and supervise the activities at all times.

The Benefits of Multisensory Storytelling

'There are many benefits to multisensory storytelling, for me, the real magic is the bond created between the storyteller and the story explorer as you share your adventures'

Victoria Navin - Founder of Rhyming Multisensory Stories

1. **Create a Bond**
Sensory storytelling creates a unique bond between the storyteller and the story explorer enhancing and enriching experiences as they share their adventures.

2. **Subjects, Themes & Topics**
Stories connect learners to literacy, culture, history and topic in a fun and engaging way that is meaningful to their lives providing opportunities to explore the world around us.

3. **A Foundation to Scaffold Learning**
The stories form a foundation on which to scaffold learning and to work on personal targets and goals.

4. **Spark the Imagination!**
Through their sensory explorations the story explorer becomes the author of their own story.

5. **Promote Communication Skills**
The activities within the sensory story promote eye contact, listening, shared attention and language development.

6. **Self-Confidence & Wellbeing**
The stories present opportunities for students to try new ideas and skills, practice self-care, independence, and enjoy achievement.

7. **Promote Self-Awareness**
Asking for 'help,' 'again,' and 'more.

8. **Build Anticipation Skills**

9. **Physical Development**
The development of fine and gross motor skills through the manipulation and investigation of the story props.

10. **Creativity**
There are many opportunities within the storylines for students to explore their creativity through arts & crafts, movement, music & sound, and role play.

11. **Exploration of Scientific Concepts**
The activities within the storyline provide opportunities for students to engage in mathematical concepts and scientific exploration.

12. **Explore the Concept of Cause & Effect**
Many of the story props present opportunities to explore cause and effect e.g., torches, fans, lights and musical instruments.

13. **Social & Emotional Skills**
When sharing a story as a group students practice turn-taking, sharing, listening to others' ideas and teamwork.

14. **Sensory Expression**
The use of props provides opportunities for the student to explore and express their likes, dislikes and sensory preferences in a safe and therapeutic environment.
This information can help to identify motivators to calm an individual when anxious or stressed.
This record of sensory preferences can also be used in the writing of behaviour and care plans to enhance areas of daily life.

15. **Have Fun!**

Rhyming Multisensory Stories
STORYTELLING THROUGH THE Senses

The poem and notes on presentation are presented on the next two pages. The actual poem is in the left hand column and details about props and activities and tips are in the right hand column. Note that I have abbreviated 'Story Explorer' to S.E.

Further Information

If you would like a free copy of the 'Dear Santa' Teaching Pack, which includes a fully resourced, step-by-step multisensory story, festive activity ideas for sensory learners, a guided multisensory relaxation adventure with props, plus notes on how to adapt the story into a play, you can:
email rhymingmultisensorystories@outlook.com
or download from the website:
www.rhymingmultisensorystories.com/story-libraryandshop

You can watch a free recording of the story walk-through on YouTube youtu.be/dXIWhsMqQk0?si=d_EiRkw31ank6ZtV

Your questions, queries, comments and feedback are always welcome.

IN LOVING MEMORY OF
MY DEAR DAD - JOHN PEACE

Contact Details

Victoria Navin is the Founder of Rhyming Multisensory Stories.
Email: rhymingmultisensorystories@outlook.com
Website: www.rhymingmultisensorystories.com
LinkedIn: https://www.linkedin.com/in/rhyming-multisensory-stories-6bbb71208/
Facebook: www.facebook.com/storytellingthroughthesenses

'Dear Santa – A Sensory Story'	
Lines of Poem	**Notes on props and presentation**
*'Dear **Santa**'*	**Santa** Present a Santa hat or cotton wool representing Santa's beard for sensory exploration. Option to spritz with a little aftershave.
*'I'm writing my **letter** early this year* *As you get lots of mail from people I hear'*	**Letter** Open a large envelope containing the sensory story with the S.E. You can use this to help you deliver the lines of the story.
'Here's a list of things I would like ***Play-Doh®**, **bubbles,** a **bell** for my trike'*	**Play-Doh®** Make vanilla or pine scented **dough**. **Bubbles** Build Anticipation Skills Give the cue *'Ready...steady...'* wait for a response, (this could be a movement, vocalisation, gesture or sign,) say and/or sign *'Go!',* then blow the bubbles. Can the S.E track the bubbles? Can the S.E pop the bubbles? Can the S.E communicate a request for *'more'* bubbles? **Promote Listening Skills** Make a popping noise as bubbles pop. Can the S.E listen to the sound of the bubbles popping? **Promote the Development of the Mouth Muscles** Can the S.E blow the bubbles? **Extend Learning** Explore using one long, slow breath to blow a large bubble, and one short breath to blow lots of bubbles. **Bell** Listen to a bicycle bell/horn.

'A toy car,** a **boat** and a **jet plane'	**Toy car** Roll a toy car down a cardboard tube/ramp or dip the wheels into paint and mark-make. **Boat** Float a toy boat on the water in a washing up bowl. Nudge the boat towards the S.E. Can the S.E nudge the boat back towards you? Mist the air using a water spray bottle. **Plane** Explore the settings on the fan to re-create the air from the airplane's jets. Explore different types of fans, wind-up/squeeze/dynamo fans. **Tip -** Explore different types of toy cars, boats and planes: Clockwork (wind-up) Interactive (have lights & make sounds) Pull propeller Remote control Push-along
*'Track for my station, a very fast **train'***	**Train** Shake a box of dried rice to re-create the train rattling down the tracks. Could pair with toy train or photo of train as the box is rattled
*'A **shaker**, **tambourine** and a loud **drum'***	**Shaker, tambourine, drum** Present the instruments for sensory exploration. Can the S.E choose their favourite instrument? Can the S.E communicate a request to listen to the instrument again? Explore playing beats and rhythms. Can the S.E copy any beats or rhythms? Practice starting and stopping. Practice playing together. Play and sing along to a Christmas song e.g. Jingle Bells.
*'A Tuff Tray and **slime**, now that would be fun!'*	**Tuff Tray and Slime** Place slime into a Tuff Tray and present for sensory exploration. **Slime Recipe** You will need ¼ cup chia seeds and 1 ¾ cups of water Mix the ingredients then leave to swell for 30 mins. Discard after use. **Tip** Add green food colouring or wilted spinach for an authentic slime colour.
*'A new **physio ball**, (my old one's gone flat)'*	**Activity** Inflate a flat physio ball using a pump. This is a great activity if working in a group to promote team building. **Promote Gross Motor Skills, Balance, Sensory Regulation** Explore exercises with the **physio ball** (You may wish to consult with the person's physiotherapist or plan.)

