

PMLD LINK

sharing ideas and information

Access

Winter 2023



Vol 35 No 3. Issue 106

ISSN 2042-5619

Winter 2023 contents

Page



13 Accessible art



20 Power of connection



36 Remembering Stansfield View

- | | | |
|----|--|---|
| 1 | Guest Editorial: Access | Wendy Newby,
Michael Fullerton,
Maureen Phillip
and Annie
Fergusson |
| 2 | Ravenscliffe School
'Flourishing Curriculum' Part 2 | Julia Barnes and
Andrew Colley |
| 5 | Access to relevant CPD for staff working in a
specialist setting | Ange Anderson |
| 7 | Making relationships and sex education
accessible for people with PMLD | Rachael Baker |
| 10 | Conversations about using Intensive Interaction
techniques during musical activities with
children with profound and multiple learning
disabilities | Peter Burgess |
| 13 | Accessible art at the Children's Trust School | Sarah Townsend |
| 15 | Simple ideas for access using the senses | Sarah Hall |
| 20 | Power of connection and communication | Debbie Austin |
| 23 | It's an IDDSI bit confusing, but mealtime
matters! | Speech &
Language
Therapy
Community
Learning
Disabilities Team |
| 26 | Teaching Reading to All Learners | Sarah Moseley |
| 30 | Accessible picture books: bold, clear, sensory
and strong | Ailie Finlay |
| 31 | The Next Chapter Club | Anke Gross-
Kunkel and Tom
Fish |
| 34 | Recipe for a Hanging Out Café | Sheridan Forster |
| 36 | Remembering Stansfield View | Gerard Wainwright |
| 38 | The future of PMLD research – what happens
next? | Neil Mullen |
| 40 | Inclusion at its best, access to a mainstream
holiday club | Jane Godfrey |
| 41 | In the next issue: Wellbeing | Becky Loney,
Annie Fergusson,
Martin Goodwin,
Maureen Phillip
and Bella Travis. |

GUEST EDITORIAL

Access

Welcome to the Winter edition of PMLD Link, with its focus on access.

Firstly, many thanks to all who contributed to this journal – it simply wouldn't exist without you! When thinking of access, we could easily be drawn into a narrow perspective. Considering access is much more than just the physical ability to enter a building, get on transport or go to a museum etc. Although these are important, access runs a lot deeper and relates to the very fundamental rights and needs of people with profound and multiple learning disabilities (PMLD) to have equity in society. Without these, how can we ensure that they have access to a meaningful quality of life?

In this issue we explore an array of articles that provide us with some valuable and inspiring ideas of how we can work towards this. We do consider basic needs, such as accessing nutrition safely, communication, interactions but we would also argue access to genuine enjoyment, love and a sense of belonging are essential to a fulfilled life. This needs to be viewed as a lifelong journey of progress, right from a young age where education and a relevant curriculum enables children to learn to interact and respond to their environment and the people in it – something that continues across the lifespan. Enriching lives with creative approaches like using sensory approaches in daily life, combining music and Intensive Interaction or innovative ways to access art. Articles also tackle more sensitive issues of how to provide support and genuine access to relationship and sex education provides access to adult life. How do we cover issues such as consent with people with PMLD? How can we encourage them to enjoy their sexuality?

Developing communication and empowering connections are underlying themes throughout this issue. Whether it is valuing access to literacy and reading as a way to create a window on the wider world, ensuring the repetition of familiar and predictable experiences within accessible environments or perhaps the use of accessible communication by unfamiliar people and professionals, our authors valuably share varied ideas and opportunities to enable greater access. We have come a long way from the disability hospitals, such as Stanfield View. Only a few decades ago these institutions were the most common option for children and adults with learning disabilities; people were segregated and hidden away, denied access to the community. People with learning disabilities are now more and more visible, cared for in their own communities and with the right access, live lives with a sense of choice and control. They now have greater access to society. However, we can, and must, go further. One step towards understanding how to do that is providing people with PMLD access to meaningful inclusion in research.

As always, we try to bring you the latest relevant news, along with all our regular features – reviews, useful publications and resources and information of future training opportunities and events.

We hope you enjoy reading this issue of PMLD Link and thinking more about what access means to you, or your situation – as always, we'd love to hear! It has been a pleasure for our volunteer editors to create this Winter journal.

Wishing you all a happy and healthy new year. Thank you for supporting all we do at PMLD LINK.

Guest Editors: Wendy Newby, Michael Fullerton, Maureen Phillip and Annie Fergusson.

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

The journal number is ISSN 2042-5619

Contact Us

The registered address for PMLD LINK is:
Caerludd, Cilgerran,
Cardigan, SA43 2SN

To contact the charity editors or trustees:
Email: info@pmldlink.org.uk

Social media

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

Production of the journal is by:
Paul Bramble

Ravenscliffe School 'Flourishing Curriculum' Part 2

Julia Barnes and Andrew Colley

In the last edition of PMLD Link, we set out the theoretical background behind the development of an innovative curriculum at Ravenscliffe School in Halifax. We showed how the Capabilities Approach, as described by Nussbaum (2007) and others could be used as a framework for teaching and learning with young people with profound and multiple learning disabilities (PMLD).

However, the Capabilities Approach itself cannot be called a 'curriculum' in any of the more accepted meanings of the word. Nussbaum's 10 capabilities are a framework of opportunities, or focus of experiences that students need to access to learn, develop and achieve a good life. Nor are the 10 Human Capabilities 'targets' in the traditional meaning of that word, but essential elements required to make life not only worth living, but worth living well for those with PMLD, for whom after all those elements that can be said to make up a 'good life' for many - a job, a car, exam results may be out of reach. So, it was decided at Ravenscliffe School to use the term 'Flourishing Curriculum'.

The 'Flourishing Curriculum' at Ravenscliffe is a flexible framework for teaching and learning, which does away with the need for any other more rigid or traditional curriculum. Students have opportunities to work on developing all 10 capabilities within a school week. Capabilities have multiple ways to be presented that can be tailored to different contexts or individualised approaches, even, for example, Capability 8: 'Other Species', as time within nature, in green spaces and with pets is recognised as an essential element of the curriculum.

The first two capabilities - 'Life' and 'Bodily Health' - underpin the students access to learning as they are supported by a multi-agency team of nursing and therapy staff alongside the educational team. Capability 7 - Affiliation - is also key to wellbeing as it encompasses not just simple communication of needs, wants and desires but also phatic communications that are pleasurable to those involved (Hewett, 2012). Intensive Interaction (Hewett et al., 2012) underpins communication alongside adaptive, augmentative, and alternative communication (AAC) methods to support an individual's autonomy.

It could be argued that 'topic' or 'theme-based' teaching and learning is antithetical to such an open-ended approach as the Flourishing Curriculum since it is often seen as the 'stuff' of mainstream classrooms superimposed on traditional curricula to make the

content more accessible. However, at Ravenscliffe School they take a broad and inclusive approach to themes and topics, seeing them as loose frameworks which provide coherence and opportunity for both the teachers and the learners. So, the 'Flourishing Curriculum' takes place within a termly topic, for example The Life and Times of Van Gogh.

The table on the next page is intended to give a flavour of the use of the Capabilities Approach within a theme to provide multiple options for practical application of, for example, mark-making, growing of plants and exploring emotions, with wellbeing underpinning the individual's learning and development, as well as linking to the outcome areas of each student's Educational, Health and Care (EHC) Plan. Ravenscliffe's Curriculum recognises that the capabilities of 'Life' and 'Bodily Health' underpin students access to learning at all times. Capability 7, 'Affiliation' is the other capability included as an example within the table:

To demonstrate in more detail how the content of the table on the next page is applied in the classroom we will briefly introduce Chloe and her classroom experiences on a Wednesday afternoon working on the capability of 'Affiliation'.

Chloe is a vibrant 18-year-old with a diverse taste in music. She has a diagnosis of Aicardi syndrome which causes her to have profound learning difficulties, epilepsy resulting in seizures every day, severe visual impairment and a scoliosis which requires her to use a wheelchair and impairs her lung function, so she is intubated with oxygen. She receives nutrition and fluids directly into her stomach via a gastrostomy and is fully dependent on others for all her care needs.

On Wednesday afternoons Chloe participated in lessons to explore the transport depicted in Van Gogh's early paintings whilst on working on the capability of 'Affiliation'. At this time Chloe was frequently positioned on a side-lying frame which a physiotherapist recommended to enable optimum lung functioning and

Aspects of Nussabaum's Capabilities Approach	Areas of EHC that form Outcomes and Next Steps	The Application of Each Aspect to Students	Appropriate Pedagogy, Activities and Experiences	Learning Activities Specific to Van Gogh Topic
1.Life 2.Bodily Health	Sensory and/or physical needs	Students need access to equipment and experiences that maintain health, and ultimately life, and staff who are competent to support their access. This may include moving and handling, postural equipment, physiotherapy exercises, hydrotherapy, rebound, enteral feeding, medication and oxygen administration, suctioning and personal care.	Movement, physiotherapy, hydrotherapy, rebound therapy, postural equipment, personal care, nutrition, medication – advised and supported by the relevant professionals. Access to green outdoor spaces.	
7.Affiliation	Communication and interaction & Social, emotional and mental health	- Students need to be fully involved in the school and wider communities. - They need to be supported to develop meaningful and fulfilling relationships with peers and adults in and out of school. These relationships need to be maintained as students move throughout the Key Stages, including virtual access. - They need opportunities, and time, to develop their phatic communication through Intensive Interaction. Their strengths and achievements will be recognised and celebrated.	Belonging: as part of the school community, peer group, pastoral group and lessons. Part of the wider community locally and nationally. Positioning: Within specialist equipment and within classrooms and communal areas to ensure access to others and the learning environment. (staff team trained Jan 2022) Intensive interaction: 'Any time, any place, anywhere' application. AAC as student's 'voice' between home and school: Messages recorded onto AAC devices shared between home and school to share information about activities & responses, funny incidents and celebrating achievements. Where possible contextual sounds, voices and music should be recorded. Achievement celebrations: shared video, sounds and photos of achievement in assemblies and pastoral/lesson groups. Wheelchair Dancing: dancing with others, responding to pusher, partner, other dancers, high-fives, collaborative writing of dances.	Belonging: Exploring the art & life & times of a world-recognised artist. Expanding exposure to music from a previous century. Awareness of a country other than England and the language, foods and aromas etc. Positioning: To access outside learning environment to be able to grow and nurture sunflowers and crops. To enable paired/parallel play e.g. with farm/boats/train resources Wheelchair Dancing: collaborative writing of dance to Don McLean's <i>Vincent</i> and dancing to music from 1880-1890.

Table 1 – Demonstration of how the capabilities of 'Life', 'Bodily Health' and 'Affiliation' are embedded into the Flourishing Curriculum.

drainage.

Toy boats were floated in a shallow tray of water in front of a fan. Chloe was physically supported to explore the boats and water with her accessible hand before they were placed within her line of vision. Adaptive technology was used so that Chloe could interact with a switch to activate the fan to blow the boats across the water – the motion attracting her attention visually. Oliver (a peer) frequently chose to work with the boats alongside Chloe. Oliver was attracted to the tray of water which he could reach towards and splash. Chloe was able to interact with Oliver, responding with vocalisations or laughter when hearing or feeling the splashes and indicating she wished to experience 'more'. The importance of repetition for learners with PMLD (Lacey, 2009) meant that this activity was offered to Chloe every Wednesday afternoon for the first half of the term.

Assessment informs the outcome and next step planning of an individual's EHC Plan, which should themselves be 'outcome based' and staff delivering lessons identify which of the individual's next steps towards their outcome they will work on in each lesson that term whilst exploring the topic.

The Routes for Learning (RFL) Assessment Tool (Welsh Assembly Government, 2006) is used to baseline, assess and monitor this cohort's progress. The teacher had selected Chloe's RFL Next Step towards Outcome 1, from her EHC Plan for her to work towards in this lesson which is included in following table.

Outcome 1: Chloe will socialise with students both physically and virtually. Recognising familiar voices and responding to her name (Capability 7 – Affiliation).
Next Steps: (RFL22 <i>Responds in ways that can be interpreted as meaning 'more'</i>) Communicate 'more' to her friends when experiencing activities, she enjoys e.g. massage (RFL9 <i>Responds consistently to one stimulus</i>) Indicate a response that is consistent when hearing her name (RFL5 <i>Responds to familiar voice or other personal identifier</i>) Indicate through sound or movement on hearing familiar voices

Table 2 – Chloe's Outcome 1 and Next Steps taken from her Education, Health and Care Plan.

The teacher's professional judgement was that Chloe's laughter and positive vocalisations in response to her peer splashing can be identified as her as recognising Oliver (RFL5) and 'requesting more' splashing (RFL22). Curriculum deliverers have very imaginatively embraced the topics and been able to tailor learning opportunities

for students to work at their personal outcomes and next steps. Staff have been able to use the concept of 'flourishing in the here-and-now' to decide when activities should be continued or changed, both during the lessons and week-to-week.

The topic content within lessons has helped to broaden the variety of experiences offered. For example, individual's musical preferences are often well known by familiar staff members and opportunities are created to listen and respond to them e.g. during hydrotherapy sessions. In response to Van Gogh's painting 'The Café Terrace on the Place du Forum' Parisian café music was explored alongside smells, tastes and objects. A couple of students responded positively to this style of music and those preferences could then be shared with families and offered in different situations which is a wonderful example of the application of the capability of Affiliation. We hope that by writing these two linked articles we have been at least to start a dialogue with and amongst other schools about The Capabilities Approach and its relevance so that we can develop it further and support other people with PMLD.

Contact details

Julia Barnes is a Senior Teacher and Manager of the Sensory Pathway at Ravenscliffe High School in Calderdale. She is studying for an Educational Doctorate at The University of Birmingham and is currently researching the touch encounters of a few of her pupils whilst they are at school.
Email: julia.barnes@ravenscliffe.calderdale.sch.uk

Andrew Colley taught in special schools in Essex and Cambridgeshire, and is a former senior lecturer in special education at the University of East London and the author of a number of books and articles about teaching and learning, social justice and inclusion with respect to young people with pml.

References

Hewett, D. (2012) "Blind Frogs, the nature of human communication and Intensive Interaction." In Hewett, D. (ed.) *Intensive Interaction: Theoretical Perspectives*. London: Sage.

Hewett, D., Firth, G., Barber, M., et al. (2012) *The Intensive Interaction Handbook*. London: Sage.

Lacey, P. (2009) Developing the Thinking of Learners with PMLD. *PMLD Link*, 21 (63): 15–19.

Nussbaum, M. (2007) *Frontiers of Justice: Disability, Nationality, Species Membership*. Cambridge, Massachusetts: Harvard.

Welsh Assembly Government (2006) *Routes For Learning Assessment Booklet: Assessment Materials for Learners with Profound and Learning Difficulties and Additional Disabilities*. Cardiff: Crown Copyright.

Access to relevant CPD for staff working in a specialist setting

Ange Anderson

Rhys sat in his wheelchair, unable to move his body. His big, brown eyes were everywhere, taking everything in. He was desperate to learn. His smile could brighten up even the most disagreeable person's day.

I remember the joy on Bev's face when she rushed into my room to tell me that he just told her to go for her lunch. He used the Eye Gaze machine to do so. As headteacher, I managed to find funding for the technology. A very necessary piece of equipment for those who cannot vocalise and find difficulty with body movements. All of our students were given access to the Eye Gaze. Bev, as well as other staff members were trained in its delivery.

