PMLD LINK
sharing ideas and information

What matters?

Summer 2020

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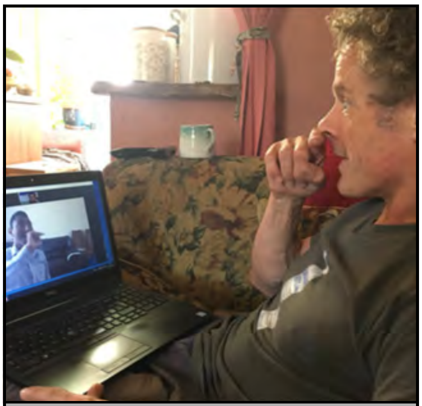

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GUEST EDITORIAL

What matters?

Our call for articles for this issue of PMLD LINK was at an unprecedented time, one that will go down in history. Almost overnight Covid-19 brought the world to a standstill and our lives changed beyond imagination. For some this was a time to slow down and more mindfully appreciate their lives, some enjoyed opportunities that had previously never existed but for others, this virus removed the vital supports and human connections that enabled them to live their lives or, it brought great suffering and loss. These consequences were identical too for people with profound and multiple learning disabilities (PMLD).

At this unimaginable time, we posed an open question to readers, to reflect on the lives of people with PMLD. We simply asked – *What matters?*

Whilst our pages don’t directly reflect the complete picture of their lived experiences over the past six months, the indirect, ‘hidden content’ of the articles and extensive pages of ‘resources’ do. Although very different, they each offer inspiration and challenge, but they also share some important common themes. Every item in the journal depends on human connections, for a meaningful quality of life. In usual times these social, emotional and physical interaction are always face to face, close up and personal. Moving forward we will continue to need to be creative in how we achieve that, whatever the restrictions, to ensure people do not become socially isolated.

Be inspired and challenged by what you read here, but we encourage you to look beyond these pages and explore everything signposted in this issue. Follow up the links and downloads, create your own stories or try out the activities, view the videos and listen to the recordings – these will uncover the real innovation of the contributors. But mostly, appreciate and understand the real stories behind these contributions - about the real lives of people with PMLD, their families, carers and support providers.

Currently, with a real possibility that ‘lockdown’ and shielding is prolonged, this group will remain invisible. In her blog about their library of podcasts, Lucy Garland from Frozen Light reveals the biggest danger;

> ‘.... the overwhelming response to lockdown coming from the families and friends of our audience was, "Don't forget us" ‘.

It is essential we learn from these coronavirus experiences, by considering the losses and the gains. To do that, we need to ask again – what matters?

Guest Editors: Martin Goodwin, Sue Thurman and Annie Fergusson

References: Lucy Garland’s Blog: http://frozenlighttheatre.com/resources/documents/ [Accessed 1.8.2020]

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Surviving through Story - documenting lives in lockdown and beyond

Katrina Arab, Nicola Grove, Flo Hopwood

Our project aims to use personal stories to develop resilience to cope with the pandemic and its after-shocks, in children and adults with profound and multiple disabilities and their families and carers. How have their lives changed? What have been the losses and the gains? How can we make sure that this population of our citizens and communities are included in the building of the collective memories which will assuredly echo down the generations?

The idea for a website to document stories arose when looking at resources developed for learning disabilities and special needs during lockdown. Charities and organisations were quick to respond with some excellent “easy read” information and guidance. But what WE were all doing, as these extraordinary events unfolded, was sharing our experiences and our feelings with friends, families and the people we stepped two metres away from in the street. The panic buying and search for alternatives to hand sanitiser; the hours spent trying to book online deliveries; the amateur haircuts; the passion for baking. These are the small stories - but there are the big stories too that we need to share: random acts of kindness; the shock of sudden hospitalisation, and in so many cases, death at a distance; the special events that have to happen online; the reactions to events on the news. It is through sharing these experiences with others, who can empathise, and to whom in turn we extend our imaginative sympathy, that we come to realise we are not alone.

There didn’t appear to be any spaces or resources that made it possible for people with learning disabilities to take part in this universal outbreak of storytelling, though projects are emerging now. Further impetus came from Craig, who is co-chair of the Social History of Learning Disabilities Forum at the Open University. Craig wanted to know how other people were coping with the lockdown, and worried about how to manage feelings and reactions when there were deaths.

When it comes to individuals with profound disabilities, it is easy to make assumptions. After all, the level of their cognitive and sensory impairments surely reduces their awareness of their surroundings or others? For those living at home, maybe it is just like a long holiday from school, college or activity provision? Maybe they simply don't notice that friends, teachers, care staff and personal assistants are not there. For those in residential care, maybe again it feels as though the time between visits from friends and family has just got a bit stretched. Readers of PMLD LINK, and indeed anyone who has got to know someone with PMLD, will know how such impressions are deeply misleading. The following example is someone with severe, not profound, learning disabilities, but does, we think, provide some interesting insights into how conceptual understanding builds up.

Jeffrey, aged 17, has severe learning disabilities and a passionate interest in trains. His parents explained he couldn't go out or to school 'because of the bug'. A couple of weeks into lockdown he looked up and said to his mother "No school. Bug". He once said 'Bug go away?' to his dad. When told he was going back to school next week he said 'no'. When they're out on their walks, he knows to stand back when someone else is going past, although he is not consistent about this. Jeffrey appears to have a 'psychic' sense of time relating to his favourite activities. He can't read a calendar, but when February half-term arrives he knows it's time for their annual trip to Dorset, and will ask "hotel?" He was in the habit of repeatedly requesting his favourite activities, but now only occasionally asks "forest?" "shopping?". This suggests that he is in fact aware at some level, of the limits operating on activities. It's clear that Jeffrey has made connections from hearing explicit instruction, from practising behaviour and, some incidental learning from overheard conversations or broadcast media. He's developing new coping skills, new vocabulary and new habits, even if only in a small way.

As we might expect, however, the lockdown is taking its toll on people separated from their family members and friends, with indicators of severe depression reported, particularly for those in residential care. We believe passionately in the power of storytelling for support, inner strength, consolation and entertainment.

Sensory stories about lockdown

We began by thinking of sensory stories that families, carers or teachers could use to help individuals make sense of what was happening. We gathered nine story scripts that were designed specifically to be customised to suit any individual, each story relating to real-life events. We have very generous partners, providing us with free resources to use on all our materials;

- symbols - Pictologue (https://www.pictologue.co.uk),
- a set of line drawings for signs - Makaton (www.makaton.org)
- a licence from Photosymbols (www.photosymbols.com)

CLAP FOR THE NHS	*Sounds, words and vocalisations*	*Gestures, signs and body movements*	*A sound or word recorded on a big Mack*	*Showing a photo, either on a card or an iPhone*	*Showing an object*
Every week we clapped for our workers		clap		Pictures of workers – nurses, doctors, care workers, drivers etc	Saucepan and wooden spoon/drum/ rattle
We stood at the door. We waited till 8 o'clock	eight	WAIT	Sound of chimes for 8pm		
(Family members) went… (name each in turn)	hooray	clap	Hooray		
Individual's name/person went… We all did it together		Bang on saucepan lid or show banging movement			Bang on saucepan lid with wooden spoon

A story script example - 'Clap for the NHS' (an iconic community event that everyone can remember together)

Example resource: Joe Wicks and Me (exercising at home with everyone's favourite fitness instructor)

We set up a Facebook page through which we offer training and resources to explain and demonstrate how to support individuals to tell their own stories - either by adapting one of our scripts or, by developing their own. For this we draw on our practice with Storysharing® - an approach developed over two decades, with a wide range of special needs and disabilities.

Storysharing®

The fundamental principles are that everyone has a story to tell, and that everyone can participate in the telling/sharing of a story (Grove, 2014). It's based on our own knowledge, and on research, about the ways in which ordinary people share anecdotes in daily life.

Developmentally, although children don't generally narrate stories independently in sequence until they are between 3 and 4 years old, they do take active roles in story-conversations from a very early age. They may make a sound, smile or laugh or frown, wave an object, look in a particular direction. As Trevarthen (2011:6) says: 'It turns out a newborn infant person has clear expectations of human sense, and is active in starting a personal quest for meaningful stories in good company.' We found this also applies to children and adults with profound disabilities, provided the right opportunities are available.

Functionally, the approach draws on the concept of "partial participation" (Baumgart et. al., 1982), developed as part of a Canadian project aiming to ensure that people with severe disabilities could authentically be part of the community. Put simply, what this means is that people can't do everything, but they can do something. The aim is to identify what that "something" is. So, in storytelling, we look for at least one small authentic way in which a person can contribute and we work hard to ensure that this action lies at the heart of the narrative. There are examples of Storysharing on our site, notably the film with an adult supporting a young girl to tell her story of going into hospital by ambulance. (shorturl.at/kvIN5).

Life in lockdown - some reflections from Katrina

As a PMLD teacher working in a generic special school, I found myself feeling incredibly lost in the midst of the unknown that is Lockdown. I have seen colleagues jump straight in with both feet to virtual-teaching roles; I questioned how to do this in a meaningful way with my pupils. Engaging with my class via online platforms has proved very difficult in lockdown and has left me completely reliant on families for anecdotes about their day to day lives. I regularly share videos with my pupils, telling stories or sharing sensory activities with tutorials from myself and other staff members. I'm always keen to find out how the pupils have interacted with theses.

One mother provided an example that demonstrates the subtle but meaningful cues whereby our pupils with PMLD signal their recognition of a life before lockdown. Her daughter is usually very motivated by screens and associates them with her favourite songs and games. However, in lockdown, she will only briefly engage with a video, probably because it does not provide what she expects. Her mother mentioned in passing though, that she became very happy and engaged when the video showed a staff member singing her favourite song on video - the very song she always choses in class. Despite the negatives, some families are finding that precious memories can be created, especially for those lucky enough to have increased time and fewer pressures. One such example is a pupil who is absolutely

Milly

thriving and her mother takes such pride in sharing ‘first experiences’ with me. Lockdown has given the family time to support the pupil with self-help skills and she is now able to bring a loaded fork to her mouth independently; a skill she had not yet developed at school.

Taking the time to create and tell new stories about new experiences can really help, as this story created by Ellie Ward from a L’Arche community illustrates. Milly Beswick is in her twenties, a people-person who enjoys being in the middle of things, with a smile that lights up the room. She is tube-fed, uses a wheelchair and because of scoliosis can only manage a wave / slight raise of one hand in greeting. Her main way of communicating is vocalising with eye pointing / whole head movement and facial expressions. Prior to lockdown she spent two nights a week at home with her mum and dad, who are no longer able to visit. Currently, they can only wave to each other from the garden gate. Milly loves the film Frozen - and so her support workers created an outdoor cinema by hanging a sheet on the washing line and projecting the film onto it, sitting under the stars on a balmy night. The story of how loudly they sang, and how they woke someone up, and the fun they had together, will be one of those positive memories to laugh about in times to come.

Another fun story comes from Ettie, who has complex needs and communicates using a voice output communication aid (VOCA).

Ettie, like many of us, has been experimenting with cooking. She made some unorthodox jellies - using ham and cheese … her verdict? “disgusting!”

Ettie’s more successful attempts

Our website

Thanks to our partners Open University (http://www.open.ac.uk/health-and-social-care/research/shld) and Generate (https://generate-uk.org), our new website will provide an archive of memories; written, filmed, audio recorded - as well as artworks and photographs to document the experiences of both children and adults with learning disabilities in lockdown. We are currently working through ethics procedures to ensure this is a safe space for everyone. The site will also feature a memorial page for celebrating lives. We are actively reaching out to make links with similar projects - so do contact us if you know anyone who would like to be featured.

Conclusion

When we emerge from this pandemic, it will be stories that sustain us, and it is stories that will give us a stake in our communities and circles of relationships. We need to ensure that everyone is included in the telling the story of the Covid19 pandemic. As Colwyn Trevarthen says, *'A healthy mind builds proud memories in loving company with specially trusted family and friends, making a good story. Loneliness, shame, depression and sadness are the emotions that identify loss of this collective story-making…'* (Trevarthen, 2011:3).

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Email: nicolagrovesend@gmail.com
Facebook: https://www.facebook.com/survivingthroughstory/ - includes short films demonstrating Storysharing® in practice, links to online training, webinars, workshops and self-guided practice.

Acknowledgements
Many thanks to Maureen Phillip, PAMIS; Naomi Hewerdine, L'Arche; and the Middleton family for their help with this article.

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Grove, N. (2014). *The big book of Storysharing*. London: Speechmark.

