

PMLD LINK

sharing ideas and information

Reflections: Life during the
Coronavirus Pandemic

Summer 2021



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Cover picture from the article by Delyth Williams

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GUEST EDITORIAL

Reflections: Life during the Coronavirus Pandemic

This issue of the PMLD LINK journal was supposed to be our annual general issue without any specific theme but, almost inevitably, most of the articles deal with concerns arising from and responses to the coronavirus pandemic and successive lockdowns. The articles share different people's stories of their experiences and their ways of coping with the pandemic which will probably resonate with many readers. Many thanks to all our wonderful contributors.

During the past fifteen months of the Coronavirus pandemic children and adults with profound and multiple learning disabilities and their families and carers have suffered a great deal. Sheila Moorcroft presents accounts from three mothers of adult children with PMLD that reflect on how they and their children have coped; how the loss of services has had significant impact on them; and how poor communication and inaction from service providers and commissioners have added to the challenges and difficulties they have faced. Dreenagh Lyle expresses similar frustrations with local authorities and describes how much her daughter's daily life has changed and the impact on her. It is pertinent to note Julie Calveley's article about increased stress and anxiety and trauma resulting from the pandemic and what can be done to protect mental health. She emphasises that positive relationships are critical for restoration of health and wellbeing and fully enjoying life. This is reiterated in Sheridan Forster's latest thoughts about communication and relationships.

Personal health budgets are difficult to manage but can give families greater control of what support and experiences are available. Peter Glick describes his development of a practical, online resource of templates and documents to support parents and other family members who want to use personal health budgets themselves to recruit, employ and manage personal carers and the myriad of other services that are needed.

Matthew Laurie gives an account of Rapport-Based Music as an inclusive way to make positive connections and build relationships with the people with PMLD. Delyth Williams describes one school's approach to using music as a powerful motivator and foster greater engagement of pupils in school life as a whole. Peter Blaker describes an impressive art project developed to tell the lockdown story of people with learning disabilities and showcasing the art produced in a virtual art gallery online.

The pandemic has forced change in every type of service. Judith Cooper describes the transition of a young man with PMLD from full time education in a specialist school setting to a service which provides nursing care and how the service team had to develop methods of home schooling in the case of this young man that benefitted him and others subsequently. Louise Molineux describes how one service, faced with a ban on face-to-face working with adults with PMLD, developed the use of Facebook portals to provide interactive stories, visual, voice, and face changing effects and various eye-catching backgrounds that would engage its service users with a bespoke virtual offer to meet their sensory needs. Sam Murray and Beccy Johnson describe ways they have had to adapt to deliver the best quality education possible in their respective schools and how they responded to challenge to provide access to meaningful, online teaching. The impact of the COVID-19 pandemic on schools is yet to be documented properly but Ange Anderson and Carrie-Anne Sutton describe the changes in lifestyles of both staff and pupils and working patterns and the complex decisions that have to be made by school leaders to ensure that the possible education is still available.

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Despite the problems experienced since March 2020, there have been positive developments by individuals and services illustrated in these articles and others. Lina Graham describes her work as a volunteer trustee during lockdown to develop a dedicated sensory room, which underscores how much depends on volunteers and charities. Leanne Tonks describes how Gillian Robinson has been creative in her use of available resources to introduce Lili Nielsen's Active Learning approach in her classroom. Joanna Winstler gives us information about an online resource developed as a good substitute for a multisensory day. Pete Wells has produced a popular sensory story which he designed to give parents some ideas of things to do with their children who could not attend their college.

Last but by no means least there are reflective pieces which are not related to the pandemic at all. Antony Morris recommends that people living or working with individuals with PMLD should always consider how an individual's sensory processing may motivate their behaviours since this may suggest ways of improving that person's development, learning and experiences exponentially. Rachel Gale works in Further Education and reflects on the design of the curriculum for learners older than nineteen years that will meet their needs and Government requirements for accessing funding.

Our final article, by Melanie Nind, signals a new partnership with the British Journal of Learning Disabilities. She provides the first of a new regular feature in PMLD Link by looking back at two key papers on listening to people with PMLD. Future articles will hopefully provide summaries of new research including people with PMLD as well as reflection on landmark papers from the past. Melanie explains her motivation for writing this piece; her aim is to spark dialogue with PMLD Link readers and promote research in support of people with PMLD.

The coronavirus pandemic and insufficient government response at national and local levels has made plain the lack of services, inequalities and, what Dreenagh Lyle, calls 'general cracks in the social fabric'. Readers will know that these concerns have been expressed by many for years. It is to be hoped that people with PMLD and their families and supporters will be resilient and bounce back as some kind of normality is to be restored. But not all that was normal before the pandemic was good and there are lessons that must be learned in the long term by all service providers and commissioners at all levels. The timing is right for more dialogue between families and services and, probably, campaigns to increase awareness of these issues and bring about more flexible, responsive and inclusive services that are better resourced. But it must also be borne in mind that services have responded to the pandemic threats by creating novel ways of engaging with people with PMLD and their families (e.g. use of Portals, development of online resources, organising home loans of resources) and these will continue to have value in future in strengthening partnerships and relationships if they are properly maintained and developed.

Guest Editors: Wendy Newby, Martin Goodwin and Rob Ashdown

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Three mothers' perspectives on the pandemic

Sheila Moorcroft

The pandemic has put pressure on everyone and every service. Three mothers of children with PMLD reflect on how their children have coped; how the loss of services has had significant impact on them; and how poor communication and inaction have added to the challenges and difficulties parents of children and adults with PMLD have faced. On the upside, they also show how a 'can-do' attitude and rethinking how to do things have brought positive changes. They hope that the right lessons will be learned, in the long term.

Whose views?

Three mothers, whose children are aged 48 (Alex), 29 (Kim) and 16 (Chris) and all of whom have PMLD, talked about life in the pandemic for them and their children, and their hopes for the future. (Their names have been changed to protect identities.) The two older ones are both in residential provision, and have been for many years. Chris lives at home and was shielding for 6 months, with both parents working throughout the pandemic, mostly at home, a brother who was home schooling and another doing university course work. School and after school care stopped, – leaving the parents with sole responsibility during the day, but night time care continued 6 nights a week.

None of their children has any verbal communication and all have complex needs including: Rett Syndrome, a rare chromosomal condition, autism, epilepsy, osteoporosis, double incontinence, a high pain threshold, scoliosis, obstructive sleep apnoea – requiring ventilation and waking night care.

Although the experiences of the three mothers differed, there were also shared issues and concerns.

Short and long term problems as things shut down

Before the pandemic all their children received a variety of therapies, treatments, regular checks, external activities and support, including respite care for Chris. Virtually all of that disappeared over night. The result was, not surprisingly, social isolation, lack of stimulus, boredom, but more significantly also physical deterioration for the children and huge pressure on parents.

Before the pandemic, Alex could walk in the park a bit with help and frequent rests; now, the last remnants of mobility have all but disappeared. The use of alternative therapies was also having a positive effect prior to the

pandemic, bringing greater relaxation and a new ability to reach out and grasp someone's hand. That too has all gone. The fear is that it has gone for good. Alex's epilepsy also resulted in about 10 trips to A&E, for one of his drugs to be administered. After each trip, Alex had to self-isolate for two weeks in a bedroom and spent a total of 20 weeks out of 52 alone most of the time. Again, the fear is that the impact especially on mental health will be permanent.

For Chris, it was a happier story. Chris 'thrives on social interaction' and with six months of isolation during shielding was bored, miserable and low and missing peers. Within a few days of returning to school however, Chris was back to normal - more alert and noticeably happier – and exhausted by all the stimulus of chatter and activity.

Poor communication causes more concern than necessary

Alex's and Kim's mothers both felt in the dark most of the time. There was little or no communication from the staff at the services about how their children were or what they were doing, and as time went on a lack of clarity about visits. Kim's mother said, 'I have no real idea what they have been doing, and the danger is that we assume the worst. They need to recognise that a little information can radically change perspectives and reduce parents' anxiety.'

'I have not been able to hug Alex since March last year, and s/he thrives on hugs. Apart from one or two emergency visits last summer when Alex completely lost the ability to weight-bear (because of self-isolation), until May this year I was only allowed to visit once or twice and wave through the window, but Alex does not really understand, and I have no idea if s/he actually knew I was there.'

This lack of contact, and little information from staff, plus Kim's and Alex's own inability to communicate increase their mothers' worries about their mental health. As Kim's mother said 'it's difficult to know if there is a sense of time passing. Are they aware that it was weeks before we could visit them? Did it have an effect on their mental health? Are we able to determine that? We learned that Kim did manage a separation of several months, and seemed to be ok with it. But how do we know for certain?'

For Chris' mother the issue was social care. Chris has always had an allocated social worker, but they heard nothing from anyone in social care until June 2020 when they received a 'token check in call'. That would not have revealed any child protection issues - had there been any. That social worker then left and the family heard nothing till April 2021 when a new social worker visited. But he had not informed himself about the level of complexity of Chris' needs, especially the palliative care and the emergency protocols that were in place. Again, poor communication and preparation undermined trust and confidence.

'COVID-19 brought out the best and the worst'

On the plus side, Alex, Kim and Chris have stayed free from COVID-19, with staff in their services taking great care. In Chris' case not catching COVID-19 was something of a miracle as both parents, who were doing all the caring, had it quite badly.

Technology also helped - sometimes. Chris' mother found that the GP and some specialist services used technology really well. Instead of appointments being a major undertaking, sometimes taking up a whole day, she could talk with people much more quickly and easily. Sadly, technology did not make communication with Alex or Kim any better – they were unable to cope with the challenges of WhatsApp or Zoom.

But there was a down-side. Until February 2020 Chris had worn a back brace because of scoliosis. Progress was good and it was removed – a cause for celebration. But, that meant adjustments were needed, in particular to the wheelchair. The school made all the necessary adjustments to equipment within a few days. However, despite repeated emails and calls from Chris' mother the local wheelchair service prevaricated, delayed, did nothing apart from suggesting inserting a rolled up towel for support, during a call in July. The delays potentially endangered the progress that had been made. Eventually, after Chris' mother involved another physiotherapist, the wheelchair service acted in September – and an extra X-ray confirmed, thankfully, that all was well.

For Kim the issue was an ingrowing toe-nail and a foot that became infected. None of the staff seemed to have noticed the toenail problem – despite having to put on Kim's support socks every day. Kim's parents had to contact the minor injury clinic and then the foot clinic – who were brilliant, finding the time for an emergency appointment.

Looking to the future

All three mothers live in 'determined' hope, but also fear for the future, not only because of their children's complex needs, but also the need to overcome the impacts of the pandemic on them as individuals and the support they receive.

They hope that all services will genuinely learn and understand the need for much better communication; that timely contact can radically reduce the level of support needed at a later date and reduce parents' legitimate and genuine concerns; and that working with parents and not shutting them out of discussions or ignoring them could radically improve the quality of life for people with PMLD unable to say how they feel or what is happening to them.

For example, during the pandemic Learning Disability England (LDE) has facilitated regular workshops where people with learning disabilities, family members and people from support organisations share ideas and create solutions. This approach to collaborative working will be pivotal in removing barriers and giving people with learning disabilities and their families a strong voice in creating good lives for people with PMLD.

While some staff in residential services are great, many need to be more pro-active and more creative in finding ways to engage with and support people with PMLD. Better training and recognition, not to mention more pay, would help.

The uptake of technology in enabling more flexible access to NHS specialists, appointments and GP consultations has been a success and should remain – where parents are willing.

More frequent peripatetic health services/checks could reduce the need for trips to A&E by identifying issues earlier.

Above all, service commissioners and especially of social care need to recognise that the pressures on families have been immense; and that although many parents have coped, they are 'only clinging on by their fingernails'. As Chris' mum said 'lockdown was a horrendous monotonous hamster wheel of getting through the day, and guilt that Chris was getting a bad deal'. There is a real fear that services that were reduced

or temporarily withdrawn will disappear permanently. Chris' mother said they would not be able to cope if services were not restored, and Chris would have to go into residential care, and that would be far more expensive.

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Learning Disability England is England's only national movement where people with learning disabilities, families, friends and people that work in services come together on an equal basis. Members work together to build a world where people with learning disabilities have good lives with equal choices and opportunities as others. Find out more at www.learningdisabilityengland.org.uk.

Celebrating

100TH ISSUE

The Winter 2021 issue of the journal is special. PMLD Link will be celebrating our 100th issue of the journal.

For more information and about how you can share your stories, go to page 60

Access recent issues online

Subscribers can log on as a members of 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

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.

Echolalia: from the Greek work meaning to echo or repeat

Dreenagh Lyle

My daughter Odyssey doesn't use language in a conventional sense although she does have a fantastic store of words and phrases. These are apparently random sayings and lyrics she has heard somewhere and repeats to herself, mostly for the sensory effect.

I have always used these with her as a 'turn taking' game (Prizant and Duchan, 1981, cited by Ockleford, 2017, 214-215). 'Ticka Tacka Toe' is the latest. She loves it when we repeat it back to her. Recently I discovered how excited she gets if I repeat it in the EXACT same tone. Her big sis did not know about this new rule. When she visited recently and thought Odyssey was telling her 'tooessem' and repeated it back as one word, Odyssey didn't seem very impressed. I had to point out (Duh) that in fact Odyssey was saying '2 S M', the Sydney radio station. Why she suddenly remembers a radio jingle from the 1980s is anybody's guess. And she found it hilarious that her sister had gotten the rules so wrong.

Her vocabulary seems to have really extended this past year. Normally she will sing a couple of words of some song, usually Whitney Houston in high C mode, on a loop, in the middle of the night, for hours. Thankfully that phase seems to have passed for now. We heard a full verse recently of 'Sons and Daughters'. This was the theme tune to an Australian soap opera. We lived in Sydney for a few years so she may well have heard it in the early 80s, but why has it surfaced now? We even heard 'Humphrey The Fun Loving Bear'. This was an Australian children's television show. The last time she would have heard it was as a toddler. Why has it surfaced now, over forty years later?

This repeating or echoing of words and phrases is described as 'echolalia' or parrot speech. It can be delayed or immediate. It is quite common in people with ASD (autism spectrum disorder). Whilst Odyssey's echolalia is mostly delayed, when it comes to music it can be immediate. I was dumbstruck recently when I heard Elvis Costello singing 'It's Been A Good Year For The Roses' on the radio and almost immediately Odyssey joined in. Singing the verse as well. Ditto Robert Palmer 'She Makes My Day' or any number of songs.

She has always sung the odd snatch ('ya givin' love and stick to me') but where are these verses coming from? Probably YouTube. For years Sunday used to be our music day. Odyssey would sing snatches from some song and I would scabble through my records and play it for her. Since I am at my computer most mornings, as I hear the snatches I can find them on YouTube and play to her.

I'm pretty good at guessing from a few notes now. Some songs she recognises literally on the first beat. Wild rocking out and a beaming smile tells us we got it right. Other songs she listens to intently, but doesn't catch on until the chorus kicks in and then away she goes. Music really is her world.

I wonder if the initial silence of lockdown helped. We live in central London and it is always very noisy. Traffic, sirens, helicopters are common sounds. The silence in those early lockdown days was palpable. Also, no activities, so no demands were being made of Odyssey. She settled into a new routine. Breakfast, personal care, getting ready to go out, local stroll, back home listening to music, eating dinner and bed. Lots of very intense listening occurred, which I hadn't really seen for such lengthy periods before. Those early weeks of lockdown may have been much less stressful for her than normal as well. However, as the weeks and months progressed, I grew concerned at how much time she was spending sitting on the couch. Her squawking returned whenever I tried to encourage her to do things she would normally access quite easily. This high-pitched vocalisation is her response when she really doesn't want to do something. The less she did, the less she wanted to do. When your entire routine is suddenly disrupted it makes perfect sense. However, it is not an informed choice to simply do nothing all the time.

In fact, her various activities had been curtailed long before lockdown. As we all know provision of 'activities' is precarious at best. SENSE (a charity specialising in working with people who are deaf blind and who have complex needs) struggled to source funding, so her yoga sessions stopped for almost a year. Her support workers were astonished she managed to access the class when it did return, once, before lockdown. Now it is unlikely to return post COVID-19. She had not been able to attend her Sensory Story group for almost two years due to lack of available support. When she did return, her worker was astonished at the ease with which she accessed the site. Again, one week later we were in lockdown. Now the session has returned, but in a building that is inaccessible for Odyssey due to her issues with noise. Odyssey is autistic and has a condition called hyperacusis, which means she has an extreme sensitivity to certain

sounds. Her music therapy stopped for a very long time. When they did re-commence, she didn't even make it to one session. Thankfully they have placed her on a new waiting list so hopefully in another six months or so she will be ready to return. Her wonderful massage therapist has returned, although Odyssey has only managed to access the massage table once. It took her five years to access initially, so we were prepared to go back to square one and start all over again.

The coronavirus pandemic and government response has shone a light on existing lack of services, health inequalities and general cracks in the social fabric. Many of us have raised these concern for years. People like my daughter need a lifetime of therapeutic support. They need truly person-centred approaches. They need meaningful activities to engage in. They need consistency and structure in their day. I employ a team of support workers on her behalf. I maintain the most important aspect of their job is observing support guidelines scrupulously and building a relationship with her. I outlined the turnaround a truly person-centred approach can make to an individual in Chapter 4, 'All in the same direction' of my book *Understanding Profound Intellectual and Multiple Disabilities in Adults* (Lyle, 2019). I also know how quickly gains may be lost.

We had the perfect storm of COVID-19 and the onset of demolition and construction work where we live. All our gains over the last ten years have slipped. I am trying not to focus on how annoyed I am with our Local Authority. They describe themselves as a 'co-operative council' yet have no understanding of notions of 'mitigation' or their statutory requirement to offer Odyssey Reasonable Adjustments. Onwards and upwards is always my answer to setbacks and negativity. Currently the team and I are working on a new approach, 'Trauma Informed Care' (Frankish, 2019). We are at the Observation stage. Reading up on the approach is fascinating and making our observations to map her emotional developmental levels is so insightful.

I know we all feel we can turn things around as we've done it before. And Odyssey has always had a great capacity for recovery. And the cherry on the cake? Yes, there is one. We have just had a new session confirmed

with a music performance group called Entelechy Arts: Ambient Jam. Fingers crossed this could be a whole new horizon. Or as Odyssey is more likely to say, 'Please welcome your host Nicky Campbell'.

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Note - Entelechy Arts is a charity based in Lewisham, South East London. It produces vibrant cultural programmes, created by and for communities, including those living with profound and multiple disabilities. The Ambient Jam Collective has around 30 members and includes volunteers, older people and care staff who dance alongside our lead members with profound disabilities and a team of dance artists, musicians, and sculptors. The group comes together to shape new choreographic and music practice.

<https://entelechyarts.org/projects/ambient-jam-collective/>

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“I don’t want more advice, I want stuff done”

Peter Glick

For our family, gaining a Personal Health Budget or PHB (Davies, 2014) was a hugely positive transformation. We’ve had one for over three years now and our son of 20 years, who has lifelong complex disabilities, is a happy person after the one-size-fits-all services offered in our area failed to deliver the care he needed.

We have a budget that pays for all our son’s healthcare needs, which is paid directly to us and we recruit, employ and manage his carers and the myriad of other services that are needed to make him smile every day. Running the budget is hard though. We did not want to become employers, to manage staff, and perform all the administration, accounting, the paperwork that seems to be a constant in our lives. It is worth it though. What was the hardest was getting started, with little or no practical help available for even the simplest of things, so we had to start from scratch, and, when we talk to other families, they are still having to do this. In fact, this article’s title is a quote from one such family. This was my motivation to undertake a four-year PhD research programme with Newcastle University, to use that time to improve families’ lives that are on their PHB journey.

After many conversations, focus groups and workshops, we decided that we (as in myself and the participants on this research) will focus on those about to get a PHB, who can need over fifty different templates and documents to get a team of care staff up and running in their homes. Some of these documents are simple, such as a staff leave request form, but others, like the staff rota, are complicated, living documents. Regardless, being offered no templates, and finding little on the internet, you have to write every single one yourself, all the while caring for your family and gaining that PHB. Yes, PHBs can be offered as a third party supported service, where an organisation can administer some of this, but good ones may not be available in your area, and we have found that many people want to be in control rather than handing that off to someone else.

It’s early days but we now have an online resource for these templates and documents. It’s a wiki, so it works like Wikipedia, but more important to us, it’s written, amended and added to by people like us, that have the lived experience. So we know what’s needed and we know every family is different.

www.mycarebudget.org already has over 30 documents ready to be downloaded in Microsoft Word, PDF or Google Docs formats. You can browse and download without even signing in. If you do register and sign in, we

can keep you up to date with changes to what you have downloaded and tell you what’s new. The home page offers three main route to browse: for those starting out with a PHB showing a set of useful links; then a selection of templates; and then staff policy documents. It is a living space that is growing all the time from documents and comments we receive.

Can you join in? Yes please! We would love to see what templates you use. You can create your own page, join in the discussion forum, upload your documents. Don’t have the time or not your thing? Not a problem, you can email us at contact@mycarebudget.org with your documents in any format and we’ll do the work for you. We know that trust us important, so we check all the resources before they are made publicly available. This all started from my research project so I may well contact you to talk through your experiences of using the online site, but taking part is purely optional, anonymous, and totally up to you.

This online resource won’t end as the research ends, since we have committed to ensure it will continue, nurtured by those that have needed it the most. The aim is for a publicly available resource that anyone can use and anyone can add to. We look forward to seeing you there.

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Lockdown trustee: an opportunity to set up a sensory room on a shoestring for people with PMLD

Lina Graham

I applied to be a volunteer in March 2020! By July 2020 Kingston Mencap (KM) had interviewed me to be a trustee. I felt very honoured to be asked - it's a big responsibility. The most exciting thing was that KM lease the Searchlight Centre from the local council; in it was a dedicated room - the sensory room. Unfortunately, funds had run out and there was only this wonderful interactive projector in the room- called the magic projector (a Tovertafel). Fortunately, it was decorated and had been carpeted; what it needed was the equipment to make it a functional space. The room was being used as a store room, Christmas fair CDs and other varied interesting 'stuff' was in it.