Bev, a teaching assistant, was released from classroom for five mornings a week to deliver Eye Gaze training to our students. Rhys used it daily with Bev for a half hour a day for just ten days when he told her to go for lunch.

Rhys had recently moved into the catchment area and came to our special school in 2014, aged six. Within a week, our excellent, well-trained classroom staff expressed their concerns regarding his statement which specified that he had cerebral palsy and profound and multiple learning disabilities.

In 2018 Jonathan Bryan, aged 12, diagnosed as having profound and multiple learning disabilities, wrote a book. He learnt to read and write by having access to an Etran frame. In that book he wrote a poem about *profound and multiple learning disabilities* (PMLD) and he has given me permission to use that poem.

This is not to say that Jonathan or Rhys didn't require a high level of support with respect to all activities of daily living. However, they both needed access to technological communication aids. In Rhys's case it was high tech with the Tobii Eye Gaze. In Jonathan's case it was a low-tech aid - the Etran frame. They would not have had access to these aids before 1980 in the case of the Etran frame, and 2001 in the case of the Tobii Eye Gaze. We could look back with regret for all of those who missed out, but it makes more sense to look forward to the opportunities that technological innovations offer our students now and in the future.

There is no doubt in my mind that teachers and support staff today, particularly those who work with students who have physical disabilities need access to more training days and continuous professional development

PMLD

We are not capable of learning
So do not tell me
There's something going on behind the disability.
Treated as useless handicaps
Minds with nothing in there, tragically
Stuck in a wheelchair,
Disabilities visibly crippling-
Just incontinent and dribbling,
We are not
Academically able.
You should make our minds
Stagnate in special education!
We cannot
Learn to read,
Learn to spell,
Learn to write,
Instead let us
Be constrained by a sensory curriculum.
It is not acceptable to say
We have the capacity to learn.
School should occupy us, entertain us; but never
teach us
You are deluded to believe that
Our education can be looked at another way!

NOW READ THE POEM BACKWARDS.

(Bryan, 2018)

(CPD) to ensure effective support for students' health and mobility, communication and engagement needs and in the use of the equipment used by each student in their care.

As a headteacher of a special school and part of the North Wales Association of Special School Heads (NWASSH) ably led at that time by Maxine Pittaway MBE, petitioned to the education secretary in the Welsh government for more training days because the needs of our students are so complex. Since 2019, the Welsh government has given all schools in Wales an extra training day to focus on additional learning needs and equity in education as schools introduce the new

curriculum for Wales. This is not good enough. The range of skills required, responsibilities and knowledge needed to support students with complex needs are consistently undervalued by governments.

Initial teacher training (ITT) and teaching assistants training do not cover all of the training required to work in a specialist setting.

Consider some of the training updates required by all staff in manual handling, personal care and postural care, assessment, signing, behaviour, feeding, speech therapy. Physiotherapy, innumerable therapies the students receive such as rebound therapy, hydrotherapy, Move, music therapy, vibroacoustic therapy etc. as well as staff training in specific conditions such as ADHD, ASD, PMLD; staff training in using objects of reference, symbols etc. and the time it takes to make these. Then consider how the school can fit in training for staff in things such as attunement and in the latest technological advances. Where does the time come from?

We set up a rota system to avail all staff of access to the amazing online training that is now available for free in all aspects of alternative learning needs. There are many free sites such as: Training materials for teachers of learners with severe, profound and complex learning difficulties (complexneeds.org.uk). Staff took pride in keeping a record of training certificates gained that they kept in their CPD files. Time had to be given during directed time as we did not have enough training days to cover all staff training needs. I know that I was lucky because I had staff willing to stay after school to attend training that would help them understand the students, but they shouldn't have to give up their own time and those with young families need to get home. It is a scatter gun approach and not very effective or targeted. We ended up assigning the role of CPD coordinator to a senior manager and staff CPD was computerised so that we could check in an instant who needed an update in Team Teach, PECs, hydrotherapy board training. However, all of that necessary training did not include up to date training in the very latest technological innovations and interventions. Children in mainstream schools today sometimes know more than their teachers in how to use technology. It is time we faced our fears and demanded governments set aside access to extra training days for specialist school staff so that they become experts and leaders in the field of alternative learning needs.

Access to CPD for all staff in understanding how every student in their care prefers to communicate is vital so that students are supported to make their preferences known and take part in supported decision-making in their daily life. We are all born into two worlds. Our inner world and the outer world. Sometimes it can feel safer to stay inside our inner world because our attempts at

communication have been misunderstood.

Attunement is the ability to emotionally connect with another person and what they are feeling by entering their inner world, understanding their physical and non-verbal cues. As an adult we show attunement in the way we respond. Our facial expression, tone of voice, the way we hold and touch. Attunement can help us understand how a student prefers to communicate.

Not all students diagnosed with PMLD are incorrectly diagnosed as Rhys and Jonathan were. Access to continuous comprehensive assessments of communication is vital because children grow and change and develop all of the time.

Staff working with students like Rhys and Jonathan require access to training in all forms of AAC available and that training must be regularly updated because we are living during the 4th Industrial Revolution and technological advancements that can change the lives of our students are happening on a daily basis. It would be a disservice to our students not to be able to offer them these life changing technologies and for our staff not to be aware of the existence of these technologies. PS. Rhys went on to have a wheelchair mounted eye gaze so that he could use an eye gaze system throughout the day to communicate.

Contact details

Ange Anderson is a full-time writer and consultant on therapeutic and technological interventions for those who are neurodiverse. She is the SEN advisor to a global VR company.

www.teachustoo.org.uk
Email: angelique5@hotmail.co.uk

References

Anderson A (2019) Virtual Reality, Augmented Reality and Artificial Intelligence in Special education. Routledge. London and New York.

Bryan J (2018) EYE CAN WRITE. Bonnier Books Ltd. ISBN:9781911600787

Simplify punctuation to match house style: Doukas, T., Fergusson, A., Fullerton, M., and Grace, J (2017)

[Available from: [https:// www.pmlmlink.org.uk/ resources/#pmlid-standards](https://www.pmlmlink.org.uk/resources/#pmlid-standards)]

Making relationships and sex education accessible for people with PMLD

Rachael Baker

Access is such a key theme for my work with educators around Relationships and Sex Education with young people with severe learning disabilities. As Senior RSE Specialist at Sex Education Forum, I deliver training to teachers and caregivers around how to deliver meaningful and accessible RSE, to support people with disabilities to understand their body and be able to make informed choices about their sexuality. The statutory relationships and sex education (RSE) guidance for schools (DoE, 2019) stipulates that RSE must be accessible for all pupils, and is particularly important when planning teaching for pupils with special educational needs and disabilities, but what does accessible RSE look like? The most common question I get from teachers and educators working with learners *with profound and multiple learning disabilities* (PMLD) is 'how can I make it relevant to my learners?'

Understandably there is often anxiety from teachers, parents and caregivers about the idea of delivering education about relationships and sex to learners with PMLD, not least of all because of our learners' extreme vulnerability and reliance on other people. Relationships and sex education is all about access. Access into adult life, with a skillset and values that will enable young people to be able to make autonomous choices about their body and be able to enjoy their sexuality. Access is the key that unlocks the wider world. But with access comes responsibility, and understandably for many parents, educators and caregivers, the anxiety about relationships education sits closely with a fear that a person may not have the capability to take this level of responsibility for themselves, or that people around the person with PMLD might not act with responsibility which may in turn limit someone's rights over their body.

Accessing the community – a shared goal

As a teacher in special settings, one of my favourite aspects of the curriculum was Community Access, taking my class out on simple excursions to experience being out independently in the world. We might go on the minibus to a supermarket café, or walk into the nearby town to buy some vegetables, or go to the park for some nature-bathing. Community Access is vital and allows learners to practise being out and about in various settings within the safety of a learning space, and with staff who are prepared for the conversations and potential hurdles which may present. It is a way to bridge the gap between the classroom and the community, and to deliver teaching around independent living, and preparing for adulthood.

Community Access is surprisingly relevant to RSE. The aims of RSE are to equip people with the information, skills and positive values to have safe, fulfilling

relationships, to enjoy their sexuality and to take responsibility for their sexual health and well-being. How we interact with other people is an important part of these events, and it is essential that our learners develop a clear understanding of what is allowed when, and with whom. The rules may be different out in the community to within the safe bubble of special school or adult services. The people we encounter out and about do not know us, they do not know our back story or have an obligation to cater for our needs. For our learners to understand intrinsically the rules outside, we must ensure that we model appropriate touch and consent in our school, college or social settings.

Touch is important every day

Touch is extremely valuable to people with PMLD, and within our settings there may be a range of touches that form the fabric of our day. Handshakes, high 5s and hugs might feature in our greetings; therapeutic touch and massage might help regulate emotions; a touch on the hand might bring someone back into the learning space when they have drifted; personal care, feeding and medical interventions might all happen as part of the day to day for our people.

For most of us, touch is sparse, and is predominately limited to people we already know and have an ongoing relationship with. With the exception of a brush of a shop assistant's hand as they give you change, or the gentle chill of a stethoscope on our chest, or the arm-to-arm touch of a fellow passenger on a crowded bus, most of us do not touch the people we encounter outside of our homes. Touch with professionals for most of us is rare, and must be consented, and purposeful. Touch with strangers should be even more minimal. How do we explain that to our learners and service users?

Modelling consent

We need to model appropriate touch and consent at all times in our classrooms and services. We need to carry out regular work with our learners to explore consent and touch, including modelling consent seeking. We must always ask before we touch, and respect the 'no' if consent is declined. When administering personal care we must ask, and recognise the communication style of the person in our care. We must commentate as we work, explaining not just what we will do, but why. 'I am going to clean around your vulva now, because I am helping you to change your pad.' We need to ask, not tell – 'would you like your jumper off?' instead of 'I am going to take your jumper off' and we need to make our peace with the 'no'. If someone declines personal care at this moment, we wait. Not forever – of course there is a safeguarding aspect to consider – but for a few minutes to support the person to be in charge. Use a sand timer, and say 'ok, I will come back again in a few minutes when you are ready'.

Public and private

Of course, teaching about whether we can touch a stranger may feel a lot easier on professionals and parents than teaching about intimate and sexual touch. Even finding ways to frame how and when we might touch friends or family can be difficult, and there is a complex spectrum of how much touch we expect and are comfortable with from different people in our lives. The notion of our learners embarking on an intimate or sexual relationship can feel incredibly uneasy, and unfortunately that can lead to a situation where learners with PMLD do not get their entitlement of education about their body and their sexuality. For many young people with severe learning disabilities or PMLD, the shape that their sexuality takes in adulthood might be rather different to their able counterparts, but sexuality and disability are not mutually exclusive, and in fact sexuality is a fundamental part of being human.

As abstract and complex as it may feel, we must find an accessible way to teach learners with PMLD to understand:

- What body parts they have
- Which body parts are private
- Which places are private, and where it is ok to touch their private body parts
- Who else might touch them, and why
- How to recognise consent in others
- How to communicate whether or not they consent
- How to tell someone if an inappropriate touch happens

Exploring one's own body, including touching one's own genitals for pleasure is not in itself problematic, but becomes problematic when a young person does not

understand where that touch may take place, or how to touch themselves safely without risk of hurting themselves. Tensions exist for educators and parents, with common anxieties being voiced including 'will this make them want to masturbate?' or 'am I allowed to teach about masturbation?' and with the underlying worry being about whether teaching about sexuality and masturbation presents a safeguarding risk.

With our older learners with PMLD, we must teach about intimate and sexual touch, including masturbation in a way that is relevant to their chronological age, but differentiated to cater for an individual's cognitive ability. Not understanding where you can and cannot masturbate is extremely limiting in adulthood, because it creates isolation. A person who is highly likely to masturbate in public will find that they are not included in Community Access activities, and will miss out on so much because of this. Instead of excluding people from the experiences that community access offers, we need to find ways to make that underpinning education meaningful and accessible.

The skills and tools for educating about RSE

There are lots of resources designed to support RSE for learners with SEND that educators will already be familiar with. We need to use our cloth dolls to practise personal space and proximity and use photos of people displaying different behaviours and gestures to talk about when we can touch, and who. We need to practise recognising public and private spaces, and understanding which behaviours can happen where. For people who receive personal and intimate care, we need to use resources and social stories to demonstrate and embed what to expect and not accept when it comes to someone touching or looking at someone's private body parts as part of their job. We need to support our learners and service users to recognise that certain activities may only happen in certain places, and to wait until the right time and place.

In planning for Relationships and Sex Education with learners with PMLD, as with any aspect of curriculum for them, we must focus on what they can do, how they learn and show their interest, how they communicate, and plan to suit that skillset. We need care staff, parents and family on board, and delivering the same consistent message. Being able to access the learning about relationships and sex will support our learners and service users to access society and develop independence in their adult lives. We need to practise and commit to a lengthy process of skill development with our learners and service users, and be assured that whilst this may be a long game, we will get there. We need to commit to supporting our educators, carers and parents with the confidence and skills to deliver this vital area of the curriculum, to support our learners and

service users to have autonomy and rights over their body.

Join me on Wednesday 28th February 2024 for our popular one-day course Inclusive RSE for Learners with PMLD. This unique course is designed for teachers working with learners with profound and multiple learning disabilities, or combined and complex learning disabilities, and examines how to create meaningful and inclusive RSE for learners with PMLD. This course is ideal for SENCOs, RSE and PSHE subject leads, senior leaders with subject responsibility for the subject, and class teachers delivering RSE to learners with profound and multiple disabilities, and significant learning and physical needs.

Sex Education Forum Calendar: Inclusive RSE for learners with PMLD.

Sex Education Forum offers a range of SEND specialist RSE training and a membership scheme for educators.

Visit www.sexeducationforum.org.uk or email info@sexeducationforum.org.uk for more details.

About the Sex Education Forum

The Sex Education Forum is a national charity in England, working together with our Partners and members to promote and protect the physical and mental health of children and young people by improving their access to relationships and sex education. Registered charity number 1193467.

Contact Details

Rachael Baker is Senior RSE Specialist at Sex Education Forum. A qualified teacher and SEND specialist with broad experience in mainstream, SEND and alternate provision settings, Rachael's goal is to support teachers and educators to deliver meaningful and inclusive RSE to all learners. Rachael has an MA in Education from Birmingham City University, focusing on wellbeing in education, and examining techniques and strategies that schools can employ to support learners with Autistic Spectrum Conditions to access learning. Rachael continues to work directly with learners in SEND settings, as well as delivering ongoing support to schools around RSE.

Email: Rachael@sexeducationforum.org.uk

SUBSCRIPTIONS 2024

Subscription rates

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

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

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

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

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

If you pay by BACS, the account details are:

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

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

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

Conversations about using Intensive Interaction techniques during musical activities with children with profound and multiple learning disabilities

Peter Burgess

Making music is an important and vital part of my life. Whether it is rehearsing with my band or interacting musically with participants at my music club, music is a key component in what makes me tick. I'm lucky, I am able to access music making in a number of ways when I choose to. Children with profound and multiple learning disabilities (PMLD) do not always have that choice. A number of barriers may stop these children from accessing music making. These might include access to the right support to play instruments or access to responsive musical partners who will encourage their music making. In my professional life I support children with PMLD to take part in collaborative music making. This collaborative approach almost always has elements of improvisation and will often use Intensive Interaction (II) techniques within a musical context.

The following is an abridged version of an investigation into II in a musical context. This investigation arose out of an interest in exploring II and music with children who have PMLD. I know from my experience that music and II are both engaging activities for children with PMLD. I also know that combining them is enjoyable and effective in developing relationships with children with PMLD. I have a good understanding of the theoretical framework that supports II. However, my use of II in a musical context has always been instinctive and practical. I was interested in reflecting on how II works within a musical context and issues related to this.