Trevarthen, C. (2011) Born for art and the joyful companionship of fiction. In D. Narvaez, J. Panksepp, A. Schore & T. Gleason (Eds.) *Human nature, early experience and the environment of evolutionary adaptedness*. Oxford: OUP. (pp. 202-220). Available as pdf from https://network.youthmusic.org.uk

Links

Guess what Happened to Me - film by charity Openstorytellers about Storysharing® approach (https://youtu.be/B8V5iBeGGJs (www.openstorytellers.org)
Creative toolkits for developing sensory stories - PAMIS www.pamis.org

'Love in the time of Covid' - reflections on learning from people with disabilities, https://medium.com/@larcheuk/love-in-the-time-of-covid-645620faeaeb

PAMIS are collecting and sharing more direct experiences of children and adults' lives in lockdown. Here are two lovely examples from their website. httpshorturl.at/ltBXY and https://youtu.be/7_J1qG_JOzc

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Remotely Close during Covid19 Lockdown – exploring Intensive Interaction via Zoom

Jeannie Donald-McKim and Jules McKim

With the start of the lockdown in response to the coronavirus pandemic it initially seemed that our work would become nigh on impossible. Working in services that provide health and educational support to people with severe and profound learning disabilities, providing a meaningful way to maintain that support proved a challenge. With non-essential contact not advised, remote technology has been used to maintain support for families and staff and encourage social and emotional engagement for the people supported. Although this has been a necessary adaptation to a temporary situation, we have become aware of some unforeseen benefits which might allow increased engagement and inclusion for some people in the future.

Social distancing sounds like the opposite of what us Intensive Interaction (II) advocates are trying to promote. Although with II we don't have to be close, it usually helps. It enables the person with visual impairments to be able to see our facial expressions, the person with hearing impairments to be able to easily hear our vocal responses and for the person, if they so wish, to be able to reach out and make physical contact. As people's worlds shrank and we all began trying to cope with a new reality, we wondered how it would be for people who might not be able to understand the reasons for it. The usual structures and routines that we all enjoy were lost overnight. Clearly, the people we are talking about here need support and that support continued from families at home or supported living care teams in the person's own home. But our ability to support those relationships has been challenged. People's timetables of out-of-house activities and attendance at college stopped. We all know how much of a challenge it has been even though we can understand the reasons. Personally, we may have made amends with longer phone calls, Zoom pub quizzes and Thursday evening chats with neighbours. It is in this spirit of maintaining contact and social inclusion in a time of physical distancing and social isolation that we have continued making our reasonable adjustments to communication into the world of technology.

Case study (RS)

The closure of Abingdon and Witney College on March 20th 2020 due to the Covid19 outbreak was a very abrupt and sudden disruption of RS's routine, and of course as for so many people with PMLD, was completely baffling. Not only was his college routine stopped without any kind of transition or preparation made possible, but even normal trips out of the home to go shopping or visiting were also suspended. RS has a very supportive and loving family, but this sudden imposed isolation within the family home was challenging and RS was clearly bored and missing normal and familiar interaction with the supportive community .

Because college has been piloting WikiMe – a digital self-advocacy platform for people with learning difficulties – we were able to arrange Zoom sessions securely where we could explore the possibilities of using Intensive Interaction remotely.

I was not sure how RS – or his peers – would respond to Zoom sessions, however even for the most severely disabled students it was clear after a few minutes that they recognised – either by face or voice – myself and other familiar staff, and also some of the routine activities we used as markers such as opening and closing songs.

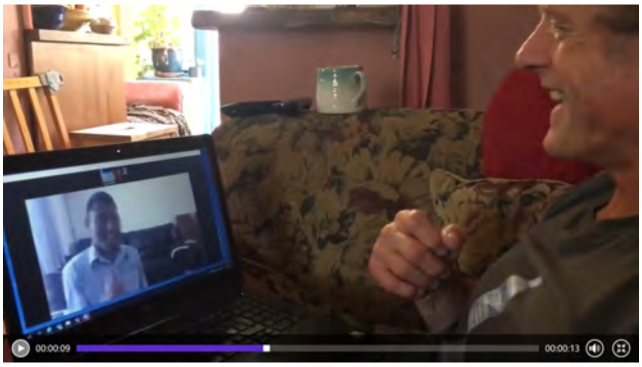
RS is a second-year student at Abingdon and Witney College who responds very well to Intensive Interaction. He has a great sense of humour and is a brilliant communicator and joker, with a marked mischievous streak. RS has a tendency to test out new II partners – once he has built a relationship of trust - in a sequence of well-rehearsed gestures, tapping his nose, using his voice etc, and once he is sure he has you following him he then tests your nerve by sticking his finger up his nose! When I mentioned this to his father in a Zoom call to see if it was something he only did at college, his dad said 'Always!' which was a reassuring confirmation that no, it wasn't just me! RS thinks it's hilarious when you shake your head and say 'Yuk!'; in fact 'Yuk!' is one of his favourite expressions!

RS has been attending college fulltime since September 2018. At first it took RS some time to adjust to the new environment and occasionally there were times when he expressed his anxiety by pinching people within his reach and becoming upset and tearful. Intensive Interaction was a very successful intervention to build relationships of trust with RS, and after a few weeks he began to settle into college and enjoy being with his new classmates and staff team.

Jules had met RS once or twice in college, but this was the first time he experimented with having an Intensive Interaction session online, with parents facilitating the technology. RS was interacting with Jules through his iPad and also large screen TV attached to the wall, Jules was using his laptop and we recorded 3 short videos and several photos of the interaction.

Some reflections on sessions:

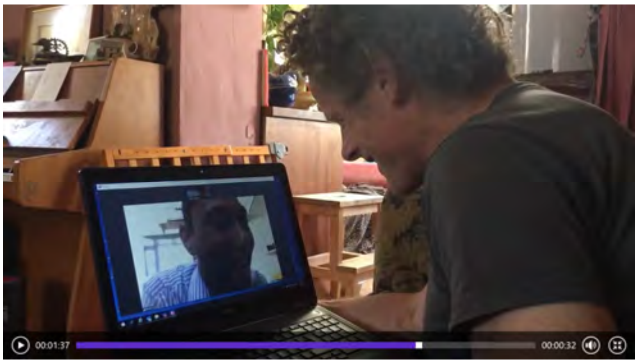
Session 1



Interacting with RS while he is at home with his family has additional pros, cons and considerations. The opportunities for passing on techniques to family are immediate and the results obvious. RS gets quite excited by the vocal imitation and moves to throwing a ball. This is how he seems to regulate his arousal levels. He enjoys this game with his family members present. When he throws the ball to me, stuck within the ipad, there is little I can do! On reflection, perhaps it would have been nice to have 'headed' the ball back to him, even virtually!
I was very aware in the first session that my face was on an ipad screen and therefore smaller than in reality. I had to work hard to amplify my facial expressions to compensate.

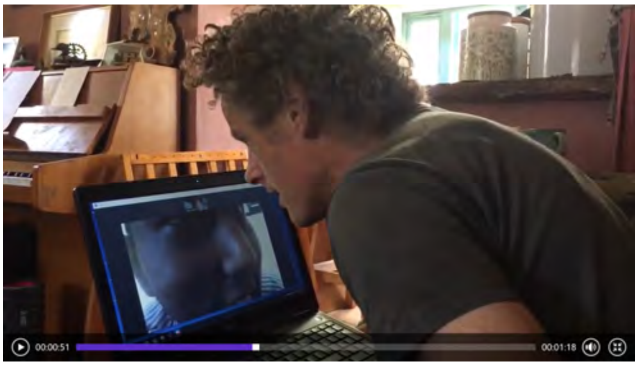
Session 2

The next time, Dad has plugged the ipad into the TV screen, so RS has two places to look. This he does, and it seems to help as although concentrated on my image, even so, there is movement possible by looking to the front, and then to the side and alternating. He even crawls back and forth at times.



Session 3

At first RS seemed slightly confused and bemused, but almost as soon as Jules started responding to his gestures and vocalisations with a smile and an availability and focused attention, RS knew what was happening and clearly threw himself into the interaction with gusto. The results were amazing!

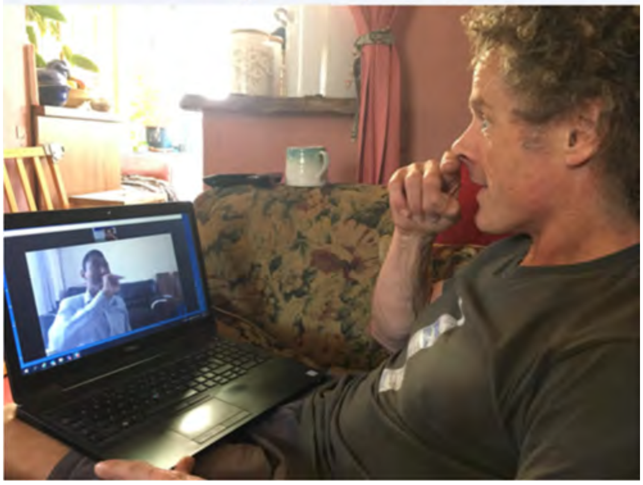


He rattled through some of his repertoire: smell your hand, nod your head vigorously, waiting to see whether Jules would respond in kind, and when he did there were a series of communicative vocalisations, testing to see if Jules was really paying attention. When this was confirmed there were huge smiles, giggles of complicit hilarity – 'Here's someone who knows how to interact with me! On screen! Wow!' And a 5 - 10 minute sequence of interaction followed.

After establishing a connection, RS moved away to digest this new visitor through the screen, then, crawling to his iPad, he moved his face really close to the screen – perhaps testing whether he could actually touch Jules through it. Jules moved his face closer to his laptop screen, so they were eyeball to eyeball, which seemed to fascinate and delight RS. He moved away again, and then shortly after repeated the same experiment. RS is excited but has quiet moments too when he gives sustained eye contact. Jules repeats the game of moving his head closer, a sort of "I'm coming closer" gesture that doesn't involve getting any physically closer at all. This results in great delight! It becomes a visual game without encroaching on RS' personal space.

RS moved on his knees around his living room, interacting with the 2 Jules he could see – one on his iPad and another on the big TV screen attached to the wall. This allowed him freedom of movement, yet continued focus, something not so easy to do if they had been in the same physical space.
RS went through a repertoire of gestures and

21 May 2020 Noses!



vocalisations, conveying – let's play, who's boss? Will you do this? He waited to see if Jules would respond, enjoyed it when he did, and eventually had had enough and moved away.

Discussion

Moving forward we still aim to develop and maintain everyones' experience of and confidence with face to face interactions. Social distancing should not become social isolation hidden by a veneer of this virtual social connection. The terminology is incorrect: it is physical distancing, not social distancing. Social engagement can continue even at 2 metres distance, even via computers.

We can speculate how much is lost with this type of interaction. If 80 to 90% of communication is non-verbal how much of that is lost via video conferencing? Nuances of tone may be lost. The precise timings of responses may be compromised. For the people we support who are non-verbal, they are more reliant on everything apart from speech, and hence more is lost for them. But it is better, a lot better, than nothing!

When interacting in this way, I clearly add less to the sensory environment and bring less social pressure with me, and for those who may find social interactions a challenge, this may provide a 'way in.' Interactions with another person these last weeks often finish with her leaning across and turning her ipad off! My departure is instant rather than a protracted and potentially irritating process when I visit her at home and maybe miss or misinterpret her signals.

These screen interactions are clearly not for everyone. People need to have had some history of engaging with screens. This might favour the younger generation. Traditional phone calls are much easier for my mother, for example, than Skype calls to her in the care home. Data protection and information governance issues have been at the forefront of our planning. Agreed video conference media were used at all times. There were some understandable restrictions here if the person at the other end didn't have the approved media. In these situations, necessary justification of the uses of alternative platforms were recorded. Where students had WikiMe online digital care plans, details of the ID and password sign in protocol allowed the secure use of alternative media.

Observing staff interactions via screens has also proved successful. It is speculated that here there might be an advantage in some cases. If the person doesn't move around, my presence via a screen is less intrusive to the interaction. The staff member may feel less obviously observed.

Conclusion

This does not feel like a substitute for face-to-face interactions. Rather, it is an ongoing attempt to maintain contact and to provide staff mentoring and support through these extraordinary times. For our work, we do desire a return to normal, not a "new normal" of distanced interactions. However, in some circumstances it may be an ongoing alternative. Geographical isolation, aiming to reduce travel costs and carbon emissions could lead us to increasing use of digital consultations. Those at higher risk may be shielded for a longer period and we desire that interactions continue to try to combat the inevitable feelings of social isolation. There may be other additional risk factors that preclude face-to-face interactions and perhaps in these situations a friendly responsive face on a screen provides social and emotional connection and some reassurance.

Our experience offers a great confirmation that even in these difficult times, it is possible to have a very positive close encounter though far apart. This opens up the possibility of conducting Intensive Interaction sessions with people who might not be able to meet, either because of Covid 19 or for other logistical reasons. As long as they have access to a screen, let's experiment – it might just allow something wonderful to happen!

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For more information about WikiMe, please visit www.multime.com

A SEND teacher's journey of transitioning to remote teaching for pupils with complex needs

Amy Perkins

If you had told me this time last year, or even this time a few months ago, that teaching as I knew it would have changed beyond recognition and that I would have to adapt to a completely alien way of working, I would not have believed you.

But here we are! Week seven of lockdown, and teaching and learning has become very different indeed!

Some would say teaching a class of children with complex physical and medical needs within the four walls of a classroom is a challenge in itself. But it is a very rewarding challenge to say the least! However, remote learning is a completely different kettle of fish!

