

# PMLD LINK

sharing ideas and information

Research

Summer 2023



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# GUEST EDITORIAL

## Research

Welcome to the Summer 2023 issue of PMLD Link Journal. Many thanks to everyone who has contributed articles. The focus of this issue is 'Research' and it is fitting to be able to share a wide variety of articles with you on this broad topic.

We are starting the issue off with an opinion piece. Helen Edgar shares her reflections on labels, the use of the word 'profound', and her experience of working with children with profound and multiple learning disabilities over many years during her teaching career. We think a focus on people is a good beginning to an issue about research – a reminder to consider how research can be applied to real lives.

In the journal, we have two 'report back' pieces: a summary of the IASSID PIMD special interest research group conference and a summary of research highlights relating to people with PMLD from the Nordic Network of Disability Research (NNDR) conference. Many thanks to Julia Barnes and Rosie Rushton, and Elspeth Clark for reporting back and giving us an update on current research topics along with insights into the presentations and rich discussions.

In addition to these reviews, this issue includes several articles written by some of the researchers who presented at the conferences, giving us a valuable opportunity to find out more about their work. These include: an article from researchers from The Covid-19 and people with learning disabilities study, sharing the findings in relation to people with PMLD from the latest phase of the study; Maren Hueffman's article on Personhood at the margins of society; and Catherine de Haas' piece on Using lived experience in research.

Elsewhere in this Issue, we have thoughtful pieces focusing on the themes of belonging and identity, engaging and communicating, personalised learning in schools, and parental perspectives of research. We also have a lovely article - and fantastic photos - from Gwyn McCormack, sharing her inclusive literacy model developed from her own evidence-based practice, 'Marvin's story time show'.

We hope you enjoy this Summer Issue.

It is definitely too soon to be thinking about Winter...but do have a look at the focus for our Winter journal on page 39 and let us know if you would like to contribute!

Guest Editors:

Bella Travis, Maureen Phillip, Annie Fergusson and Rachel Hughes

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# 'Profound' in relation to those with PMLD / PIMD - an opinion piece

Helen Edgar

The International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) has a Special Interest Research Group focusing on individuals who have profound intellectual and multiple disabilities (PIMD), an international description. IASSIDD define this group of people by saying that 'they are characterized by very severe cognitive, neuromotor and/or sensory disabilities, which lead to very intensive support needs'. From my experience as a class teacher working with children who have PIMD for almost twenty years, it is important to note that these terms are not a diagnosis, and they are not a description of a person.

## **PIMD / PMLD**

The word profound is used to describe the deep and complex needs these individuals have. An abbreviation of four letters does not reflect the amazing individual children I have been privileged to have worked with and developed relationships with over my teaching career. However, on setting up my new website and blog 'Autistic realms', I began to question how appropriate these terms 'Profound and Multiple Learning Disabilities (PMLD)' and 'PIMD' were, especially as I was making a conscious effort with my own family to move away from deficit-based language to advocate for my neurodivergent family.

## **Language**

Following discussions with Joanna Grace (The Sensory Projects) regarding the language used for children described as having PMLD or sometimes also described as having PIMD, I reflected over my teaching career. We consistently used the term PMLD within the school setting I worked in, however, on reflection, I now feel PIMD to more accurately reflect the complexities these children have beyond learning disabilities. I feel PIMD moves beyond the focus of learning needs that is implied by PMLD; it reinforces the profound aspect of the multiple difficulties and disabilities these individuals have across ALL areas of their life due to their profound intellectual and multiple disabilities and complex health needs.

This is a group of individuals who are severely disabled but are often further disabled by the barriers that are in the environment and our society. Their profoundly complex needs affect every aspect of their lives, they are fully dependent upon others to access the world and have their needs met. To have a life that is as rich and as meaningful as possible, it is the responsibility of those that are caring for them to take the time to gain a deep understanding of them as unique individuals, to support them to access and experience the world in their own way.

## **Relationships**

It is through the relationships those with PIMD have with the key people who are in their lives that meaningful connections can be made. It is the responsibility of the people that are with those who have PIMD to provide opportunities beyond just meeting care needs; these individuals need and deserve to experience a rich sensory environment that will support their mental health and give their lives quality and enrichment. It is essential to take the time to develop meaningful relationships, so moments of connection can be created that can really give meaning to their lives.

This connection can only happen if the space between you is led by those with PIMD in their own way and in their own time. It is the responsibility of those who are working with the person who has PIMD to work collaboratively with their families and other multiagency professionals to understand their needs and also personalities. You will then be able to gain a greater understanding of not only their health and care needs, but you will learn the unique ways they communicate, their likes and their responses to their sensory world through their vocalisations and body movements, you will be able to develop this further to help enrich their lives.

## **Sensory Beings**

I attended Joanna Grace's 'Sensory Lexiconary' course a few years ago. Throughout that course Joanna Grace referred to those children with profound intellectual and multiple difficulties as 'sensory beings'. I loved this term and I resonated with the idea that for the children she was talking about (my own class of children with PIMD) the sensory system was their main way of accessing the world. The concepts of 'Sensory-being: the enveloping of natural presentness and awareness in an unfolding sensory moment,' and then; 'Sensory Beings: people whose experience of the world, and meaning within it, is primarily sensory. Often these are the people who do



not have access to language' (Grace, 2018). The sensory world is how communication can be enhanced and developed and a means to create connections with the world and others.

### **Sensory world IS their world**

**H**owever, as an autistic person, I am personally aware that I also deeply feel the need for a sensory connection and that for everyone to have a good quality of life we need to have a regulated sensory system. Everyone needs to balance various sensory input throughout the day to meet their needs and so they can function and have a good quality of life. In essence 'we are all sensory beings'. We are all sensory beings regardless of our intellect, disability or difference of neurotype. The difference being for those with PIMD is that it can be viewed that the sensory world IS their world, and they need people in their lives that understand this and can support them to access and experience it with them.

### **Identity and language**

**I** empathise with the reasons why Grace (2018) wanted to find a term more positive than 'PMLD / PIMD' for these individuals that are already so severely marginalised and are the most vulnerable group in our schools and society. The term 'sensory beings' sounds positive and encapsulates a wonderful thought process into a world that is not full of medical deficit; it captures the spirit of what I was trying to create in my classroom with the children. In much the same way this is how the neurodivergent movement has been advocating away from the medical deficit model and campaigning for people to use identify first language (e.g. autistic person rather than person with autism). Lynch (2019) wrote in the online journal, Neuroclastic, 'Individuals with disabilities are more than their diagnosis. They are people first.'

I am currently trying hard to support the neurodivergent movement and I am tentatively becoming an active member of various online communities, trying to get a balance of knowledge between what is described as the 'Actually Autistic' community (made up of autistic adults diagnosed or self-identifying) and other neurodiverse education and parent led communities. We need to move away from the medical deficit model of disability and move towards a more person-centred social approach where people are treated as individuals.

It is the environment and the relationships with those around us that determine the extent disability impacts people and we need to do much more to make the world more accessible for everyone (Beardon, 2017). I am aware I have a lot more reading to do around the various other models of disability that I have not mentioned here. I believe 'sensory beings' was a step in the right

direction for these children. However, within the specialised setting I worked, all our classes were focused on meeting the sensory needs of all the children in the school. As in many specialised settings, our whole curriculum was multisensory and personalised for every single child, however, not all class groups had children that could be classed as having PIMD.

### **Importance of the word 'profound'**

**P**MMLD or PIMD are not ideal terms, but they are all we have for now. They describe the highly complex needs these children have across every single area of their life. They are the highest needs group in our society and they need high levels of support every day and night of their lives. Any word less than 'profound' would feel almost disrespectful; to use a word with less weight than 'profound' would not feel 'right' to me. I was recently reminded that it was Emma Murphy, (who has a son that she describes as having PMLD and who attended one of Joanna Grace's sensory teacher training courses with me many years ago) that prompted some of my initial thoughts around the use of the word 'profound'. She is quoted as saying "anything less (than the word profound) almost belittles the challenges he faces" ([www.littlemamamurphy.co.uk/](http://www.littlemamamurphy.co.uk/)).

### **Reflection on teaching those with PIMD**

**W**hen asked about my career I have always said 'I worked with children who have profound and multiple learning disabilities and complex health needs'. I often add the word complex to try and emphasize the extent their disabilities and difficulties impact their lives. I have always had difficulty finding the right words that I feel truly represent those I worked with and got to know. Which is what led me to writing this article when setting up my website.

I have always taken the time to describe the individual children in my class and to describe the sessions, interactions, and time we spent together, not because they had PIMD but because of the wonderful experiences we shared together. It is through these relationships I have created memories that I will treasure forever. There are no words or language that can describe the moments of connection created between us, moments that were made in their own time and in their own way. No training or qualification or any number of textbooks about teaching, education, medical conditions, or disabilities can ever teach you how to create these connections; they evolve through developing a relationship, spending shared time together and a willingness to be open and join them in their own space (with lots of sensory exploration and fun along the way!). Regardless of the language used and the multiple labels and diagnoses these children have, I looked forward to being with them every day. I feel privileged to have had the opportunity to work with such amazing children and

to have been able to learn from their families and my class teams and other professionals along the way. I grew to understand and learn from all the children I worked with, they have become a massive and important part of my life and have taught me infinitely more than I could have ever anticipated when I began my teacher training around 20 years ago. My career has provided me with the opportunity to learn what I consider to be the true value of teaching, interaction, and communication.

### Connection not words

The terms PMLD and PIMD are based on deficit language, but the people they are describing are not deficit-based individuals, a word less than profound is not enough to describe the depth of their needs and difficulties. For these children with the most complex, profound intellectual and multiple disabilities there was never a need for any words between us at all, there was just a deep understanding and a connection between us as two individuals (and lots of sensory play!).

This article is an adaptation of a blog Helen previously published on her website in November 2022  
<https://www.autisticrealms.com/post/a-reflection-on-the-use-of-the-word-profound-in-relation-to-those-with-pmld-pimd>

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Helen developed the Autistic Realms website to advocate for a better understanding of neurodivergence and mental health in education. Autistic Realms is a space for parent support and teacher guidance. It is not a business or a charity.  
<https://www.autisticrealms.com>

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# Exploring belonging through arts-based practice

Jill Goodwin, Melanie Nind, Laura Dunne, Zoë Howe, Kerry Martin, Chris Mellor and Asha Ward

Despite all the positive developments in disability rights, legislation, attitudes and practices over the last fifty years, there remains a ‘hierarchy of disability’ (Reinders, 2008, p.26) that consigns people with intellectual (learning) disability to its lower ranks, and people with profound intellectual disability to its lowest of all. For those who can self-advocate, some rights and independence have been legitimately claimed, but self-advocacy is not readily available for all. Nonetheless, it is important that we explore ways in which people with profound intellectual disabilities can belong in self-advocacy groups.

In this article we discuss some of the challenges and successes of a small UK project that sought to explore the potential of arts-based activities to bring people with profound intellectual disabilities together with learning disabled self-advocates. The project was inspired by the provocation of a parent who felt excluded from the self-advocacy movement because her daughter needed others to speak up on her behalf, and by a self-advocacy organisation being keen to do more to include people with profound and multiple learning disabilities. People First Dorset (PFD) are founding members of SPIRIT – the Southampton Platform for Inclusive Research and Ideas Together – and work regularly with Melanie Nind and Andrew Power at the University of Southampton on research that matters to members.

## Background

In the book, *Belonging for People with Profound Intellectual and Multiple Disabilities – Pushing the Boundaries of Inclusion* (Nind & Strnadová (Eds.), 2020), Palmer & Walmsley argue that there ‘has to be another basis for including people than the ability to speak up for yourself’ (p.131). Palmer questions whether people with profound and multiple learning disabilities are welcome in the wider learning disability community:

As the mother of a daughter with PMLD I find so many of the conversations and ideas do not include us. Elinor cannot “speak up” for her needs and wishes, as the self-advocacy movement promotes and encourages. She needs other people, who understand her, have the commitment and skills to work with her, to advocate for her. (Palmer & Walmsley, 2020. p.129)

This comment was an important call for action that impelled Melanie Nind and PFD to discuss working together to explore ways to address the problem. PFD operations manager, Laura Dunne, was only too aware of

the issue, recognising that historically, as an organisation, PFD has always found it very challenging to meaningfully engage with people with profound and multiple learning disabilities and often find it is very hard to forge links.

Funded by the University of Southampton’s ‘Public Engagement with Research Unit’, together they devised a pilot project to explore the potential of an arts-based approach for bringing people together. PFD wanted to build a sense of belonging for people with profound intellectual and multiple disabilities within their organisation by bringing people together in interactive activities that did not rely on spoken language. Artists/researchers Jill Goodwin and Asha Ward were tasked with planning three exploratory sessions, and adapting and developing them in response to the feedback and reflections of the wider group. PFD self-advocates/staff, Kerry Martin and Chris Mellor, together with Zoë Howe and Laura Dunne, took part in the planning meetings as well as the sessions themselves. A steering group, comprising researchers Joanna Grace, Catherine de Haas, and Jo Hope gave input to discussions along the way. After getting NHS Research Ethics Committee approval, we teamed up with two local day centres for people with PMLD and, accepting the practical limitations on getting around which were still exacerbated by the pandemic era, decided to gather in one of the day centres rather than bring everyone into a community venue or PFD premises.

We had a shared purpose and aims to:

1. Explore the potential of arts-based activities as a foundation for friendships and self-advocacy work that includes people with profound learning disabilities.
2. Continuously reflect on and address the challenges of engaging people with profound learning disabilities in self-advocacy and in research.

3. Identify or develop an evaluation approach that is sufficiently sensitive and nuanced to understand what is going on, how people feel about it, what they gain, what they do differently, and what difference this makes.

In this article we focus on the first two aims and on our research question: How can we use arts-based approaches to engage a sector of the public that is very rarely enabled to belong in self-advocacy or research?

### The Sessions

In planning each session, we thought hard about how we might foster positive connections within the group, which meant finding ways to be together that would encourage shared exploration and fun without the need for words. We chose to offer 'large materials', such as big rolls of paper and card, plastic dust sheets and thick cardboard tubes, to encourage whole body engagement and interaction between participants for our first session; sound-based activities, to encourage listening and playing with sounds and vocalisations for our second; and game/play-based activities for our third. It felt important that the room where the sessions took place didn't feel too known and familiar because we wanted to encourage new ways of being together in the space. For each session we cleared the existing furniture and hid it behind a convoluted wall of corrugated cardboard, creating a calm but transformed open space.

We share here a selection of photographs from the sessions.



Exploring music making apps



Creating a sense of group



The unfamiliar space



Interacting through the materials

### Reflections

Our joint critical reflection (Zoom meetings and written or recorded reflections shared onto Padlet platform) highlighted some successes in our shared purpose of engaging without the need for spoken language and also identified many unresolved challenges. For example, there were differing views about the value of directed/undirected activity. While some of the team felt happy with the (deliberate) lack of direction in the first session, others were less comfortable with it:

*"It felt quite strange at the beginning going into a room with no instructions. I think other people found this hard too."* (Chris, PFD)

*"It was interesting there was no structure, but it made it uncomfortable for people, I think."* (Kerry, PFD)

And after the second session, which ended with a more directed activity, Jill commented:

*"I was aware that the second part of the session was popular for many, but for me it was very language-based (something we wanted to avoid) and too directed."* (Jill, artist)



While for Chris and Kerry the direction was welcome:

*"I think this session went really well, I found it more engaging than the last one."* (Chris, PFD)

*"I think it was more successful in getting people involved than the last session, but it still felt very difficult to try and know how to involve people."* (Kerry, PFD)

If we had more time, we would have explored this aspect of the delivery further to achieve a balance of both directed/undirected and known/unknown activity.

Another (inevitable) issue was that this short project did not allow the necessary time to get to know participants whose means of communication was non-verbal. We often found ourselves feeling uncertain about whether they were enjoying an experience or not.

*"I found it difficult to try and interact with the people who couldn't talk."* (Chris, PFD)

*"I tried to be with the 3 men in wheelchairs but because I don't know them I was kind of waiting for a bit more instruction from the staff to know how to communicate with them."* (Kerry, PFD)

*"We were all awkward about not knowing people's ways to say no or stop – working without information about people is hard."* (Melanie, UoS)

At times, the support staff seemed to hold back, possibly unsure of what was expected of them, and with hindsight we could see that we hadn't factored in the importance of bringing them on board with the aims and workings of the project. Having said this, there were moments when we witnessed interaction, fun and connection between individuals (as can be seen in some of the photos). We also noticed that over the course of three sessions people from PFD became less reliant on usual verbal introductions and were more comfortable to use the materials as a vehicle to initiate an interaction. With time, and a cumulative bank of joint experiences, we could see the potential was there for more sharing and connection.