The proposal for developing the sensory room

One of the other new trustees (Helen) applied for a grant for £2500. My job was to set up a sensory room for that amount. This amazingly was all organised on Zoom! I had only met the grant-writing trustee once face to face. Then she asked me what equipment I needed in the room and why? I emailed her the information and lovely Helen did the rest - I didn't know filling in Grant applications was such a skilled job, using the right terminology etc.

The way I managed was not to make it a 'Snoezelen' type, soft furnishing room, but a distraction free sensory room/dark room. My email contribution for the grant application for developing the sensory room shows my intent: 'A sensory room is a quiet space dedicated to stimulating, developing and relaxing the senses. A sensory room allows MENCAP members the freedom and autonomy to explore the environment for themselves, in their own time, using all of their senses. The décor of a sensory room might include low lighting and adjustable lighting projections, fibre optics, mirrors and bubble tubes. It will typically contain a choice of comfortable places to sit, a variety of interesting objects to examine, and it might also feature sounds and soft music.'

Our aims were to:

- Create an appropriate space for our MENCAP members with severe learning difficulties (SLD) and profound and multiple learning difficulties (PMLD) who need a place to go where they can have minimal visual and auditory distraction.
- Make the space and equipment in the Sensory room so that it offers opportunities to stimulate learning and engagement, which, in turn, promotes independence and choice-making for our MENCAP members.

- Provide a distraction free space which can be used as a dark room as well. This will help our MENCAP members with a visual impairment to use their residual vision; focusing on a variety of light sources (UV & White) in a dark room.
- Create an interactive sensory environment that can be easily controlled by the MENCAP members. We aim to do this by making a lot of the equipment switch operated. These pressure pad switches require very little pressure to activate them making them accessible to most of our members.
- Use music and calming lights to encourage Sensory integration activities; they can be brilliant as relaxation tools for individuals with all sorts of complex needs, including autism.
- Provide 1:1 sessions with specific aims; encouraging communication, using intensive interaction techniques, visual stimulation sessions, functional vision assessments etc.
- Provide a space that people with SLD/PMLD can use with their parents and carers, by booking the sensory room to use for visual stimulation, relaxation, or sensory sessions.
- A sensory room that has a clear purpose and aim.

See Figure 1 for proposed equipment for the sensory room.

We start the development of the sensory room

January 2021: we got the grant!! So exciting. We had to have a trustee meeting on Zoom on how I would be reimbursed once I had bought the equipment since the Searchlight Centre was essentially closed! Vikram, another wonderful trustee and the treasurer, helped. (All trustees are volunteers and it's incredible what can be achieved on this basis.)

Figure 1: Proposed equipment for the sensory room

Name of Equipment:	From:
Switch Socket Adapter	Adapter for pressure switches to operate equipment. (from Inclusive Technology)
4 X Jelly Bean Switches	Pressure switches @ £39.00 ea. (from Inclusive Technology)
Table fan	To be operated by Jelly bean switch.
Juice maker	To be operated by Jelly bean switch.
Foot Spa	To be operated by Jelly bean switch.
LED cool table lamp	To be operated by Jelly bean switch.
2x Max Indoor / Outdoor Bean Bag, Black	To aid comfortable postural seating. £85.00 ea. (from John Lewis & Partners)
Bubble Tube - Extra Large (183cm / 6ft) Bubble Lamp incl 15 fish, balls, LED colour changing lights.	Relaxation, visual stimulation encouraging looking and vibration sensory feedback. (from Amazon)
Bubble tube wall bracket	To secure bubble tube to the wall.
Fibre optic sensory lights PVC covered FLEXIBLE (30 x 200) 3.2mm diameter sideglow sensory lighting	Relaxation, visual stimulation encouraging looking. (from Amazon)
UV Blacklight Strip Bar Light with Glowing Neon Lamp Fluorescent Tube	UV light to enable the use of fluorescent equipment in the dark room. (from Amazon)
Fluorescent equipment	Variety of equipment that glows under UV light.
Pack of various light up equipment.	Hand-held light-up equipment, e.g. torches, glow spinners, fibro optic lamps etc.
Panasonic Bluetooth Hi-fi.	Music centre with USB and speakers.
Schlagwerk RTF60 Drum with a floor frame	To encourage interaction and communication.
Rockjam 61 keyboard piano with stand, stool and headphones.	To encourage interaction and communication. (from ARGOS).
6 Extra deep tray double trolley unit.	Storage for sensory equipment that is easily accessible in trays. (from TTS)

It was really exciting sitting on my computer at home buying online. My neighbours thought I was having a spending spree as often they were left with the parcels! By the end of February 2021 – I had got most of the equipment delivered. Another absolutely amazing trustee, Peter who is wonderful at DIY - put up the mirrors, the bracket for the bubble tube and he even found an old tripod to attach the UV lamp – ingenious as its height adjustable now! I had a little anxious wait for the delivery of the Powerlink for the switches as it is the key component, making the sensory room totally interactive. In our monthly Zoom trustee meeting I presented an information leaflet about the ‘Sensory Room’ (see Figure 2).

Guidance and induction for users

As explained earlier, KM leases the Searchlight Centre from the council and I had retired after working in state schools for nearly 40 years. I hadn’t really thought of RENT! So obviously this would be a facility for members but it also could make money and be hired out. This is when I had to quickly think of clear rules, for safeguarding, health and safety, and of course, a risk assessment. So not so simple as having an idea in a state school, as I had done many times before and ordered bubbles tubes etc. to make dark rooms into interactive sensory rooms.

My evolving rules so far:

- Maximum usage 2 participants from same establishment + 3 carers/staff.

- All participants have to have a free Induction Session and feedback of the Induction sent to them before they can join a session. This is crucial as it gives me an opportunity to spend quality time with the participant, assess their mode of communication, try and do a functional: vision, hearing and motor skills assessment. Figure 3 is an example of a record of one of these inductions.

As of June 2021, I have done six inductions of participants who use the KM clubs and inducted about 15 staff, carers and trustees. Nobody is allowed to use the KM Sensory Room without doing the induction with me as teacher and I have a register of all the people who have had the induction.

I couldn't have achieved any of this without the help of Michelle, the wonderful supportive but questioning trustees, and of course Peter. Let's see how it evolves but at least I used my lockdown constructively.

Contact Details

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Further Information

Tovertafel: <https://www.tover.care/uk/>

Inclusive Technology: <http://www.inclusive.co.uk/>

Schlagwerk drum: <https://www.schlagwerk.com/en/products/ethno-drums/frame-drums/frame-drums-natural/rf60-frame-drum/>

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Cultivating and restoring feelings of safety

Julie Calveley

This article discusses the impact of COVID-19 on the emotional wellbeing of children and adults with profound and multiple learning disabilities (PMLD) and how, for some, this has increased stress and anxiety and caused trauma. The neurobiology of stress and trauma indicates that a sense of safety must be restored for a healing process to begin. This article suggests some practical ways we can help.

The impact of COVID-19 on mental health

There has been widespread awareness of the detrimental effects of COVID-19 on mental health. People with PMLD are more vulnerable to the illness, loss, change, uncertainty and restrictions caused by the pandemic. The British Psychological Society (2020) pointed out that the pandemic has had various psychological effects and there have been positive outcomes for some people with learning disabilities. However, Bradshaw et al. (2021) found that most family carers and paid support staff reported the wellbeing of the person with PMLD they cared for to have worsened since lockdown began.

Writing about children with learning disabilities in their 'Think Piece' proposing the need for a 'Recovery Curriculum', Carpenter and Carpenter (2020) point out that the pandemic has led to losses of routine, structure, friendship, opportunity and freedom, which can trigger anxiety, trauma and bereavement. The Challenging Behaviour Foundation (2020) have also found that the lack of access to care, support and treatment throughout the pandemic has been a cause of trauma.

People with learning disabilities are known to be more vulnerable to mental health problems, more likely to experience traumatic events, and more susceptible to suffering from trauma in response to events that others may have the coping resources to manage (Cowles et al, 2020; Keesler, 2020). Change and disruption stimulate the stress response and when unpredictable, uncontrollable and chronic (as life has been for many people with PMLD during the pandemic), can be overwhelming (Perry and Winfrey, 2021). Not having the words to talk about, explain and make sense of difficult events makes it more likely that the stress response will be activated (Perry and Winfrey, 2021). Furthermore, the pandemic may have exacerbated any pre-existing mental health problems people with learning disabilities have (The British Psychological Society, 2020). These are just some of the reasons why people with PMLD are more vulnerable to suffering from stress and trauma as a consequence of the pandemic.

Our body responds to threat to support survival but when chronic or activated in the absence of actual or immediate danger, becomes maladaptive and harmful. Stress and trauma can affect our whole being and show up in different ways. As well as emotional distress, chronic abdominal pain, headaches, chest pain, fainting, and seizure like episodes are common symptoms related to a sensitised stress response (Perry and Winfrey, 2021). The regulatory systems of the body are altered by stress and trauma, giving rise to an overactive and overly reactive nervous system, dysregulation, hyperarousal and hypervigilance, or dissociation and withdrawal.

We may therefore see an increase in regulatory behaviours such as rocking, tapping, over-eating and self-injury. Some of these behaviours may have harmful effects, and therefore we would want them to be replaced with healthier, more effective alternatives. However, it is important to understand such behaviours may be serving to self-regulate, soothe and thereby cope with the inner turmoil and distress that is being suffered.

When exposed to trauma, unpredictable or extreme stress, fundamentally we experience a loss of sense of safety. Feeling safe is crucial for mental and emotional wellbeing (Van der Kolk, 2014). In order to be able to function optimally and thrive emotionally, relationally, psychologically and physically, it is crucial to, not just be safe, but to feel safe.

What we can do to support mental health

There is clearly a need for greater awareness of the emotional wellbeing needs of people with PMLD and professional help should be sought when signs and symptoms of concern are evident (Keesler, 2020; Skelly et al., 2021; Calveley, 2021). There are also things that we can do on a day-to-day basis at home and in health, social care and education services to lower anxiety and stress, support regulation and cultivate feelings of safety. Some of the things that can be soothing to the nervous system and help us to feel safe involve;

- Consistency, familiarity and predictability
- Co-regulation through interactions.
- Engagement in calming sensory experiences.

These suggestions are based on an understanding that mind and body are inextricably linked and that affective and emotional wellbeing can be supported through the body, the senses, relationships and interactions (Van der Kolk, 2014, Porges, 2017, Perry and Winfrey, 2021).

Making daily life as predictable as possible through, for example, consistency, familiarity, routine, repetition and providing meaningful cues can help because novelty is stressful to the nervous system and whilst it can create interest and be exciting, when the nervous system is already highly sensitised, it can be too much to cope with. To enjoy and benefit from such experiences a person needs to feel safe first.

For more ideas and 'how to' guidance on increasing consistency and expectancy and engagement in calming sensory experiences visit the NAC (Non-Verbal Affective Care) website (www.nacwellbeing.org). A person with PMLD is reliant on others to facilitate these opportunities and experiences, and therefore quality of interactions and relationships are essential for their effectiveness. Furthermore, interactions have a crucial role to play in fostering safety and wellbeing through co-regulation.

Relationships as a bedrock for safety

Relationships are critical for restoring a sense of safety (Van der Kolk, 2014). We evolved to be connected and we feel safest when we receive signals of acceptance, understanding and empathy (Porges, 2017). These signals are largely unconscious for both sender and receiver and come from facial expressions, tone of voice and body language. The more positive interactions you experience, the more your brain senses that person as familiar and safe and therefore trustworthy. Trusting relationships allow for co-regulation which, can be described as the way in which one person's autonomic nervous system sensitively interacts and is modified by another person's autonomic nervous system in a way that facilitates better emotional balance and wellbeing. This occurs largely through the non-verbal communication signals that we send and receive. Therefore, your presence, reassuring touch (in a way that can be tolerated), kind tone of voice and warm smile matter.

The brain networks involved in relational connection and regulation are very responsive to repeated moments of interaction. Repeated positive, safe, secure interactions are crucial for supporting someone who has a highly sensitised stress response and when suffering from trauma a 'meaningful dose of therapeutic interaction' may be only seconds long (Perry and Winfrey, 2021). Therefore, the people who are spending most time with a person may be best placed to offer co-regulatory support.

Why it is important to look after your own mental wellbeing

Your health and wellbeing matter for you and also for the people around you. You need to be fully present and to fully 'listen' to regulate another person, and this will be enhanced if you are regulated yourself. So, self-care is good for you and good for others. The experiences that are promoted on the NAC website on using arts and creativity, interactions, mindfulness, movement, music, nature, senses and touch have been chosen because there is evidence that they can be beneficial to wellbeing, not just for people with PMLD but for anyone. However, we are all different and therefore, what works for one person may be different to another, so choose approaches that work for you.

If you only have a few moments, there are some quick things that you can do to regulate, 'centre' and bring calm. Some ways are to slow down your outbreath, to place your hand and awareness on your heart, and to allow your tongue to hang loose and your jaw be soft with your lips slightly open. Your state of regulation and calmness will be conveyed in your non-verbal communication and allow you to most effectively co-regulate (Porges, 2017; Perry and Winfrey, 2021).

Taking an individualised approach

As previously mentioned, the pandemic has affected people in different ways and what is needed is determined partly by individual traits and on the state a person is in at any particular time. We therefore need to assess needs individually and consider any previous trauma, stress or anxiety the person may have suffered.

Whereas some people may be eager to get back to doing things they did before the pandemic and cope just fine with the changes going forward, those whose stress response is highly sensitised may need to take it slowly. Relational connectedness helps manage transitions and change and has been found to be the best predictor of mental health (Perry and Winfrey, 2021). The restrictions caused by the pandemic have reduced contact with loved ones and communities and therefore reduced possibilities for belonging, which we know to be essential for wellbeing (Nind and Strnadová, 2020). Having co-regulatory support within a trusting relationship will support re-engagement in the wider community.

When the person appears to be most at ease, what are they doing, where are they, who are they with? What appears to enable the person to feel most safe? Addressing these questions involves a process of compassionate inquiry, identifying emotional and affective expressions and ensuring that we are observant for what all forms of communication are telling us about what works and what doesn't. The Royal College of Speech and Language Therapists (2013) 'Five good

communication standards' can help to support this process. Only when the person feels safe and is regulated will they be able to experience optimal health and wellbeing, fully connect with others, learn, feel pleasure and enjoy life.

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Celebrating

100TH ISSUE

For The Winter 2021 issue of the journal is special. PMLD Link will be celebrating our 100th issue of the journal.

For more information and about how you can share your stories, go to page 60

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Not everybody is autistic, but...

Antony Morris

Recently I authored a piece in SEN Magazine outlining why we are not all autistic (Morris, 2021). The article was prompted by the flippant use of the phrase: 'we are all a bit autistic', something I have heard said in various disability related settings. The article was not a condemnation of people who throw this phrase about, but rather an appeal to further our understanding of the challenges many autistic individuals experience. So, with that article on record and accessible online, let me make a slight U-turn. No, not everybody is autistic, but there are undoubtedly people with autism who, for different reasons, do not have a diagnosis. This brings me to some of the wonderful folk with profound and multiple learning difficulties (PMLD) we may encounter. Do they all have autism? Almost certainly not. But, there is a case to be made for family members and professionals who spend time with people who have PMLD to give similar considerations for their sensory processing as we often do for people with autism.

Autism literature is ripe with research on the fundamental mechanics of sensory processing impairments and how these deficits affect up to 96% of children on the spectrum (Marco et al., 2011). So much so that if an individual has an autism spectrum diagnosis, in any setting, this will elicit considerations for any potential sensory processing impairments. A good practitioner will consider the individual's day to day sensory experience and this will influence the environment they work in and inform many aspects of their daily routines. So, what is my problem? Well, I truly believe that all pupils with intellectual difficulties should be afforded the same sensory considerations.

With autism-like sensory impairments recorded about people with Dyslexia, Dyspraxia and several other conditions related to cognitive development (Schwartz, 2014), it is hardly a stretch to imagine a person with profound intellectual difficulties, one who cannot articulate their lived experience, may also suffer with one or more of the potential sensory deficits reported.

While there is data that suggests the more severe an individual's intellectual disability is, there is a higher chance of them having autism (Baron-Cohen, 2010), we are unlikely to see a considerable increase in diagnosis amongst those with PMLD. This may be due to a combination of economical, medical and social barriers that include parents' choices and professional opinions. Still, common methods of assessing autism in people with intellectual impairments are not adequate and do not differentiate between mild, severe or profound and multiple learning difficulties (Sheahan and Howlett, 2019; NICE, 2020).

Autism is typically diagnosed in individuals with intellectual difficulties through observations over a range of contexts with professionals understandably focused on repetitive stereotypical behaviours i.e. rigid routines,

self-stimulating (stimming) and atypical responses to sensory stimuli (NICE, 2020). When considering the potential physical restrictions many individuals with PMLD may have, it is unlikely that all would have the ability to exhibit the range of behaviours typically consistent with an autism diagnosis. Furthermore, their movements and behaviours that are self-stimulating and rigid in nature, may not get due consideration. For example, moving limbs in a simple pattern or making noises and rocking in a certain rhythm may not be considered as stimming. People with PMLD may have their autism undiagnosed due to a lack of mobility and ability to express themselves, and as such, they often have their sensory experience and potential deficits overlooked.

At present, the current observational assessment tools used to diagnose autism require a higher volume of complex behaviours than a person with PMLD can often exhibit. Current assessment methods would benefit from re-evaluating how autism-like behaviours may present themselves in people with PMLD.

My primary concern for addressing this issue is to highlight the likelihood of an individual with PMLD processing sensory information differently, and that autism is currently our best way of understanding this potential diversity (or acknowledging it in many cases). In support of assessing individuals with severe and profound learning difficulties for autism, Rita Jordan, Emeritus Professor in Autism Studies at the University of Birmingham, argues that to ignore the potential of sensory processing impairments in an individual who cannot express their experience can be detrimental to further development (Jordan, 2016).

Given that ignoring sensory processing issues may have negative consequences, and that taking them into consideration can have benefits, I would like to share a

slightly tweaked quote from Jordan. Exchanging Jordan's use of the word 'autism' for 'sensory processing impairments' it goes:

'not every child-friendly technique is a sensory processing impairments-friendly technique, but every sensory processing impairments-friendly technique is a child-friendly technique'

While an official autism diagnosis may not be accessible, this does not mean we cannot change some of our approaches to living and working with individuals with PMLD. Under the assumption that the individual may have sensory processing deficits, we can begin to consider how it may impact on their lives and what can be done.

An individual with PMLD may have a number of mobility restrictions, any regular movements, e.g. swinging legs, rolling body/head or tapping hands/fingers, could be considered sensory-seeking behaviour. People with autism often report partaking in sensory-seeking activities for pleasure, although the motivations for specific behaviours can also be related to being hyposensitive to certain stimuli (Bogdashina, 2016). An individual tapping or banging body parts may have an under-sensitive sense of touch and be seeking tactile stimulation; somebody flapping a material may be after visual stimulation; a person rocking their upper or whole body may have under active vestibular (balance) and proprioception (body awareness) systems and seeking to compensate for their hyposensitivity, in an effort to better understand where their body is in space.

For a family member or professional, considering any movement or vocal routines that an individual with PMLD does as sensory-seeking can have benefits. Firstly, it can tell us what the person enjoys, with even the slightest movements potentially having multiple points of sensory pleasure. For example, a person sat in a wheelchair swinging their legs may be seeking vestibular stimuli from the movement while also receiving tactile stimulation on the back of their knees, in addition to gaining proprioceptive feedback that may give the person an indication of where their legs are positioned. If we are to consider actions in relation to all primary senses, we may find new opportunities to increase the pleasurable and meaningful interactions we have with individuals with PMLD.

In an attempt to use movements and sounds that are meaningful to the individual with PMLD, while potentially helping to compensate for any hyposensitivity, family members and professionals can use a range of sensory techniques and tools to enhance enjoyable experiences. For any potential tactile or proprioceptive sensory-seeking, items that can provide firm, yet harmless, sensations can have a positive effect; e.g. a vibrating

hand massager, tooth brush or weighted clothes may be introduced (Caldwell and Horwood, 2008). Due to the impact that proprioceptive sensory feedback has on an individual's sense of self (Tversky, 2019), I would perhaps give extra thought to what the person with PMLD's actions tell us about their body awareness.

Knowing the potential motivations of an individual's sensory-seeking activities is an excellent opportunity to access communication. By knowing that an action a person chooses to do regularly has meaning to them, we can attempt to tap into this knowledge. Established approaches such as Responsive Communication and Intensive Interaction, encourage family members and professionals to reproduce and replicate body language, vocalisations and any sensory-seeking behaviours back to the individual with PMLD, in an attempt to create reciprocal interactions built on a foundation of stimuli that is meaningful to the person (Caldwell et al., 2019; Nind and Hewett, 2005).

As equally important as a person's hyposensitivities, individuals with autism often report being hypersensitive to either very specific stimuli or a collection of different stimuli. A common example given in autism literature is that many individuals dislike soft, light touch to their body and much prefer to sense firm pressure when coming into contact with something (Grandin, 1995). Suspecting that somebody with PMLD who you work or live with may be hypersensitive to light touch could then inform some of the following considerations. Clothing, perhaps trying tighter and smoother items with no labels could reduce light touch and increase pressure. In addition, using firmer pressure when communicating through on-body sign language, or while working hand to hand with an individual, may provide aid to any who avoid light touch.