*'And for my new trike, a shiny hard **hat**'*	Would the S.E like to try on the cycling helmet? Present a safety mirror so they can see their reflection. Mime or sign cycling. (See sign at: https://www.signbsl.com/sign/bicycle
***'Chocolate coins** to suck and chew'*	Can the S.E communicate a request for 'help' to remove the foil from the **chocolate coin**? Can the S.E communicate a request for 'more?' (You may wish to consult with the person's speech therapist especially when tasting foods.)
*'A **Christmas Cracker** to pull with you'*	Build anticipation skills as you pull the **cracker** together. Some people dislike loud bangs. So remove the banger or make a cracker by popping a party hat inside a cardboard tube and wrap in crepe or tissue paper.
*'A **Koosh**, a **torch**, bright **lights** for my tent. I will make good use; it will be money well spent'*	Present the three props for the S.E to choose from. Explore cause and effect using the **torch** and **lights** **Tip -** Dim the lights in the room for more impact.
*'Mum says I must write for my sister who's two. Bring her a **doll** and a **shape sorter** too'*	Explore the **doll.** Explore slotting shapes into the **shape sorter**.
*I will look for you Santa, high in the **sky'***	Present a **kaleidoscope** or **shaker bells** to re-create the sound of Santa's sleigh. Encourage S.E. to look up.
*And leave you some milk and a tasty **mince pie***	Option to taste some of the ingredients contained in mince pies (**apples or apple sauce, orange zest, raisins, currants, sultanas**) Be allergy aware as many mince pies contain nuts. (You may wish to consult with the person's speech therapist especially when tasting foods.) Non-food activity - Touch and smell mincemeat spices: **cinnamon, nutmeg, clove powder, allspice**
*'I must go now as it's getting quite **late'***	Explore the passage of time by listening to a ticking **clock** or watching the sand in a **sand timer** empty from the upper bulb into the lower bulb If the lights are not dimmed, dim the lights or roll down the blinds in the room.
'Thank you, Dear Santa, Johnny Aged 8'	Practice signing 'Thank You' using Makaton or BSL; your flat hand starts with the fingertips on your chin then moves down and away from the body. (See sign at: https://www.signbsl.com/sign/thank-you) You may wish to alter the last line to include the child's own name At the end of the story, place the props into a Christmas bag and offer the person to choose from the bag one at a time, or lay them out for free exploration.

Remember to tag us on social media ~ @PMLDlink

Twitter: @PMLDlink

Facebook: PMLD LINK

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

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

PMLD LINK
sharing ideas and information

Winter 2024, Vol. 36 No.3 Issue 109

Point5 Network: an update since 2017!

Liz Baxter

Point5 now has the support of Tower Hamlets and Redbridge Education Partnerships which help to facilitate the administration and organisation of the network's meetings and events. Having taken a pause during the Covid Pandemic, Point5 was reinstated in February 2022 following a search for professional development opportunities for teachers of children and young people with PMLD (profound and multiple learning difficulties) from Stephen Hawking and Beatrice Tate Schools in The London Borough of Tower Hamlets. The headteachers of these schools wanted to create a network that would be open to other schools for pupils with PMLD and the fruits of this search revealed to them the existence of Point5!

Further to the ambition of providing professional development for classroom teachers; the schools' leaders wanted to ensure that our needs are met. We have found the development of a mutually supportive forum to share strategic thinking and to offer one another feedback and challenge contributes to the ability of our schools to be outward facing and collaborative in our work. The leadership of schools for children and young people with PMLD is a bespoke field within education; finding a group of like-minded and collegiate school leaders is an aspect of Point5 that we feel immensely proud of.

The title Point5 was decided upon by the original group of schools back in 2012 as this number is reflective of the percentage of the population of school aged children and young people with PMLD.

A summary of the make up of the Point5 network is provided below, written by Sophie Weir, Deputy Headteacher of Richard Cloudesley School in Islington:

A network for teachers wishing to develop and share good practice

Point5 is a growing network of educators dedicated to supporting students with Profound and Multiple Learning Difficulties (PMLD), Multiple Sensory Impairments (MSI), and complex needs. Our core mission is to provide practical, class-based Continuing Professional Development opportunities for teachers and school leaders. These initiatives are rooted in current educational practices, specifically tailored to enhance the learning experiences of this unique and complex group of students.

Format

The Point5 network has two strands:

The leadership strand who meet termly to review the impact and agree the focus for the following term.

The practitioner strand who meet in smaller focus groups visiting each school over the course of a term. (approximately three schools)

The practitioner strand is made up of lead practitioners and teacher participants. Schools typically have 1 lead practitioner and 1 teacher participant.

Lead practitioners: Teachers with more than four years' experience of working with students with the most complex needs and are consistently good and outstanding in their practice. Lead practitioners are chosen by members of the lead school to ensure consistency of standards. Part of the lead practitioner's role is sharing their best practice with visiting teachers. Therefore, they must be willing to welcome other lead practitioners and teacher participants into a lesson.

Participants: Teachers new to working with pupils with the most complex needs or who would benefit from working with teachers with lead practitioners. Participants must be willing to be self-reflective and able to take on friendly advice when it is appropriate for their setting.

Participating school obligations

This is a free network, and participating schools are welcome to send one or more teachers to the network.

- Each school will host a half day visit over the course of each term.
- The visit should include a short tour of the school sharing context and an opportunity to visit the lead practitioner's lesson.
- A short meeting to discuss, reflect and agree any next steps.

As these meetings are planned specifically for teachers, school leaders will not need to join these school visits, however they are invited to attend Point 5 practitioner meetings when they are the host school.

(Sophie Weir, Richard Cloudesley School, Islington)

Leading successful, innovative and outward facing schools for children and young people with PMLD means that leaders must look carefully at the professional development requirements of teachers and support staff. Leaders within the network all share a firm belief in developing practice from learning within practical and everyday classroom experiences. We are excited to share with PMLD LINK readers some of the opportunities this has created.

At the conclusion of the academic year 2023-24, we asked members of the network to reflect on their experiences and share examples of their learning. Participants commented on:

- the time and space afforded to them to observe other people's practice and learn about how different systems, such as assessment and recording systems, can be linked into day-to-day practice within the classroom and impact positively on pupils' development
- the network providing a platform to ask questions and to share ideas with confidence
- opportunities to receive constructive feedback from practitioners outside of their own setting
- opportunities to share classroom methodologies, for example about the deployment of support staff or using input from therapists

In recognising the uniqueness of every pupil and the different contexts within which we are teaching, these inter-school relationships offer a precious forum for discussion and collaboration.

For school leaders, setting aside dedicated time to discuss matters that are wide ranging and pertinent provides a great sounding board and more opportunity for learning. Over the last 2 years, topics have covered;

- teaching phonics and early reading and what this means for those with PMLD,
- sharing experiences of Ofsted inspections,
- developing and refining robust assessment systems,
- developing and refining curricular for learners with PMLD,
- taking care of the emotional wellbeing of ourselves and of our school communities, particularly in relation to bereavement.

Our meetings have all been a hugely valuable experience leading to strong relationships across the leadership strand of the network.

Schools within the network have begun sharing training opportunities; for example, inviting Dr Sarah Mosely to deliver a short session on literacy for learners with PMLD to the leadership group in June which was a great!

If you would like to hear more, or are interested in joining our network, please contact:
Sue Blows – sue.blows@the-partnership.org.uk or
Gail Weir – head@stephenhawking.towerhamlets.sch.uk

Contact Details

Liz Baxter is currently SENAR Team Manager (Special Educational Needs Annual Review Team Manager) for the London Borough of Tower Hamlets.

Email: lizhelenbaxter@gmail.com

Setting Up a Standing Order

As part of their entitlement for their subscription, subscribers are sent hard copies of three issues of the journal in a 12 month period. A reminder renew is always sent with the third hard copy.

People have asked whether it is possible to have automatic renewal of subscriptions. From the point of view of PMLD LINK, the simplest way for a subscriber to achieve this is by them setting up a standing order with their bank for an annual payment. Many people do this already.

The PMLD LINK account details are:

HSBC Bank

Account name: PMLD LINK

Account No 81156284

SORT 40-39-06

If you do set up a standing order, please let the Treasurer know that you are doing this so that he can look out for the credit appearing on bank statements. Email: info@pmldlink.org.uk

PMLD LINK
sharing ideas and information

Winter 2024, Vol. 36 No.3 Issue 109

Respiratory Community of Practice

Laura Canning

Community acquired pneumonia is recognised as a leading cause of death amongst people with a learning disability. Whilst also contributing to increased hospital admissions, longer stays in hospital and recurrent admissions. With this in mind, the South West NHS England Learning Disability and Autism Programme are seeking expressions of interest to establish a multidisciplinary regional (South West) Community of Practice (CoP). Initially, this will focus on the holistic management of community acquired pneumonia and respiratory complications associated with long term neurological conditions.