I was awarded a bursary to explore this subject. I conducted a small-scale literature review and also interviewed two practitioners who used II in a musical context. This article will focus on the two interviews and what I learnt through these interviews. It assumes that the reader has some knowledge of II. If you would like to

find out more about II the following web page is a good starting point.

<https://www.intensiveinteraction.org/>

The Interviews

Two practitioners were approached who had a background in music and supporting people with PMLD. The first interviewee was Emily Tully who is head of music at a specialist school and also delivers music sessions privately to people with additional support needs. The second interviewee was Rosie Rushton. Rosie is a researcher at the University of Birmingham, director of the charity Melody and co-director and founder of community interest company Big Top Adventures.

A number of questions were discussed. One question was: What activities take place during an II in a musical context session? The table below shows what the interviewees described.

What Activities take place during an Intensive Interaction in a musical context session	
Rosie Rushton	Emily Tully
• Using Open Vowel Sounds and imitations • Turn taking and anticipation activities • Using big, shared instruments • Letting the participant lead by conducting • Giving control of the environment to the participant • The participant's contribution is the starting point • Providing a stimulus to get the activity going • Mirroring	• Turn Taking • Taking a participants sound and developing it • Responding with different sounds so they can learn the difference between the same and different • Exploring and developing rhythms • Improvising • Follow breathing with different sounds • Follow, match and extend their vocal sounds • Create situations where they can be physically enabled with instruments (Instruments that go round a finger)

Benefits of Intensive Interaction in a musical context

Rushton describes what can happen during a session and its implications for redressing the power balance between everyone involved.

“You can facilitate the person you are working with to be able to be proactive contributors to the musical sound world. They are not just passive in responding to what you want to give them. If you join them in a moment of Intensive Interaction, they are able to guide the development of that sound world, or create something new, or take it in a different direction..... The hierarchical imbalance between abled and disabled shifts and the individual who perhaps for the entirety of their lives receives care and is often on the receiving end of a relationship can actually be on the giving end of a relationship and they can proactively contribute.” (Rushton, 2022)

Tully described why music is so effective when working with children with additional support needs.

“Intensive Interaction joins the conversational level of the person I am communicating with; we can engage with one another, and they can feel empowered. Music is the start of conversation and language; this is what they find familiar. They are not having to think about the complexity of language and words because music is the beginning. We start with heart beats and white noise before we are born. We start with listening to the voices of the people around us. We start very much with music and the world as a musical place... I see music as the foundation of it all and for children with PMLD music is the one thing they can access on the same level as everybody else. All they’ve got to do is be present and listen and be a part of it.” (Tully, 2022)

There is evidence to suggest that very young children engage with music and display musical abilities before the development of language (Corke, 2002). As many children with PMLD are at the very earliest stages of development using music alongside II is a good fit. It is important to note that using II on its own will also elicit musical elements through following; vocalisations; rhythmic burst-pause sequences; and through following the rhythms found in a child’s repetitive behaviour. However, intentionally using music and musical instruments alongside II does appear to enhance the interaction with the child with PMLD. Rushton and Tully both describe this phenomenon. Tully (2022) explained that when she plays guitar during her sessions some children are more responsive and engage with its tactileness in a way that wouldn’t necessarily happen if

she was just singing. Rushton also notes that using musical instruments brings something extra to the interaction. She explains that instruments can help develop a shared focus that can be the starting point of communication (2022).

Knowing your instrument

Rushton made a valuable point about knowing your instrument.

“You have to know your instrument really, really well to be able to use it. Otherwise, you will be thinking how I play this note or have I got my chord shape right. You can’t possibly be thinking about the instrument. The instrument needs to be an extension of you. That’s how well you need to know it in order to be able to be readily available to respond to those interactions. If not, it will become a complete barrier and you will be thinking, what note shall I play or how shall I play this. It’s not about that... it’s about having that instrument as an extension of your communication possibilities.”

This was an interesting point and has implications for who can do II in a musical context. It can be argued that a practitioner must be able to demonstrate an ability to respond accurately to a child either rhythmically (following the child’s rhythms) or melodically (following the child’s vocalisations or their playing of a tuned instrument). This could set the bar quite high for II practitioners who may want to use music in their practice. It would be interesting to explore this issue further and see whether there were ways of enabling non-musicians to engage in II in a musical context.

Conclusions

This investigation raised a number of issues. It reinforced my view that combining II and music is a powerful way of working with children with PMLD. I was able to reflect on the process of using II in a musical context and identify with what the interviewees said about the benefits of this methodology.

It also challenged the way I view my interactions. I was quite taken by Rushton’s (2022) assertion that co-creating music with a child with PMLD can shift the power balance between the child and the adults in their world. When the child leads the creative process, the adult is giving up their power and letting the child be autonomous for a period of time. Of course, this shift in power sits within the framework of II. In II we enter the child’s world and allow them to lead the interactions. It would be interesting to explore this power dynamic further and consider other ways in which children can be empowered to have more control over their lives. Finally, it has provoked some thoughts around non-musicians using music and II. I wonder whether there are

ways of enabling those who are not musicians to use music alongside II. For example, singing or using easier to play instruments such as percussion instruments or kazoos might lower the bar and introduce this wonderful way of working to a wider audience.

Contact Details

Peter Burgess, BA (Hons) PGCE (PCET) M.ed, is Co-founder of Fantastic Journeys CIC, a creative arts social enterprise. He has 17 years experience of supporting people with additional support needs. Peter is also a multi-instrumentalist and currently performs with folk and bluegrass band The Bearwood Bandits.

Email: fantasticjourneyscic@gmail.com

References

Corke M (2002) Approaches to Communication through Music, David Fulton Publishers

Rushton, R (2022) Interview with Peter Burgess, October 2022, Birmingham, UK

Tully E (2022) Interview with Peter Burgess, October 2022, Birmingham, UK

Access to Recent Back Issues on the PMLD LINK Website

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

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

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

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

A limited number of printed back copies are available at £7 (inc p&p). Contact info@pmldlink.org.uk

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



Accessible art at the Children's Trust School

Sarah Townsend

Art has no boundaries and here at The Children's Trust School we use it as a medium to motivate and engage our learners. We create fun, imaginative sessions that aim to promote autonomy and independence ensuring art is accessible for all. By understanding what our learners can do, we are able to adapt art sessions to ensure our learners are free to create and grow as artists. This article highlights some of the resources and activities that we have created which are relatively inexpensive but have been very effective.

Mirror ball motors are a very cost effective way of making things accessible as they can be easily switch adapted. To adapt a battery operated mirror ball motor a battery interruptor can be used and for an electric mirror ball motor a power link box can be used.

The pouring acrylic masterpieces have been made by using our adapted mirror ball motor held in place with a phone clamp holder. A small block of wood has been attached to the pin and one side of the Velcro secured to this. The other side of the Velcro is attached to a cup. Each learner is supported to pour paint into the cup, and this is attached to the Velcro on the motor. The learner then presses the switch to make the cup tip and paint pours out. We have used this method to decorate canvases, Christmas baubles, vases, and mirrors, all of which we have sold to reinvest in more accessible art resources.

To create Pedulum art we attached an arm to an electric mirror ball motor and mounted it on to a tripod, we then tied a bucket with holes to the ceiling. The bucket is then mounted on the tripod and filled with paint, the arm can be activated by pressing a switch which releases the bucket full of paint, sending it swinging over the canvas.

The results are amazing!!!! We have also created manual pendulums by using A frames with paper cups tied to them, the learners are encouraged to hit the cup with any means possible. The photos below demonstrate this in action.

We have had great fun making pictures that spin, we have used a large switch adapted spinning machine, made from a right-angled drill. The machine creates wonderful effects, not only do the learners have more independence to create their own work but they love the





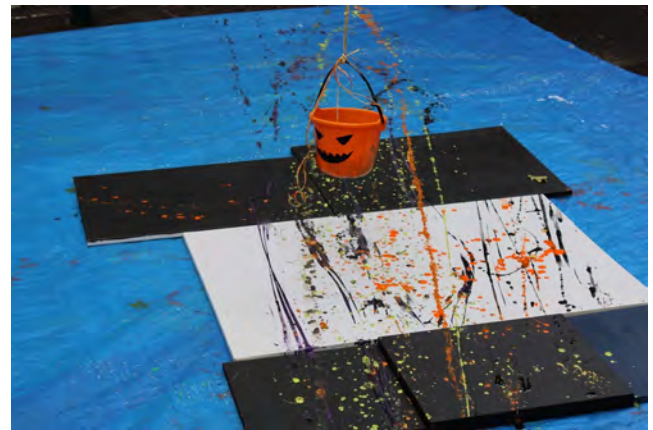
sound the of the machine and visual effects that are created. Here a record is being spun to make into a decorative clock.

We have also used a switch adapted electric potato peeler to create smaller pieces of artwork.



Remap are a charity that aim to design and custom-make equipment to help people with disabilities live more independently, we have worked with them to design a trebuchet which enabled the learners to pull a handle to catapults paint out of the box, covering canvases and occasionally staff!

Other ways we tried to make art more accessible include adapted lazy Suzanne's and fans to make them switch activated to enable the canvas or paintbrushes to spin. We have also explored ways learners can use different parts of their body to paint. One useful resource that was cheap and easy to create was a head paintbrush, we placed the inner part of a hard hat on the learner's head and adjusted to fit. A paint brush was then secured to the head gear and hey presto!! Learners were able to paint



independently using their head movements. The picture below shows how this cheap resource has enabled some of the learners to complete independent masterpieces.



All for these resources and activities have been created to make art more accessible, we are always looking for new ideas and innovations. If you would like to know more about what we do or have any ideas, you would like to share we would love to hear from you.

Contact details

Sarah Townsend
Professional Expertise Training and Learning Lead
The Childrens Trust School
stownsend@thechildrenstrust.org.uk

Simple ideas for access using the senses

Sarah Hall

Multisensory approaches can very easily and naturally lend themselves to motivating access and engagement, but all too often we get stuck before we even get started! This photo story is a starter for ten – ideas to show just how simple it can be.

Knowing how to use a sensory approach and where to start can be confusing – but it's simply about tuning in to OUR own senses first, that helps us become more aware of the part all our senses play in understanding and accessing the world. The more we tune in to thinking in a sensory way the more we recognise the sensations, the information and the influences we all experience through our senses (most of us, usually without even thinking about them), the easier it then gets to view everyday actions and activities from this perspective – so much so, we can't stop thinking that way!

As we get to know individuals with profound and multiple learning disabilities, we build up a picture of their unique interests and preferences, their likes and dislikes, but also how they use and respond to their own senses and sensory experiences. We may discover which of their senses they tend to use most, are most motivated by or find easiest to use. Sometimes by pairing the senses, we can maximise someone's skills and ability even more, to access an activity or daily routine. A simple example might be combining vision and sound together – e.g. shining a desk lamp onto a plate of food and tapping that plate with a spoon can be an effective way to attract the attention of an individual and help them focus on what's happening; the focused light, together with the sound and vibration of the spoon on the plate may encourage them to turn their head, eyes and ears to locate their meal in front of them, on the table.

Sarah's sensory starters ...

Here are some simple photo ideas to get us thinking in a sensory way – they all use familiar, everyday items and activities to get started.



1. Touch and Vision together: Pet Snuffle Mat that comes to life under a UV source, encouraging looking and exploration through touch.



2. Vision: For someone who needs a close up picture from a projector effect wheel or light patterns from a disco light, use a white sheet or piece of white card to move the image or effect where it can be seen best.



3. Smell: Use aromas from herbs or spices e.g. add ginger spice or coffee to paint for an added tactile experience.



4. Movement and Vision together: When you shake it, this skittle lights up.



5. Sensory exploration outdoors – all senses are stimulated.



6. Sensory exploration indoors with chocolate mousse on a tray.



7. Tactile: Squidgy Bags/explorabags filled with hair gels or foam. Here the bags are shaped like 'Meet the Veggies' characters. I first saw this idea on Instagram from @beesensory who makes beautiful resources.



8. Smell: Inserting a tangerine inside a balloon whisk creates a simple smelly sensory item.



9. Sound: One lady liked squeaky resources and always chose nuggets at McDonalds. I combined her two favourites by sewing a dog toy squeaker inside these pretend nuggets for her.



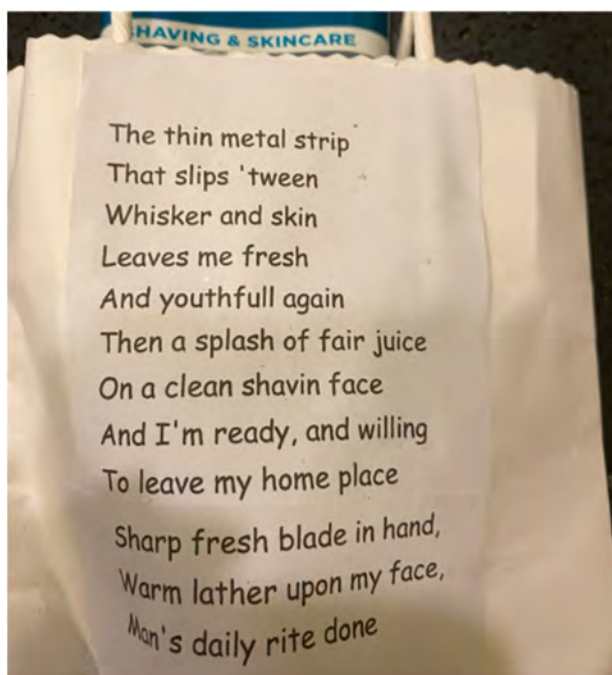
10. DIY edible jewellery for a lady who likes to crunch (caution – not suitable for everyone!).

Sensory Access ideas for Personal Care

The following ideas use a sensory approach to make personal care routines more accessible. These examples are based on personalised routines developed for specific individuals, but demonstrate the value of sensory access.



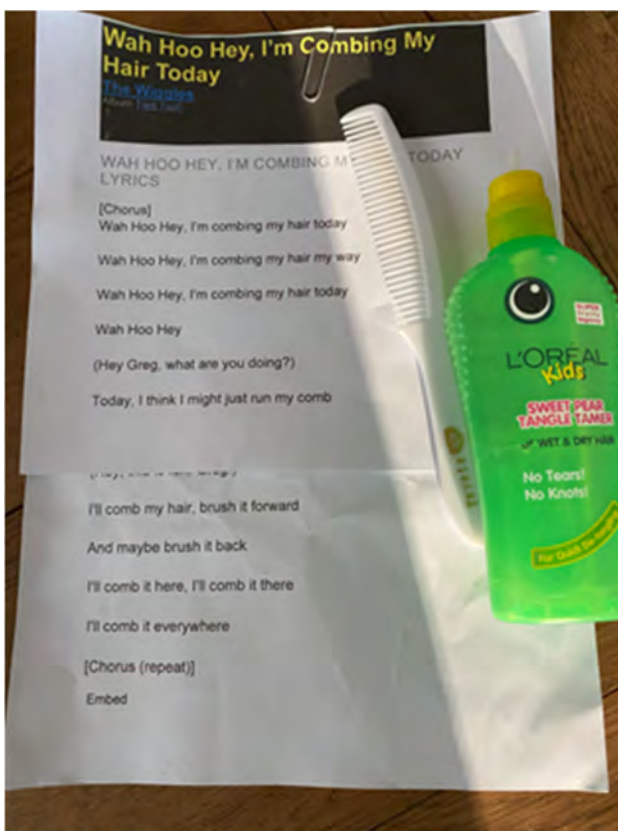
1. Vibrating Hairbrush: Can be relaxing or stimulating. Can be used to wake-up the senses before a haircut.



