PMLD LINK

sharing ideas and information

Being heard

Spring 2025

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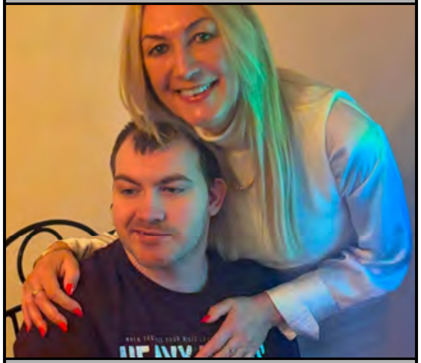

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GUEST EDITORIAL

Being heard

Welcome to the Spring issue of PMLD LINK and the all-important focus on ‘Being Heard’. We introduce this edition with a dedication to Samir El-Ziftawy, who sadly died at the end of 2024. Samir was no stranger to the pages of PMLD LINK, but usually because we were sharing happier news of his campaigning activities. As a member of Campaign 4 Change Samir was a mover and a shaker, a real influence for change, particularly in the area where he lived – he was genuinely heard. We feel privileged to share insights into Samir’s legacy here, with the generous endorsement of his family.

It will come as no surprise that our theme of Being Heard proved to be of such great interest to our readers. We were very fortunate to receive so many contributions, each sharing so much of value and from such a diversity of key perspectives.

In our current times (and avoiding politics), it feels certain groups of people appear to be given less value; their views and lived experiences ignored. We know people with profound and multiple learning disabilities continue to be amongst the most marginalised in society and their voices go unheard, and so too by association, their families and even their paid carers and supporters. This means they are often overlooked or forgotten by policymakers and services and their needs remain unmet.

The many articles in our Spring journal offer such valuable insights and practical ideas to create the ripples of change needed. They highlight the important issues, such as relationships and trust being a vital part of getting to know those with profound and multiple learning disabilities really well. Articles demonstrate that active listening helps us learn more about the very unique ways they communicate what’s important to them as individuals, particularly when we involve those who know them best, to ‘translate’. Sharing potential interpretations of responses and behaviours, allows us to begin to attach meaning to the repeated responses we might see; these expressions may even become meaningful and intentional by the individual too. Being creative with the variety of activities we offer enables us to see which opportunities enables them to interact and empowers their voice, or which situations lead to them to experience a greater sense of understanding or control in their lives. Sadly over the years (decades even) changes to government agendas and long-term underinvestment in services, has meant that vital opportunities for training and support in such fundamental approaches to promoting communication are no longer a given. This makes PMLD LINK’s role even more important to share and signpost the most relevant information and ideas. Thank goodness so many of you are still forging the way and making a difference!

In this issue you’ll notice, even the items in our News and Report Back sections focus on the vital role of those with lived experience being heard. As a consequence, the limited space here means we still have more to share on this topic, in future journals.

We encourage you to dive into the Spring journal with its theme of Being Heard and enjoy the richness and breadth of ideas and reflections shared on these pages. How ‘being heard’ may not even involve language, but simple connections of touch, sharing space or having a presence. How that sense of acknowledgement and reciprocal human togetherness is what’s important.

We’ll finish by stealing a line from the article by Gabriella Walker and Tussie Myserson. They quote from Don Mclean’s song, Vincent: “They did not listen, they did not know how. Perhaps they’ll listen now”

Guest Editor team: Annie Fergusson, Rob Ashdown, Michael Fullerton, Maureen Phillip, Clare Chalaye and Nicola Grove

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Samir El-Ziftawy

A Dedication

Self-Advocacy Group

Samir, from Hove on the south coast of England, passed away peacefully at home in September 2024, surrounded by the love of his family and support team. His loss is deeply felt, but his impact on advocacy, inclusion, and the rights of people with profound and multiple learning disabilities (PMLD) continues to resonate.

A Voice for Change

Samir was a cherished friend of PMLD LINK, playing an instrumental role in raising awareness of the needs and rights of people with PMLD. His work focused on ensuring greater visibility in society, influencing government policy, and driving meaningful change in the learning disability sector.

He rose to national prominence in 2020 at the Learning Disability England (LDE) National Conference in Manchester. Alongside his Campaign 4 Change colleagues, Samir presented ‘Making a Profound Difference,’ a powerful session that championed the right of people with PMLD to be seen, heard, and included. Prior to this, much of his work as a self-advocate was focused locally, pushing for better accessibility, increasing the number of Changing Places toilets, and improving the visibility of PMLD issues within Achieve together, the social care provider that supported him.

Transforming Self-Advocacy

Campaign 4 Change, like many self-advocacy groups, was originally made up of members with mild learning disabilities. However, when Samir and his close friend Frankie Dunne joined, it completely transformed the group’s dynamic. Their presence ensured that the rights and voices of people with PMLD were always at the forefront of discussions. Great friendships flourished, and the group became a powerful platform for advocacy at both local and national levels.

The impact of their work is ongoing. As recently as January 2025, Mary Woodall (Campaign 4 Change and LDE Representative) challenged Stephen Kinnock, Minister of State for Care, to ensure that people with PMLD were included in Baroness Casey's Commission on Adult Social Care Reform. Samir's influence continues to shape national discussions on inclusion and social care reform.

Championing Inclusion Through Action

Samir's advocacy was not confined to policy—he believed in action. He played a key role in organising an Athletics Championship for people with learning disabilities in the London Borough of Sutton in 2018. The event was a huge success, with Samir providing essential input on the sensory wheelchair races. In recognition of his efforts, he was invited to afternoon tea with the Lord Mayor of Sutton, accompanied by his proud sister and nephew.

He was also a passionate supporter of Stay Up Late, presenting at their 'unOrdinary Conference' and speaking at national webinars hosted by PMLD LINK and LDE. His involvement extended to charity work—during the pandemic, as restrictions lifted, he took part in a sponsored walk for breast cancer charities.
Samir's commitment to change was recognised in 2019 when Campaign 4 Change won a Learning Disability and Autism Leaders List Award for its work in promoting Changing Places toilets.

Making the Invisible Visible

One of Samir's most memorable contributions was his involvement in the #MindYourLanguage campaign, challenging disrespectful and outdated

language in social care and beyond. He also supported PMLD LINK's 'Removing the Cloak of Invisibility' webinar in 2023, where he was literally hidden under an invisibility cloak—only to have it lifted to symbolise the visibility and inclusion of people with PMLD.

Samir was frequently featured in PMLD LINK journal, serving as an inspiration and role model. His contributions also extended to academic and professional development—Erren Wheatland (Head of Health & Clinical Governance) and Katie Easton (Healthcare Facilitator) highlighted his advocacy in the Supporting People with Profound and Multiple Learning Disabilities Self-Study Guide (Wheatland and Easton, 2019).

A Lasting Legacy

Samir may no longer be with us, but his impact lives on. He was a true force for change, proving that even without speech, he could be seen, heard, and understood. His legacy is one of inclusion, determination, and unwavering belief in the rights of all people with PMLD.

His work is not over. The movement he helped build continues, ensuring that every person with profound and multiple learning disabilities is valued, respected, and included.

Samir El-Ziftawy – forever an advocate, forever an inspiration.

References

Reid K and Wheatland E (2019) *Supporting People with Profound and Multiple Learning Disabilities Self-Study Guide.* Shoreham-by-Sea: Pavilion Publishing

Finding his voice: how listening to Jordan's needs opened the door to social inclusion

Bev Simmonds

Our journey with Jordan during his two-year course at Derwen College, moving from school refusal to socialite, and how the most powerful word can be 'No!'

A reluctant start

Jordan started with us as the stricter Covid-19 regulations were coming to an end, but it was clear how much they had impacted the last couple of years of his school life. Jordan had appeared to suffer from school refusal and was often late or didn't go in to school at all. Although he would plan to go somewhere at the weekend, if the plan needed to change, he was unable to 'substitute' the activity with another choice; and he would stay at home. He was very used to being at home, cosied up in his waterbed with the company of "Loose Women" on TV. It took a few attempts to persuade Jordan to come to college for his application assessments and we were initially concerned that he wouldn't attend college at all.

Jordan did start college and fortunately his attendance was good, which we put down to curiosity about the new space, and possibly our small, new department being quieter than his previous large busy school. However, he was still quite clearly opting out of any social activities. Jordan utilised his ability to cough and splutter on demand to show his support staff that he wanted to leave. The pattern of this behaviour quickly became clear. He was opting out of situations where people were consuming food and drink: at the Student Union; when visiting cafes; or at the lunch table. Jordan was PEG fed and didn't need to access any of these environments for his nutrition, and was not enjoying the social aspect, unlike his PEG fed peers.

Barriers to inclusion

Behaviours that challenge inclusion is a phrase that seems to have fallen out of favour recently, and for many reasons that's understandable. However, in this instance, it is a fitting description of Jordan at the start of his college course. His deliberate coughing behaviour meant that he wasn't including himself in social situations.

Inclusion is central to what we do in the SEND (Special Educational Needs and Disabilities) education and care sector, with increasing focus on community inclusion and participation. The PMLD Core and Essential Service standards list 'Meaningful/Quality relationships(S3)' and 'Social and Community Life (S4)' amongst their key principles. Standard 5 discusses 'Meaningful time', and highlights that people need to share enjoyable activities with "people they like to spend time with" (Doukas et al, 2017) .

So, how do we approach Jordan? How do we listen to his communication that tells us that he wants the opposite? That he wants to be excluded.

Well, we decided to listen to him, and let him be.

Barriers to communication

We began by offering Jordan alternatives to the activities he was rejecting, particularly lunch times. Initially we used pictures and gauged his non-verbal language to judge what activity he wanted to do. Jordan would clearly lift his right arm to say yes to something, and would frown, shake his head and cough if he wasn't happy with a choice. Staff would then model the sentence on his eye-gaze device. Jordan had been using eye-gaze technology for a few years and was good at it in structured activities. If you asked him a simple question about his activity resources, he could answer it, but he didn't seem to recognise the device was actually his 'voice'. When Jordan found himself in situations that he didn't want to be in, he would access his 'escapism' phrases ("Where's the minibus", "I want Nanna") as well as long strings of random phrases that didn't seem to have meaning, which he would repeat over and over again.

So, every lunchtime, staff would offer alternative activities and model the conversation using his eye-gaze. "I want… Mats". Jordan tried a few different activities, including going for a look around local shops or catching up on the latest episode of Love Island, but after a particularly tiring day he opted to come out of his wheelchair and spend some time on mats. This went down very well, and Jordan enjoyed stretching out without the pressures of an educational activity.

Positive choices

Jordan enjoyed spending time on the mats over lunch time and, over time, was able to make further adjustments to his activity, choosing where in the room to be and that he wanted staff to 'leave him alone' during this time. So, the space was made safe and he was left to be on his own, often turning away from the group, with some discreet observation from his support staff. Staff would re-engage with him when lessons were due to begin again.

A voice for inclusion

Jordan seemed happy having time out of his day with no interaction. As a staff team, we discussed our own lunchtime preferences and while some people liked to sit with others to eat, some liked to go to the shops, go for a walk or even sit in their car to scroll social media. Jordan's choice was no different.

However…

After a while, Jordan wasn't waiting for staff to include him again at the end of lunch. He started turning to face the group, laughing along to the social conversation and, eventually, vocalising to gain staff attention.

Jordan was also much happier and engaged in session activities, even those that were social and even those that were in food and drink environments. He opted to go to the Student Union at break time knowing that he could use his eye-gaze device to say he wanted to leave at any point. To begin with, this was almost immediately, but, over time, he built up to spending the whole break there, interacting with students on other courses and getting to know less-familiar staff. He also accessed cafés in the community with his close friend and developed relationships with the people who worked there, as he got to know them. Jordan started to enjoy the social aspects of these environments, even though he did not access them to eat or drink. Two of Jordan's favourite people were Tracey who worked in the kitchen, and Taylor who worked in the restaurant; these relationships were new and he wouldn't have formed these previously.

Throughout all these occasions, Jordan's intentional coughing and spluttering almost completely disappeared.

Jordan used his eye-gaze device more and more independently, too, making choices over where he wanted to go, and who he wanted to work with. He was able to tell us who he had seen on the weekend, or about the Blackpool holiday that was booked for the next break. He could tell us where on his body he was feeling in pain or if he was feeling generally unwell. The Jordan that would lift his hand up for yes and pout for no seemed a distant memory.

A long-term impact

Two key things happened in this approach to Jordan. Jordan learned he was listened to. Inclusion was not sought for inclusion's sake: instead, Jordan was able to find his own path. As he was able to opt out of some group situations, he had enough 'social battery' to enjoy others. Inclusion was practised with Jordan, not to him. This had an impact on his time at home too. Jordan was able to enjoy activities with the confidence that he would be able to leave whenever he chose and that staff would listen to him and act on his communication. Jordan was able to choose social activities more spontaneously and learned to choose something different if an original plan fell through. Jordan made meaningful relationships. Jordan also learnt to use his voice through his eye gaze. He realised that the eye gaze was not just an activity to be completed at college, but a means through which he could control the outcomes in his life. Jordan learnt to ask for things spontaneously and meaningfully, even managing to say "Stop. Green. T-shirt" when passing by his favourite sportswear shop (yes, he came home with it, and the trousers too!). But first, he learned that the eye-gaze device was the voice that could stop those things that he didn't want to happen.

For Jordan, he needed to say 'no', before he could open up the world of 'yes'.

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See also: www.derwen.ac.uk/parents-professionals/learning-pathways-programmes/nurture-programm

Further reading

Colley, A. and Tilbury, J. with Yates, S. (2021) *Enhancing wellbeing and independence for young people with profound and multiple learning difficulties: lives lived well.* Abingdon: Routledge.

Doukas,T., Fergusson, A., Fullerton, M. and Grace, J. (2017) *Supporting people with profound and multiple learning disabilities:core and essential standards.* Available online at: https://www.pmldlink.org.uk/wp-content/uploads/2017/11/Standards-PMLD-h-web.pdf

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YouTube: @PMLD_LINK

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

How can we improve listening to learner voice for students with PMLD?

Rachel Gale

As a teacher in a specialist college for young people with a variety of disabilities, I am involved in a lot of discussions about Student Voice. There are a huge number of challenges that we are faced with when supporting young adults with profound and multiple learning disabilities (PMLD) to have their voices heard, but I wanted to share a document that we have found helpful when supporting our learners.

When talking about student voice to people, sometimes there is confusion in the difference between “knowing what the individual enjoys”, and “how we know what that individual enjoys”.

These learner voices can be represented by staff members who know them well, sharing what they know about the learners likes and dislikes. However, there is a small risk of this resulting in learners having their opportunities to try new things limited, by well-meaning communication partners who are keen to give them more of the activities that they already know they like.

Due to the fact that some of our communicators’ responses are really subtle, knowing what signs to look for when gathering their opinions enables us to potentially have a more accurate idea of their thoughts than we would gain from a list of their likes and dislikes.

At St Martin’s we use various template documents and personalise them by adding photos and descriptions of the ways a learner uniquely communicates (see example on facing page) .