To start with, I was like a fish out of water! How would I continue to support my children and their families from afar? So much of what we do at Chailey Heritage is hands-on, face-to-face and intensive in its nature. As a mainstream teacher by background, the prospect of remote teaching may not have thrown me quite so much, but adapting within the SEND world was no mean feat.

Finding resources

To begin with, I set about finding suitable resources for the various children in my class. I spent many hours searching the web, considering what would work at home and what wouldn't.

Our curriculum at Chailey Heritage is a personal one. Each child has their own set of unique next steps (targets) designed for them. Within my cohort of six children, I have varying degrees of needs; from the most 'Sensory Beings' (Joanna Grace http://www.thesensoryprojects.co.uk/books) - who have reduced or little vision and complex physical and medical needs - to those who are learning to speak, read and move for the first time. Within the classroom with the specialised teaching assistants this disparity in needs isn't really noticed. In fact, they often complement each other, in that the children develop deeper and different relationships with one another. Turn this on its head and take it out of the classroom, and it presents various challenges. Challenges I was determined to overcome! There is a wealth of resources online, many of which are being offered for free during the current climate.

Resources such as:

- Soundabout - https://www.soundabout.org.uk/ - a charity offering music sessions for children and young people with severe and complex needs. They are now offering online sessions twice a week.
- Singing Hands - https://singinghands.co.uk/ - a signing based duo. They are offering a variety of sessions throughout the week from Makaton signed stories to 'Wine and Sign' evenings for adults!
- Story Massage - https://www.storymassage.co.uk/ - a way of combining story telling and positive touch. They are also offering online sessions twice a week.
- Joanna Grace, founder of the Sensory Projects - http://www.thesensoryprojects.co.uk/covid19-resources has collated a lot of the resources to form a COVID-19 Educational Resources List and she adds to it regularly. In addition, there is a wealth of materials for reading, maths and other subject areas also available online.
- Having selected relevant resources, what was I going to do with it all? How would I maintain contact with both the children and their families?

Communicating with children and their families

I was very keen to keep the relationships I had built with the children and their families going, and felt that contact with them was needed now more than ever as we all adjusted to a changing world.

Initally, I made some calls, used FaceTime and e-mail to make contact. I sent resource ideas through the post, by e-mail and started to do some online sessions with some of my children.

To begin with, it was hard to grasp this new concept and way of working, both for me and the children. For those who could, I ran online sessions involving reading, maths, communication and even physio sessions. The families and I had to be very inventive; from 'milk crate' box-sitting group, to adapting a space bar with cardboard and a switch to overcome the Windows to Mac issues. Over time it has become easier as I get into the swing of things with certain children.

However, this was not enough. I felt I was unable to support all my learners in this way and I felt I needed to do more to bring my class ‘back together’. This was where I needed a remote platform that I could adapt to meet not only my needs, but the needs of the children and their families.

When searching for a learning platform that worked for everyone, I quickly came to realise such a thing didn’t exist! Many of the remote platforms are not secure enough for us to use and so I was left having to adapt one. This was where Microsoft Teams came into play. I had never used Teams before, and by its very nature it is more designed for the business market rather than for schools. It has its own challenges; from using the interface itself to trying to add parents as guests. As always in the IT world, there is that one issue that crops up which you can never fully work out. After ironing out the creases, I set about creating my own class team.

Having set up Teams by inviting my children’s families, I was then able to use it to message all families at once (using the general post page) and individually (using the chat feature). I used the files section to upload resources that I thought would be helpful to parents, to which I continue to add . My most successful use of Teams to date is the video chat feature, which currently isn’t quite up to standard. Hopefully, Microsoft will solve this shortly when they introduce their 3x3 grid so I can see all of my class at once. Using video chat has enabled me to have one-on-one sessions with my children and their families, and I have experimented with whole-class sessions which have become a weekly fixture.

I may have a class with a wide variety of needs and some may get more out of it than others, but I think the benifits outweigh all of this. The children and families can hear and see me as well as one another, and we can continue to recreate some elements of the school day so the children don’t think they have been abandoned. Hearing the children vocalise to each other, show toys, choose songs to sing and say hello is the highlight of my week. In addition, I am currently trialling using the class notebook as a sort of photo library for the children. I take screen shots during the sessions I run and add them to the notebook. Similarly, parents can also add photos of their time at home.

Now, more than ever, communication with families is crucial. As yet, I may not have it all right, but I am making the best of what I have for the good of the children. We can never replicate the experiences we offer in school, but we can try our very best to keep the fun of learning and connection going while we are all so far apart.

Lessons learnt in lockdown

1. Be creative and don’t be afraid to try things out - we are all learning this new way of life!
2. Find a way to communicate with children and their families that works for them.
3. Support each other and share ideas - what works for you may work for others too.

If we can’t bring them to the classroom, bring the classroom to them!

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Raising our expectations of physical activity and exercise for people with Profound and Multiple Learning Disabilities

Alistair Beverley

As readers of this journal I am sure you live and breathe the needs of those with Profound and Multiple Learning Disabilities (PMLD.) I won't patronise you into thinking I know more about the person you support than you do. What I do want to reflect on is what I feel is a blasé attitude that some healthcare professionals have towards exercise for those with PMLD.

Many people with PMLD will be seeing neurologists, orthopaedic specialists, and cardiac specialists; but how many see a professional for the purpose of exercise? I believe that physiotherapists should be the 'go-to' profession for people with complex needs to engage and support with exercise. It has been said that if exercise were a pill, medical science would hail it as a wonder drug. The multi-system benefits of physical exercise for body as well as mental health are expounded to many of us through the World Health Organisation (WHO) and National Health Service (NHS). A target of 150 minutes of moderate intensity exercise or 75 minutes of high intensity exercise per week plus two strength sessions are prescribed as what we should all aim for. So, let me ask you this, how many minutes does the person you support achieve and more importantly what support do they get to do this?

If you or I were to visit the G.P. and say that we had grand plans of sitting on our sofa for the next month, the GP would likely warn us of the pitfalls of doing so. Issues such as reduced cardio-vascular health, increase in risk of illnesses including diabetes, cancer, osteoporosis and more would be cited. Pressure area formation may not be top of their list but is also an issue which plagues people who find it difficult to alter their position. Likely even lower on their list but of equal importance is postural deterioration. Now imagine the reaction if you told your G.P you're planning on sitting on your sofa for the rest of your life?

So, why then is it accepted for people with PMLD? This isn't to suggest that your G.P doesn't care or is somehow poor at recognising these needs. It's a wider, systemic issue within healthcare itself. It's about the externalised value we place on others. Sadly healthcare, as an industry has a poor track record of valuing the lives of people with learning disabilities. That isn't to say this is true for every staff member who works in healthcare. But you only need take a stroll through a google of health inequalities in learning disabilities to find that there is some serious work needing to be done. I know a good number of you are excellent advocates, I know some excellent self-advocates too, and Mencap, Scope to name a few, support people with these processes. I see and hear less from healthcare practitioners (as a group) though.

To garner change we need allies within the healthcare system, vocal people who can advocate for the needs of people with learning disabilities and can garner the collective professional "ears" of colleagues and professional bodies. People on "the inside" who can stand up and say, "this isn't good enough." So in this short article I want to make a stand to say that attitudes and approaches to maintaining physical health for people with learning disabilities (and specifically profound and multiple learning disabilities) are not good enough. From my own professional background, I firmly believe that physiotherapists should act as exercise support specialists for people with PMLD. We understand the complexity of healthcare issues faced by people with PMLD, be that respiratory, musculo skeletal, neurological and developmental. But we need to understand more. In its purest form exercise is hard, painful and exhausting. Do I exercise? Of course I do. Why? Because I understand the underlying health benefits exercise gives me, if you take away that understanding it's just blooming hard work! So, for people with PMLD who may not understand the health benefits, where's the incentive? When people are given a list of physio exercises without support to understand the reason behind them or ongoing support to complete them on a regular basis, compliance is pretty abysmal. We know this from studies and, if you've ever seen a physio you probably know it too. If we operate in this way with people with PMLD then what is the point in our assessment, the time of the individual, family and professional? You might as well not bother.

If ‘lockdown’ has taught me one thing, it’s that it’s nigh impossible for me to “teach” my daughter, she is 5 (and ¾ - that bit is important.) Her prompt retorts to my feeble attempts at going through schoolwork include, “you’re not my teacher”, “it’s not proper school”, “I don’t have to do it” and usually result in nothing getting done. Speaking to many families through lockdown, they report similar responses when it comes to exercise and people with Learning Disabilities. However when the face of the physio (or sometimes uniform – a light teal t-shirt in my case) pops up on Microsoft Teams, the response is quite different; 30-40 mins sessions with engagement, smiles, effort, happy position changes and perhaps a greater tolerance to “being faffed about with” in wheelchairs or sleep systems.
People with PMLD have lifelong conditions, so the traditional model of physiotherapy; 6-10 weeks (if you’re lucky) and a “here’s a home programme, crack on” simply do not hold water. For people with PMLD, we need to be offering a lifetime of support, not having to re-refer back for a reassessment or new programme. This just creates more hoops for families and carers to jump through. To be able to achieve this vision of the healthcare industry valuing people with PMLD enough to take their physical exercise levels seriously we will need to demonstrate the need for change and the power of exercise for people with PMLD. Everything from undertaking adapted resistance work with weights, practising rolling or just controlling your little finger. If it is done regularly, with targeted support and is meaningful to the individual, then we will see an improvement in physical and mental health. This will mean happier, healthier people.

Top tips to facilitate engagement in exercise/physical activity:

- Use the person’s function. whether it’s full upper limb control and create activities focussed on that. For example, if I’m working with someone who can perform some type of roll (it doesn’t even have to be a complete roll) in lying then I’ll engage them with that, using whatever motivates them, toy, picture, or allowing yourself to be bashed on the head seem to work nicely. The reason I enjoy rolling is if you’ve ever injured any body part, you’ll know about it when you roll over in bed at night. This demonstrates the level of effort and control required to perform a roll.
- Make it fun and manageable. Like many of us, we set off with new exercise plans with high hope and lots of energy. It’s important to remember the associated physical health conditions many people with PMLD may have and how exercise may affect these. Also, the loading of body tissues including muscles and tendons needs to be taken into consideration. You wouldn’t go and pick up 100kg without building up to it. People with PMLD need to build up similarly, start small and make it fun. Don’t set the bar too high or expect too much and remember, as my colleague the Mike James ‘The Endurance Physio’ says “the best exercise is the one that gets done”.
- Don’t take no for an answer. Services in PMLD are often more geared towards children’s services. This is the sad reality, but when you transition into adult services, owing to a number of factors, the intensity of support drops considerably. People holding purse strings are going to be under ever increasing pressure to control costs, therefore in order to access services that are necessary, the narrative needs to be one of “need” not “want”. I know, you shouldn’t have to always have to point out yet again the downside of supporting a person with a disability and I have been reminded of how exhausting this is for families/carers. It is, in my experience, effective in reminding people that the person you are advocating with/for does have additional needs which impact upon quality of life and that what it is you’re asking for is something to support that quality of life. It is a need, not a want.

I am a physiotherapist who has worked in community NHS services, private healthcare provision for those with PMLD and with private clients. I currently manage physiotherapy provision to around 100 students with learning and physical disabilities at Portland College in Mansfield. I am also privileged to hold two volunteer roles for Special Olympics Great Britain, first of which is as Team GB Physiotherapist, providing support for athletes and team members during competition. The second is as Clinical Director for Health and Wellbeing for Special Olympics Great Britain.

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Hanging Out Program

Sheridan Forster

Imagine this. You've had an infuriating day, and somebody sits down with you for ten minutes. You've had a seizure and feel horrid, and somebody sits down with you. The place you're in feels like a train station at rush hour, and somebody sits down with you.

Sometimes the person who sits down with you talks. Sometimes they share something with you. Sometimes they just smile. Sometimes they sing a song. They always watch you, your hands, your movements, your sounds, your interests.

The person might touch your knee. The person might sit two metres away. The person might walk beside you. The person might lie on the floor with you. For ten minutes, there is someone there just for you. This might be what I call HOP or the Hanging Out Program.

I wrote the Hanging Out Program nearly 15 years ago for a day service that I was working at. I wrote it because I saw and had been informed by my own research, that sometimes the biggest barrier to engagement was a culture that did not see sitting down and spending time with a person as a core part of the job of providing support to people with severe and profound intellectual disabilities. Spending time with a person was seen as an optional extra, for when the other work was finished.

The goals of HOP were therefore simple "spend 10 minutes with the person giving 100% of your attention and write down what happened". The purpose of writing down was partly to ensure that the time happened, partly to help people refine what they did, but mainly to build a culture that saw the small things that happened (that were often prefixed as "just this or that") begin to be seen as great, wonderful, celebratory things that were the basis of a life of quality.

I guess over time, the core maxims of HOP have grown in my mind as:

- We often know how to engage, but sometimes need to be given the permission, or more importantly, the expectation to do it.
- If a service cannot give a person ten minutes of focused engagement, then what is the point of the person being there?
- There are so many barriers put up to genuine engagement with people with profound intellectual disabilities; we need to talk about them to find a better way, and not allow the barriers to become festering sores which perpetuate isolation.