2. Poetry Pockets: Use songs and poems to prepare. Repetition acts as a rehearsal, a prompt for instructions or clues.



3. Make functional activities fun. Practice shaving with a toy razor. Explore shaving foam.



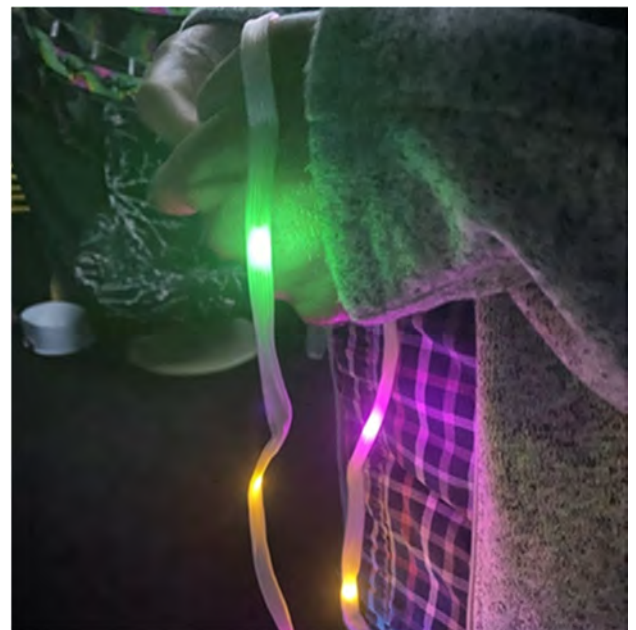
4. Sensory songs, here I've added a comb and scented spray.



5. Messy exploration may encourage us to touch, reach, extend fingers, hold, release, squeeze, poke, squidge.



6. Use a vibro- tactile nail spa as a sensory way to wash hands.



7. Light up shoelaces in shoes could help someone locate their foot and further awareness that their foot belongs to them.



8. Explore soaps and sponges. This one is grated Dove and loo roll in warm water.



9. Spray teeth with mouthwash in an in art activity or story.



10. Smell calming oils on a hanky to help a dentist or hospital visit.



11. Designed as a timer this light-up toothbrush adds a great sensory element in a darkened room.



12. Sensology routines in personal care: Face massagers, including vibro-tactile massagers really wake up the senses and can have a de-sensitising effect, before having a shave.

Contact Details

Sarah Hall is a Sensory Engagement specialist and Aromatherapist. She provides bespoke, face to face sessions in her multisensory room, online sensory activities and training. Her Multisensory room is available for hire.

Email: willowssensory@virginmedia.com

Website: www.willowssensory.co.uk

Facebook: Willows Sensory Service

Instagram: @willowssensory

To get a copy of "Sarah's Sensory Starter Pack" - a book, filled with simple, practical ideas for using sensory approaches, contact Sarah via email.

Power of connection and communication

Debbie Austin

I trained as a physiotherapist in the 1990's and have had the pleasure and privilege of meeting many people with profound and multiple learning disabilities and their families in my clinical work. A passion for the social model of disability and disability rights led me to a career in posture, mobility, and seating. I worked in several wheelchair services across the UK and later in a community learning disability team. All of which stood me in great stead when my daughter Lucy was born in 2008 with a learning disability.

My interest in communication developed and grew alongside Lucy, who has Down's Syndrome. When Lucy was five, we found out that she is also autistic, the way in which Lucy communicates, interacts, and understands the world has been a constant source of wonder to me.

Lucy needs considerable support to communicate - she can use words, can answer simple questions about concrete things phrased in the right way, but is not conversational. She enjoys scripted interactions or chats, preferring to know what each person will say and what she will say in return so that there are no surprises - that is until Lucy adds something new to make you laugh.

Lucy struggles with social conversations - social greetings do not make sense to her, saying hello and goodbye often requires support and modelling. Abstract concepts are not accessible, such as asking her how she feels about things, what she wants. Any sentence that starts with the word because renders the sentence out of reach.

Discovering intensive interaction approaches have been powerful and enlightening. Lucy loves it when people repeat back to her what she says to them, she will come up close and look into your eyes, wanting you to continue the conversation. A few years ago, she particularly enjoyed the notification sounds from mobile phones and liked to repeat them while swiping her finger along her cheek, in the same way you do to swipe away a message on a phone screen. "Gotloob" "Gorday" "gerrherrr" made complete sense to her and joining in with this conversation brought us a feeling of closeness, connection, and fun. I remember modelling this to a new carer who came to support Lucy at home. She clearly felt uneasy copying Lucy's personal words, but with time and support became relaxed and comfortable and then enjoyed the relationship she developed with Lucy from communicating with her in this way.

Lucy is always at risk of being left out and ignored, she cannot use her words to ask to be included or talked to - but the need to connect is so powerful and so visceral



that if she does feel left out, or if someone who she is spending time with diverts their attention to someone else, she responds. Her responses could at times be described as challenging behaviour- though I prefer to describe it as distress - feeling lonely, left out and ignored. Things we can and should put right for her. We have so many ways of meeting our own needs for connection with others be it in the virtual or real world. Lucy and people with severe or profound learning disabilities have significantly fewer options. I applaud Lucy's tenacity for not ever giving up.

I never describe Lucy's behaviour as attention seeking, this tends to bring out an unhelpful response from others. Responses such as "We must ignore attention seeking behaviour, you can't give into it". All very nonsensical, we certainly don't have that response to behaviours that indicate needs such as thirst or hunger.



By describing Lucy's experience as feeling ignored and left out tends to evoke a more compassionate and appropriate response of "That's terrible, how can we include her?" Needing connection and interaction is fundamental and we must all try to minimise the times when people with learning disabilities and significant communication challenges are left out. We should work to ensure everyone is included in and have access to an abundance of meaningful social interactions.

So many of Lucy's behaviours over the years were telling me to include her, or that she saw a situation where she might be left out - pulling me away when we meet others in the street, hitting me when I was putting her shoes on and answering a question asked by someone in the house etc. All very understandable when seen through the lens of connection.

I no longer work clinically but as a Strategic Learning Disability Workforce Manager for Family Carers across the North-East and North Cumbria ICB. As part of this role, I joined a group facilitated by Inclusion North called Involving Everyone. It is for family carers whose loved ones have profound and multiple learning disabilities. During a meeting a mother spoke poignantly about a time when she took her daughter to a local health centre to see a nurse, she spoke about how her daughter was ignored by the health professional saying "If I had taken a dog into the surgery it would have got more attention than....."

This was clearly a training need for how many undergraduate courses equip nurses, medics, and allied health professionals with sufficient skills to confidently interact with people who do not use words? Many children who do not use words do not attend

mainstream schools. This lack of integration has many implications, but a big one is that our future leaders, health workers, commissioners and policy makers miss an opportunity to learn how to connect with people whose communication is different. If these skills began in childhood, it is likely they would be embedded by the time those classmates are adults in positions of power.

We began a small project to co-produce a resource to support health professionals who do not regularly meet people who do not use words to communicate, to empower them to engage with the person who has come to their service and not ignore them and speak only to the person supporting them.

This project has overlaps with my lived experience, my daughter has words but is not conversational and doesn't answer social questions such as "How are you?", "How was school?", "Are you looking forward to Christmas?" and so on. When these questions are asked there is a pause, a slight discomfort that I try to alleviate by answering for her. Justin Fletcher gets it right in *Something Special* - he greets his guests with a statement not a question. "Hello good to see you!"

Top Tips

Working together a small group of families came up with ten top tips for health professionals who meet someone with a profound and multiple learning disability for the first time. A wonderful designer has bought these to life, and we hope to have coasters, posters, banner pens and small cards that will fit inside name badges to help health care staff to communicate with our loved ones. Here is a preview of the resources- though they may look different when the final processes are complete.

It takes time to get to know and build relationships with people who have different forms of communication. The resources described above are to support people working in environments such as GP clinics who do not have the opportunity to develop rapport. However, there are many situations in which relationship building is possible such as in schools and social care settings, and it fills me with despair when a new school year brings a new room of teaching and learning support assistants, who each have to get to know how to read the verbal and nonverbal communications of distress and contentment of each new student. The reasons I hear are that it is done to prevent children and young people getting dependent on a few people. I still fail to understand why our system does this so often - surely, we all want to be around people who know us, can read us, know how we tick, what we like and what we don't.



To finish I wish to say to all the professionals reading this - always remember the family as someone to include whenever you are working with someone with a learning disability but especially a severe or profound learning disability. Families are your biggest ally - they know their loved one better than anyone else and can be creative beyond words if there is a problem to solve. Remember us, include us, and value us as part of your team.

Contact details

Debbie Austin, Strategic Learning Disability Workforce Manager for Family Carers North-East And Cumbria Learning Disability Network.
deborah.austin9@nhs.net
www.nenclidnetwork.co.uk
www.learningdisabilitymatters.co.uk
www.pbs.nec.co.uk

Connect with us on social media

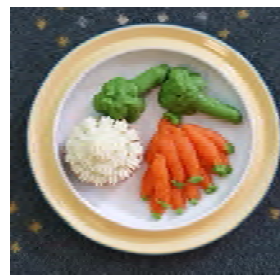
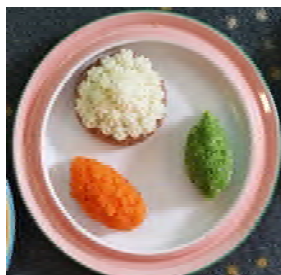
Remember to tag us on social media ~ @PMLDlink

X : @PMLDlink

Facebook: PMLD Link

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

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



It's an IDDSI bit confusing, but mealtime matters!

Speech & Language Therapy Community Learning Disabilities Team Herefordshire and Worcestershire Health and Care NHS Trust

Parents and carers have supported people with learning disabilities at mealtimes, often without any concerns since they were babies. Then an increase of coughing at mealtimes, a choking incident or recurrent chest infections can result in a referral to the local Speech and Language Therapy (SLT) team. Suddenly you are hearing the terms Dysphagia, aspiration, choking risk and IDDSI which all sounds frightening.

Dysphagia is a generic term used to describe any problems with swallowing and can have many different causes and severities. A person may aspirate (when liquids or solids go into the airways) on food, drink or saliva or choke (physical blockage of the airway). Management may include looking at everything around ensuring a safe swallow for drinks, snacks and mealtimes – safe positioning, pace of eating/drinking, level of support and the specific equipment needed. In addition, it will often involve texture modification (adjusting the consistency of food and drink) e.g. cutting food smaller or puree or making drinks thicker.

to ensure meals can be checked by anyone preparing food. Each level is backed by a consumer handout and audit sheets suitable for families, carers and professional chefs. Similarly, IDDSI has given us a clear definition, specifying the size of bite sized foods-for adults (15mm) and children (8mm), meaning food is now prepared consistently at home and in schools, colleges, hospitals, day services, etc.

In 2013 the International Dysphagia Diet Standard Initiative (IDDSI) was set up with a goal of developing international standardised terminology and descriptors for dysphagia diets that would meet the needs of individuals with dysphagia across the age span, across all care setting and across all cultures. (www.IDDSI.org). This standard was based on research and evidence around how we eat and what can reduce the risk of aspiration and choking. It has now been adopted by Speech and Language Therapists and dysphagia practitioners around the world.

IDDSI developed a framework which identifies common terms and defined levels to help with the modification of food textures and the thickness of drinks. (see image below) For instance, what does soft and bite-sized mean? Without a standard measure this could vary from person to person. How do you measure soft? IDDSI has developed a simple 'fork test'



Copyright: The International Dysphagia Diet Standardisation Initiative 2016
@ <https://iddsi.org/framework/>

Raising Awareness

As a small community team of learning disability SLTs, covering 2 large rural counties, it has been a challenge supporting families, carers and service users to make mealtimes safer and understand texture modification. The adults with learning disabilities we support often have large numbers of carers, in different locations, who all need to understand about eating and drinking difficulties. During the pandemic we were forced to rethink how we could reach out and connect with our audience, in a way that allowed us to continue meeting the needs of an often vulnerable service user group. Alongside our direct patient contact, we set about updating our presence on our Trust's website, and we revamped an existing Facebook page. Our aim was to have an online presence that was relevant, up to date, useful and useable for services and carers who support individuals who have learning disabilities.

We are able to use our Facebook page to share resources that we have created, as well as signposting and sharing other helpful sites and materials – hopefully offering a hub of information about all things SLT in the world of learning disability. Our webpage host a range of our resources including our Something2say information sheets and online Eating and Drinking Skills Awareness training, which is free of charge and can be completed at your own pace.

Our most recent piece of work is set to launch in December this year (2023). We identified a need to raise awareness of the risks of choking and aspiration amongst our service user group and to support an understanding of IDDSI. With this in mind, we have created a series of resources and plan to launch our Mealtime Matters booklet – which provides information for services and carers about reducing risks and increasing enjoyment of mealtimes and drinks. Our sheets are simple, easy to understand summaries around a variety of mealtime topics. See an example resource on page 25.

Considering the wider impact

Choking and aspiration can affect anyone not just those with eating and drinking difficulties. However, the risk to people with learning disabilities is higher due many factors including their level of awareness, number of health issues, mobility issues and need for assistance. Whilst the dysphagia itself can be managed to reduce risk, it's impact also spreads into other areas of life. Think of the birthday party your child or adult is invited to. Can they eat the birthday cake or snack foods provided? Will the host modify them or do you have to send in your own food? Or will they just not go to the party because it is too risky. Social isolation can be a consequence of eating and drinking difficulties. As a nation we have seen the growth of food related outlets, having coffee with friends is a common activity. How would it feel if you had to go

without because the café or restaurant could not modify your food? Raising awareness of the needs of people with eating and drinking difficulties goes beyond individuals and families. Making places wheelchair accessible has provided greater opportunities now we need to move towards places being dysphagia friendly. Texture modification takes time to learn. Most foods can be modified and made to look appetizing (see images at the top of this article), but this can be time consuming. The Learning Disability SLT team will be sharing some recipes during our December, Advent Mealtime Matters event- including our modified Christmas meal information.

Here are a few tips to keep you going:

- Blend foods separately to maintain taste and appearance
- Use cake and cookie cutters or ramekin dishes to shape food and improve presentation. Remember, 'we eat with our eyes' too.
- Cook food in batches and make use of your freezer.
- Taste what you are serving, sometimes food needs more seasoning or extra liquids if they are pureed, you can also understand how easy it is to eat what you have prepared.

Wishing everyone a good Christmas, happy holidays and a great new year!

Contact details

Learning Disability Speech and Language Therapy Team
Herefordshire and Worcestershire Health and Care NHS Trust
Email: whcnhs.ldslt@nhs.net
w. <https://www.hacw.nhs.uk/ld-slt>
f. <https://www.facebook.com/LDSLTT.HW/>
t. <https://mobile.twitter.com/Ldsltworc>





Aspiration and Choking

NHS
Herefordshire and Worcestershire
Health and Care
AHS Trust

Why is this important?

A person may be at higher risk of choking or aspiration if they have Dysphagia. Dysphagia is the medical term for swallowing difficulties. All choking incidents should be reported to a Speech and Language Therapist. They can assess eating and drinking and provide advice on environment, assistance, positioning, equipment and food and drink texture for safer mealtimes.

Aspiration

Aspiration refers to fluid or food entering the airway and potentially going down into the lungs.