Purpose

To provide a space for learning, to reflect on practice, share ideas and explore opportunities for service improvement whilst providing on-going support to peers and colleagues. Aiming to improve care pathways and reduce the inequalities experienced by people with a learning disability and autistic people, across the region, by sharing knowledge and skills.

Audience

This is open to all of those with an interest in improving respiratory care pathways, associated with long term neurological conditions, and is not limited to those supporting or working with adults with a learning disability. This is open to those both internal and external to the NHS.

CoP offer

- Online CPD and learning opportunities
- Peer support through discussion
- Sharing skills and knowledge
- Networking
- Opportunities to support positive change

Express your interest

Please complete this form to register your interest:
https://forms.office.com/e/A2RHxYqVHR

Upcoming meetings and other information

A “hold the date” for an initial meeting in December 2024 will be shared with those who have expressed an interest in the CoP. The initial meeting will be interactive and focus on “Exploring existing practice; challenges and enablers”. This meeting will also provide the opportunity to agree a direction, priorities and learning needs for future sessions. Future meetings will be held every 3 months.

Look forward to seeing you soon!

Contact Details

Laura Canning is an NHS physiotherapist and the Health Inequalities Lead (Secondment), South West NHS England Learning Disabilities and Autism Programme.
Email: laura.canning@nhs.net
Tel: 07872 814697

Editor note: It is possible that the initial meeting in December will have already taken place by the time you read this article. Please do register your interest anyway to join the Community of Practice and future meetings.

References

LeDeR (Learning from lives and deaths - People with a learning disability and autistic people) (2002) *Action from learning report 2022/23*
https://leder.nhs.uk/images/resources/action-from-learning-report-22-23/20231019_LeDeR_action_from_learning_report_FINAL.pdf

PMLD LINK
sharing ideas and information

Creating a resource that captures the social histories and lived experiences of the PMLD community: which stories should be collected and shared, and how?

Ben Simmons, Becky Churchill and Katie Crouch

In this short article we introduce a new project that aims to develop a resource that shares the stories of the PMLD community. By 'PMLD community' we mean people with profound and multiple learning disabilities (PMLD), their loved ones such as family and friends, and those who regularly support people with PMLD, including day centre staff and paid carers. Our project involves working with the PMLD community to identify what stories they would like to share, with whom, and how. We will then work with the community to co-create a resource and share this with readers of PMLD LINK in a future issue.

Background

Our project began with an exploratory phase that investigated the research priorities of the PMLD community (i.e. the topics that the PMLD community wants more research on). We put out calls in PMLD LINK asking for reader's suggestions (e.g. Read, Simmons and Parfitt, 2023; Simmons, Read, Parfitt and Bush, 2022; Read, Simmons, Levinson and Bush, 2021), presented our work at conferences and asked people to feedback, and also contacted families and services in South West England asking for their suggestions. The exploratory phase generated a range of potential projects such as research to improve the public's awareness of people with PMLD, research to improve social workers and doctors' knowledge of the communication needs of people with PMLD, and research that can improve the accessibility of cultural spaces such as museums.

Instead of choosing one topic ourselves, we shared our findings with an advisory group (or what we call a 'working group') consisting of family members and day centre staff. Whilst all the themes resonated with members of the working group, the group felt that a cross-cutting issue was a need for more publicly accessible resources written by the PMLD community itself. In other words, whilst each of the research topics were important, the group felt that the topics were a product of society's misunderstanding of people with PMLD and those involved in their day-to-day lives.

The working group suggested developing a project that can shed light on the everyday lives of people with PMLD, a project that can lead to a resource that can inform both trainee practitioners (e.g., social work students) and the public more generally about what life is like for the PMLD community. We are about to begin this project and seek reader suggestions for what the resource could look like.

Next steps

Over the next 10 months (September 2024-July 2025) we will be co-creating a resource with our working group. We are in the early stages of imagining what this resource could look like and are open to suggestions from readers of PMLD LINK regarding the resource's form and content. For example, which stories should a resource include? How can we best collect and share the stories of the PMLD community? Which formats of story-sharing are most impactful? If you have any suggestions, please feel free to get in touch with our team.

The research is funded by the Wellcome and forms part of the 'We Are The People Project'. More details online at: https://www.bathspa.ac.uk/projects/we-are-the-people

Contact Details

Ben Simmons, Reader in Inclusive Education and Disability Research, Bath Spa University.
b.simmons@bathspa.ac.uk

Becky Churchill, WATP Community Research Fellow, Bath Spa University.
b.churchill@bathspa.ac.uk

Katie Crouch Senior Lecturer and WATP Research Fellow, Bath Spa University.
k.crouch@bathspa.ac.uk

For references in this article, please see page 47.

PMLD LINK
sharing ideas and information

Winter 2024, Vol. 36 No.3 Issue 109

The PMLD LINK 'Reference group' – Themes that have been raised

PMLD LINK Editors

This year we started a PMLD LINK 'Reference group' to help shape the work of PMLD LINK. We did a call-out for volunteers to join it and were delighted to hear from a number of families, practitioners, and others working in the field of profound and multiple learning disabilities. We have had two online meetings of the group (each with around 8 attendees) and plan to do the same next year.

In the meetings, people have shared their views about the key current issues for people with profound and multiple learning disabilities (PMLD) and their families, and topics they would like to see PMLD LINK focus on in future. So what issues have been raised in the reference group this year? The following are some of the key themes and issues brought to the fore in the reference group meetings.

1. People value PMLD LINK (and all its contributors) for sharing information. Too often families are spending valuable time searching for information about local and national support and services they require. They were conscious that services may not be proactive as they are often divorced from everyday life as lived by people with profound and multiple learning disabilities and their families. It was discussed that care providers come and go on a weekly basis (e.g. handing back contracts to local authorities in this financial climate), and many day services closed during Covid and haven't re-opened. It is a changing landscape and hard to get up-to-date information.

2. There was discussion about the rising cost of living for families generally and additional costs for families that care for people with profound and multiple learning disabilities, especially:
   - electricity to charge equipment, heat /cool homes to meet sensitivities to temperature changes, for increased washing and drying requirements, 24-hour monitoring and care etc.
   - the rising costs of continence products which they have to buy because they do not get enough from services, if these are provided at all.
   - the rising costs of mobility aids and equipment required for postural care which again are not always fully funded.

3. Housing was also mentioned as an issue - the impact of inadequate and temporary housing on children with profound and multiple learning disabilities and their families. More broadly, the importance of suitable housing and housing models for people with profound and multiple learning disabilities.

4. Transition from child to adult services was described as 'horrific on every level'.
   - Young people with profound and multiple learning disabilities not being listened to, not being treated as if they have a right to be heard – 'My daughter has a lot to say but they are not listening to her.'
   - The person with profound and multiple learning disabilities left without equipment and their basic needs not met.
   - The issue that once a young person becomes an adult, too often the authorities don't properly listen to/involve their family.
   - The assumption that parents don't know what they are talking about and aren't competent, whereas often the professionals haven't done their research and it is the family who really know the issues – having lived these first hand.
   - The huge stress of this and having to fight a lot of parts of the system to ensure that a person's needs are met.