Another common example of hypersensitivity in autism is related to sound (Sarris, 2016). This is often the result of a collection of sounds or an unexpected loud noise, considering this possibility may influence the way we communicate with the individual. For instance, while attempting to reduce any additional sounds – moving bodies and outside noises in particular – in the person with PMLD living or working environment, we may also employ simpler and clearer language, giving the individual plenty of processing time before talking again. It is, moreover, important to know both an individual's sensory-seeking and sensory-avoidance behaviours. For many individuals with sensory processing deficits the cost of their hypersensitivities being ignored – and often exacerbated - can result in extremely negative consequences.

Colloquially known as a sensory overload, individuals with autism often describe negative effects of being exposed to excessive stimuli. Overloads can result in

'shutdowns', where the individual often becomes unable to move or react and may appear unresponsive to other people while their brain is processing information. Alternatively, overloads can lead to 'meltdowns' that, for the individual having one, can result in concerning behaviours such as self-harm or aggressive actions (Bogdashina, 2016). Described as causing debilitating physical pain, individuals often respond to either the anticipation or occurrence of a meltdown with predictable and repetitive behaviours. These responses, regularly triggered by stimuli in the environment, are an attempt to counter the negative experience of meltdowns by providing the brain with repeated and recognisable stimuli (Williams, 1996).

For an individual with PMLD, responses to sensory overloads may not be as overt or obvious as when a person without a dual diagnosis suffers one. While those who are familiar with the individual will be best placed to know what to look for, any displays of unexplained pain or periods of being unresponsive may be due to excessive sensory stimulation. Additionally, an increase in the intensity of the individual's sensory seeking behaviours may indicate an attempt to avoid or minimise the effects of a sensory overload.

In the hope of reducing the likelihood of a person with PMLD having a sensory overload a concerted effort should be made to minimise unnecessary stimuli in the environment - sensory clutter. This might include a rethink of any bright or montage style decorating in favour of soft plain pastel colours. In addition to this we should consider any busy patterned clothing we wear when interacting with people with PMLD, any jangling jewellery, extractor fans or background noises in the environment should be reduced to the best of our abilities.

So, with those considerations in mind I would like to finish by saying: no, we are not all autistic, but, we are all human and as such we all experience the world in a variety of ways. People living or working with individuals with PMLD should always consider the effects of divergent sensory processing. With a few thoughts for how an individual's sensory processing may motivate their behaviours, the potential for expanding a person's development, learning and experiences exponentially grows.

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Supporting the transition from children to adult services of a young person with profound and multiple learning disabilities

Judith Cooper

This article describes the planned transition of a young man with PMLD and complex health needs from full time education in a specialist school setting to a service which provides nursing care for adults with multiple profound learning disabilities and additional complex health needs. The COVID-19 pandemic in March 2020 forced closure of the normal service and shielding of clients and the service team had to develop methods of home schooling in the case of this young man that benefitted him and others.



Carl (not his real name) was referred to the service I manage in 2019. At the time he was in full time education at a local SEN school and lived with his father. In many ways Carl is a typical teenager; he doesn't like getting out of bed in the morning and can be moody at times. He enjoys positive relationships with his carers and loves spending time outside; engaging in activities that involve water, as well as ball games and sensory lighting. He is tall, well built, has short dark hair, and walks with 2:1 support using a handling belt. Prior to the transition his father was his primary carer and the person who knew him best.

Carl has severe refractory epilepsy, and as a result medication is not always effective in managing his seizures. He is unable to have rescue medication as he doesn't respond to buccal midazolam. He experiences convulsive seizures where his body jerks and he is at risk of falling. He previously underwent an EEG scan which identified the left side of his brain is smaller than the right side. He has significant learning disabilities, is autistic, has progressive degenerative neurological disorder (PDND) and dyskinesia.

Carl is the youngest person to be referred to the service and this was our first experience of supporting someone who attends school. He moved to the service shortly after his eighteenth birthday. The transition began when he was still seventeen. His father was present at all visits until he turned eighteen, after this he dropped him off so staff could get to know him better. Over the following few weeks Carl spent longer periods of time at the service culminating in an overnight stay, after which he was taken to school to ensure a positive understanding of how to support him to maintain his education. The team supported him during the transition visits alongside his father as well as attending his local SEN school.

Prior to his referral Carl was experiencing 8-15 seizures a day. At school he had 1:1 support and at home his father

slept, or cat napped, on a settee in the living room next to his son's bedroom with an audio-visual monitor so he could always respond immediately to any seizure activity. Carl begun an Epidyolex (cannabis oil) trial at this time which appears to be having a positive impact in reducing his seizures. As a nursing service we were able to take a multi-disciplinary approach to work proactively to support this.

During the transition process Carl's father came into the service to talk to the support workers and spent time with them explaining his son's support needs. He also attended a one-hour session with our learning disability nurses to explain Carl's medical needs and to answer any questions. This was the first time the service had organised these sessions as part of the transition process and it appeared beneficial to all as well as fully involving Carl's father and working in partnership with him. The team benefitted from his account and were able to ask questions to alleviate any concerns. It also provided his father with confidence in the services efforts to learn about his son and gave him an opportunity to meet the team.

Carl moved to the service on 1st December 2019. He was assessed as requiring 1:1 support 24 hours a day 365 days a year. This was provided in service by the learning disability nurses and the support team. At his SEN school it continued to be provided by the teaching and support staff.

With the advent of the COVID-19 pandemic in March 2020 the service closed to visitors and shielded our clients. This impacted on Carl being able to attend school. Discussions took place prior to this between his continuing health care nurse, the school, his father, and the service to agree the best course of action as Carl is

not due to finish his education until 8th July 2021. As a result, the service took on the role of home schooling, a whole new concept for the team. Carl's teacher sent the service information and ideas on activities and regular contact was maintained between the manager and teacher.

It soon became clear that the pandemic and the change in working practices were impacting on staff completing the activity ideas sent by school and that the team required guidance and structure around educational support. The team found the concept of home-schooling challenging, as this had not been provided before. Despite this, Carl was clearly benefitting from the increased interaction with staff within the service and the team were getting to know him and the activities he enjoys most and benefits from. As he developed into adulthood his personality was evolving and as a team and service it was a wonderful opportunity for us all to be part of his journey.

The ideas provided by school had the positive impact of benefitting the whole service. After the initial hesitation the service began to embrace the concept of home schooling - developed themed months and identified different ideas such as a Pirate and Caribbean Day. This helped engage all our clients in sensory, visual and art and craft activities. The team have supported clients in many in-house activities because of this. Carl was supported to participate in these to help meet his educational development. It also highlighted many hidden creative talents within the team. Each themed month then culminated in a socially distanced outdoor celebration with music and food and both clients and staff dressing up.



Carl's home schooling also benefitted those he lived with who joined in with cultural activities and they all enjoyed a Bollywood event and the multiple sensory opportunities this provided. Carl and his peers watched live feeds from his school on the TV of baby chicks hatching.

When Carl returned to home schooling following the summer break the service developed a more structured approach to the activity ideas and incorporated his school activities into a daily activity chart. Providing an opportunity to document his interaction and responses to these and evidence why they had been able to complete an activity or if they needed to adapt or change it. Carl's named nurse has also built on the school activities and researched a variety of other educational activities to build into this. The service wanted to ensure Carl was offered the opportunity to participate in as much of his home schooling as possible therefore the activities are offered over seven days, rather than five. This ensures he has an opportunity to complete at least five days' worth of activities. As he still experiences frequent seizures, and these can impact on his ability to participate. Activities are split into morning and afternoon sessions with two different activities a day being offered.

The Manager, clinical leads and Carl's named nurse had discussions with the team about the importance of him continuing his education. Staff have benefitted from having a structured activities rota and it ensures Carl's

home schooling has taken place.

The whole concept of home schooling has evolved from a process of which the service had no experience to something that ensures Carl is getting the most out of this regarding his continued educational support as well as being something all our clients have benefitted from. It has heightened the service's awareness of sensory engagement which we continue to build-on with the recent purchase of equipment (height adjustable stands and trays) to further expand home schooling by enabling Carl to access outside water based activities which he is known to enjoy.

Comment from Carl's Father

"The process of transitioning my son from home to the service was more traumatic for me than him. The level of professionalism shown made my son feel at ease with the whole process, from teatime visits to get him used to the environment and surroundings and staff, all the way through to the actual move. I was kept informed at all times and all the staff listened to any concerns I had and any advice I gave. All my questions were answered, and reassurance given. I can't thank all involved enough."

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Coronavirus and People with Learning Disabilities Study: latest reports

The Wave 2 Results of the *Coronavirus and People with Learning Disabilities Study* have now been published and are available online at: <https://warwick.ac.uk/fac/soc/cedar/covid19-learningdisability/results/wave2results/>

This project aims to answer three key questions:

1. What are the wellbeing, health and social effects of the COVID-19 pandemic, including social restrictions and changes to how people are supported, on the lives of adults with learning disabilities across the UK over time?
2. What actionable factors are associated with better outcomes for: a) people with mild/moderate learning disabilities; b) people with severe/profound learning disabilities?
3. What urgent issues concerning people with learning disabilities are emerging over time?

The Wave 2 survey included people who were unable to take part in interviews themselves, so these reports include insights into the lives of well over one hundred people with profound and multiple learning difficulties, their families and paid carers. Of particular interest are the reports on the mental and physical health of people with PMLD and on the impact on carers.

The Wave 3 interviews and surveys will be starting in July 2021 for people who took part in the Wave 1 and/or interviews and surveys.

HOP Part 4: HOP and the Five Good Communication Standards

Sheridan Forster

The Hanging Out Program (HOP) and the Five Good Communication Standards may be a perfect match, with HOP being an example of actions under several of the standards. Spending time reflecting on the standards has, however, made me want to change one major thing in the HOP booklet.

In 2013, the Royal College of Speech and Language Therapists published the Five Good Communication Standards. The standards are:

1. There is a detailed description of how best to communicate with individuals.
2. Services demonstrate how they support individuals with communication needs to be involved with decisions about their care and their services.
3. Staff value and use competently the best approaches to communication with each individual they support.
4. Services create opportunities, relationships and environments that make individuals want to communicate.
5. Individuals are supported to understand and express their needs in relation to their health and wellbeing.

The HOP, a commitment to spend 10 minutes with a person giving them 100% of your attention, is an example of Standard 4. The interactions that happen and are documented in HOP sessions inform Standards 1 and 3. Subsequently the relational bonds made between support workers and people with PMLD provide the necessary foundations for supported decision making (e.g., Jacobs, Quayle, Wilkinson, and MacMahon, 2021; Watson, Wilson, and Hagiliassis, 2017).

Working with the Standards, however, has driven me to want to make one edit to the HOP booklet... and perhaps also the Standards. It is something implicit in both documents, but, I think on reflection, should be made explicit in both documents. The relationship between disability support workers and people with PMLD is the cornerstone to good practice and good quality of life.

Now, some may say, that is an obvious statement. But I think about all of the subtle examples in the field that undermine the statement.

Too often we hear the comment "I'm (you're) just a support worker". In some places, emotional attachment between the "client" and "worker" are discouraged

explicitly or implicitly. The meaning of a professional relationship between the two people is often vague, modelled on professionals in very different contexts. Time and time again I hear of comments discouraging warm relational practice.

For years, many researchers examining the social networks of people with learning disabilities, have positioned the staff-client relationship as lesser. Some researchers have viewed only relationships with people without disabilities and people who are not paid, as the best relationships. People only having relationships with paid staff has been viewed as terrible.

Please don't get me wrong, I do believe in the value of relationships outside of one's paid circle. I acknowledge that there are differences in drives in paid relationships and relationships subject to staff-turnover are difficult for many. There are boundaries needed. But does that mean we should completely devalue the relationship between the support worker and person with a disability, or that we should scaffold it within different concepts that simultaneously value and recognise some constraints. For many years, in the field of psychology, it has been known that the relationship between the therapist and client is one of the strongest factors for intervention success.

Excellent staff-client relationships are needed to model to the broader community how best to interact with people with unique interaction needs. Sometimes the discovery of new ways of interacting and use of "best communication practices" can support existing family or friend relationships, if they are explained in an informed and sensitive way: such as explaining why Intensive Interaction may work with someone.

I would like to add to the HOP booklet "the relationship between disability support workers and the people they support is a foundation to good communication and a good life". I would like mantras spoken in organisations saying that the relationship matters. I would like posters that celebrate disability support workers engaging with people, photos of fond looks and shared joy.

Without explicitly supporting, building, reflecting upon the interactions had between people with PMLD and their workers, important initiatives such as the 5 Good Communication Standards and HOP will be compromised by a lack of authenticity and missed celebration of gains made by two important people.

Contact Details

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Watson, J., Wilson, E., and Hagiliassis, N. (2017). Supporting end of life decision making: Case studies of relational closeness in supported decision making for people with severe or profound intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 30(6), 1022-1034. <https://doi.org/10.1111/jar.12393>

Further Reading

You can read about the Communication Standards in:

Felicity Court (2019) Five Good Communication Standards, *PMLD LINK*, 31 (1), Issue 92, 6-7.

Royal College of Speech and Language Therapists (2013). *Five good communication standards: Reasonable adjustments to communication that individuals with learning disability and/or autism should expect in specialist hospital and residential settings*. Available at: <https://www.rcslt.org/wp-content/uploads/media/Project/RCSLT/good-comm-standards.pdf>

BILD webinars

BILD - have a series of webinars: Growing Older with Learning Disabilities among others. A recent webinar is called 'Growing Older, Living Well: End of life care planning and people with learning disabilities'. It addresses what end of life care planning is and how to approach this with people with learning disabilities. It explores some of the particular challenges arising from Covid-19, in relation to end of life care planning.

For more detail about this and other webinars go to: <https://www.bild.org.uk/resource-type/webinar/>

PCPLD Network webinars

The PCPLD (Palliative Care for People with Learning Disabilities) Network also has a series of excellent webinars available for general viewing. They cover a variety of important topics: for instance, involving people with intellectual disabilities in end-of-life decisions, supporting people in bereavement, assessing distress and discomfort in people with difficulty communicating, etc.

For more detail about these and other webinars go to: <https://www.pcpld.org/home/webinars-and-podcasts/>

Rapport-Based Music

Matthew Laurie

Rapport-Based Music is an inclusive way to make positive connections and build relationships with the person you support. The practice is simple and straightforward and you don't need previous musical experience. This article introduces the practice, the underpinning theory, some ideas for sessions and offers free resources that will help you to use music more confidently with people with PMLD.

Two ways to make music

Before we dive into the practice, it's important to recognise that there are two ways that music can be used in special needs education and social care settings. The first way (which I suspect is more prevalent, particularly in schools) is to try to teach music. The music leader or teacher typically leads a task-based activity with an objective in mind, teaching rhythm and pulse perhaps, or maybe teaching a person to sing a melody or song. The strength of this approach is that we can, in the words of one teacher I met, *"expand a person's musical horizons."* And I agree that this has value. Truly, it is wonderful when, as a consequence of the activity, a learned disabled person learns a new song and can sit down and join in with a singalong. But this approach has limitations as I will explain later in the article.

The second way is to use music to connect positively with a person or group of people. This approach is more concerned with process and is the basis of my community music practice - offering music in a way that allows each person to shine and be the best that they can be. Since 2003 I have made music with learning disabled people, autistic people, people with PMLD and elders living in dementia care settings. And the more music I make, the more I find that the same practice, even the same songs, works with everyone regardless of their disability.

Making connections

When supporting people with a communication disability, particularly those with PMLD, there is sometimes so little in the way of communication that even the slightest glimmer of connection can be incredibly rewarding. That moment of eye contact, a smile, reaching out...I'm sure you've all been there. These are the moments that we live for and they can make us feel like "This is why I came to work!" or "This is why I'm supporting this person today!" Even though this experience seemed so central to the practice, there was a time when I knew of no language to describe it and neither did any of my colleagues. Also, at this time I was delivering a lot of Intensive Interaction induction training and was looking for neat ways to describe the value of the practice.

After lots of research, I found the answer I had been looking for in a chapter of Daniel Goleman's book 'Social Intelligence' (2006) where he refers to a 1990 study at Harvard University by Tickle-Degnan and Rosenthal (1990) investigating 'rapport', an experience of high quality interactions that has three ingredients:

1. Mutual social attention
2. Mutual positivity
3. Mutual co-ordination

These three ingredients seem to accurately describe the experience of connection that I have with a person when doing Intensive Interaction or Musical Interaction. When I join in with a person's behaviour, they usually look at me (assuming the person doesn't have a visual impairment), smile and repeat what they were doing (not necessarily in that order). Michael Burns (2002), writing about childcare practice, goes further to explain that "the most important technique for any care giver to master is the ability to develop a good sense of rapport with the child" and that this "first feeling of trust and respect must be present before even the most basic positive relationship is formed". So what is this technique? What do we have to do to find rapport?

The three Cs

I initially developed the three Cs as an easy way to remember how to start Intensive Interaction and find rapport. Doing the three Cs can help you to share the space of the person you support in a way that can lead to deeper interactions. Each of the three Cs relates to offers - the in-the-moment interests and behaviours of the person (Laurie 2021). Typical offers are rocking, humming, tapping, grabbing, dancing, singing etc. The three Cs are:

C the offer - to see the in-the-moment behaviours of the person as a potential starting point

Copy the offer - to join in with what the person is doing using 100% of your attention

Celebrate the offer - to use facial expressions, body language, tone of voice to bring warmth

By copying what the person is doing, we are using postural mirroring, the most effective technique for creating rapport (Tickle-Degnan and Rosenthal, 1990). This technique is of course common to Intensive Interaction but can also be found in many other social interventions that predate this practice, including dance and movement psychotherapy (Coaten, 2011), and early years music practice (Pitt and Arculus, 2018). Michael Burns (2002) refers to this technique as pacing, reflecting and mirroring and states that “this technique is probably the most effective way of establishing quick rapport and is the one, used either consciously or unconsciously, by most care givers and therapists”.

But the three Cs are not just a learning disability practice...they would work with you too! Have you ever been watching TV and someone has entered the room and tried to start a conversation with you? I imagine that you would probably want this person to go away or shut up. But what if this person followed the three Cs? First by seeing you sat on the sofa as the offer; then copying this offer by sitting on another seat and watching the TV too, while making sure to do this like there was nothing they would rather be doing. Would you be happier for them to share your space? I think so.

So the three Cs work to establish rapport with people with or without disabilities and, since the practice offers a new language for the central experience, and because the practice is relevant across people with PMLD and those with learning disability, autism and dementia care, I chose to give the practice a new name: Rapport-Based Communication.

So what is Rapport-Based Music?

Rapport-Based Music is underpinned by Rapport-Based Communication and the three Cs. By responding to the behaviour of the people we are working with, we can ensure that the practice is inclusive to all people regardless of their disability and that we meet the person's fundamental need for autonomy, competence and relatedness (Laurie 2021). If, for example, the only thing that a person can do is lie down and breathe, then we can respond to this behaviour, playing in time with the breathing perhaps, or celebrating lying down by joining in and involving this in the song. By focusing on process we can make sure not to exclude anyone, a problem that often arises for people leading task-based, product focused activities. Teaching a campfire song may be the perfect thing for one person but people with less capacity may be at risk of exclusion. This means that Rapport-Based Music is particularly useful for working with people PMLD.

Creating more offers

In Rapport-Based Music, we play an instrument to support the songs. I often play ukulele but it is just as

effective to use a thumb piano or large drum. In the process of Rapport-Based Music, one tangible purpose of playing the musical instrument is to create more offers. When an instrument is played to people, they tend to move to the music, tapping, dancing, humming and singing. These are the in-the-moment behaviours that we have labelled as offers, so the music literally has the power to create more starting points for interaction. So begin your session by just playing whatever instrument you have to hand and then see what happens. You can then use the three Cs to join in.

The songs

Rather than using songs with a fixed structure, the interactive songs allow for the music leader or teacher to use the three Cs to respond to the offers and sing about them. I have created a repertoire of eight songs that I use in all my sessions. Rather than try to describe the songs in text, I have produced a series of video backing tracks that are available for free on YouTube by following this link: <https://www.mattlaurie.com/musical-interaction>

The songs are also described in the online course that you can access for free using the details at the end of the article.

Music session design for people with PMLD

The most striking change that I made to my music sessions for people with PMLD is that I don't follow the typical format of arranging participants in a circle or horseshoe shape. Sitting in a circle can offer participants a stronger sense of being an equal member of a group and this can also help the teacher or music leader to facilitate the session. But there are weaknesses to this session format, particularly for people with PMLD. Sitting side-to-side, as people do in a circle, is not the most available position for interaction: to interact with the person next to them, each person needs to turn to face that person. So why not just start sitting face-to-face? For people with PMLD, I think the value of having a person available for interaction outweighs the value of group inclusion offered by sitting in a circle. Also, when sat in a circle I would find that the staff would sit and wait their turn too and I suspected there was a more enjoyable and effective role for them to play. So we now forgo a circle in favour of staff sitting face-to-face with the participants, so that their face can be in the ideal position for interaction ie where the person's gaze naturally falls. In a special school, to achieve a 1:2 or 1:1 staffing ratio, we devised a session for 4-5 children that involved a single child and staff member from a few different classrooms. Most classes were able to release a staff member for the 20 minute duration of the session.

I found the staff enjoyed this new format much more as they had the time to do what they loved the most -

enjoying musical ways to connect with the child and find great moments of rapport.

Learn more about Rapport-Based Music

If you would like to learn more about Rapport-Based Music and Rapport-Based Communication then I have produced an online video based course that can be accessed for free using the link below.

<https://www.mattlaurie.com/introduction>

PMLD link readers can access this course for free by using the password: RMB2020

And the songs page that I link to is here

<https://www.mattlaurie.com/musical-interaction>

These are all free resources that I have created and there are no hidden fees.

I also offer regular online Rapport-Based Music training and have been using this format successfully to teach staff how to play the ukulele to support sessions. Get in touch by email (info@mattlaurie.com) if you would more information.