The important difference about these documents is that they do not mention activities that the students like or dislike, they only mention how the individual’s responses may show whether they like or dislike something. This means that communication partners can support learners to try new activities without any pre-conceived expectations of whether or not they may enjoy it, based on previous experiences.

As their teachers, it is important to remember that, if a student shows that they do not like something, then we do not stop offering them the opportunity to revisit this. They may have been responding to something other than the activity on offer – an internal pain, for example, or a strange sound or smell in the environment. They need to be exposed to the opportunities several times, with support staff or communication partners taking careful note of their responses, to be able to draw as accurate a conclusion as possible as to their opinions.

Every learner is different and will show their feelings and opinions in different ways, and, while not perfect, documents such as these might be able to help us to interpret and understand opinions from our earliest communicators.

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If I **like** something I might smile, vocalise, and/or drum my tray. I will engage with the activity, give eye contact and be tolerant of hand under hand assistance. I may also reach out if you hold it near to my hand. Also, my choices will be a lot clearer.

If I **do not like** something, I may give a nervous smile, I might vocalise and drum my tray. I will disengage, and my choices will not be clear. I could hold my arm over my face or bite my hand and shout.

It can be difficult to know if I am excited or anxious, because I can smile when I am anxious as well as when I am happy. You may need to look at some of my other body language to help you:
Eye contact - fleeting or flickering can indicate anxiety or uncertainty (even with a big smile), slightly more sustained indicates that I am seeking to engage with you, am comfortable in your company.
Hands - my hands are almost constantly moving. It is possible that the faster they move, the more anxious or uncertain I am feeling. If I am cross they will clench and be very tense.
Banging tray - take note of my eyes and hands. If they are moving fast, this could indicate anxiety. If eye contact is sustained, and my hands seem relaxed, I may be excited or bored, depending on context of the room.
Vocalising - again, take note of my eyes or hands. Fast movements could indicate anxiety, or discomfort. Sustained eye contact or slower hand movements could indicate excitement, boredom or a way of seeking interaction. Sometimes I am vocalising because I am feeling cross.
Reaching out - if I reach out and withdraw quickly, pinching staff, I am probably feeling cross or anxious. If I reach out and just tap your hand whilst giving you prolonged eye contact, I am probably greeting you or asking for interaction.

Photograph

I can make choices between two items by looking at the one that I would like. Sometimes I prefer to interact with the person holding the options - just give me plenty of time to make my choice.

Sometimes I can use pictures to make choices, if the pictures are really meaningful to me. I can show you what I would like by pointing at it with my eyes. Watch me carefully, as my glance may be fleeting.

I am learning to use the eye-gaze computer to make choices. I find it easier to do this in a quiet environment, and sometimes I am distracted by my helper, so you may need to sit slightly out of sight to help me to realise that I can engage with the screen.

I am learning how to make my choices clear. I am trying a method that is new to me called partner assisted auditory scanning. Please tell me what my options are first. Then go through them one at a time waiting for a response. You can ask me to **give a slow blink** when I hear the word or item that I would like. It helps me if you hold up the item at the same time as you say the word but try not to move the item or make it interesting, so that I learn how to respond to the words and not the item.

Photograph

Please be aware that pictures and items can help my understanding. I have a visual impairment and can see things better if you hold them within my eyeline on my right-hand side.

It really helps me to make choices if you use simple language and give me lots of time to respond.

Sometimes I feel upset or worried and I might cry. You can help to reassure me by coming close and putting your hand on my shoulder. If you tell me what is happening in the room, and what is happening next, this can help me to feel better. Please stand where I can see you on my right. I can also be reassured by having a story read to me.

Sometimes I will give a slow blink or change my facial expression for a “yes”. Sometimes I will quickly flick my eyes away or briefly move my head away for “no”. This is not always consistent, so you might like to ask me the question again to be sure.

If I **like** something my eyes might widen and I will turn my head to look at you. I might smile or laugh. I will track items and show engagement.

If I **do not like** something, I will vocalise and you will see in my facial expression that I do not like it. I may also cry or push up in my chair.

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Storysharing® at Dorothy Goodman School

Rachel Barker and Grace Campton with Shane and Amelia

Dorothy Goodman School began the use of Storysharing as an approach during the pandemic. Storysharing was devised by Dr Nicola Grove and focuses on enabling people with communication difficulties to co-tell their experiences as personal anecdotes. It aims to shift the tendency for people to tell stories about others to telling them with others.

Initially Rachel used it as a way of connecting with the pupils she taught, and their families, who were shielding due to complex health and medical needs and for whom online learning seemed completely inaccessible. It not only gave us a way to connect through video learning, but also enabled pupils and their families to find joy in what was a hugely difficult time, emotionally and practically. Many pupils and families lost access to community support and respite during this time, further amplifying their isolation. We helped them to feel less alone. Following their return to school, we used Storysharing as a class team to build on this initial work, using the approach during communication sessions to both share experiences about the pandemic and to celebrate and navigate the return to normal.

Since the initial launch, we have slowly introduced Storysharing into various phases of the school. We currently have a trained tutor and practitioner within the school, and several staff soon to embark on the practitioner training. Enabling pupil voice through fidelity to the approach and building staff confidence and skills have been prioritised over speed of implementation. In Summer 2024, Storysharing was introduced with six young people, to support them to communicate about their experiences. During the following autumn, two of these young people continued with Storysharing, both still needed lots of input to be able to share their experiences. We also introduced a Storysharing group at our sixth form centre. The success of the first group led to another group being introduced with a different profile of young people and we plan to roll out across the Early Years Foundation Stage, next summer.

Adult facilitation is a significant part of Storysharing and during this journey we have learnt many vital lessons which have enabled us to develop and improve the quality of our practice in co-telling stories. The role of supporting adults in enabling children to recall and express narrative is recognised as crucial by many researchers, in particular the adult's capacity to respond and scaffold the telling of the narrative (Bunning et al, 2018 and McCabe and Peterson, 1992). However, due to the communication challenges many of the children we work with face, adult facilitation of Storysharing is much more than just supporting the retelling of a narrative; adults are not just "active co-narrators" but facilitators of the entire process from finding the stories to co-telling them (Bunning et al, 2018: p. 26).

This facilitating of the process for Shane, one of our original Storysharers, was multifaceted. Grace, our intervention lead, considered many factors including what stories he might like to tell, how he could best tell them, and the role an adult would need to play in the co-telling of his stories. Grace reflected on his current level of communicative skill, cognitive level and physical ability and how best to enable advocacy, contributing through the skills he already had (Grove, 2025). Through the implementation process, we found that using consolidated methods of communication and physical skills reduced cognitive load and best enabled young people to co-tell their narratives most effectively and with as much agency as possible. For Shane this meant we prepared stories that enabled contributions through eye, facial and hand/arm movements, utilised in different ways.

Another crucial element in using Storysharing is providing plenty of opportunities for young people to rehearse stories. People with communication and learning difficulties often find it hard to tell comprehendible stories; challenges with recalling memories and coherently structuring these can be hindered by poor working memory, reduced vocabulary and difficulties with generalisation (Bunning et al, 2018). Grace and Shane spent time together, practising his story multiple times before sharing this with different audiences. This gave Shane the opportunity to connect the pressing of his sensory prop (a plastic bag with holes in it) with the verbalised word, 'Splash!' and to practise moving his hand/arm to complete the refrain, "Shane went…" at the right time within the narrative. We also wanted Shane to recall the fun of the splashing experience and connecting past and present sensory experiences supported his memory recall (Brouillet, 2020). Since people with PMLD primarily experience their world through sensory means, it seems logical to assume that sensory sensations are also going to play a crucial role in communicating about their experiences (Van Den Tillaart and Vege, 2015; Janssen and Rødbroe, 2007; Vege and Nafstad, 2021).

These rehearsals also allowed Grace to closely observe Shane's contributions to the narrative, enabling her to attune to his methods of sharing stories (Bunning et al, 2018). She could then facilitate Shane's sharing of stories outside of planned, structured times, recognising the communicative cues he used to indicate he had something to contribute. Bunning et al (2018) observed similar occurrences during their use of Storysharing, observing that the "process appeared to reveal not only something of the children's communication skills and confidence, but also something of their sense of agency." Since beginning to use Storysharing with Shane he has shared lots of stories, but most importantly, Shane has been able to indicate he wants to tell a story. A selection of stories that Shane has co-told can be found in **Table 1 below.**

In addition, when we hoped to share Shane's experience in a blog, Grace wanted to find a way to ask him how he felt about this, as well as eliciting his family's views.

Foundation for People with Learning Disabilities (2012) argue that multimedia advocacy is "a way of framing, structuring and implementing good advocacy practice" so Grace showed Shane the video and explained that other people would like to watch it. When Grace told him other people would be seeing him on the screen, Shane vocalised loudly, with a high pitch, for an extended period of time. Conversely, he vocalised quietly with lower intonation, and only for a short time, when she said they would also be seeing her on the screen. Using Grace's knowledge and attunement to his contributions to narrative developed through Storysharing, we were fairly confident interpreting the initial response as excitement and the latter response as indifference!

Storysharing and Active Listening

Shane splashed all the staff during his swimming lesson and found it hilarious. Shane shared this story through splashing the audience with water.	The pool was closed and Shane's swimming lesson was cancelled. He shared this story through showing a sad face and hunching his body, vocalising quietly and softly, using a low pitch.
Shane was given a sneaky preview of the new sensory room and lights He shared this story through looking at adults with wide eyes, using loud, short vocalisations and looking up at the lights.	Shane had an operation to fit a VNS. He shared this story through looking at his audience and then lifting his head to show people his scar - as he told this multiple times, Shane began to instigate the telling, raising his head to show the scar when new people walked by.

Table 1: A selection of stories co-told by Shane

As a trained practitioner, Grace has also taken a lead on the introduction of both sixth form groups, supporting other staff to develop their skills in both finding the stories and co-telling them (Grove et al, 2024). It can be easy to make assumptions about the stories we think might be important to young people but in working with them and their families we have tried to be true to their voices. Staff have grown in confidence in co-telling stories and recognising how this process enables the children to express their own identities (Bunning et al, 2018) and celebrates the small stories, the anecdotes, the moments from our lives that are valuable or meaningful enough to us to share with others (Bamberg & Georgakopoulou, 2008: p356) and it has been a privilege to learn what the young people we are supporting value and want to tell us. One pupil's experience, both as a Storysharer and as an active listener of others' stories, is shared here:

Being a Storyteller: Amelia's Christmas

Grace: This is a story about Amelia's Christmas…

Amelia looks at the picture in anticipation.

Grace: …Amelia's Christmas was very special *signs 'special'*

Amelia smiles as Grace explains the picture.

Grace: At Amelia's Christmas, Amelia had a Christmas dinner…

Amelia smiles, vocalises and moves her arms in response to the photo of her family at dinner being shown.

Grace: …with all of her family! *points to each family member in the photo*

Amelia vocalises (in agreement) as Grace points out and names each family member.

Grace: At Amelia's Christmas, everyone said…

Amelia looks at the switch and vocalises in anticipation of the high-point of the story.

Grace: *supports Amelia HuH to press the switch*

Amelia becomes very animated as she is supported to

press the switch.
Grace: …Merry Christmas!
Amelia laughs in response to pressing the switch.

Grace: At Amelia's Christmas, everyone had Christmas presents- even the dog!
Amelia laughs loudly when Grace verbalises that the dog got a present.

Grace: Thank you for listening to Amelia's Christmas story.

Amelia smiles as the story reaches its end, looking at Grace.

Being an active listener: Amelia responding to others' stories

Context: Grace sharing a story to the group about a time her young son was unwell and required an inhaler.
Amelia vocalises, moves her left arm and turns to look at Grace.

Context: A peer shares a story about a time that they went to the garden centre to see the fish.
Amelia smiles, loudly vocalises, looks towards her peer, and moves her arms up and in when recognising a shared experience.

Context: Grace shows Amelia the photos a member of

staff has printed to show the group. The photos are of differently decorated tractors from a 'Tractor Run'. Amelia quietly vocalises each time a new photo of a tractor is shown to her, acknowledging each one.

In summary

The responses of the young people to the groups have been joyful; they are excited to be there, keen to take part and have already developed a strong sense of community. The staff are equally enthusiastic and value the time spent listening to and learning about the young people's experiences. The approach is also supporting staff to further appreciate the contributions that the young people can make, and celebrates the impact of 'being heard' on their wellbeing. Currently the groups are building a resource bank of stories, with visual representations of each displayed. Some young people are already indicating they would like to share a story again through pointing or looking at the photos and pictures on display. As Grove (2024) says, "Everyone can tell a story. Everyone's story should be heard." and the goal at Dorothy Goodman School is to enable just that.

Contact details

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Dorothy Goodman School - Open Thinking Partnership

References

Bamberg, M. and Georgakopoulou, A. (2008). 'Small stories as a new perspective in narrative and identity analysis.' Text & Talk – An Interdisciplinary Journal of Language, *Discourse Communication Studies*, 28, pp. 377–396.

Brouillet, D. (2020). 'Enactive Memory' *Frontiers in Psychology*, 11, p. 114. Available at https://www.frontiersin.org/journals/psychology/articles/10.3389/fpsyg.2020.00114/full (accessed 3 January 2025).

Bunning, K., Gooch, L. and Mohammedson, M. (2017). 'Developing the personal narratives of children with complex communication needs associated with intellectual disabilities: What is the potential of Storysharing?' *A Journal of Applied Research in Intellectual Disabilities*, 30, pp. 743-756.

Bunning, K., Muggeridge, R. and Voke, K. (2018). 'Teachers and students with severe learning difficulties working together to co-construct personal narratives using Storysharing: the teacher perspective.' *Support for Learning*, 33, pp. 23-37.

Foundation for People with Learning Disabilities (2012). *Involve Me Independent Evaluation Report.* Available at: https://www.mencap.org.uk/sites/default/files/2017-05/Involve%20me%20evaluation%20report.pdf (Accessed 13 December 2024)

Grove, N. (2024). Hear my story. Available at: https://www.ndti.org.uk/hear-my-story (Accessed: 28 January 2025)

Grove, N., Harwood, J., Ross, V., Peacey, L. and Jones, M. (2010). 'Sharing stories of everyday life with adults and children who have severe/profound intellectual disabilities.' *Contemporary Issues in Intellectual Disabilities*, pp. 225-230. New York: Nova Publishers.

Grove, N. (2025). Storysharing. Available at: https://Storysharing.org.uk/ (Accessed: 11 January 2025)

Grove, N., Hopwood, F., Arab, K. 'Storysharing Licensed Practitioner training'. Module 1: Get the Story. Available at: https://Storysharing.thinkific.com/courses/Storysharing-practitioner-online-course (Accessed: 2024)

Grove, N., Hopwood, F., Arab, K. 'Storysharing Licensed Practitioner training'. Module 2: Share the Story. Available at: https://Storysharing.thinkific.com/courses/Storysharing-practitioner-online-course (Accessed: 2024)

Grove, N. (ed.), (2021). *Storytelling, special needs and disabilities: practical approaches for children and adults*. Abingdon: Routledge.