5. Education
   - Staff shortages in SEN schools were discussed.
   - How to negotiate the boundary between Health carers/nurses and support in education settings was discussed. In one area, it was mentioned that the school is seeing pupils with increasingly high medical needs and more medical care is falling on learning support assistants and teachers – with less health funding. There was another example where the children with tracheostomies have a healthcare assistant in school provided by Health.
   - There were concerns about diminishing access to post-19 education: 'We are increasingly seeing EHCPs ceased at 19 rather than allowing

19-25 educational provision for young people with profound and multiple learning disabilities'.
- An issue was raised about Ofsted's understanding of what learning, language and literacy reasonably look like for young people, and that their perspective has become very skills-focused rather than recognising lateral progression, 'scruffy targets', etc.
- Life-long learning was discussed as best practice – this is the approach currently used by PAMIS.

6. Health services remain a major concern. There are staff shortages in hospitals and community health services and the Covid pandemic continues to have a knock-on effect on provision.
   - One example given was an increase in pupils with nasogastric tubes and not PEGs due to NHS backlogs post-Covid.
   - Shortages of essential medication and medical supplies has been a real issue too.
   - People are still not getting annual health care checks as a matter of course.
   - Accessing funding for continuing healthcare and managing personal budgets are a big headache.

7. What people do– holidays, days out and opportunities
   Just organising and having a great day out or a longer holiday takes a huge effort to research and plan. It was discussed that there are lots of holidays, days out and opportunities out there and there was a desire to hear from more families about where they've been and what things they've done as 'that is how you hear about things – from other families'.

8. The topic of bereavement and loss was discussed.
   - Bereavement and loss is an issue for both families and people with profound and multiple learning disabilities. Life expectancy is shorter for people with profound and multiple learning disabilities and those people may also suffer due to losing a number of people around them.
   - It was discussed that death and loss is an important topic, though people rarely want to talk about it – and the importance of helping families reach out and get support, for themselves or those with PMLD.
   - Discussion also focused on the grief experienced around having a child with profound and complex disabilities which was not expected. There can be a lot of trauma and grief, and no one recognises the post-traumatic stress disorder (PTSD) which can follow these early experiences. Over and over again, each time there is a transition and hoops have to be jumped through to access services and cope with change, the same emotions can be re-activated.
   - Who cares for the carer? Faced with a lack of suitable support, some parents talked about investing their own money in counselling to help validate their feelings.

9. Last, and by no means least, is the continued use of language that is at best insensitive and at worst offensive and disrespectful to people with profound and multiple learning disabilities and their families and carers. It is of real concern that this is still an issue after so many decades of improvement in received knowledge of their abilities and needs, and the enhanced respect for minority groups as full citizens who can make a valuable contribution.

Other suggestions for areas to focus on:
- Something on friendship
- Cultural differences
- Protecting people with disabilities in war zones
- Articles on more difficult/ taboo topics e.g. debating what profound and multiple learning disabilities is, sexuality, intersectionality.
- Ethical issues e.g. the ethics of doing research with people with profound and multiple learning disabilities and their families.
- Reaching out to contributors/ reference group members from more diverse backgrounds.

Many thanks to everyone who has joined the reference group, we really value your contributions. If anyone else would be interested in joining the reference group, please let us know. The next online meeting is planned for January 2025 (exact date TBC).

Please also free to get in touch by email to share what topics you would like to see PMLD LINK focus on: info@pmldlink.org.uk

Further information about some of the topics raised in the PMLD LINK Reference group

In the rest of this piece, there are pointers to some themed issues and articles that may be found in the archive of back issues of the journal and on the PMLD LINK website. This overview only looked at issues in the past 13 years (forty issues of the journal) and previous issues can also have relevance.

The rising cost of living

This issue was last looked at in the Summer 2017 issue (Issue 38) by Bella Travis and Eve Jackson. Remember that this was the pre-pandemic days when the biggest

concerns related to the impact of austerity and concomitant cuts to services, but their article sets out a range of issues that still have resonance today. So too do their methods for challenging unfair decisions.

Individuals need to understand their rights, as set out in law, and a series of 'Know your rights' guides are available on the Mencap website: https://www.mencap.org.uk/what-we-do/campaigns-and-activism/know-your-rights-guides

Citizens Advice does provide advice about coping with the cost of living and it could well be worthwhile making an appointment with an advisor at your local offices. For more details about online advice and your local office got to: https://www.citizensadvice.org.uk

Ofgem are currently consulting about the impact on disabled people of raising price caps for electricity for households (see the article by Maddy Rose in this current issue) and watch this space for more news.

Transitions

The last themed issue on Transition was in Summer 2014 (Issue 78) in which the editors stated: 'Transition, far from being a once in a lifetime fixed event, is an ongoing series of changes that occur throughout life. From home to school, class to class, the move to "big school", college, adulthood, a place to live, relationships and the ultimate transition of end of life care; we all pass through many transitions in our lives. What unites them all is that each create challenges as well as positive opportunities. For people with profound and multiple learning disabilities, the navigation through often bewildering and emotionally demanding times of transition can be particularly challenging.'

The Summer 2014 issue contained several relevant articles. Sarah Townsend describes the training approach that she had developed to help smooth the path of transitions. Chris Cooper and Jo Lawson described some outcomes of a transition project they undertook within special schools in North Lincolnshire. They developed a 'Record of Preferences' to record each learner's responses to key experiences and analyse them in order to fully understand their likes, dislikes for activities, interactions, and experiences. For individuals with significant learning, language and communication needs this was a valuable tool for identifying how 'like' and 'dislike' preferences are shown, along with responses to a range of experiences and sensory activities. The editors commented that the most powerful stories of good transition in this particular issue have all had one thing in common: the person in transition has been supported by people with a strong commitment to putting that person at the centre of the process. Anybody going through any transition process needs to be accompanied on that journey by support, resources and opportunities, but more than anything, by people who love and care for them.

In Summer 2017 (Issue 87) Sam Bergin Concalves described how, as a family, they started to think about their son's adult life when he was about fourteen. They developed an easy read multi-media website for him called a RIX wiki. It contained information about the family, his communication, mobility and care needs, the things he liked to do, his spiritual life and school life. For more details go to: https://www.rixwiki.org.

Reflections on Life Transitions were made in pieces by Jean Willson and Linzi Ellison in Summer 2012 (Issue 72). Jean shared difficult dilemmas with us as well as some very valuable practical information, as she described her family's journey to ensure her daughter Victoria could live her life to the full, with family and friends around her. Linzi reflected on the life of her brother Lee and of her own memories, as she looked back and considered them growing up together. In the Winter 2021 issue (Issue 100) Fran Childerhouse describes how her family hit crisis point when their son became a teenager, and the fraught process of finding a suitable, safe, alternative to him living in the family home. She argues that greater awareness of the problems faced by many other families and a more enlightened approach, sensitive to her son's needs and those of the whole family, could have delivered a better outcome for everyone.

Health Services

PMLD LINK is proud of the range and quality of articles about physical and mental health that have been published. There are also more useful resources on the PMLD LINK website. The Summer 2024 issue is the latest of many themed issues. As the editors point out it is our TENTH issue dedicated to health and wellbeing, with previous issues remaining relevant today despite dating back almost twenty-five years. But they also note that it is quite salutary to reflect on the lack of progress in some areas, for people with profound and multiple learning disabilities.