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Staffordshire County Council's virtual offer for adults with complex learning disabilities

Louise Molineux

Staffordshire County Council provides care and support services to 189 adults with learning disabilities. This includes the provision of Specialist Day Opportunities, with six centres located across the county. Staffordshire County Council's adult learning disability services specialise in working with people with complex needs and profound and multiple learning disabilities. Our customers engage and experience the world around them on a sensory level, meaning sensory engagement is important to support their communication, and emotional and mental wellbeing.

How our virtual journey started

The onset of the COVID-19 pandemic in March 2020 saw our Specialist Day Opportunities close their doors during the first lockdown. To support our customers sensory needs, we had to think carefully about how we were going to create opportunities for this to happen. Sensory engagement takes place in the here and now, often requiring a variety of physical sensory experiences for the person to experience, explore and enjoy.

An opportunity presented itself to explore a virtual way to deliver services to our customers. Using a pilot by NHSX and Accenture, the Specialist Day Opportunities team obtained ten Facebook portals to be placed in the homes of the people we support. Facebook Portals utilise video calling technology via Facebook or WhatsApp accounts.

The virtual sessions started in July 2020 with seven families who were willing and able to take part in the new service. Staffordshire County Council have been delivering on average fifteen virtual sensory sessions per week with our customers and their families across the county.



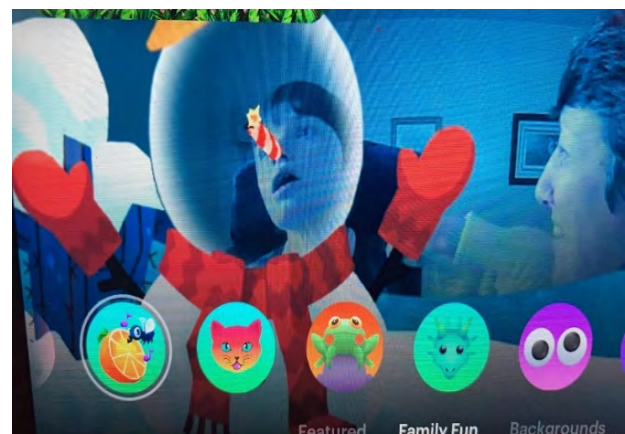
How we supported our customers using the portals

The integral features of the Facebook portals include colourful interactive stories, visual, voice, and face changing effects and various eye-catching backgrounds. As engaging as this is, our customers would gain more from a bespoke virtual offer to meet their sensory needs.

When attending the service before lockdown, customers had benefited from a varied menu of sensory based activities. During lockdown we wanted to continue offering opportunities for them to take part in sensory engagement whilst at home.

We knew that sensory stories would be the way forward, as they were already being used and enjoyed within the centres. They offered a means to support the wellbeing of our customers by offering the sensory engagement needed for our customers to thrive. Sensory stories are approximately ten lines long, each line of the story is accompanied by the relevant sensory experience.

We partnered with families who were at home with their loved ones. A co-facilitation approach was adopted, where a staff member became the virtual facilitator sharing the sensory story via the Facebook portal.



The relatives became the sensory partner helping to deliver the story's sensory experiences.

Initially, two sensory stories were developed, 'Blackpool Charabanc' and an adaptation of Tim Hopgood's wonderful colour filled story 'Wow'. To accompany the story, we developed sensory bags, which were sent to families. Each sensory story bag contained a laminated story sheet, guidelines about sharing sensory stories and the relevant sensory props and experiences.

The story bags were duplicated, meaning the families and virtual facilitators were issued with the same stories and resources. This way we would work in harmony with the customer and the sensory partner who would be sharing the stories and experiences simultaneously.

The sessions are bespoke and other meaningful activities are incorporated, such as favourite music and songs; Facebook portal stories; reading and adapting favourite authors and audio books (especially those that make rude sounds!); science and cookery and seasonal activities such as Easter bonnet making also take place.

Examples of story bags can be seen below:



Wow story bag contents

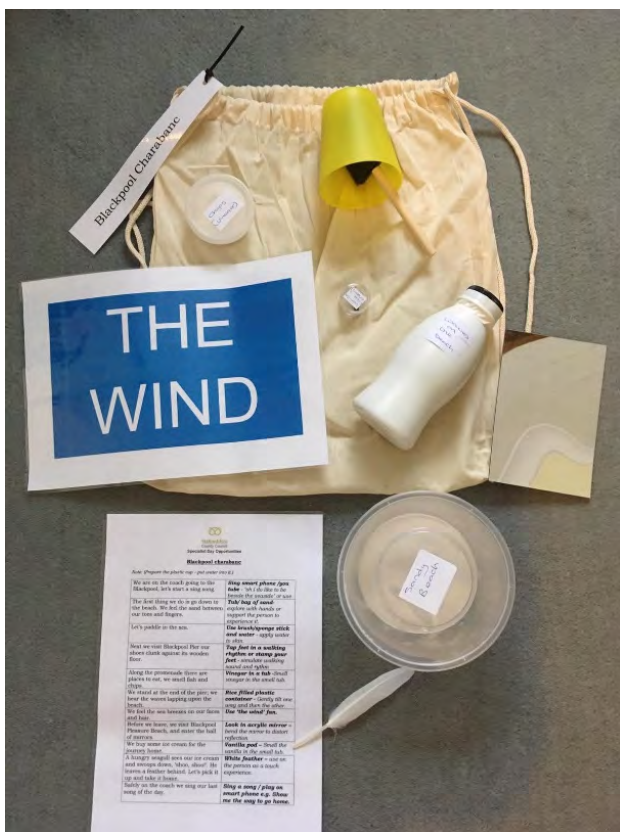
Since commencing this offer, Staffordshire County Council have been pleasantly surprised about the outcomes and benefits this service is having for staff, customers, and their families.

Staffordshire County Council has received recognition of our virtual offer from the West Midlands ADASS group and Skills for Care West Midlands Registered Managers Network. Digital Social Care also featured an article about our work. Here is the website link to view the article, including a video recording of a virtual session taking place. <https://www.digitalsocialcare.co.uk/success-story/staffordshire-county-council-using-facebook-portals-to-deliver-sensory-services-online/>

Benefits for customers

Over the past eleven months the customers have benefited from regular virtual sessions. The families and the facilitators have observed wonderful examples of increased levels of engagement and participation from customers.

One customer, JS, is non-verbal and has restricted movement in his hands. During the lockdowns and in-between he has used his portal to connect with his girlfriend, and they have maintained contact throughout. JS strives to interact as independently as he can, selecting the stories, interacting with the props, and generally communicating with smiles, laughs and great facial expression.



The Wind story bag contents

Another customer, AR, besides benefitting from the sensory story portal sessions, used the portal to connect with their caravan club during the lockdown. AR was at the heart of the portal get together with his parents and their friends. The caravan club is such an important social link, and they all know AR well. The interactive face and voice changing features generated lots of fun and laughter.



Voice and face changing effects

A customer, AS, spontaneously used a feather from one of the stories and to everyone's surprise went up to the portal screen and tickled it using the feather. In response to being tickled the facilitator laughed, which generated a spontaneous interaction and connection which carried on long after the session was over.

This is a great example of how AS often surprises us when interacting with the sensory story's props. His Mum shares that 'they are always laughing during a portal session'.

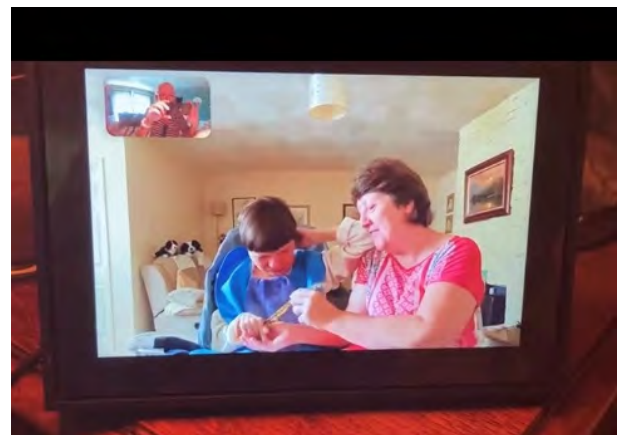
Another customer, JH, has PMLD and complex health needs, the accumulative impact of the portal activities and the consistency of the sensory stories, have resulted in such positive outcomes. JH's carer stated that 'It's as if a light has been turned on'.

Prior to using the portal, we questioned whether JH would focus on the small screen. To our surprise as soon as JH's virtual activities started, she appeared to connect straight away, looking towards the screen, and listening intently to the facilitator's voice. After the first two weeks when the family would prepare for the portal session, JH would look towards the blank screen, as if anticipating the start of the activity.

The sensory stories had an immediate impact, and with the support of her sister, JH engaged with the sensory experiences. Together, they have an amazing chemistry and it is wonderful for the facilitator to observe how well

JH's sister presented the experiences, allowing JH time to explore and interact. Over time JH's sister has sourced her own stories and props. JH enjoys Julia Donaldson books, so her sister would collect sensory props and experiences to use with these stories. For example, 'The Stick Man' and 'The Flum, Flum Tree'.

The family reports the virtual offer has done JH the world of good and that, "she has come on so much more in the way she reaches out and actually holds things, there has been an improvement in her hand and eye coordination".



Following a virtual session, the families share that their relatives remain alert throughout the rest of the day

Based on customer responses, facilitator and family feedback, the virtual sessions are actively promoting emotional and mental wellbeing for customers, as there are plenty of opportunities for sensory engagement, interaction, and fun.

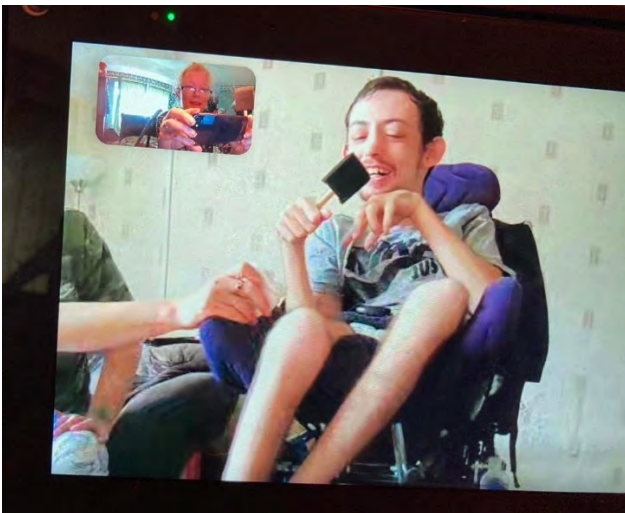
Feedback from families about the virtual offer

'Andrew has struggled immensely with the lockdown months... We were then offered sessions with a portal... He has slowly adjusted to the sessions and now asks for them. He joins in with Michelle who constantly praises Andrew and encourages him to sing along... [Andrew] is now starting to pick things up to engage with different parts of the story, he will start singing the songs randomly in between his sessions, he really is enjoying them. The portal sessions are a big part of Andrew's routine'.

'Just wanted to congratulate the team on the success of the Portal sessions. Jane enjoys her hourly interaction with Michelle immensely. My wife and I didn't expect Jane to engage as well as she does. They were dark days at the beginning of lockdown, but the Portal was a ray of sunshine to us all. Jane seems more aware because of it. Thanking you'.



A customer and their carer using a torch prop as part of a sensory story.



A customer using a sensory prop during a virtual session

We had wondered as to whether knowing the customer was impacting upon the positive outcomes when using the Facebook Portals. The opportunity of a new customer with PMLD was an opportunity for us to explore this. This young woman looks forward to her weekly virtual session. She uses the sensory stories and has participated in a virtual live cooking session amongst other sensory based activities. The customer, JW, looks forward to her portal time and loves to share her sound books with the facilitator.



Sensory cooking

Benefits for families and unpaid carers

Benefits for unpaid carers have been an unexpected outcome of this new way of working. During lockdown, carers were isolating or shielding, and caring for their loved one 24 hours a day. Feedback from families stated the sessions have been a lifeline, as they have at times felt isolated and alone during the pandemic. Carers have stated the sessions have had a positive impact on their mental and emotional wellbeing as well.

Their role as 'sensory partners' allows them to step away from their caring duties for a short period of time in the day, offering them the opportunity to spend quality time with their loved one. The sessions are focused on fun and laughter, which has helped the carer to connect and bond outside of their caring role.

One of the carers has explained how, during lockdown, life centred purely around care routines. Both the carer and her son were shielding, and she was feeling socially isolated. When the virtual activities were offered, she decided to give it a try. The stories together with her role as sensory partner had a positive impact on them both.

She has reported looking forward to the sessions as much as her son. The virtual activities gave them the opportunity to have fun together, and this was evident throughout. The carer even sourced additional props and puppets to use during the activities. This carer has cited the virtual offer as the best thing to have come out of the COVID-19 pandemic and the lockdown.

Benefits for staff

When the services shut during the first lockdown of the COVID-19 pandemic, this was a difficult period for staff as they knew customers would be missing their day opportunities and carers missing out on much needed respite. Being able to provide support sessions virtually has provided a renewed sense of energy and motivation within the staff teams. They have been able use their existing skills and expertise about sensory work and learn new skills about virtual facilitation and technology. Staff have reported increased job satisfaction and are energised and excited to develop the virtual offer, sourcing and researching new story ideas. Staff have reported the sessions are reciprocal and have a positive impact on their mental wellbeing as well.



Sensory story 'The Clown'



Background effects



Interactive story

Virtual champion, Nikki, has shared how much she enjoys her role as a virtual facilitator, as it gives her the opportunity to get to know the families in a different way. Nikki is always thinking of new ideas and sourcing new activities, stories, and music, developing new stories and making the props and experiences for the story bags. Staff report the virtual offer requires them to be creative and is much more than just a video call.

The future of our virtual offer

The virtual offer has transformed the provision of Specialist Day Opportunities during the COVID-19 pandemic. What started as a response to the COVID-19 threats has established itself as a valuable service, achieving significant improvements in outcomes for customers and their families. This approach has proven it is not limited to location or affected by COVID-related restrictions on building-based services and group numbers. The sessions can be delivered at a time and duration which suits the user, and the sensory content can be bespoke to ensure it is always person-centred.

The virtual offer is currently offered to families who access our Specialist Day Opportunities. However, we have started providing sessions in our residential homes, supported living and respite services, with their staff being our 'sensory partners'.

We are expanding the virtual offer and trialling virtual sensory massage sessions with customers and unpaid carers, which has had some initial success.

Now that centre-based services are open we are connecting with each other countywide as each service has a Facebook portal and TV portals available to use. As part of the national response to COVID-19 our customers have reduced days in the centres. Those who received virtual offer sessions during the lockdowns continue to receive virtual sessions on the days they do not attend the centre-based services, which has resulted in a blended service offer.

Implementing the virtual offer over the past year has been a sharp and enlightening learning curve. We are at a place where we can confidently share our expertise and experience in the delivery of virtual sensory activities, which are designed to engage customers with profound and multiple learning disabilities.

The virtual offer will have an important position within the future service model for learning disability specialist opportunities within Staffordshire.

Contact Details

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Online Information

Digital Social Care also featured an article about our work

<https://www.digitalsocialcare.co.uk/success-story/staffordshire-county-council-using-facebook-portals-to-deliver-sensory-services-online/>

Useful Websites

<https://www.storymassage.co.uk>

www.thesensoryprojects.co.uk/

<https://portal.facebook.com/gb/product>

<https://www.staffordshire.gov.uk/Advice-support-and-care-for-adults/Adult-learning-disability-services.aspx>

<https://www.facebook.com/staffordshirelearningdisability>

Get Involved

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

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

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

For more information contact The Editors (info@pmldlink.org.uk).

‘Beat the Corona Blues’ literally a viral sensory story

Pete Wells

Although the COVID-19 pandemic feels like it’s been with us for twenty years now, I do try and look for the positives in the whole sorry affair. This is partly because I am one of those irritating glass-half-full kind of people, and also because I’m far too much of a cowardly custard to think of the potential consequences the virus could have had on my learners (mercifully, none of my bunch have been affected).

I teach and manage the curriculum at Catcote Futures, a wonderful specialist college for adults with severe and/or profound and multiple learning difficulties in Hartlepool, in the North-East of England. The government’s confused and befuddled announcement of the first lockdown came crashing into our lives in the same week that OFSTED had decided to come crashing into my college. A week that will be forever etched on my brain and my underwear!

Instead of celebrating our very positive inspection, we had to immediately batten down the hatches, reengage our frazzled brains and come up with innovative, engaging, and most of all, USEFUL ways of supporting our learners and their parents at home. Cue some absolutely superhuman heroics from my exhausted and extremely anxious staff, who, as ever, went above and beyond, coming up with well over 100 exciting challenges and activities for our learners and their parents to do at home.

Amongst the many activities I’d sent for my learners with PMLD, was a brand-new Sensory Story which I designed to give parents some ideas of things to do with their offspring, that would replicate some of the wonderful activities we do at college. Hence, the “Beat the Corona Blues” Sensory Story was born!

I sent this out to all of the guardians of all my learners with PMLD but, like the virus itself, it soon mutated and spread itself across the globe! I dutifully popped the story on my website (www.sensorystoriespodcast.com) and was amazed when it got over 2000 downloads in a single weekend. My daughter had recorded the vocals on the multimedia presentation and was thrilled - it was like going viral on a particularly uncool Tik-Tok!

To my delight I received several wonderful emails from very thankful parents and practitioners, which I must say meant the world to me during those unprecedentedly dark times. One such email came from Hanna Rún Eiríksdóttir, a teacher in Iceland. She loved the story and asked if she could translate it into her native Icelandic tongue to help children and adults in her own country. Wonderful!

Shortly after this, I was contacted by Leigh Warton, a fine practitioner from the excellent Ysgol Ty Coch School in Wales, asking if she could translate it to Welsh! Again, I readily agreed and it was both strange and wonderful to hear my words - or most of my words - being said in a different language!

I say ‘most of my words’ because the colloquial nature of the final cheeky line, which thuggishly states that we will ‘Kick COVID in the cobbles’ has had to be tweaked to serve those different dialects. So interestingly, Hanna made it friendlier to Icelandic ears by saying “Let’s throw that bloody virus into the sea!” whereas Leigh made it more palatable to the Welsh by saying “Let’s grab this COVID virus, and kick it upside-down!” In addition, an Australian teacher named Krista-Ann Fostrum asked if she could record the story for her learners, but change that controversial final line as her school wisely operates a strict no kicking policy!

So, I proudly present “Beat the Corona Blues”. I do hope you find it useful, it contains many principles and activities that are universally popular, wholly appropriate and linked very firmly in developmental learning.

Contact Details

Pete Wells has been writing and animating amusing, Multi-Sensory Stories for over twenty years

Website: www.sensorystoriespodcast.com
Email: sensorystoriespodcast@gmail.com

You can download a multimedia version of the “Beat the Corona Blues” story from <https://sensorystoriespodcast.com/COVID-virus/>

Beat the Corona Blues!

If you're social distancing, don't feel sad and don't feel blue!
While you're staying safe inside your home, there's lots that you can do!

Why not try a bit of sand play? It's a great way to explore!
Digging for hidden treasure, like shells and toys and more!

(Find sensory objects in sand)

Why not do bit of cooking? Make some biscuits or Milkshakes!
On that elderly neighbours doorstep, why not leave some fresh-baked cakes?

(Taste biscuits, cakes or milkshake)

Keep your social distance, but still get out and about!
Take some exercise around your home! Let's shake those cobwebs out!

(Vestibular 'walk'/ feel leaves/twigs or wadding)

Play with some running water! Making soap bubbles is very nice!
While you're there why don't you wash your hands? Singing 'Happy birthday' twice!

(Waterplay)

Why not potter in the garden? Smelling flowers, feeding birds?
Or make mischief with your Big Mac, with the rude sounds or cheeky words!

(Smell flowers, bird Whistle, practise AAC)

Spend some time playing with bubbles, see how many you can pop!
Have a popping competition, see who'll come out on top!

(Bubble machine (with switch))

Why not listen to some music, and dance a little jig!?!
Or make your own musical instrument, and put on a special gig?

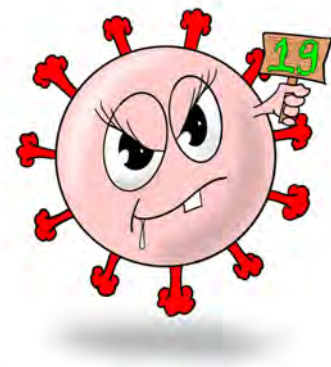
(Listen to music, shake musical instrument)

Why not get your favourite blanket, and in your living room make a den?
Or have some guided massage, feeling calm, and chilled, and Zen!

(Time in a blackout tent/ massage, guided massage (YouTube))

Let's all beat this thing together! We are fierce! We're not toddlers!
Let's grab this COVID Virus, and kick it in the cobbles!

(Physio on legs followed by a nice massage!)





Ten tips for providing a home learning offer: the things that we learnt during the pandemic

Sam Murray

The scale and the timescale of the COVID-19 pandemic will no doubt go down in history. Living through it, the longevity and severity have been compounded by the changes in lifestyles, working patterns and, for those in education, the way that we have had to adapt to deliver the best quality education possible to the school population. For the special school population this has provided major challenges, as our pupils' learning styles and access to online teaching is extremely variable and individualised. This article aims to share the positive aspects of the changes we have made to our working patterns and what we will endeavour to continue as future practice.

Curnow School is an all-aged special school set in Redruth, Cornwall. We were very lucky in Cornwall to have been one of the areas of Great Britain with smaller case numbers during the pandemic; however, in terms of our education system and the impact upon teaching, we have faced the same challenges as the rest of the country. Being a special school, our immediate thoughts when considering our home learning offer was how we could develop an offer which would be both manageable for our staff to resource and for our parents to deliver. We also knew that we faced challenges in the way that the learning would be accessed by our pupils and how much meaning this would hold for them. The great thing about being a special school is that having to think 'outside the box' is daily practice for our teachers.