Aspiration can be caused by:

- Food/drink entering the lungs while eating.
- Struggling to maintain own secretions.
- Stomach contents moving back up the food tube (oesophagus) and spilling over into the airway.

This can cause **aspiration pneumonia**.

Most people cough violently when aspirating but some people do not. When aspiration occurs without coughing, it is **silent aspiration**.

Signs of silent aspiration include:

- Frequent pneumonias.
- Chronic congestion.

If a person aspirates often enough it can cause permanent damage to the lungs.



OR Choking

Choking is the obstruction or blockage of the airway.

Signs of choking:

- Noticeable change in breathing.
- Weak cough and difficulty talking.
- You will likely hear a wheeze.
- Change in facial colour.

This is an emergency if the person is unable to clear their airway on their own by coughing.

Immediate basic life support:

- Back slaps and abdominal thrusts may be used.
- When BLS is used, evaluation by Health Care Provider should follow to ensure no damage is done during the procedure as well as ensuring the airway is completely cleared.



Teaching Reading to All Learners

Sarah Moseley

In our ever-changing educational landscape, the importance of literacy remains constant. Reading is not just a skill; it's a gateway to understanding and communicating in the world. The aim of my recently published book was to foster a deeper appreciation for literacy, especially when teaching children with diverse abilities, including those with profound and multiple learning difficulties (PMLD) (Moseley, 2023).

I wanted to bridge the gap between theory and practice. To support us to understand the link between sensory engagement and literacy learning, and reconsider how we view literacy and the abilities of those learners we support.

One of the reasons for writing this book was the conversations that I have had with professionals, families, and learners over the last 20 years, who work within special education, as well as my own research findings. I have been influenced by the work of so many including my supervisor Dawn Male, Penny Lacy, Keith Park, Flo Longhorn, Nicola Grove, Richard Hirstwood, Jonathan Bryan and many more.

The Essence of an Inclusive Literacy Curriculum

It is important we remember that literacy is not just about reading words on a page. It's a multifaceted journey of exploration, understanding, and expression. Reading can mean many things from decoding letters, exploring sensory stories, or even interpreting facial expressions and interactions. By acknowledging these diverse pathways, we empower our learners to become part of the reading community (a community that everyone else is automatically a member of!) and opens opportunities for all.

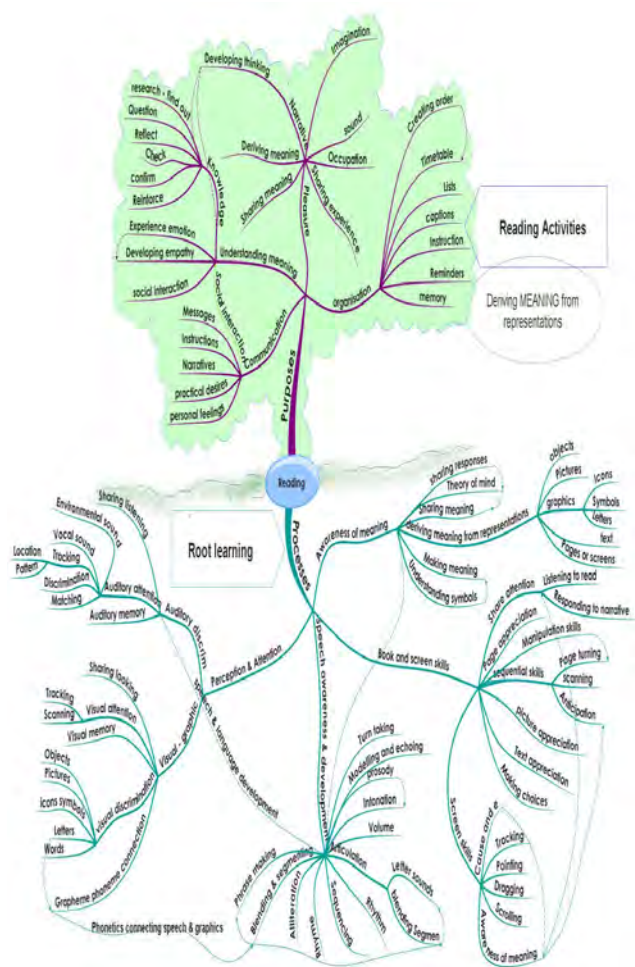
Teaching literacy to learners with PMLD is a complex task that comes with unique challenges. Historically, educational policies and strategies have not always adequately addressed the needs of these learners, leaving educators and families uncertain about the most effective approaches. However, recognising and acknowledging these challenges is the first crucial step toward finding solutions that cater to the individual needs of all learners.

My PhD research, focused on teaching reading to learners aged 11-15 with Severe Learning Disabilities (SLD) and complex needs, who 16 years ago were excluded from the reading community (Moseley 2009). The positive results found, included increased engagement with print and improved self-perception as readers, these highlight the importance of literacy education for all learners, regardless of need. Today those learners would be part of the reading community.

Since my PhD, my work has enabled me to meet some incredible learners who have demonstrated why we need to change how we define our reading community within special education. In today's educational landscape, where mental health is a significant concern, promoting literacy, including reading, is essential. Reading not only supports cognitive development but also contributes to emotional well-being. Embracing inclusive definitions and leveraging technology, such as AI, can help ensure that everyone, including those with PMLD, could participate in the world of literacy and enjoy its benefits.

For our learners with PMLD the role of reading has an even greater significance. In a world of uncertainty, it can provide a known experience, a consistency that we can all share. In the last three years, environments and experiences of all learners have been further reduced due to the pandemic, and for those with the most profound and complex needs, this impact is huge. Exposure to literacy and the teaching of reading can provide a window into a wider world that we can all enter, regardless of our ability. Reading a story requires extraordinarily little to begin – just us, imagination, enthusiasm, and aspirations for our learners. Yet there is a lack of clarity around the appropriateness of teaching reading to learners with PMLD, and this does not support an inclusive education system for all learners.

Print is everywhere, as are people reading and talking about literacy/books. It is part of our world, regardless of our ability to access it. However, there are mixed feelings amongst professionals, academics, and researchers as well as families about the appropriateness and applicability of the teaching of literacy, specifically reading to all learners. Early in my career, I was influenced by academics and experienced practitioners such as Les Staves, who discussed the importance of developing 'Roots to Reading' (Staves, 2019). His diagram below influenced me to look at some of the key aspects that can be considered foundational skills required for the pathway of teaching reading to all learners.



Roots to Reading (Les Staves , 2019)

Building Strong Foundations

Effective literacy instruction is built on a solid foundation. We must consider the unique needs of each learner, including sensory preferences and communication styles as part of their reading journey. This foundation extends beyond traditional reading strategies and embraces a wide range of approaches, from sound discrimination to interactive storytelling. In my experience, I have found that the implementation of previous government led strategies have made many people wary. For example, the National Literacy Strategy led to some blanket expectations and experiences for learners within special school classrooms where mainstream practice was expected to be replicated (Lacey et al., 2007). All learners were included within the traditional structure of the literacy hour, within the National Literacy Strategy unless there was clear evidence that a different approach was needed. This led to many practices which were deemed as inappropriate for learners with more profound complex needs.

In her influential work in this area, Flo Longhorn emphasises the importance of literacy as providing ways in for all learners in terms of their emotions, communication, and expressing themselves through literacy (Longhorn, 2001). Although this is the case in

some contexts, learners are labelled from an early age as non-readers within special education, unable to access something that we are all immersed in. This can lead to a lack of expectations for our learners with PMLD and a narrowing of the curriculum. If we believe they cannot, then we will not provide the opportunities, and this therefore becomes a self-fulfilling prophecy (Rosenthal & Jacobson 1968). I would recommend reading 'Eye Can Write: A memoir of a child's silent soul emerging' by Jonathan Bryan (2018) about his journey with literacy. In some curriculum frameworks for learners with PMLD, literacy is included. It is acknowledged that literacy provides learners with the opportunity to experience and gain a greater understanding of the world around them. For some learners on a pre-formal pathway, literacy and specifically reading is not part of the curriculum offer, or a key aspect of this environment. In a framework whereby literacy and specifically reading is not referenced, there may not be any suggestions as to how it may be incorporated. There may be no bridge between a curriculum without literacy and one that supports the development of a learner's understanding, awareness or even access to a key element that exists within all our worlds.

My book is full of practical success stories that illustrate the potential of inclusive literacy education (Moseley, 2023). Schools like Ash Field Academy and Fairfields Special School have demonstrated how tailored approaches, such as using learners' names and incorporating sensory experiences, can ignite a passion for reading. These provide the foundations of literacy linking oral language to print in a meaningful way. These examples serve as beacons of inspiration for us all.

Ideas in action: A special school's journey

Context - Ash Field Academy a specialist school catering for pupils from age 4–19. The pupil population has a wide range of cognitive ability, from those with profound and multiple learning difficulties (PMLD) to those with more moderate learning difficulties (MLD). In addition to physical and learning needs and disabilities, many pupils also have communication and sensory needs.

Intent – To increase pupils access to print in relation to meaningful context, starting with awareness of learners' names. The class group contained learners with PMLD.

implementation – After becoming aware that some learners recognised their names, staff began to widen the use of names in relation to meaningful activities. They began to use them for the register, paired with photos of the learners for all.

Impact – Learners were able to recognise their names regularly and have now shown an increased interest in the text contained in books. The classroom is now a place where names hold appropriate value.

We talk about reading in many senses, e.g., reading situations or people's faces for meaning. Yet we have a restrictive definition when we talk about all learners reading. Being provided with specific reading opportunities provides expectations that they are part of this world. If the view is held that one specific approach is better than another, this can lead to the exclusion of existing practice which is established as fundamental to specific aspects of learning, in this case the teaching of reading.

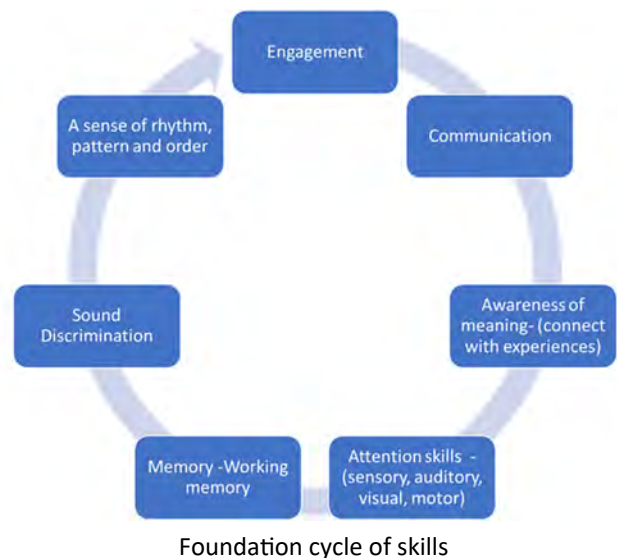
In my work I advocate an 'Inclusive Literacy/Reading Curriculum' (Moseley 2023), using a wide definition of reading as gaining meaning from some form of stimulus. This means we look at how our learners are reading interactions, people, situations, objects, events, images, and, for many, texts. I emphasise an inclusive framework of literacy-rich opportunities and experiences that supports the development of existing practice as part of this, including sensory stories, storytelling, call and response, intensive interaction, choice making/communication approaches, sound discrimination/music-based approaches, multi-sensory activities, and more!



A Richard Hirstwood sensory umbrella

A more inclusive definition enables us to view reading as a continuum, that learners may begin and end at any point (although do any of us ever end the journey?). This does not imply that we are trying to make cognitive leaps or treat everyone as being able to move along the continuum in a set way, but that all learners are part of this journey.

In my experience in schools, I found that sometimes views that are polarised leave professionals in a position of deciding if a learner should be thought of a reader as opposed to considering all learners as readers and moving forward from there. We can then focus on their strengths as a way into the wonderful world of literacy and develop our understanding of how reading develops! MY cycle of skills (below) illustrates the foundations of an Inclusive Literacy/Reading Curriculum (Moseley 2023).



The cycle consists of several skills that contribute to the foundations required for learning and, specifically, learning within literacy and reading. This cycle of foundation skills is a way to look at approaches and strategies used within existing sensory or pre-formal curriculums as part of a wider inclusive curriculum. This will include opportunities to develop an understanding about the link between oral language and text and includes sound discrimination as a foundation skill of the heavily debated teaching of phonics.

Ideas in action: A special school's journey

Context –Fairfields Special School for learners with complex needs including PMLD. Although literacy has always been a focus, accessing physical books and phonics for these learners has been limited and centred more around simple sensory activities.

Intent – To develop a language and literacy rich environment for all learners.

Implementation –We supported the inclusion of more words around the classroom in meaningful contexts, and the inclusion of Makaton to reinforce language. As well as using physical copies of the stories alongside the sensory story.

Impact – Reading and exploring physical books including touch and feel, flaps, and interactive stories has also been introduced daily into the morning routine, which has had a massive impact on the interest in reading with all students. Some students are demonstrating an awareness of repeated stories and anticipating certain aspects, whilst others are showing more focus on the images and awareness of the book itself. All students are more engaged and show positive reactions to physically interacting with the images and pages of books.

A Vision for the Future of Literacy

As the world evolves with technology and new forms of communication, literacy takes on new dimensions. My vision is to foster motivation and engagement in literacy for all learners. The future requires joined-up thinking that involves all professionals, families, and learners, focused on an understanding of learning styles and barriers to learning that may exist, combined with the importance of clear purposeful learning opportunities and experiences aimed at creating an inclusive reading community for all.



Read Amy's story of becoming literate at www.teachustoo

Literacy is at the heart of education; everything that we do revolves around the development of the ability to understand and communicate about the world around us. With the rise in technology, communication, and different ways to understand the world, literacy can be conceptualised in a much broader way. There is no one answer or scheme that will be the best fit for all learners, if we do not include opportunities to experience and develop an understanding about the world of literacy, then we can never be sure of what might become relevant for that learner. The beginning is to promote motivation and engagement in literacy for all learners; the end is not yet known!

Contact details

Dr Sarah Moseley, author, trainer and consultant. Sarah is a literacy and inclusion specialist focusing on empowering all learners, embracing neurodiversity and SEND.

Email - send@drsarahmoseley.com

Social media Twitter @drsarahmoseley

Linked in Facebook Instagram Threads - Dr Sarah Moseley

Website www.drsarahmoseley.com Subscribe for newsletter.

References

Bryan, J. (2018) *Eye Can Write: A memoir of a child's silent soul emerging*. Lagom Publishers

Lacey, P. (2006) *Inclusive Literacy* [online] Available at: <https://studylib.net/doc/7569318/inclusive-literacy> [Accessed: 23/05/2022]

Lacey, P., Layton, L., Miller, C., Goldbart, J. & Lawson, H. (2007) What is Literacy for Students with Severe Learning Difficulties? Exploring Conventional and Inclusive Literacy. *Journal of Research in Special Educational Needs*, 7, (3), pp. 149–160 [online] Available at: <https://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.672.2404&rep=rep1&type=pdf> [Accessed: 16/07/2022]

Longhorn, F. (2001) *Literacy for Very Special People*. Catalyst Education Resources Ltd.

Moseley, S. (2009) *The Effect of Reading Instruction on the Self-concept and Self-esteem of Pupils with Severe Learning Disabilities*, Unpublished PhD thesis, London: University of London Institute of Education.