Grove, N., Harwood, J., Ross, V., Peacey, L. and Jones, M. (2010). 'Sharing stories of everyday life with adults and children who have severe/profound intellectual disabilities.' In Prasher, V.P. (ed) *Contemporary Issues in Intellectual Disabilities*, pp. 225-230. New York: Nova Publishers.

Janssen, I. and Rødbroe, M. (2007). *Contact and social interaction: communication and congenital deafblindness.* St. Michielsgestel: VCDBF/Viatal.

McCabe, A., & Peterson, C. (Eds.). (1991). *Developing narrative structure*. Hillsdale, NJ: Lawrence Erlbaum.

Ochs, E. & Capps, L. (2001). *Living narrative: creating lives in everyday storytelling*. Harvard University Press, Cambridge, MA.

van den Tillaart, B., and G. Vege. (2015). Bodily Emotional Traces. Accessed November 18, 2024.tps://library.tsbvi.edu/Play/13204.

Vege, G. & Nafstad, A. (2021) Personal storytelling with deafblind individuals. Chapter in N. Grove (Ed.). *Storytelling, Special Needs & Disabilities: Practical strategies for children and adults*. London: RKP

Voices Unlocked Project: Empowering adults with profound and multiple learning disabilities

Rachel Shepherd and Helen Broadfield

The Myriad Centre, in Worcester, is delighted to have been awarded funding from the Dr Carl Ellson Innovation Fund, enabling us to expand our work supporting adults with profound and multiple learning disabilities (PMLD). This grant marks a significant step forward in our efforts to improve communication access for those who need it most.

Communication is a fundamental right, yet many individuals with PMLD face significant barriers. At Myriad, we believe that every person, regardless of ability, should have the tools and support to express themselves and connect with the world around them. Thanks to this funding, we are developing a practical framework to help adult day centres and care settings create environments that foster meaningful communication.

What the Funding Will Achieve

With support from the Dr Carl Ellson Innovation Fund, Myriad will become a Centre of Excellence for Communication, creating and delivering resources designed to help care providers set up effective communication-friendly environments. This will include guidance on:

- Adapting physical spaces to promote interaction
- Training staff in communication strategies tailored to adults with PMLD
- Strategies for encouraging engagement and increasing communication skills

By the end of the year, we plan to be offering practical advice and step-by-step support to centres looking to enhance their communication approaches. Our goal is to ensure that individuals with PMLD have the best possible opportunities to make choices, express preferences, and engage with those around them.

Next Steps

Over the coming months, Myriad will be working closely with professionals, families, and our clients to develop the centre and create our support materials. We want to ensure that the support we offer is practical, effective, and rooted in real-world experience.

We will also be running pilot sessions with selected centres to refine our approach before rolling out resources more widely. By the end of the year, organisations will have access to tools and advice that will enable them to make meaningful improvements in their communication environments.

A Lasting Impact

Winning this funding is a milestone for Myriad, but more importantly, it represents a step towards greater inclusivity and better communication access for individuals with PMLD. We look forward to working with centres across the country to implement lasting, positive change.

If you are interested in learning more or getting involved in our upcoming work, please get in touch.

Together, we can create environments where every voice is valued.

Contact details

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Myriad Centre
Possibility, Not Disability

The rhythm of life: reflecting on a year of music therapy with Dan

Sarah Walker, Denise Walker and Jessica Vaughan

“Never underestimate someone and how clearly they can communicate their needs to you, no matter how profound their disability, if you just listen and give space for them to be heard” - Jess. Dan Walker’s sister Sarah, his Mum Denise, and music therapist Jess, share their reflections on music therapy.

Sound Decisions – Sarah Walker

How could I resist sharing our experience of Music Therapy in the ‘Being Heard’ edition of PMLD Link? Dan has always had a true passion for creating his own music although he does find attending music performances and groups a challenge. Accessing Music Therapy at home allows Dan to focus on the session without additional pressure and his music therapist Jess, is very skilled at adjusting the tone of the sessions to match how Dan is feeling. So much of mine and Dan’s shared communication is through music. I have a song for almost every stage in his day and he shares his deep resonant humming with me in return, reaching much lower notes than I could ever achieve. I love supporting Dan during Music Therapy with Jess. Dan’s stamina, skill and confidence in the sessions have drastically increased and the three of us always seem to end a session exhausted, hot and uplifted! In this article we share tips for creating music yourself and our combined experience of finding, delivering and enjoying Music Therapy sessions.

A Mum’s Perspective – Denise Walker

I think I'd probably been trying to find a music therapist to work with my son for about 2 decades! I was aware of the Nordoff-Robbins approach (https://www.nordoff-robbins.org.uk/the-nordoff-robbins-approach/) and started to look for a therapist who would work with Dan, preferably in our own home, where he is most relaxed and can be himself. What I discovered in those early days of searching, was that the therapists seemed to be based in a special school or day service. Dan was home educated from age 12 and although we would have tried travelling to a centre, this wasn't possible. I knew a family

who had found a therapist who would visit in the home, so I contacted her. However, that therapist didn't feel she could travel the distance. She suggested I try the British Association for Music Therapy, which I did online and found I could search geographically. Only a few numbers came up, and the first one happened to be in Sheffield (too far!). However that therapist kindly told me he had a friend who was just completing her training and was in the Cheshire area. So, he got in touch with her, and then passed me her details! Hoorah! As soon as I spoke to Jess on the phone, I felt she would be a great "fit" for Dan and it has been wonderful to see them working together.

Jess asked me what outcomes I was looking for from music therapy. I explained it was to get to know Dan and encourage, with her knowledge and training, his musical communication. We have always felt that Dan is very creative in his use of musical instruments, or sound makers. Jess has supported that. Dan works so hard in the session, as does Jess and my daughter Sarah, (who supports Dan in the session) who both have lovely, powerful soprano voices! Dan's self-confidence, expression and choice have all grown through the sessions. I'm delighted with how it has all worked and the very positive bond between Jess and Dan. They take it in turns to teach and learn.

Jess can you recommend any simple techniques/top tips that can be used if someone isn't able to access a trained music therapist?

"Be present with the person offering them the instruments, follow their lead and hints for how they want to access them"

"Sing songs to and with them, gently tapping the pulse on their hand or arm."

"If you don't feel confident singing yourself, sing along to familiar music with them"

"Create playlists of favourite music that have different regulating effects; calming, arousal, stabilising mood, uplifting, memories of holidays etc.

This can be used in different circumstances and by family/ friends."

Q&A with Jess Vaughan, Music Therapist

What inspired you to work in Music Therapy?
I originally trained as an opera singer and often performed in concerts. Seeing the effects music had on audience members when I was performing made me curious about how music could be used on a deeper level therapeutically. While researching music therapy it struck me how music can be used as a form of communication. Being partially deaf myself, communication and feeling like I'm heard, has always been important. I feel that everyone deserves the right to be heard and express themselves and I loved the idea of facilitating this through music.

What did the training involve?

Music Therapy is a 2-year Master's Degree which results in being Health Care Professional Council (HCPC) registered at the end. The training involves academic coursework, clinical training placements across the life span, developing a strong level of musicianship and learning about psychology theories to underpin the work. We also had to learn more about ourselves through personal development and therapy. Following on from the course I was fortunate enough to be accepted onto a mentorship course run by the British Association for Music Therapy (BAMT) to continue my professional development.

What are the benefits of Music Therapy?

How long have you got?! Music therapy can help with meeting and supporting a variety of mental, physical, emotional and social needs. To name a few it can:

- Improve mood and encourage relaxation
- Build and develop social skills
- Be a tool for communication and self-expression
- Improve cognitive skills
- Improve/promote physical health
- Be a space to explore emotions

How long have you worked with Dan?

I have worked with Dan on a weekly basis for over a year now and it has been such an enriching and rewarding time. In fact, my work with Dan was my first job after graduating.

What changes have you seen in Dan since the start of his sessions?

I have seen Dan's confidence grow and therefore his musical expression has become more varied and each week it seems his musical creativity knows no bounds. As our therapeutic relationship has grown it has been wonderful see how Dan communicates physically and musically what he wants to play himself but also what he wants from me. I've also loved seeing Dan's motor skills develop as he changes his grip or angle on beaters to create the sound he desires.

Is there a favourite moment from your sessions with Dan that you'd like to share?

There are so many wonderful moments that it's difficult to choose but seeing the joy on Dan's face when he discovers a new sound, in particular when he used a shaker as a beater on the drums, resulting in several rhythmic patterns at once. As this has now become a firm favourite it makes me wonder about the physical feedback he receives, as well as the auditory feedback.

Learning from Dan

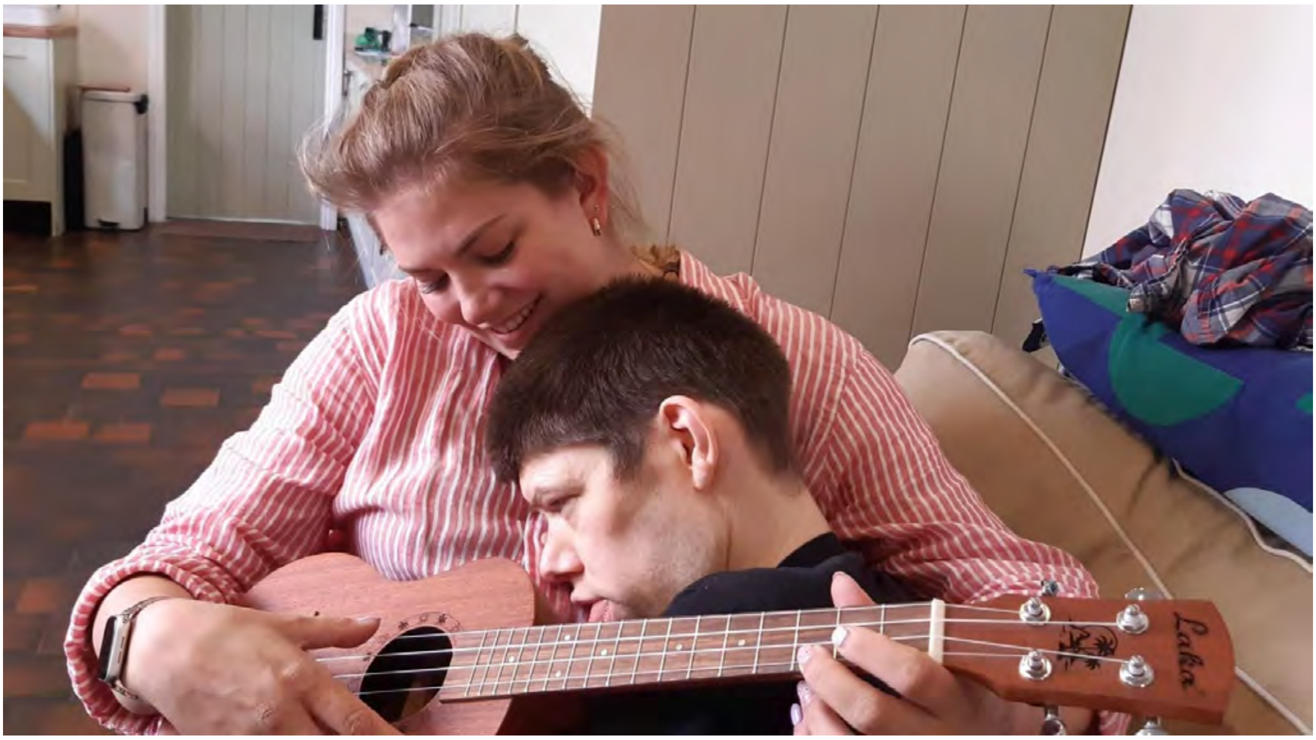
Why not try out our Top Tips ideas on the opposite page!

Contact details

Sarah runs Dan's Facebook page: @makeachangecheshire where you contact any of the Walker family.

Jess runs Cheshire Music Therapy. Email: jess@cheshiremusictherapy.co.uk or contact her on Instagram or Facebook: cheshire_music_therapy

If like Sarah, you are in the UK and are an adult sibling to someone with lifelong disabilities you can join Sibs private Facebook community at @#siblife



Dan & Sarah’s tips for creating music without instruments

SHAKERS

Shakers are easy to make using items from your recycling. Experiment with different sealable items like Pringles tubes or plastic bottles and jars.

Put a handful of dried grains or pulses and see what different sounds they make. Rice and lentils both work well.

Secure by gluing the lid on. If you like you could decorate your instruments with tape or paint.

DRUMS

Experiment drumming a beat with kitchen utensils on plastic or metal mixing bowls, trays and tins.

VOICE

Don’t be shy to use your voice whether you consider yourself a singer or not. Try different volumes and pitch. Vary vocalisations “Zzzzz” “Ooooo” “Mmmmm” observing what sounds your fellow musicians like to make and including their names and any favourite songs. Test out how the sound changes when you sing into a large box, bowl or through a tube.

Jess can you recommend any simple techniques/top tips that can be used if someone isn’t able to access a trained music therapist?

“Be present with the person offering them the instruments, follow their lead and hints for how they want to access them”

“Sing songs to/with them, gently tapping the pulse on their hand or arm.”

“If you don’t feel confident singing yourself, sing along to familiar music with them”

“Create playlists of favourite music that have different regulating effects; calming, arousal, stabilising mood, uplifting, memories of holidays etc.
This can be used in different circumstances and by family/ friends.”

Listening to Odyssey

Dreenagh Lyle

How is my daughter heard? Who hears her and how do they interpret what they hear? For many years there was a particular way she was heard by teachers and support workers. Reading back through her school reports and her later ‘Communication Books,’ it is clear she was heard. But there was always a certain tone to these reports. She was seen as delightful but difficult. Expressive but non-compliant.

Odyssey can burst into delightful peals of singing. Oftentimes simply a few words of a verse repeated in a loop. And woe betide anyone who thought they were helping by completing the sentence and trying to sing along with her. I learnt long ago that you don’t try to sing along or help out with the missing words. That’s not the point of the singing. I have always felt the loud bellowing voice was a shield or a barrier she created for her own safety. People whistle or sing in the dark to allay their fears. I think it’s the same for Odyssey. If you robustly bellow out a loop of sounds no one can get a word in. They can’t make demands you don’t understand for a start.

So ’being heard’ is clearly not the same as being understood. My daughter is nearly fifty now, so I’m probably attuned to her many different tones, frequencies and patterns. However it still surprises me when people don’t hear any difference in the sounds she makes. I’m used to strangers telling me ‘oh she’s having a sing is she?’ when she’s muttering and repeating echolalic phrases. ‘If she was singing you would know it,’ I tell them. Being echolalic and totally blind since birth she has absolute pitch (Ockelford, 2017, p205). High C’s are no problem for this woman. More recently we have noticed she can quietly sing almost a whole verse. Whenever she sings or chatters quietly, we focus intently to try to hear what she is saying. Her first music therapist believed this was her true voice. As her big sis says, it’s her shy voice.