Previous health-themed issues were: Spring 2001 (Issue 38), Spring 2004 (Issue 47), Winter 2007 (Issue 58), Winter 2009 (issue 64), Winter 2011 (Issue 70), Winter 2013 (Issue 76), Winter 2016 (Issue 85), Winter 2018 (Issue 91), and Spring 2024 (Issue 107). In Issue 91, Rob Ashdown provided an overview of about sixty articles that had appeared in PMLD LINK on Health and Well-Being and there have been many since in both health-themed and other issues. The piece in Issue 107 on 'Improving Health Outcomes' is valuable for offering a selection of approaches and relevant resources that can

support improved healthcare experiences and lead to better health outcomes.

The specific topic of accessing funding for continuing healthcare and managing personal budgets was specifically looked at by Helen Leonard in Issue 107. Michael Ormian in Spring 2020 (Issue 95) and Peter Glick in Summer 2021 (Issue 99) commented on the positive outcomes for their child and family of gaining a Personal Health Budget. But they commented on the complexities involving in getting started, with little or no practical help available for even the simplest of things. They had to start from scratch, and, recognise that other families are still having to do this. Peter Glick contributed to research centred on designing digital tools to enhance access to state-funded Personal Health Budgets which seem useful. Go to: https://mycarebudget.org/mediawiki/index.php/Just_starting_out

Days out and holidays

This has been the subject of themed issues and some articles: Spring 2003 (Issue 44) and Summer 2016 (Issue 84) and there were some very relevant articles in Summer 2022 (Issue 102) which had the theme of Fun. This is definitely a topic which needs fresh exploration.

Visit England does have a scheme which may help people find accommodation to suit their needs. Assessed properties will have facilities such as handrails, ramps, level-access showers, etc. but they may not run to hoists and equipment required for people with physical needs. https://www.visitengland.com/https%3A/www.visitengland.com/plan-your-visit/access-all/national-accessible-scheme. Similar schemes are run by Visit Wales - https://www.visitwales.com/inspire-me/holidays/accessible-holidays/accessible-holidays-wales - and Visit Scotland - https://www.visitscotland.com/inspiration/accessible

AccessAble provides people with disabilities with the detailed information they need to work out if a place is going to be accessible for them. Go to: https://www.accessable.co.uk

EuansGuide.com is another disabled access review website that shares information about the accessibility of venues. Go to: https://www.euansguide.com

The charity Hft produces a Holiday Information Guide with information to help people with learning disabilities and those closest to them choose an accessible, disability -friendly holiday. Go to: https://www.hft.org.uk/our-services/family-carer-support-service/fcss-updates/holiday-information-guide/?_sf_s=holiday+guide

Bereavement and loss

A good deal has been written in PMLD LINK about experiencing loss and preparing for the end of life. The whole of the issue in Winter 2019 (Issue 94) was devoted to the theme of 'Loss; looking ahead'. Jean Willson describes how her family, her circle of friends, a service provider and a palliative care team gave outstanding end of life support to her daughter Victoria. Other heartfelt contributions offer valuable reflections on loss and coping with death from families and professionals. In Spring 2020 (Issue 95) another moving piece was provided by Lucy Williams, who talks about the pain of loving and living with a child with a life-limiting condition. In Spring 2024 (Issue 107) Sarah Helton provides guidance on supporting people with profound and multiple learning disabilities with a sense of loss, bereavement, and grief.

Not much could be found about the grief experienced around having a child with profound and complex disabilities. This is certainly something to revisit.

What counselling or other support is there for carers to acknowledge and process feelings of grief and loss? Parents on the PMLD LINK Reference Group commented that they found the podcasts of Julia Samuels helpful: Julia Samuel offers a series of podcasts at: https://www.juliasamuel.co.uk/podcasts/therapy-works (but some require subscription to access). In her excellent article in this issue, Heather Bailey recommends that Affinity Hub signposts to emotional support (including counselling) for parents and carers of children with special needs. This website is managed by Dr Joanna Griffin, a chartered counselling psychologist and mother of a disabled son: https://www.affinityhub.uk

Some guidance for parents of children with life-limiting conditions is offered by the charity 'Together for Short Lives': https://www.togetherforshortlives.org.uk/get-support/emotional-and-listening-support/looking-after-yourself-emotionally/ Similar guidance is offered by The Rainbow Trust: https://www.rainbowtrust.org.uk/support-for-families/for-parents. These may provide some pointers for carers for looking after their emotional wellbeing, but PMLD LINK would welcome hearing more about the experiences of parents and other carers.

The family doctor should offer access to free services to help with any mental health worries, like talking therapies and counselling. The mental health charity Mind can provide information about local support and services. They offer confidential helplines which can help with mental health and related legal issues, as well as an online toolkit of practical tips. Got to: www.mind.org/need-urgent-help/using-this-tool. Citizens Advice has a page that provides information on how to protect your

own mental health and wellbeing. Go to: www.citizensadvice.org.uk.

Insensitive Language

PMLD LINK often hears about professionals and the general public making negative assumptions about people with profound and multiple learning disabilities. One of the greatest barriers faced by people who have profound and multiple learning disabilities is the attitude of others. Most people do not truly understand their abilities and needs, and relatively few people get to know them as individuals.

In part, in relation to professionals, this is a training and professional development issue, although it is also about what questions about attitudes are asked at the time of recruitment. In Spring 2020 (Issue 95) Rachel Wright asked questions about staff training. She said (p.8) 'Practitioners might be an expert in their field, top of their game and the best in the business but the single most important thing for the parent juggling to care for someone with profound and multiple learning difficulties is the way those practitioners communicate and work with them.' She strongly expressed her belief that all practitioners should have training in communicating and working well with families.

Contact details
For more information, contact the editors
Email: info@pmldlink.org.uk

Advice About Legal Issues

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

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

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

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

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

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

1) Access Social Care: Legal Network. This service (previously called the Legal Coalition Network, then hosted by Mencap), is now on an independent footing. They work with families to find solutions to situations. For referrals go to: www.accesscharity.org.uk/need-help. Complete online form to start the process or phone 02476978903.

2) Another organisation is CASCAIDr - https://www.cascaidr.org.uk/ run by Belinda Schwer who offers regular webinars, templates & other free resources to respond to issues where the Care Act is not being upheld.

3) Some areas have local law centres which offer legal advice, casework and representation to individuals and groups. Specialising in social welfare law, the staff will have an in-depth knowledge of the issues that communities face, and in some cases can support people to access legal aid'.

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

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

PMLD LINK
sharing ideas and information

People with profound and multiple learning disabilities in war zones around the world

PMLD LINK editors

We have all been extremely troubled that 2024 has been marked by massive destruction, death, loss and suffering for people around the world. Among them will be many people with disabilities and presumably many who we would describe as having profound and multiple learning disabilities.

The PMLD LINK charity does not have a political agenda but it must still strive to influence people who can act to improve the quality of living for people with profound and multiple learning disabilities in war zones.

What do we know about the impacts of war on people with disabilities?

Much has to be guesswork or from anecdotal evidence, in the relative absence of properly collected data. In May, a United Nations (UN) committee of specialists expressed horror that the survival and the physical and mental integrity of persons with disabilities still remains at stake (OHCR, 2024). The committee asserts that there is evidence that they are at higher risk of dying, becoming injured and acquiring further disabilities as result of intensive bombings and proximity to combat areas. Women and children with disabilities feature disproportionately among the civilians killed and injured. Persons with disabilities, adults and children, have lost access to appropriate sanitation facilities, safe and accessible shelter and, crucially, secure supplies of food and water to survive.

Children with disabilities have been exposed to a heightened risk of family separation, others have lost their assistive devices (including wheelchairs). Thousands of children with recognised intellectual disabilities have had their education severely disrupted with the closing and the destruction of many schools and the use of schools as temporary shelters. At present, the UN committee notes, in the refugee camps, children displaced with their families, have little opportunity for education and rehabilitation that are crucial for their development. Another UN office has published a report which examines the impact of armed conflict across the world on children with disabilities and provides recommendations, as well as aiming at informing policy discussions on conflict-affected children (OSRSG CAAC, 2023).