Sheridan is a speech pathologist and researcher with a special interest in adults with profound intellectual and multiple disabilities.

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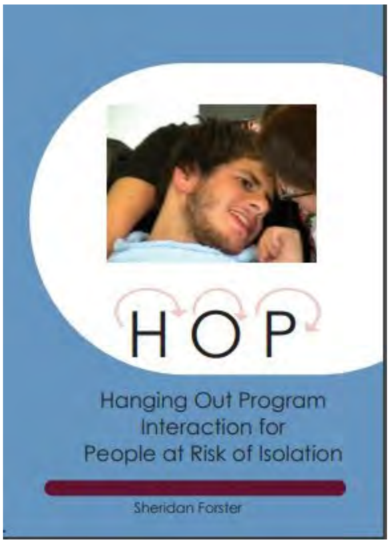
You can download the Hanging Out Program booklet at: https://sheridanforster.com.au/passions/hanging-out-program-hop/.



I developed a short workshop that I offer for staff, which I'm happy to share. You may consider doing this with your own teams.

Colleagues, Kaisa Martikainen and Katia Burakoff in Finland have translated the HOP booklet into Finnish and Swedish, and run workshops to share the ideas there https://www.kehitysvammaliitto.fi/tikoteekki/toimintamallit/hyp/.

Their video (though in Finnish), gives a wonderful example of HOP, or HYP as known there.

Finally, there is a small community of people interested in HOP, sharing resources and thoughts on Facebook. Please join us:
https:// www.facebook.com/groups/334617066670161/? ref=share.

PMLD LINK
sharing ideas and information

Summer 2020, Vol. 32 No. 2 Issue 96

What is a person in the world of complex disability?

Maren Hueffmann

As a PhD student in Anthropology and an occupational therapist of thirty years standing, this article introduces the research I am undertaking with children with complex needs. My focus is on the question of what makes someone 'a person'. The project draws on extensive fieldwork at a special school, while also seeking contributions from parents and carers of children with profound and multiple learning disabilities (PMLD).

My career as a paediatric occupational therapist has led me to work in a variety of different settings, including both medical establishments and schools. In the true spirit of the profession the enhancement of functional abilities, engagement in appropriate occupations and achieving independence to maximum potential has formed part of a daily mantra when working with children and their families. However, a genuine curiosity about human life in all its dimensions - from religion, philosophy, history and culture to the mundane activities of daily living–have driven me to consider my professional objectives in the wider context of society's make-up and norms. As a consequence, I embarked on a parallel journey through the academic discipline of Social Anthropology. Both these strands are now coming together in my research project involving children with complex disabilities. I seem to be coming full circle. My first job in London included working at various special schools, including one for children with severe learning difficulties. Now I find myself again at a special school, but this time as a researcher of a social science discipline.

The background to my research is formed by numerous factors relating to childhood disability. Firstly, the numbers of disabled school children with complex needs rose by nearly 50 per cent between 2004 and 2016 (Pinney, 2017), a phenomenon linked to medical advances improving life chances of preterm and disabled babies. Secondly, disabled children are up to four times more likely to suffer violence than their non-disabled counterparts (NWGSDC, 2016; NICE, 2013), which has been associated with attitudes and assumptions of society members, skills gaps (e.g. communication skills, knowledge of needs), barriers to provision and dependency on multiple carers. Thirdly, in 2014 the risk of being 'looked after' continuously by a local authority (i.e. children in care) for at least 12 months was 31 in 1000 children for those with severe learning disabilities (SLD) and 40 in 1000 children for those with profound and multiple learning disabilities (PMLD), as opposed to 5 in a 1000 for all children (Public Health England, 2016). In adulthood, a heightened risk of premature death was estimated to be 42% in 2015 for people with learning disabilities (Public Health England, 2016). The lack of appropriate facilities and increasing reports of abuse in adult care homes are currently being investigated by the Care Quality Commission (2019).

Except for the first point, these statistics make for grim reading for anyone involved with the lives of children with complex disability, which is associated with a variety of labels, PMLD being one of them. Still, a lot has changed for the lives of these individuals over recent decades. As the head teacher at a special school told me: "Thirty years ago we just cared for them, now we educate them." As such they are included in the education system. The recent changes in planning a curriculum and assessment structure that fits more appropriately than the P-levels, which have been used up to now for those students learning below the levels of the National Curriculum, have meant that the 'Engagement Model' will become statutory from the academic year 2020/21. Education norms and standards are being re-written to grasp these children's exceptional existence in our world, a world that emphasises rationality, cognitive intelligence and verbal communication. These aspects of human life are generally seen as the pillars of personhood in philosophy circles, but also in everyday life. As a result, individuals with severe or profound learning disabilities are often viewed as objects of care and denied the dignity of being treated as persons.

The philosopher and mother of a severely cognitively impaired daughter discusses themes around moral personhood in a number of books and articles. Here she sums up aptly what she has learned from her daughter:

> Sesha would never live a normal life. … The worst fear was that her handicap involved her intellectual faculties. … Yet … it never even occurred to me to … think of her in any other terms than my own beloved child. She was my daughter. I was her mother. That was fundamental. … We didn't yet realize how much she would teach us, but we

> already knew that we had learned something. That which we believed we valued, what we—I—thought was at the center of humanity, the capacity for thought, for reason, was not it, not it at all.
> (Eva Feder Kittay, Love's Labour 150; cited in Kittay, 2005:100)

Kittay points out how important it is to acknowledge interpersonal relationships that do not rely on cognitive ability and raises the issue of objectifying human beings with learning disabilities. She states that the emphasis on functional independence and modification of the environment, while crucial to supporting the disabled person, can also highlight the disability further. Instead, she adds, we also need to look at what capacity within the child there is to develop, e.g. the ability to experience joy or to form emotional relationships. Regarding the wider context of human society, she argues that we need to question the belief that the value of people derives from their ability to contribute, to participate or live independently, or to reciprocate the care they have been given.

With this in mind, I am tailoring my research around the following questions:

1. How can we discover the person behind the label 'complex disability' or 'PMLD'?
2. Is personhood an individual attribute applied when certain eligibility tests have been passed? And is it a static condition that one possesses?
3. Is personhood an aspect of one specific individual in one specific body? Or is it interactive and changeable?
4. How is personhood constructed in the absence of verbal communication skills and limited physical engagement with the environment?
5. What is the relationship between the recognition of the other as person and the quality of daily care and interaction?

Since January this year, I have been welcomed to a community special school as a researcher and volunteer support assistant. This allows me to get to know the students and to take part in all the everyday activities in the classroom, while also engaging in conversations with everyone to learn about motivations and attitudes. I have been eager to learn alternative means of communication, such as sign supported language (Makaton) or picture exchange communication symbols (PECS), and to familiarise myself with the use of eye-gaze technology. My methodology is based on the use of phenomenology and sensory ethnography with the employment of multi-sensory methods to come to a closer understanding of my participants life-worlds. Their limited verbal communication skills are only one facet to be considered. While they do not have the ability to verbalise their take on the world, it will be important to understand the ways in which they process sensory information, display intentionality and agency, communicate and generally extract from or give meaning to their lives. While I would never be able replicate their perspectives, even if I were to lie on the floor and look up or close my eyes to perceive without seeing, by engaging directly and closely with the children in their world, I will be able to take a step closer to an understanding. This requires the active participation in classroom activities in close physical proximity to the children. Observation of and engagement in direct interactions are at the heart of my discovering more about what it takes to be and to be recognised as a person.

Currently, of course, my fieldwork is interrupted due to the Covid-19 emergency and I have to say that I miss students and staff, and being part of the commitment to engagement in and innovative approaches to discovery and learning. While the school is open to a select number of pupils, understandably only staff are allowed on the premises. Therefore, what better way to stay engaged with my study than reading, which includes back issues of the PMLD LINK journal, writing and looking for alternative ways to add to my research. I am hoping that everyone who has read this far may also take a look at the invitation to participate in my study. I am keen to hear from parents, carers and anyone linked to the 'world of complex disability', as my research is driven by the experiences and perspectives of its participants. Thank you for taking an interest!

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

Watch this space! PMLD LINK want to review the standards and their use - your help is essential. The PMLD Standards are a set of coproduced standards to quality assure services and support for children and adults with profound and multiple learning disabilities. They outline key principles and aspirational benchmarks that should be evident across all education, health, and social care services.

Ideally these standards need to be adopted by commissioners, providers and regulators of services. Families, advocates and other key stakeholders, with awareness of the standards, should gain clarity of what level and type support they can expect to receive, and be able to recognise gaps in service delivery.

PMLD LINK has been encouraged by the widespread endorsement of these standards across the UK and Ireland. Our annual ‘Raising the Bar’ conferences and our journal have shared presentations of inspiring practice from people using the Standards to great effect, enhancing life opportunities for people with profound and multiple learning disabilities.

Do take time to read and reflect on these standards yourself.

The PMLD Standards are free to download - http://www.pmldlink.org.uk/resources

The PMLD Standards are available at:
http://www.pmldlink.org.uk/resources/#pmld-standards
http://www.pmldlink.org.uk/wp-content/uploads/2017/11/ Standards-PMLD-h-web.pdf

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How can theories about installation art help us articulate the inclusive value of immersive spaces?

Jill Goodwin

As an installation artist I am fascinated by how entering a space with an ‘arresting’ atmosphere can heighten our sense of being in the present moment. In my doctoral study (Goodwin, 2019) I created a large sensorial installation, Golden Tent, within a school for pupils with PMLD and explored how class groups responded to the space. Installation art is a form of visual art that aims to impact directly upon the whole body of the viewer. It is often described as ‘theatrical’, ‘immersive’ or ‘experiential’ and this focus on the experiential (as opposed to the intellectual) makes many forms of installation art fundamentally inclusive for both ‘sensory beings’ and ‘linguistic beings’ (Grace, 2017).

In this article I discuss how and why immersive sensory spaces can provide opportunities for sensory and linguistic beings to be together in new ways. I begin by drawing on some art history to explain why installation art can be understood in this inclusive way and then I reference the philosophy of phenomenology and the term ‘affect’, both of which are used in the fields of art and PMLD. Finally, I explain a little about my own study and why I think immersive aesthetic spaces are of value to us all.

The genre of installation art

Understanding a little about installation art as a genre is helpful in appreciating the value of immersive environments for cognitively-diverse audiences. Installation art emerged during the 1960s, in part as a critique of the fine art gallery system and as a protest against the commodification of art. Some artists took their work beyond the gallery, creating happenings or land art that could not be bought and sold by rich collectors. Others highlighted the social contexts in which their art was seen by making the whole space, rather than just the objects within it, part of the artwork. The viewer’s presence within the artwork is a central feature of installation art, with a focus on their embodied experience. Instead of trying to represent texture, space, light and so on through painting and sculpture, installation artists offered these elements for viewers to experience directly. Colours, forms and sensations were to be ‘felt’ rather than intellectually analysed. This shift away from ‘object knowledge’ and towards ‘subject experience’ is an important one that equalises the accessibility of the artwork, increasing its potential to provide a cognitively-diverse audience with a mutually shared experience.

Phenomeonology

Phenomenology seeks to discover new meanings by getting behind linguistic and conceptual frameworks and focusing on the ways in which phenomena are received by the body. When installation art was emerging as a new genre, the French philosopher Merleau-Ponty was writing about the phenomenology of perception and many artists and critics drew upon his work to help explain and discuss installation art. Merleau-Ponty wrote about the embodied nature of perception, and argued that the perceiving subject (the person looking or touching, for example) and perceived object (the thing they are looking at or touching) are inextricably linked because an object only comes into being when it is perceived by a subject. These phenomenological ideas of perception and embodied experience became central to theories of installation art. In addition, they have been used to help us think about how individuals with profound cognitive impairments engage with the world free from linguistic and conceptual frameworks.

Several researchers who want to challenge deficit-based conceptualisations of people with PMLD have also turned to phenomenological frameworks to provide new ways to think about their abilities and agency. For example, Simmons and Watson (2014) apply phenomenological concepts in their search for alternative understandings of pupil self-awareness and capability, and Taylor (2019) is using a phenomenological approach to reimagine assessment and to understand the process of learning for children and young people with PMLD. Although phenomenology is a complex philosophy, in trying to understand the world of our companions with PMLD it is helpful for us to be aware of just how much we categorise and abstract our own sensory experience through language, and to try and bypass this in order to connect with our own sensory-being.

Affect

The term ‘affect’ is also one found in both writing about art and writing about people with PMLD. Affect is the word used to describe the experience of feelings before words can be used to articulate them. In the PMLD literature, ‘affect attunement’ describes the matching of an emotional quality/mood of an individual with PMLD by their carers. In art theory, the term affect is used by theorists attempting to explain art’s intrinsic power on the body. O’Sullivan (2001), for example, speaks of affects as ‘moments of intensity, a reaction in/on the body at the level of matter’ (p.126). Indeed, he implores spectators of art to apply a different quality of attention when viewing art, one in which they are physically still, patient, and listening in a kind of meditative way, in order to ‘allow’ the experience of the art to reach them at the level of ‘affect’. Although O’Sullivan was an art theorist writing for a very different audience, it is reasonable to conclude from his work that when aesthetic experience is understood in terms of affect rather than intellectual understanding or knowledge then variations in cognitive ability are irrelevant. His words confirm the equalising potential of art, particularly given that this kind of mindful attention is the province of a great many sensory beings.