Years ago, a speech and language therapist who was helping me with her anorexia told me I should always respond to a request for food immediately, no matter when. All these years later it is still there. The tiny quiet voice, as I tuck her into bed that utters ‘and an egg sandwich?’ still means, I’m hungry -. Feed me. Compare that to the worker I observed placing a plate of food in front of her, telling her ‘there’s your food.’ And when Odyssey replied, ‘No, she doesn’t want it’ the worker replied ‘Okay, that’s your choice’ and removed the plate of food. I don’t blame that worker as she believed Odyssey understood her. This is not uncommon in the social care field. Interviewing care workers over the years I often hear, ‘oh she understands everything I say’. Unfortunately she doesn’t. I think when Odyssey constantly says ‘no’ or ‘no she doesn’t want it', that is her way of saying, ‘I’m confused. I don’t understand you.’

I explain to new workers that learning disability is a continuum. That there are many people with a learning disability who use language and can voice their needs and wishes and who can make informed choices about what they want to eat or where they want to live. But at the other end of this continuum are people like my daughter. We have to interpret their communication. If we accepted that when Odyssey says ’no’ she literally means ‘no’ she would never eat, drink, have a bath, go out, anything. Because for my daughter the answer to any question will always be ‘no’. When I took over managing her care this was one of the primary aspects of inducting new staff. Understanding when ‘no’ means ‘no’ and when it doesn't.

How do I explain to policy makers and commissioners that being heard for my daughter means making an assumption? Yes the assumptions are now made, after very keen and attentive listening and observing. But they are assumptions nevertheless and we ought never lose sight of this. Odyssey cannot tell us directly if she is thirsty, hungry, bored, tired or in pain or if she would like to listen to music, go out to a park, visit a swimming pool, or attend an art class. (This list is far from exhaustive.) For those like her these everyday decisions are most likely being made for the individual. Then there are the decisions to do with where people live, what the arrangements are, who they live with and who provides their support and care. If they do not have family members involved, there will usually be a number of people making decisions for them in their ‘Best Interests’ (Mental Capacity Act, 2005). Studies have shown those people making the decisions do not always understand the MCA and it implications for people deemed to lack capacity.

Hence the vital need for a significant other. Someone who will function as their communication partner. Grove and colleagues (2001) detail research, which has demonstrated how difficult it is to ascribe communicative intentionality without imposing one’s own perspective, and how easy it can be to interpret ambiguous behaviours, which the individual with profound intellectual and multiple disabilities (PIMD) cannot then refute. Fogel (1993) describes communication as a continuous processing model reliant on the ‘active role of the listener’ (Bunning, 2009 p48). Bunning further describes the need for attunement to individual’s behaviour in order to recognise subtle changes in mood, body language, facial expressions, vocalisations or even by accepting or rejecting something within a familiar context. Finally, she refers to Nind and Hewett (1994) who focus on the need to develop a desire for joint attention. This requires ‘observational acuity and response sensitivity amongst communication partners to any behaviour that has the potential to be signal bearers of meaning’ (Bunning, 2009 p57).

In the clamour to be heard in a world of competing identities, people with profound intellectual and multiple disabilities are too often overlooked. Frequently policymakers and commissioners of services have little direct knowledge of this group of people. Even if they do, they will overlook them, in order to promote the group characteristics that better fit their policy. Notions of independence, employment and mainstream inclusion are all problematic policy ideas for this group. Within one-size-fits-all service planning this focus means there is less capacity to meet their life-long specialist, complex and individualised needs. Acknowledging human diversity by recognising value and worth in all relationships, including dependent, can only lead to greater acceptance and understanding of the issues.

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During the pandemic and the following few years of increased solo caring duties , Dreenagh took this as an opportunity to further her own understanding of trauma informed care. She is currently working on ideas for a new book and a podcast with carers.

References

Bunning, K. (2009). ‘Making sense of communication’. InPawlyn, J. & Carnaby, S. (eds). *Profound Intellectual and Multiple Disabilities: Nursing Complex Needs*. West Sussex United Kingdom: Wiley-Blackwell, pp 46-61.

Fogel, A. (1993). ‘Two principles of communication: co-regulation and framing’ in Nadel, J & Camaioni, L. (eds.). *New Perspectives in Communication Development*. London UK: Routledge. pp 9-22.

Grove, N., Bunning, K. & Porter J. (2001). ‘Interpreting the meaning of behaviour by people with intellectual disabilities: theoretical and methodological issues’. in Columbus, F. (ed.). *Advances in Psychology Research. Volume 7*. New York: Novia Sciences Publishers. pp 87- 126.

Mental Capacity Act. (2005). (online) Available from http://www.legislation.gov.uk/ukpga/2005/9/section/32

Nind, M & Hewitt, D. (1994). *Access to communication*. London: David Fulton.

Ockelford, A (2017) *Comparing Notes: How We Make Sense of Music*. London: Profile Books

Bibliography

Lyle, D. (2014) *Policy to Practice: A critical analysis of the ‘Valuing People’ strategy* . https://repository.mdx.ac.uk/download/3ec40cda03f661d725766c0167fa169e7bd9a9ff3405beca5cc844e0f89ac8ef/2077580/DLyleThesis.pdf

The role of touch and being heard: a personal reflection

Sam Bergin Goncalves

Reading about touch in the lives of people with profound and multiple learning disabilities (PMLD) has made me reflect deeply. It's a subject that intertwines with love, respect, dignity, and the very human need for connection. Conversations with my sister over the weekend only deepened my thoughts, and an experience with my son, Shane, brought it all into focus.

Photo: Sam and Shane

Shane recently came home after spending three days engaging in activities with his carers preparing for my birthday surprise —buying plants, making a card and baking a cake. When he saw my joy, he responded by rubbing the arm of one of his support workers. That was his way of saying thank you. It was a moment of pure emotional expression, and the support worker, clearly moved, instinctively gave him a hug. It felt right. It was a human response to a human moment.

I believe people like Shane, whose cognitive ability was once measured at 2.5 to 3 years old, experience emotional growth and understanding beyond what tests can measure. He lives in the moment and, if he reaches out to someone in trust and affection, who are we to say that touch should not be reciprocated? It is about recognising and respecting the emotional needs of people with PMLD. However, it also raises a complex question - how do we balance the need for human touch with maintaining appropriate boundaries?

For Shane, I am there to provide hugs, warmth, and reassurance, but what about people in care homes whose families may no longer be present? Who ensures that their need for affection, comfort, and belonging is met? Writing about this has been one of the hardest things I've ever done because I want to acknowledge this vital need while also respecting the importance of boundaries.

Touch, like any form of interaction, depends on the context and the relationship. If a two-year-old child reaches out for a hug, would we deny them? No. So why should we deny a person with PMLD the same recognition of their emotional needs? However, if a small child stuck out their tongue, we wouldn't instinctively reach to touch it. This same logic applies—what feels natural and appropriate must be respected for people with learning disabilities just as it is for others.

At the core of this discussion is emotional well-being. It's not just about physical safety but about how we nurture relationships. People with PMLD are often assumed to be stuck at the most basic level of need, as described in Maslow's hierarchy of needs (see Note), but I believe otherwise. If they are supported, if they feel safe, they can experience love, belonging, and even personal achievement just like anyone else.

The example of Shane's interaction with his support worker is key. This was someone he had known for a long time, a relationship built on trust. Their moment of shared joy was spontaneous and genuine. If the same action had come from a stranger, a bank staff member on a one-day shift, it would not have been the same. People with PMLD build relationships in their own way, over time, just as we all do.

This is also true for personal assistants and carers who work closely with people every day. These are deeply personal roles, where a sense of connection develops naturally. Just as we may embrace a friend going through a hard time, these moments of support and reassurance are part of being human. The question, then, is not whether touch should be part of care but how we ensure that it is always appropriate, consensual, and rooted in understanding.

So where is the boundary? How do we guide professionals, carers, and even researchers in understanding what is appropriate? There is no single answer, but one guiding principle is clear—people with learning disabilities should be given the same respect and dignity as anyone else. If an interaction would feel inappropriate in another context, then it should be reconsidered. If it would feel natural, then it may well be the right response.

Ultimately, this is about being human. It is about seeing and hearing people with PMLD as individuals with their own emotions, needs, and rights. We must ensure that those who care for them understand how to build relationships in a way that fosters trust and safety while also meeting fundamental human needs. If we approach this issue with thoughtfulness and care, we can ensure that people with PMLD experience the warmth, love, and connection that every person deserves.

Contact Details

Sam Bergin Goncalves is a parent carer of Shane who has complex health and care needs. She delivers person centred planning training for RIX Inclusive Research at the University of East London and has done a range of voluntary work with organisations supporting people with learning disabilities and developing Health and Social Care standards.

She has written in this journal previously about using digital technology and multimedia packages to support a more integrated approach by services for her son's needs (*PMLD LINK*, Summer 2017, Vol. 29 (2), Issue 87, 24-25).
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Note
Maslow's hierarchy of needs is a conceptualisation of the needs (or goals) that motivate human behaviour. For more information go to: https://en.wikipedia.org/wiki/Maslow's_hierarchy_of_needs

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Building trust and the benefits of positive touch for individuals with profound and multiple learning disabilities

Sophie Kidd-Munnery

Building trust is central to creating meaningful interactions with people with profound and multiple learning disabilities (PMLD). Here I describe the positive relationship between my 20-year-old daughter, Maisy, and a private physiotherapist, who has gained her trust.

There is evidence to show that many people with PMLD are missing out on opportunities for safe, nurturing touch. Fears and confusion surrounding inappropriate touch and 'age-appropriateness', combined with lack of awareness of the vital importance of this, can lead to limited or non-existent meaningful touch for many individuals. So how can we ensure that people with PMLD can enjoy positive touch from professionals?

Physiotherapist, Katherine (Kat) Mead from KLM Physio, has worked to build a trusting connection with Maisy over the past eight years. It is a relationship that I value highly as Kat has helped Maisy overcome many physical and emotional difficulties and given her comfort and joy in her life whilst providing a vital provision and support to Maisy and to those who care for her.

My name is Maisy!

Maisy was born 9 weeks premature due to my suffering a severe case of pre-eclampsia, which led to Maisy being born by an emergency C-Section, to save both our lives. She weighed a tiny 2lb 12oz and spent 6 weeks in the special care baby unit at Colchester

Hospital. Shortly after her birth, a routine head ultrasound found that she had two significant bleeds on the brain. It was touch and go for around a week or so as Maisy was extremely poorly and needed support with her breathing. Fortunately, the bleeds stopped and she continued to fight her way through numerous infections, severe jaundice, febrile convulsions and much more. Miraculously, she was able to come home after 6 weeks, fully breast fed but still incredibly fragile. However, it was soon clear to see that she was not developing as expected. Within the first year of Maisy's life she had many diagnoses including, Periventricular Leukomalacia (PVL) with a Bilateral Germinal Matrix Haemorrhage and Quadriplegic Cerebral Palsy. She was also registered Blind, developed a severe epilepsy condition called West's Syndrome (Infantile Spasms), had Microcephaly (reduced head growth), severe Scoliosis, severe respiratory issues, learning disabilities and she is also now fully fed via a nasogastric (NG) tube. Maisy is fully dependent on others for all her day-to-day needs and care. Despite all her issues, she has an incredible strength, unbelievable resilience and has a great love for life. Maisy has grown into an amazing, beautiful young lady and is loved by all who know and care for her.

It became very obvious from an early age that, as she grew, Maisy would need constant monitoring of her mobility, skeletal and movement needs. The input of a professional physiotherapist over the years, has had great benefit and been of great importance to Maisy. It has helped her to: enhance and manage muscle strength and flexibility, improve and maintain a good range of movement, promote independence in daily activities, and manage pain. It also has a massive impact on Maisy's general well-being, physically and mentally, as well as supporting her changing needs and multiple health issues - such as her respiratory function. This input has and continues to be a vital resource for training of the people that care for Maisy, which is often overlooked when it comes to any type of therapy provision. It is often just assumed that Parents/Carers have the knowledge or will have to pay to educate themselves on how to support their child/adult or the individuals they care for.

1. Call the individual by their name

Maisy understands her own name. She is blind so she is not aware if someone comes into the room. Maisy is also non-verbal. but can sometimes respond through various vocal sounds and body movements. If you address her directly by her name, she knows that you are there for her and she will respond in her own little way. Saying her name validates her as an individual. It is her identity, just like it is ours. It is a privilege to share the same space as a person like Maisy, and building trust begins by recognising and respecting the individual you are working and communicating with.

2. Get to know and understand an individual's responses

Kat has learnt to read Maisy's mood, cues and tolerances, so that she can adapt her sessions to suit how Maisy is feeling on the day. We can never predict how she will react. It is incredible how Kat can read Maisy's nuanced facial expressions and body language. She understands her personality and sense of humour. It is great to see them laughing and giggling together! Maisy responds really well if you use certain noises when you want to help her understand what is being asked of her. For instance, when Kat wants Maisy to move her leg, she makes a sound like a cat purring. She also praises Maisy if she achieves what is being asked of her by again using her name and using a joyful tone of voice, so Maisy recognises it was a good and positive thing. They have built a wonderful bond and rapport! As a parent it is really nice to watch Maisy respond and work so positively with someone else, and we can see how much she trusts Kat from her responses.

3. Approach the individual with kindness

Kat is always gentle and softly spoken when she approaches Maisy at the start of the session. She is calm and takes her time so that Maisy is fully aware of her presence and feels safe. She waits to see how Maisy is feeling and then responds. Too many people either ignore Maisy, talk in a loud voice, or rush in and handle her with impatience. This attitude is very distressing for Maisy and for us too. It can also massively impact on Maisy's tolerance to the sessions and has greatly upset her and caused a great deal of anxiety when others have done this in the past.

4. Build your own confidence through experience and training

Being trained to work with people with PMLD is central to building trust. Maisy can pick up on the anxiety of people around her. You can see from her body language that she doesn't want to be touched by anyone who is apprehensive. Kat is very confident and knowledgeable because she has read so much, has years of experience, and continues to further her knowledge and training in relation to working with individuals who have complex needs, so that she can facilitate the very best care and therapy at an exceptional standard.

4. Build the trust of the family and caregivers

Due to lack of funding, we are not able to see Kat as often as we would like and not nearly as much as Maisy needs. Maisy has only been given funding for 4 sessions a year! Now Maisy is in adult services, there is no ongoing, regular physiotherapy or occupational therapy provision via statutory services. We know how much Maisy would benefit from more regular input, but we just feel very fortunate that we had already established such an amazing relationship and connection with Kat before her transition from children's services took place. It is vital that Maisy has access to regular physiotherapy to help us maintain and manage her ongoing, ever-changing posture and skeletal issues. Kat works with us to create a programme of movements, stretches and massage which are tailored specifically for Maisy's needs and to what Maisy can realistically achieve and maintain. We know that Kat is dedicated to helping us support Maisy. We know that she is completely thorough in her examinations and picks up on things that we may miss or not be familiar with. She also advises us on any concerns about changes we have noticed. She respects us and listens to us. We are fully confident in Kat's work with Maisy, and I am sure that Maisy recognises this. Kat has also gained a lot of trust with us too, which is so important when she is coming into our home and working so closely with Maisy. We greatly appreciate all the professionals we have been fortunate to have as part of Maisy's team over the years.