For much of recent recorded history different parts of the world have experienced wars that have had devastating and documented impacts on civilians and, therefore, likely on people with disabilities disproportionately. Human Rights Watch (2021) made a submission to the UN Special Rapporteur on the Rights of Persons with Disabilities based on research in Afghanistan, Cameroon, the Central African Republic, Israel, Gaza, Jordan, Lebanon, South Sudan, and Syria. The submission focussed on six issues in particular:

1. Higher risks for people with disabilities during fighting
2. Lack of availability of assistive devices
3. Lack of access to basic services
4. Disrupted education for children with disabilities
5. Abuse and stigma of people with disabilities
6. Mental health impacts

The recommendations in their report detailed a set of reasonable expectations of the UN, all states and humanitarian organisations.

Similarly, Amnesty International (2023) submitted a report to the United Nations Committee on the Rights of Persons with Disabilities which documented violations of the rights of persons with disabilities, including war crimes and crimes against humanity, related to armed conflicts and emergency situations in Afghanistan, Armenia, Azerbaijan, Mozambique, Myanmar, Nigeria, Sierra Leone, Ukraine and Yemen. Amnesty International's submission focussed on similar issues, including elevated risks from violence, inadequate inclusion in humanitarian responses, and lack of access to services, among others.

What is in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) about the rights of disabled people in armed conflicts?

According to Article 11 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), adopted in 2006:

> *States Parties shall take, in accordance with their obligations under international law, including*

international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.

In 2019, the United Nations Security Council adopted Resolution 2475 which recognised for the first time officially the impact of armed conflict on persons with disabilities and highlighted the obligations of all member states. Unfortunately, being a signatory to the CRPD does not guarantee the implementation by a state of these protections.

The world needs to see that these statements are followed up by the UN and world leaders and that protection, access to information, and basic services (hygiene products, health care, assistance, transportation, etc.) are made available to the refugees from war and those who have to stay in the war zones.

Contact details

For more information, contact the editors
Email: info@pmldlink.org.uk

References

Amnesty International (2023) *Persons with disabilities in situations of risk and humanitarian emergencies*. Submission to the Committee on the Rights of Persons with Disabilities. https://www.amnesty.org/en/documents/ior40/6454/2023/en/#:~:text=Over%20the%20past%20five%20years%2C%20Amnesty%20International%20has,Mozambique%2C%20Myanmar%2C%20Nigeria%2C%20Sierra%20Leone%2C%20Ukraine%20and%20Yemen

Human Rights Watch (2021) *Persons with Disabilities in the Context of Armed Conflict.* Human Rights Watch submission to the UN Special Rapporteur on the Rights of Persons with Disabilities. https://www.hrw.org/news/2021/06/08/persons-disabilities-context-armed-conflict

OHCHR (Office of the High Commissioner Human Rights) (2024) *Palestinians with disabilities subject to unbearable consequences of the ongoing hostilities and violence in the OPT*. United Nations: OHCHR. https://www.ohchr.org/en/statements/2024/05/palestinians-disabilities-subject-unbearable-consequences-ongoing-hostilities

OSRSG CAAC (Office of the Special Representative of the Secretary-General for Children and Armed Conflict) (2023) A new discussion paper highlights the devastating impact of armed conflict on children with disabilities. – United Nations: OSRSG CAAC. https://childrenandarmedconflict.un.org/2023/12/a-new-discussion-paper-highlights-the-devastating-impact-of-armed-conflict-on-children-with-disabilities/

Further Reading

Grove, S., Grove, N., Myerscough, T. (2010) Intellectual disabilities and war: Issues for consideration. *Journal on Developmental Disabilities*, (16)/1, 82-90

References from article on P40

Read, S, Simmons, B and Parfitt, A (2023) 'Creating authentic and positive stories about personhood for people with profound and multiple learning disabilities: a call for reader expressions of interest.' *PMLD LINK*, 35.1 (104).

Simmons, B, Read, S, Parfitt, A. and Bush, T (2022) 'What constitutes 'ethical' research for people with PMLD? A call for reader responses.' *PMLD LINK*, 34.3 (103). pp. 38-40

Read, S, Simmons, B, Levinson, M.P and Bush, T (2021) 'A call to action for conducting research with people with profound and multiple learning disabilities.' *PMLD LINK*, 33.3 (100). pp. 6-7.

In the Next Issue: Being Heard

Our Spring issue, the first journal in 2025, takes the important theme of Being Heard.

In such times of uncertainty and change, we offer this topic in the very broadest sense. Being heard is essential to our fundamental human rights being met - in being noticed, having a voice and some sense of control in our lives. Having our views and priorities heard are so vital to living a good life.

Being heard is a key issue on every level, from its impact at a very personal level to its greater influences across society.

It's essential that we hear and highlight what is of greatest importance to you, our PMLD LINK community, by sharing your stories and articles through our journal pages. Examples might include contributions about:

- day to day opportunities for people with profound and multiple learning disabilities to make their needs and preferences known (and for families and paid supporters too!)
- the battles families and carers experience to overcome unmet needs or navigate confusing systems to access services
- campaigning for genuine access and reasonable adjustments and for more appropriate services
- showing how professionals and policymakers should work to remove current barriers to equality
- acknowledging the valuable contributions people with profound and multiple learning disabilities have to offer when given full citizenship rights

Importantly, at a time of great political change globally, it is important our journal reflects everybody's views: that our focus includes how people are heard by their elected representatives and their governments.

We hope this theme inspires you to want to contribute!

We are always open to all sorts of submissions: a simple photo story or even a single photo with caption (with permissions); short or longer written articles (up to 1500 words); items of news; or reporting back on relevant events or resources. If you have the seed of an idea, we're happy to help – just get in touch!

All items and contributions needed by **10th February.**
Email to: info@pmldlink.org.uk

Guest Editors: Annie Fergusson, Maureen Philip, Michael Fullerton and Rob Ashdown

Our Guidelines for Writers and Sharing Photos are on the 'Get Involved' pages of our website https://www.pmldlink.org.uk/get-involved/

IN THE NEWS

Bamboozle Theatre Company: Enabled Space Conference

Bamboozle Theatre Company have organised a conference for 25th January 2025 at Curve Theatre in Leicester. This will be an opportunity for Bamboozle to share their experiences of making theatre accessible for learning disabled and autistic young people. There will be workshops to hear from headteachers from special schools, parents of disabled children and the Bamboozle team. The day finishes with a sharing of one of Bamboozles productions for learning disabled young people.

Tickets cost £50 per person (plus £3.90 booking fee), which includes lunch and hot drinks throughout the day.

To book a ticket go to: https://bamboozletheatre.co.uk/events/conference/
@nhs.net to be added to the mailing list.

A webinar exploring factors impacting end of life care and decision making for people with profound and multiple learning disabilities

This workshop, hosted by the South West NHS England Learning Disability and Autism Programme, aims to explore advanced planning and clinical decision making when a person is acutely unwell. It will discuss how we effectively hear the voices of people with profound and multiple learning disabilities whilst embedding person centred care. This is an opportunity to share good practice and provide a space to engage in meaningful discussion. It is for anybody with a passion for improving care for people with profound and multiple learning disabilities by supporting cultural change.

This workshop will be held online in Jan/Feb 2025 – date to be confirmed.

Please contact the South West NHSE Learning Disability and Autism team; england.learningdisabilityandautism-sw@nhs.net to register your interest.