This short project was rich in learning, although the limited time period did not allow for full exploration of the questions it generated. People seemed to leave the sessions feeling good, and some of the materials and activities supported novel experiences. The day centre staff were willing, and PFD have seen some potential ideas and resources they can use to increase inclusivity in their organisation in the future.

Our field notes include the observation:

As things wind down I ask staff what they thought and hear 'That was the best afternoon we've had in a while' and 'It was like Intensive Interaction on a grand scale'. I tell Matt we wanted to find out if the materials could facilitate points of connection between us. This seems to him a daft a question as he comments 'of course they can' and 'we saw that', followed by 'anything can facilitate'. (Melanie)

It was frustrating to have only dipped our toe into an area that deserves sustained effort to develop new ways of coming together on a more equal footing, but we have each taken away some valuable insights (along with more questions) for the future, and we understand a bit more about how we can use arts-based approaches to engage people with PMLD who are rarely enabled to belong in self-advocacy or research.

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# Identity and Belonging for people with profound intellectual and multiple disabilities

Jo Grace

I am currently studying for a PhD in Identity and Belonging for People with Profound Intellectual and Multiple Disabilities. I am supervised by Dr Jo Hope and Professor Melanie Nind at the University of Southampton and have the privilege of having my studies funded through the Economic and Social Research Council (ESRC) via the South Coast Doctoral Training Partnership. Combining studying with running The Sensory Projects and bringing up my two little boys is tough, but it's such a gorgeous topic it is hard not to be carried away by it. However, it is also a very confusing topic. In just reading this first paragraph you may already have had some ideas about identity in relation to people with profound and multiple learning disabilities. Perhaps you thought "Well of course they have an identity!" Or did you think "Of course they have identities" (Is it a singular thing or a plural thing?). Maybe you thought "It's not possible for someone with a profound intellectual disability to have an identity" (or indeed identities).

As I imagine is the case for many a PhD student I started out quite certain about what my own views on the topic were: people – all people – are born with an innate identity, an essence of themselves as it were, which you see expressed through the things that they do and in their interactions with people and the world around them. Surely that much is obvious thought I; no one in their right mind would disagree. Oh but they do, and they are very much in their right mind. "You have Identity muddled up with Character, Jo" they told me, or "You're thinking about the Self, not Identity". Identity, they said, is a constructed thing, created between people. And then there are similar splits as with the identity/identities with some people believing this construction takes place through the use of language and other people pointing more to institutional structures and experiences of power.

Doing the PhD is in many ways like an amplified version of running The Sensory Projects. Since starting the Projects over a decade ago I have always read what research I could lay my hands on that relates to the work I do, and I have listened to people's experiences. I am doing that still, only being a student at the university enables me to lay my hands on so much more research than ever before, and when I listen to people I am tuned in for particular things, or I am actively asking probing questions trying to get to the bottom of this.

You might think that amongst the family members and friends of people with profound and multiple learning disabilities that there would be some consensus as to how identity relates to their loved ones, but we are just as disparate in our views. Linderman (2014, p.8) says of her sister who had hydrocephaly, that her family 'gave her all the identity she [her sister] had'. In contrast,



Esther Veale, who recently presented at The PMLD Conference and who has appeared in PMLD Link, told me of her sister Mary who had profound and multiple learning disabilities, that she and her family got to see Mary's identity more and more through the experiences Mary engaged in. (Mary was famously an adventurer and after her death Esther's family set up the Mary's

Beat fund to enable people with profound and multiple learning disabilities in the southwest to have adventures like Mary did. Happily, The PMLD Conference was able to make a donation to this fund). Esther spoke about Mary's identity both being revealed and growing through these experiences. Is identity something that increases and decreases?

When exploring the relationship between identity and people with profound and multiple learning disabilities it is not just the people themselves that others comment on. Listening to The Skies We're Under Podcast (which if you have not yet, you simply must!) you can hear Rachel Wright describing how she felt a loss of her own sense of identity as she entered the world of advocating for and defending her son in a medical context. In contrast to this, Heather Bailey who has also recently appeared at The PMLD Conference told me in relation to her daughter, "She is my identity". How can someone else be the source of your identity? But in exploring the field of dementia research for nuggets that might be useful to my work, I came across Hydén (2021) reporting work that shows that couples who have lived together for a long time have a shared sense of self, and as one loses the ability to articulate that as their capacities are stolen from them by the progression of dementia, the other is able to uphold their shared identity on behalf of both of them.

I am fortunate not to be studying alone, alongside me is Catherine de Haas – who has also been a regular between these pages, and whose daughter Johanna, readers in education may know her through her collaboration with Flo Longhorn on the Spirituality of people with profound and multiple learning disabilities. Early on in my studies I was asked to give a presentation to a room full of far more senior academics than I. I worried about what to say, and then had an 'ah ha' moment: I would not tell them anything, instead I would use the opportunity to be in front of the concentration of so many brilliant minds to ask them things instead! I asked a list of questions about identity that lasted for about five minutes. I have a lot of questions about identity! Somewhere towards the top of my list was the simple question: "Who are you?" Many thinkers think that your identity is the answer to this question. As I asked it I heard a somewhat frustrated Catherine mutter "but I don't know who you're asking me about". I stopped to talk to her afterwards to try and understand why my questions had been frustrating. She explained "I did not know if you wanted me to answer as me or Johanna".

No one else in that room had any doubt who the question "Who are you?" referred to, but as the only person in that room who was the parent of someone with profound and multiple learning disabilities the question for Catherine had not been so simple.

The field of identity began way back when, in the realm of the hard sciences and mathematics, if we are to count 1, 2, 3 then it is important for us to know where one thing ends and the next begins; it is important to be able to pin down precisely what a thing is; what its identity is. Leibniz defined identity as  $X=X$ . Years later Bertrand Russell joked that no one outside of a logic text book would ever need to say anything so obvious. To give an example, if the King of Spain is Maria's daughter, then Maria's daughter is the king of Spain. (Whether that elucidates things for you or just perplexes you more I cannot say). Centuries on from there, those same hard sciences, once so keen to establish the separateness of one thing from another, now admit of something they call "fuzzy boundaried identities". They know there is a thing there and another thing there, but they're not separate, but they also could not be said to be one. Catherine lives the fuzzy boundaried identity she shared with Johanna.

There is a Bantu word: ubuntu, which can be translated to mean: I am who I am because we are. Ubuntu strikes me as a good description for the fuzzy boundaried identities experienced by the loved ones of people with profound intellectual and multiple disabilities. Winnicott (1964, p.88) said "there's no such thing as a baby", indicating that whenever we think of a baby we also think of the person holding and caring for the baby. In the same way there is no such thing as a person with profound intellectual and multiple disabilities, Kittyay (2019) writes of her daughter with profound intellectual and multiple disabilities' enduring dependency on care, and Davy (2019, p.106) points out that "no one is born independent and autonomous".

Years ago when Chlöe and I delivered our TEDx talk: Inclusion: For Pity's Sake? (Grace & Salfield 2017). I made the argument that the world is a better place when people with profound and multiple learning disabilities are included in it. Standing there, with my innocent looking face (don't be fooled it is just my face) and my pigtails, it is easy for a statement like that to be taken as lightweight and naive. My current studies are me living that sentiment. Why study this topic? Yes I hope my work will benefit people with profound and multiple learning disabilities. Goffman is famous in the field of identity studies for writing the book 'Stigma' in which he documented the experience of having an identity others think ill of. People with profound and multiple learning disabilities hold this kind of stigmatised master identity, in that all too often all that is seen is the profound disability and not the person. Most horrifically exemplified recently by people with learning disabilities automatically having Do Not Resuscitate orders put on their medical records during the pandemic. I hope my work will show the identity of people with profound and multiple learning disabilities beyond that master identity of the profound disability, but far more than that. I plan

to work WITH people with profound and multiple learning disabilities as I conduct my research and I have faith that what we will learn will be useful to understanding identity for everyone. The world is a better place when people with profound and multiple learning disabilities are included, and likewise research is a more informed place when they are included. Some might argue that someone with an intellectual disability has no place in academia, I will argue that they belong.

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## What's in a handshake

Sandra Archibald

You know those moments where you and the crow clock each other and maybe being human you say “hi Crow” - and he tilts his head taking you in. You feel a connection, right? You're conversing with a crow! Maybe you're a little amused, charmed by this interaction, so you share a bit of your breakfast and toss him a crust. It's no more than that, just a moment in which you pause and interact, though you do not share an exact language.

**S**itting in the kitchen of the respite unit for Disabled people – he grins, chuckles, claps his hands. Is he unhappy? the care worker asks, casting her solemn gaze over him.

The bored and disgruntled PA complains bitterly that he tugged her hair and growled angrily into her face. It's a behavioural issue she seems to be saying. Indeed it is. Hers not his.

Bumping into an old acquaintance, our daughters were in the same class some years prior. It's been a while. We greet each other smiling and chattering. From his chair my son reaches out a hand, unaware that covid had imposed a barrier – she smiles and takes his hand, “how are you?” she asks leaning into the greeting – his eyes smile a response to the warmth in her voice. The young Sikh man (new to PA work) who on being introduced to my son, offered him his hand for a formal

hand shake; waits every day for his arrival by the school gates. On this particular day as I puff my way up the path, my son, serene in his chair and most definitely not breathless, surprises me by raising his left hand to the PA. Neither smile but the PA takes the offered hand in his own and shakes a greeting.

Not that complicated, right? I don't know bird speak but I know a greeting when I see it or hear it or feel it. An enquiring tilt of the head, the steady holding of eye contact, the impatient caw in response to my slowness of comprehension and action.

Yet it seems there are people who are nonplussed by a smile or an offering of a hand. Is that because he does not stand at their height or engage in speech or because his wheelchair sets him apart? Whatever the reason it seems people like him are seen as non-sentient, less like than alike.

So what is important for him, to me? It is that people who care and advocate for him, first believe that he is a willing communicator; that they can learn first to be companionably together and the rest will follow. There is so much knowledge that can be imparted, if you are curious and desiring of knowing. But it starts with the belief that someone is worth the effort of being known. Communication is so much more than words.

If you or I believe my son is a blank, no thoughts, no feeling, no awareness, how then will you or I be able to treat him with thoughtfulness, feeling and awareness.

It is not enough of course, to guarantee his safety from those who are simply disinterested, careless, bored or even cruel. I dread the day I am unable to do what I do to protect him from such a fate. But if that day comes, I hope there will be enough people who care, enough of a societal change in attitude, a willingness to share our resources and value 'those less fortunate than ourselves.' We need also to recognise and value the right people, those empathetic, curious folk who enjoy the connection and simplicity of communication, who know the importance of a moment and will pause in it.

My big hope is that my son will be safe from abuse and cared for by people who believe his life has value.

Hope, it's not enough. Yet sometimes the simple practice of two people shaking hands - says that we are more alike than different.

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# HOP 8: Are you ready to engage?

Sheridan Forster

Recently I stumbled across an article by Gustaaf Bos and Tineke Abma published in 2022 called Putting down verbal and cognitive weaponry: The need for ‘experimental-relational spaces of encounter’ between people with and without severe intellectual disabilities (2022). Initially the title befuddled me: weaponry, experimental-relational spaces? But as I read (and got past the detailed description of methodological approach and other big words), I was drawn into the researchers’ description of meeting Harry, a Dutch man described as having a severe intellectual disability.

**T**he encounter and sections go from “confusing, unsatisfactory encounters” to observing “enriching examples” followed by “a changing perspective on responding” resulting in “a silent, mutually satisfactory encounter” (subsections of the research results). He describes a journey from an absence of engagement with Harry, to finding satisfaction, and shall I say a new joy, in engaging with a man who did not use words to communicate. Their modality of meeting became about sharing space together, silence, facial expressions, places walked and followed.

These points of togetherness tie us to the title, that in order to find space together, the use of words and higher cognitive stuff needed to be laid aside. I can highly recommend reading this article and several other accounts written about navigating communication with people with severe or profound intellectual disability in the face of uncertainty (Bogdan & Taylor, 1989; Brison, 2019; Forster, 2020; Goode, 1994; Hingsburger, 2000; Nouwen, 1997; Taylor & Bogdan, 1989).

The article made me reflect on two things: what do I need to do in order to be ready to engage with individuals with profound intellectual and multiple disabilities (PIMD), and how do I support other people to be able to be ready to engage?

## What do I need to do to be ready?

**A**s per much of my writing, I do not write this paper with answers, but write it with questions. If I was meeting your son, daughter, sister, brother, client, consumer, friend with PIMD what would I need to be thinking in order to be with them?

Some may suggest I should “presume competence”, however, as some may have read on my blog, it is not in my nature to presume anything, but to explore in each moment of interaction (Forster, 2004). What I do bring, however, is a watching eye searching for what holds interest and meaning for the person. Each step, word, move of my face, as I move towards someone is accompanied by a wondering “how do I need to be in

order to be with you?” I move forward with a readiness for communication to be had in several of many options of means: words, gaze, sounds, smiles, touch to hands, arms, pictures, muscle movements, proximity. Any of these means may serve as our language of encounter. An open mind, a curiosity, and a flexibility.

## How do I support other people to be ready?

**T**hen I wonder if the researcher Gustaaf Bos was interested to engage with someone that I know, how would I prepare him to not have to go through the lengthy steps and time that he went through in order to find a mutually satisfying way of being with Harry. How would I support Gustaaf to keep down the “verbal and cognitive weaponry”, and be open to find a space together with my friend?

It strikes me that more often than not, new people aren’t given much information about how to find that “relational space”. They may be told briefly that someone is “nonverbal” as if that single descriptor gives any direction of how to communicate with the disabled person. They are often left to trial and error alone, with some showing themselves to have “the it-factor” that makes them a person who can engage, but too many cease to find communication together and instead, as the Bos and Abma comment, fall back to just providing care routines to the person.

So I imagine now that I might tell Gustaaf, “My friend needs your face to be about 30 cm from his, he may smile and repeat sounds if you repeat the sounds he makes (even though they might sound really odd), that he will know your presence by your touch to his hands and arms, AND I will support you and let you know if I see any signals that show he is not happy with what you are doing... I will help you not feel bad and feel like withdrawing from this strange encounter, but I will help you subtly shift what you are doing so you can find a new space where you are both comfortable.”

So I leave you with these two challenges: how do you prepare yourself to be ready to engage?, and, how will

you help me or anyone else know how to find engagement and belonging in small moments of togetherness with a person you know?

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# Mainstream placements for children with PMLD: the perspective of teaching staff and parents

Ben Simmons

There is on-going debate about the extent to which mainstream schools are appropriate for children with PMLD (Simmons 2022, 2021a, 2021b). However, the people who are arguably in the strongest position to talk about the issue - parents and school staff with relevant experience of supporting children with PMLD in mainstream settings - are rarely consulted. To date, there have been no published studies that report the perspective of teaching staff and / or parents of children with PMLD who experience mainstream placements in the United Kingdom.

This paper begins to address this significant gap in the literature by sharing the findings of a research project that investigated how mainstream schools and special schools offer different approaches to supporting children with PMLD. During the research, two special school teachers and three special school teaching assistants (TAs) were interviewed. The teachers and TAs were directly involved in supporting mainstream placements for children with PMLD (e.g. accompanying children to mainstream schools, observing and supporting their placements). A mainstream teacher and three parents of children with PMLD were also interviewed. The interviewees were asked to discuss their experiences of mainstream placements for children with PMLD, referring to the benefits and limitations of mainstream placements for children taking part in the study. Four main themes emerged through analysis and are discussed below.

## Having fun and making friends

Social interaction between children was a central theme in the research and a key reason why mainstream schools were seen as important by parents and staff. Staff described peer interaction in special schools as 'rare', 'extremely limited', and 'once in a blue moon'. This was due to small class sizes ('Less kids means less opportunities to play') and a heavy reliance on adults to deliver education and care ('We probably do get in the way a bit. Children with PMLD need a lot of one-to-one input from us, and I think this creates a barrier to interaction'). One teacher suggested that limited peer interaction was 'inevitable' in a class made up of children with communication difficulties ('It's hard for two children to interact with each other when they are preverbal, when they have their own communication and sensory and movement difficulties').

Whilst peer interaction in special schools was deemed to be scarce, staff felt that there was an abundance of peer interaction in mainstream schools. They described peers helping children with PMLD with school work and playing with them at breaktime. This social interaction was celebrated by staff and described as one of the central purposes of mainstream placements, as one TA stated:

Just look at what went on – Harry was laughing his head off! He loved it. Look at all of the attention and help he got. The kids are smiling and playing with him, messing about with playdough and having fun. Harry's looking around, laughing, reaching out to others and having the time of his life. He just...he just doesn't get this kind of thing normally. This is what it's all about. In [the special school] it's the staff who interact with him, but at [the mainstream school] he has me with him, but it's the kids that bring him out of his shell.