My only wish as a parent and someone who is deeply passionate about raising awareness of the on-going provisions that are very much needed for individuals with such complex needs, regardless of their age. It needs to be recognised when transitioning into adult services that these services and provisions are essential to the young person's health and wellbeing and that vital regular, ongoing support from professional be continued. Instead of the current situation where these services are looked upon as non-essential and that support is completely withdrawn.

It is a celebratory occasion when our young people reach adulthood, but for them it is only an age. Their needs remain very much the same, so the support around those needs still needs to be recognised as vitally important. Their therapies and provisions must remain in place, for the benefit of the individual and for those who love and care for them.

Contact details

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Speculative Care Futures- Exploring creative approaches to sharing practice and advocating for playful and connected lives for individuals with PMLD

Max Alexander

Play Sessions at Cherry Road. Over twelve weeks in early 2024 I had the pleasure of collaborating on a project with Cherry Road, a day service catering to individuals with varying and complex needs including those described as having profound and multiple learning disabilities (PMLD). The project involved me, a play worker and artist, facilitating one on one play sessions for their service users and members of staff. Separately for three sessions each. and then together for three sessions.

I had previously worked with Cherry Road in a few ways on a few different projects over the years and had always found their community to be welcoming of different ideas and keen to try new things. When I approached them I had a list of questions I was curious about. A lot of these were around how staff could be better supported to engage in playful and sensory ways with service users. I wanted to approach this by exploring what might happen if staff are given the opportunity to tune into their own playfulness and needs in a space that was just for them. Other questions I had were about reimagining ways staff and service users could share space; ways that didn't prioritise verbal language, ways that felt spacious and non-rushed, and ways that valued non-typical ways of relating to each other.

The sessions in that project were incredibly varied, they involved silent laying together and casting shadows on the ceiling, humming through pipes, a makeshift punch bag made out of a yoga ball and a net hammock, duck noises, bouncy balls galore, pacing in tandem, a mirror ball on a stick, soft giggles, cheeky mischievous laughs, tired-lets-just-sit days and energetic-lets-not-stay-still ones.

As an autistic being who thrives on being in my body and connecting without words; moving into a being, sensing and playing space is a joy and often, relief. But when facilitating play spaces for adults who are more comfortable in spaces where language and ideas are the main mode of expressing themselves and communicating, I'm often very aware that it can feel like the opposite. In large part, I think because of the expectations they are used to and the vulnerability of stepping out of them. I was very aware when working with staff that I was potentially asking a lot of them; Inviting them into spaces that involved being less-verbal, tuning into their own play instincts and sharing space with another adult who was doing the same thing, all whilst being in their workplace. I worked to find different ways of framing and guiding the sessions, making space for talking and being in the more comfortable realm of words and ideas- as well as creating pockets of guided and non-guided sensory exploration and play. It was ultimately a positively challenging and rewarding experience for me, and staff also provided positive feedback. I feel like there is a lot of value in this approach and a lot more to be explored.

Speculative Care Futures

Following the collaboration with Cherry Road I wanted to create some kind of report or resource to share my learning and encourage more conversations and explorations. I wasn't sure what form this should take and was initially a bit stuck and overwhelmed about how

Image 1:Space set up for a Play Session including a hanging white sheet, spotlights, a yoga ball suspended in a net, buckets of tinsel and various spotlights and mirrors.

Image 2: An illustration from Speculative Care Futures exploring the idea of “Words as a comfort blanket” and what can happen when we leave it behind.

much I wanted to say and not knowing how I could say it all in a way that was accessible to different readers. I wanted to talk about the Cherry Road project but I also wanted to bring in my thoughts and experiences from many years of doing this kind of work with all sorts of different people. Once I got out of my own head a little and stopped trying to create the “perfect” piece of work, I realised I just needed to approach it in the best way that I could; as an artist. I decided to create a “Speculative Report” drawing on the practices of Speculative Fiction and Speculative Journalism which blend real experiences, facts and evidence with fictional narratives to explore and express often complex ideas in an accessible and relatable way.

The report, “Speculative Care Futures”, centres on an imagined day centre, in a similar vein to Cherry Road, and traces the journey of a staff team who decide to shake things up a bit and take a compassionate look about how they might reshape the culture of their community to be a more equitable and meaningful space for all. It documents their journey through several ‘explorations’ including themes of play time for staff, non-verbal spaces, slowing down and creating shared sensory experiences. It also contains case studies of four individuals; two service users, one staff member and a visiting artist.

The experience of writing and sharing this work has brought a few specific themes to light that I’m keen to keep thinking about and exploring; Sensory Beings as Cultural Beings, the value of Neurodivergent knowledge and the Role of Creativity in Advocacy.

Sensory Beings as Cultural Beings

A lot of the report could essentially be summed up as “What if the culture of the space was more representative of people with PMLD or Sensory Beings?”. Culture can be a tricky word because it has been co-opted to mean something created by a few special people and gifted to the rest of the population by those people. To a lot of people “Culture” can mean “That thing artists create” or “Things that happen in Cultural Spaces”. But actually, Culture is much broader and more grounded than that. Yes it includes art but it also includes how we communicate with each other, how we behave, how we play and what we think is important when we come together. Everyone has culture but not everyone’s culture is given the space and value it deserves. The culture of people with PMLD certainly isn’t but it should be and we all can have a role in changing that.

Value of neurodivergent knowledge

As a speaking autistic adult without a learning disability, I do not have the same experience as an individual with PMLD. This is true on many vital levels. But I, like many others who have autistic and/or otherly

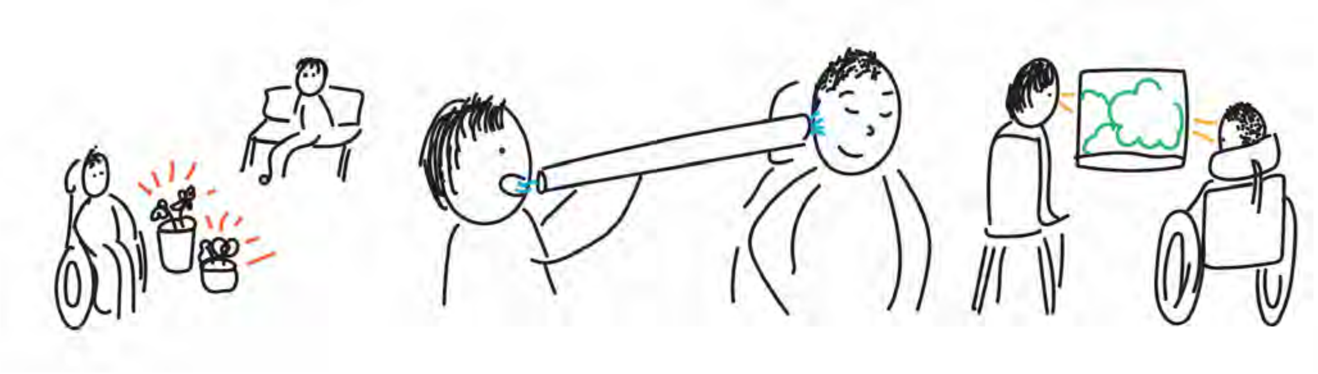

Image 3: An illustration from Speculative Care Futures showing different ways of being alongside one another.

neurodivergent body-minds, do often have specific insights that can be extremely valuable for connecting with and supporting folks with PMLD. I believe strongly more Neurodivergent and Disabled input is needed into services that provide for this population. This does however also mean exploring ways of knowledge sharing that aren't 'typical'. Because a lot of the people who will have important and useful things to share will be less likely to do so within the parameters of academia, research, consulting, writing etc. So how do we find and construct ways for that knowledge to be created and shared?

Role of Creativity in Advocacy

The things I write about in the report are all pretty simple human things which most of us already know are important. Things like talking less, slowing down, exploring our own sensory experiences and emotions as part of our relationships with each other. All the case studies and descriptions of experiences are based on things I've experienced and witnessed myself. Yet I kept bumping up against the idea or feeling that certain things were 'unrealistic' because I'd just think of the reasons why they often don't happen or are made more complex. Things like scarcity of resources - be that time, money or people, clashes of needs and the pressure of outside agendas. Using creativity to step outside of that and let myself imagine what could actually happen if the conditions were right felt like a bit of a revelation for me. Advocacy and activism are essential in the context of the lives of people with PMLD. A lot of that is about fighting systems and dealing with immediate problems but, when we can, I believe stepping back, letting ourselves dream, and imagining alternatives , are a vital part of change.

Speculative Care Futures is available for download in written form and listening in audio form at www.playradical.com/portfolio-2/speculative-care-futures/

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Being heard

Gabriella Walker and Tussie Myserson

Initially, in this piece Gabriella talks about her own experiences which led to the genesis of Iris which is a small social enterprise supporting children with the most complex needs and their families to access supports and services which are their entitlement. Next, Gabriella and Tussie write about how they struggled to respond in a very short time frame to recent important consultations.

Since the mid to end of December there have been three very large and important government consultations that will hugely impact children with additional needs:

- the Law Commission have carried out a review of legislation related to disabled children's social care (Law Commission, 2024);
- the Government have launched the 'Change NHS' initiative (NHS England, 2024), to seek views on how they should shape and prioritise their response to the recent review by Lord Darzi of the state of the NHS, commissioned by the new Labour Government (Darzi, 2024); and
- the SEND (Special Educational Needs and Disability) Select Committee in the UK Parliament launched a call for evidence to 'solve the SEND crisis' (House of Commons, 2024).

For all of these consultations, the various bodies asked for submissions from families and third sector organisations, including those working with disabled children, to understand how best to address the myriad issues confronting so many different communities across all of these areas.

Having spent my career in the health service, working on national policy, I believed the rhetoric of 'No decision about me without me' (DoH, 2010); I believed "Every Child Matters" (HM Treasury, 2003); and I believed that faced with some of the worst news a parent can receive, the system I worked within would step up and I would see the things I had spent my career working for spring into action. It was no accident that I ended up working in health policy; I always wanted to support vulnerable children and had toyed with the idea of becoming a social worker. However, I read about the abuse of Baby P by his carers and watched the case unfold (BBC, 2010). I saw the systemic gaps and lack of accountability and decided I wanted to work in the system, behind the scenes, to ensure that those at most risk of vulnerability - of all kinds - had access to the types of supports and services that worked for them. These would be services that met them where they were at, were non-judgemental, flexible, trustworthy and supportive.

My experience however was the reverse. My young daughter, Thea, had a neurodegenerative disease that caused profound and multiple disabilities. Diagnosed just before one year old, my husband and I spent her short life struggling to provide her with the support she needed and unable to access any support to help us keep ourselves - and her - safe. Her big brother didn't get a look in. Being questioned and interrogated about why we might need support no matter which way we turned; unable to access appropriate nursery provision; unable to access the equipment that would have saved her life; one of us ripped from the workplace plunging us into financial uncertainty. We didn't have a chance to come to terms with the fact that she was dying, let alone understand how to best prevent her death and maximise her life chances. We struggled to do our best, focusing on whatever made sense, constantly reacting and playing catch up, whilst drifting apart and becoming functional shells of human beings. She had a wonderful life, but it came at a huge cost.

Thea died in 2019. In 2020 I completed my Health Policy MSc with a piece of research exploring the psychosocial support needs of families of children with complex needs. I then moved into the National Learning Disability and Autism Team at NHS England. During the years that followed I devoured any information, research and intelligence I could about disability and supporting children with complex needs, but I also learned more about the inner workings of the system and became absorbed in trying to understand why none of the previous initiatives had led to any tangible change, despite the rhetoric. Eventually, inspired by the Support Brokerage approach advocated by Liz Leach Murphy (https://imagineer.org.uk/home/lec/self-directing-my-support/support-brokerage/), I left the NHS with a very heavy heart to set up Iris to demonstrate that there was a better and cheaper way of doing things.

Iris supports families using support brokerage, but most importantly we are dedicated to systemic change. Without this our work will never see the change we need. Every day we work with families, we are dismissed, gaslit and hoodwinked by those in the system; always 'passing the buck' and looking to blame families. This is not malicious, although it feels it. These are the actions of untrained, inexperienced and institutionalised individuals, trying to and thinking that they are doing their best and believing the argument that there is 'no money' and unable to see another way of doing things.

We use the intelligence gathered through our work with families to advocate for system change across the NHS, education and social care: every part of the system has to pull together for this group of children.

But saying this is nothing new to those of you who have lived this. It's nothing new to many who work in this system. And the fear is that it doesn't make a difference - how can one small organisation make any change in a system ensconced in judgement and prejudice; a system so many good people before us have tried to change? How can we be heard when there are three government consultations, each of which require time, careful thought and research to provide evidence to, ongoing at the same time? Iris receives no funding and these all took place over the most difficult of time of the year, Christmas, when there is already so much to do, when our trauma comes to the fore and is impossible to ignore.

To be honest, it is uncertain whether we and the families we support can be heard. but we have to try. We ran four webinars and engaged with a number of existing groups for input into and feedback on the Law Commission Review. We heard nothing new. Experiences haven't changed. We have children born twenty years apart. Tussie's daughter, Emmy, and Thea are perfect examples that nothing much has changed, and in fact things have arguably got worse. As the SEND agenda grows and mainstream disability – rightly - has more of a voice and society is more inclusive for so many, our children, born literally with no voice and reliant on others for every single aspect of daily life, defying the odds every day they stay alive, become easier to ignore. You ignore them and they die. It's cheaper. Except it's not. Thea's lack of care and support cost hundreds of thousands in acute hospital admissions in the end - admissions that could have been prevented with better support for us at home. We plan to do an economic evaluation of our children and the amount of money that delay and obfuscation cost them and the system. If no one is valuing the lives of these children and their families, perhaps money is a language they will understand.

In the meantime, in between therapy, painful meetings with local authority officers in which little is achieved, and trying to make sense of our lives, we will continue to fight - for the families we support and those we have never met. We spent our Christmas analysing data, devouring scientific papers and literature, and writing a response to each of these consultations, which might just give us a voice.

But what does that voice say? It won't come as a surprise: treat us like people. Our children can't survive without us and the state certainly does not want to look after them. So, show us some respect, understand the complex but beautiful mess that is our lives, work with us, don't treat us like the enemy. We frequently hear that there is no money and that any decision made about one child impacts what is available for another child. They say our children are too costly and no one wants to put their hand in their pocket. Yet there is money for tribunals; there is money to waste saying no; there is money for assessments that lead to damning, traumatising reports; there is money for endless meetings involving numerous senior professionals but which lead to no action. The money is being spent in the wrong places. Spending it at the beginning, having proper conversations, that problem solve and actually meet individual needs rather than just ticking boxes; something that offers the possibility of turning our chaotic, messy but wonderful lives into something manageable that doesn't leave us traumatised and picking up the pieces for us and our other children for decades after our loved one has died.