Intensive Interaction Week

It was Intensive Interaction Week from Monday 14th to Sunday 20th October. Us in a Bus did a series of vlogs during this week. The related articles, and others, can be viewed at the resources page of the charity's website. https://usinabus.org.uk/resources . The MacIntyre charity has blogs and videos on in its website relating to activities during the week. Go to: https://www.macintyrecharity.org/news-blogs/wrapping-up-intensive-interaction-week-2024. You might like to read some of the blogs about Intensive Interaction from Graham Firth for more ideas and insights. Go to: https://connectingwithintensiveinteraction.com/blog
And of course, the Intensive Interaction Institute offers a range of training opportunities, videos and various resources. Go to: https://www.intensiveinteraction.org/

Training in Sherborne Developmental Movement

Training is available in 2025 from the Sherborne Association UK for anyone that wants to learn about Sherborne Developmental Movement or build on their existing experience. The approach can be used with anyone with or without a physical disability, anyone with health conditions or impairments, young children and their parents, school aged children, students and the elderly. The Sherborne Association UK offers training courses throughout the UK provided by its internationally qualified course leaders.

For more information get in touch through the website (www.sherbornemovementuk.org) or email contactus@sherbornemovementuk.org

Hear my story

It was Advocacy Awareness Week from the 14th to the 18th October. To celebrate, the National Development Team for Inclusion shared a blog from Nicola Grove, founder of Openstorytellers and Storysharing.
In this blog Nicola shares why small personal stories are so important in advocacy. Nicola draws examples from her work with children and adults who face profound and multiple barriers to becoming part of society. She shows how they can communicate in many ways – through their bodies, through sound making, through using their eyes, their hands, their sensory responses.
https://www.ndti.org.uk/hear-my-story

Sign up to be a Mencap Policy Shaper

Sign up to be a Mencap Policy Shaper and help tell the government what life is like for people with profound and multiple learning disabilities and their families.

Policy Shapers are people with a learning disability and their families, who support Mencap's policy work by answering a short survey each month. The surveys take, on average, less than 3 minutes, are co-produced by people with learning disabilities and cover topics like cost of living, healthcare, social care, and benefits.

Your responses are used in meetings with government, regulators and other decision-makers to improve laws, policies and services for people with a learning disability.

For example, Policy Shapers stories demonstrated to NHS England the need for training and resources for healthcare professionals in the roll-out of the Reasonable Adjustment Flag.

By sharing your experience, you help make a bigger impact. Please sign up here!: https://www.mencap.org.uk/get-involved/campaign-mencap/our-work-parliament/become-policy-shaper

Kidz to Adultz Exhibitions 2025

Kids to Adultz exhibitions are for children and young people with disabilities and additional needs, and the people who support them. All members of the public can attend free of charge once registered.

Everyone is welcome to attend, including children, parents and professionals. Assistance dogs are also welcome. They are an opportunity to try out the equipment and products of manufacturers, join in the fun and participate in the activities taking place throughout the day. The exhibitions will be useful for a range of professionals across the health, social care and education services.

There are events in various regions of the UK in 2025. For more information, go to: https://www.kidzexhibitions.co.uk/our-events/

Event showguides are available in advance to help you plan and make the most of your day.

Accessible Book Festival—report back

On 13-14 September, I had the great privilege of joining this wonderful festival organised by Ailie Finlay of My Kind of Book. This was a first of its kind - held at the Scottish Storytelling Centre in the middle of town and it was such a feast of multi sensory stories. There were contributions from Oily Cart; Maureen Phillip and Gill from PAMIS; a framework for attention and engagement from Rita Gerkema-Nijhof; mindfulness; and the sensory qualities of language. These were just a few of the sessions on offer to an audience who had come from all over the UK and abroad. Do look at the website and contact Ailie if you would like to know about future events. This festival is sure to become a fixture in the PMLD LINK calendar. - Nicola Grove

When the World Turns

Bookings are now open for 2025 for When the World Turns, the sensory theatre production crafted by Oily Cart. As described in this issue of PMLD LINK (p.11), When the World Turns is an accessible, intimate, interactive show, expertly crafted for visitors with profound and multiple learning disabilities who experience the most barriers to access. You can expect lots of up-close sensory moments, a gentle pace, and plenty of breathing space for processing. Immersed amongst hundreds of real plants, watch, hear and feel as music, puppets, sounds, scents and shadows come to life around you. Tour dates are from February to March at venues across the UK. Spaces are very limited so booking early is advised. Go to: https://oilycart.org.uk/shows/when-the-world-turns/

Frozen Light Theatre Tour

Frozen Light is touring its latest accessible theatre production The Ancient Oak of Baldor with dates announced for January- February 2025.

Frozen Light's production explores a story from the realm of fantasy. This is a multi-sensory experience for audiences with profound and multiple learning disabilities and their companions.

For more details about this and other tours go to: https://www.frozenlighttheatre.com/shows/theancientoakofbaldor

Separating Intensive Interaction 'means' from 'ends'

Having had an enforced break during 2020/21/22/23, the latest Intensive Interaction Residential weekend happened 11th-13th October.

In a break from tradition, it took place at Bell Heath Boundless Outdoors centre near Stourbridge rather than Malham in North Yorkshire.

In another break from tradition the organisation and delivery was shared between Us in a Bus and the Intensive Interaction Institute, and as well as offering opportunity to strengthen that connection, it also proved the perfect occasion to absorb the energy and positivity from other Intensive Interaction Practitioners from across the country.

Keeping the traditions of shared meals and dormitory accommodation ensured maximum opportunity to socialise and get to know fellow attendees. Connections made, re-established (several people had attended more than one previous weekend).

Under the guidance of Graham Firth and Lynnette Menzies from the Institute, and supported by Victoria Goody and Anne Laney from Us in a Bus, the group considered exactly what Intensive Interaction provides to recipients/purchasers/practitioners and adjacent individuals (donors perhaps), and how this can be best communicated to those people when trying to establish services in which II is embedded and funded to the extent it needs to be. Complex and emotive stuff, and something that the widely differently experienced attendees engaged in fully and enthusiastically.

There was a full programme for the weekend, with informal discussion happening throughout the less structured parts of the weekend. Often until quite late in the evening!

RESOURCES AND BOOK REVIEWS

A chat bot about social care

In Control is a national charity that aims to provide people with advice and information to enable them to access the support they need. It makes available resources, such as fact sheets, toolkits, presentations and template documents and reports. For more details go to: https://in-control.org.uk/

In Control is trialling a new resource. AccessAva is a robot (sometimes called a chatbot or Artificial intelligence). It can give you information and guidance about Health and Social Care at any time and it is FREE to use! Ava will ask you some questions to find out more about you and your issue. From your answers, it will give you information and guidance. It can even draft you a template letter, which you can personalise to send to your Local Authority or Integrated Care Board. Go to: https://in-control.org.uk/welcoming-ava-onto-our-website/

AccessAva has been developed by ASC (Access Social Care). ASC provides free legal advice and support to people in England to get the care to which they are entitled. To find out more, go to: https://www.accesscharity.org.uk/accessava

ASC have a team of qualified solicitors and review the content regularly.

In Control do not own or maintain this chatbot but hosts and supports it on behalf of Access Social Care. Using the chatbot is at your own discretion and any letters produced cannot be endorsed by In Control.

If you have not been able to find the help you need on AccessAva, you can find someone to speak to by contacting admin@in-control.org.uk who will link you to a human.