The views of parents closely aligned with the views of staff on what was commonly referred to as the 'social side' of mainstream education. Parents described the importance of making friends and interacting with children outside of special schools. One parent described how his son was in hospital for four months and experienced very little social interaction outside of his immediate family and hospital staff. Against this backdrop, the prospect of attending a mainstream school and making new friends was seen as a remedy to social isolation:

He's a social kid and needs more social stuff. You know, more interaction with kids his own age. He's just a kid but spends most of his time around grown-ups. Yes, he's got disabilities, but that doesn't mean he should be locked away. He's gonna love going to [the mainstream school] and meeting other kids, he'll get loads out of it.

Parents spoke positively about the impact of mainstream education on their children. For example, one parent noticed a change in mood on the days that her daughter attended mainstream, describing her in high spirits at the end of the school day: "She just comes out with her happy head on and I can tell that she's had a great day!". Another parent described his son as being 'happy and calm, tired, like he's been busy' at the end of the school day.

### Learning with and from one another

In addition to having fun and making friends, parents and school staff talked about the importance of children learning beside each other, and from one another. Mainstream staff described how a diverse student population was key to learning about and developing respect for difference. The simple presence of children with PMLD in the mainstream classroom was seen as beneficial. As one teacher put it: 'it helps everyone to understand that we all have different bodies and abilities, and it's OK to be different'. By contrast, staff members from the special school typically highlighted how learning took place through peer interaction (rather than simple peer observation). For example, specialist staff described children with PMLD developing their communication skills by engaging with mainstream children. This included children with PMLD learning how to take turns, express a preference for an object or activity, make eye contact and develop confidence and comfort around others. Mainstream peers were described as learning to initiate interaction and wait for a response from children with PMLD, learning to read body language, and having a growing understanding of the communicative actions of children with PMLD. One TA suggested that:

Her placement benefits everyone. She's now making more eye contact and is generally more alert. She's definitely benefited from it, having the social interaction has been amazing for her. The other kids have figured out how to talk to her too, they say 'hello', hold her hand, wait for a response, and go out of their way to make her feel welcome.

### Community belonging

Parents and teaching staff felt that children's participation in mainstream schools contributed to their inclusion in the local community. Teaching staff suggested that special school provision had an important role to play in educating children with PMLD, but also described specialist provision as a 'double edged sword', as one teacher described: 'We segregate to educate, but then there's nothing for them [children with PMLD] at the end of it, there needs to be more community integration and that needs to happen from a young age'. Mainstream placements were seen as a 'way in' to the community in order to 'raise people's awareness' of



disability. The views of teachers resonated with parents, who provided concrete examples of changes that took place during the research. Parents felt 'surprised' and 'shocked' when their children began to be approached by mainstream peers. Children with PMLD would be greeted by peers in everyday spaces such as parks, supermarkets and cinemas, and some were invited to birthday parties and playdates for the very first time:

I just wanted to cry. Children watch him when we go out, they're fascinated with him but they've never spoken to him, you know? Now we go out and people call his name, some kid ran up to him the other day in the shop and just started talking to him, and he's even going to a party in a couple of weeks!

### Challenges

Although the paper so far has reported largely positive views and experiences, there were some concerns raised in the interviews. The phrase 'age-appropriate' was used by staff and parents and there was doubt about the ability of secondary schools to support the education of children with PMLD. This, according to one teacher, was a product of a narrow, subject-based curriculum, the government's drive for increased GCSE attainment, and schools' accountability for students who struggle to keep up with peers. Furthermore, whilst mainstream primary school teachers involved in the project were typically praised by special school staff for being flexible, imaginative and supportive of children

with PMLD, there appeared to be negative consequences if the regular teacher was absent, as one TA noted: 'If the normal teacher is away, other teachers come in and don't care. They hand out worksheets and demand that the class works in silence. That's no good for our lot'. Successful placements required dialogue between schools, shared planning, and staff – particularly teaching assistants – who can support relationships between children and help make lessons meaningful for children with PMLD. When this structure was not in place, where there was no desire or thought about how best to include children with PMLD then staff from the special schools were heavily relied upon to 'wing it and find a way to make it work'.

### Conclusion

This short paper described the views of parents and staff regarding the participation of children with PMLD in mainstream schools. The aim of the paper was not to describe generalisable findings, but to present seldom heard voices on the 'inclusion debate'. This paper provides a small window on this complex topic by discussing what some teachers and parents value with regards to mainstream placements for children with PMLD. As discussed, parents and teachers celebrated peer interaction as something fun and intrinsically rewarding in itself and as a vehicle for learning. Parents also described how mainstream placements led to children with PMLD being recognised and talked to outside of school. Whilst interviewees were mainly positive about mainstream education for children with PMLD they did highlight some concerns such as the

extent to which mainstream secondary schools were appropriate for all learners, and the need for teachers to be committed to inclusion.

To date, researchers and policy makers have overlooked the views of families and staff who advocate for some kind of mainstream education for children with PMLD. Until we listen to all perspectives, policy development in the field will remain ignorant of the realities of the many ways that children with PMLD are educated.

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# Quality everyday life experiences for learners with PMLD in schools

Eve Devlin

This academic year I have undertaken research funded by SWALSS (South West Association of Leaders in Special Schools) to explore how schools can support learners with PMLD with mental health concerns.

To provide quality everyday life experiences and opportunities for learners with PMLD, we must also consider those who support them. In school, staff require a considerable amount of training to support learners with PMLD. This ranges from manual handling, feeding, training to undertake physiotherapy programs and to use a range of specialist equipment such as standers. Questionnaires used within my research highlighted that educational and medical professionals, alongside parents and carers, agreed the most important factor for promoting positive mental health for learners with PMLD whilst at school, is to ensure high ratios of consistent, well-trained staff. However, shouldn't this factor be applied to all areas in school and throughout life to ensure our learners experience quality everyday life experiences?

Quite often in schools, training includes meeting the basic needs of the learner. This includes meeting personal care needs and feeding. Within my research, I interviewed staff working in special schools who indicated that this basic training was not enough to meet the needs of this learning group. Due to complexities of the support individuals require every day, the danger of only providing basic training could lead to as one participant described, viewing learners with PMLD as 'bodies to be looked after', rather than individuals with personalities, interests, and a voice. Maes et al (2007) emphasise that the quality of support individuals receive is crucial to their quality of life. Initial training should also include areas such as communication and understanding mental health. Following on from this research, I will be developing mental health training for staff within schools. This will aim to raise awareness and support staff in beginning to recognise potential signs of poor mental health alongside proactive and reactive strategies.

Research by Rose et al (2009) and Fergusson, Howley and Rose (2008) suggests that there is a lack of mental health training available to schools specifically for learners with PMLD. Carpenter (2015) promotes mental health professional development opportunities for staff working with learners with complex needs. Aird (2000) and Martin and Alborz (2014) promote the need for specialist

training for staff supporting learners with PMLD. The SALT Report (DCSF, 2010) urged government to train more teachers as it predicted a shortage in this specialist area, mainly due to retirement.

Is there a danger of schools only meeting the basic needs of learners with future school budget cuts? This potentially could lead to less funding available to provide high ratios of consistent, well-trained staff. Alongside this, there are concerns about the recruitment and retainment of specialist support staff. Special school headteachers in Wales have reported to the Welsh Assembly Government concerns in this area and warn of a potential crisis. This is a direct threat to the everyday lives of learners with PMLD who require consistent, well-trained staff. Learners with PMLD require increased support compared to other additional learning needs groups to access educational activities, support in communication, to feel trust in staff and to develop a feeling of belonging within the school they attend.

Black and Halstead (2021) suggest that the mental health and wellbeing of staff directly impacts learners. When PMLD classrooms are not staffed correctly this puts emotional and physical pressure on staff. It also leaves less time for staff to build positive relationships and ensure quality learning opportunities. Current struggles in the retainment of support staff also means that there are not as many experienced staff in classrooms for new staff to learn from. One interviewee for my research, highlighted how deep the connection between support staff and learners with PMLD can be:

*It's almost if there is a piece of string that is tying your heart to theirs. When they are upset, I am heartbroken too.*

Support staff often become the advocate for the learner. They notice the small changes, pay close attention and develop strong professional relationships. Ware (2004) describes how learners with PMLD require a 'proxy' and 'enabled adults' to understand and interpret behaviours, which impacts on their quality of life. Colley (2015) promotes high staffing levels and a consistent staff team to promote positive mental health for learners. When



ensuring quality everyday experiences for our learners with PMLD we must also promote the positive mental health of staff as both impact each other. Ensuring classrooms are staffed safely and staff are well trained directly impacts on both staff and learner wellbeing, increasing quality classroom experiences.

There are differences between English and Welsh curriculum expectations for learners with PMLD. England appears to have moved towards a more PMLD focused curriculum using the 'Engagement Model' (Standards and Testing Agency, 2020). Wales has also made changes with a new curriculum, where traditional subject areas have moved together to form the six areas of learning (Welsh Government, 2020). Imray and Hinchcliffe (2014) promote pedagogical approaches more suitable to the differing needs of learners with PMLD. Traditional subject based curriculums are not suitable due to the developmental needs of this learning group. The 'developmental pathways' curriculum for Welsh nursery settings (Welsh Government, 2022) is a step towards, but still not suitable for learners with PMLD.

School assessment procedures also can potentially impact on everyday life experiences for learners with PMLD. Where quantitative assessment procedures are in place with percentage increments of targets required, this puts direct pressure on the classroom. Progress and attainment are then focused on whole school data requirements rather than focused on individual progress. There then is a danger of learners working on targets which are not suitable for them but meet whole school data arrangements. This links to Turner (2011) describing the pressure on staff to produce the 'end product'. Here the end product is achieving and producing evidence of a target which increases the percentage of what the school measures as 'success'. Progress for learners with PMLD is often in smaller steps and potentially slower, which makes data arrangements more difficult. This does not mean their progress is less important. Qualitative approaches towards recording and reporting achievement could provide richer data and more pupil centred approaches to curriculum and targets. This also puts less pressure on staff as they are focused on where the learner is and how to get them to the next appropriate step in learning. It would also recognise the very real nature of regression or the need to focus on maintaining skills due to medical or mental health needs.

The Government report No Health without Mental Health (2011) states that positive mental health is central to quality of life. As the lives of our learners with PMLD are often shorter than that of the general population, shouldn't quality of life be central to curriculum? Maes, et al (2007, p.8) used the following quality of life indicators in their research into interventions which promote quality of life for learners with PMLD: *physical well-being, material well-being emotional well-being,*

*interpersonal relations, self-determination, personal development, community participation, and rights.*

Lacey et al (2015) recommend a move away from a 'one size fits all' curriculum and towards approaches that encourage personalised learning, play and communication. They promote the following curriculum drivers:

*helping learners to become effective and willing communicators, enhancing language learning, promoting their independence and self-reliance, fostering creativity and curiosity. Above all, authors [of chapters in the book] stress the importance of making opportunities for learning meaningful and fun (p.414).*

Using both Lacey et al's curriculum drivers and the quality of life indicators could provide an approach to ensure appropriate curriculum, assessment and promoting positive mental health. Effective and willing communicators links to engaging effectively socially. Creativity and curiosity link to being aware of internal and external environments leading to responding to them in a more positive way. Independence and self-reliance link to being able to meet your basic and higher functioning needs providing a young person with PMLD the opportunity to have as much physical independence as possible. Opportunities for learning meaningful and fun could link to self-worth and wellbeing, as learners enjoy exploring, investigating and developing new skills within their curriculum, developing individuality and a sense of purpose.

To ensure high quality everyday experiences for learners with PMLD within schools we must firstly invest in, then continually develop and be aware of the wellbeing of staff within classrooms. As learning and progress for this group of learners is different to that of other additional needs learning groups, different pedagogical and assessment approaches are also required to be more tailored towards learners with PMLD. This directly impacts on the pressure of classrooms as planning and assessment becomes more 'pupil' rather than 'target' focused. Finally, the curriculum needs to focus on quality of life rather than traditional curriculum subject content. Where quality of life is the focus, personal centred planning develops naturally and learning opportunities can be maximised. This allows time for developing strong working relationships, developing a sense of belonging, encouraging autonomy, engagement in learning, and promoting positive mental health. When lives are shorter, we must ensure that everyday life experiences are richer, fuller, and more meaningful.

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# Ravenscliffe School 'Flourishing Curriculum' – Part 1

Julia Barnes and Andrew Colley

Ravenscliffe High School and Sports College is the only secondary special school in the Calderdale authority and has been consistently graded 'outstanding' by the Office for Standards in Education (Ofsted) since 2008. The school currently has 244 students on roll, all of whom have Education, Health and Social Care (EHC) Plans. 20 of the pupils at Ravenscliffe are currently identified as having profound and multiple learning disabilities (PMLD), and until 2020 had followed a sensory based approach to The National Curriculum, differentiated to meet their individual needs and including areas of the curriculum typically offered to younger learners. Integral to the curriculum already was a strong ethos of wellbeing, with staff at school (2022) supporting pupils with their physiotherapy, positional equipment, access to hydro and rebound therapy, care and medical needs.

The COVID-19 pandemic had a significant impact on the wellbeing of people with learning difficulties and when a new head teacher joined the school in the midst of the pandemic, she was keen to mitigate as far as possible its impact by developing the best possible curriculum for the students with PMLD. Lead teacher Julia Barnes took on the task of developing a flexible curriculum which would enable her pupils with PMLD to flourish, both during, and beyond, the pandemic.

In this 'Part 1' article, we will outline the theoretical framework behind the Flourishing Curriculum developed at Ravenscliffe. The 'Part 2' article will appear in the next issue of PMLD Link and will show how the new curriculum was made accessible to our students with PMLD in the classroom and beyond.

Solms (2022) has suggested that historical prejudice towards cognition in learning could be replaced by learning through experience and through emotions and Moljord (2021) proposes that the main purposes of learning for young people with severe learning difficulties are citizenship, later life and vocation. 'The most important educational experiences for these young people being to live their own lives and to encounter the world' (ibid, p.5).

Julia and her colleagues were motivated by these ideas in their search for a truly appropriate and personalised curriculum for those with PMLD. They began to consider the 'Capabilities Approach' as defined originally in economic terms by Amartya Sen (1985) and subsequently in philosophical and political terms by Kyoto prize-winning philosopher Martha Nussbaum, as a way to provide people with PMLD with the means to flourish, and live their best lives, not as a future goal, but specifically in the here and now.

The Capabilities Approach is essentially an 'outcome orientated approach' (Nussbaum, 2007, p.156 and p.174) and in a recent e-mail exchange with one of the authors of this article, Professor Nussbaum emphasised that although people use the Capabilities Approach in many ways, her own version focuses on outcomes as basic constitutional rights. Those basic constitutional rights, she maintains, can be defined in the form of 10 'Central Human Capabilities', which she also describes as 'core human entitlements that should be respected and implemented...as a bare minimum of what respect for human dignity requires' (Nussbaum, 2007).

Nussbaum's 10 Central Human Capabilities, which all have equal importance, are:

1. Life
2. Bodily Health
3. Bodily Integrity
4. Senses, Imagination and Thought
5. Emotions
6. Practical Reason
7. Affiliation
8. Other Species
9. Play
10. Control Over One's Environment.

In Nussbaum's 'Frontiers of Justice' (2007) she discusses how the Capabilities Approach can be applied to people with disabilities. Other writers have already begun to imagine how adopting Nussbaum's 10 Central Human Capabilities might enhance the lives of people with special educational needs. Norwich, feels that the Capabilities Approach may have potential to replace the language of needs with that of capabilities which enables individual choice (2014). Terzi (2010) suggests that placing the wellbeing of learners with disabilities and special educational needs at the centre of their own

education as well as expanding their capabilities will enable a shift from academic educational goals to social, relational and participatory elements, and Robeyns (2006) proposes that the capabilities model is multi-dimensional and therefore enables the intrinsic and non-academic role that education plays for learners of all abilities.

When asked whether her work can be applied equally to people with PMLD, Nussbaum answered 'in the affirmative'. Johnson and Walmsley (2010) ask what would happen if Nussbaum's 10 capabilities were made the focus of work towards wellbeing for people with PMLD (2010), and Simmons and Watson (2014) suggest that Nussbaum's Capabilities Approach may enable fuller participation in society by those with the most complex needs (2014).