From ‘doing’ to ‘being’

In my PhD study I created Golden Tent, a large yellow satin enclosure with a golden floor, as a space for staff and pupils to spend time within. I wanted to see if an immersive environment could bring those of us who are linguistic beings into a different mindset, and to explore whether this would influence our experience of being with our companions with PMLD; ‘These are people supremely good at being in the moment’ Grace (2020:21) tells us, and I wanted to facilitate meeting them there.

I was interested in shifting the quality of our attention and presence, given that we spend so much of our time with busy minds and full schedules. Perhaps by bringing us more in touch with the sensory in ourselves we could become more present and available for our companions? I defined this as a shift from a ‘doing’ mindset to a ‘being’ one. The feedback I received from staff suggested that the form and qualities of the tent did indeed prompt a

shift in mindset, heightening awareness of the body and facilitating meaningful non-verbal encounters with pupils. Some felt that Golden Tent created a 'held' space that allowed them to sustain a quiet and attentive presence alongside their pupils for longer than they might have done inside a busy classroom. Other staff spoke about the space offering the pupils a chance to express themselves.

In order to articulate the true value of these moments inside the tent, I felt it was crucial to find a framework that did not compel us to look for pupil progress towards learning targets (I do not have the space to write about how I did this here, but if you are interested to know more there is a link to my thesis below). I wanted to value simply 'being' and 'being together' as something profoundly worthwhile for both sensory and linguistic participants. Although many of us instinctively recognise these moments as mutually valuable, it can be difficult to argue their worth within a school context where our efforts are sharply focused on learning outcomes and pupil progress. However, if we can occasionally flip the notion of staff as the competent ones facilitating the progress of (incompetent) pupils, to one of mutually rewarding experience, then we can acknowledge how much individuals with PMLD have to teach us about being-in-the-moment. Immersive environments, indeed the arts in general, can help to level the playing field, connecting us with our embodied, non-verbal sensory selves and increasing the potential for these shared moments of mutuality.

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To view Jill's amazing 'Golden Tent' in its true magnificent splendour, look online at the full colour version of this article. Log in using your subscriber details http://www.pmldlink.org.uk/login/

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Vissi d’arte (I Live for Art)

Sandra Taylor and Martin Goodwin

Over the past year, Welsh National Opera (WNO) has been working with pupils at Mayfield School (Birmingham) who have profound and multiple learning difficulties (PMLD). WNO has an established communities' programme and wanted to enable pupils with PMLD the opportunity to experience live opera. This article discusses the coproduction of creating an opera performance with and for pupils with PMLD.

Exploring Opera

As few of the artists had worked with pupils with PMLD, an initial training session was delivered. This training supported the artists to understand fundamental principles and approaches in working with pupils with PMLD such as interactive and sensory-based approaches. As this was a developmental process, reflection time was built-in between the teaching staff and artists so that a process of 'listening and responding' to the pupils was facilitated (Goodwin, 2013).

To ensure the performance responded to the diverse range of needs, artists worked with pupils who had a range of abilities. This enabled the artists to explore and develop how to differentiate interactive approaches used to engage pupils. Over time, artists built their confidence in engaging and interacting with pupils. Artists became comfortable with singing closely, using touch as a form of communication and actively using principles of intensive interaction such as burst pause, sharing attention, having fun and using playfulness with the music (Hewett 2018). In one example, an artist played with up and down sounds and combined it with physical movement reinforcing the concept on her body, to which she seemed to anticipate the coming sound; the pupil looked intently for more and giggled in response. Artists saw the humanness of our children and looked beyond their needs by responding to their abilities and nurturing their participation and engagement.

The first stage of the project was to introduce pupils to opera music gently. Initially, short musical motifs encouraged space for pupils to react and respond and for the music to react to their communication. From this, we gained an understanding of instruments, tone and dynamics that pupils preferred and tolerated. Pupils had time to experience a range of instruments such as the harp, flute, clarinet, double bass, piano and, soprano, alto and baritone singers. Two pupils who usually fleetingly encounter stimuli persisted in exploring the sound of a clarinet by resuming their attention when it was immediately presented and attending to the vibration and sound of the double bass by seeming to concentrate on the stimuli intently. One pupil showed interest in the trombone by looking around and tracking the movement of the instrument. Other pupils seemed to be captivated by the sound of singers. One pupil who typically has brief periods of eye contact intently listened to a soprano while another pupil stilled in the presence of the singer and looked for the sound when it stopped.

A greeting song based on 'Pick a Bale of Cotton' was initially a piece accompanied by a squeaky pig which initiated much response and laughter from our pupils. Over time as the ensemble of instruments became involved, the song was presented with each instrument saying hello to the pupils in the group while the singers sang the song. Similarly, a goodbye song based on the same piece communicated the end of the session.

Developing an Opera Piece

From listening and responding to pupils' preferences, ideas were formed about which opera arias to try with the pupils. During the project, some pupils responded to the music by vocalising their sounds and body movements. The sounds were made during songs that provided a strong pulse beat and some songs which were slower. Most of the vocalisations were interpreted by staff as indications of enjoyment, requesting more stimuli or interaction. In contrast, other vocalisations seem to express being relaxed or emotional connection such as sadness. Body movements or moments of stillness were also listened to as potential indications for preferences of music and stimuli.

At times pupils' engagement was affected by the impeding challenges they face, such as tiredness and the impact of medication. During a song from Carmen, one of the pupils slept to the singing which was accompanied by a piano. The worker who noticed the pupil was asleep carried on singing and carried out a gentle massage of his shoulders. This approach respected his minimal participation by giving him every opportunity to respond should he have momentarily awoken and be included. Pupils also gave honest reactions which were not concealed. These reactions were embraced as they supported us to structure the piece in a way that responded to their preferences. One pupil with Rett Syndrome displayed a deep emotional connection to pieces of music which she showed happiness and sadness through a tear. Opera is a medium that evokes a range of emotions. On the majority of occasions, we would offer the pupil reassurance and some time to process the emotion by giving them a hand massage. However, if we felt the pupil could not control their feelings, we would allow them to exit the room and then re-introduce them at a later point.

As a piece, we wanted pupils to encounter a broad dynamic of emotions, texture and colour of opera, so decided to curate the piece thematically on seasons. The theme of Seasons enabled the production to respond flexibly to the musical interests of the pupils as we would not be tied to certain songs and for a range of musical styles and dynamic texture to be explored. The seasons provided an opportunity to explore different emotional contexts such as awakening for spring, winter-restfulness and sleep, summer – a time for parties and socialising and autumn-a brewing storm.

In working with staff, we quickly realised that the key to increasing pupils' engagement with the pieces of music was to get the staff on board by making it stimulating, so we decided to use well-known pieces of opera. As indicated by the recent report 'Raising the Bar' through Inclusive Theatre, the engagement of staff within the theatrical piece and the effectiveness of support that they provide is crucial to the quality of the experience for people with PMLD (Fergurson, 2019). Instantly the pieces that staff knew, such as 'Habanera' from Bizet's Carmen heightened the pupils' experience as staff were singing and improvising movements to use with the pupil.

Arias within operas had to be changed as they were too short for the pupils. Repetitions of parts of the melody were added. The Can-Can was adapted to enable pupils responses; such as to a trombone that quivered and rolled in response to the pupil's communication. Additionally, significant changes to the tempo of the piece (gradual speeding up) and deliberate pauses within the music to allow opportunities for pupils to respond, proactively cooperate and make initiations within the piece. Pupils took part by proactively drumming or initiating shaking a shaker. Other pupils responded to body awareness work. One pupil responded by moving his head in the direction of the sounds, stretching his arms out, making laughing sounds and seeming to anticipate the shaking of the bells over and across him.

Traditionally, opera is a grand occasion and is commonly set in large auditoriums where there is often a divide between 'audience' and 'performers'. This production aimed to provide the pupils with the essence of opera. Within this production, the proximity between the actor and audience was changed to being staged 'within' and 'around' the pupils. The pupils became active participants in the piece by performing with the artists. This alteration enabled musicians and opera singers to interact with the pupils and the pupils to engage with the artists directly. For pupils with PMLD, the proximity of the artist is key to processing the experience as some pupils may not have distal awareness within the room and beyond their personal space (Northern Ireland Curriculum 2020).

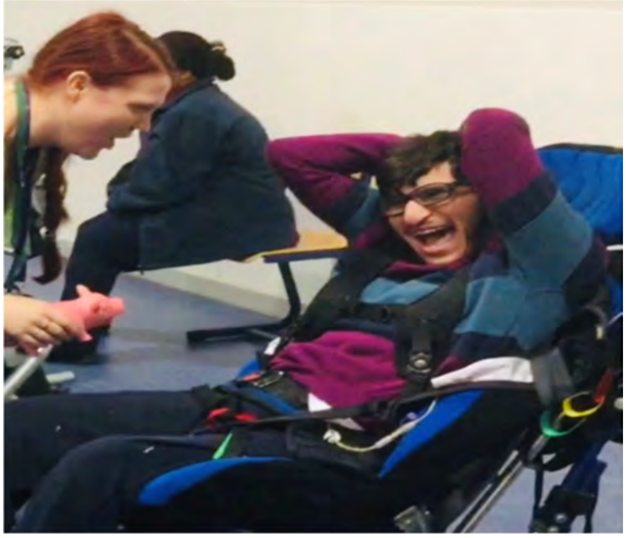
Traditional opera uses large sets and costumes to evoke the dramatic qualities of the music. Stimuli such as props, puppets, instruments, material and lights were utilised to augment the arias and make them interactive. Props were selected to represent the seasons and to provide stimuli that represented the feeling evoked within each song. Some examples include silver circle hoops and diamonds with white lights attached to represent winter, hand puppet butterflies to represent the movement of butterflies during spring, a rustling and flowing use of a space blanket to represent the movement of a storm.

Opera Concert

During the final stage of the project, a group of 10 pupils experienced the piece as a whole. This was an essential stage of the project as it enabled the creative team the opportunity to observe how pupils responded to the whole piece. The process revealed some initial challenges, such as the optimum way to position pupils so that they could be involved, the need for transitions between songs. Also, we contemplated the notion of how or whether to fill the space where clapping may ordinarily take place; however, one pupil initiated clapping to fill the pauses and became louder when he realised everyone was listening to him!

The season of spring included the orchestral pieces ‘Mood Morning’ (Peer Gynt Suite) and the ‘Flower Song’ (Lakme). ‘Mood Morning’ was played instrumentally by the ensemble and butterfly finger puppets were fluttered at different proximities against a black background to promote attention, locating and tracking skills. During this song, a pupil with CVI (Cortical Visual Impairment) blinked and responded by looking towards the butterflies and another pupil seemed to be interested in their fluttering movements as he calmly explored them with his hands. The flower song, was performed by two opera singers, whilst accompanied by the piano and fragranced flowers. During this song, one pupil who usually shows only fleeting responses to stimuli seemed captivated by the music she was hearing by moving her head, extending her arms and opening her eyes wide for the duration of the piece.

Included in the summer season was the ‘The Birdcatcher’s Song’ and ‘Papageno’ from The Magic Flute and ‘Brindisi’ from the opera La traviata. Pupils laughed at the sound of the puppet bird, showed anticipation by looking for more when the sound stopped or the bird disappeared and some pupil's independently initiated contact, feeling the bird’s feathers.



Vivaldi's ‘Autumn’ represented the turning of the season. During this song which was played by a cello, violin and flute, accompanied by hand fans and a wind machine, a silver piece of space blanket was waved dramatically in front and over the pupils. One pupil reacted to the song by reaching his hands out; trying to clasp and chase the material while other pupils responded to the starting and stopping of the fans by noticing their gust.

Two of the pieces that were chosen to represent winter were ‘Ave Maria,’ and the ‘Evening Prayer’ from Hansel and Gretel. Both items reflected the stillness of winter and were devised to enable relaxation and secureness. During the aria ‘Ave Maria’, performed by an opera singer to piano accompaniment, pupils took much interest in the lights that were presented nearby, by stilling, intently looking and reaching out to explore their shape. During the ‘Evening Prayer’ sung by the ensemble and accompanied by piano, violin, cello and flute, furry blankets were given to pupils to provide security and warmth on a winters' night while pupils responded to peek-a-boo style games and calming interactions.

Throughout the project, pupils showed many moments of positive engagement and showed a range of potentially communicative/expressive reactions to the pieces of music. During sessions, the staff gave positive feedback regarding how pupils responded to the live instruments and singing, particularly in terms of developing opportunities for communication and cognition. The performances allowed pupils to respond to social events, interact and communicate with others, show awareness, explore and control stimuli. Similarly, through the exploration of full range stimuli, the project supported the development of physical fine motor skills, sensory integration, visual and hearing skills. Importantly, pupils had opportunities to practice and maintain previously learnt skills and generalise concepts with new people and within novel experiences.