New financial support from Motability

Motability have issued details about financial support with leasing new cars, scooters and powered wheelchairs. It is called the New Vehicle Payment. It is currently £750 for cars. It is called a New Product Payment for scooters and powered wheelchairs and is worth £100. So it is well worth a quick check to see if you're eligible and for how much. Go to: https://www.motability.co.uk/get-support/end-of-lease/scooters-wheelchairs/next-product/new-product-payment/

The Changing Places interactive map

The Changing Places Consortium is a group of organisations and individuals who work to support the rights of people with disabilities and who have come together to promote a Changing Places Campaign in the UK. The aim of the campaign is that Changing Places toilets should be installed in all big public spaces so that people can access their community. Currently, 2543 Changing Places toilets are registered. You can find a Changing Places toilet near you by using an interactive map. Go to: http://changingplaces.uktoiletmap.org/find...

The Sensory Projects PMLD Conference presentations

About 50 presentations from the PMLD Conferences organised by Joanna Grace of the Sensory Projects are now available to everyone. The PMLD Conference playlist on YouTube is a marvellous resource for training supporters of people with profound and multiple learning disabilities.

You can find these on The Sensory Projects YouTube: www.youtube.com/@TheSensoryProjects and click the PMLD Conference playlist.

Report on the state of our nation when it comes to social care

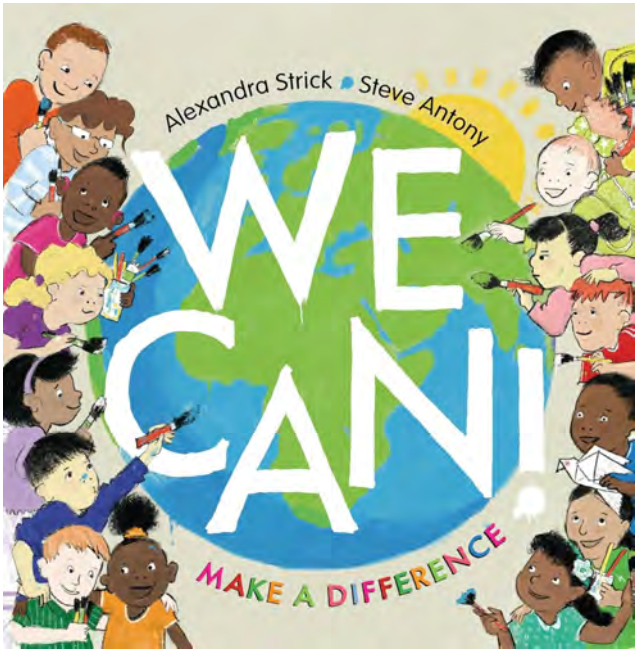
Access Social Care (ASC) is a legal rights organisation that exists to make sure older people, disabled people and unpaid carers get the social care they need and have a right to. Every year since 2020, ASC has worked with the advice sector to gather and analyse social care data to gain insights to the state of our nation when it comes to social care. The latest 'State of Nation' report sets out findings for 2023/24 and describes trends over time since this project began. The new report has found a doubling in the number of requests for social care information across major advice and helplines. For more info go to: https://www.accesscharity.org.uk/stateofthenation

Ethical issues in sharing online images with people with PMLDs: consent, awareness and representation

13.00-15.30 Online Webinar Rix Centre Thursday 20th February 2025

This online webinar is an invitation to discuss how we can collaborate to develop ethical guidelines for online sharing with people who lack capacity for informed consent. There will be panel presentations and a Keynote from Professor Maíre Messenger Davies, Emerita Professor of Media Studies and Policy at Ulster University.

Link to register for the event: https://www.eventbrite.co.uk/e/ethical-issues-in-sharing-online-images-of-people-with-pmld-tickets-1088523696679?aff=oddtdtcreator



We Can

Maureen Phillip

At PAMIS we love picture books and book festivals. People with PMLD and their families are fully included in both Edinburgh International Book Festival and Wigtown Book Festival, in particular, thanks in the main to funding distributed through Shared Care Scotland.

People with PMLD are fully involved as audience members but also as active participants in the author events. Working together, PAMIS and people with PMLD support authors to make their events accessible and fun for everyone. One such event a few years ago was the launch of the book, You Can, by Alexandra Strick and Steve Antony. Everyone had fun and the PAMIS online art group developed their own stories about what they enjoyed and they titled this, I CAN.

Through the collaboration with Alex and Steve people with PMLD and PAMIS contributed to the new book, We Can.

Like, You Can, We Can, is quite a rare book in that it genuinely consulted with many children and their schools/ families to ensure that all the text came from their ideas and that the illustrations were authentically inclusive. The images including the inclusive playground, wheelchair-accessible swing, the PAMILOO, (PAMIS mobile Changing Places toilet) children wearing ear defenders, hearing aids, all ensure the messages are about equality and ensuring that everyone is able to have adventures.

It is the first mainstream picture book to incorporate a Changing Places logo in the illustrations. Three proud contributors with PMLD and their families were Brody, Freya and Lauren who appear along with everyone else in the book.

We are also excited for another book by Alex to be launched in February 2025 by Child's Play. This is a touch and feel book that is as genuinely accessible as possible to children with many different needs. The new one, Let's Play, features different textures, shapes and labelling in Braille and Makaton.

Bold, Clear, Sensory and Strong: Creating Accessible Picture Books

My Kind of Book has produced this report which was written by Ailie Finlay and Deanna Bangs. This 2023 report shares findings from two studies on picture book accessibility conducted by My Kind of Book. The first study aimed to capture and share teachers' experiences and knowledge in this area. The second study gathered feedback on prototype books designed with increased accessibility in mind for children with complex additional needs.

My Kind of Book hopes that this report will stimulate further research into the issues around accessibility in children's books and will improve understanding about how to improve the structure, design, text and illustration of picture books to enable inclusion and access. It provides a good range of information to support authors, illustrators and publishers.

My Kind of Book is a not-for-profit community interest company with all profits being re-invested in the company for pioneering research and to create innovative books.
https://mykindofbook.org.uk/

Subscription form

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

Name of Subscriber: ……

Address: ……

……

Telephone No. …… **e-mail:** ……
(this email address will be your username for your website account)

Contact name within organisation (if applicable)……

I/we enclose a cheque for £ (made out to PMLD LINK)

I/we have set up a standing order for £ with our bank starting on ……
I
/we have paid using PayPal through the PMLD LINK website

Date:……

Please send this form with payment to:

PMLD LINK, Caerludd, Cilgerran, Pembrokeshire, SA43 2SN

If you require a receipt please enclose a stamped addressed envelope marked Receipt.

Gift Aid Declaration

Name of Charity: **PMLD LINK**

***Details of donor*:**

Title ……..Forename(s)……Surname……

Home Address:……

……

……Post Code:……..…

I want all subscriptions and donations that I make from the date of this declaration to treated as Gift Aid until further notice

You must pay an amount of Income Tax and/or Capital Gains Tax at least equal to the tax that the charity reclaims on your donations in the appropriate tax year (i.e 25p for each £1 you give on or after 6 April). If you are unsure whether your donations qualify for Gift Aid tax relief, refer to help sheet IR65 on the HMRC web site (www.hmrc.gov.uk)

Date ……/……../……..

STANDING ORDER MANDATE (Send to *your* bank)

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: …….. and thereafter annually until further notice

Account to be debited: ……

Account No. ……

Signature(s): ……

Date: ……

PMLD LINK
sharing ideas and information

Winter 2024, Vol. 36 No.3 Issue 109

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

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

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

Currently the trustees are:

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

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

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

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

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

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

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

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

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

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

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

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

Vol 36 No 3. Issue 109
ISSN 2042-5619