The strengths of the Capabilities Approach for enabling fulfilling lives for those with PMLD are that it focusses on actual functioning in terms of being and doing (Nussbaum, 2007) and on realistic opportunity. It also calls for a society in which persons are treated as each worthy of regard, and in which each is put in a position to live human lives of dignity (Nussbaum, 2000). Placing the well-being of students with PMLD at the centre of their own educational process opens up broader aims for their learning, including social, relational, participatory and communicative elements (Terzi, 2010, p.151) with an emphasis on exploring the 'voice' of the learner, and finding innovative ways of listening and understanding (Nussbaum, 2007). What is more, by creating 'a space for diverse possibilities of flourishing' (Nussbaum, 2007, p.182) for the students, teaching and learning can be placed very firmly in the here and now. Nussbaum sees her 10 key Human Capabilities as being applicable equally to the person with disabilities as well as their parents or guardians, since flourishing for parents, carers and the communities around these young people (Reinders, 2002) can only really be possible if their children are also flourishing.

In the next issue of PMLD Link we will show how the team at Ravenscliffe High School and Sports College set out to make the school possibly the first one in the world to apply the Capabilities Approach to its pupils with PMLD on a day-to-day basis.

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# Learning beyond the label

Michelle Galloway

Hi there, look at me  
I'm more than just a label of P.M.L.D  
I am a person  
I have a name  
I am extraordinary in my own way.

I smile and laugh and communicate through my eyes.  
I giggle and wiggle but sometimes from inside.  
I sometimes get sad or mad, but that's OK too. My emotions are sometimes hard to fine-tune.  
I am alive, and here, and I'm trying my best.  
So have understanding and patience. Not label me with tests.

My engagement may fluctuate, my energy levels may change.  
My body holds me a prisoner, but sometimes I can loosen these chains.  
So give me some structure, repetition and a chance to exist.  
Your faith and your encouragement and I will show you my gifts.

I can move, although it may be little.  
So stretch my body and give my hands a good wriggle.  
Talk to me, sing to me, enable me to learn.  
By exploring, sometimes snoring, but let it be on my terms.

Don't overload my brain with too many things,  
Don't you know that processing is a very complicated thing?  
Adapt my surroundings, make the world a predictable place.  
Make learning relevant, exciting, and at my pace.

I don't need a curriculum with one million things to learn.  
I need learning that is unique to me, learning on my terms.  
Basic needs learning, independence around me.  
Communication, stimulation, and maybe a range of AAC.  
Ways to process, ways to consent.  
Ways to relax and to be part of social events.  
V.I enhancements, light sensory too.  
Play and entertainment and relaxation to snooze.

Hi there, look at me  
I'm more than just a label of P.M.L.D  
I am a person  
I have a name  
And I can be extraordinary  
If learning is my way.

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# Let the pupil lead the learning!

Martin Goodwin

Within Education, the concept of a sequenced curriculum is specified by Ofsted. This article explores potential issues in determining a sequenced curriculum concerning pupils with PMLD.

## The Sequenced Vs a Process-based Curriculum

Of late, the Ofsted 2019 guidance stipulates a sequenced curriculum which is 'coherently planned and sequenced' (Ofsted, 2019; accessed May 2023), which poses methodological and ethical challenges to the teaching and learning of pupils with PMLD. Furthermore, in teaching pupils with PMLD, the Ofsted 2019 guidance is incongruent with the recommendations of the Rochford Review (Standards and Testing Agency 2016), which sets out the importance of non-hierarchical learning. Whilst the Rochford review set out considerations for assessment, if assessment and curriculum are closely entwined, the learning experiences that pupils receive may be rigidly taught and assessed. Therefore, as curriculum can quickly become conflated with assessment it risks narrowing the quality of the pupils' experiences and educational outcomes.

A sequenced curriculum that meets all pupils' needs with PMLD is a fallacy. One curriculum will not meet the unique and diverse needs of the pupils we support. A sequenced curriculum becomes problematic as, firstly, it may not accurately assess where a pupil is with their learning; secondly, it may then isolate the development of a skill so that pupils are not supported to make intrinsic connections and develop their schema; thirdly, the rigorous pursuit of the development of isolated skills if taught using an overt behaviourist pedagogic style risks undermining the importance of context within teaching. When pitching learning experiences to the pupil, it is vital that we fully consider the pupil's zone of proximal development (Vygotsky, 1987) - the gap between what they can do currently and what they could with appropriate 'scaffolding' (Bruner, 1960).

Developmentally sequenced curriculums are typically based on normative child development sequences and do not consider the complexity of multiple disabilities that pervasively impact (WAG 2020) and which alter a pupil's developmental trajectory. Furthermore, a framework of learning objectives or inflexible sequenced stages is unlikely to provide sufficient sensitivity to the learning needs of the pupil. Skills-based teaching, in conjunction with objective-based sequenced frameworks, commonly utilise a unit approach where 'A'+ 'B' joined together will enable 'C' to be met. Skills often resist being broken down into isolated parts, as

they often rely on interconnections with existing subsets of knowledge and need to be taught contextually, as part of a process so that pupils can make links. Skills-based teaching that is highly target-based can sometimes feel like fitting elephants into thin straws as the sole agenda of teaching becomes fixated on the development of a particular skill. Furthermore, if the pupil does not make progress with a particular skill, practitioners often face the dilemma of which targets are pursued next. This often strict structure of the sequence enforces a readiness model (Wilcox et al. 1987) where the pupil cannot continue to make progress with the sequence unless the current skill is achieved.

Sequenced teaching and learning, evident within a process-based learning model through teacher articulation of extensions where the pupil is progressively challenged based on what and how the learner is progressing, differs from a sequenced curriculum where the learning is set through curriculum objectives or assessment framework. Rosenshine establishes that teaching should be sequenced (Sherrington, 2019), and this emphasis is very different to the stipulation of a sequenced curriculum. The location of sequence within the curriculum, rather than within the teacher and the pupil, detaches the interactive process of teaching and the value of 'listening to children's voices, building on their own interests and children taking the lead in their learning (Lacey in Hewett et al. 2012; pg 51).

Within sequenced teaching, through an interactive teaching approach (also termed as a process-based approach), as Collis and Lacey (1996) advocate, pupils have agency, and the learning is negotiated. Process-based teaching requires sensitive interactions with pupils with PMLD that centre on building their strengths through motivating and engaging contexts and approaches. Successful learning requires the teacher to know how a person with PMLD learns and the level of support they need to engage actively. In attempting to develop a person-centred curriculum, an embedded process and culture of listening and responding (Goodwin, 2013) is significant in harnessing the development of meaningful learning opportunities that are increasingly pupil-informed or initiated. These exist within an interdependent relationship between the pupil and the teacher, outside standardised frameworks that

offer limited flexibility or personalisation (see Taylor and Goodwin in Imray et al 2023 in press). Such a process can equally enhance the development of a curriculum which is based on the principle of a spiral-based model (for more information, see Bruner, 1960) so that it enables continued reinforcement of valuable learning opportunities and engagement behaviours that are conducive to active learning. Which as Lacey states 'is vital to the development of understanding, as it lifts pupils' from 'learned responses' to 'intelligent behaviour' (Lacey in Hewett et al. 2012; pg 41).

Early years guidance details the importance of frameworks not limiting the pupil's development, and frameworks should 'be a support to help adults to recognise and interpret what a pupil is showing at the present moment (Early Education 2021: pg 49)'. Unlike the concept of a prescribed sequenced curriculum, this tact does not define or limit, but enables the capabilities of pupils' to be recognised.

Whilst the unprescribed process central approach appears riskier as 'it may not be possible to be precise about when all the learning outcomes emerge' (Hewett in Hewett et al. pg. 139), nevertheless, its benefits are conducive to reaching the desired outcomes for pupils with PMLD. Through a spiralling approach that facilitates 'responsiveness, repetition and repertoire' emergent outcomes are uncovered (ibid; pg. 148) and highly engaged learning occurs.

Alternatives to prescribed sequenced curricula do exist. Chailey heritage school has a highly personalised curriculum, as their raison d'etre is the 'Child is Curriculum'. The school establishes unique curricula for the pupil's development based on their needs and wishes (Colley et al 2021). To cater to PMLD pupils' divergence, Routes for Learning utilises a flexible assessment framework in which different routes can be taken through 43 key milestones. Further, MAPP suggests a process of forming personalised learning intentions. Using a bank of milestone statements that guide, teachers are supported to identify priorities for teaching and learning through a motivation, strengths, and needs analysis, but 'there is not an assumption that learners will approach [milestones] in a fixed order' (Sissons 2018, Pg 9). This seems key - the sequence of learning should be personalised, not standardised.

Of concern, due to the Ofsted stipulation of a sequenced curriculum, some curriculums have rigidly followed the requirement of sequencing. These models may replicate the damaging consequences of assessment frameworks that utilised the p-levels as a hierarchical order. It may be the case that schools need to be more interpreting of the Ofsted stipulation for a sequenced curriculum. Due to historical practices which utilised p-scales as a tick box,

special schools may be stuck in a developmental vacuum, where assessment is conflated too closely with the curriculum.

An overly rigid and prescribed sequenced curriculum and assessment framework needs to be more consistent with the personalisation agenda and person-centred curriculum that can be deployed within special schools. Carpenter (2016) advocated that pupils with PMLD require a highly personalised learning environment. Imray and Hinchcliffe have argued that pupils with PMLD require a distinct curriculum (2013). Whilst Imray et al. (2023) further advocates that a 'different, not differentiated' approach (forthcoming) to curriculum and pedagogical approaches are required. Ultimately the curriculum must fit the pupil; the pupil should not have to fit into the curriculum.

Whilst some of the Ofsted expectations of curriculum design may be applicable, the guidance at best only details research that is generalised from the broad population of special needs and is not specific to the fundamental differences concerning pupils with PMLD. Imray et al. (2023) argue against the misuse of research in treating pupils with SEN as a homogeneous group and cautions against research that has sparse evidence of its applicability to the population of pupils with PMLD. Empirical research into curriculum and pedagogy for pupils with PMLD is limited (Kossyvaki, 2019). However, schools need to use the available research to make informed decisions. Therefore, special schools need to discern evidence that does not make sense for pupils with PMLD and use interventions that are at least evidence informed. Research needs to be undertaken to ascertain the impact of implemented sequenced curricula.

Care must be taken that the curriculum and presented learning opportunities promote active listening and responding to the 'dialogue' that we are sharing with the pupil so that personalised pathways that are engaging to the pupil are pursued. Schools that have implemented standardised sequences in response to the Ofsted inspection framework need to be more consistent with the philosophy and personalised pedagogy of the Engagement Model (see Goodwin 2016), and the principles set out by the Rochford Review have been overshadowed. Whilst developmentally sequenced curriculums may be supportive in thinking about the next steps for the pupil, the frameworks should not determine the learning sequence, as the sequence of teaching should be personalised in relation to the pupil. Curriculum objectives and assessment frameworks may provide guidance; however, frameworks should not replace teacher enquiry and development of reflexivity based on the needs and agency of the pupil. A teaching and learning sequence does not need to be set and

prescribed at a curriculum level, as learning sequences can be negotiated and extended through a sensitive partnership with the learner. For excellent outcomes - let the pupil lead the learning!

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## Literacy beyond the storybook

Gwyn McCormack

Bringing stories to life beyond the typical story book, with success. For children/young people with PMLD and their families.

Imagine the joy for a family.....

The little girl traces around the bright sparkly characters.

She blows kisses to the storyteller.

Her mom says, "The Story Time Show is the highlight of this little girl's week. She just loves the Story Time Show."

This little girl has participated in an inclusive story time with her family for the last 2.5 years and she absolutely loves it. She responds and has shown increased vocalisation, visual attention, concentration, engagement.

The reason why this is successful is that this very simple, stripped back inclusive model of literacy places children with PMLD as the starting point for story rather than the final add on. It focuses on having fun.

For many, many children around the world the typical story book is not accessible, impacting on their important participation in family story time. They want to be included. Marvin's Story Time Show offers a bridge. Through this model, story is brought to life beyond the typical story book and literacy and learning happens – with success! Inclusion of children with PMLD needs

becomes the starting point for story time rather than always being the final add on or afterthought. The model can work for all children, young people, and adults inclusively of those with PMLD, hearing impairment, vision impairment, cerebral vision impairment, their siblings and wider family members too.



Mom Teresa describes this eloquently in her Story Time Show Wish.

"My wish for the Story Time Show is exposure because so many children who are challenged in learning nationwide, worldwide, would benefit



from this. My family was introduced to Positive Eye through our child’s therapist and her witness of the joy it brings for another client. We are grateful someone took the initiative to design this form of teaching, specifically for these children. With Positive Eye these children are absorbing what is presented. They are responsive, they are engaging, they are learning and happy to be included. They need something too and this is the bridge.”

**What is the inclusive literacy model, Marvin’s Story Time Show?**

The model is designed to incorporate teaching and learning strategies and accessible opportunities to participate in an online story time by the whole family or class, inclusively.

The core literacy skills threaded through the model are:

- Fine Motor
- Auditory and Language
- Tactile Discrimination
- Concept Development (all skills come from this point. This is the Jumbo Jet plane)
- Visual Skills: Visual Awareness, Visual Attention, Fixation, Tracking, Scanning, Visual Discrimination of Objects and Images, Identification of print, number, shape
- Book and story (this may not necessarily have to be in the shape of a typical book for every child)
- Taste and smell

In my courses for professionals, I refer to these core literacy skills as Rainbow Arrow Planes that fly with the child through their lives. Each literacy skill represents a Rainbow Arrow Plane. The planes will never leave the child but the package of skills the child requires to access literacy will develop and change. This model provides the opportunity to strengthen these skills and can easily be adapted to meet the individual need of each child easily.

Marvin’s Story Time Show uses high contrast glittery characters presented against an uncluttered black background to maximise access, develop visual attention, engagement and increase connections. Each show follows the same structure incorporating specific elements to maximise the opportunity to increase the literacy skills: a huge welcome, rainbow wheel spins, time spent saying ‘Hi’ to each child by name, a chat/wave to Marvin, a story told with high energy using glittery homemade characters and a craft made live on the show linked to the story.

Let’s look at some of these aspects and why they are included:

**Marvin**

Chatting mid-show with Marvin promotes friendship, imaginary play, social interaction, and connections. Marvin loves every child/young person/adult who watches the show, and he wants to be friends with everybody!



**Rainbow Wheel Spins**

- The rainbow wheel is bright and colourful and I spin it at the beginning and end of the show
- This visual stimulating action is repeated to encourage visual attention (looking) towards the screen
- I purposefully use a loud ‘wheee-wheee-wheee!’ as I spin the wheel to engage the children and encourage them to know where to look
- I build the anticipation with an enthusiastic voice and count down to the rainbow wheel spinning
- So many parents have shared with me how their children love this, either the rainbow spinning or the sound, or both!





**Name call outs**

I wear red gloves with large yellow pompoms glued to the palms. This provides an additional point of high contrast focus. I give out a name call to every child who would like one. Imagine how exciting it is to hear your name! I call the names in turn, using an enthusiastic voice to encourage engagement and connection. Working with high energy helps connect with children who do not know me and who I am expecting to connect with through the screen. It works and the children and young people connect with me, even those who you think might not. Repeating each child’s name repeatedly using a sing-song voice gives time for connection.



**The story**

During the show I read a chapter of the Marvin adventure. I use glittery story characters to attract the children’s attention. The glittery paper promotes visual skills: Visual Attention and Fixation. Everyone participates in their own way during the story:

- Some children read along in braille or print
- Some children listen to the story
- Some children love to look at the glittery characters and enjoy their movement
- Some children love listening to my voice
- Some children love the rhythm and song during the story
- Some children love to call out to me during the story!



There are songs for each adventure. Songs to welcome, to say goodbye and a song composed for the parents bring a special quality to this purposefully home crafted show.

The show is purposefully home crafted, which has the benefit of encouraging parents that this is something they could recreate themselves with, or for their children. Gwynnie-Gwyn-Gwyn the storyteller is neither actor nor singer, it is not a rehearsed theatre performance. If this model were to change significantly, it would lose its purpose and may no longer be as effective.

The model works in several ways:

- Engages, increases vocalisation, concentration, participation and as a result increases the child’s literacy access skills because access has been enabled to story time which includes them
- Empowers parents and gives them confidence to know the starting point for story time for their child
- The whole family feel included in Story Time
- Children that you wouldn’t think would watch for one minute watch the whole hour and cry when it’s over and watch it again!
- Children who don’t lift their head because it’s too hard, lift their head and watch the whole hour. Jade pictured below shows us how much she loves the show and will watch without moving for the whole hour. Her family are overjoyed!
- Children who may sleep or not engage with other media, wake up for this show and watch the whole hour
- Parents love to see their children having the best joy and FUN that this simple show brings. They want to participate in fun story time at home just like everyone else.



Many of the parents have said that this show has been life changing for their child. They say they want to see this show on the world stage, they want all children with PMLD around the world to access this show. They absolutely see this show as the starting point for inclusion so that all children can participate equally in story time in a way that works for them.