Access to a theatrical experience provided much pupil enrichment and promoted opportunities for improving the wellbeing of pupils. The opportunity to encounter playful interactions, explore objects and stimuli, respond to and co-create musical experiences supported the development of interactive and cooperative play, the development of emotional responses, self-determination and further formation of pupil's preferences.

The Welsh National Opera (WNO) aims to initially make this production available to schools in the West Midlands. The production will be for ten pupils at a time and an education pack is currently being devised.

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Truly meeting Caleb: A detailed account of the impact of long-term music therapy for a boy with profound and multiple learning disabilities

Leanne O'Keeffe

Caleb is nine years of age and was born with cerebral palsy, dystonia, epilepsy and severe global developmental delay. Caleb has a severe visual impairment and does not communicate intentionally. He finds it difficult to use his body and relax his limbs. Caleb is a gentle, happy and sociable boy who has responded positively to music from a young age. Caleb's parents knew that they wanted to explore the possibility of music therapy as soon as they could. I am a therapist at the West Midlands Music Therapy Works group and I began work with him in February 2014.

Working with Caleb

I see Caleb for weekly or bi-weekly sessions, depending on his availability at his family home. These sessions last for between 45 and 60 minutes and to date he has received 175 sessions. Sessions are ongoing and form an important part of his regular routine. Caleb and I work on a range of aims which are continually under review in order to meet his current needs. Caleb has been consistently interested and attentive in sessions and has made stable and constant progress. Music therapy has been funded partly by The Amber Trust (2014-2017) and partly by friends and relatives.

Music therapy is essential to Caleb's development and wellbeing. It has consistently been Caleb's most significant clinical intervention and provided clear progress in his education and development. Caleb's sessions vary from week to week and follow no consistent structure apart from at the beginning and at the end of the session we utilise the same 'hello' and 'goodbye' songs for consistency and familiarity. As his muscle tone and ability to control his limbs varies, I adapt activities with this in mind. I try as much as possible to include a range of both structured activities, and improvised music, though the use of instruments and voice.

Why Music Therapy?

Music therapy is the applied use of music to achieve clinical goals. Therapists within Music Therapy Works use a clear model of music therapy which means we have a detailed working knowledge of counselling and psychotherapeutic processes (https://www.musictherapyworks.co.uk/mtw-model-of-music-therapy). This understanding enables us to go beyond a purely musical intervention, providing clarity and support in processing issues such as trauma, attachment, bereavement, developmental issues, life limiting problems and mental health concerns. Music is an incredibly versatile medium and as a result the therapeutic benefits for clients can be vast and varying.

In our early sessions I focused on encouraging Caleb's physical movement. He was incredibly motivated by the music and so would try hard to move his hands, fingers, arms, feet and head in order to participate. It became clear that music therapy was not only having an impact on his physical needs i.e. things that we could observe, but it was also benefitting him emotionally and psychotherapeutically through empowering him to connect and express himself.

Recently, Music Therapy Works created a video which highlights the benefits of music therapy for Caleb and raises awareness and understanding of the impact that music therapy can have on individuals. This video is entitled 'Truly meeting Caleb' (https://www.youtube.com/watch?v=xAbyEV8qUrc). Following completion of this video I received a thought-provoking message from Caleb's mother:

'I loved the bit on the video where you talked about Caleb's mental health. No-one has ever mentioned that before - which is something I now find pretty shocking! Thank you. It has made me think how important it is to frame things in the light of mental health as well as physical health when talking to the various professionals involved in Caleb's life, especially to those who don't seem to fully understand him...Unfortunately, both the system and certain individuals often see Caleb too simplistically and not holistically, which is part of why it can feel like a battle to ensure that he is accurately understood and advocated for, and that his needs are genuinely met.'

Encouraging Empowerment

Music and sound exploration are meaningful to Caleb and sessions empower him both physically and emotionally. Caleb can hear his achievements immediately, providing a sense of confidence and self-worth. He can show others his level of understanding and prove that he can achieve more than some may presume. Caleb shows his determination and drive to succeed during music therapy and this impacts on his mental wellbeing. He is also able to experience independence within sessions. He feels empowered and in control.

Music therapy provides Caleb with a safe space where he can explore both his abilities, and the world around him. This is a time where he can be at 'his best' which has numerous benefits for him, including for his mental health. Caleb can experience trust and he is able to explore and share aspects of himself, which is only possible through a strong interpersonal relationship within a therapeutic environment and without recourse to words.

Working with the Whole Family

Through psychotherapeutically informed work with the whole family system, Caleb's family can relate to each other in new ways and reflect on their experiences of each other. Music therapy serves to enhance and explore relationships and allows family members to express feelings, both joyous and difficult. Music therapy enables everyone to interact and respond at an equal level. Everyone is heard and everyone is important. Having his family around him showing their support encourages Caleb to achieve further and to explore who he is. Music therapy has provided his family with a deeper insight into Caleb, his personality and abilities.

At times, Caleb participates in joint activities with his twin brother. He knows that he is an equal in these activities and that he has the power to make his own decisions within an environment where he is being heard. At other times Caleb can socialise with his entire family, again on an equal level, providing further positive experiences and a sense of belonging. Music Therapy provides a profound experience for his whole family as they participate in activities together with mutual acceptance.

The Importance of a Long-term Intervention

Short-term work would have provided only simple practical ideas and solutions for the family e.g. turn taking and basic musical exercises. It would not have allowed for a successful psychotherapeutic intervention, built upon a strong interpersonal relationship. Consistency and routine are important to Caleb and this helps him to gain more from his sessions. Caleb now recognises my voice as soon as I step into his house. Over time Caleb has been able to pre-empt aspects of our sessions and the feelings that they evoke for him. Caleb trusts me, and he can explore and share aspects of himself which is possible only through our long and ongoing relationship. Due to the long-term time commitment of all members involved, music therapy has enabled a shift in the whole family dynamic. It has enabled them to 'really get to know' each other (hence the title of our video: 'Truly Meeting Caleb'), relate at a deeper level, develop firmer and more profound attachments, and show their enjoyment and need for each other's company.

Communication and Interaction

Caleb needs to be allowed ample time to process and respond to questions, and it can be difficult to know whether Caleb is communicating intentionally. As a result, I have sought to explore clear ways of communication that Caleb can access. Our current work, with support and guidance from his speech and language therapist, includes trialling the use of two AAC switches for choice and decision making. We use one switch on the right-hand side of his head and one on the left-hand side of his tray, to be used by his left hand. For Caleb to use the switches with intention requires prompting, modelling and time. He can now indicate simple choices such as yes/no, stop/more, your turn/my turn and different musical instruments. He repeats these activities at length in his music therapy sessions so that we can encourage consistency and understanding within a motivating environment.

Music therapy sessions also allow Caleb to communicate non-verbally through improvisation. Caleb utilises instruments or voice to express himself in ways that are of his choosing, and he is aware that he is continually heard. His music is met by mine and together we can relate without the use of words. Caleb's music is personal to him and it allows him to interact on a different and more creative level.

Cognition and Learning

Caleb can show understanding of simple repetitive activities in music therapy sessions and will act accordingly. Modelling is important and it is through this that Caleb can show his ability to learn new activities. Caleb focuses well during sessions, and continually shows that he is eager to learn. For example, Caleb knows exactly how to move when playing different instruments that he hears. As soon as the ukulele begins, he stretches out his hands and fingers, ready to strum the strings. Or, if I ask Caleb to stretch his arms out, away from his body to reach the drum he understands these instructions immediately.

Sensory and Physical Needs

Music therapy has enabled Caleb to tolerate sound better, to cope with loud and unexpected noises and to be able to distinguish between different sounds. Sessions have also allowed for Caleb to focus more intently on himself and his current activity within a safe space, supporting his ability to block out background noise. As he is fully visually impaired and given his level of vulnerability, Caleb relies heavily on his hearing. The ability to refine his listening skills within a supportive environment is crucial for him. Through our work, Caleb also now copes better with touch and physical sensations. He will tolerate all manner of feelings on his hands and he is much more willing to explore with them.

Where possible, music therapy tries to cater to Caleb's physical needs too. Caleb can grip for short periods and use a beater independently. Caleb can also move in a variety of ways (i.e. forwards, backwards, out, in) when instructed, and tries very hard to do so on his own. His motivation to succeed and to create encourages Caleb to want to move more and further. Playing different instruments allows Caleb to use his body in different ways and to remember these variations when he hears each instrument.

Music and sounds assist with relaxing Caleb's muscle tone throughout his body. Playing instruments allows him the opportunity to think about how to relax parts of his body that at times appear stiff and uncomfortable. As we repeat these activities, he can associate feelings and movements with each instruction and relate these to different instruments. Music therapy also allows Caleb a chance to explore his voice, and the physiology around voluntarily making sounds, through our joint vocal improvisations.

Conclusions

Caleb's family feel that music therapy is the most effective intervention to genuinely enable Caleb to meaningfully engage and succeed. Music therapy allows for exploration and acknowledgement of the mental health and wellbeing needs of a child with profound and multiple learning disabilities. It also provides an accessible environment for the client to benefit developmentally, cognitively, socially and physically. Music therapy has been crucial to Caleb's development to date and has assisted him in his self-exploration and identity. Moreover, it has allowed he and his family to know each other and celebrate their relationships in an entirely new way.

For more information about music therapy and the services that we provide then please visit our website: - www.musictherapyworks.co.uk. Here you will also find the video 'Truly Meeting Caleb'.

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sharing ideas and information

Sensory stories as a meaningful occupation for people with profound intellectual and multiple disabilities

Rebecca Haythorne

This article discusses the history of sensory stories and their role in Occupational Therapy practice as an occupation to increase meaningful activity engagement for individuals with profound intellectual and multiple disabilities (PIMD). This terminology is used more often in international circles, although in the UK the description of profound and multiple learning disabilities (PMLD) is more commonly used.

Multi-sensory stories, a history

First envisioned by Fuller (1990) and Park (1998) multi-sensory stories (MSS) were created to include persons with profound learning disabilities in storytelling culture (Lambe and Hogg, 2011). MSS have since been used effectively with individuals with a range of needs (Burg et al., 2016), for example, Deborah Marr and Victoria Nackley (2005) developed the idea of MSS in Occupational Therapy practice as an intervention for children, with autism, who displayed hypersensitivity to sensory input (Martins, 2017).

But what are they…?

'Telling stories is one of the simplest, most enjoyable and most transformative activities on earth'(Grove, 2013, p1) .Storytelling exists in all cultures and all settings, and stories have been used to entertain, to make sense of the world and events, to share understanding and to help with coping (Grove, 2013). Martins (2017) identifies MSS as a concise narrative in which each section of a stories text is partnered with a relevant sensory experience, each story typically targeting a broad range of senses. Story experiencers may engage with the narrative through the text, the stimuli, or both; no part has dominance (Patterson, 2016). A reference stimulus is usually presented to the listener when the story starts thus making the activity recognisable to the listener (Burg, et al., 2016).

According to Lambe and Hogg's (2011) general guidelines for sensory storytelling, stories should consist of 6 to 16 short sentences, which are supported by 6 to 8 stimuli. Every 1 or 2 sentences are linked to one stimulus. The stimuli are selected according to the content of the sentence and the assumed preferences and abilities of the individual with (Grace, 2015). Martins (2017) proposes that an effective story includes distinctive elements that focus the individual's sense of sight, sound, taste, touch and smell. For example, touching a pencil may not be strongly stimulating but touching something gooey is more likely to elicit emotion or communication (Patterson, 2016). Other examples may include having a stimulus which emits heat to illustrate the word "hot" or having an object that spins to demonstrate the word "spinning" (Grace, 2015).

Profound intellectual and multiple disabilities

Individuals with PIMD are vulnerable to sensory deprivation (Grace, 2014) and have an increased need for non-verbal communication (Mansell, 2010). MSS can add significance to the lives of people with PIMD by creating opportunity for meaningful occupational engagement. The term PIMD (or PMLD) can be used to describe a range of conditions which may include a sensory impairment (such as visual impairment or hearing loss), cerebral palsy or other physical disabilities, an autism spectrum condition, mental illness, medical conditions such as epilepsy or a debilitating or degenerative medical condition (Mansell, 2010).

Multi-sensory stories as an occupation

Sensory stimuli don't just support the words in telling the story, if well chosen, they tell the story in their own right. This means that the story can be understood and enjoyed equally by someone who understands the spoken word, and by someone who does not understand the spoken word (Grace, 2015). Understanding what makes great sensory stimuli comes through building an awareness of the sensory experiences encountered in day-to-day life. Concurrent with the person-centred underpinnings of occupational theory and in line with standard 5 (meaningful time) as outlined in PMLD Standards (Doukas et al, 2017:34), , MSS offer a person-centred approach in supporting individuals with PIMD to participate in a meaningful occupation, making the enjoyment associated with stories accessible to people who cannot be captivated by the voice of the storyteller and pictures alone (Burg, et al., 2016). For example, the content of MSS can be individualised with sensory stimuli (i.e. tactile, olfactory and/or visual) being selected and presented in relation to the abilities and preference of the individual (Burg, et al., 2016 and Grace, 2015).