Rosenthal, R. & Jacobson, L. (1968) *Pygmalion in the classroom*,. *The Urban Review*, 3, pp. 16–20 Available at: www.semanticscholar.org/paper/Pygmalion-in-the-classroom-Rosenthal-Jacobson/59c14fab51544dc9c5ec4e56c5a962346859c06a#paper-header [Accessed: 29/06/2022]

Staves, L. (2019) *Roots to Reading illustration from in person training 'Very Special Literacy training'*. Reproduced with permission

Accessible picture books: bold, clear, sensory and strong

Ailie Finlay

Calling all picture book lovers! The accessible book organisation [My Kind of Book](https://mykindofbook.org.uk/) is keen to hear from any picture book fans out there: children, families, teachers...are there picture books you love to share with children with profound and multiple learning disabilities (PMLD)? Are there books that you wish existed that you have not been able to find?

My Kind of Book is a not-for-profit organisation that creates books and sensory stories for children with complex additional needs (including those with PMLD), and campaigns for greater accessibility in the children's book sector. We have been conducting research into the accessibility of picture books for children with additional needs. Our full research report *Bold, Clear, Sensory and Strong* can be downloaded from our website: <https://mykindofbook.org.uk/resources/>

We surveyed teachers and families throughout the UK asking them detailed questions about how they use and adapt picture books. The majority were teachers or parents of children and young people with needs in the severe to profound range. We found that they were very often frustrated with the picture books that are available to them. Teachers of children with PMLD in particular said it is difficult for them to find picture books they can use 'off the shelf'. They are putting many hours into adapting books to make them accessible for their pupils. We want to start a conversation in the world of children's books – with publisher, authors, illustrators and literacy organisations. At the moment, there is a growing awareness around inclusion when it comes to images and characters with additional needs in children's books. But there is still very little understanding when it comes to the children with additional needs themselves accessing picture books.

Access to enjoyable, engaging books is vitally important to a child's education and wellbeing. It is time to make sure that people working in the world of children's books are aware of the issues around accessibility. This would be the first step to ensuring that children with PMLD have the same access to books as their peers. The second step would be to make sure that they realise how enjoyable the challenge of creating accessible books can be! Our survey respondents had many practical suggestions to make. The parents and teachers of children with PMLD who we surveyed said they want more high interest books with minimal text. (And no babies on the cover!) They want less cluttered illustrations. And books with photo illustrations. They want more tactile books – especially for older children. They want flexible books that are appropriate for a range of ages. They want stronger books and book with pages



that are easy to turn. They want books that include sensory aspects or that easily convert into multisensory stories. But what they also said again and again is that they want beautiful, bright, bold, exciting books. Surely beautiful, bright, bold, exciting books will be a pleasure to write, illustrate and publish! At a recent accessible book event I was asked by an audience member if I saw it as a duty for people writing, illustrating and publishing books to consider how a child with additional needs might engage with the book. Actually I see it not as a duty but as an opportunity – a wonderfully creative opportunity.

Please do get in touch if you would like to tell us anything about the picture books you love, or the picture books you wish you could find! We would love to hear from you: (admin@mykindofbook.org.uk) We plan to continue our research into this and to continue to tell the children's publishing world about the books that are needed for children with PMLD.

Contact Details

Ailie Finlay has been writing and telling sensory stories for many years. She founded My Kind of Book in 2020 to create and research accessible books and stories and for children with complex additional needs, including those with PMLD. Subscribe to their newsletter: <https://mykindofbook.org.uk/email-newsletter/> or follow them on Facebook. Email: ailie@mykindofbook.org.uk



The Next Chapter Book Club –promoting cultural participation and well-being for adults with profound and multiple learning disabilities (PMLD)

Anke Gross-Kunkel and Tom Fish

This article shows that adults with PMLD have a strong need for reading experiences and literature participation; regardless of their reading skills. It focuses on the Next Chapter Book Club (NCBC): A program helping people with disabilities enjoy books, friends, and their community promoting cultural and social participation. The name "Next Chapter" says it all, because the project opens a 'new chapter' in the support of people with disabilities.

The first Next Chapter Book Club established in the U.S. over 20 Years ago were closely tied formally and organisationally to the Nisonger Center at the Ohio State University. Accompanying research has therefore been an important component of the project since the founding of the first Next Chapter Book Clubs and has seen itself as practice research from the very beginning. Based on the results of the scientific observation of the

first two clubs, Tom Fish and colleagues developed an analytical model for the Next Chapter Book Clubs, which consists of the three pillars: Literacy Learning, Social Connectedness, and Community Inclusion. This model has been the basis for evaluating and developing the Book Club idea ever since.

1. Cultural participation

Questions of cultural participation, adult education and inclusion of people with disabilities gained more importance during the socio-political developments in the last years. But even today questions of the cultural participation of people with disabilities are still a minor focus for research. This is why we still do not know much about the importance of cultural participation for people with disabilities and what their cultural needs are; how cultural participation can be put into practice is still relatively unexplored.

Our research on the Next Chapter Book Club shows that reading together (as in utilizing literature) can be one way of putting cultural participation into practice. The methods used in our program for reading in a group together is one way of creating cultural materials in accessible formats and enables everyone to be part of the reading experience (Gross-Kunkel, 2017). Besides the NCBC model we used the Social Literacy Theory by David Barton and Mary Hamilton (2012) to look at our qualitative data from a sociocultural perspective. Social Literacy Theory distinguishes between literacy events and literacy practices. Literacy practices are what people do with literacy based on a text (Barton and Hamilton 2012, 6). "Literacy events are activities where literacy has a key role. Usually there is written text, or texts, central to the activity and there may be discussion around the text. (...) The notion of events stresses the situated nature of literacy, that it always exists in a social context" (Barton and Hamilton, 2012, 7). In our research we see a great potential in Barton and Hamilton's theory for the field of disability: it helps us overcoming a skills-based understanding of reading and brings the meaningful social functions of the occupation with literature into focus (Gross-Kunkel, 2017).

2. The Next Chapter Book Club – a novel idea

The Next Chapter Book Club (NCBC) was founded in 2002 by Tom Fish and his colleagues at The Ohio State University. The purpose of NCBC is to provide adults with a wide range of disabilities a chance to engage in literacy, socialize and hang out in a community setting. Book clubs meet weekly for one hour in such places as book stores, coffee shops and libraries.

The inspiration for the Next Chapter Book Club came to Tom Fish from seeing more people with disabilities out in the community, but rarely interacting with one another. The aim was for people with disabilities not only to go on a group outing but to also have the chance to engage in a purposeful and social activity right in the middle of a public space (Fish & Rabidoux, 2009). There are between 4-8 members with disabilities and 2-3 volunteer facilitators in each book club and they read together out loud. The club reads a page or two and then stops to discuss what is going on in the book. The clubs

are all about supportive friendships and having fun. The books allow the members to feel respected and included in their communities.

When Fish and his colleagues started the Next Chapter Book Club, they began with two clubs. Both clubs met in a coffee shop within a large bookstore. All the members loved the experience. It was as if the members had been given a chance to do something that others had never thought they were interested in or capable of doing. For many years, society thought people with disabilities were not interested in or capable of learning as adults. The Next Chapter Book Clubs shows that this notion is simply not true. When book club members are with friends and reading is not presented as a chore, they enjoy the experience immensely (Fish et al. 2013).

When the NCBC was started it was always the intention to include everyone who wanted to participate. They used the expression "We take all comers". Members didn't have to see, hear, read or be able to talk. We would like to give you two examples of how members with profound and multiple learning disabilities participate in our book clubs:

Ann was 23 when she joined NCBC. Her mother, a disability advocate, brought her to the club and served as a co-facilitator as well. Despite having no formal verbal language and sitting in a reclining wheelchair, often completely on her back or side, Ann was openly accepted by other book club members. There was no fanfare or wonderment about how she would participate or did she fit in. While it was not initially clear what Ann was comprehending while others were reading out loud, soon Ann responded to subject matter through physical gestures and vocalisations. When it was her turn to read, one of the members or facilitators would sit next to Ann and read on her behalf.

Alice is a 32 year old women with cerebral palsy and intellectual disability who has been a book club member for over ten years. Her father supports her to attend the book club and acts as her facilitator, when needed, during book club sessions. He sits beside her and clarifies what his daughter wants to communicate when and if he perceives other members may not be comprehending her. Alice's enthusiasm for books and social participation is beyond belief. In spite of her significant communication challenges, Alice is persistent in her efforts of self-expression. Next Chapter Book Club is the love of her life. It is also a special time every week for her to hang out with her Dad.

The intent of "We take all comers" means that the NCBC would do everything possible to include anyone in the clubs and we have almost always been able to accommodate people by using a certain amount of

commitment and creativity. The book clubs are about diversity in every possible way and we embrace it to the fullest extent.

Now in our 21st year, NCBC has over 300 book clubs throughout the United States, Canada, Australia and Germany – where the program is called LEA LeseklubÖ. About 70% of the new book clubs in the US have been sponsored by libraries. Often one of the volunteer facilitators is a librarian and the other one a high school student for example.

3. Conclusion

The Next Chapter Book Club experience is an enjoyable life-affirming cultural experience for facilitators as well as members, marking a high spot in each week. Next Chapter enriches the lives of all involved. NCBC is actually very simple. The book clubs are based on having fun with friends, being in the community, and being exposed to literature. Of course it takes organization, commitment, and support, but most successful programs do. The beauty of the Next Chapter Book Club is that members and volunteer facilitators make it happen week after week.

This short introduction to the NCBC shows that the Next Chapter Book Club is one way of putting cultural participation into practice and presenting cultural materials in accessible formats. There are other ways of supporting people with profound and multiple learning disabilities in the area of cultural participation concerning literature. For example: the concept of the Multi-sensory storytelling or the German program of mehr-Sinn GeschichtenÖ.

We do encourage you to think about starting a Next Chapter Book Club in your community. To learn more about NCBC, please also see our website at <https://www.nextchapterbookclub.org/> or <http://www.kubus-ev.de/lea-leseklub>

Contact details

Thomas Fish Ph.D. Founder of Next Chapter Book Club
Anke Gross-Kunkel Ph.D. Founder of the German LEA LeseklubÖ
Email: info@nextchapterbookclub.org

References

- Barton, D.; Hamilton, M. (2012): Local literacies. Reading and writing in one community. London/New York: Routledge.
- Fish, Thomas R.; Rabidoux, Paula (2009): Next Chapter Book Club. A Model Community Literacy Program for People with Intellectual Disabilities. Bethesda, MD: Woodbine House.
- Fish, Thomas R.; Graff, Vicki; Gross-Kunkel, Anke (2013): Next Chapter Book Club: Lifelong learning and community inclusion. In: Heward, W. L. (Hg): Exceptional children: An introductory survey of special education, 10th ed., Upper Saddle River, NJ: Merrill/Prentice Hall, 594-595
- Groß-Kunkel, Anke (2017): Kultur, Literacy und Behinderung. Teilhabe verstehen und verwirklichen mit den LEA Leseklubs. Bad Heilbrunn: Klinkhardt

Gift Aid

Are you a tax payer?

Is your subscription to PMLD LINK for yourself and do you pay tax? If this is so and if you sign a gift aid form, then PMLD LINK can get an extra 25p for every £1 you pay to us for your subscription, in a tax refund from the government. This will help PMLD LINK significantly.

If you pay online via the website, you will be given the opportunity to fill out a gift aid form. If you have forgotten to do so or if you are paying by cheque or by setting up a bank mandate, please fill out the subscription form available on the last page of this journal or downloadable from the subscribe page of the PMLD LINK website (www.pmlmlink.org.uk). Send it to the PMLD LINK Treasurer at the address shown on the form.

You can cancel this Declaration at any time by notifying PMLD LINK. If you pay tax at the higher rate, you can claim further tax relief in your Self Assessment tax return.

If you are unsure whether your donations qualify for Gift Aid tax relief, refer to help sheet IR65 on the HMRC web site (www.hmrc.gov.uk)

Many thanks for your support.



Recipe for a Hanging Out Café

Sheridan Forster

The Hanging Out Café is a get together and celebration of people who primarily use body, gaze, reach, sound, and movement communication. It has been inspired by the Hanging Out Program, principles of reverse inclusion, and the need for accessible environments for people with profound and multiple learning disabilities (PMLD).

Ingredients

- A large room where people can move around easily, booked for 3 hours (30 minute set up and pack up, with 120 minutes for the café)
- Some basic catering stuff – nothing too flash
- Some chairs
- Some handy resources that people can take away like the HOP booklet or copies of PMLD Link
- Up to 15 people with PMLD and their support workers
- Up to 15 people who are used to interacting with people with PMLD
- Up to 10 people who haven't had much experience being with people with PMLD (e.g., experienced peoples' partners, students)
- Many, many hours to advertise, explain, beg, beg again, convince people that "yes the person you

support sounds perfect to come along," and patience to deal with the many gatekeepers between the event and individuals with PMLD.

Method

1. Get people to register for the event, including request for consent for photos.
2. On the day, set up the room. A table for some foods, a drinks area. Groups of 3 chairs spattered around the room (remembering that prolonged quality engagement has reduced likelihood if people are standing as opposed to sitting next to someone). A room with a quiet end and more active end can be useful.
3. Allow your 12-year-old son to plonk himself in a corner with his computer, knowing that even if he doesn't engage directly, just being there helps him

to be part of the disability community. Take up his suggestion that maybe he can bring some friends along next time to help out.

4. Expect people to arrive at different times. Welcome them. Be mindful of encouragements you might need to give to support workers to allow people to move about the room freely (to discourage hovering or well-meaning controlling behaviours that might be ingrained in their workplace culture).
5. Engage with people as they come in, or encourage other partners to engage.
6. Keep an eye out for anyone who might not be being engaged with.
7. Offer to make cuppas or show people where food is BUT it is critical that people know that the main ingredient of the experience is Hanging Out, not the food and drink. You do not want people coming in, eating, drinking, thinking they are done, and leaving – missing the best meal of the day of - engagement with another person.
8. Try to take photos.
9. Support experienced and inexperienced people to be able to engage – they might need ideas, highlighting of the focus of the individual with PMLD, ideas for sharing that focus, permission to play, or share silence. They might want to ask questions without feeling judged.
10. Be ready to support support workers, who may not have seen the level of engagement with the person that they support. They may have been in cultures missing good quality interaction.
11. Let people float in and out.
12. Go with the flow.
13. After pack up, send out photos of individuals to their contact person, so the celebration and modelling of great interaction continues on after the event.

Comments

Resist the urge to overengineer. Before each Hanging Out Café you might be thinking of all the switch



equipment, toys, lights, vibrating things, and stuff that you can bring along. Perhaps bring along what you need to address your own sensory needs (my diffuser goes everywhere). Pulling out communication apps for picture sharing or YouTube AC/DC is permitted. But resist the urge to complicate. Bring things back to basics – attending to the person in front of you. Don't get lost behind bells and whistles.

Be aware you may have a desire to orchestrate every item on the list, but this is not possible, so delegating photographing, trusting others to do things, and allowing yourself to share moments with people is needed.

Thanking those who attended the 2nd Annual Hanging Out Café. The Hanging Out Café has been an event run with AGOSCI Australia in celebration of International AAC Awareness Month in October. It is part run to highlight that body, sound, gaze, reach, and movement communicators need as much celebration as people using formal communication devices and communication books.