A Mom shares the life changing impact for her daughter

“My wish for the Story Time Show is for more families to learn and explore this wonderful platform. The way my daughter has tracked the movement on this show and be able to engage in the crafts afterwards has been a life changing experience for her. It is a true testament of accessibility and inclusion for all children. What is even more amazing is that my daughter is able to watch and engage with these stories with her siblings. It’s a bridge in learning that allows her to share true enjoyment with her family. We are forever grateful to Gwyn and the Story Time Show for bringing the joy of learning to our daughter.”

### Developing the model

I originally developed the model during COVID as a means of using my skills positively. I built the concept and went live on Facebook at 4pm three times per week for a total of four months. Families from all over the world joined this joyful hour and I created the magic! The parents would message me before saying ‘we can’t wait, you are bringing joy to us everyday!’ I started to receive videos and photographs from the families watching and I realised that the show was strengthening literacy outcomes for children.

Since then, I have collaborated with 27 Deafblind Projects across the United States to further develop the model. I have presented the show to hundreds of children and their families with success. Although I have worked with the Deafblind Projects across these States the show works inclusively for both neurotypical children and children with a wide range of needs. It would work anywhere in the world because it brings joy, fun and happiness first and foremost.

To date it’s brought the greatest joy, love and happiness and is so deeply loved by the families. This show is about making children with PMLD needs the starting point for story rather than the final afterthought.

But... most importantly this show is primarily about having the best FUN EVER as a child, young person, or adult!

### Contact details

Gwyn McCormack founded Positive Eye in 2008 after spending many years as a Qualified Teacher of Vision Impairments. Gwyn has become internationally known, providing training and her uniquely designed programmes to parents and educators in over 12 countries.

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## Personhood at the margins of society

Maren Hueffmann

My research into the construction of personhood in the context of the lives of disabled children with complex needs includes ethnographic fieldwork, which I conducted part-time at Oak Hill Special School over a period of two years. The children I spent time with fall broadly under the umbrella term of PMLD. I also talked with parents and carers of some of them. As the special school remained to be the main location of my interactions, I need to consider the role of special education within my study of personhood. (Names of location, classes and individuals have been changed).

Children with extensive and complex disabilities are rarely seen in public in the UK, not only due to their numbers being low in comparison to the general population, but also because public buildings and a lot of activities are often not accessible to them. Special schools offer them a place to learn, a place to be accepted in all their diversity, a place to be supported and protected. The special school as an educational institution has its place among other educational categories, or rather: it is placed at the periphery of an imagined map of categories. From the time of birth, or most likely already before birth, a human being is being classified according to medical, developmental and social measures. Without going into detail, all these classificatory systems will influence the child's path into the education system. If there are concerns about a deviation from a "normal" trajectory in mainstream education, remedial lessons may be added to their programme. However, if the deviation from the norm exceeds what can be offered at a mainstream school, a special school placement will be considered. Here the

children are separated from the mainstream. Their hope for inclusion relies on the efforts of their own school in linking up with mainstream facilities. An educational journey that starts in a special school will rarely lead back to the mainstream. This is a journey, which will continue through special institutions, even, if 'special' is no longer in the name.

Within this marginal space we can discover various aspects of these children's lives defying categorisation, a space of individualisation within interrelationships as well as through personal agency. However, within UK society as a whole, their lives continue along marginal lines. In the UK, the purpose of schooling is to provide a formal education with the aim to lead to a recognised qualification and thereafter further studies and employment, in short: to become a functioning and contributing member of society (Great Britain. Department of Education 2016; Gibbs 2015). The individuals who participated in my research may escape specific classification (such as physical disability or



autism) through the sheer multitude and complexity of their disabilities, but they do not escape the expectation to fit into social categories and their associated behaviours, those associated with a disabled body and mind (Avery 2020). While the aim of educating is present, those with significant and complex disabilities will never have the endpoint of gaining a qualification in sight. Even the aim of gaining some functional independence in caring for themselves will at best be partially achieved. This will result in these children, and later adults, remaining on the threshold of inclusion in society. They will continue to rely on the assistance of institutions. For example, the medical establishment offers formal supervision of health and care needs, and social services monitor living conditions, safeguarding and welfare needs. A disabled individual with such complex and extensive impairments as the youngsters in my study will never advance from a status of needing financial and practical support to a 'functioning' and accepted member of society. They will be continuously tied into an imagined and largely invisible community at the margins of society.

The outsiders' perspective of a special institution preventing disorder from spilling out into society (Avery 2020; Simons and Masschelein 2018; Stiker 1997) is met by the highly regulated inside of a special school through physical and time structures, as well as specific teaching approaches. In the following, I will briefly refer to selected examples from my fieldwork to illustrate how physical and time structures try to facilitate the ordering of movement and behaviour, the supervision of actions and 'normalising' procedures, which are there to support the students' journey towards independence and acceptance into society.

### **Little space for lots of stuff—the physical environment**

The outside of a special school would initially not provide any obvious signs that this is an exceptional kind of place. However, the design and layout of the building says something about the people who inhabit it, as well as the society they live in. Like any other school, Oak Hill School has a reception area, where visitors report in and follow the necessary procedures to be allowed entry. All classroom doors have window panels and magnetic locks, which signifies the first difference between a special and a mainstream school. Staff and regular volunteers wear a key-fob on their wrist or lanyard to gain access to the rooms behind locked doors. Behind each classroom door lies a room which is equipped and laid out to accommodate a class of up to 12 students. One of the main features of special school education at Oak Hill School is the aim to address the specific needs arising from the disability alongside the students' learning potential. To that end, the classes are structured into three streams. My fieldwork was placed

in the stream, which catered for students with the most complex needs, who were perceived to be very limited in terms of their potential to learn. They may also be particularly vulnerable in terms of health or physical needs. This stream consisted of three class groups with 8 to 10 pupils in each.

The classrooms of this stream, Ash, Maple and Beech class, were immediately recognisable through having adjacent bathrooms, ceiling track hoists in both rooms and an abundance of equipment, both stored and used. It was also noticeable that the original structure of the school was not built with extensive physical disabilities in mind. There never seemed to be enough space to accommodate the vast amount of equipment. Therefore, convenient or not so convenient spaces, corners and niches had to be found inside the rooms. For example, Ash class stored equipment in the bathroom, which made the bathroom inaccessible unless a vast amount of it was removed. In the morning the initial equipment to be used was taken from the bathroom into the classroom, creating a certain order at the start of the day.

While the choice of equipment was justified through their health benefits, for example change of positions through standers for physical health and digestions, the use of this equipment depended on staff initiating the action and controlling locations and duration of use. The children were subject to the intentions of staff, who aimed to alleviate their condition in absence of a cure. The fixed and moveable parts of this physical environment set the boundaries for the students' school day. Their lives were controlled and managed through these physical parameters and on the instigation of staff who were following set instructions for its use. However, these physical structures also set the boundaries for how school staff could work and facilitate the students learning.

### **Time structure**

The division of space in the school was complemented by class and room timetables. A class timetable typically contained lessons that suggested a sensory approach to teaching/learning: sensology, atmospheric, sensory cooking, or swimming. Swimming had to be scheduled according to available slots in the pool, as well as the changing beds. The same was true for a focus on visual skills in the 'light room'. The timetable for each class merely suggested the possibilities for the day. The days I encountered at the school rarely adhered to the timetable. It seemed that certain priority slots always came first in the morning discussion of classroom staff. The use of the swimming pool occupied the top position. The use of this designated slot then depended on the staff available (including them having brought their swimming kit), the timetabled children (also including their swimming kit), as well as there being a sufficient

number of staff remaining in the classroom. The swimming slots on the timetable merely indicated that the class would have the swimming teacher assigned to them and changing beds available for the non-walkers.

The school day for staff started officially at 8.30 am. At this time staffing levels were confirmed. Information about any events or situations that might affect the delivery of the timetable were distributed, such as pool closure or an orthotics clinic. At 9.00 am it was time to collect the children from the buses and parents waiting outside the building. Staff, all equipped with high-vis vests to signify their belonging to this authorised group, would gather in the small hall awaiting the opening of the double doors. The timetable suggested that all children would have settled in their class by 9.15h to start the routine of morning greetings. However, this goal was rarely achieved. Steering everybody into class, taking coats off, checking bags and changing the majority to their school chairs was rarely completed before 9.30. By this time, or even earlier, some children were already leaving to go swimming and could not take part in the morning routine. Actual lessons would regularly start delayed and were often shortened in those two classes, which had children eating a snack at the designated time of 10.15 am. The timetable was even more loosely applied in Ash class, where each child had their own feeding plan, including specific times to provide snack or water in the morning.

Time structures were not only disturbed by clinics, staff absences and extraordinary events, but also by everyday activities taking more time than planned, as there was no way of speeding certain actions along. Everybody knew that tasks, such as toileting or feeding would last “as long as it takes”. Some communication with children took longer as additional explanations or sensory props were needed. The sense of time passing seemed to adapt to this. Inside the classrooms and school, time seemed to take on a new meaning. Everyone appeared to accept that time passed at a different speed within this environment. The occurrence of lessons and use of specialist rooms were also interlinked with the number of staff present as well as their expertise and knowledge they could bring to a situation. The specific times of daily school openings and closures and lunch times were the only unmovable daily time structures to adhere to, however, the latter only for those who received school lunches. The rest of the group timetable was closely intertwined with the distribution of staff, medical emergencies, variations in personal needs and other extraordinary situation, which had to be addressed. The daily timetables marked the intentions of the school to provide an education for those excluded from the mainstream of society with the broad objective to improve the quality of the children’s by gaining maximum independence.

### Concluding remarks

A special school, like the location of my fieldwork, offers a secluded protective space away from mainstream education. One could frame the promise of an education and admission to special school as the threshold to a potential entry to and acceptance by society. This type of education will rarely fulfil this promise, in particular not for the disabled child with complex needs. This is not for lack of individual effort, but because societal expectations of order are unattainable. Once segregated from the mainstream, life at the margins continues indefinitely for persons with PMLD. The seclusion of special education from the mainstream underlines their existence at the margins, a space to contain some of those members of society, who are perceived to disrupt the expected order. Most students who go through special education will merely transition to yet another institution, which shields them from the rest of society and vice versa. They will continue with their lives in parallel to the rest of society, staying mostly invisible.

Within this space of special education, I have found numerous ways how the children with PMLD are acknowledged as persons. These affirmative interactions are mirrored in accounts from parents and carers. On the other hand, there are also plenty of examples of the opposite happening within the wider community and society. My research aims to discover alternative and constructive interpretations of ‘what makes a person’ in order to support inclusive practices in wider society.

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# Parents' perspective on research for individuals with profound and multiple learning disabilities (PMLD)

Fathima Nowshard

As a parent of a child with profound and multiple learning disabilities (PMLD) and a researcher for a Master's degree, I believe that all research available for and about individuals with PMLD should be easily accessible to parents and carers. As part of my dissertation, I am currently researching on parental perspectives on research. This article will include some of the findings from my research. Kosyvaki (2019) state that research is a concise and efficient way to improve the lives of people we work or live with and care about. Therefore, it is important that researchers work in partnership with parents and other stakeholders, in order to understand what parents want from research that include individuals with PMLD.

**M**ost research involving individuals with PMLD, is largely aimed towards providing results and recommendations to educators, researchers or medical professionals. It may often seem that although parents' views are included in data collection during research, they are not necessarily included or have access to study results (White et al, 2022). Therefore, by understanding what parents want and expect from research studies, it is possible that they may have access to the results from the research study. This may in turn, have positive implications for the individuals they care for.

Most individuals with PMLD were advised to shield during the COVID-19 pandemic. This therefore meant that parents had to take the role of educators. As a result of this, some parents were interested in learning about different interventions etc., that they could use at home. Some parents found it challenging to access research around effective interventions etc. for individuals with PMLD. Francis et al (2022) believe that parents had to take the role of "student", as they had to learn to engage their children in individualised learning programmes. There is a need for researchers to reach out and involve parents in their studies, as their perspectives are vitally important for any research around individuals with PMLD.

## Aims and purpose of the research

**T**he preliminary aim of my research is to understand parents' perspectives about research for young individuals with Profound and Multiple Learning Disabilities (PMLD). Pearlman and Michaels (2019) state that, it is essential to gather different views of key people (i.e. parents and carers) around these individuals. Parents and carers are often the voice and advocate for individuals with PMLD. This study will investigate the

awareness that parents of individuals with PMLD have of research.

Furthermore, the data obtained from this study may provide recommendations to researchers, to make research accessible to the general public (i.e. parents and carers). This is to ensure that parents and carers of individuals with PMLD are not excluded from information on new interventions, therapies and innovative technology available to them. Moreover, the data collected from this study may give researchers the understanding on how to better include parents and work together to provide the best possible outcome for individuals with PMLD.

## A brief review of background literature

**B**radley (2020) states that the lack of relevant research that include individuals with PMLD is an issue that most researchers encounter. Nind (2013) adds that in the past, research was done with a professional or medical gaze. She believes that this made many people with learning disabilities and their families feel uncomfortable or unhelpful.

Harniss et al (2021) asserts that individuals with disabilities, including children with disabilities and special healthcare needs are frequently excluded from research. As a result of this, they become missing data which compromises the ability of health and educational systems. Harniss et al further explains that excluding individuals with disabilities in research would have implications to develop, implement and evaluate person-centred care, support and education services that address their needs. However White et al (2022) argues that parents of individuals with intellectual and developmental disabilities, are reported to be willing to

allow their children to participate in research when there are perceived benefits for their child.

On the other hand Shen et al (2016) argues that, parents of individuals with PMLD remain advocates for the voice of these individuals for most or the entirety of their lives. Furthermore, Sinclair et al (2019) asserts that parents strongly feel that they can and must have a voice in health and education research that will have a positive impact on their child's everyday life. Their study outlines that, parents' needs are often incongruent and researchers do not clearly understand the issues that are important to them. They further state that, parents and carers participating in research need to be involved in the process of prioritising research questions.

Parenting individuals with PMLD and complex medical conditions, can present a unique challenge that may not be faced by other populations. Shen et al (2016) therefore state that these parents have extensive knowledge about certain aspects of caring and understanding individuals with PMLD. They explain that parent involvement was largely absent from the conceptualisation of studies, demonstrating that professional researchers generally engage parents in research after the study focus has been finalised. They further state that the development of interventions, their implementations and impacts were largely observed when there was a greater level of parental engagement in the project (Shen et al, 2016).

In childhood disability research, engaging families, including parents and caregivers are recognised as essential to undertake research relevant to the needs of children and families (Pozniak et al, 2022).

A study conducted by Knisley et al (2021) outlines that some parents would like information about certain interventions or programs available for their children. They would like to be updated on the research teams and results of specific studies that may be of benefit to them. These findings mirror results from other studies and reviews that, have shown parents are interested in learning about the research and its results (Martin-Kerry et al, 2019).

However White et al (2022) argues that scholarly articles and research papers, are neither publicly accessible nor written in a way that an ordinary person can interpret. They suggest that the research community need to share research findings online with the support of non-profit foundations. This will enable everyone including parents and carers of individuals with PMLD, to have access to valuable information regarding their children.

**Methodology**

26 parents (21 mothers and 5 fathers) of young individuals with PMLD were invited to participate in an online survey. Parents from two special needs schools in the area, one a primary and other secondary schools participated in the survey.

**Survey questions and results**

1.Children with PMLD should have access to innovative learning and therapeutic methods, such as sensory based activities, yoga etc'. Do you agree with this statement?

Agree	25
Neither agree nor disagree	1
Disagree	0

2.Will you be interested in trying new and proven learning and therapeutic methods with your child at home?

Yes	25
No	0
Maybe	1

3.Do you know where to find information about these learning methods and interventions?

Yes	1
No	20
Maybe	4

4.Have you or your child been asked to participate in any research?

Yes	6
No	20

5.Have you come across any research for children with PMLD?

Yes	6
No	20

6.Were these research items easy to find?

Easy	3
Neither easy nor difficult	4
Difficult	12

**Possible limitations to the study**

All data collected for the study was gathered from parents of young individuals with PMLD. It is important to remember that these parents may be stressed and vulnerable individuals (Bradley, 2020), due to the complexity of the disability their child may have. Bradley also states that, some parents are easier to reach than others, though it is likely all parents have important views. This could be due to access to emails or internet facilities, other family commitments or parents with learning disabilities themselves. Bradley also stresses that language barriers could be another factor impacting on participation. Some parents may not speak English as their first language or may experience literacy difficulties, therefore it is important that support is provided when necessary (i.e. interpreters or phone call).