The fact is these three consultations are running alongside one another, asking the same people for the same information in a slightly different way and looking at it all separately. But there is no 'health' and there is no 'social care' when it comes to our children: we endlessly fall through the gaps because of the simple, basic lack of understanding of how to live a good life with complex disability. But we'll keep trying and talking, because our children can't.

As Don Mclean so eloquently puts it in his song, Vincent: "They did not listen, they did not know how. Perhaps they'll listen now".

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References

BBC (2010) Baby Peter 'was failed by all agencies' Available online at: https://www.bbc.co.uk/news/education-11621391

Darzi, Lord. (2024) *Independent Investigation of the National Health Service in England* (accessible version). Available online at: https://www.gov.uk/government/publications/independent-investigation-of-the-nhs-in-england/independent-investigation-of-the-national-health-service-in-england-accessible-version

DoH (Department of Health) (2010) *Equity and excellence: Liberating the NHS*. Cm 7881 Available online at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/213823/dh_117794.pdf

HM Treasury (2003) *Every Child Matters* Cm 5860 Available online at: https://www.gov.uk/government/publications/every-child-matters

House of Commons, Education Committee (2024) *Solving the SEND Crisis: Inquiry – Call for Evidence*. Available online at: https://committees.parliament.uk/call-for-evidence/3517

The Law Commission (2024) *Disabled Children's Social Care.* Consultation available online at: https://lawcom.gov.uk/project/disabled-childrens-social-care/

NHS England (2024) *Change NHS: help build a health service fit for the future* Available online at: https://www.england.nhs.uk/long-read/change-nhs-help-build-a-health-service-fit-for-the-future/

Pathways to Work: Reforming Benefits and Support to Get Britain Working Green Paper

This is an open consultation from the Department for Work and Pensions published as a Green Paper on 18 March 2025. It seeks views on concrete proposals from the government for some of its much talked about reforms of the health and disability benefits system and employment support. This consultation closes on 30 June 2025. The earliest that the changes could be in place is April 2026.

The Department is keen to hear views from a wide group of people, in particular disabled people and people with health conditions and disability organisations. This consultation applies to England, Wales and Scotland. All the proposals apply in England but the proposals in the consultation will only apply to the UK Government's areas of responsibility in England, Wales and Scotland. Social security and employment support are transferred in Northern Ireland but comments from individuals and organisations in Northern Ireland are still welcome and will be shared with the Department for Communities in Northern Ireland.

A series of public events related to this consultation are being held between April and June 2025: All events are ticketed, and the number of attendees may be limited by location and venue. Tickets are available through Eventbrite. There is a statement that reimbursement may be available for reasonable travel expenses for individuals with tickets for events. For more details go to: https://www.gov.uk/government/consultations/pathways-to-work-reforming-benefits-and-support-to-get-britain-working-green-paper

The Government's priority is to address the high number of people who were out of work and classed as long-term sick and claiming health related benefits. The UK is seen as an international outlier when it comes to this issue; the only major economy whose employment rate hasn't recovered from the COVID-19 pandemic. The Government's view is that the structure of the benefits system is a factor contributing to significant increases in claims for incapacity and disability benefits.

It remains uncertain what the implications are for people with severe and profound learning disabilities and their families and carers. There is recognition in the document that there will always be people who cannot work due to the severity of their disability or health condition and there should always be a safety net for those in genuine need.

The consultation document runs to 80 plus pages and chunks of it may not be relevant to PMLD LINK readers but some proposals are significant. LDE (Learning Disability England), among others, has voiced concerns about changes to PIP (personal independence payment) and PIP assessment. LDE has previously stressed the value for individuals of PIP, the need for a more human and kinder assessment system, and the general wish for minimal bureaucracy surrounding payments (https://www.learningdisabilityengland.org.uk/wp-content/uploads/2024/08/Learning-Disability-England-PIP-Consultation-Response-2024.pdf). There are also suggestions in the Green Paper of temporary freezes of the value of benefits whilst reforms take hold and making 18 instead of 16 the age for young people to start claiming PIP.

PMLD LINK does urge its readers to check out this consultation document and see if it has implications for you or family members or people you support. Do share your views with other people and urge them to respond to the consultation as well.

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Being heard during difficult times

Danielle Shull and Andrew Smart

Experiencing bereavement is sadly something we will all experience in our lives. Though the way we feel it and how we navigate grief will be unique to each person and each circumstance, we all grieve. It is widely accepted that people will experience a range of emotions in different ways and at different stages of grief.

Do people with PMLD experience grief?

People with profound and multiple learning disabilities (PMLD) will also experience emotional pain and difficulty following a bereavement, and it should be expected that they will grieve too. However, their experience following the loss will often be different, less empathetically considered or perhaps not even recognised in society - even in spaces well acquainted with joining a person with PMLD in their unique emotional landscape.

People without learning disabilities will be able to share their sadness, take time to try and process the emotional difficulty they will experience as they try to find their own ways of coping with grief. They will often be offered support and share painful emotional difficulties following the death of loved ones. But far too often, the voices of people with PMLD will not be heard following a bereavement, adding to their sense of loss.

Recognising the need for grief education in a PMLD context

Bereavement is not an easy thing to talk about, and this is further complicated when considering how to navigate this difficult and sensitive topic whilst supporting someone with PMLD through their grief. As a means to better understand and recognise the grief experience of someone with PMLD, and to help them get their voices heard, it is important that the conversation begins with listening. In 2014, PAMIS (Promoting a More Inclusive Society) undertook this important work with our project around understanding grief, loss and death in the context of PMLD. That research spanned numerous topics, from better understanding about how someone with PMLD may express their grief to what causes them to feel it. The revelations of this work revealed far more than even the families at the heart of it could have imagined.

PAMIS's previous research could not sit in a silo so following the findings around what is needed to better support people with PMLD and their families with their grief and bereavement, a new way of sharing this learning emerged. Since 2014, we have delivered a dedicated course which spans more than 12 hours of learning focussed on ensuring that families feel supported in their grief and that the voice of individuals with PMLD can be heard throughout their bereavement. Since this research was undertaken, the conversation has grown to include more families, other scholars, professionals and even organisations who are interested in better understanding their role in supporting someone with PMLD and their families through the experience of loss.

Learnings from a decade of listening

Though there is no easy answer, we have learned that it starts with recognising awareness of the process of grief. For many families, the starting point of support begins with asking the question at all - have you recognised a loss in the life of the person (or people) you support? In delivering this course, we have learned that reflecting on this question can be jarring, painful and even shocking for families who may abruptly recognise a grief which, to this point, has been unresolved and unacknowledged.

Instead of collecting and collating our own thoughts on the subject, we prefer to allow the voices so often ignored to speak of their own experiences. Below, we have highlighted some of the powerful learning which was found in the original research and continues to dominate the conversations which occur during the course. These are a mix of experiences, from how a family may feel when someone with PMLD dies, and how a person with PMLD may feel when they are bereaved. They are listed in no particular order, and instead each should be considered as a unique point which is an opportunity for reflection, instead of a finished finding:

- The support network around someone with PMLD is primarily patchworked through paid staff and support directly tied to their care. When the cared for person dies, the network of support around the family is often withdrawn too.
- Without language, how can you share something which feels upsetting, overwhelming or frustrating? In grief, distressed behaviour or physical changes may become a key component of communicating the emotional distress of the loss felt by someone with PMLD.

- When care staff leave, or similar transitions in life occur (new school, new home, new routine), this can feel like a bereavement for someone with PMLD. How are they to know the difference between death and a new job, if no one acknowledges this change in their world?
- What mental health support is available to someone with a profound learning disability? Who has considered their emotional needs, and what considerations were made?
- Giving someone with PMLD control over when and how their grief is acknowledged and can be done through things like a memory box, but should never be forced if the person seems distressed by the experience.
- When someone dies, a family and caregiver may feel a mix of emotions as they begin to navigate and process their grief. It is particularly impactful to allow space for this as often, the grief is a culmination of their lived experience in a caring role as well as grief.
- The equipment collection and return process can be cold, callous and deeply personal. Some sensitivity training should be delivered to anyone in this role, particularly if it involves entering a family's home.
- A person's capacity for memory is not limited to their understanding of time.
- Did any of these stand out to you? Did it surprise you, or even make you feel a bit restless in reflection of a past experience?

It's understandable if the reality of grief, and the lost stories of how it's felt by someone with PMLD, feels overwhelming. This list is but a fraction of the incredibly powerful learnings which arise when we can only listen to what others have been through, and give their stories space to share their lessons. People without learning disabilities are given the opportunity to find support, and to navigate their grief in their own unique ways. It is with many thanks to the families who took part in PAMIS's original research, and many of our families since, that we are able to make a list at all.

We are only at the beginning, but we believe that together, we can ensure there is recognition for, and support within, the context of bereavement and loss for people with PMLD and their families.

The value of feeling heard

Since 2014, the conversation has grown from "Do people with PMLD grieve?" to recognising that "how can we make space for people with PMLD to grieve?". Of course, in retrospect, we know that the human experience of grief is not unique to those of us who can share our worlds and words with language. Now that we have that knowledge, we're learning to listen in new ways, and along the way, ask new questions. People with PMLD have emotional landscapes and experiences as rich and as vibrant as yours or mine, and recognising that diversity in honouring their grief comes in many ways. Whilst there may never be an easy answer, or a solution to the pain of bereavement, there can certainly be a recognition, and the compassion to be shoulder to shoulder with someone so they never feel that their only option is to navigate loss alone.

Through our course, the work of people like Sarah Helton (https://backpocketteacher.co.uk/) ,and the words of every family who offers up their wisdom to our collective community, we are still taking steps toward meaningful change in our understanding of grief, loss and bereavement. This work is critical and, though it may be sensitive, messy, and difficult, it is a gift to give space to the grief of every individual who chooses to trust us enough to share it. For someone with PMLD, that choice may look different, but by listening, we can create the opportunity to recognise it and support the human experience of loss for each person and ensure their grief is being heard and acknowledged.

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Grief and Cherishing Together

Peter Blaker

On the 24th December last year, Reflect PMLD lost Shally, a beautiful, gentle soul who I felt had the heart of a poet. Day support at Reflect is founded on Intensive Interaction, and while the loss of anyone with profound and multiple learning disabilities (PMLD) is heartbreaking, I believe that the depth of relationships coming out of encounters like that intensifies the sense of grief and bereavement when someone dies.

It is also a bereavement for the other people supported by Reflect. They all had relationships with Shally, their own sense and knowing of his being there with them, sharing their lives and space and the things they did together. And now he wasn't. Grief is something we sense in each other, and I have no doubt that Shally's friends were aware of the change in feelings of the staff, of the sense that things are different now. Somebody who was part of the caring circle of Reflect is no longer there.

I was asked to provide an occasion that could mark a sharing of those feelings together, something that spoke to staff and to Shally's friends alike, an emotional and sensory response to loss and grief.

A date was set and then came a second devastating blow. On Friday the 17th January came the news that Si, from the same Reflect day support centre, had also lost his life.

Si, the joyful, exuberant gentleman whose face beamed with joy on the cover of the 100th edition of PMLD LINK!

The blow to everyone at the Hornblotton Reflect centre was overwhelming. The need to commemorate was now more than pressing.

Just a week would have passed from the news of Si's loss to the event, and I felt it was too soon and too raw to hold a 'celebration', nobody was yet in that frame of mind so I took on the alternative of a 'cherishing'. This felt like an expression that bound together everybody who was there in love and grief. The initial challenge was that I needed to invent the content of the occasion. I could find nothing online that suggested activities conveying an appropriate response to the pain and distress experience at Reflect, I needed to create it. I settled on a sequence of three activities.

Mark, a Reflect Director, welcomed everyone into a large, darkened room where nine sensory star projectors created an intimate, soothing ambiance. His introduction was concise, language was limited throughout the event to maximise the extent to which everyone there was able to access the experience equally.

1 Heart Meditation. I sought advice from practitioners I know and respect, and this event was suggested by Sophie Horsman, a very talented Special Yoga practitioner. I asked everyone to place their hands on their upper chests, their heart space, and to sit in peace and stillness for a brief period of silence, and then through a recorded song. Support staff could, with signalled consent, place their free hand on the chest of the person they supported, or on fellow staff. Where there was shared touch, the energy and consolation flowed in both directions. Similarly, the chosen song, 'Bridge Over Troubled Waters,' reflected the mutuality of the relationship between staff and those who Reflect supports. Although the lyrics spoke best to those who

understand spoken language, the emotion of the voice and music of the song gave a message that all could hear. Becky Maddison, the incredibly wise and compassionate support leader at the Reflect centre spoke of Shally and Si between events, and a period of silence was held in which staff were able to speak or play a piece of music of their own. Kelly read her own poems, which powerfully conveyed the love and sense of grief felt for Shally and Si.

2 The foil parachute. This was made from six foil blankets taped together. There is something collectively engaging in using parachutes, but the qualities of foil blankets set them apart. They move more slowly, are lighter and reflect the sensory lighting in a way that fabric parachutes cannot. I asked for participants to rise and lower it slowly, as if it was creating a deep, meditative breathing pattern, and indeed the sensory experience was enhanced by the way it puffed out air to the sides with each descent. Participants were welcome to hold it, or go underneath, or simply watch it sparkle as it rose and fell. The music used was ‘The Memory of Trees,’ by Enya.

3 The candle ceremony. The candle ceremony is adapted from an intervention I used many years ago while caring for abused youngsters. We would sit in a darkened room equipped with tealights and recall positive memories from that child’s life. For each one, we would light a tealight and carefully place in on the table. By the end, we were able to gaze at the warm, golden glow of light from dozens of candles, reflecting the beauty and worth that also resided in the child’s life to balance their pain. In this version, we lit two tall battery candles and set them on a table in the centre of the room. We distributed one hundred battery tea lights, and while I played Enya’s ‘Only Time’, they were gently, wordlessly added to the table. The collective light was an entrancing focus for calm meditation and togetherness.

We came to the end and Steve, Mark’s co-director, spoke a few words. After we finished, everyone continued to sit, watching the glow in the darkness and with lights in their cupped hands or balanced on chairs, each quietly ending in their own time.

Contact details

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Starfish

Being present in the world of social media

Mark Blaker

For some it's extremely controversial, so I'm writing this in hushed tones, because: yes, here at Reflect Day Service we dare to put photographs of people we support on social media. We celebrate their lives, experiences and achievements with pictures that depict them as real people in the real world, just like everybody else.

This is far from universal practice in the care sector, and many would condemn us as rash, buccaneering rascals. In fact, for many the starting position is they are vulnerable adults and we must protect them by keeping them hidden and anonymous. The "vulnerable" label, when used to define a person, is great if you want to crush freedom and individuality, because the inevitable solution to being defined vulnerable is a suffocating kind of protection - being kept behind closed doors, perhaps staring at a TV or out of a window at an empty bird feeder. The damaging assumption is, if they can't articulate yes, the world must always default to no.