Contact details

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

References

Forster, Sheridan (2008) HOP: Hanging Out Program: Interaction for people at risk of isolation.
Available from: <https://sheridanforster.com.au/wp-content/uploads/2014/08/hop-a5.pdf>



Remembering Stansfield View

Gerard Wainwright

In 1990 I started my life as a learning disability nurse. It's been said 'the past is another country; they do things differently there' (1). In terms of how we view and relate to many people with learning disabilities looking back to that time, it's undeniable how much the landscape of health and social care has changed. My career began in a long stay learning disability hospital, Stansfield View in Todmorden; situated high on an isolated moorland hillside above the local mill towns and villages, it served the district of Calderdale. Most areas throughout the country had their own institutions, where many people with learning disabilities were routinely segregated from their families, local community, and the right to lead a normal life. Remembering Stansfield View (2023 Trailer) - YouTube: https://www.youtube.com/watch?v=7_RW4QZEe2A

In retrospect the institution is emblematic of a model of care, an ideology, and a social construct which we now find difficult to comprehend. Indeed, many people I speak to are unaware that a generation ago this was the only option offered to most parents of a child with a learning disability. In this respect for future generations there is a real risk that what is a hidden history, could be lost.

With that in mind and being conscious that this year marks thirty years since the closure of Stansfield View under The Community Care Act in 1993 (2). I felt compelled to create a lasting record, not so much to the building but to the people who lived and worked there. "For once a thing is known, it can never be unknown. It can only be forgotten." (3). What became very clear to me during the process of making the documentary film Remembering Stansfield View Remembering Stansfield

View (2023 Documentary) YouTube: <https://www.youtube.com/watch?v=B6lnKtc7m3A>) is that any history of a place is really the history of its people. The project was very much driven by a wish to celebrate the lives of the many people with learning disabilities who lived at the hospital; to acknowledge what they went through and recognise the resilience that many showed. It's difficult to separate my personal life and career, some of the people I first met at Stansfield View are still part of my life, our lives have changed in parallel. As a learning disability nurse, I've been part of the journey from segregated care to care in local communities, working in partnership with people with learning disabilities in terms of greater visibility, independence, choice, and inclusion.

I'm indebted to inspiring individuals with learning disabilities who have taught me how to communicate

differently, to see the world from an alternate perspective and to try to understand some of the harm that historic care practices have caused, as well as focus on the current inequalities people with learning disabilities continue to face. We live in more enlightened times, with many organisations and individuals now taking a trauma informed approach (4), I'd urge anyone working with older people with learning disabilities to consider their past and how it may continue to inform their present.



I'm currently making a parallel film of life at the hospital with friends and people I support with profound and multiple learning disabilities. A sensory film with minimal text, and voice-overs from those who lived at the hospital, survivors of that time. It's difficult not to be conscious of the disparity of the interior and exterior world of Stansfield View, which made a deep and lasting impact on me. That between the bleak beauty of the surrounding landscape where the hospital was located; miles of moorland, Pennine hills, birdsong, the constant soundtrack of the wind on the tops, heightened colours, sounds and smells. Evocative of the elements of life. Contrast this with the interior of the hospital, which in the early 1990's when I was there was run down, desolate, stripped of individuality, largely devoid of personal possessions, the acoustics of footfall echoing through endless corridors, antiseptic mixed with the odour of human waste, crumbling plaster, everything broken or no longer of use.

I'm incredibly fortunate that friendships and alliances I made back then have endured. Many of the people I first met at Stansfield View continue to be part of my life. In most cases, these are people I'm all the better for having known, people who have enriched my life and often brought joy, companionship, and stability. People who have not only marked significant points in my career but who have profoundly impacted on my personal life and helped make me who I am.

In thirty years, I've seen unprecedented change in the way people with learning disabilities are viewed, the opportunities available and the growing move towards not only greater equality but an acceptance and an understanding that difference is good, it brings colour to our lives, I feel a personal and professional responsibility to do what I can. If previous generations were somehow complicit in the sometimes inhumane care people with learning disabilities received then surely, we all have a responsibility not only to ensure we learn from the mistakes of the past but that we do all we can to create a better present and brighter future for the people we support, care for and love. In the words of Ben Frensz; "Don't leave a place as you found it - leave it as you would like to find it." (5)

Contact Details

Gerard Wainwright
Email: gerard.wainwright2@st-annes.org.uk
Gerard Wainwright - YouTube channel:
<https://www.youtube.com/@gerardwainwright4304>

References

1. LP Hartley (1953) *The Go Between*. Penguin Classics
2. The National Health Service & The Community Care Act (1990). The Statutory Office Limited
3. Anita Brooker (1984) *Look at Me*. Panther Books
4. <https://www.gov.uk/government/publications/working-definition-of-trauma-informed-practice/working-definition-of-trauma-informed-practice>
5. <https://www.dailymail.co.uk/news/article-11955237/Nuremberg-prosecutor-Ben-Ferencz-revealed-believed-vengeance-NEVER-answer.html>

The future of PMLD research – what happens next?

Neil Mullen

Within the world of academia, there has been a significant increase of research into the lives and experiences of people with profound and multiple learning disabilities. Prior to this, the research examining the lives and experiences in both education and community settings typically included people with a wide range of special educational needs and disabilities (SEND), some of whom had profound and multiple learning disabilities (PMLD).

Murray & Colley (2017) advocate that for a long time, and potentially still (in some cases), people with profound and multiple learning disabilities' lives, inclusivity, and views on their experiences, have not been effectively researched. Additionally, Tilbury and Colley (2020) argue that the educational policy framework that supposedly guides education for people with PMLD such as the SEND code of practice (DfE/DoH, 2015), is setting expectations and goals which are often completely at odds with their capabilities and complex lives. They propose that the SEND code of practice, typically overlooks people with PMLD and research underpinning the design of the document does not consider the lived experiences of this population.

Consequentially, researchers conducting research into lived experiences both in education and at home often find that this policy documentation is irrelevant, whereas research that focuses on wellbeing and individuality that can effectively express lived experiences and views a more effective alternative when working with people with PMLD. Current and future research needs to begin focusing on how to articulate the experiences, views and indeed wishes of people with PMLD. This should be focused on both within education and their own communities. Research prior to the early 2000s highlighted a lack of impactful and specific research around people with PMLD. This research was often conducted at arm's length from people with PMLD, often overlooking their views and unique experiences. In other words, not inclusive of their participation. Additionally, the impact of such generic research did not provide new ways of working that would benefit people with PMLD, or provide increased inclusivity or indeed showcase or express their experiences and views.

Watson (2020) advocates that it is essential to include people with PMLD directly in research. She highlighted that negative attitudes lead to people with PMLD not even being considered as research participants which is clearly problematic. Furthermore, she puts forward that one of the prevailing negative attitudes towards children with PMLD is that their level of impairment means that

including them directly in research is too difficult, or that inclusion will be tokenistic. Research needs to fully incorporate and validate the inclusion and involvement of people with PMLD. Researchers need to ensure that people with PMLD are fully included and involved in purposeful and meaningful ways. Moving forward, attitudes need to change to realise that people can be involved in a way that is meaningful and not tokenistic.

New research such as Grace (2022) and Nind & Strnadova (2020) has often included people with PMLD at the very heart of their research. This often centres around consent and assent with people with PMLD. Research conducted in conjunction with people with PMLD should be at the very forefront of research methodology, thus ensuring views and experiences can be expressed, developments/improvements to experiences identified, and refinement for service providers detailed.

Inclusive research proposed by the Scottish Learning Disability Observatory (2019) discussed with people with PMLD and their families directly about how they would like to be included in health research. This project highlighted that pre-research work with people with PMLD and their families is vital in establishing how to genuinely include them. Researchers must be adaptive to meet the needs of participants with PMLD to ensure they can contribute to the research aim. Such adaptations can include undertaking research in the field (visiting schools, care settings, family homes etc.), pre-research preparation to get to know participants, plus potentially changing research aims or focus depending on what its impact may be.

The future of research in conjunction with people with PMLD can be further fostered into new areas. This could include better links into educational policy, specifically for people with PMLD. It is important to develop provision both in educational and community sectors and how best to support people with PMLD to become happy, fulfilled, and empowered adults. To enable this, more academic research needs to take place in the

relevant field which will support empowerment and real inclusion of people with PMLD, including involvement in developing the research aims.

In relation to the area of education, educational policy needs to be revisited to make sure that it fully includes students with PMLD. The SEND code of Practice (DfE/ DoH, 2015) needs a radical rewrite to ensure that it includes and benefits students with PMLD rather than it not being fit for purpose (as it is in its current form). Eight years into the implementation of this policy and there have been significant calls for policy changes for students with PMLD –these foundations need to be in place to enable better outcomes for student with PMLD. There needs to be a shift from tokenistic inclusion of people with PMLD to meaningful inclusion where people with PMLD are supported to contribute in a meaningful way and their contributions valued. In order for this to take place, there needs to be an increased focus on the benefits of including people with PMLD in research.

Contact details

Neil Mullen
Neil has taught in a variety of schools, colleges, community and voluntary organisations. He currently teaches Post-16 learners with special educational needs and disabilities for Durham Learn
Email: nmullen1988@yahoo.com

References

Department for Education and Department of Health (2015) Special educational needs and disability code of practice: 0 to 25 years. Available at: <https://www.gov.uk/government/publications/send-code-of-practice-0-to-25> (Accessed: 25 March 2021).

Imray, P., & Colley, A. (2017). Inclusion is Dead: Long Live Inclusion. London: Routledge

Nind, M. and Strnadová, I. (2020). Belonging for People with Profound Intellectual and Multiple Disabilities. London: Routledge.

Watson, D (2020) Changes in the lives of people with profound intellectual and multiple disabilities. Chapter in Nind, M. and Strnadová, I. (2020) Belonging for People with Profound Intellectual and Multiple Disabilities. London: Routledge.

Get Involved

All contributions to our journal PMLD Link are welcomed. Share your ideas about future topics for the journal or make suggestions of authors we might approach. If you want to write for us yourself, it's easier to get your experiences and thoughts into print than you might think. We also welcome shorter items about new resources, books, websites, events, courses or news in general.

PMLD Link readers include family members, carers and professionals working across child and adult services for people with PMLD. To see typical contributions, look at some recent back issues. You can download a free copy of PMLD Link from www.pmlmlink.org.uk or sign up as a 'Guest' to view back issues of our journal.

Our Editors are keen to support new writers. We will provide support at every stage - from the germ of an idea through to the finished piece in print. Articles are usually between 1- 4 pages of A4 (about 350-1500 words). They can be very practical in nature or have a more research /academic approach. We are very flexible in our requirements! To see our Guidelines for Writers visit the 'Get Involved' pages on our website www.pmlmlink.org.uk.

For more information contact info@pmlmlink.org.uk

Inclusion at its best, access to a mainstream holiday club

Jane Godfrey

We live in a part of the world with outstanding natural beauty and lots of tourism, but with this comes a lack of resources and services completely stretched to the max. The limitations of specialist schools and care make it difficult at times. This is what led me to think outside the box for my child. Our son Joel is a 14-year-old young person, a full-time wheelchair user with profound and multiple learning difficulties (PMLD), whom we try to offer as many experiences as possible to enrich his life and support his well-being. One of the limitations of our area is the lack of childcare available for children with disabilities, which has also been highlighted in the news recently.

However restricted and sparse our services are, we found a little gem of a local personal business that offers after-school support and holiday clubs during the school holidays. As our son is an only child, I wanted to look for somewhere to support him in social interaction with other children. The specialist schools did not offer any holiday clubs, so I asked a local lady, Yvonne, who runs the "schools out club" in our area if she would be happy to accept our son at the club. I was absolutely delighted and overjoyed when she said yes, not a problem. I think I cried at the sheer joy that my plan could and was going to become a reality! We have encountered people on our journey who are accepting, and disability is not a barrier to them. These people have a positive outlook; we call them our "can do" people. This wonderful lady was certainly one to be added to our list of "can-do" people. I couldn't believe this was happening for our son, who has PMLD, was going to attend and access a mainstream holiday club.

We assessed what he needed to enable him to attend the club and be able to meet his needs in the best way possible. We spoke to our Occupational therapist, who totally understood what we wanted to do and the reasons behind it. She was able to source a reconditioned mobile hoist that we could have on loan and leave at the club throughout the school holiday period. Joel's physio team also visited to support him with the physical aspects, offering support and advice to the staff on how best to position him into his specialist seating following a transfer. We agreed to give Joel short sessions in the morning because this would offer him the maximum from the intervention of social time with the other children. Whilst still offering a coping time from his point of view. The hoist was used so that he could be hoisted to be changed. The holiday club sourced a P.E. mat to use for changing and a separate room for privacy, although the hoist was also used to give Joel a break from sitting in his wheelchair; he would lie on the mat and have story time where he would be joined by other children sitting with

him. We reviewed his medical needs, including the emergency plan for epilepsy and some of his favourite things to do, including his likes and dislikes. They put in a contingency plan for if there was ever a fire, ensuring his safety whilst he was there.

I started by attending the club with my son and staying with him while he got used to the new experience, transitioning him slowly and carefully. Yvonne allowed me to continue attending until we both felt very comfortable and happy that it was a good time to leave him and that he would always be okay, keeping in touch by phone if needed. While I stayed with Joel, I initially supported the children in playing with him, explaining his visual impairment needs and how he likes people to talk to him regardless of the two-way exchange. I didn't need to worry about this, as the children just seemed to do this naturally anyway, supporting Joel's hands to enable him to play and access the toys the way they did. (He attracted the girls who wanted to help him with many play activities!) Joel has made friends at the club, and the other children will come and greet him when he arrives and say goodbye when he leaves. Their presence stimulates him, and he loves to watch what they are doing, as one of his strengths is that he is very observant of his surroundings and likes to know what is going on.

He communicates through his sounds and movements, and when he returns from the club, he is very "happy", with his vocalisations being very upbeat and telling his dad how much he has enjoyed it.

The holiday club owner, Yvonne, charges us the same rate as the other families. He has an adult, Julia, who oversees his needs whilst he is there and supports the other children in their interaction with Joel, but equally recognises when to step back and allow this interaction to continue independently, giving Joel unrestricted open time with them.

On one occasion during the school holidays, one of the fire doors (Joel's only access in and out of the club) had become unavailable to use, so Yvonne relayed the information to me about this and then said they had another plan to enable Joel still to attend the club as she didn't want Joel to miss out because she knows how valuable it is for him. The plan was to build a tent outside where the other children could still come outside and be with Joel, and they could play, snack, and talk together. The children enjoyed helping build the tent and were excited about its existence. Joel spent the time under the tent for some of the session, with the children joining him to spend time with him throughout the session. The tent was used for one club session because the owner and caretaker had sourced a ramp that they could borrow for the rest of the school holidays. Giving Joel access to the building for the rest of his time at the club.

This showed how the staff at the holiday club went the extra mile, above and beyond, to ensure my son still had access to the holiday club regardless of the barriers put before them. Yvonne says, "The staff and children feel that Joel is a valid member of the club, and all activities can be adapted for all children to participate in." So, after four years of attending the holiday club, it is a very special place for my son in more ways than one! Not only does my son have access to a mainstream provision, but he is also included and treated with respect and understanding, which allows him to enjoy this magical experience. There are also many benefits for all involved, but this could be another piece of writing for another day!

Contact Details

Jane Godfrey
Email: richjanegodfrey@gmail.com

In the Next Issue

The theme for the Spring 2024 issue is 'Wellbeing'.

Wellbeing is a broad concept' (The Care Act (England) 2014, and Social Services and Well-being Act (Wales) 2014, statutory guidance). This is something many of us recognise- that our 'wellbeing' relates to and is affected by many aspects of life. It is a term we use and hear regularly in day-to-day life and that also appears in policy and legislation, e.g. it is a guiding principle in the Care and Well-being Acts, and it is a key focus in the 'Supporting people with profound and multiple learning disabilities, Core and Essential Standards' (2017).