Once the initial concerns had been aired and deliberated over, the team got to work to consider what they could do to deliver the school offer in new and different ways. It soon became clear that the great relationships that we have with our parents was going to be key in moving forward if the offer was going to be a success.

For our PMLD cohort the meaningful delivery of sessions was a new and interesting challenge, but the pandemic restrictions severely limited our options. We were understandably sceptical about how much meaning a Microsoft Teams link [see notes] would have for our students, and we knew that empowering parents to be able to become the child's learning partner would be the key to success.

Jenny Buckland, our PMLD lead at Curnow, outlines her initial concerns:

'Once we knew that everyone was safe and well, our minds turned to how we would deliver our curriculum remotely. Being in class is very up close and personal and this way of working seemed so different to the everyday classroom experience. In school the curriculum is very rich and specialised, and we wanted to make sure that we empowered parents to support the delivery of sessions in ways that held meaning and felt comfortable to them. We knew that some things would not be possible, for example working with eye gaze technology, however, the provision of the COVID funding from the government allowed us to support in areas like physiotherapy and sensory curriculum more easily.'

The relationship with our parents has been key to the success of our home learning programme. Frequent contact, open dialogue and a commitment to getting things right for everyone has meant that many of our teachers became the main 'go to' for parents on a wide range of issues and concerns, which has resulted in even further strengthened relationships with our families. One of our parents, Joy Constable, explains how the lockdown affected her family and what the support of the school community has meant to her family during this difficult time.

'I had no worries about how my child would access a home learning offer - on the contrary, I was intrigued as to how it would work. The communication and innovation of her class teacher, Jenny Buckland, was exemplary. My child lacked for nothing, and I felt totally supported through telephone, email and Class Dojo routes [see notes]. The fact that Jenny has helped us as parents, build links with other parents was a huge help as well. I never once felt "out on a limb", I never felt as if I was just being left to "get on with it". Considering the calibre of not only actual resources, but the clear and concise, but never condescending explanations that came as well, lockdown was quite a time for me to learn with my child. The on-screen face to face, for her, was invaluable, and I firmly believe that all these things led to a very seamless return to school. To summarise, my initial reaction was one of intrigue, and I had no worries about how it would work. I have faith in her teacher, and her school. I have started to learn "how" my child learns and that's been awesome. I have always been a "re-use and recycle" type of person, but since lockdown, Jenny has shown me lots more uses for everyday household objects!! On a personal level, lockdown and home learning has allowed me to slow down a bit, and really rejoice in the small steps of life. It has truly taught me that there is no such thing as a silly question, and I do believe it has enhanced the relationship I have with her teacher, and therefore made me even more comfortable when leaving her at school. Would I like to go through another lockdown?....only if the sun was shining!'



Three become six happy children when the Microsoft Teams link is set up.

On return to school we conducted a home learning survey, allowing us to get a full picture of the most useful ways to support children at home and this has enabled us to inform the lessons that we will embrace and draw on for the future. These will help us to provide better support for children in need of periods of home learning, due to illness or vulnerability, meaning that no child's educational provision should be paused because they are unable to attend the school.



Many parents have commented on the relationships that were developed between siblings through the home learning offer.

These are our top ten tips for providing a solid and supported home learning offer.

1. SET UP DAILY ROUTINES THAT MIRROR THE SCHOOL OFFER

In school we used Class Dojo a lot to provide videos of transitional songs, morning and afternoon routines and examples of regular daily sessions. Setting up the routines to be used at home allowed the parents to provide structure to the days and has also really supported the children to reintegrate back into school life.

2. PROVIDE INFORMATION ON HOW AND WHY SESSIONS ARE DONE IN SCHOOL

Once an adapted timetable was set, staff were able to provide brief information sheets explaining the how and why of specialist sessions. This then allowed the parents supporting the children to understand the session intentions and look for the responses linked to that. Parents now have a deeper understanding of how and why we teach as we do.

3. CONSIDER HOW OFTEN A TOPIC WILL CHANGE

In school we will continue a topic area for a half term on average allowing the consolidation of skills and for children to build on anticipation. For parents this was not

always the best time scale, so during lockdown we worked on 2/3 week cycles. Open dialogue, after time, allowed us to adjust our offer where necessary, for example where parents did not want to change so frequently.

4. SEND HOME PACKS OF RESOURCES LINKED TO SESSIONS BEING DELIVERED

This sounds so obvious, but some of the things that we have and use in school on a frequent basis were not readily available to all – e.g. scarves or sensory materials. We also had to take into account that not everyone was able to get the resources due either to shortages or access restrictions. This, of course, will be true of future packages being delivered to children who are ill or vulnerable.

5. FILM DEMO'S, USING CHILDREN WHERE POSSIBLE/ RELEVANT

Some teachers used their own children at home, and some used children who were still attending school to film activity demonstrations. Activities like massage stories work well like this as you can really show the pace and the key language in action. We will be taking this forward in future to deliver awareness sessions/training for families.

6. SET UP MICROSOFT TEAMS LINKS FOR SESSIONS

Once all of the materials had been delivered the teachers were able to provide small group Microsoft Teams links, allowing the children to see each other on screen and hear each other's noises as well as hearing the teacher. Again this has really helped with reintegration, but has also allowed some parents to meet each other and to see the other children when this would not have been possible.

7. SET HOME FRIENDLY IEPs

This was a really good way to support progress at home, while maintaining an area of assessment. The IEP targets linked directly to the EHC plan and were adapted and resources so that they could be delivered in the home by parents.

8. USE VIDEO CALLS WITH CHILDREN

Some of the most successful interactions were conducted using video calls, and some of the children were able to connect directly with each other using this method. Without the pandemic this would not have happened, but post pandemic some of the children are still keeping in touch this way! The children loved seeing and hearing their teacher and other classroom staff over the video calls that were made.

9. CONDUCT DOORSTEP OR GARDEN VISITS

The visits to the parents – socially distanced! - were a great way of showing support, delivering resources and

of giving less formal advice and guidance. These visits often led to conversations that would not have happened in a more formal phone call and were very much welcomed by families, as they reduced the sense of social isolation.

10. TRY ANYTHING!

Some of the most successful methods were initially those that we thought would not work. Our children are remarkably resilient and resourceful and have surprised us in many ways, and our parents are always keen to learn new ways to support and connect with their



children.

Cooking with mum using ingredients and recipes provided in the home learning packs.

In a Home Learning Survey in March 2021 parents made the following comments:

All the resources my child would have had in class have come home, with clear instructions

It was fun and informative learning how they learn and we have all enjoyed doing it.

The work packs sent home were amazing! There was always enough for us to do and a big variety. The teacher was always on hand to offer support with this.

Really useful to have a daily message/video from the teacher, it helped my son to manage his day.

During lockdown my son was always made to feel part of the class. The live lessons were amazing and as parents we were able to see the true friendships between our son and his friends. Thank you - you are all amazing!

Contact Details

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Notes

Class Dojo allows instant sharing of photos, videos, and announcements or privately messaging with parents. Find out more at: <https://www.classdojo.com/>

Microsoft Teams allows group chats and video conferences. Find out more at: <https://www.microsoft.com/en-gb/microsoft-teams/group-chat-software>

Delivering special school support during the pandemic

Ange Anderson

At the start of the coronavirus pandemic most children were home-schooled unless the family had members who were key workers. I had contact with special schools during this time and supported schools through Microsoft Teams and Zoom meetings. I also provided links to useful sites for parents (Anderson, 2020).

I remained in contact with many schools that I have worked alongside in the past, and I know that they fully supported their students during this time. This meant for some staff working in school with key workers' children and working online with the rest of the students. Music continued to play a big part in students' education. If you were to visit most special schools' websites during that time, you would have seen links to singing and signing videos, dancing to music videos and links to online yoga, therapeutic and technological music. Students could still benefit from meditation and mindfulness via online links established by the schools. Throughout my recent book, *Music, Sound and Vibration in Special Education*, I refer to these online links (Anderson, 2021). The added bonus is that now all those schools have these links for parents to access in the future when needed. There is always a silver lining.

What are the best ways for schools and parents to work together during this time of uncertainty to ensure that students need are being met?

The Assistant Director for Peterborough and Cambridgeshire is Toni Bailey. He is responsible for SEND and inclusion and he told me *"We have seen an impact on the ability for schools to deliver the whole of the EHC [education and healthcare] plan provision over the course of the pandemic, although in England there was a period of 'easements' on the duty to provide elements of the EHC plan allowing local authorities (LAs) to use their 'best endeavours' in order to meet the duties. It has been hugely challenging to ensure that children get access to all of the services they need. This has had a tremendous impact particularly on families, who have been managing our most complex children at home for many months."*

The easements to legislation came to an end in September 2020 and this has left LAs with the duty to provide the full EHC plan, including meeting any social care or health needs and providing therapies outlined. This has presented some significant challenges as the DfE guidance and the NHS England guidance have not always been aligned.

At Peterborough and Cambridgeshire, they have been successfully managing to work with colleagues in health to work with the differences in guidance and where it is deemed necessary to interact face to face (in person) in order to get the required outcome then therapy services are delivered in person, utilising the appropriate risk assessment and personal protective equipment (PPE). Toni says *"In the main this has been really successful and partnership working with parent forums has been key in managing the expectations of parents and young people. I think we have managed to find the right balance and we do have therapy services going into schools regularly, but it is reduced and our ability to provide remote options that can be effective has massively improved, with some young people and families' feedback outlining how they prefer the remote approach (especially with our ASC [autism spectrum conditions] community) This means we need to review our long-term approaches and learn for the positives from the last 6 months. There are still challenges ahead, but we have to embrace the possibility that a different mode of delivery may have to be the new standard if we are to do what we can to reduce the spread of COVID-19, which remains a priority."*

I believe that the most difficult part of the pandemic for students was not having access to individual hands-on therapies. I believe that parents and carers of students with PMLD and those students themselves possibly suffered more than most. This is because a special school has such amazing facilities these days and students can be free of their wheelchairs for a good part of the day and have appropriate therapeutic input from trained staff.

In the autumn of 2020 students returned to school unless they needed to self-isolate at home or required shielding. Remote education continued for these students. I have spoken to many headteachers during the pandemic and also during the first month of those students being able to return to school. All headteachers agree that this has been a very difficult period for parents and headteachers have tried their very best to support parents and students during this time. I am reliably informed that headteachers have worked twelve-hour days seven days

a week throughout the lockdown and continued to do so when schools reopened in order to be fully versed on every COVID-19 update as well as produce up to date risk assessments for every student so that PPE was personalised. (PPE can be basic from simple face coverings to including aprons and gloves to the full surgical kit when dealing with gastrostomy tubing for instance).

Headteachers have praised the dedication of their staff in meeting the needs of students both in school and those educated at home under school direction. As Chris Britten, headteacher of Ysgol Y Deri in Penarth (the largest special school in Great Britain and subject of a BBC documentary in September 2020 <https://www.bbc.co.uk/programmes/p08qj7yx>), told me, "School staff have to be looked after so that they are there to look after the children. One member of staff affected by the virus can impact on a lot of the students. As a school we offer both in person and remote learning. We have to keep our staff safe as well as keep our students safe." He likened it to the needle on a record player. If you take care of that needle, then all records play well.

I spoke to both Noel Fitzgerald, headteacher, and Julian Lewis, assistant headteacher, both of Ysgol Pen Coch. Noel told me *"We have physios and SALT [speech and language therapists] back in school but in a carefully managed way. They are both using the school hall at present as we are unable to use it for lunch or any other activities due to the restrictions."* Julian added *"Staff take students to the hall, rather than them dropping into class to collect them, as they did in the past. It's all about protecting the class bubble where possible."* He continued *"So we had to change home time procedures for minibuses, use of playground – only one class out at a time, lunches taken in class, no community trips."*

Noel has found Music the easiest subject to deliver throughout the crisis and now that staff and pupils are back in school music plays as important a part as ever in transition times. He went on to tell me *"We are using the other therapy rooms but are having to tightly timetable sessions for "bubbles" of pupils and have factored in cleaning time in between. Hydrotherapy has continued as it is a relatively safe activity given the amount of bug killing chemicals in the pool. Rebound therapy is one we haven't run up to now - the cleaning of the trampoline and safe use for staff/ pupils is one which I am hoping to come up with a solution for, so it can return after half term."*

Julian added that some therapies continue minus some resources. For instance, Soft Play continues without the ball pool as it would be too time consuming to clean the plastic balls after every session. He confirmed that

hydrotherapy was happening for students in the school but that all those students from other schools, who would benefit from being out of their wheelchairs and free in the pool, cannot attend due to the restrictions.

Julian told me that the hands-on therapies from external services obviously could not continue so they have been postponed for now. The same applies to some therapies delivered internally include Neurofeedback, some play therapy involving small toy parts, magic therapy, and auditory integration therapy. Noel is trying to encourage therapy sessions within the class delivered by the class team rather than peripatetic staff and has engaged on sharing good practice between experienced therapy-trained staff to support other staff to deliver this. This means they can access therapies while safely remaining in their class bubble with their class staff team.

Julian told me that some students have shown a dip in attainment or behaviour which the senior management team believe can be linked to time away from school but overall, they don't believe that there has been any negative behaviour that they can link directly to any anxiety arising to the lockdown. *"That's not to say there isn't but there is nothing that we can specifically associate it with."* Noel added that *"On the whole the children have been very happy to be back and have just got on with school. A couple of children and staff have tested negative following concerns about temperature, but we are following guidance regarding that to the letter."*

Donna Roberts, headteacher of Ysgol Hafod Lon in Penrhyndeudraeth, told me *"Being in school at this time is tough, staff shortages due to self-isolation and also just general illness is a huge struggle, but staff are anxious and at times overwhelmed by the responsibility and restrictions. We are continuing with all therapies except for hydrotherapy at the moment but staff wearing PPE and cleaning in between each session means less time for the pupils to receive the actual therapy"*

Andreas Huws, headteacher of Ysgol Y Bont on the island of Anglesey, has found it difficult to get the external therapy services such as the physiotherapy team and the speech and language team to visit the island school and a lot of partnership work has initially been done via Microsoft Teams and Skype, meetings though he is applying pressure to have this extended as *"I really want them on the shop floor assessing/interactive/advising."*

Jonathan Morgan, headteacher of Ysgol Gogarth in Llandudno, told me *"We have had to adapt and change some of our practice and the biggest change is that we cannot give as much therapeutic intervention to some pupils as we would like. This is mostly because of restrictions around "bubbles" and trying to minimise the*

spread of infection when we do have a positive case in the school (staff or pupil). At the same time, we have recognised that attending school without some essential therapies would be detrimental to some children's wellbeing and future progress. Currently we are continuing to do some hands-on physio despite health [services] not currently providing it. We are reopening the hydrotherapy pool to certain "bubbles". We are still allowing music and have a music therapist and art therapy student in school every week. School would be very boring without the important therapies for our most vulnerable learners."

Rhona O'Neil, headteacher of Ysgol Tir Morfa in Rhyl, has used the time to ensure staff therapy training during the lockdown and has continued to deliver music in all its forms via the internet as have all of the schools I have been able to speak to. It just goes to show that some therapies, particularly music, can still be delivered by a special school and enjoyed by its students even during a lockdown.

Contact details

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50 years of education in Special Schools

This year marks the fiftieth anniversary of a step change in the development of the education of children and young people with severe, profound and multiple learning difficulties. For a number of years establishments known initially as 'occupation centres' and later as 'junior training centres' had provided a form of basic education for some of these children. The 1944 Education Act made local education authorities (LEAs) responsible for the education of many 'handicapped' children but about 10 per cent of them were considered 'ineducable' and were provided for by the local health authorities. A rudimentary education was offered but for some children but many were either placed in institutions called 'hospitals' or remained in their own homes.

From 1st April 1971 the training centres became 'special schools' for pupils who were described as 'severely educationally subnormal' (ESN(S)). The Education (Handicapped Children Act) of 1970 had mandated the transfer for providing for their education to the local education authorities (LEAs) from the local health authorities.

Change did not occur overnight in the former training centres. But fifty years on, so much has changed. Now it is time to celebrate the role that special schools play and recognise the fantastic work that goes on in them. A good account is given in an online exhibition with films, interview recordings, and fascinating stories about the history and present of Birmingham's special schools. It has been developed as part of an oral history project run by CASBA, a charity that provides advocacy and support for adults with learning disabilities across South Birmingham. The project was supported by The National Lottery Heritage Fund. Go to: <http://educationisspecial.co.uk/>

The impact of the coronavirus pandemic on the education of children with profound and multiple learning disabilities

Carrie-Ann Sutton

From the public sector to the private sector, the entire nation has felt the impact of the coronavirus pandemic. What's extensively clear, however, is the significance it has had on the education of children with PMLD (profound and multiple learning disabilities). Recent research and explorations in my own professional practice, combined with my hope to pursue a career in teaching children with PMLD, the impact of coronavirus on education for the children with disabilities, has sparked a major interest in my current and future planning.

Coronavirus has disrupted every-day life around the world and will continue to affect those with and without pre-existing vulnerabilities. As the nation continues mass vaccination, we hopefully begin to see a glimpse of normality. Recently, I had an assignment to research (for a M.Ed. course that I am pursuing) and this provided an insight into the impact of coronavirus on the education for children with PMLD. Throughout my research and conducting questionnaires with teachers, teaching assistants (TAs), and several learning support staff, a number of key themes became apparent.

Challenges and changes

The COVID-19 pandemic has meant schools have had to face many challenges and disruptions to daily routine. For many schools, lack of staff due to illness or isolating and no longer being able to employ agency staff would cause major disruption and add extra pressure in the classroom. In my research, staff discussed an increase in anxiety from lack of support they have received. Many discussed changes to daily timetables and how they have had to be extremely flexible and make quick changes depending on number of staff and pupils.

Lessons were no longer structured or delivered as usual due to pupils mainly being in pastoral groups instead of ability groups. Children who normally receive specialist provision outside the classroom would be isolated and therefore miss out on hydrotherapy, physiotherapy, etc. Due to temperature checking and hygiene schedules there would be less time for activities and classwork. The transition process for new pupils has been hugely impacted - visits to school and home are not permitted. Changes to the classroom environment such as temperature/ventilation and ensuring classrooms were properly ventilated would cause issues for children with PMLD who struggle with being too cold. This has made it difficult to carry out certain tasks and activities.

There was also a lot of mention about the lack of resources due to the need for regular cleaning, and not being able to use anything like fabric as this may hold the virus for an extended time and can't be wiped down. These then impact the sessions such as sensory stories.

These challenges and changes link with what types of measures schools have had to implement to keep their children safe, such as staggered timetables entering and leaving school, use of full PPE (personal protective equipment), changes to the room layouts and the number of staff and pupils in a classroom. The need for proximity within encounters has also compromised quality interactions with pupils.

Risk factors

Due to many associated medical conditions children with PMLD are highly vulnerable to the COVID-19 virus (Mid Yorkshire Hospitals NHS Trust, n.d.). Throughout my research I wanted to gain an insight into risk factors. Each questionnaire response touched on a large variety of risk factors for the children with PMLD, the teachers and support staff, along with some responses mentioning the parents.

COVID-19 has prohibited the use of some therapeutic interventions which children with PMLD would usually receive in school. Staff had noted this as a contributing factor to development deprivation along with children's existing vulnerabilities. For the children with respiratory health problems, the pandemic has caused a lot of anxiety for parents and in some cases the children themselves.

Schooling and therapeutic interventions normally provide children with touch and socialisation; My questionnaire results have shown that COVID-19 has decreased education and increased shielding, subjected more pupils to hospitalisation, created delay in existing medical

appointments and operations thus creating an anxious atmosphere for both parents and staff.

With regards to social distancing, it's been difficult for many members of staff to distance themselves from pupils who require close observations, those who may require suctioning, monitoring feeds via gastrostomy, etc.

Findings of my questionnaire showed an importance to therapeutic interventions and how COVID-19 has impacted the support of wellbeing for staff, pupils and parents. While some continue to carry out therapies, the impact of this mentally on staff with a fear of transmission was and is still evident even with the use of PPE.

Online learning

The consensus of opinion throughout my research, was that children with disabilities benefit very little from online learning. Responses to my questionnaire shared that they all tried some form of online learning with their pupils and their families in an attempt to keep in contact on a regular basis throughout lockdowns and school closures and to still aim to provide a sense of routine. Many of the responses discussed that online learning proved problematic.

One reason for this was that families required some form of technology insight and, no matter how simple online learning was made, they experienced issues. Some discussed how difficult it was for parents/carers to know how much input they were supposed to have and found it hard to let their child have some independence. The respondents also stated how difficult it was for pupils with PMLD to join in with the class zoom lessons as they would normally have separate 1-to-1 interventions, especially those who need close physical contact. Zoom also poses a problem as many pupils with PMLD have visual or sensory impairments and therefore find it difficult to engage with 2D images. It was also mentioned how pupils have found it hard and struggle to understand why things that are supposed to happen at school are now happening at home.

For a small proportion of pupils and their families online learning was recorded to have worked well, especially for those who had access to technology and the skills to use it. For some, online learning was recorded as difficult and time consuming. It was mentioned that "Time out of an education setting is detrimental to cognitive and academic development, particularly for disadvantaged children and young people. This impact can affect both current levels of education and children and young people's future ability to learn" (Interview).

Social inclusion and interaction

Schools and classes are now limited to those within their "bubble" making it difficult for specialist sessions to take place. Limited interaction with peers has impacted on everyday routine. School assemblies have had to be delivered via teams and/or zoom and therefore the physical contact that children with PMLD are used to having has been taken away. This meaning sights/sounds and smells they experience have disappeared. The lack of this form of interaction can have a negative impact on a pupil's well-being and development.