This isn't just about sharing nice pictures. This is about a fight for survival, or at least a fight for a living standard that rises above the level of basic existence. There have been studies about life after death or, more specifically, the anticipated life of a disabled person after their parents die. In "I Hope I'll Outlive Him" (Kruithof et al, 2021), twenty-seven parent-carers in the Netherlands were interviewed, and most said they hoped they would outlive their child. They anticipated a hugely reduced quality of life for their loved one when they are gone and feared the possibility of a life in which their child was no longer valued, respected or cared about. It's a fear shared by many family carers I talk to and borne out by other studies too. For many parents their own death is an act of terrifying abandonment of their child.

Part of this fear has to be due to society at large not seeing the need to provide the kind of support that enables the life of a profoundly disabled person to thrive. And part of that must come from the invisibility of their emotional connections. The world does not see them.

I often think of one of the very few times someone with profound and multiple learning disabilities (PMLD) has been represented in a major film. In the otherwise very watchable "Last Orders", Helen Mirren's character visits her adult daughter in a residential home each week, but soon decides to use that time as an opportunity to have sex with Bob Hoskins in the back of a camper van instead (questionable on several levels). Eventually she does see her daughter, who is busily stacking blocks, and tells her bitterly she is not coming to visit ever again because she never gets anything back from her.

Who, with any experience or connection with family carers would recognise this as typical, or even common? Instead, daily we see only insight and devotion. It can come with a dollop of frustration and even despair, but that is because of their circumstances, not because of their child. Yet that is not the story the wider world hears.

So, we must prove a point by breaking out of our bubble and revealing the truth of that person and the love that surrounds them. Our hope has to be that these stories will be heard, but they will only be heard if we make them public. In turn those stories might help influence care standards, to a point where anything less than a rich, well supported existence is unacceptable…even after mum and dad have gone.

Being seen and being heard and being present leads to everything. It's life and death.

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For information about Reflect Day Services see:

Jones, S. (2023) Laying the foundations – delivering excellent personal care support *PMLD LINK*, Vol 35 No 1. Issue 104, 3 – 4

Or go to the website at: https://www.reflectfutures.co.uk/

References

Kruithof, K., Olsman, E., Nieuwenhuijse, A. and Willems, D. (2021) "I hope I'll outlive him": A qualitative study of parents' concerns about being outlived by their child with profound intellectual and multiple disabilities *Journal of Intellectual & Developmental Disability*, 47(1):1-11. Available online at: https://www.researchgate.net/deref/https%3A%2F%2Fdoi.org%2F10.3109%2F13668250.2021.1920377?_tp=eyJjb250ZXh0Ijp7ImZpcnN0UGFnZSI6InB1YmxpY2F0aW9uIiwicGFnZSI6InB1YmxpY2F0aW9uIn19

No Blue Monday 2025: a national snapshot of sensory heritage and the lives of people with profound and multiple learning disabilities

Julia Collar

No Blue Monday, 20th January 2025, was designed and organised by Collar & Cuffs Co as part of our Heritage Lottery-funded project, Profound & Multiple, supported by the University of Bedfordshire. The event aimed to create a national snapshot of the lived experiences of people with profound and multiple learning disabilities (PMLD), which could then be compared and contrasted with a local snapshot, developed through our partnership with The Chiltern School. Students with PMLD at The Chiltern School are co-creating an exhibition with us, about their lives offering insight into their everyday experiences.

Through this exhibition and its underpinning methodology, we are exploring the concept of sensory heritage—a way of capturing the lived experiences of people with PMLD through sensory engagement. By documenting and valuing their direct responses to sensory experiences, we centre their 'voices' as primary sources, ensuring they are recognised as active participants in our shared cultural history. Additional narratives from parents, carers, and teachers provide valuable context, offering a broader understanding of their life stories and circumstances. However, these accounts are not intended to speak for these individuals, but to complement and enrich the understanding of their sensory experiences. The recordings of sensory engagement stand alone as meaningful expressions of their identities, while the contextual information adds depth without overshadowing or redefining their perspectives. One key aspect of this methodology is the exploration of sensory archetypes—key sensory resources and experiences that people with PMLD are likely to have encountered repeatedly from birth. These may include common sensory materials such as lights, water, fabrics, reflective surfaces, and rhythmic sound patterns. Importantly, these resources are not just momentary stimuli but are imbued with layers of personal history, as these individuals bring their years of lived experience into each new encounter. This allows for an exploration of how people with PMLD interact with their environment over time, providing valuable insights into both individual and collective sensory heritage.

A National Celebration of Everyday Brilliance

No Blue Monday provided a unique opportunity to observe and record how individuals with PMLD across the UK engaged with these sensory archetypes. With 112 organisations and families taking part across all four nations of the United Kingdom - including special schools, adult day services, creative practitioners, theatre companies, and storytelling projects - the event painted a rich and diverse picture of the daily lives of this particular population. What's really special though is that none of the participants planned any special events or activities for the day: rather it was about what they would typically be doing on that day within regular routines, within ongoing projects, and within existing relationships and in familiar environments.

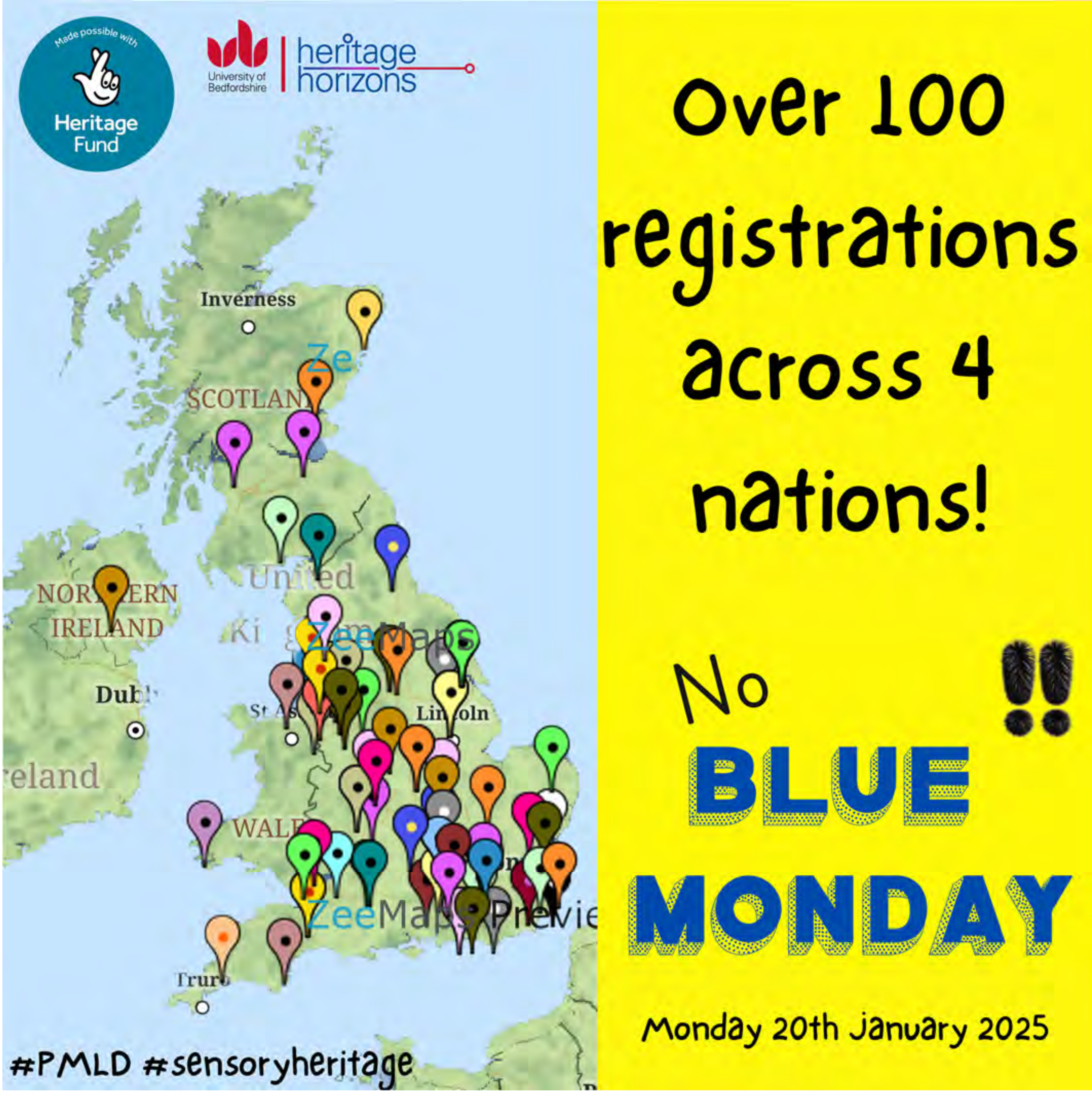
Participants were asked to describe their experiences using five-word phrases, offering a striking glimpse into the joy, engagement, and sensory exploration that defined an ordinary day:

- "Fun, happy, meaningful, present, seen"
- "Engaging, fun, exploration, communication, colourful"
- "Heartwarming, happy, busy, productive, connected"
- "Energetic, exciting, noisy, fun, rhythmic"
- "An empowering and joyful experience"

Key Moments and Insights

Throughout No Blue Monday, participants recorded notable moments of interaction, communication, and learning. Some of the most significant observations included:

- Sustained Engagement: Several individuals who typically struggle with maintaining their focus were observed fixating on sensory elements for extended periods - whether through eye-tracking, sustained hand movements, or attentive listening. One young participant, for example, maintained eye contact for over two minutes, an achievement that was celebrated as a significant sign of engagement.
- Communication and Choice-Making: A participant who had been reluctant to engage initially lit up with enthusiasm when offered an alternative sensory experience, clearly expressing a preference



and sense of agency in the process.

- The Power of Sound and Rhythm: Several individuals responded joyfully to music and rhythmic storytelling, demonstrating heightened awareness and participation through vocalisations, movement, and facial expressions. One participant, who is usually quiet, vocalised loudly and repeatedly in response to a rhythmic story - recognised as a clear sign of enjoyment and interaction.
- Social Connection: One young participant who had been showing signs of distress immediately calmed when repositioned near a friend, showing that relationships play a crucial role in emotional well-being and regulation.
- Determination and Learning: A participant with complex physical needs successfully pressed an AAC button after several attempts, triggering a cause-and-effect response with a burst of coloured light. This moment was described as empowering and confidence-boosting, highlighting the importance of accessible technology in fostering autonomy.

These moments reinforce that ‘breakthrough’ moments can occur at any time with and for people with, often within the rhythms of daily life. It’s a reminder that learning, connection, and joy are not confined to special occasions - they unfold in the everyday. In that sense, our community truly embodies ‘the wonderful everyday,’ to borrow a phrase from IKEA!

Reflections on meeting core care needs

While No Blue Monday was a celebration of sensory heritage and engagement, it also provided valuable insights into the barriers and challenges faced by those who support people with PMLD in daily care and education.

Many practitioners highlighted the sheer amount of time spent on core care needs, sometimes to the extent that educational and enrichment activities take a back seat. One participant reflected:

"The core care needs take up most of our day. Sometimes the whole day can turn into a full day of care. Being just one member of staff down impacts on the ability to meet the core care needs of people with PMLD as well as their educational needs."

Despite these challenges, respondents emphasised that every moment is a learning opportunity, and that care itself is a form of engagement and interaction. One educator noted:

"Every experience for these learners is a moment of learning; do not rush any of it". Others stressed the importance of purposeful silence, allowing time for individuals to process and respond in their own way. This was particularly evident in the use of intensive interaction techniques, where practitioners matched the rhythm and pace of each individual's communication style.

Some also raised the issue of staffing and support structures, particularly in settings, like schools, where medical care is delivered by external professionals who are not part of the core teaching team. While this ensures necessary medical provision, it can sometimes create barriers to holistic support, as external staff are unable to assist with wider learning activities.

The role of mental health in PMLD was another key area of reflection. While changes in behaviour are often attributed to physical health factors, some practitioners actively consider mental well-being as an integral part of care. As one participant noted:

"We are very quick to attribute changes in behaviour to physical health without considering their mental health, so this is something I am trying to get better at."

The Future of Sensory Heritage and No Blue Monday

The success of No Blue Monday has opened up new possibilities for research and advocacy. The University of Bedfordshire is keen to continue working with Collar & Cuffs Co to develop a longitudinal study on sensory heritage and PMLD , with the aim of securing additional funding to expand this work for further iterations of No Blue Monday.

By refining and developing sensory heritage methodologies, we aim to create a lasting record of the lived experiences of people with PMLD, both those who are no longer with us and those who continue to shape our understanding today. We are incredibly grateful to all those who participated, shared their insights, and helped shape this initial snapshot of the lives of this particular group of people.

Together, we are redefining inclusion by ensuring that the daily experiences of people with PMLD —their sensory engagements, interactions, and expressions—are recognised as part of our shared history. Their lives are not outside of history; they are shaping it, moment by moment. By acknowledging and valuing their contributions, we challenge the invisibility they too often face and ensure their voices are heard—now and in the future—in the language they know best: the sensory.

For more information, or to contribute further data, photos, or media, do please contact us.

Contact details

Julia Collar, founder of Collar & Cuffs Co (2016), develops sensory access in museums, galleries, and historic sites, working with institutions like MK Gallery and Kew Gardens. She also creates sensory theatre, winning several awards. Julia, autistic herself, provides training and research on sensory heritage methodology around PMLD.

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‘Nothing about us without us’

Kate Sainsbury

This famous disability rights slogan has been used for thirty years to express a desire for inclusive societies, for the full participation by disabled people and opportunities for them to shape policies and practice that affect them.

I have written here previously about my son, Louis Sainsbury, (PMLD LINK, 2024 Vol 36 No 1, Issue 107), who was detained in hospital as care of last resort and now lives well in his own home, with full-time professional care and family support. Louis’ home is called Appletree Community, acknowledging and naming the importance of wider social networks for everybody.

Louis is a generous man, who loves offering hospitality. It seemed right to me to tell his and our story as a formal research project to help others. Louis is our named Lead Researcher as we all learn from him. Our research team was Aaron Pycroft, Karl Nunkoosing, University of Portsmouth; Michael Wamposzyc, Imogen Grieve, Leo Philp, Sam Abdulla, Natasha Spassiani, University of Edinburgh Napier; Maureen Phillip, Director of Creative Arts and Storytelling at PAMIS; and myself, Louis’ mother. The research, ‘Louis’s Story: the story of Appletree’, can be seen here: www.theaitealtrust.com/research

On 27th February 2025, Louis presented this research at a Reception at Scottish Parliament, sponsored by Jackie Baillie, MSP, called ‘Coming Home: a Community for One’. Louis’ physical presence is his participation. Our research was shown on visual panels, using the metaphor of a river which is at the heart of our KAWA storytelling method (https://www.kawamodel.com/v1/tag/kawa-model). There were also printed, folded leaflets for guests to take away and video loops of life in Appletree Community, photographed by carers, family and Louis himself.