Another limitation to the study was the scarcity of literature on this research topic. Parent engagement and involvement (i.e. what parents want from the education system etc.) in education and schools, are explored by many researchers. However, finding literature on parental awareness around research, what parents expect from research and barriers they may face accessing research were a possible limitation to the study.

**Contact details**

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**Remember to tag us on social media ~ @PMLDlink**

Twitter: @PMLDlink

Facebook: PMLD Link

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

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

# COVID-19 and people with profound multiple learning disabilities: What did people tell us at Wave 4

Jill Bradshaw, Chris Hatton, Sue Caton, Amanda Gillooly, Andrew Jahoda, Rosie Kelly, Roseann Maguire, Edward Oloidi, Laurence Taggart, Stuart Todd and Richard Hastings

Our Coronavirus and People with Learning Disabilities Study has been collecting data from people with learning disabilities and family carers/support workers since 2020. The team wanted to make sure that the experiences of people with learning disabilities were visible during the pandemic. We have been collecting data from people with learning disabilities who were able to take part in an interview (cohort 1) and from family carers and support workers for people unable to take part in an interview themselves (cohort 2). Cohort 2 included people with Profound and Multiple Learning Disabilities.

Family carers, support workers and organisations who work to support people with Profound and Multiple Learning Disabilities, including PMLD Link and PAMIS, have worked with us to help us to ask the right questions. The research has focused on three key areas:

- What are the wellbeing, health, and social effects of the COVID-19 pandemic, including social restrictions and changes to how people are supported, on the lives of adults with learning disabilities across the UK over time?
- What actionable factors are associated with better outcomes for different groups of people with learning disabilities?
- What urgent issues concerning people with learning disabilities are emerging over time?

This article is a summary of the information about People with Profound and Multiple Learning Disabilities. The data on which this article is based was collected between September and December 2022, Wave 4. You can read the [full report](#).

## What did we collect information on?

In Wave 4, eighty-six family carers or support workers who completed the survey told us that they were answering about someone identified as having Profound and Multiple Learning Disabilities. People were living in all four nations of the UK. They mostly lived at home with family (66%). The mean age of the person with a Profound and Multiple Learning Disability was 33 years (16-73 years). Just over half of the group were male (56%) and 92% had been identified as being White British.

## What were key issues?

### COVID-19

Most people with Profound and Multiple Learning Disabilities (71%) were reported to have had COVID-19 and to have had COVID-19 vaccines (74%). Over a third of people with Profound and Multiple Learning Disabilities were reported to be still testing for COVID-19. Whilst the majority of the UK population were no longer taking any action regarding COVID-19, most people with Profound and Multiple Learning Disabilities were reported to be doing at least something to keep safe from COVID-19. This included shielding, staying away from groups and continued use of PPE. See figure 1 on the following page.

### Physical and Mental Health

By the end of 2022, around one third of people with Profound and Multiple Learning Disabilities (35%) were reported to have had a new health condition and/or an existing health condition that was getting worse in the four weeks before the survey. The health of people with Profound and Multiple Learning Disabilities was reported to be worse at Wave 4 than at any of the previous waves. At Wave 4, 28% of people with Profound and Multiple Learning Disabilities were waiting for a medical test and 65% of people had NOT had an annual health check since Jan 2022.

Like the general population, COVID-19 impacted people's mental health and wellbeing. We asked questions about whether people were feeling angry or frustrated, sad or down and worried or anxious. Whilst everyone in Cohort 2 who was not identified as having Profound and Multiple Learning Disabilities were generally reported to have felt less angry or frustrated, sad or down and worried or anxious over time, there was a different trend for people with Profound and Multiple Learning Disabilities. More people with Profound and Multiple Learning Disabilities

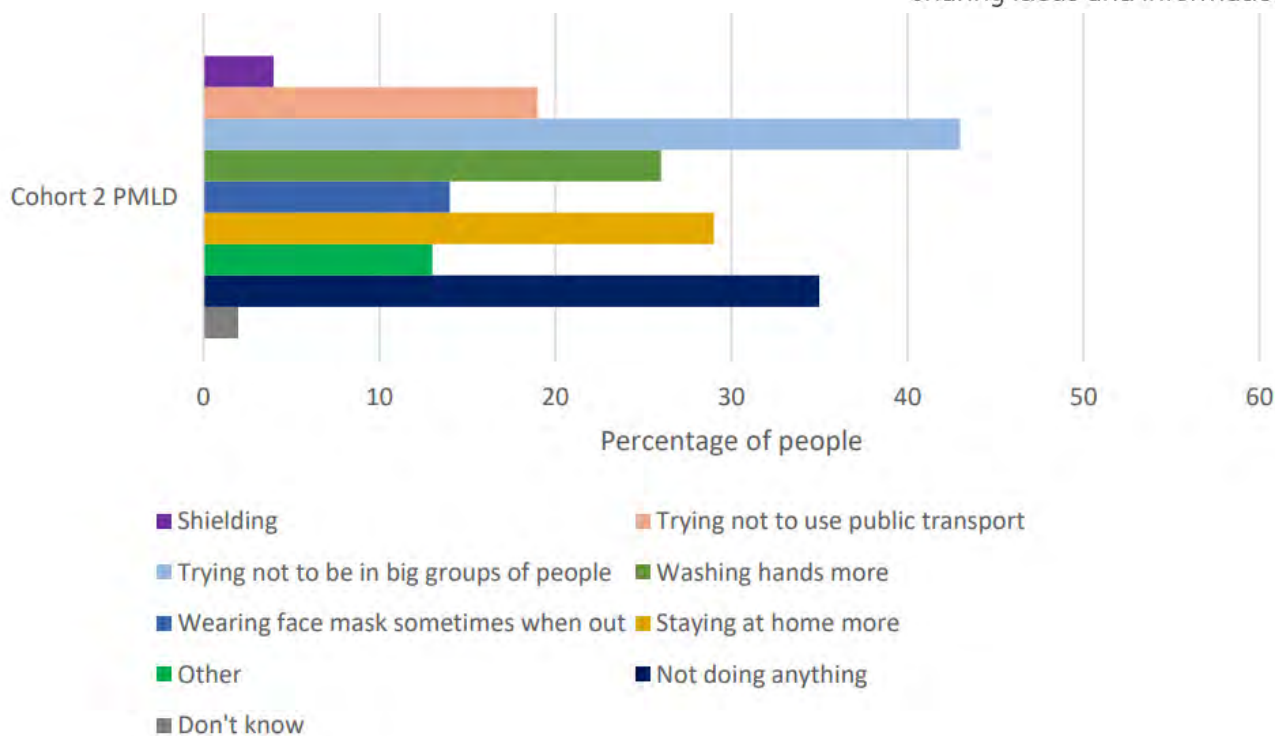


Figure 1 .1. What people with Profound Multiple Learning Disabilities are reported to be doing to keep safe from COVID-19 (tick all that apply)

were reported to be feeling angry or frustrated over time. More of this group were also reported to be feeling worried or anxious at the end of 2022 than was reported in Wave 3 (July to August 2021).

**Support**

Most people with Profound and Multiple Learning Disabilities (86%) were seeing family at least weekly by Wave 4. For those people with Profound and Multiple Learning Disabilities who were living in housing organised by services (34%), at least some form of visitor restrictions were reported to be in place for 29% of people.

At Wave 1 (December 2020 to February 2021), it was reported that 69% of people with Profound and Multiple Learning Disabilities used to regularly go to a day service before the pandemic. At Wave 4, 46% of people with Profound and Multiple Learning Disabilities were reported to have been to a day service in the last 4 weeks. In terms of community activities, the figures were 78% and 47% respectively. Personal assistants/support workers helping at home was also still lower at Wave 4 (62%) than reported at Wave 1 (71%). Fewer people with Profound and Multiple Learning Disabilities left the house for almost any reason compared to other people with learning disabilities at Wave 4. At Wave 1, 78% of this group reported regularly going out of the house with paid support before the pandemic. At Wave 4, only just over half of people with Profound and Multiple Learning Disabilities (55%) were reported to have been out of the house with people who

were paid to support them in the last four weeks. Although increasing over time, fewer people with Profound and Multiple Learning Disabilities were going to a short break or respite service (24%) in the last 4 weeks at Wave 4. At Wave 1, nearly half of people with Profound and Multiple Learning Disabilities (46%) were reported to be regularly using these services.

**Family carers of people with Profound and Multiple Learning Disabilities**

The self-reported general health of family carers of people with Profound and Multiple Learning Disabilities generally got worse from Wave 1 to Wave 4, with 48% of family carers of people with Profound and Multiple Learning Disabilities rating their health as fair or poor at Wave 4, compared to 38% at Wave 1.

We asked family carers about the impact of their caring role on their health and wellbeing. By Wave 4, reports of impact of their caring role on their health of feeling tired, stressed and disturbed sleep had increased in comparison to reports at Wave 1. By Wave 4, 94% of family carers of people with Profound and Multiple Learning Disabilities reported that at least one of the listed impacts of their caring role on their health applied to them.

Family carers and support workers of people with Profound and Multiple Learning Disabilities were asked when they thought that life might return to normal. Nearly a third of respondents (32%) thought that life for this group would never return to normal.



## Reflections

It is apparent that the impact of the COVID-19 pandemic was still being felt by people with Profound and Multiple Learning Disabilities and their family carers by the end of 2022. Most people with Profound and Multiple Learning Disabilities were not accessing services and community activities as much as they were previously. People with Profound and Multiple Learning Disabilities and those who supported and cared for them were still making adaptations to their lives to protect themselves and others from COVID-19. The physical health and wellbeing of People with Profound and Multiple Learning Disabilities were reported to be worse over time. Support and services had not returned to pre-pandemic levels in many areas. Almost all family carers reported that their caring role had impacted on their health.

In previous Waves, carers highlighted the need to prioritise the protection of existing skills of people with Profound and Multiple Learning Disabilities. We also identified three areas regarding what would make life better for people with Profound and Multiple Learning

Disabilities (Bradshaw et al, in submission). Carers suggested that they needed better access to health and social care, increased opportunities for social contact and activities and to be supported by consistent, responsive staff. In general, across all of the questions we asked at Wave 4, things were less positive for those people who had greater support needs and these differences have been increasing over time. We need to continue to highlight these inequalities and to prioritise the health and wellbeing of both People with Profound and Multiple Learning Disabilities and those who care for them.

## Contact details

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# In the Next Issue

The theme for the Winter issue is 'Access'. When thinking about access the mind can often automatically go to physical access within communities, public transport, toilets and the like. Access is much broader than that however, and within this issue we would value consideration of access in a variety of ways. Ultimately we all seek to benefit from a good life, a life which is fulfilling, meaningful and in which we feel valued – for people with profound and multiple learning disabilities that requires access to a wide range of opportunities, being present and heard, the right support at the right times. It also relies on the interdependence we have on each other. If life in general is accessible for people with profound and multiple learning disabilities, then it follows that life is accessible for us all.

The 'Supporting people with profound and multiple learning disabilities, Core & Essential Service Standards' focus on aspects of life that are considered important for us all to live a full and 'accessible' life. Inspiration may be drawn from the standards related to individuals, but the request is to be as creative as possible, and where there are barriers to access, please offer solutions and examples of how those barriers are overcome. Please submit contributions by the 30th of October 2023

The Winter 2023 issue editors are Annie Fergusson, Michael Fullerton, Maureen Phillip and Wendy Newby

All contributions by 30th October 2023 please.

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



## Using lived experience in research

Catherine de Haas

This article is about communication, different types of knowledge, my various identities and how all this comes together in my research.

### Various Identities and different types of knowledge

This is a photograph of our daughter Johanna smiling, because she had a brilliant smile that lights up your heart and it is her smile which people remember about her. One of the ways that I would describe myself is as her mother, or the mother of a person who lived with PMLD for 31 years. She would be 35 if she was alive. This experience of living together is a source of knowledge for me and through me for our research group at the University of Southampton, where I am studying a PhD with Melanie Nind and Jo Hope as my supervisors. The rest of our small research group is Jo Grace, Elspeth Clark, David Haines, and Jill Goodwin. We are all focusing on the belonging of people with PMLD. The seven of us have shared interest in people with profound and multiple learning disabilities (PMLD) and how to support them in belonging, learning and living a good life'. We are clear that we are not doing this 'for' them or 'on' them, but 'with' them.

I am using the label people with PMLD because I am writing this article in the UK, where this is the widely used term. It is not comfortable to label Johanna and people like her as 'people with PMLD' (Goodwin and Griffiths, 2022; Nind and Strnadova, 2020). I am reluctant to use their deficits to mark them out. They are people before they are people who have a different way of being in the world because of their characteristics. I aim to increase the understanding of their life experiences, and to do this I need words to talk about them. For practical reasons I have chosen to write the abbreviated version 'people with PMLD' rather than the more cumbersome and word count consuming 'people with profound and multiple learning disabilities'.

As I write this article, I am adding my knowledge, skills and experience as a speech and language therapist, to my knowledge as a mother and a PhD student. I qualified 10 years before Johanna was born and worked for a further 13 years during her childhood. A great deal of my professional work was with people with learning disabilities and as it dates back to 1978 - 1975 if you

count my training - it includes work in the old institutions. However, I describe myself as a person who used to be a speech and language therapist, as I have not worked in a clinical setting since 2001. A fourth way I can describe myself is as retired, as I am old enough to qualify for a state pension.

These identities lead to different types of knowledge: 'professional knowledge', 'parental/familial knowledge' and 'scientific' knowledge' which intersect and create tensions. Some of those tensions play out inside me, my 'inner cop' can be my own parents' voice absorbed in my childhood or I can talk to myself as a speech therapist, or as Johanna's mother or my other daughter's mother, or my grandsons' grandmother or as a doctoral researcher or as a person who would otherwise be retired. How do I use these voices, tensions, and knowledges in my research?

### Communication

I am going to take the example of communication to illustrate what happens in my reflective processes. I made this choice in part because of my professional background. Thinking about communication is one of my default settings.

When Johanna was born, I considered myself an experienced therapist with knowledge about how people communicate. I had been qualified for ten years! It was a strange experience to receive speech therapy as the mother of a child with cerebral palsy. It was difficult to know how to react, when the speech therapist explained to me that the communication that I was doing with Johanna was intuitive. I knew it was more complex than that suggests. How it was more complex was difficult to put into words. I am going to try so bear with me. I wrote a long piece about communication for my thesis. Let's see if I have managed to have a breakthrough and I am able to describe succinctly the science behind my inner tension as my knowledge as a mother and a speech and language therapist struggled for a diplomatic response when faced by increasingly young speech and language therapists who were being paid to help us. Was my communication with Johanna just intuition? If it was, I was appallingly bad at intuition judging by the times when Johanna was upset, and I did not know why. I used to resolve it by trying this and that until something worked. Eventually, I was using experience of previous episodes of upset and knowledge of her as a person to calm her. Kruithof and colleagues (2020) described this same phenomenon that parental knowledge develops by trial and error over time.

### A small story

In my research I plan to take photographs of my co-researchers who will have PMLD and collect stories alongside them. This is an idea inspired by the work of

Bamberg and Georgakoploulou, (2008). These stories I will thematically analyse until the story of my research emerges to answer my research question: How is community experienced by people with profound and multiple learning disabilities (PMLD) and their families?

Before I go deeper into the science or research knowledge I suggest that you look at the other photograph in this article as I tell you a small story. In the photo Johanna is enjoying the company of Katie whom she had just met. (They are not just smiling for the camera. Johanna could not do that anyway).



Johanna enjoying the company of Katie.

There were people who we met, who seemed to know how 'to be' with Johanna. Katie is one and her hairdressers, Helen Chester and Stacey Tomlinson, other examples. These hairdressers had an interchangeable social routine with Johanna. If Helen was unavailable Stacey cut Johanna's hair and vice versa. I was having my hair cut when I was planning this presentation, so, I was able to ask Helen what she saw in Johanna when she cut her hair. Their relationship lasted for probably around twenty years. Helen talks from knowledge and experience. Helen said she saw her smile and lots of hair. There was lots of noise, but she worked around it. Johanna did not like having her head touched and expressed this clearly. Toward the end of her life there was a pump feed on the back of Johanna's chair. Helen worked around this too, she just went off and found the clothes pegs that she kept in her shop specially for Johanna. These were used to join two hairdressers' gowns, one for the front of the chair and one for the back of the chair, pegged together down the sides of the chair. If Johanna moved forwards in her protest Helen



cut the back of her hair and if she moved her head back Helen cut the front of her hair. She worked fast, deftly and with skill. Helen kept calm and turned up the music on the radio. Johanna loved music and Helen knew that by experience.