People with PIMD may struggle to engage in a range of meaningful occupations, MSS supported by the use of relevant objects chosen for their sensory qualities and appeal has been identified as an enjoyable and fun activity for individuals with PMLD (Grace, 2015 and Fuller, 1999). MSS can help facilitate the relationship between caregiver and individual with PIMD and provide a form of occupation, one that insights the senses and gives meaning. Telling a story creates opportunities for connecting with others and MSS have been shown to increase activity engagement (Young, et al., 2011). The shared goal of identifying stimuli can provide a purposeful focus, empower individuals with PIMD and the people around them (Park, 2013).

Sensory storytelling places emphasis on sharing and experience in the here and now? (story) rather than being 'told' a story. Patterson (2016) suggests that Occupational Therapists can use MSS to address goals centred around; expressing preference, initiation and responsiveness, participation and joint attention and life skills. Occupational Therapists trained in sensory integration can provide valuable input to selecting appropriate sensory stimuli to ensure that the experience is an enjoyable and meaningful one. If a sensory integration-trained advisor is not available MSS should still be considered, however, it is still necessary to establish some sensory preferences. For example, is the person calmer with a firm or light touch? Are loud sounds over stimulating? Readers may wish to consider using some form of sensory profile tool to help guide this process further. Sensory profiling tools can measure an individual's response to every day sensory events and provide a picture of processing patterns and inform intervention strategies (Jorquera-Cabrera, et al., 2017). There are a number of tools freely available online based around Dunn's (2014) sensory profile or Bogdashina's (2003) sensory profile checklist for those who would like to pursue this further but my not necessarily be able to utilise an Occupational Therapist trained in sensory assessment.

Research involving the usage of MSS has found that targeting MSS at an individual level can help a person to increase their attentiveness and alertness skills (Ten Burg, et al., 2015) and support people to ascribe meaning to stories (Pearce and Mackintosh, 2010). The repeated use of an MSS as a predictable part of an activity session has also been found to build familiarity, reduce anxiety and bring comfort (Grace, 2015). Research by Grace (2014) and Lacey (2006) further identified MSS as being beneficial for increasing wellbeing and cognition.

How can multi-sensory stories be used to further advance Occupational Therapy practice?

Sensory stories have been established as useful in supporting people achieve specific learning targets i.e. making choices (Lambe and Hogg, 2011) or at dealing with sensitive topics like understanding period pains (Young et al. 2011) and dealing with bereavement (Dowling, 2011). There could be further potential for Occupational Therapists to use this in their practice, not only as a form of a meaningful leisure occupation but also to promote and encourage self-care and productive occupations.

Conclusion

MSS can create opportunities to communicate stories through sensory stimuli and give people with PIMD the chance to engage with a storytelling experience and learn new skills. MSS may not be appropriate for everyone and they are not posited here as a replacement for any existing approach. Rather, they are an addition to the toolbox of approaches that can be used to support people with PIMD and there is a role for Occupational Therapist's to further develop MSS as an intervention in various parts of activities of daily living. Finally, implications of Covid-19 restrictions have resulted in the closure of many day services which serve as a form of meaningful social activity for many people with PIMD, practitioners may wish to reflect on the value of sensory stories in supporting individuals with PIMD maintain meaningful social interactions during this time.

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Trialling visual aids to tell stories: parent-carers exploring their transition support networks

Katharine Slade and Sarah Cox

I (Katharine) am currently enrolled on a PhD at Aston University to study the support needs of parent-carers of young people with profound and multiple learning disabilities and complex healthcare needs at the point of transition from paediatric services to adult health care.[1] This article is about the evolution of that PhD, the help I am receiving from a public involvement group, with a focus on Sarah and her son Simon's story, and how visual methods are being trialled.

Background

The seed from which the PhD grew was planted in 2013, when I gave a talk to undergraduates on the topic of "Diagnosis and Support". I mapped out the services my son had accessed over his lifetime, which were weighted in the areas of social support and education. Sarah helped me by mapping her son's services, which were heavily weighted in the area of healthcare (Fig 1). We discussed what this impact had on us as parents. My experiences were of countless carers and social workers coming into our home, Sarah's were of endless medical and hospital appointments. At that time we were the co-ordinators of the care our children received, and our sons were still in children's services.

This topic of parents as care co-ordinators and multi-service users was picked up by Shropshire Parent and Carers Council; I was asked to undertake a Healthwatch Shropshire funded project on the subject (Slade & Thomas, 2016). A pattern emerged whereby the parent-carers of young people with PMLD accessed at any time over twenty different services, many more than other parents.[2] Key people were cited as the paediatrician, the school nurse and the community children's nurse. A finding of the report was that transition to adult services was seen as a seismic shift for parents who lost the support of these key people, who up to that point had helped them co-ordinate their child's care. The responsibility had fallen back on the parents as they

Fig 1. A mind map showing services which had been accessed by Sarah' son, 2013

moved away from paediatric services. The report recommended that professionals should recognise that the parental role as an advocate will sometimes extend beyond transition, and often well into adulthood, for those young people with high needs.

Reflecting on our own findings locally, in conjunction with the published literature, and against the legislative backdrop, it was decided to explore the topic further. The question arose that if the parents are supporting their (now adult) children, who supports the parents once familiar services have disappeared, and what are their own support needs? Discussions with Dr Rachel Shaw at Aston University led to me be accepted as a PhD student. The project has two studies: the first following parents in their transition journey; the second exploring the views of professionals who work with young people with PMLD and their families.

Public Involvement

Despite my own son having some complex needs of his own, I recognised that my understanding of the world of PMLD and complex healthcare needs was sketchy. I decided to recruit a group of people, known as the Transition Research Advisory Group (TRAG) who had experiences in nursing, education and social care as well as parent-carers to help me shape the project; in particular, to help me understand the nuances of caring, as well as the medical terms, to prioritise the issues, and to help with trialling the methodology and preparation for NHS ethical approval.

Relational mapping

In designing the first (parents') study, I returned to the parents' stories and the services mind maps. Parent-carers often complain of having to tell their story repeatedly to professionals and consequently suffer from a type of information-sharing exhaustion (Slade & Thomas, 2016). The maps were a useful visual representation of the number of services accessed, however, they were based on my interpretation of what I had been told. I therefore realised that for the parents in my future study to have more control over the representations and what they want to tell, they have to construct the diagrams themselves. I found another method, the Pictor method of relational mapping (King et al, 2013), where a person uses arrow shaped post-it notes to map the key people involved in the care of an individual, and the resulting map is used as a tool for discussion.

We trialled this method with the group, and Sarah undertook this exercise on two separate occasions. In the first she mapped the services and people important to her son's welfare, which included carers, NHS staff, family and friends (Fig 2). Since the 2013 mindmap, her son had moved into adult services and also residential care, so the Pictor chart was complex. I asked Sarah who

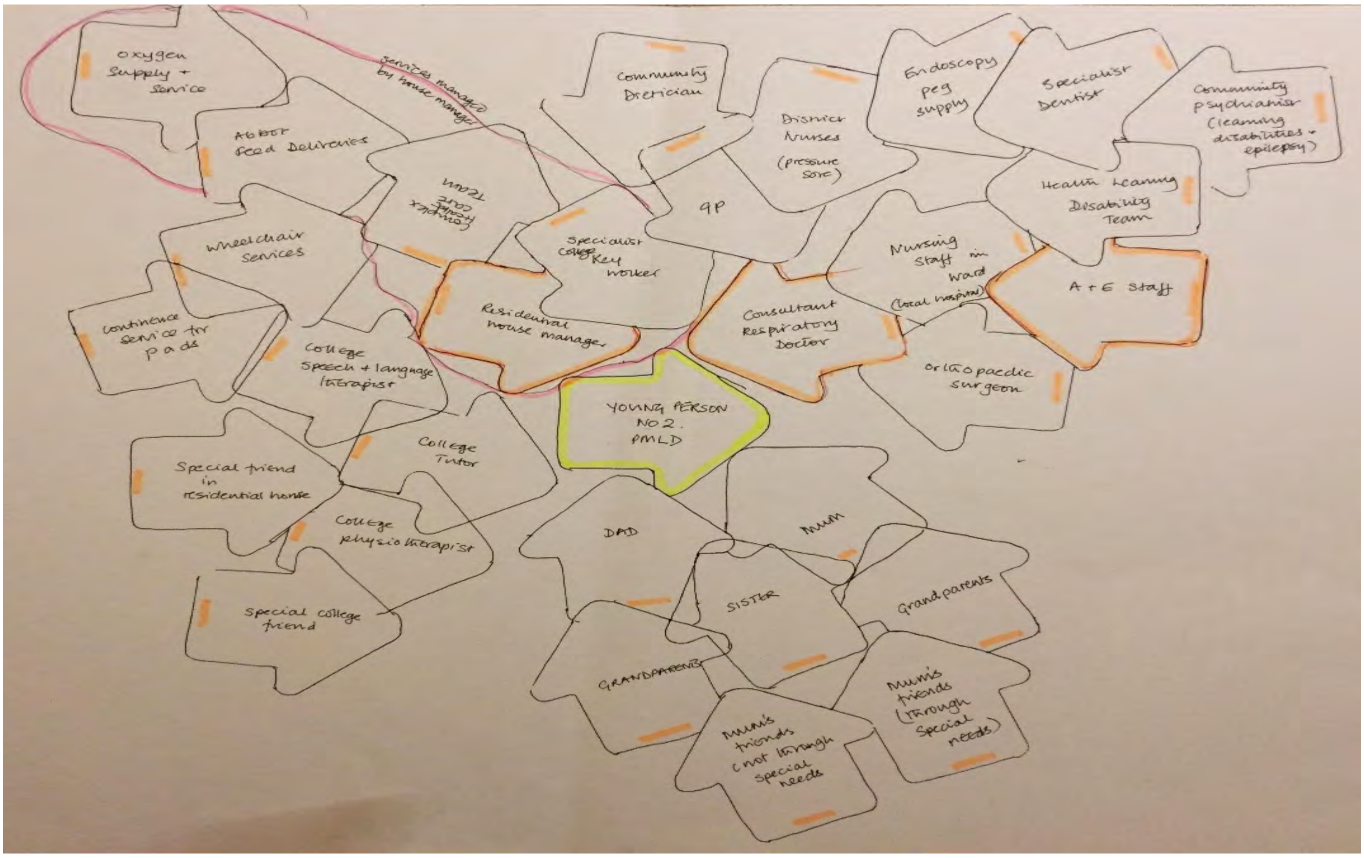

Fig. 2 Sarah's Pictor chart showing the support networks for her son. Post-It notes have been drawn around and removed; names have been anonymised to job titles

was there to support her and she drew a circle around one section of the chart. It was hard at this point to draw out her own support network (or identify the support needs), so we revisited the chart and I asked her to construct a chart specifically identifying those people who were important to her in supporting her to support her son. This second chart was a much simpler, highlighting the key people, reflecting that the majority of co-ordination fell on the shoulders of Sarah and the manager of the home in which her son lives now. It also brought out the importance of good communication, the effect of poor communication, and a shift in relationships with family members, as point of discussion.

Sarah's story

Despite Sarah's son being known to healthcare services since he was baby, when it came to transition he fell into a void. The Transition Care Plan prepared by his social worker was lost in the process and, Sarah commented it was as if they had just moved to the area.

"Transition from children's services was particularly stressful trying to get in touch with Continuing Health Care. Every time I left a message I was then waiting for a reply not knowing when I was likely to get one, so being near a phone was imperative because the minute you stepped outside you were sure the phone would ring and you would miss the call and then have to wait again…". Eventually things fell into place for Sarah and her family; her son moved into a residential home, although she felt the loss of the support of her son's social worker. Sarah commented "I came to realise that in our area if a PMLD young adult who is 100% health funded moves into a residential home, the manager will be the care-co-ordinator in all areas of their life. If a young adult stays living at home and accesses day services the parents will be co-ordinating care, because social care do not provide social work support if they are not paying any costs."

She reflects: "There was no map or plan for this journey, no well trodden path. All parents have found their way through slightly differently depending on the year of their child's birth, the area of the county they live in and the level of knowledge and pro-active involvement of each professional. I will always be extremely grateful to those professionals who were involved with Simon who gave us practical and emotional support and did extra research to help with unanswered questions or finding the "path " again when we had inadvertently strayed away from it."

The public involvement group have discussed many of the issues around PMLD and transition in particular. Using novel visual methods as prompts for interviews has proved popular, and even fun, with the group, and it is hoped that these experiences will be transferred to future participants. Sarah comments "I found making the Pictor charts an extremely interesting activity and it made me realise the extent of the journey Simon and I had been on during his childhood years through to adulthood. This is an excellent tool for clearly showing what has been involved and for comparisons."