Louis’ presence is key. ‘Nothing about us, without us’ as the slogan goes. It fulfils Louis’ right under Article 8 of the United Nations Convention on the Rights of Persons with

(L-R: Charlie Macmillan, former Chief Executive, Scottish Commission for people with Learning disabilities, Louis, Jan Savage Chief Executive Scottish Commission for Human Rights, Kate Sainsbury, Professor Angela O’Hagan, Chair SCHR, Cathy Asante, SCHR, Report Author)

Disabilities (UNCRPD) to contribute and be seen contributing to society. It manifests values of inclusion, equality, fun, mutual respect and participation at the heart of the Convention and fulfils Article 19, Louis' right to live in community.

We prepared thoroughly by making two visits to the Scottish Parliament, met with key figures, familiarised ourselves with security procedures and, with the Changing Places toilet. From these visits we adapted timings to work for Louis.

Louis had recently attended the launch of a report on Deinstitutionalisation by the Scottish Commission for Human Rights: (https://www.scottishhumanrights.com/media/2947/designversion-execsummary-spotlights-deinstitutionalisation-2025.pdf). His lived experience of detention informed this report and his presence at the launch made a reality of theoretical Human Rights materials. Louis led the room singing 'Happy Birthday' to another guest at this launch.

Louis shows in life and in our research, that it is possible to live life well, that 'nobody is too difficult to care for'. He demonstrates that Love - gentle, low-arousal, informed care, with personalised communication aids (like Social Stories, 'Now and next' cards, Makaton signs), with trust and understanding, meaningful activities and routines, wider community support - is the answer to meeting complex needs, rather than detention and restraint, currently practised against hundreds of people with learning disabilities.

Louis getting used to the Burns Room, Scottish Parliament, where the Reception was held in February 2025

Louis was keen to get into Scottish Parliament

Louis in a breakaway office in the Scottish Parliament

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REPORT BACK

The 1st of PMLD LINK's Webinar series

PMLD LINK held our first live Webinar in February. As a new initiative, which we aim to continue, this Webinar followed on from the publication of the Winter Journal, with the theme of 'Current Issues.' The aim was to bring to life a small selection of the articles within that latest issue.

Contributors to this first webinar were Maureen Phillip (from Pamis), Taylor Anderson and Sharon Clark (from CBF), Ellie Griffiths and Flossie Waite (from Oily Cart) - each of the short presentations was based on their journal articles in the Winter journal.

It was lovely to both gain a lot of interest and attendance in the Webinar and great feedback about the presentations themselves.

A recording of the Webinar is freely available on PMLD LINK's new YouTube Channel, @PMLD_LINK. Please watch and listen (and LIKE) to these inspirational speakers, at your leisure. While there please subscribe to our channel, make others aware and look out for upcoming webinars. We hope this is just the first of many!

What Matters to Me launch their project materials

The Challenging Behaviour Foundation (CBF) are close to completing their three-year What Matters to Me project. This work has engaged directly with 11 young people with severe or profound and multiple learning disabilities, alongside working closely with their families and their familiar circles of support.

The project aim was to recognise and acknowledge the unique experiences, preferences and views shown by these young people as they transition into adult services and to then use their views to influence important policy change within the sector.

In two launch events the CBF shared their project methodology and findings through a number of valuable resources. These include an interactive manifesto, a framework for intervention and a still developing toolkit that includes a series of videos to support these approaches. One launch was a prestigious in person event, held in the Parliament building at Westminster and included many of the young people involved in the project in attendance. The second event was a webinar giving an overview of the whole project approach. The very large audience in attendance at this webinar highlighted the great level of interest in this important area for people with severe or profound and multiple learning disabilities.

PMLD LINK has featured two articles about the progress of this 3 year project in recent journals and we hope to share more details of the resources and practical toolkit in a forthcoming issue.

Information about the project and these resources can be found on the Challenging Behaviour Foundation website: https://www.challengingbehaviour.org.uk/what-we-do/projects-and-research/what-matters-to-me/

Rix Centre host Ethics webinar

Ethical issues in sharing online images with people with profound and multiple learning disabilities: consent, awareness and representation.

Social media is now a primary channel for chat, information sharing and marketing – and its use is advancing and changing with the introduction of AI (artificial intelligence) faster than we can track it. There is a wide diversity of practice in the sharing of online information that features people who have severe or profound and multiple learning disabilities. Whereas some prioritise protection of vulnerable individuals who cannot understand the implications of online sharing, others feel passionately that restricting access means that this group will continue to be invisible, and their rights to representation compromised.

We wanted to bring these debates into the open, identify good questions to ask, and lay the foundations for some practical guidelines – and we think we succeeded in meeting our aims. Over 130 people signed up to hear from our keynote speaker, Professor Màire Messenger Davies, and a panel made up of families, professionals, and researchers.

Professor Davies provided a fresh perspective from her research on broadcast media, press regulation and on the views of young children on their participation. The panel presentations provided food for thought in sharing values, practice and challenges. The views of one (more able) teenager on her feelings about social media, were represented through the skilled use of a Talking Mat.

This webinar was only the starting point – we will be writing a paper and sharing some further thoughts for collaborative action. We look forward to more stimulating debates in the future.

You can view a recording of the Ethics webinar video :https://vimeo.com/1064315046

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In the Next Issue: Communities

Our summer issue is all about Communities. Community means many things to many people, and it resonates differently for every individual. It can evolve over time and is diverse in its meaning. For some people community is defined geographically where people live in the same region, town or neighbourhood. In this type of community there is a sense of connection through a common history, where shared experiences such as local events and neighbourhood safety often bring people together.

Community can also embody a sense of belonging through an opportunity for shared interest or purpose and mutual support. It offers a context for shared identity or experience, ethnicity or religion.

Digital communities today offer opportunities to connect with people across geographical regions and in fact across the world, regardless of physical location. The digital age has its pitfalls and problems but for those communities who are ill or isolated and who can’t physically get together, the online community offers inclusion, friendship, opportunities to share knowledge, create music and art and connect with others.

People with profound and multiple learning disabilities (PMLD) are often said to exist on the margins of society and not always included in their communities. A healthy society is one that embraces a diverse tapestry of community that fosters inclusion and where everyone feels they belong.

We would love to hear your experiences of community and what communities mean to you through your articles and personal stories. We also welcome shorter items in different formats, including photo stories or even single images with captions. Hopefully, this broad theme inspires you to contribute to our Summer journal.

Send all contributions including items of news, reviews or relevant resources and events to info@pmldlink.org.uk by 16th June.

As always, the PMLD LINK’s team are happy to help at any stage – just get in touch.

Guest editors for this Summer issue: Maureen Philip, Bella Travis and Annie Fergusson

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

Family carers involvement in a new resource for GPs

The two year Tired of Spinning Plates project set about to explore and better understand the mental health experiences of family carers of adults with learning disabilities, by listening to their stories and reflections on their lived experiences. Family carers of this population were identified pre-pandemic as making up to nearly a quarter of the 9 million family carers in the UK.

Doing Better in Health Care

Supporting Family Carers of People with Learning Disabilities

University of Sheffield
Manchester Metropolitan University
Sibs
Queen's
NIHR | National Institute for Health and Care Research

Learning from this research led to a number of co-produced outcomes, including information for family carers and for people with learning disabilities, as well as teaching and learning materials for the many professionals who are involved in the lives of this group of family carers. One example is this resource for GPs, available from : https://socialcaretalk.org/wp-content/uploads/2024/11/GP-RESOURCE-Tired-of-Spinning-Plates.pdf

Many of the family carers involved in thE project shared their reflections in creative ways through film, words and artwork. These can be viewed at: https://sites.google.com/sheffield.ac.uk/tired-of-spinning-plates/films

This NIHR project was led by Katherine Runswick-Cole from the University of Sheffield and Sara Ryan from Manchester Metropolitan University. It was also supported by Sibs Charity UK (a charity supporting brothers and sisters of disabled children and adults), and RosaSenCis film production company.

How We Survive and Thrive: The People with Learning Disabilities Pandemic Inquiry

People with learning disabilities experienced the greatest impact of the Covid-19 pandemic. Despite it being well known this group already experience great health inequalities, they were just not acknowledged or prioritised and many people died as a consequence. Five years on, its important we learn from this experience to ensure whenever a future pandemic or national emergency arises, we are well prepared to not only safeguard the lives of people with learning disabilities, but to enable them to do well or have the best possible outcomes in such challenging circumstances.

This new inquiry intends to identify the important learning from the recent pandemic by listening to the voices of people with lived experienced, their families and those directly involved in their care and support. This project aims to ensure the views and experiences of those too often marginalised are heard and valued- people with profound and multiple learning disabilities and those from minoritised ethnic groups.

The Inquiry is being led by Andrew Lee and Dame Phillipa Russell, supported by 10 Commissioners working on the project. There are 6 Commissioners with a learning disability and 4 commissioners representing families, where 2 of those represent a person with profound and multiple learning disabilities. The Inquiry is also supported by Academics from Manchester Metropolitan University and the University of Birmingham.

Co-chairs and Commissioners
Despite the early stages of this project, key topics of focus have already been identified for this inquiry:

- Voice and Decisions Making
- Health and Mental Health
- Social Care
- Housing
- Having Purpose
- Communication, Information and Digital

Some thoughts from the project team
“I hope this Commission will ensure that we have learned hard lessons and can coproduce a better future.” – Philippa Russell, Co-Chair
This work is important because during the pandemic and lockdowns, people with learning disabilities had a terrible experience and it is important that we learn from what

has happened to get it right in case it happens again. – Mark Brookes, Commissioner

I feel during the pandemic people with learning disabilities and their families were not represented and valued, so being a commissioner I am hoping to use my life experience and skills to make a difference in the future. – Fiona Walker, Commissioner

The voices of people with learning disabilities must be at the heart of this commission as no planning for future pandemics should be done without them. This commission gives us the opportunity to reach people who may not always take part in giving evidence which will influence policy. It is important that this work does that and will hear from many people whose lived experiences will support our recommendations. This is an opportunity for us to influence policy makers. – Ramandeep Kaur , Commissioner

Based on people's real experience, the Commission is a powerful way to come up with recommendations that would make a real difference and which command support.- Jonathan Senker, Commissioner

Visit the project website for more information and details of how you can get involved and see updates as the project progresses: https://www.learningdisabilityengland.org.uk/prepared-to-thrive-learning-for-pandemic-readiness-for-people-with-learning-disabilities/

Co-production in research – A toolkit for research with family carers of people with a Learning Disability

A new toolkit has been launched which may be of interest to Allied Health Professionals who are undertaking research and are interested in co-production with family carers and other people with lived experience.

Our project
The Co-Production in Research project ran for much of 2024. Its aim to produce guidance to support researchers to involve family carers of people with learning disabilities in their research in a meaningful way.

The Co Production in Research Team was made up of 7 researchers and 8 family carers. The meetings were co-chaired by the lead researcher and the CEO of The Challenging Behaviour Foundation both of whom are family carers of people with a learning disability. All those involved had experience of being involved in co production projects. I believe that having professionals with lived experience chairing the meetings and leading the project added an extra layer of authenticity to the project.

What is co-production?
Co production, which is a type of Patient and Public Involvement and Engagement (PPIE), emphasises power sharing between the researchers and the family carers. This is more than simply asking family carers to advise on a project or part of a project. The group came up with an initial definition of co-production:

'We define co production in research as relevant stakeholders (e.g. family carers/commissioners) working as equal partners with researchers, at the earliest stages of a project, to share their lived experience. This ensures research is shaped round real-world experience and can make a positive difference to the lives of people with a learning disability and their families, for example through changes to services and support."

7 Golden Rules of Co-production
The team met as a whole and then split into working groups resulting in the 7 Golden Rules of Co-production.

1. Work together as Peers. Working together in equal partnership involves recognising and valuing the many different skills and perspectives that family

carers and others can bring.

2. Make it meaningful. Meaningful co production values family carer input from the start to the end (and beyond). It Is not just a tick box exercise.
3. Listen and keep an open mind. An open and transparent approach builds positive relationships across the team and ensures meaningful contributions.
4. Communicate clearly. Use plain and accessible language. A clear remit and expectations of family carers ensures you get people with relevant experience/characteristics for the project. Be clear about the aim of your research and how this will contribute to improving families lives.
5. Pay appropriately. Ensure that family carers are suitably compensated for their time and expertise.
6. Be sensitive. Consider the wellbeing of family carers who contribute their lived experience throughout the research process. Sharing on sensitive topics can bring up a variety of emotions and it is important that everybody feels supported.

Be flexible to support family carers needs. Think creatively and be prepared to work in different ways to avoid some of the barriers families face.

The Toolkits.
As a group we produced a toolkit for researchers guidance for family carers.

The guidance is available here: https://shorturl.at/ZAsbo coproducing research along with further information about the project. The toolkit for researchers describes the reasonable adjustments that family carers need, ensuring family carers are valued and able to contribute. It explains why co production is worth the time and investment.

The guidance for family carers aims to support family carers who might be asked to take part in research, to empower them with the knowledge of what good co-production looks like, and hopefully, the confidence to ask for it. Although the toolkit was designed for research with family carers of people with a learning disability, it has valuable insights, suggestions and recommendations for researchers wanting to work with people with lived experience, for anyone who is interested in co-production, and for anyone working with families who have a loved one with a learning disability.

Why is this necessary?
Family carers of people with a learning disability report many challenges navigating the disjointed health, social care and education systems in the UK and beyond. As a family carer, a Chartered Physiotherapist and now Lived Experience Manager for an ICB I know first-hand how different our experiences can be.
I have experienced parent blame and gaslighting from simply advocating for my daughter's rights and quality of life. Family carers are creative- we must be, we are insightful, and many of us work within systems and services and can see where and how improvements can be made, where things work, and where and why things fail. This knowledge if gathered and used in the right way can be transformational for researchers and services alike.

I believe that the toolkits can provide useful insights for clinicians whose work involves liaising and consulting with family carers. My daughter has support from many professionals across health, social care and education. The outcome for her is always best when we work together in partnership, when my input is valued in an equal way. Sadly, this is not always the case. The golden rules listed above, and expanded in the toolkit, provide researchers and clinicians alike with insights into the needs, experiences and perspectives of family carers.

Feedback
We gathered feedback from family carers involved in the project, some of which are outlined here:

Knowing that my insights as a parent carer researcher are being heard has empowered me and highlighted the importance of our collective voices.

As parent carers, we often inhabit a world where we don't have a lot of control, we don't have a lot of say, we're typically referred to as 'Mum' or 'Dad' regularly by people who aren't our children, and actually you can really feel a sense of a loss of identity. It's not what happens for everyone, but I know that it happens frequently. And so, to actually be involved in something where you're being really listened to intently, it's not tokenistic, and what you say can make real change, can just feel hugely, hugely empowering.

It's just amazing to be able to use that really hard-won experience to actually make change happen. So, to be able to sit in these meetings and see things shift because of what we say, and know it's not tokenistic, it's not tick box, we're respected as equals, is hugely empowering, actually. And interestingly, from a mental health point of view has a really positive impact on my mental wellbeing.

Funding
The project was funded by the University of Warwick Participatory Research Fund and led by the Centre for Research in Intellectual and Developmental Disabilities CIDD. The Tizard Centre University of Kent and The Challenging Behaviour Foundation were co applicants.

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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:

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

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