### **Bringing various identities, different types of knowledge, communication and the stories of people with PMLD with research.**

**H**ow does this experience of being in the hairdressers relate to our family's wider experience of being with people in the community? There were variations in people being comfortable in being with Johanna and abandoning verbal communication. They may be afraid of looking undignified, or ridiculous, or that other adults would think less of them if they acted in a playful manner with her (Caldwell, 2007). To interact with a person with PMLD you must believe that they are a person, believe in them and believe that they recognise you (Forster and Iacono, 2008). Some people need to put down their own ways of being to create a relationship with the person with PMLD (Caldwell, 2007). Bos describes how when he was doing research alongside people with PMLD that he felt discomfort with non-verbal encounters as a verbal person (Bos and Abma, 2021). These encounters felt 'eerie, confusing, frightening, and even threatening', (p. 7), unless he was in a position of doing a care task. Yet, other people feel comfortable when they meet people with PMLD for the first time. This was true of Katie in the photograph, and Helen and Stacey the hairdressers in my story.

What creates these differences in people so that some people appear to communicate intuitively, while other people struggle to cross a communication chasm that did not exist for me? I wanted to know what they were feeling, so that I could help them and Johanna to directly interact. Martin and colleagues (2022) developed the 'Theory of Reconciling Communication Repertoires' and this provides some answers. This theory says that communication partners need to have skills or strategies in their communication repertoire that they can reconcile or match to each other. The person with PMLD may be motivated to interact and be trying to create a connection with a verbal person, but the verbal person may miss their overtures because the verbal person has low motivation to interact, low expectations, the overtures were too subtle or because there are other people in the environment with whom they can have a less effortful conversation.

Also, it takes time to learn to communicate with a person with PMLD (Forster and Iacono, 2008). Helen and Stacey had decades in which they routinely interacted with Johanna. Johanna lived with idiosyncratic communication methods which affected her interactions with us. We were overcoming barriers to communication such as

Johanna's level of alertness and her sensory and physical impairments. We could not use previously taken for granted everyday communication methods (Forster and Iacono, 2008). We talked to each other about what worked. As Kruithof and colleagues found in their synthesis of empirical research (2020), parents develop deep knowledge of their children with PMLD which they transfer to others. A haircut is a social routine which can lead to the development of communication and understanding of how to relate to each other. It can be a high-quality interaction if the hairdresser is emotionally responsive like Helen and Stacey. These everyday social routines are crucial to the quality of life of persons with PMLD. I will explore experiences of community like these with people with PMLD and their families during my research. As I conduct my research I will use my awareness of my different ways of knowing which have resulted from my various identities. I have a hunch that more ways of knowing will emerge as I collect stories alongside people with PMLD and their families.

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# IN THE NEWS

**The Challenging Behaviour Foundation**  
making a difference to the lives of people with severe learning disabilities

## What Matters to Me:

*Influencing policy with the experiences, preferences and views of young people with severe or profound and multiple learning disabilities*

THE **Blagrove** TRUST  
Supporting young people

#iwill

Department for Digital, Culture Media & Sport

COMMUNITY FUND

SUPPORTED BY **BBC CHILDREN IN NEED**

## What Matters to Me’ – new project launched by the Challenging Behaviour Foundation

The Challenging Behaviour Foundation is excited to share details about our new project which is just getting underway. ‘What Matters to Me’ will bring together the experiences, preferences and views of young people with severe or profound and multiple learning disabilities through relationship building and the use of creative engagement methods. From this, a multi-media manifesto will be developed to evidence the findings, ensuring that these young people who may not use conventional methods of communication are consulted and included in things that impact upon their lives. We will use this impactful manifesto to influence policy with key stakeholders.

The project will be run with young people aged 16-25 years across various settings in the Southeast of England. We have partnered with two local organisations; a local children's hospice/respite care, and a post-16 educational provision to work in partnership with their expert staff and use their facilities to carry out the project engagement. The CBF project officer will also be working with individuals within their own homes. The first phase of this project will involve building relationships with young people, gathering information about their communication needs and learning from those who know them best.

Phase two will involve carrying out a range of various engagement activities; following on from previous work with the Seldom Heard Voices project and using the methodology developed by the leading academics at the Tizard Centre.

The project will focus on transition and the evidence obtained from our engagement work will be documented and become an instrumental tool in being able to demonstrate that this group of young people who are often not consulted, can and should be. We hope that the findings from this project will provide invaluable learning and positive changes in relation to transition from childhood to adulthood for young people with severe or profound and multiple learning disabilities. What Matters to Me is a 3-year funded project and we are very grateful to the Blagrove Trust and Children in Need for funding this vital piece of work.

To find out more about the project, ask questions or sign up to our network list: [whatmatterstome@theCBF.org.uk](mailto:whatmatterstome@theCBF.org.uk)

## A new study on Down syndrome

Learning Disability Today have recently reported on a new study published in The Lancet. They state: The study has examined 33 health conditions associated with Down syndrome and the risk of multiple morbidity across the lifespan.



Using this evidence, the authors of the study have suggested specific health guidelines to give people with Down syndrome the best chance of living long and healthy lives.

The research is the largest study of multiple morbidity in Down syndrome and those with other forms of learning disabilities to date in comparison with the general population.

Read the full Learning Disability Today piece here: [www.learningdisabilitytoday.co.uk/new-study-explains-how-people-with-down-syndrome-can-lead-longer-healthier-lives](http://www.learningdisabilitytoday.co.uk/new-study-explains-how-people-with-down-syndrome-can-lead-longer-healthier-lives)

Read The Lancet article on the research here: [www.thelancet.com/journals/lanpub/article/PIIS2468-2667\(23\)00057-9/fulltext](http://www.thelancet.com/journals/lanpub/article/PIIS2468-2667(23)00057-9/fulltext)

## Accessing continence supplies

Cerebra, a national charity dedicated to helping children with brain conditions and their families, have received frequent reports from families about the difficulties they have encountered when trying to access continence supplies for their disabled child. As a result, their Legal Entitlement and Problem-solving Team (LEaP) are carrying out a survey in co-ordination with the University of Leeds' School of Law under the supervision of Professor Luke Clements, Cerebra Professor of Social Justice.

They want to understand more about the experiences of families of disabled children who have encountered these kinds of difficulties, when/ how they happened and what the consequences were for the family. They are also interested in any possible explanation about the refusal/ limitation of continence supplies provided to people by their local health services.

They have compiled a list of useful resources/ information for anyone who may have encountered such difficulties in accessing suitable continence supplies: <https://tinyurl.com/bdzvyc8k>

Cerebra plan to publish the findings of this research in the Spring of 2024

## Co-production Week 2023

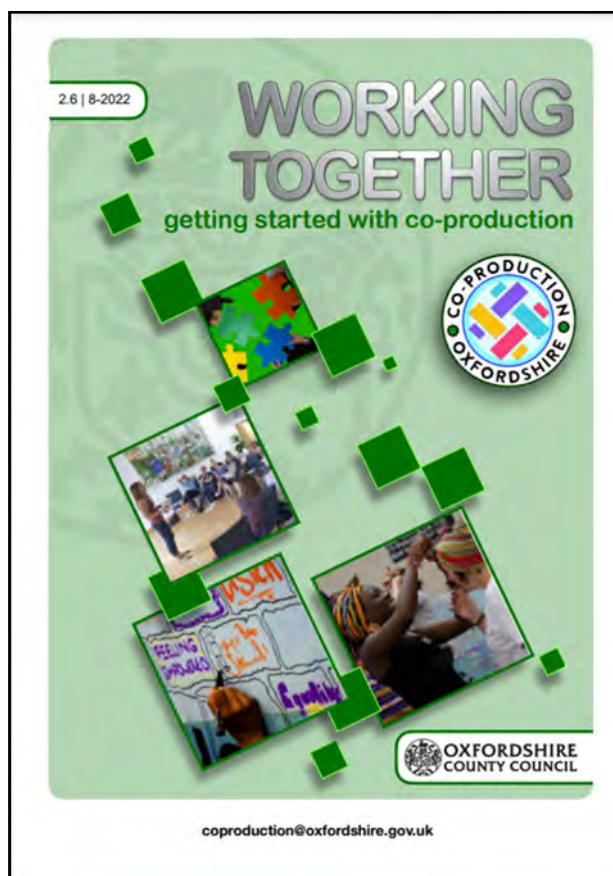
National Co-production Week was back for an eighth year in July 2023. It celebrated the benefits of co-production, shared good practice and promoted the contribution of people who use services and carers in developing better public services.

Co-production is about working in equal partnership with people using services, carers, families and citizens. Co-production offers the chance to transform social care and health provision to a model that offers people real choice and control.

Working Together, from Oxfordshire County Council, is just one of many useful guides to getting started in co-production.

View or download this resource: <https://www.oxfordshire.gov.uk/sites/default/files/file/our-work-communities/WorkingTogether.pdf>

For more information and signposting to resources search #coproweek #coproduction on social media



## Launch of NHS Constipation Campaign & Resources

People with a learning disability are much more likely to experience constipation, and to have their symptoms overlooked.

Constipation can be a life-threatening issue for people with a learning disability who are at heightened risk from complications if it is left untreated.

The NHS have developed resources to:

- Drive awareness of the seriousness of constipation
- Help people recognise the signs of constipation at an early stage
- Empower people to take action and ensure that people with a learning disability experiencing constipation get the right health support straight away
- Raise awareness of the steps which can be taken to prevent Constipation.

Get involved in the campaign and download the resources at:

[www.england.nhs.uk/publication/constipation-campaign-toolkit](http://www.england.nhs.uk/publication/constipation-campaign-toolkit)



## Freestyle – new exhibition in national gallery



So often when we hear talk about opportunities for people with profound and multiple learning disabilities (PMLD) in the community there is sometimes a sense that there isn't much available for them and what is out there isn't always purposeful or meaningful to them. We ask that you take time to visit the current exhibition titled 'Your Art World' at the National Galleries in Edinburgh. Here you will find Freestyle, a display by young artists with PMLD whose artwork is part of a larger exhibition.

The opportunity given by the galleries last summer to the families to participate in the current exhibition highlights what can be achieved by working together. This exhibition is not only a wonderful display of amazing artwork by people with PMLD, it is a celebration of how working together to create a more inclusive society provides a sense of belonging for those who often feel marginalised.

For more about the exhibition please click on the link <https://app.smartify.org/groups/your-art-world-t9bso>

## New guidance on best practice in preventing aspiration pneumonia

NHS England have published 'RightCare learning disability and aspiration pneumonia scenario'. NHS England's RightCare scenarios put the person at the centre of the story. They use fictional patients to show the difference between a suboptimal, but realistic, pathway of care compared to an optimal one.

Read the RightCare learning disability and aspiration pneumonia scenario here:

[www.england.nhs.uk/publication/rightcare-learning-disability-and-aspiration-pneumonia-scenario/](http://www.england.nhs.uk/publication/rightcare-learning-disability-and-aspiration-pneumonia-scenario/)



## Supported Decision-Making - new guidance launched by Paradigm

At a recent launch event, the main authors of this new resource presented an overview of some of the challenges people face to being meaningfully involved in having a say in decisions about their own lives and the legal frameworks in which these take place. This practical guide is a considered response to these challenges, with ideas and creative examples to meet a wide range of needs, including those of people with profound and multiple learning disabilities.

To download guidance and access the launch webinar recording here: <https://paradigm-uk.org/resources-reports/>



## The Inbetweeners – An NCEPOD report about the transition from child into adult healthcare

In June 2023, the National Confidential Enquiry into Patient Outcome and Death (NCEPOD) published 'The Inbetweeners: A review of the barriers and facilitators in the process of the transition of children and young people with complex chronic health conditions into adult health services'.

Read the report here:

[www.ncepod.org.uk/2023transition.html](http://www.ncepod.org.uk/2023transition.html)

## Oliver McGowan draft code of practice – consultation launched

This consultation considers the draft code and if it gives CQC registered providers the guidance needed to meet the legislative requirement to ensure all staff receive learning disability and autism training appropriate to their role.

The views and feedback gathered from this consultation will inform the final version of the code to be laid in Parliament.

The consultation is open until 19th September 2023. Find out more, read the draft code and submit a response here: <https://www.gov.uk/government/consultations/oliver-mcgowan-draft-code-of-practice>





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

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

The PMLD Standards are available on the home page of the PMLD Link website:

<https://www.pmlmlink.org.uk/>

An article may be found in PMLD Link, Vol. 30 No. 1, Issue 89 (Spring 2018), pages 2-5.

‘Raising standards - a clarion call to meet the challenge!’

by Annie Fergusson, Joanna Grace, Michael Fullerton and Thomas Doukas

# REPORT BACK

## The International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) Profound Intellectual and Multiple Disabilities (PIMD) Special Interest Research Group (SIRG) Conference 2023

by Julia Barnes and Rosie Rushton

The International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) Profound Intellectual and Multiple Disabilities (PIMD) Special Interest Research Group (SIRG) met in Leuven, Belgium in February 2023. This short article aims to raise awareness of the event, provide an overview of happenings and reflect on research involving people with PIMD internationally.

The conference took place in a hybrid format with approximately 50 people attending in-person and a further 15 attending online. Delegates were predominantly academics and included people from across Europe, Scandinavia, Japan, America and Canada. Several professionals such as doctors and speech and language therapists also attended.

### Participating

There were numerous presentations across the three-day event. There were examples of laboratory-based scientific research, such as Dr Juliane Dind from The University de Firbourg, Switzerland. Dr Dind presented research on the positive and negative responses of her participants with profound and multiple learning disabilities (PMLD) to scents. It was interesting to see and learn about laboratory-based research and consider the ethics of exposing participants with PMLD repeatedly to experiences which they might find unpleasant. Other research investigated social and philosophical questions involving people with PMLD. Dr Virginie Cobigo, from The University of Ottawa, Canada,

questioned whether social inclusion could be an achievable outcome for people with severe to profound intellectual disabilities. After which the delegates of the conference spent time together discussing how and what belonging for people with PMLD might be, and what this entails. Again, it was interesting to gather, and consider, international perspectives on this important topic.

A particularly interesting symposium that discussed Tacit Knowledge in the Care and Support for Persons with PMID, was presented on the second day of the Roundtable event by researchers from The Netherlands, Marga Nieuwenhuijse, Kasper Kruithof and Maartje Hoogsteijns. It considered how caregivers and professionals' use embodied knowledge in order to sense, read and feel when engaging with a person with PMLD who they know well. The presentation discussed how this tacit knowledge may develop, its value, and how it could be transferred within the team of individuals supporting a person with PMLD.

### Presenting

At the Early Career Research's meeting we presented on the methodological aspects of our research, discussing how we were doing the research, and what we were doing. The two presentations were entitled; *Developing Inclusive Research: A Participatory Design With Proxies Method*, and, *Exploring How 'Photovoice' Might be Captured for People with Profound and Multiple Learning Difficulties*.

The following day we both presented with a focus on the importance of acknowledging the preferences of people with PMLD in presentations entitled, *Exploring the Musical Preferences of People with PIMD and 'Listening' to the Touch Preferences of a Teenage Participant with PIMD*.



Julia presenting 'Listening' to the Touch Preferences of a Teenage Participant with PIMD.



### Reflecting

Networking at the conference and evening social events allowed for more conversations and a greater understanding of the perspectives of, and research involving, people with PMLD internationally. Doctoral study appeared to have greater accolade in Europe, with students working as part of a wider team, contributing to research that is often influenced by governmental agendas.

One of the most reassuring experiences of attending a conference with delegates from many Western countries was that we all seemed to be investigating similar topics, motivated by similar concerns, and attempting to answer similar research questions. The main themes highlighted across the conference were communication, inclusion and belonging, balancing the care needs of people with PMLD and supporting their families and carers. There were multiple perspectives and methodologies deployed in trying to answer a huge variety of research questions, however it was encouraging to hear of research being conducted across the world which involved people with PMLD.

Attending and presenting at conferences such as this one is a privilege. We would like to acknowledge and thank the people with PMLD and their families, carers and teaching staff who have shared their time, thoughts and lives in participating in, and contributing to, this research so far.

More information on the IASSIDD and future events can be found online: <https://iassidd.org/sirgs/profound-intellectual-and-multiple-disabilities>

Contact details: Julia Barnes and Rosie Rushton are both doctoral researchers supervised by Associate Professor Lila Kossvaki in the Department of Inclusion and Special Needs (DISN) at the University of Birmingham.

Julia's research interests are focused on the touch experiences of people with PMLD, her attendance at the conference was supported by the COSS PGR Student Development Fund, University of Birmingham.

Rosie's research is focused on music, playfulness and people with PMLD. Rosie is supported by the Economic and Social Research Council (ESRC).