Other forms of interaction come from respite care, which currently has been put on hold due to the pandemic. The benefits of respite care for families includes reduction in carer stress, new experiences for disabled children, and carers having time with their other children. Throughout the pandemic respite care has not been available for many. These services are integral service for both carers and the people they care for. Families of children with PMLD face considerable additional stress and heightened emotion by the increase in their caring role.

Therapies and interactive programs

Specialist SEN therapies and interactive programs such as Intensive Interaction, Sherborne Developmental Movement, Story Massage, Tac Pac, etc. are normally used across schools for children with PMLD and other disabilities. Many responses from the questionnaire touched on how difficult it has proven to deliver these sessions whilst wearing full PPE and trying to maintain a safe distance.

1:1 work has been put on hold for many pupils due to lack of space and no travelling around schools. These therapies have been impacted in that they are "no longer delivered in discrete groups with similar ability students" and they can no longer be delivered in a relaxed manner as staff feel anxious with being in close proximity.

Not being able to move around the school to certain rooms has put a stop to some of these therapies. With the relevant resources, some staff have adapted and come up with alternatives but with the hygiene schedules, hand washing and full PPE these have proved to be extremely time-consuming.

Children who have access to regular therapies as part of their development are now unable to access them. There have been offers to carry some therapeutic interventions online but, although these are an option, this process cannot be fully adapted to meet all the children's needs.

Conclusion

This research assignment was used by me to determine if the coronavirus pandemic has had an impact on the education for children with PMLD. My

research, both primary and secondary, shows that COVID-19 has impacted the education system, particularly for children with PMLD. Children with PMLD constitute a group that is particularly vulnerable to the constant changes that have accompanied the COVID-19 pandemic. Routine changes, hygiene schedules, lack of staff and resources are just a small amount of issues schools have had to deal with and adapt. However, many of the responses to my questionnaire also shared their concern for pupils with PMLD returning to school settings. Whilst many of the responses noted how COVID-19 has disrupted and impacted their education, many also shared their concern about the safety implications of their pupils returning to school. Due to COVID-19 changing and mutating many of the topics discussed in this assignment may be reassessed daily by school leaders.

Throughout the pandemic children with PMLD have experienced social exclusion and the lack of contact with other children and adults. Throughout the pandemic 1:1 provision has not been available to all those who require it and therapies and interactive programs have been affected. Measures put in place such as social distancing and PPE have created difficulties in completing tasks. Lack of technology and internet access have also played their part in impacting the education. Through this assignment and researching the impact of the coronavirus pandemic on the education for children with PMLD, there was a variety of other findings that go beyond the school education.

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Musically motivated: a case study in engagement

Delyth Williams

Music: the great motivator, especially for our learners with PMLD. As an experienced teacher of learners with PMLD I have seen the positive impact that sound and music can have for our special young people so decided to base a school project around this.

Unfortunately, the pandemic meant that a lot of our learners weren't able to attend school. We tried to reach out to them via Zoom and even a few home visits (on occasion accompanied by our very talented deputy headteacher) but it was evident that nothing beats the joy of live music.

As life began to return to normal the staff of our school's 'PMLD department' began to renew their enthusiasm for the Sounds of Intent Framework. If you aren't familiar with it, make the website your first port of call. Because my school took part in their initial accreditation project (which sadly ran out of funding) we had been introduced to the sub-steps they created for accreditation

(Emerging, Achieving and Excelling). This gave us a good idea of how we wanted it to look and it was up and running as an assessment framework pretty quickly. However, at the first departmental moderation/pupil progress meeting, some of the teaching staff raised concerns that the data was not reflecting the progress their pupils were making.

In Lucy Osborne’s study, ‘An Exploration of Music Therapy Practice with Children with Visual Impairment and Profound and Multiple Learning Disabilities’, she proposed a 3-stage model for working with pupils with PMLD (Osborne, 2019). Her study collected data from three music therapists who were working in schools with pupils who had multiple disabilities including visual impairment. The data highlighted that music should be and was used to work on three main areas: “facilitating engagement, musical approach, working towards a sense of self” (p.4). Each stage must be achieved before proceeding to the next.

It was clear at this point that we needed consider musicality and engagement simultaneously, using the ‘engagement model’ for assessment (DfE, 2020), in order to drive forward pupil outcomes in both of these areas. (The engagement model for assessment is due to become statutory for schools from September 2021 as an assessment tool for pupils working below the standard of national curriculum tests).



Riley: a case study

Riley has quadriplegic cerebral palsy, high muscle tone and epilepsy. He finds it difficult to relax his limbs and have control over his body. Having taught Riley myself in the past, I know first-hand that he loves music but what he truly adores is interaction with people. His current teacher has used this knowledge of him as an individual to build on his existing musical skills, or, as we might call it in the world of Engagement, develop his Realisation.

Previously he has shown some interest in a range of instruments, but mainly maracas seem to ‘float his boat’ as it were. His class team engaged him in familiar songs and sounds patterns and reciprocal games (e.g. I shake, you shake). Using Sounds of Intent as a framework for assessment and learning, staff supported him to move through a sub-step of the Sounds of Intent Framework from Emerging to Achieving, but we noticed something more. It wasn’t just his realisation that improved but his anticipation and persistence also developed. And as his skill-set increased and he was able to engage in interactive play via the maracas, he began to initiate therefore his engagement scores continued to rise.

As this happened his teacher noticed he was more willing to engage in other activities so his well-being increased. He has developed his gross motor function and is more easily able to control his movements. Riley’s teacher hopes that now he has learnt the gross motor control to shake a maraca that he will be able to pick up and control his use of other objects, which so far has been a tricky skill for him. He has extended his ability to have meaningful interactions with adults through sound and music. In short, his world has opened up.

Conclusions

On discussion with the staff of the PMLD department, everyone agreed that music was a significant part of all of our pupils’ lives in one way or another. They said that using Sounds of Intent as a framework helped them

to have a uniform assessment tool that allowed them to further develop pupils learning with clear next steps. It provided clear direction for the teaching and learning that was occurring. They believed that this gave support staff a solid structure when they were asked to complete 1:1 sessions with pupils. It helped staff to find new ways to develop sound work and cater to different tastes and interests.

They felt that using the 'engagement model' in conjunction with the 'Sounds of Intent' framework was inevitable as sound is such a big part of how PMLD pupils engage with the world around them. They felt that engagement added another level of assessment and direction when pupils had "plateau" periods. They found that, because music is such a good motivator, pupils were more engaged in school life as a whole. It helped pupils to build lasting connections with the world around them and develop their abilities in a multitude of areas, including movement, co-ordination, cognition and communication.

Last but by no means least, our pupils are happy, and isn't that what it's really all about?

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My experience of engaging pupils and families during the COVID-19 Pandemic

Beccy Johnson

This year has brought with it a huge range of new challenges, unprecedented teaching and learning experiences and the anxiety and uncertainty. In this article I will be discussing my personal experience of how I tried to maintain engagement with my pupils, many who have profound and multiple learning difficulties (PMLD).

Our pupils with PMLD respond best to those who know them well, who can interpret their communication and behaviour and who learn best through hands on, practical, multi-sensory experiences. When the pandemic started many of our most vulnerable pupils were learning from home in a new and “virtual” world. We were left with many questions which needed quite rapid answers! How would we meet their needs via a computer screen? How would we ensure parents felt supported by the school and remained part of our school community even from a distance? How would we meet the physical and emotional needs of pupils who we are used to working so closely with?

During the first lockdown most of our pupils were learning from home. Some pupils were in school on a reduced timetable and as time went on some pupils were visited by teachers or teaching assistants in their gardens or near their homes. Parental concerns over the new and rapidly spreading illness was further magnified by the fact that many of their children had additional medical risk factors such as weakened immune systems, asthma or other breathing difficulties.

Whilst managing our own fears and anxieties around COVID-19 as senior leaders, teachers and teaching assistants we were immediately thinking of ways we could continue to support our pupils and their families whilst they were shielding and whilst school, for the majority, was closed.

Teachers worked closely with families to identify what sort of support we could offer, how we could best support their son/daughter and how they would like to be contacted. For some parents it would be difficult to take phone calls due to the needs of their children. Many of our families had more than one child at home, some balancing main stream home learning, some supporting two or more pupils with additional needs. We were acutely aware that our support would be important but also unique to each family. This meant we would need to carefully manage our time and ensure we could meet all the needs of our classes to the best of our ability.

We started with the support of some excellent teaching assistants who started to make weekly home learning packs. These consisted of a range of materials for sensory play activities, art and craft activities, motivating items like bubbles as well as some printed resources. For some pupils we were able to lend sensory items such as noisy toys or cause and effect toys. We knew which items would be most motivating to our pupils and could collect items and send home new items to keep pupils engaged. We were also lucky enough to receive some grants and were therefore able to order some specific items for those who needed it. For example, a highly motivating dancing robot toy! For some pupils it was borrowing equipment such as specialist trikes, standing frames or seating for long sitting which was the most important for their physical well-being and health.

At the start we had no idea how long lockdowns would last so teachers created supporting documents to go on the school website; for example, different activities parents could do at home with their children, websites to support learning, sensory ideas and physical activities. Over the following weeks we started to share adults reading stories, singing songs, drawing tutorials and all sorts of other exciting pre-recorded resources. There were class specific activities, subject specific areas and parents could access all of the content whenever was best for them.

Our IT (Information Technology) leader was one of the busiest and most-in-demand colleagues. He worked tirelessly uploading resources, formatting, editing, being on hand for a million and one questions from teachers. We thought we knew about computers! His hard work made sure pupils had the best resource that they could – access to our faces, our voices, songs and stories from key adults in their lives who suddenly they weren’t able to see. As I mentioned initially, everything we do is based on relationships and in the absence of face-to-face connection this was the most powerful means to support our pupils. Pupils who were suddenly not attending school knew we hadn’t disappeared, we were still there, just in a different way. The amazing number of resources on the home learning section of our school website is

testament to how much we all wanted to sustain our bonds with our school community.

Throughout the time we were in lockdown I developed my own IT skills and was able to respond to the needs of my pupils in a more specific way. I gradually overcame my initial self-consciousness about being filmed. What helped me was the thought of my pupils watching me and this helped me to gain confidence and enthusiasm on screen. I filmed "Bucket" sessions, stories and some examples of sessions we did at school. The example "lessons" could be replicated by parents at home. I had to ensure that they had access to the resources they would need so tried to keep the activities simple and used items from around the home. One example was a listening game – they could use a visual aid I sent home to identify sounds they heard on screen. Another was an activity based around fine motor control and object permanence, opening a range of containers to find items.

On my weekly emails/telephone calls to home I would ask which activities had been engaging and I was able to adapt and develop what I was offering based on feedback. One pupil particularly enjoyed our more sensory science style activities – here I learnt how to edit using Movie Maker, add music and add text to give instructions to parents for activities such as "Cloud in a Jar" and "Make your own Lava Lamp". The resources could be revisited as many times as parents and pupils wanted as repetition is so important to our learners.

After some time listening to other teachers with different cohorts talking about live Zoom calls, I started to think of ways I could interact with my learners via Zoom. Initially I didn't think this would work and was slightly sceptical. Up until this point my pupils could see me but we weren't interacting. I mentioned the idea of a "Sing and Sign" session live on Zoom and the response was good. The first session was a real moment, I may have shed a tear afterwards. I had discussed the format prior to the session and sent home song lyrics to the parents. We used simple, very familiar songs and I had props and music ready. I managed to have support from one or more of my wonderful teaching assistants for most sessions. Managing technology, props, singing and signing was tricky but it was so lovely to see the response of the pupils (and their parents!). We did have pupils with a visual and/or hearing impairment but they were able to access the sessions. I added a preferencing element by holding props and asking pupils to indicate which song they would like next. Again, repetition was important so I repeated songs each session and noted which were most successful.

As lockdowns continued, we started to arrange some visits to pupils. For some parents it was their support with taking pupils out for a walk. For others it was

support with using the different supportive equipment; for example, standing frames. Some just wanted short visits whilst dropping off resources so their child could keep some contact with adults from school. There were some families who chose to have no direct contact. Our school created detailed timetables to make these arrangements, adapting and revisiting depending on family needs and the weather!

Looking back, and whilst writing this article, I have been able to recognise what we all did to unite as a school in order to best support our pupils, all the while balancing our own home lives, our own children's home learning or time in school, our worries, our confusion. I feel like what we achieved was spectacular and I know many parents would agree. However good the provision was, nothing replaces in school day to day contact and I am very glad that we are all back together. I have also reflected that if we have to support pupils at home for a range of reasons we can use the skills we have learnt to best support them. We have learnt what works, we can adapt when we need to and this experience has given us confidence of what we are capable of.

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How can we create a meaningful curriculum for adult learners with profound and multiple learning difficulties?

Rachel Gale

As a further education (FE) tutor, I spend a lot of time thinking and talking about the curriculum for learners with PMLD. I have found plenty of enjoyable activities that are of benefit to our students, but it can be challenging to show progress within these activities. This can present problems when designing a curriculum, as learners beyond the age of nineteen need to show progress in order to secure funding for the next academic year.

For me the word curriculum refers to the academic part of the day, and the learning that is on offer. However, due to the complex needs of many learners with PMLD, they may need time in the day allocated to personal care, sensory diets, postural management, or varying health needs. It is therefore imperative that any time left in the day for the curriculum has as much meaning as is possible for these learners, and offers as many opportunities for real and meaningful learning to take place as is possible.

The role of FE providers is to offer engaging activities and experiences that allow learners to become as independent as possible, and to be ready for their next step (Allen et al., 2015). The next step varies completely depending on the individual, and colleges are lucky because we have more control over designing our curriculum. It enables us to really dig down and consider the individual learner, and the knowledge and skills that are most important for them to develop in their very limited time with us.

The learning priorities for people with PMLD are not completely different to skills that are important for everyone (Nind, 2007). We wish for them to be as independent as they can, for them to be able to communicate their wishes and have their voice heard, and for them to feel happy and valued as an individual as part of a community of their peers. Therefore, we believe that our PMLD curriculum should focus on three areas:

- Developing communication skills
- Developing independence skills
- Developing self-awareness

Given our limited time in the day with pure curriculum focus, we focus on developing knowledge and skills within these areas only, while still providing a broad range of activities, which we consider to be the “themes” of lessons. For example, a weekly timetable may still include subjects such as English, mathematics, science, history, drama etc., but the targets or learning objectives of the lesson will focus on developing one of these three key skills, as well as maintaining positive emotional wellbeing.

Completing a baseline assessment of learners is imperative to be able to individualise their curriculum (Allen et al., 2015; Farrell, 2012). This baseline should show the learner’s prior knowledge, any potential barriers to learning, their learning styles and motivating activities (Fergusson and Byers, 2015), and should be built up taking in information from as many people who know the person as possible. This baseline should be flexible and subject to change as the practitioner and learner build their relationship and become more familiar with each other.

For learning to be meaningful, it is important that sessions are carefully planned, as not only is this the best way to ensure that all of the developmental needs are met, but it also ensures that the students have access to a wide variety of experiences (Farrell, 2012; Peter, 2015). The learner should be placed at the centre of every activity, as person-centered planning creates a clear focus for both teacher and learner, and takes into account their starting points, and probable destination (Allen et al., 2015).

When planning, practitioners should bear in mind that, if a topic has no meaning for the individual, then the experience, however ‘sensory’, is unlikely to convey what is needed (Farrell, 2012). Therefore when designing learning experiences, Peter (2015) says that the justification of use, needs to depend on whether it makes a difference. So, given our potentially limited curriculum time in the day, how should we prioritise student experiences so that they are not only having fun, but also having meaningful opportunities to progress?

First of all, keep it simple. If equipment is complicated or takes a long time to set up, not only will the students find it challenging to stay focused, but staff may lose interest and decide not to use it (Lacey et al., 2015). Don’t be afraid to use repetition. Learners with PMLD need a lot of experience of their action having a consequence before they realise the association (Goldbart and Ware, 2015). For every activity, take the time to consider individual targets in relation to skills they need for their next step, or for positive emotional wellbeing. Ensure that support staff know why each student is taking part in each activity, and what their individual focus is. Consider whether the activity genuinely provides opportunities for development, and how you can individualise it for each learner so that the activity is meaningful. Have high, but realistic expectations. For some learners, progress may be working with a wider variety of support staff, or showing an increased level of engagement. Finally, encourage independence wherever possible. Good learning should enhance someone’s self-worth, so ensure that there are opportunities for learners to feel empowered, and to take ownership of their own learning (Nind, 2007; Staves, 2019).

In addition to significant learning challenges, many learners with PMLD may have a range of other difficulties, such as one or more sensory impairments, physical disabilities or complex medical needs. These learners are likely to need to concentrate harder to obtain information, and so are more likely to become fatigued (Hodges and McLinden, 2015). Teachers need to monitor what we expect of learners throughout the day, and whether the planned activity will still be meaningful at this point for the individual. Remember, however carefully you prepare, things do not always go according to plan, so it is important to stay flexible and not be afraid to change direction.

Learners with PMLD are likely to take longer to process information, and so Goodwin, Miller and Edwards (2015) advise giving them plenty of time, and ensuring that they are not overwhelmed by information.

There are a variety of experiences that are commonly found in the PMLD classroom, but they are not always used to their full potential. For example, as well as being a nice experience, sensory stories can be used to develop communication skills (Grace, 2014), develop exploration skills, promote positive self-awareness, encourage learners to be mindful of the space they are in, and of other people in the room. They are at their most meaningful when carefully planned and tailored to the individual’s targets.

The equipment in a sensory room may encourage responses from the learner, and/or help individuals to relax or overcome distress, but it is important that users

think critically about how to use this resource meaningfully (Farrell, 2012). Sometimes the environment can be overwhelming or overstimulating. As staff it is easy to become distracted by the equipment, and miss learning opportunities or forget what the purpose of the visit was in the first place. It may be that an individual might benefit more from some one-to-one time with a helper in the classroom participating in intensive interaction, or a hand massage. It should always come back to what that individual needs, and whether the activity has a genuine purpose for them.

Drama can be a great way to build group awareness and to begin to learn about facial expressions and body language, and it is often straightforward to incorporate it in the interests of the learners, and is therefore a motivating activity.

When offering opportunities within the classroom, it is important to consider input from a wide variety of people, as this builds up a big picture of the individual. However, be wary of the broad advice that a learner 'does not like an activity'. We should not stop offering activities if they are declined the first time, as it might not have been that activity that elicited the negative response, or the person might change their mind or only like it sometimes. The important thing to consider is, if we believe a learner is struggling to tolerate an experience, how important is it that we ask them to experience it (Grace, 2014)?

Essentially, learners with PMLD can take part in any activity that they enjoy, or are interested in. The key to creating a meaningful curriculum is not in what the activity is, but in considering why we are offering the activity, and what opportunities are within it for learners to develop key skills important for their future.

Contact Details

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Active Learning for pupils with PMLD

Leanne Tonks

A teacher at a school in South East Northumberland for children and young people with profound and multiple learning disabilities (PMLD) is helping pupils to take miraculous steps towards a better, more independent way of living by getting creative with items typically found around the house.

Gillian Robinson, a primary teacher at Castle School, has introduced the concept of 'Active Learning' into her classroom to help give a sense of freedom back to pupils who are typically dependent on those around them to support their needs.

Devised by Danish psychologist, Dr Lilli Nielsen, as a solution for teaching children with visual impairments, Active Learning has adapted over the years and is now recognised as beneficial to children and young people with a wide range of severe and multiple disabilities (see Note below).

Gillian first came across the approach during lockdown while researching ways to better manage the complex range of needs within her classroom to ensure that while individuals' medical, hygiene and feeding needs were attended to, that the rest of her class remained stimulated.

Using everyday items such as buckets, A-frames, Tupperware boxes, blackout curtains and plumber's piping, Gillian has created a sensory paradise for her learners to support their mobility and cognitive skill development, alongside their emotional and social wellbeing.

"Many children with profound and complex needs develop 'learnt helplessness' – the idea that they have no control over their environment, so they learn to wait patiently and that eventually, someone will provide them with what they need. Over time, this kind of behaviour can lead to passiveness where children stop communicating altogether," Gillian commented.

"Active Learning is designed to encourage the children to do things for themselves, it teaches children how to interact with their environment and explore their immediate space with confidence and shows them how their actions can affect the things around them."



While specialist equipment to support Active Learning is available, many of the manufacturers are based in the United States, which makes sourcing equipment tricky and expensive – luckily, Gillian is quite creative.

“Lilli Nielsen recognised that children with sensory and physical impairments needed to be taught to explore the space around them using all of their body,” said Gillian.

“A few of the children in my class have very limited movement and rely on specialist positional equipment like wheelchairs or work chairs, which can make accessing sand and water trays, foot spas and play spaces very difficult.

“By combing the internet, I was able to find designs for DIY versions of almost all of the resources I needed to bring Active Learning to life in the classroom in a way which would meet the very specific needs of my pupils.

“I made my own waterfall curtain out of plumbers piping and a window blind cord with small bells added onto the end; our echo bucket is simply a metal bucket with holes cut into it attached to a rope pulley system so I can lower it over children sitting in wheelchairs. Our A-frames and wall-mounted sensory boards are made from materials found at B&Q and the voice activated light box is just a large Tupperware container lined with some reflective foil and fitted with a disco light that reacts to bass sounds



- which has made a huge difference to our non-verbal children, showing them that using their voice has a purpose and will be listened to.

“After some searching, I was even able to find a design to make accessible foot exploration trays from decking boards which the children can use while in their work chairs to help them develop awareness and purposeful movement of their feet.”

Sara Wild, Principal at Castle School, commented:

“We’ve been amazed by the improvements shown by some of the children in Gillian’s class since the introduction of Active Learning into their daily lessons.