It is probably fair to say that 'wellbeing' is important to us all - the wellbeing of those we love, the wellbeing of those we support and our own wellbeing too.

We would love to receive contributions about anything to do with the wellbeing of people with profound and multiple learning disabilities, their families and those who support them. We would particularly encourage contributions focusing on emotional wellbeing and mental health, and how these needs are recognised and supported, for the Spring issue (as the Summer issue will focus on 'Health' more broadly). But any and all contributions are hugely welcomed.

We look forward to reading your contributions.
Please submit by 26th February 2024

The Spring 2024 issue editors are Becky Loney, Annie Fergusson, Martin Goodwin, Maureen Phillip and Bella Travis.

To submit any items, for further guidance or to discuss your ideas, please contact the Editors at: info@pmlmlink.org.uk

REPORT BACK



Removing the Cloak of Invisibility – Kent, Surrey & Sussex Learning Disability Community of Practice Conference, 1st December 2023

by PMLD Link team

PMALD Link were joined by self-advocacy group, Campaign 4 Change to focus on 'Removing the Cloak of Invisibility' that surrounds people with profound and multiple learning disabilities. At the KSS Learning Disability Community of Practice 'Living healthy, safe and fulfilled lives' Conference at Kingston University, delegates were asked what we can all do individually and collectively to ensure people with profound and multiple learning disabilities are considered with policy making, commissioning, and at a community level with presence in meetings, events and society in general.



Michael Fullerton (PMLD Link) was joined by Alex Starley (Campaign 4 Change) and Rachel Harman representing people with profound and multiple learning disabilities. Rachel managed the presentation slides using switch technology while Alex strongly advocated for greater visibility for this group. People with profound and multiple learning disabilities were also present as delegates to reinforce the importance of people being present and involved.

Further details of the KSS CoP can be found on their website, ldcop.org.uk



The Review of the International Short Breaks Association (ISBA) Conference, Wroclaw, Poland

by Fiona Souter, Pamis

PAMIS presented and facilitated a workshop recently at the International Short Breaks Association Conference (ISBS) in Wroclaw, Poland. This four day event saw over two hundred delegates attending from eighteen countries worldwide, sharing expert knowledge and best practice with a view to developing innovative and pioneering solutions and diverse respite opportunities for people disabilities and their families.

PAMIS presented on the topic of making memories as a family and the work our organisation is doing to improve physical and social accessibility for people with profound



and multiple learning disabilities (PMLD). We were delighted to receive such positive feedback from other delegates about the work we are doing to develop and improve access to appropriate toilets here in Scotland which is inspiring other countries to create their own network of Changing Places toilets. Without appropriate toilet facilities there is a shared global consensus that opportunities to live a rich and fulfilling life with access to purposeful and meaningful activities is severely restricted. We had many powerful conversations around this topic over the course of the week. Our Creative Programme Director spoke about developing opportunities within leisure and cultural sectors.

A key outcome was the commitment from professionals in other countries to collaborate with PAMIS and other partners longer term to improve the lives of people with PMLD. We are thrilled that since hearing Pamis' ISBA presentation, founder and executive director of the Latika Roy Foundation, Jo Chopra, has committed to installing multiple Changing Places toilets in plans for a large new centre the Foundation are currently building in India. PAMIS were invited to join the International Break Exchange (Building Respite Evidence and Knowledge.) The group are committed to building a culture of evidence based respite care. Learning about Poland's Imago Foundation's nature and adventure therapy basecamp programme gave us plenty of ideas and inspiration for potential future activity programmes here in Scotland.

The greatest strength of ISBA's conference was the power of the personal stories told over the course of the week with a strong focus on the individual within every workshop and plenary session. A very practical and grounded conference experience. Spending time with other Scottish delegates was another highlight and thanks to Shared Care Scotland (<https://www.sharedcarescotland.org.uk/>) CEO Don Williamson for arranging a valuable pre-conference meet up.

Full conference notes and learning will be available on the ISBA International website (<https://isba.me/>).

IN THE NEWS

Latest LeDeR Report is now published

The 2022 LeDeR Report which seeks to learn from the avoidable deaths of people with a learning disability, and now also autistic people was published on the 30th of November. The report includes a focus on the review of 2,084 deaths of individuals who died. Of this number only 37 people were identified as having profound and multiple learning disabilities. PMLD Link will continue to discuss the report findings and learning for this group, and will report further in our next issue. All formats of the report, including easy read and video, available here <https://www.kcl.ac.uk/research/leder>

NEW Clinical standard for oral healthcare

This clinical standard supports the vision of universal access whereby everyone receives quality health services that meet their specific needs. Although designed for children and young people, the standard and accompanying support materials have a much wider application, to individuals of any age, wherever they live. Families and paid carers will also find these of use. Available from <https://shorturl.at/gqIX9>

Investigation report: Caring for adults with a learning disability in acute hospitals

This report published by the Health Services Safety Investigation Board (HSSIB) in October 2023 focuses on people referred urgently for hospital admission from a community setting, such as a person's home or residential home. The report is intended for health and care organisations, policymakers and the public to help improve patient safety in relation to the care of adults with a known learning disability when in an acute hospital setting. <https://shorturl.at/dsS67>

World Toilet Day 19 November 2024

A huge shout-out to Changing Places toilets campaigners around the world who celebrated progress on #WorldToiletDay! We love knowing that we're all working towards a more incLOOsive world. #incLOOsive

NEW RESOURCES

Helix of Love: A collection of poems from parents of children with rare genetic conditions

This free e-book is a collection of poems written by parents of children with rare or undiagnosed conditions, most of whom have profound and multiple learning disabilities.

The poems are one part of a creative project run by Brighton and Sussex Medical School and funded by the Wellcome Trust. They give an insight into these people's lives.

The free e-book is here: <https://shorturl.at/qTV04>
Please contact the project leaders, Rich or Bobbie
R.Gorman@bsms.ac.uk - B.Farsides@bsms.ac.uk



VLOG - #Top Tips Tuesdays!

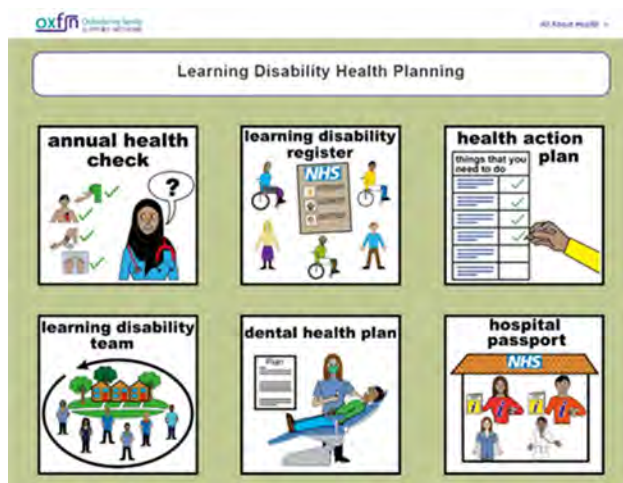
Rachel Wright from 'Born at the Right Time' and 'The Skies We're Under' podcasts fame, is now sharing her weekly #TopTipsTuesday reels on social media platforms X, Facebook and Instagram.

Her short videos offer very practical top tips for daily living. Rachel tackles familiar, everyday issues and challenges with simple ideas on access and adaptations to make life easier and more fun. Topics so far leave no stone unturned - from having a wee, to music on the go!

www.bornattherighttime.com/
social media: Born at the Right Time

All About Health

Here's one example from the newly developed interactive resource website by Oxfordshire Family Support Network. It hosts locally and nationally available easy read healthcare information for people with a learning disability, their families, carers, professionals, and anyone who supports them.
<https://allabouthealth.oxfsn.org.uk/>



End of life plans- trial of new resources

How do you involve people with learning disabilities to be involved in decisions around the end of their life? The Victoria & Stuart Project and the PCPLD Network are trying to answer this question and have coproduced some resources to help.

If you want to try them out, email Sarah for more information: S.L.Gibson@kingston.ac.uk or sign up on their website: <https://www.victoriaandstuart.com/evaluation>



COURSES, CONFERENCES AND EVENTS IN 2024

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.

January		Title:	Policy & Politics for Good Lives LDE Conference 2024
January Title: Date: Location: Provider: Contact:	Marvin's Winter Wonderland Story Time Show Starts January 7 Online Positive Eye/Gwyn McCormack. https://marvinstorytimeshow.co.uk/product/marvins-story-time/	Date:	21 February
		Location:	Online
		Provider:	Learning Disability England
		Contact:	www.learningdisabilityengland.org.uk
	Title: Date: Location: Provider: Contact	Title: Date: Location: Provider: Contact:	The PMLD Conference IV 24 February Online/Facebook Jo Grace/The Sensory Projects Eventbrite
February Title: Date: Location: Provider: Contact	Positive Looking Visual Skills Course Starts January 8 Online Positive Eye/Gwyn McCormack gwyn@positiveeye.co.uk	Title: Date: Location: Provider: Contact	Inclusive RSE for learners with PMLD 28 February Online Rachael Baker RSE Forum info@sexeducationforum.org.uk
	Title: Date: Location: Provider: Contact:	Title: Date: Location: Provider: Contact:	A Special Kind of Grief 28 February Online Zoom Sarah Helton - Back Pocket Teacher backpocketteacher@gmail.com www.backpocketteacher.co.uk
	Title: Date: Location: Provider: Contact:	March	
	Title: Date: Location: Provider: Contact:	Title: Date: Location: Provider: Contact:	Positive Looking Visual Perceptions 4 March Online Positive Eye/Gwyn McCormack https://positiveeye.co.uk/our-products/positive-looking-perception/
	Title: Date: Location: Provider: Contact:	Title: Date: Location: Provider: Contact:	Grief & SLD/PMLD 6 March Online - via Zoom Sarah Helton Back Pocket Teacher backpocketteacher@gmail.com www.backpocketteacher.co.uk
February Title: Date: Location: Provider: Contact:	Winter Wander 24 - Sponsored Walk 27 January Putney Bridge – Kingston bridge – Us in a Bus events@usinabus.org.uk	Title: Date: Location: Provider: Contact:	Using Good Grief Toys ® 19 March (9.30am-12.30pm) Online Sarah Helton Back Pocket Teacher backpocketteacher@gmail.com www.backpocketteacher.co.uk
	Title: Date: Location: Provider: Contact:	March	
	Title: Date: Location: Provider: Contact:	Title: Date: Location: Provider: Contact:	Positive Looking Visual Perceptions 4 March Online Positive Eye/Gwyn McCormack https://positiveeye.co.uk/our-products/positive-looking-perception/
	Title: Date: Location: Provider: Contact:	Title: Date: Location: Provider: Contact:	Grief & SLD/PMLD 6 March Online - via Zoom Sarah Helton Back Pocket Teacher backpocketteacher@gmail.com www.backpocketteacher.co.uk
	Title: Date: Location: Provider: Contact:	Title: Date: Location: Provider: Contact:	Using Good Grief Toys ® 19 March (9.30am-12.30pm) Online Sarah Helton Back Pocket Teacher backpocketteacher@gmail.com www.backpocketteacher.co.uk
February Title: Date: Location: Provider: Contact:	Policy & Politics for Good Lives LDE Conference 2024 7 February Leeds Learning Disability England www.learningdisabilityengland.org.uk	Title: Date: Location: Provider: Contact:	Using Good Grief Toys ® 19 March (9.30am-12.30pm) Online Sarah Helton Back Pocket Teacher backpocketteacher@gmail.com www.backpocketteacher.co.uk
	Title: Date: Location: Provider: Contact:	March	
	Title: Date: Location: Provider: Contact:	Title: Date: Location: Provider: Contact:	Positive Looking Visual Perceptions 4 March Online Positive Eye/Gwyn McCormack https://positiveeye.co.uk/our-products/positive-looking-perception/
	Title: Date: Location: Provider: Contact:	Title: Date: Location: Provider: Contact:	Grief & SLD/PMLD 6 March Online - via Zoom Sarah Helton Back Pocket Teacher backpocketteacher@gmail.com www.backpocketteacher.co.uk
	Title: Date: Location: Provider: Contact:	Title: Date: Location: Provider: Contact:	Using Good Grief Toys ® 19 March (9.30am-12.30pm) Online Sarah Helton Back Pocket Teacher backpocketteacher@gmail.com www.backpocketteacher.co.uk

Title: Date: Location: Provider: Contact:	Intensive Interaction Training 26 March 24 Online Us in a Bus Info@usinabus.org.uk
April	
Title: Date: Location: Provider: Contact:	Confidence, Communication & Creativity 25 April (9.30am-3.30pm) Online Sarah Helton Back Pocket Teacher backpocketteacher@gmail.com www.backpocketteacher.co.uk
Title: Date: Location: Provider: Contact:	Policies & Procedures 30 April (9.30am - 2.30pm) Online Sarah Helton Back Pocket Teacher backpocketteacher@gmail.com www.backpocketteacher.co.uk
May	
Title: Date: Location: Provider: Contact:	Europe in Action conference 7 to 9 May Glasgow Inclusion Europe https://www.inclusion-europe.eu/conference-europe-in-action-2024-glasgow/
Title: Date: Location: Provider: Contact:	A Special Kind of Grief 10 May (9.30am-3.30pm) Online Sarah Helton Back Pocket Teacher backpocketteacher@gmail.com www.backpocketteacher.co.uk
Title: Date: Location: Provider: Contact:	Developing the Curriculum 15 May (9.30am-12.30pm) Online Sarah Helton Back Pocket Teacher backpocketteacher@gmail.com www.backpocketteacher.co.uk

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

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

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

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

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

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

For online study opportunities visit The Sensory Projects Online College.

NAC (www.nacwellbeing.org)

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

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

New course starts 3 January 2023, weekly over 5 months

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

Contact: julie@nacwellbeing.org

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

Subscription Rates:

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

Name of Subscriber:

Address:

.....

Telephone No. **e-mail:**

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

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

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

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

I

/we have paid using PayPal through the PMLD Link website

Date:.....

Please send this form with payment to:

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

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

Gift Aid Declaration	
Name of Charity:	PMLD LINK
Details of donor:	
Title	Forename(s)..... Surname.....
Home Address:.....	
.....	
..... Post Code:.....	
I want all subscriptions and donations that I make from the date of this declaration to treated as Gift Aid until further notice	
<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>	
Date/...../.....	

STANDING ORDER MANDATE (Send to your bank)

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

The sum of: £.....

Commencing: and thereafter annually until further notice

Account to be debited:

Account No.

Signature(s):

Date:

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

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

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

Currently the trustees are:

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

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

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

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

Becky Loney: (Vice-Chair) Independent advocate and has supported people with profound and multiple learning disabilities for over 30 years.

Wendy Newby: (Secretary) Headteacher at The Shrubberies School, Stonehouse, Gloucestershire, for students with Severe and Profound and Multiple Learning Difficulties .

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

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

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

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

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

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

The content in this journal is the intellectual property of PMLD Link. You may not reuse, republish, or reprint such content without our written consent. All information given is merely for educational and informational purposes. It is not intended as a substitute for professional advice. Should you decide to act upon any information in this journal, you do so at your own risk. While the information in this journal has been verified to the best of the editors' abilities, this is not a guarantee that there are no mistakes or errors. The opinions expressed by contributors to the journal are not necessarily the opinions of PMLD Link.



sharing ideas and information

PMLD Link is a journal for everyone supporting people with profound and multiple learning disabilities.

Visit www.pmlmlink.org.uk

Vol 35 No 3. Issue 106

ISSN 2042-5619