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## Diverse perspectives from the frontline of international research – a review of the Nordic Network of Disability Research (NNDR) conference

By Elspeth Clark

The NNDR is a multidisciplinary network which focuses on the cultural, social, and environmental dimensions of disability and marginalisation; themes that resonate strongly with my work as a doctoral researcher and as an occupational therapist. I embarked on my doctoral studies in September 2022, and I aim to work collaboratively with young people with profound and multiple learning disabilities to establish an understanding of the relationship between engaging in meaningful occupations and the experience of belonging.

The NNDR conference is held bi-annually, this year in Reykjavik, Iceland and the next conference in 2025 will be in Helsinki, Finland. What follows is a summary of the research highlights from the conference, relating to people with profound and multiple learning disabilities in particular:

The range of speakers and presenters was vast, including issues as diverse and compelling as the sterilisation of deaf people by the Finnish state through to the challenges and support that Nepali mothers of children with intellectual disabilities encounter, and everything in between. The conference programme is available here: <https://nndr2023.is/programme/> for further information.

Over the preceding days before the conference began, the University of Iceland hosted two workshops aimed at PhD students in the field of Disability Studies. These were very popular and PhD students from several countries presented their work. This included Maren Hueffmann from Brunel University, London. Maren is exploring the construction of personhood for disabled children with complex needs (see page 31). In her paper, she highlighted the marginal position of children with profound disabilities in education as well as in UK society in general. The rift between ideology and the lived experience was discussed, and how both students and staff are expected to be able to manage this.

The conference programme was packed, and detailed

planning was required to navigate the timetable. Presentations were in myriad locations across two hotels and unfortunately timetabling clashes meant I was unable to attend all the talks I had hoped to see. Sessions I missed that related directly to people with profound and multiple learning disabilities included a discussion on the experiences of fathers who care for adult children (by researchers from the The Maria Grzegorzewska University, Poland) and a presentation on the findings from a survey conducted by researchers from across the UK which explored the impact of the Covid 19 pandemic, (see page 37 in this journal for further information on this study or in this article <https://onlinelibrary.wiley.com/doi/10.1111/bld.12501>).

These examples illustrate how research relating to many aspects of the lives of people with profound and multiple learning disabilities was represented on the programme, and that Disability Studies as a genre absolutely includes research where people with very profound disabilities are included as subjects. Presentations relating to projects where researchers worked alongside people with learning disabilities were also included in the programme, but these were mostly limited to research co-produced with people with mild to moderate cognitive disabilities.

There were limited exceptions to this. Synne Nese Skarsause from VID University in Norway presented work relating to embodied ways of being and people with profound intellectual and multiple disabilities. She highlighted how certain characteristics can support the empathic process – enhancing the possibility of empathy as a tool for connection. Synne suggested that despite the challenges inherent in this approach, the concept of empathy could contribute to supporting the inclusion of people with profound and multiple learning disabilities in the research process, positioning them as subjects of knowledge.

Later on the first day, Catherine De Haas, my colleague from the Centre for Research in Inclusion at the University of Southampton, continued on this theme and delivered a presentation on the use of ‘small stories’ to extend the boundaries of inclusive research to people with profound disabilities (see page 40). Catherine discussed her research plan, illustrated with ‘small stories’ from her own experience of living for 31 years with her daughter, Johanna. Catherine’s work aims to explore the experience of belonging and community for people with profound and multiple learning disabilities and their families.

Simo Vehmas, from Stockholm University, also gave a presentation on the first day. He has written extensively on philosophy relating to the lives of people with profound and multiple learning disabilities (for example

Vehmas & Mietola, 2021). His talk concentrated on the management of language relating to people with learning disabilities in Sweden, with a focus specifically on the term “flerfunktionsnedsättning” (which is the official Swedish equivalent for Profound intellectual and multiple disabilities). Simo highlighted the need to utilise vocabulary that is accurate and appropriate both in evaluative and descriptive terms. This discussion on terminology followed a previous presentation by Melanie Rimmer from the Open University and Cameron Richards from The West Midlands Self Advocacy Network where they discussed the social construction of learning disability. In their presentation, they referred to the “euphemism treadmill” that exists in relation to labels used to describe people with learning disabilities. As a researcher from the UK, I identified with this, having changed the language of my poster to use the term intellectual disabilities but using learning disabilities at University and at work. Cameron has a learning disability and co-presented two sessions at the conference. There were other presentations delivered by people with learning disabilities and their allies, for example, the members of the ‘My Life My Choice’ research group led a discussion on ‘Sticky labels and their consequences: people with learning disabilities and “behaviours that challenge others”’. The physical presence of people with learning disabilities at the conference felt significant but also highlighted how people with profound and multiple learning disabilities were conspicuous by their absence. The conference venue was physically accessible, with large lifts and wheelchair-friendly transport available between the conference hotels and the airport. It may have been possible to hire specialised equipment such as hoists locally, but perhaps the complexity (and cost) of travelling to Iceland and the somewhat frenetic atmosphere of international conferences worked against people with the most complex disabilities from attending.

On the second day, I presented my poster. This detailed the theoretical perspectives on which my early PhD work has focussed so far, illustrating the connections between co-occupation and belonging for people with profound intellectual and multiple disabilities, drawing on social and occupational science theories. The overarching concept behind my research is that, fundamentally, the interpersonal connection of people to each other as they engage in meaningful occupation can foster a sense of belonging (Wilcock, 2015). Co-occupations are defined as interactive occupations where the experiences of the people involved are reliant upon the engaged responses of the other person (Pierce, 2009). Reciprocity is considered a key factor in facilitating engagement in co-occupations, and while authentic occupational engagement for people with profound disabilities necessitates the development of familiar and responsive relationships (Haines, 2015), these relationships are

characterised both by dependency and reciprocity (Skarsaune, 2022).



I conclude by discussing the final keynote address, delivered at the very end of a packed day of seminars and presentations. This needed to be remarkable to cut through the attention weariness of the conference attendees. However, the presentation easily captured the attention of the audience. It was delivered by Marjorie Aunos, PhD., who is an international researcher and clinical psychologist from Canada. Marjorie is also chair of the Parenting and Parents with Intellectual and Developmental Disabilities Special Interest Group (SIRG) hosted by the International Association on the Scientific Study on Intellectual and Developmental Disabilities. Following a road traffic accident, she became a disabled parent, and her keynote address included her reflections on the stigma and challenges she has encountered as a newly paraplegic single parent (her son was 16 months old at the time of the accident). This was a moving and memorable ending to the conference – her story of recovery is one of resilience and hope in the face of extreme adversity. The presentation ended with the suggestion that everyone could reflect on how perhaps

we are all only ‘temporarily able’, and that challenging the dominance of ableism within society is of fundamental importance to everyone.

Acknowledgement: I was grateful to be awarded funding from the ESRC South Coast Doctoral Training Partnership and the Royal College of Occupational Therapists which enabled me to attend this conference

### Contact details

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Vehmas, S., Mietola, R. (2021) *Narrowed Lives: Meaning, Moral Value, and Profound Intellectual Disability*. Stockholm: Stockholm University Press. <https://doi.org/10.16993/bbl>

Wilcock, A. A. and Hocking, C. (2015) *An Occupational Perspective of Health*. Third edn. Thorofare, NJ: SLACK.

## Advice About Legal Issues

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

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

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

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

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

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

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

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

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

## COURSES, CONFERENCES AND EVENTS IN 2023

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

August 2023		October	
Title: Date: Location: Provider: Contact:	Fire Songs 11-12 August Kings Cross Sounds Festival, London Frozen Light Theatre Co. <a href="https://tinyurl.com/4h66ha83">https://tinyurl.com/4h66ha83</a>	Title: Dates: Location: Provider: Contact:	Intervenor Course – 5 days 2-3, 17-18, 30 October Romford, Essex Jenny Fletcher RAV.MDT@limetrust.org
September		Title: Date: Location: Provider: Contact:	Adult sibling day 7 October YHA London Lee Valley Hostel Sibs info@sibs.org.uk
Title: Date: Location: Provider: Contact:	Intensive Interaction 1st September Online by zoom Janet Gurney, Us in a Bus <a href="mailto:info@usinabus.org.uk">info@usinabus.org.uk</a>  £75 per person; £25 for parents/ family carers/students; 2 free bursary places available	Title: Provider: Contact:	The Bar at the Edge of Time – Frozen Light 2 performances each day: various dates & venues Frozen Light Theatre Co. <a href="https://www.frozenlighttheatre.com/tour-dates-the-bar">https://www.frozenlighttheatre.com/ tour-dates-the-bar</a>
Title: Date: Location: Provider: Contact:	24-hr Postural Care from Cradle to Grave 6 September Online Born at the Right Time training@bornattherighttime.com	Date: Location:	3-4 October Malvern
Title: Date: Location: Provider: Contact:	Kidz to Adultz Wales Thur, 21st Sept, 09.30 - 16.30 International Conference Centre, Newport, S.Wales Kidz to Adultz Tel: 0161 214 4592. Email: kidzteam@disabledliving.co.uk	Date: Location:	6-7 October Porthcawl
Title: Dates: Location: Dates: Location: Dates: Location: Provider: Contact:	The Bar at the Edge of Time – Frozen Light (various dates & venues: 2 performances each day) 19-23 September Norwich 27-28 September London 29-30 September Bristol Frozen Light Theatre Co. <a href="https://www.frozenlighttheatre.com/tour-dates-the-bar">https://www.frozenlighttheatre.com/ tour-dates-the-bar</a>	Date: Location:	10-11 October Brentwood
		Date: Location:	12-14 October Didcot
		Date: Location:	18-20 October Peterborough
		Date: Location:	23-25 October Blackwood, Caerphilly
		Date: Location:	30-31 October Worthing
		Title: Date: Location: Provider: Contact:	Sensory learning: a practical guide for support staff 18 October Online Hirstwood Training <a href="https://hirstwood.com/virtual-courses/">https://hirstwood.com/virtual-courses/</a>
		November	
		Title: Date: Location: Provider: Contact:	24-hr Postural Care from Cradle to Grave 1 November Online Born at the Right Time training@bornattherighttime.com



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

Title:	Personalised Care- Rhetoric to Reality
Date:	2 November
Location:	Online
Provider:	Born at the Right Time
Contact:	training@bornattherighttime.com
Title:	Difficult Conversations-Challenging Situations
Date:	8 November
Location:	Online
Provider:	Born at the Right Time
Contact:	training@bornattherighttime.com
Title:	The Bar at the Edge of Time – Frozen Light
	2 performances each day: various dates & venues
Provider:	Frozen Light Theatre Co.
Contact:	<a href="https://www.frozenlighttheatre.com/tour-dates-the-bar">https://www.frozenlighttheatre.com/tour-dates-the-bar</a>
Date:	1-3 November
Location:	Harlow
Date:	7-8 November
Location:	Cambridge
Date:	9-11 November
Location:	Colchester
Date:	14-16 November
Location:	Reading
Date:	21-23 November
Location:	Borden
Date:	24-25 November
Location:	Woolwich
Title	Intensive Interaction
Date:	16 November
Location:	Online
Provider:	Us in a Bus
Contact:	info@usinabus.org.u
<b>December</b>	
Title	Intensive Interaction
Date:	13 December
Location:	Online
Provider:	Concept Training
Contact:	<a href="https://www.concept-training.co.uk/book/">https://www.concept-training.co.uk/book/</a>
<b>January</b>	
Title	24-hr Postural Care from Cradle to Grave
Date:	24 January
Location:	Online
Provider:	Born at the Right Time
Contact:	training@bornattherighttime.com
Title	PMLD Conference
Date:	24 January
Location:	Facebook
Provider:	The Sensory Projects/Jo Grace
Contact:	Yet to be advised!

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

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

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

### The Sensory Projects ([www.thesensoryprojects.co.uk/conferences-training](http://www.thesensoryprojects.co.uk/conferences-training))

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

For online study opportunities visit The Sensory Projects Online College.

### NAC ([www.nacwellbeing.org](http://www.nacwellbeing.org))

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

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

New course starts 3 January 2023, weekly over 5 months

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

Contact: [julie@nacwellbeing.org](mailto:julie@nacwellbeing.org)

<p><b>Story Massage Programme</b> (<a href="http://www.storymassage.co.uk">www.storymassage.co.uk</a>)</p> <p>Story Massage offers online training courses and easy to access resources. These are for those wishing to use the Story Massage Programme at home or work. You can study at your own pace. You have full access to the online course materials for 6 months.</p> <p>Contact: 07899813659 or <a href="mailto:info@storymassage.co.uk">info@storymassage.co.uk</a></p>
<p><b>Pamis</b> (<a href="https://pamis.org.uk/services/training">https://pamis.org.uk/services/training</a>)</p> <p>Pamis offers face to face courses, events and other training and development opportunities for family, paid carers and practitioners.</p> <p>Contact: <a href="mailto:fiona.harper@pamis.org.uk">fiona.harper@pamis.org.uk</a> to book or make enquiries</p>
<p><b>Postural Care – Simple Stuff Works &amp; Born at the right time</b> (<a href="https://www.simplestuffworks.com/training">https://www.simplestuffworks.com/training</a>)</p> <p>A range of opportunities and CPD accredited modules, including:          Introduction to 24-hour postural care (half day workshop)          24-hour postural care: Hands-on training for the workforce          24-Hour Postural Care: Getting to the Core of the Problem</p> <p>Contact: <a href="mailto:admin@simplestuffworks.co.uk">admin@simplestuffworks.co.uk</a></p>
<p><b>Born at the Right Time</b> (<a href="http://www.bornattherighttime.com">www.bornattherighttime.com</a>)</p> <p>For 2023, a host of new courses are being launched, from entirely on-line courses to be completed at your own pace to in-person advance practitioner events.          See website for more details</p>
<p><b>Hirstwood Training</b> (<a href="https://hirstwood.com">https://hirstwood.com</a>)</p> <p>Range of online, on demand opportunities including:          Creating inspiring sensory classrooms          Sensory Impairment and Sensory Loss          Sensory Resources</p> <p>Contact: <a href="mailto:lois@hirstwood.com">lois@hirstwood.com</a></p>
<p><b><u>Learning Disabilities Speech and Language Therapy-HWHCT</u></b></p> <p>Speech and Language Therapists in the Community Learning Disability Teams across the Herefordshire and Worcestershire NHS Health and Care Trust have developed some new, free training, in line with the RCSLT 'Eating, Drinking, Swallowing Competency Framework'.</p> <p>Level 1 and 2 eating and drinking training is available to the general public through their FREE online e-learning - <a href="https://www.hacw.nhs.uk/mealtime-matters">https://www.hacw.nhs.uk/mealtime-matters</a></p> <p>For updates follow <a href="https://www.facebook.com/LDSL.T.HW/">https://www.facebook.com/LDSL.T.HW/</a></p>
<p><b>EQUALS</b> (<a href="https://equals.co.uk/training-from-equals/">https://equals.co.uk/training-from-equals/</a>)</p> <p>EQUALS provides FREE Online Training for Members covering a range of topics including: the Engagement Model of assessment, teaching learners with Profound &amp; Multiple Learning Difficulties, and EQUALS Pre-Formal PMLD Curriculum</p> <p>For further information please contact Paul Buskin at <a href="mailto:paul@equalsoffice.co.uk">paul@equalsoffice.co.uk</a></p>
<p><b>PCPLD Network (palliative care for people with learning disabilities)</b> (<a href="https://www.pcpld.org/events">https://www.pcpld.org/events</a> and conferences/)</p> <p>PCPLD makes available free webinars as well as making past webinars available as recordings. They also offer podcasts.</p>

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

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(this email address will be your username for your website account)

**Contact name within organisation** (if applicable).....

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

I/we have set up a standing order for £                      with our bank starting on .....

I/we have paid using PayPal through the PMLD Link website

Date:.....

**Please send this form with payment to:**

**PMLD Link, Caerludd, Cilgerran, Pembrokeshire, SA43 2SN**

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

<b>Gift Aid Declaration</b>	
<b>Name of Charity:</b>	<b>PMLD LINK</b>
<b>Details of donor:</b>	
Title .....	Forename(s)..... Surname.....
Home Address:.....	
.....	
..... Post Code:.....	
<b>I want all subscriptions and donations that I make from the date of this declaration to treated as Gift Aid until further notice</b>	
<i>You must pay an amount of Income Tax and/or Capital Gains Tax at least equal to the tax that the charity reclaims on your donations in the appropriate tax year (i.e 25p for each £1 you give on or after 6 April). If you are unsure whether your donations qualify for Gift Aid tax relief, refer to help sheet IR65 on the HMRC web site (www.hmrc.gov.uk)</i>	
<b>Date</b> .....	.....

**STANDING ORDER MANDATE (Send to *your* bank)**

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

The sum of:                      £.....

Commencing:                      ..... and thereafter annually until further notice

Account to be debited:              .....

Account No.                        .....

Signature(s):                      .....

Date:                                .....

## About Us

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

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

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# PMLD LINK

sharing ideas and information

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