“One child, who was quite disengaged and spent a lot of his floor time curled up and actively turning away from interactions and resources now reaches out to explore things around him in lots of different environments and his engagement in his exploration is really focused. He also has much better use of his voice to attract attention. Another, who uses a walking frame to aid his mobility, has made remarkable improvements, going from being unmotivated to move around and reluctant to take steps to now showing huge resilience and persistence when moving around large spaces to reach the toys and resources he wants to engage with.

“The success of the Active Learning initiative in Gillian’s class has seen us make time in our curriculum for Active Learning across Castle School, with Gillian taking the lead on training our teachers and support staff. We’re incredibly proud of what Gillian has achieved and can’t wait to see more of our children benefit from the programme.”

Note

More information about the work and philosophy of Dr Nielsen can be found online, e.g. at: <https://www.lilliworks.org/> ; <https://activelearningspace.org/>

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Castle School in Ashington is a specialist provision for children and young people with severe or profound and multiple learning disabilities. It operates as part of Northumberland Church of England Academy Trust. For more information, visit <https://castle.ncea.org.uk/>

YAMSEN Multi-sensory days: 'A Tree for all Seasons'

Joanna Winster

YAMSEN, the Yorkshire Association for Music and Special Educational Needs, is a charity dedicated to providing and supporting a range of quality musical activities for people with additional needs and those who work with them. YAMSEN members comprise teachers, volunteers, artists, musicians, non-musicians and participants with and without additional needs, all interested in creating inclusive opportunities around music.

YAMSEN's multi-sensory days are an explosion of colour and live music, with props to feel and share and instruments to play. The days, set in Leeds, bring together around 40 pupils with PMLD from schools around Yorkshire to a large hall for a shared experience during school hours. Pupils dress up, wave hello, dance with each other and share immersive experiences in a safe and stimulating environment.

These away days are based on a theme - it could be a famous story like Hansel and Gretel, around the world for the Olympics, or a learning topic such as space. The slow pace and tactile style of the activities are specially suited to pupils with PMLD. The project is run again later in the week with a set of slightly different activities and art projects for pupils with severe learning difficulties and those on the autistic spectrum. The activities can be repeated back at school, extending the learning and training staff.

With the pandemic, we at YAMSEN had to work out how to bring the feel of the multi-sensory days to pupils in their own classrooms. Pupils had spent a significant amount of time at home, with few places to go except outside to the park. Drawing inspiration from nature, we decided to theme it around a year in the life of a special tree, and the animals that live around it. We called it 'A Tree for All Seasons.'

We set about making videos featuring the music of our house folk duo Kate Badcock and Roddy Johnston. It was important to us to limit instruments, props and art supplies to resources that schools were likely to have. Through the magic of blue screen technology, our musicians in Scotland were able to combine videos of themselves playing with the leaders from Leeds, Diane Paterson and Joanna Winster, who modelled the activities. The theme was held together by a set of brilliant tree pictures and cape costumes created by local artist Kate Rossiter, interspersed with beautiful backgrounds full of butterflies and deer leaping in the snow.

The result is an online resource: two 40-minute videos taking viewers on a journey around the year with a



special tree and its residents, supplemented with a catalogue of art ideas. You can crunch through the snow in the winter, peck along with a woodpecker in spring, dance with the butterflies in summer and help the squirrel store its acorns in autumn. There are many more activities too! Each activity features clear visuals, simple movement or music-making, and enough time to react to the activity and repeat it. Though aimed at pupils with PMLD, we have found the activities also work well as calming activities in other SEND settings, and could be equally appropriate for adults with PMLD and other learning difficulties.

The online resource 'A Tree for All Seasons' is available from YAMSEN for £20, or £10 for YAMSEN members. Please contact YAMSEN Secretary Diane Paterson at diane.paterson@leeds.gov.uk for more information.

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Unlocked Art: using art to tell the lockdown story of people with learning disabilities

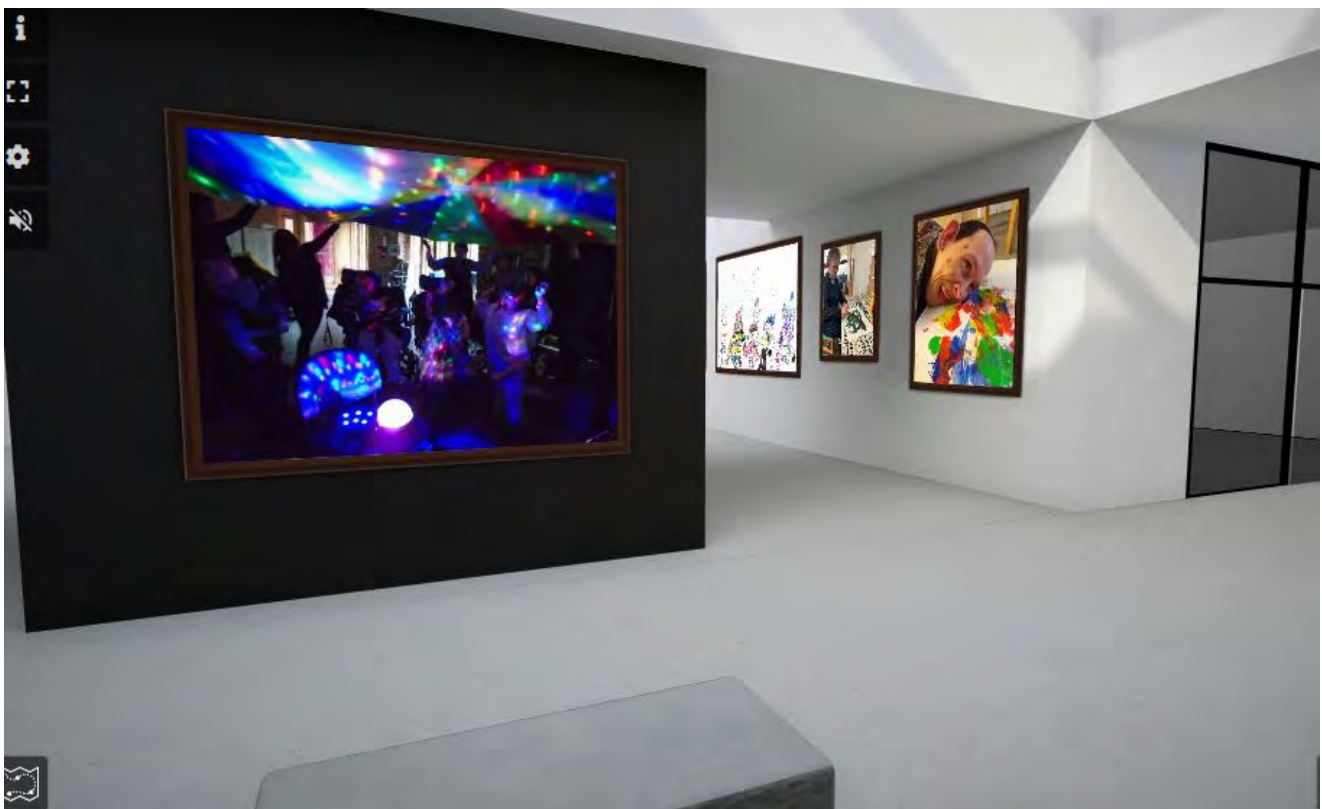
Peter Blaker

My business, supporting people with PMLD, stalled in the first lockdown when I could no longer visit clients. I was lucky enough to be able to find alternative work as a carer, but I did keep in touch with clients and their families and gradually the scale of the impact of Covid-19 and lockdowns on people with learning disabilities began to make itself horrifically clear.

The medical consequence of infection for people with learning disabilities far exceeded those for other groups, and the removal of those activities and outings that give the weeks shape and provide stimulation and something to look forward to had a devastating effect on wellbeing. The inability of parents and families to visit people in care settings was heart breaking for all concerned. Homes did their best and set up video links for 'face time', but they were a poorer substitute for people with PMLD who need to touch and smell their families to know they are near. I heard heart-breaking stories from parents who were unable to visit for significant birthdays, parents whose separation from their loved one was already an ongoing bereavement. Vulnerable people with learning disabilities had more reason than most to shield, and so gradually, they became invisible, and the public forgot about them.

Working with Becky Shaw, a creative therapist from Wistaway (<https://www.facebook.com/wistaway>), I set up a project for Taunton Mencap to highlight this group, and to show how art is helping them to express themselves and give them a voice throughout lockdown. Funding for the project came from Somerset Community Foundation.

That was how Unlocked Art was born. We reached out to local residential homes, schools and day care settings, as well as individuals associated with Mencap with leaflets, and ran a series of tutorials on art techniques and ideas on social media. When we came to gather work from participants, we had submissions from twenty-five different sources.



We were so pleased that people with PMLD were well represented; often their contributions to projects like this are notable for being missed out altogether! We wanted the project to reflect the character of lockdown, and so Becky and I never met in person, and the artists who took part sent in work electronically. It made sense to create a virtual gallery in the same spirit. Not being a 'techie', that was the bit that scared me! However, the work that came in was beyond stunning, there were individual pieces, ensemble works, portraits of artists, 2D and 3D works, annotated accounts- the whole story was right there! We had not needed to tell it on behalf of the artists, they did it for themselves.

Creating the virtual gallery to show this work became an act of humility, because, while I had thought what we were doing was giving people with learning disabilities voices, what was actually happening was that we were giving the rest of us ears to listen and eyes to see. The artists already had perfectly good voices.

So I built the gallery- here it is, you can use your arrow keys to wander around just as you would in a 'real' gallery (you will need a pc to run it, it is large!):
<https://www.artsteps.com/view/60817139d6efe0c44833ba6e>

Please do pop in!

The online gallery

I also have twenty-five large canvases made from original artworks, and a dozen information panels, ready to hang in 'real life' exhibitions as soon as it is safe to do so.

We set out to help people with learning disabilities tell their story to the wider public, but ended up learning so much ourselves!

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Connect with us on social media



Remember to tag us on social media ~ @PMLDlink

Twitter: @PMLDlink

Facebook: PMLD Link

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

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

British Journal of Learning Disabilities and PMLD Link work in partnership

Melanie Nind

When I took over as editor-in-chief of British Journal of Learning Disabilities in March 2020 I wanted to put respectful dialogue with people with learning disabilities at its heart. One of the signature features of the journal over the years has been its involvement of people with learning disabilities as authors and reviewers and, in 2012, this extended to editors as people with learning disabilities who were experienced in research guest edited a special issue (volume 40, issue 2). In 2020, I built on these foundations by introducing 'In Response' articles whereby people with learning disabilities get to talk back to the researchers who do their research on (or with) people with learning disabilities, asking questions and discussing the relevance for their lives (see Lewis et al., 2020; Williams et al., 2021; Blackley et al., 2021). Everyone involved has found the process educative and worthwhile.

What does this have to do with people with profound and multiple learning disabilities I hear you ask! This is the rub. Initiatives to include people with learning disabilities often, and not always for bad reasons, do not or cannot include people with PMLD, so what do we do about it? This leads me to the 2021 initiative for British Journal of Learning Disabilities to partner up with PMLD Link. PMLD Link is where families and practitioners who are allies of and advocates for people with PMLD come to share information, news, ideas, practical support and yes, research. I am keen that the British Journal of Learning Disabilities commitment to dialogue extends to readers of PMLD Link as a means to ensure that: (i) people with PMLD are represented in our thoughts, actions and plans, and (ii) that summaries of research published in British Journal of Learning Disabilities makes its way to you.

At British Journal of Learning Disabilities we are fortunate to have Ben Simmons (Bath Spa University), Juliet Golbart (University of Manchester), and Simo Vehmas (Stockholm University) on the editorial board to share their expertise and to champion the inclusion of the representation of people with PMLD and those who support them in what we do. We hope that by sharing summaries of the research we publish, whether it is about people with PMLD or about issues that concern them, we will stimulate more research in their interests, and crucially, more dialogue between us all! I am grateful to Simon Jarrett on the editorial board for instigating a similar partnership between the British Journal of Learning Disabilities and Community Living Magazine. It was Simon's proposal to work in partnership to enable Community Living to cover a greater variety of research findings of interest to readers - together with Rob Ashdown's invitation to write a research piece - that led me to think of this plan as a 'win-win'.

So what does British Journal of Learning Disabilities have to offer? In a regular feature in PMLD Link I will share summaries of new research, but there is also scope I think for some looking back at key papers or critical debates. In this focus on starting this dialogue between the two publications and between research and practice, I am going to summarise two papers from two decades ago on listening to people with PMLD. I have chosen them because they highlight how research in the PMLD arena often make use of a case study to explore a critical issue, and because they raise issues that remain pertinent and that might spark fresh dialogue given recent developments and the current context.

Back in 2001, Jill Porter, Carol Ouvry, Maggie Morgan and Caroline Downs wrote a paper on 'Interpreting the communication of people with profound and multiple learning difficulties'. Given the risk of misinterpreting when inferring what people might be communicating, they argued that this is a big responsibility and that interpretations need to be verified or validated across the people most involved in their life. The context for the paper was concerns that the desire for the person with PMLD to have a view on things pushed people into making (the wrong) assumptions. They proposed that the key questions to ask ourselves are: 'Is this communication?' 'Is this intentional communication?' and 'How do we know?' (p.13) and they stressed the importance of sharing information in answering these questions. The authors share a case study to illustrate the 'need to distinguish between what the individual brings to the communication process and what others bring' (p.16) as part of understanding how each influences the other. Their emphasis is on ensuring that this enables communication and fair interpretation, rather than closing interpretation down.

Relatedly, in 2004, Jean Ware contributed a paper on 'Ascertaining the views of people with profound and multiple learning disabilities'. Here the context shifts a bit from the daily lives of people with PMLD with their families and carers, to the wider drive to take into account the views of people with learning disabilities and the efforts to identify and develop innovative methods to do this. However, Ware noted, 'none of this work has involved people with profound and multiple learning disabilities' (p.175). The paper tackles some sensitive territory in asking how much and when we need to hear from the people around the person with PMLD, when wide-ranging assessment is needed, and when we need to interpret behaviour/communication. Ware grapples with whether people with PMLD can make their views known directly, arguing that a view is 'not the same as a choice or a preference' (p.176). Like Porter et al., she uses a case study to explore difficult conceptual and practical territory and the complexities of how the person with PMLD can be involved in telling us what is in their best interests.

I wonder if, in 2021, readers of PMLD Link think differently about these matters. If you were invited to discuss the research and write an 'In Response' paper, what questions would you be asking these authors?

To sum up, my main desire is that dialogue and research in support of people with PMLD flourish. Long live our partnership!

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In the Next Issue Winter 2021 100th Issue of the journal

The Winter 2021 issue of the journal is special. PMLD Link will be celebrating our 100th issue of the journal. When PMLD Link started out in 1988 it produced a very basic, hand-typed newsletter – a simple bulletin, created to share relevant information and help isolated professionals feel connected. Our early publications had their roots in education and ‘subscribers’ worked mostly within specialist school settings - day schools, residential schools and ‘school units’ within long-stay hospitals. Some learners at this time lived on the wards of these institutions.

People with profound and multiple learning disabilities were largely invisible and too often experienced exclusion – even within dedicated, specialist settings. In 1988, a right to education was still relatively new. Prior to 1971 ‘mentally handicapped’ learners were excluded completely, deemed ‘ineducable’. The Education (Handicapped Children) Act of 1970 established their entitlement to an education at school. Special schools at this time routinely had ‘Special Care’ classes where they grouped together learners with PMLD regardless of age (from 2years – often to students well into their mid-20’s), but too often this group were viewed as separate from the main school. There was an active national agenda to move people with learning disabilities out of hospitals and residential institutions and into ordinary homes in our local communities. This population were some of the last people to move.

Pioneering practitioners and researchers were developing knowledge and understanding of relevant techniques and approaches to best support and enable people with PMLD in all aspects of their lives. The well-rooted origins of interactive and sensory approaches were strong drivers for innovation and change. A better understanding of the health needs of this population, medical advancements and technology were creating new possibilities.

Over the thirty-plus years of PMLD Link’s existence, we have broadened our reach to address the needs of both children and adults with profound and multiple learning disabilities by sharing information and ideas to everyone involved – whether families or professionals, across education, health, social care, arts, community, research and beyond. PMLD Link is dependent upon voluntary contributions and we do wholeheartedly thank people for sharing their good practice and ideas and reflections over the decades? We could not have continued to produce the journal without you.

But what of the actual lives and experiences of people with profound and multiple learning disabilities (PMLD). Have lives changed since our first issue of the PMLD Link publication 33 years ago, and how? Do individuals have the quality of life outlined by the benchmarks in the PMLD Standards (Doukas et al., 2017)? Do the standards reflect the best life or do we need to update them?

We invite you to tell us about the reality in 2021. We are very keen to hear inspiring stories and great achievements, but we are just as eager for you to share the shortfalls and obstacles – hopefully with your ideas of what needs to happen to address these. Tell us what has happened since Issue 1 of PMLD Link that you feel is important to highlight! Let us know about any past article that has really resonated with you and that you would like to highlight to others, especially to newer readers who may not have read it!

Feel free to contact us if you want to contribute to Issue 100 – we’re happy to help!

Guest Editors - Annie Fergusson, Sue Thurman and Bella Travis

Send your articles, stories, news items, relevant information or resources by Friday 29th October to:
info@pmlmlink.org.uk; or annie.fergusson@outlook.com

Reference

Doukas, T., Fergusson, A., Fullerton, M. and Grace, J. (2017) *Supporting people with profound and multiple learning disabilities: core & essential service standards*. FREE to download at <https://www.pmlmlink.org.uk/resources/>

For more about writers’ guidelines or sharing photos: <http://www.pmlmlink.org.uk/get-involved/>

IN THE NEWS

2020 Annual Report from the LeDeR programme

On 10th June the detailed 2020 Annual Report from the LeDeR (the Learning Disabilities and Mortality Review) programme was published. This report contains a great deal about the needs of people with profound and multiple learning disabilities, among others, and their experiences during the pandemic in 2020.

COVID-19 was the leading cause of death for those with learning disabilities in 2020. The Review revealed that almost half of those who died from COVID-19 did not receive good enough care. Some patients contracted COVID-19 in hospital, others received delays in diagnosis and treatment. The risk of death involving COVID-19 was almost four times higher for those with a learning disability. Yet the increased risk of illness, disease and death faced by people with learning disabilities is not limited to the coronavirus pandemic.

There are some early indicators of improvements in the care of people with learning disabilities between 2018 and 2019, but there are also indications that such improvements are not felt across all aspects of service provision or groups of people with learning disabilities. Of particular concern are the significant inequalities in the experiences of people from minority ethnic groups. In addition, the COVID-19 pandemic has highlighted the impact of health inequalities and deficiencies in the provision of care of people with learning disabilities, with rates of their deaths being more than those of others'. The Report makes several recommendations.

1: LeDeR reviews should be undertaken through the lens of greater racial awareness

2: Local Authorities and Integrated Care Systems should ensure that they collect and publish local data on the health needs of children and adults with learning disabilities, capturing any characteristics that relate to specific ethnic groups, and take actions to reduce any disparities between people from different ethnic groups when planning local services for people with learning disabilities and their families.

3: A nationally endorsed standard resource is required, with local flexibility, that provides information for people with learning disabilities and their families about their legal rights and entitlements, national services available and how to access them, and local sources of support.

4: Strategically planned, long-term, targeted, joint investment is needed to strengthen partnerships with local communities and provide support for peer-to-peer networks, to build on and future-proof existing contacts and structures within local communities, and increase trusted word-of-mouth communication and information sharing.

5. Local systems, including commissioning, to be responsive and develop strategic plans that address the longstanding needs of people with learning disabilities and their families that the COVID-19 pandemic has illuminated, including the availability of specialist learning disability teams in acute, primary and community care.

The Report is available from: <https://www.england.nhs.uk/.../university-of-bristol.../>

Are you within reach of a Roofbreaker?

Roofbreakers are 'disability champions' who listen to disabled people and their families and try to make any accommodations needed to enable them to belong and participate in church life.

Through the Roof is a Christian disability charity. It believes that everyone, including anyone with PMLD, has a right to belong and a gift to contribute within the nation's church communities.

There are now well over 360 Roofbreakers in churches around the country where disabled people are welcome, regardless of the severity of their disabilities, and will be accepted and their gifts and abilities valued and celebrated.

Through the Roof now has an online map of churches and you can check (<https://www.throughtheroof.org/2020/11/25/online-map/>) to see if a church in your vicinity has a Roofbreaker.

If you know of an accessible, welcoming church, please encourage them to join the map by going to: <https://www.throughtheroof.org/2020/11/25/values-and-benefits-of-joining-the-map/>

Please visit www.throughtheroof.org for more information, news and resources

Post Graduate Certificate in Music and Special Needs: Sounds of Intent is now online

The PGCert in Sounds of Intent is online for 2021 - 2022, which should make it more accessible to many.

The Postgraduate Certificate in Music and Special Needs: Sounds of Intent is accredited by the University of Roehampton. It was developed and is delivered by Professor Adam Ockelford and consists of three modules, each worth 20 credits. The qualification can stand alone or count towards a Master's degree. The course is part-time for a year, and can be taken in person (sessions take place in Birmingham) or purely online, or flexibly, as a mixture of both. The commitment is to 30 days in the course of an academic year, with 12 days of interactive lectures, 14 days of self-directed learning, and a placement of four days.

The course is suitable for those working in special education (with or without a specialist musical background), musicians who wish to acquire skills in working with children with special educational needs and disabilities, and others, including clinicians, parents and those with a general interest in the area.

The Sounds of Intent programme enables practitioners to gain the skills and understanding necessary to use the Sounds of Intent framework in assessing children and young people's level of musical development, and devising activities and curricula that match their needs. It is based around the principle of reflective practice.

For further information about the course visit <https://www.roehampton.ac.uk/postgraduate-courses/sounds-of-intent/>

or email Adam Ockelford directly on a.ockelford@roehampton.ac.uk

Intensive Interaction Training – 20 August 2021

Join the Us in a Bus online 'Introduction to Intensive Interaction' training session led by Janet Gurney. It is being held via zoom on – 20 August 2021 from 9.30 to 3.30 via Zoom. The next available session after this one is on 7th October.

This is a one day course suitable for anyone who wishes to relate more closely with people who have profound learning disabilities, including family carers, residential and day services managers and staff teams, care managers and advocates.

The Zoom workshop is priced at £50 per person and £25 for parents/family carers. Us in a Bus also has some free bursary places available which you can apply for by emailing info@usinabus.org.uk or call on 01737 823310.

As part of their work in making sure as many families and professional as possible can access this training, The Caldwell Autism Foundation is funding £25 bursaries for Janet's on-line workshops, which Us in a Bus organise. If you are interested in applying for a bursary, please do so by email to admin@usinabus.org.uk

You can download a booking form at: <http://usinabus.org.uk/events/book-on-a-workshop/>

Between the Trees performance online

Moonbeam Theatre has an online performance for young children with PMLD - it is not a course but a good resource. Between the Trees is an online multi-sensory performance. It follows four curious woodland pixies exploring their forest home and the creatures they share it with. You will be invited by the pixies to join them in their magical woodland world, experiencing the sights, sounds and smells that surround them everyday!

This experience offers Makaton sign, story-telling, singing, music and multi-sensory exploration in your home or classroom! With your purchase of a ticket you will receive a sensory moments guide, corresponding to sensory moments in the performance and a PDF that can be printed out for a nature expedition. You will have unlimited access for a whole year, starting 14th July.

For tickets go to: https://www.eventbrite.co.uk/e/between-the-trees-tickets-153468148363?fbclid=IwAR0T6vxwUxKV3Rfyg0iVEvTFkwrVu7uGcZZdyt-_MTuv7Md8L8V_czFblvc

For more details about Moonbeam Theatre go to: <https://www.moonbeamtheatre.com/>

An unpaid carer's life: a cri de cœur

Luke Clements is a Professor of Law at Leeds University and is a solicitor. On his website he has published a guest post from a colleague which concerns a troubling account of the health system's approach to the care of a distressed and poorly young person with disabilities. This posting illustrates the challenges that many parents and/or carers face every day when trying to get help for their loved one with disabilities and why there is an urgent need for change.

The writer points out that many children with learning disabilities cannot communicate pain, and a change in their behaviour is sometimes the only indicator that something is very wrong. In the writer's experience, the vast majority of hospital staff never seem to understand this. Carers must speak for their child but their knowledge of them is too often disregarded.

To read this, go to: <http://www.lukeclements.co.uk/an-unpaid-carers-life-a-.../>

The Open Justice Court of Protection Project

The Open Justice Court of Protection Project works to promote Open Justice in the Court of Protection – an English court, established in its current form under the Mental Capacity Act 2005. The decisions made by the court on behalf of some of the most vulnerable members of society can be life-changing, and the case law it produces impacts the rights of disabled people far beyond the walls of the court rooms.

The independent Open Justice in the Court of Protection Project seeks to raise awareness of people's rights and reports on hearing observed. Recently, the Celia Kitzinger from the project team has shared an account by a mother who was a litigant at a court hearing. Clearly, this was a difficult and bewildering experience for her. Her daughter, who has profound learning disabilities, was taken into temporary respite care in 2017 when the mother became unwell. A follow-up hearing was observed by Katharine Shipley, a clinical psychologist with experience of the work of the court, who reflects on the final court judgement that the mother's daughter should not return home. These accounts raise important questions, among others, about the challenges the lawyers' everyday language and court processes pose for ordinary people and whether courts can truly assess and evaluate the unique relationship that a primary caregiver has with a person they have lived with and cared for over

many years. Yet at the same time there was evidence that due care and attention was taken to explore and explain all the options and the final judgement.

To read more, go to:

https://openjusticecourtofprotection.org/2021/06/07/an-onlooker-at-someone-elses-social-event-a-mothers-experience-of-the-court/?fbclid=IwAR02rfNUQYo-W4hmqMOJcugGQ4BKl6LXkz6pamCT9tj5rP_LvhiORL8Mmqw

PAMIS gets a grant to support its postural care programme development

In June PAMIS (Promoting a more inclusive society) announced that it has been awarded funding from The Health and Social Care Alliance Self-Management Fund which is supported by the Scottish government. This £56,742 award over two years will support PAMIS' progression with its postural care programme. This project will support families of people with a profound learning and multiple disability to learn about how to protect body shape and how to develop a digital passport (an electronic flip through book) that will support the family and the person with a profound learning and multiple disability to tell people how to care for them. PAMIS will be working across the NHS areas Greater Glasgow & Clyde, Dumfries & Galloway, Ayrshire & Arran, Highland, Lothian and Shetland making connections with families and Allied Health Professionals. This project combines two key family led PAMIS programmes - postural care and the PAMIS digital passport and comes as the Scottish postural care strategy Your Posture Matters is launched.

'Tea, smiles and empty promises'

31st May 2021 marked the ten year anniversary of the exposure by a BBC Panorama documentary of abuse and mistreatment at Winterbourne View, an Assessment and Treatment (inpatient) unit on the outskirts of Bristol. The Challenging Behaviour Foundation have marked the occasion by publishing 'Tea, smiles and empty promises' which is a collection of stories from a group of families with relatives with learning disabilities and/ or autism who were at Winterbourne View reflecting on changes in the past decade and the lack of progress in improving services.

'Tea, smiles and empty promises' calls for urgent action to avoid traumatising children and adults with learning disabilities and autistic people in the first place by providing the right support at the right time in the right place. A focus shift to early intervention and preventing admission/ readmission, as well as getting people out of inpatient units. Provide appropriate trauma support for individuals and their families

The document is available online at: <https://www.challengingbehaviour.org.uk/news/winterbourne-view-10-years-on/>

Sadly, a few weeks after its publication, the BBC Wales reported allegations of poor management and leadership and mistreatment of autistic children at a children's home in Cardiff (<https://www.bbc.co.uk/news/uk-wales-57404837>).

Free music projects for young children/young adults with PMLD

The music charity Soundabout has shared information about the two free music projects it is currently running for young children and young adults with PMLD. They are Little Soundabout and Soundabout Life. These are England-wide projects aiming both to support young children/young adults and also their family members/carers. A family member/a carer supporting the young child/young adult with complex needs can sign up for tailored music sessions with a specially trained Soundabout music practitioner to support their use of sound and music at home. Project participants will also benefit from receiving their own physical set of Little Soundabout/Soundabout Life cards and the opportunity to choose an additional resource to support their music-making. Those joining the project are eligible to receive up to six Little Soundabout or Soundabout Life sessions a year, one roughly every two months, until the end of the project in summer 2022. The sessions will either take place online, in the family home or in a supportive living setting with sessions supported by a consistent care staff member. (Please note that at present, due to COVID restrictions, Soundabout are only offering online sessions.)

Applications to the projects can be made via the application form on the Soundabout Families website: <https://www.soundaboutfamily.org.uk/about-us/application-form/>

Since the offer is only available until summer 2022, families are encouraged to sign up as soon as possible to get the most out of this opportunity. Soundabout has also been developing a series of musical resources as

part of the project which offer ideas of how to use sound and music to support both musical and wider development. These are free to access and can be found on the Soundabout Families' website: www.soundaboutfamily.org.uk.

Hidden Worlds multimedia project

Hidden Worlds is an Arts Council England funded project which begins in September 2021. The innovative project will explore the hidden sound worlds of Victoria College, a specialist setting for young people with PMLD in Birmingham. Working in collaboration with internationally acclaimed musicians, digital artists and Big Top Musical Adventures CIC, students and staff at Victoria College will explore, discover and co-create three new pieces of multimedia digital art work. The multi-sensory interactive workshops will feature musical stimuli from South Asia, West African and across the UK. Big Top practitioners will create responsive and interactive environments for individuals with PMLD to develop and express their creative identities using live music, electronics and visual art. The digital compositions of the project will be premiered online throughout 2021-22.

To find out more about the Hidden Worlds project or Big Top Musical Adventures work visit bigtopmusic.co.uk

Engagement Model

Following the recommendations of the Rochford review and the subsequent pilot, The Engagement model has been approved by the government. The engagement model constitutes a new form of assessment for pupils who are not engaged in national curriculum tests and subject specific study. The engagement model replaces P scales 1-4 and will become statutory from the start of 2021/2022 academic year. Pupils will now be assessed using five areas of engagement - Exploration-Realisation-Anticipation-Persistence-Initiation. The Standards and Testing Agency advise that the areas of engagement 'allow teachers to assess pupils' engagement in developing new skills, knowledge and concepts in the school's curriculum by demonstrating how pupils are achieving specific outcomes'.

Further guidance from Engagement for Learning is due to be issued: <https://engagement4learning.com>

The Engagement Model. Accessed from: <https://www.gov.uk/government/publications/the-engagement-model> (Accessed on: 17th June 2021)

BOOKS AND RESOURCES

Gaining Consent to Touch

Seeking consent to touch is an integral part of the Story Massage programme. For many schools, colleges and families, the programme has become a valuable way of teaching appropriate touch and the importance of saying a confident 'no' to unwanted touch.

In May, Story Massage posted on its website examples of good practice with children and young people of all ages and abilities. These show how sharing massage stories can help teach appropriate touch.

https://www.storymassage.co.uk/gaining-consent-to-touch/?fbclid=IwAR3qLWQxRtous-bEwBAtpBGPdMdt_V6x3GzHpsLbEfZEURm9z5cvE4KxAEU

Your posture matters

The national postural care group, supported by NHS Education Scotland and PAMIS (Promoting A More Inclusive Society), have developed resources to provide practical help and guidance to those with postural difficulties.

Your Posture Matters is a suite of resources including a strategy with guiding ambitions and recommendations, a learning framework to support educational development and promotional booklets and posters to support greater understanding of protecting people's posture. Also included are links to several informative vlogs and blogs.

Your Posture Matters aims to inspire service provision across Scotland to work together to minimise body shape distortion for all individuals with a movement difficulty. For more details online, go to:
https://learn.nes.nhs.scot/29658/allied-health-professions-ahp-learning-site/your-posture-matters?fbclid=IwAR3e7AQUEGmsGe_GVzpFs9EGaMdgKwHZn4KlXipWcilFwWy4nKAT7Ljm7qg

Five Good Communication Standards - Let's talk about them

The Five Good Communication Standards was published by the Royal College of Speech and Language Therapist in 2013. A new Facebook group has been developed by Sheridan Forster to discuss the Standards and share initiatives for reaching the Standards. She believes that they have the potential to help improve speech and language therapy practice and support good practice in environments where people with profound learning disabilities live and learn.

<https://www.facebook.com/groups/5goodcommunicationstandards/?ref=share>

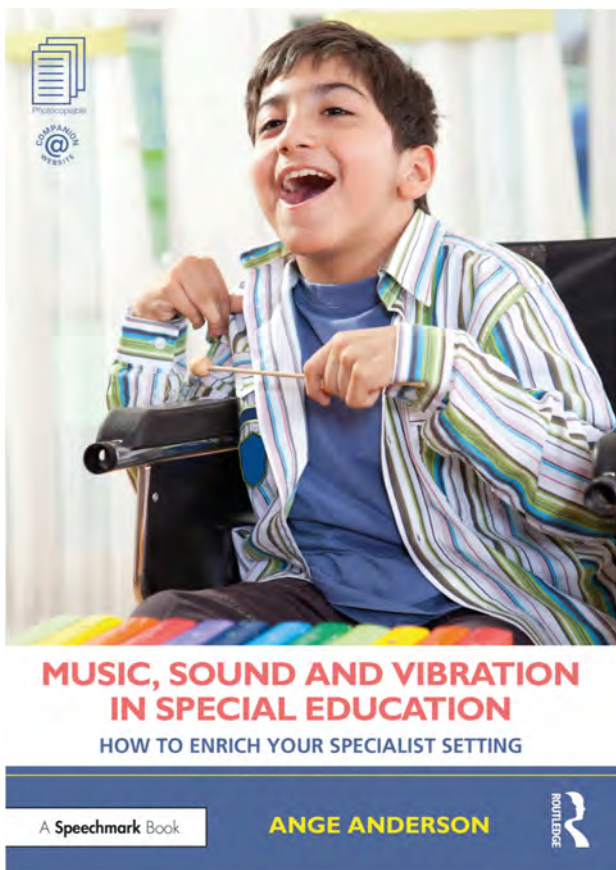
Summary Care Records (SCR)

Summary Care Records (SCR) are an electronic record of important patient information, created from GP medical records. They can be seen and used by authorised staff in other areas of the health and care system involved in the patient's direct care. At a minimum, the SCR holds information about:

- current medication
- allergies and details of any previous bad reactions to medicines
- the name, address, date of birth and NHS number of the patient

Additional Information in the SCR, such as details of long-term conditions, significant medical history, or specific communications needs, is now included by default for patients with an SCR, unless they have previously told the NHS that they did not want this information to be shared. When new patients are registered with a GP practice, there should be a check that they are happy to have an SCR.

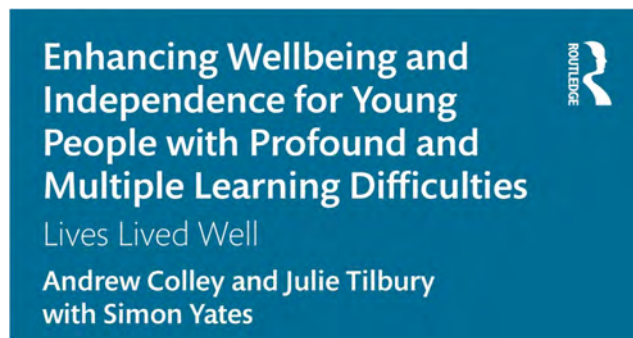
More information about SCR and opting out of having one is available at: <https://digital.nhs.uk/services/summary-care-records-scr/summary-care-records-scr-information-for-patients>



Title: Music, Sound and Vibration in Special Education: How to Enrich Your Specialist Setting
Author: Ange Anderson
ISBN 9780367708306
Published: June 28, 2021
Publisher: Routledge
Pages: 184 Pages, inc 20 B/W Illustrations
Price: £22.99 (paperback)

This book provides practical guidance on how to successfully incorporate music, sound and vibration into your special school, exploring the rich benefits that musical opportunities offer for children with physical, mental health and learning disabilities.

Chapters exploring a range of relevant music therapies and technologies. Case studies and anecdotes showcase innovative ways that special schools are using music, and provide practical examples of how to deliver, record and access music provision. The book also provides photocopiable policies, risk assessments and links to useful resources.



Title: Enhancing Wellbeing and Independence for Young People with Profound and Multiple Learning Difficulties: Lives Lived Well
Authors: Andrew Colley and Julie Tilbury, with Simon Yates
Published: September 28, 2021 Forthcoming
Publisher: Routledge
ISBN 9780367564063
Pages: 168 with 24 B/W Illustrations
Cost: £27.99 (Paperback)

Pre-order and save 20% through the Routledge website with discount code APR20. Item will ship after September 28, 2021

The authors explore what well-being, community participation and independence mean to young people with profound and multiple learning difficulties. They bring together results of their survey of over 200 schools in different countries who teach young people with PMLD and show the many innovative ways in which schools are working to ensure young people with PMLD have lives of value that are as rich and meaningful as possible.

SHORT COURSES & CONFERENCES 2021

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 the Winter 2020 issue. The following planned courses are on offer online via Zoom but do not assume that this list is exhaustive.

September 2021		Title:	24-hour postural care: Hands-on training for the postural care workforce 22nd September, 1.00 – 1.30
Title:	Postural care from cradle to grave	Date:	Online Zoom event, part of course
Date:	8th September, 10:30 - 4:00	Location:	Born at the Right Time/Simple Stuff Works
Location:	Online Zoom event, part of 2-3 day course	Provider:	https://www.bornattherighttime.com/event/24-hour-postural-care-hands-on-training-for-the-postural-care-workforce/
Provider:	Born at the Right Time/Simple Stuff Works	Contact:	
Contact:	https://www.bornattherighttime.com/event/postural-care-from-cradle-to-grave/	Title:	Got My Back - Postural Care learning event for Learning Disability Nurses 23rd September, 10.00 – 1.00
Title:	Communication and co-production with relatives and carers in a changing world	Date:	Online
Date:	15th September, 9.00 - 1:00	Location:	Changing our lives
Location:	Online Zoom course	Provider:	https://www.eventbrite.co.uk/e/got-my-back-postural-care-learning-event-for-learning-disability-nurses-registration-160719946687?aff=ebdssbonlinesearch
Provider:	Born at the Right Time	Contact:	
Contact:	https://www.bornattherighttime.com/event/communication-and-co-production-with-relatives-and-carers-in-a-changing-world-5/	Title:	Recording Intensive Interaction and Rapport Based Communication 30th September, 10.30 - 12.30
Title:	PCPLD Network Annual Conference Finding the gaps & closing the gaps: Dying, death, bereavement - and people with learning disabilities	Date:	Online Zoom course
Date:	16th September, 10.00 -15.00	Location:	Concept Training
Location:	Online Zoom	Provider:	info@concept-training.co.uk
Provider:	PCPLD	Contact:	
Contact:	https://www.pcpld.org/events-and-conferences/	October 2021	
Title:	Pre-Formal Curriculum	Title:	PMLD-Developing Creativity through Music and Movement 6th October, 10.30 - 12.30
Date:	16th September, 3.30 t-5.00, plus two follow-up dates	Date:	Online Zoom course
Location:	Online Zoom course, Session 1 of 3	Location:	Concept Training
Provider:	South West Association of Leaders in Special Schools www.swalss.co.uk	Provider:	info@concept-training.co.uk
Title:	Parenting a child with complex needs workshop	Title:	Rapport Based Musical Communication 7th October, 10.30 - 12.30
Date:	21st September, 10:00 - 12:00	Date:	Online Zoom course
Location:	Online Zoom, part of 2-part workshop	Location:	Concept Training
Provider:	Born at the Right Time	Provider:	info@concept-training.co.uk
Contact:	https://www.bornattherighttime.com/event/parenting-a-child-with-complex-needs-workshop-8	Title:	Intensive Interaction Training 7th October, 9.30 - 3.30
		Date:	Online Zoom course
		Location:	Us in a Bus
		Provider:	info@usinabus.org.uk
		Contact:	

<p>Title: Date: Location: Provider: Contact:</p>	<p>24-hour postural care: Hands-on training for the postural care workforce 22nd September, 1.00 – 1.30 Online Zoom event, part of course Born at the Right Time/Simple Stuff Works https://www.bornattherighttime.com/event/24-hour-postural-care-hands-on-training-for-the-postural-care-workforce/</p>	<p>Title: Date: Location: Provider: Contact:</p>	<p>Intensive Interaction for People with PMLD 8th October, 9.30 - 3.30 Online Zoom course Intensive Interaction Institute https://www.intensiveinteraction.org/211008am-ozt-pmld/</p>
<p>Title: Date: Location: Provider: Contact:</p>	<p>Got My Back - Postural Care learning event for Learning Disability Nurses 23rd September, 10.00 – 1.00 Online Changing our lives https://www.eventbrite.co.uk/e/got-my-back-postural-care-learning-event-for-learning-disability-nurses-registration-160719946687?aff=ebdssbonlinesearch</p>	<p>Title: Date: Location: Provider: Contact:</p>	<p>Timetables for students with PMLD to support wellbeing and learning 12th October 2021, 4.00 - 5.30 Online Zoom event NAC (Non-Verbal Affective Care) https://www.eventbrite.co.uk/e/timetables-for-pmld-classes-and-individuals-tickets-163356691261?aff=ebdssbeac</p>
<p>Title: Date: Location: Provider: Contact:</p>	<p>Recording Intensive Interaction and Rapport Based Communication 30th September, 10.30 - 12.30 Online Zoom course Concept Training info@concept-training.co.uk</p>	<p>Title: Date: Location: Provider: Contact:</p>	<p>Rapport Based Musical Communication 13th October, 10.30 - 12.30 Online Zoom course Concept Training info@concept-training.co.uk</p>
<p>October 2021</p>		<p>Title: Date: Location: Provider: Contact:</p>	<p>Introduction to Communication and co-production with relatives and carers 13th October, 1:00 - 1:30 Online Zoom event, part of course Born at the Right Time https://www.bornattherighttime.com/event/introduction-to-communication-and-co-production-with-relatives-and-carers-2/</p>
<p>Title: Date: Location: Provider: Contact:</p>	<p>PMLD-Developing Creativity through Music and Movement 6th October, 10.30 - 12.30 Online Zoom course Concept Training info@concept-training.co.uk</p>	<p>Title: Date: Location: Provider: Contact:</p>	<p>Intensive Interaction Virtual Conference 2021: Reconnecting with Intensive Interaction 18th October, 9.00 – 4.00 Online Zoom conference Intensive Interaction Institute https://www.intensiveinteraction.org/conference-2021/</p>
<p>Title: Date: Location: Provider: Contact:</p>	<p>Rapport Based Musical Communication 7th October, 10.30 - 12.30 Online Zoom course Concept Training info@concept-training.co.uk</p>	<p>November 2021</p>	
<p>Title: Date: Location: Provider: Contact:</p>	<p>Intensive Interaction Training 7th October, 9.30 - 3.30 Online Zoom course Us in a Bus info@usinabus.org.uk</p>	<p>Title: Date: Location: Provider: Contact:</p>	<p>Getting it right for siblings of disabled children (for professionals) 19th November, 9.30-1.00 Online Zoom course SIBS https://www.sibs.org.uk/sibs-workshops-and-training/conference-for-professionals/</p>
<p>Title: Date: Location: Provider: Contact:</p>	<p>The SEND Code of Practice How is it Meant to Work? 7th October, 4.30 - 6.00 Online Zoom course SWALSS www.swalss.co.uk</p>		

About Us

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

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

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PMLD LINK

sharing ideas and information

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