The way forward

It is envisaged that this method, Pictor, will be used in the project to track changes and prompt discussion with parents during the transition of their child, to explore their own support networks.[3]

The mindmaps drawn up for the Healthwatch Shropshire project have been used by the participation officer at Shropshire PACC on a number of occasions during presentations to local healthcare providers, and it is hoped the Pictor charts generated also will have wider applications

The transition experiences discussed by the TRAG have been largely negative, with some examples of exemplary care by certain individuals, but the fundamental question has come back "what does a good transition look like?", and it is hoped that this will be explored within the study. A final comment from the group: "transition focuses too much on transition of services rather than transition to adult life" - there is also a possibility that these methods might be used beyond the research, in order to facitilate information sharing and discussions around future planning between young people, their families and professionals.

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1. For the purpose of this article, Transition within a healthcare context is defined as "the planned purposeful movement of adolescents and young adults with chronic and physical medical conditions from child-centred to adult orientated health care systems" (Blum ,1993, p 570)
2. Parents-carers of children with autism were not necessarily having an easier time, but were accessing fewer health based services
3. Pictor is also being developed by another researcher, Donna Barma, at Huddersfield University as a tool to be used with young people with autism to help plan their own transitions. Therefore it may be used as a reflective tool or a proactive planning tool.

I would like to thank all the members of the Transition Research Advisory Group for all their time and input into the research process so far; they have vastly enriched the research process. I would also like to thank my supervisors, Gemma Heath, Michael Larkin and Rachel Shaw for all the help, support and inspiration they have given me.

Contact details

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A parent of a young man who has autism, severe learning and communication disabilities and epilepsy. She met Sarah when their children were two years old in a special needs assessment nursery.

Sarah Cox
A mother of a young man who has cerebral palsy, microcephaly, epilepsy, visual impairment and is susceptible to chest infections.

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Lolli Ladybird's Got Spots!

Pete Wells

Lolli Ladybird's scarlet shell is covered in big black spots, So she's off to see Doctor Roach, she's worrying lots and lots!	(Plush ladybird/ Ladybird light/ toothbrush holder/ Mirror with spots on.)
Sitting nervously in the waiting room, there are mini-beasts big and small! Of every shape and colour, oh they don't look well at all!	(Explore bag/box of Bugs.)
She sits next to a troubled snail, who's got no get up and go! He moans "I'm going to see the doctor, to see why I'm so slow?"	(Feel shell, slowly track snail)
Next sat a hungry caterpillar, who was nervous about his meeting. He said "I have to see the doctor, about my never-ending eating!"	(Eat ANYTHING!)
By the plant, a sad stick insect; who sobbed "It's just not fair! Everyone ignores me! It's like I'm not even there!"	(Knobbly stick with wiggly eyes against a cork tile)
And whizzing round the waiting room, Woody Woodlouse cries to all! "Each time that I get frightened, I turn into to a ball!"	(Bounce ball)
No one sat next to the yellow wasp, who looked angry (and a little sad!) She said "If people get too close to me, I can't help getting mad!"	(Be angry. Shake fists!)
Next a tired looking cricket, who sobbed "There must be something wrong! Instead of sleeping when it's night-time, I make noises all night long!"	(Kokiriko or binzasara / Cricket noise on BigMack)
There was a rather worried firefly, whose face was filled with fright! "Quick someone tell the doctor, my bottom is alight!"	(Disco torch with switch, finger lights.)
Dr Roach called all into her surgery, she said "There's nothing wrong with you! Your features make you who you ARE! They're all a part of YOU!"	(Make announcement / Show mirror)
So if YOU'RE a little different, you're not poorly, nor bizarre! It's just the way that you've been made, you're great the way you are!	(Massage as you discuss story)

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Find an animated version of the story at
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Five Favourite Smelly Activities from my sensory room

Sarah Hall

1. Balloons

This smelly activity supports ‘The Travelling Smellysaurus’, a song from Spaceman Sid Action Songs Volume 1 by Vo Fletcher. It is a countdown song about 4 smelly-saureses.

- blow up each balloon without knotting it
- draw a dinosaur on each with a sharpie pen.
- put curry powder inside, using a measuring spoon (the smallest you can find)

As the song begins, I blow up a dinosaur balloon and as each one ‘pops off to explore the world’, I let the balloon go. As the balloon whizzes and fizzles around my sensory room it releases the smell! One little boy found this hysterical, chasing the balloons around the room. The more we chased them, the more he enjoyed it!

2. Chocolate

Chocolate is a popular theme in the sensory room (eg Easter, Christmas, Charlie and the chocolate factory or, just chocolate!). I also run chocolate workshops showcasing sensory ideas and activities with chocolate (eg exploring chocolate mousse in a tuff tray). As a teacher and an aromatherapist, I often use chocolate massage oil to support sensory sessions too. The oil has no therapeutic values but a massage with it smells divine!

Sensory Umbrella- chocolate themed. Chocolates tied on with wool; chocolate oil sprinkled on top.

I hang shiny sweets in wrappers from my umbrella and sprinkle chocolate oil on the brolly fabric. I would then share this umbrella space with someone – great ‘space’ for looking, tracking, smelling. When you twizzle the umbrella it wafts the chocolate smell. To add to the experience, I sometimes melt chocolate or light a chocolate candle in the sensory room before people arrive. Sometimes, we play chocolate songs in the background or use the umbrella with a sensory poem. I like using shiny, cellophane sweet wrappers. Despite the empty wrappers (as in the photo above) they still smell like chocolate thanks to the chocolate oil sprinkled on top of the brolly!

One lady loved the sweet wrappers and would open and close her mouth underneath the umbrella, so in response to her communication I gave her a chocolate button. My sensory room is available for private hire so people can have it to themselves to enjoy searching for the chocolate goodies and eating them.

3 Lemon Jelly

A small group of nursery children from a local special school came for a bespoke sensory drama.

They were all sitting on the floor and I walked towards them with my wibbly wobbly Lemon jelly. Suddenly, I tripped and it all fell on the floor!

The teacher was mortified on my behalf until I pointed out they were all sitting on a tablecloth and I was acting! The children could then touch it easily. As they played in it the lemon scent was released around the room.

4. Popcorn

Popcorn machines fill the room with a glorious aroma - great for supporting songs, stories, rhymes, dramas and poems. Fairgrounds, cinemas, festivals and circuses are themes conjured up when I have used my popcorn machine. I would use it with the poem ‘Pop Poppity Pop’ by Babs Bell Hajdusiewicz at the last school where I taught.

I would pretend to be disorganised (Ha not a great acting stretch TBH) and the popcorn would almost all fall on the floor as I ran around looking for something to put it in - much to the amusement of the children.

5 Fish and Chips

Smell is the only sense to go directly to limbic system making it particularly powerful at recalling memories and experiences. Personally, I think fish and chips is an evocative smell.

With my fish and chip poem, I just put salt and vinegar onto my paper copy of the poem, we smell it, I read it.
I also use ‘Chips for Tea’ by Margaret Rose. But if you cannot find it, here’s one I wrote:

Fish and Chips

It’s Friday today
Hip hip hooray
Today is fish and chip shop day.

We’re on our way
Not far away
Today is fish and chip shop day.

Going in our wheelchairs today (or - in the car, on the train, on the bus, on our bikes)
Wheelchairs today
Today is fish and chip shop day.

We’re here, I can tell
By the delicious smell
My nose, it knows
It knows that smell!

Salt and vinegar, salt and vinegar
Nothing beats the smell of salt and vinegar!

It’s Friday today
Hip hip hooray
Today is fish and chip shop day.

By Sarah Hall

When we experience this smelly activity during my Sensory Ideas courses, the adults taking part regularly want to go off and buy fish and chips!

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Link between therapy and levels of engagement

Sarah Sansome

This article presents the outcomes of a case-study seeking to highlight the link between therapy and levels of engagement. Specifically, it investigated the relationship between postural care and levels of engagement in a nine year old with profound learning difficulties and severe physical disabilities.

Introduction

Having worked as a learning support assistant in a special school since 2003, my role was extended in 2014, to include the role of Therapy Assistant. My responsibilities comprise liaising with school physiotherapists and occupational therapists, supporting the implementation of therapy plans, and offering relevant support to class teams when therapists are unavailable. Since this change in role, I have become increasingly motivated in my practice to ensure that due attention is paid to the necessity of following therapy programmes for pupils, and to the opportunities for accessing the school curriculum that therapeutic equipment and positioning provides for them (Long and Brady, 2016).

With a view to enhancing the quality of provision in my setting and a desire to further develop my knowledge in this area, I conducted a case-study review, to highlight the link between therapy and levels of engagement.

Literature Review

In the United Kingdom, The Education (Handicapped Children) Act (1970), instigated a shift in provision for children with profound and multiple learning difficulties (PMLD), transitioning them from socialcare centres and hospitals to the education system. This in turn meant that health professionals were deployed into educational settings to ensure that medical needs of pupils were met whilst in school.

Many children with profound and multiple learning difficulties (PMLD), have difficulties with their movement as a result of a complex medical or genetic profile, which can result in poor posture (Goldsmith and Goldsmith, 2003). Poor posture can lead to detrimental changes in bodyshape, such as chest distortion and muscle contractures, and can lead to severe discomfort. It is therefore vital that a 24hr approach to postural management be in place for these individuals, in order to prevent negative outcomes. Recent government guidance highlighted the importance of 24hr postural care, noting that this 'reduces health risks and improves quality of life' (Public Health England, 2018).

The implementation of an effective 24hr postural care programme involves a myriad of professionals (Lacey, 2001). When undertaken in a school setting, where a programme is often delivered by school staff rather than therapists, there is an increased need for awareness from staff of each individual's therapy needs. This joint-responsibility raises the need for collaboration and effective multidisciplinary team working (Lacey et al, 2015). Effective collaboration ensures that 'the children are not seen as a combination of legs, hands, speech or intellect, but holistically in terms of their education and care' (Lacey, 2001:144).

Methodology

The case-study investigated the relationship between postural care and levels of engagement for one learner with PMLD. It was important to choose the right learner as the focus of this study; specifically, someone requiring 24hr postural care, and whose cognitive level is suited to assessment through 'measures of engagement'.

A 9yr old learner from the PMLD class (where I work) fitted the criteria. They were assessed as cognitively functioning at P2 on the P-scales. In order to achieve a holistic description of the learner's engagement, it was important to involve people who knew the learner well, inside and outside of school. I undertook informal interviews with the learner's mother, and with both private and school physiotherapists, posing to each the same line of inquiry - how does the learner look, behave and sound when most engaged and least engaged? The same process was repeated with familiar school staff who support the learner and would be assisting in the case-study. I looked for commonality and themes from their collective responses and created a highly personalized, four-point engagement scale (with descriptors) under the following headings:

1. Maximum engagement
2. Periods of engagement,
3. Occasional engagement,
4. Disengaged.

Over the course of two weeks, staff completed an audit of which therapy equipment or postural management positions the learner used during educational activities and recorded the learner's level of engagement in each instance, using my scale.

For each of five postural management positions identified, seven engagement scores were recorded. Care was taken by each observer to ensure accuracy in recording the scores through discussion with fellow observers and myself. Chart 1 shows the total frequency of engagement scores when in each piece of positioning equipment. rom the results, it was evident that the learner's level of engagement when in two pieces of equipment was entirely consistent. On all seven occasions of bench sitting, engagement was at its maximum. In standing, there were periods of engagement on all seven occasions. The other three positions provided a more varied set of results.

The results show that maximum engagement was reached in three out of the five positions chosen for audit. It is important to note that the two positions in which engagement was not recorded at maximum were standing and long sitting, both of which required the learner to be fixed in a position facilitating various muscle stretches. It is also important to note that the learner did not show any periods of disengagement. On all thirty-five occasions they were engaged in the activities provided, albeit to varying degrees. This is an encouraging result as it provided evidence of access to learning through provision of 24hr postural care management.

Discussion

The results showed variation significant enough to suggest that there is, for this child, a link between positioning and level of engagement. The piece of equipment that saw maximum levels of engagement was therapeutic bench sitting. In this position, the learner is supported at the hips and back in a seated position. The learner has to work hard to hold their trunk and head up, but there is no stretching of muscles required. It was assumed that by the learner having to activate their core with no apparent discomfort elsewhere, they were able to reach an alert state, ready to learn. The engagement scores when in standing, provide a set of results that can usefully be compared to this. In a standing frame, the learner is supported from feet up to chest. This is more support than when on the bench, but the position involves stretches in legs and hip flexors, and involves weight-bearing through feet, which is known to be potentially uncomfortable for this learner. The engagement scores from the stander showed periods of engagement but did not reach maximum levels. It may be interpreted that in this position, the learner is alerted to learn but what is being required of them physically, perhaps means that there is occasional distraction. It is interesting to note that similar results were recorded in a long-sitting position, which also requires a stretch of muscles. Maximum engagement was not reached in this position and occasional low scores were recorded. Therefore, it can be assumed that levels of comfort in 24hr postural management programmes can affect levels of engagement.

With regards to the results from the class chair, it is important to highlight that this piece of equipment yielded the most varied set of results. Three differing levels of engagement were recorded suggesting that maximum engagement was achievable but not always reached. The class chair provides a high level of postural support that is designed to be of maximum comfort. The learner does not have to work hard physically in this

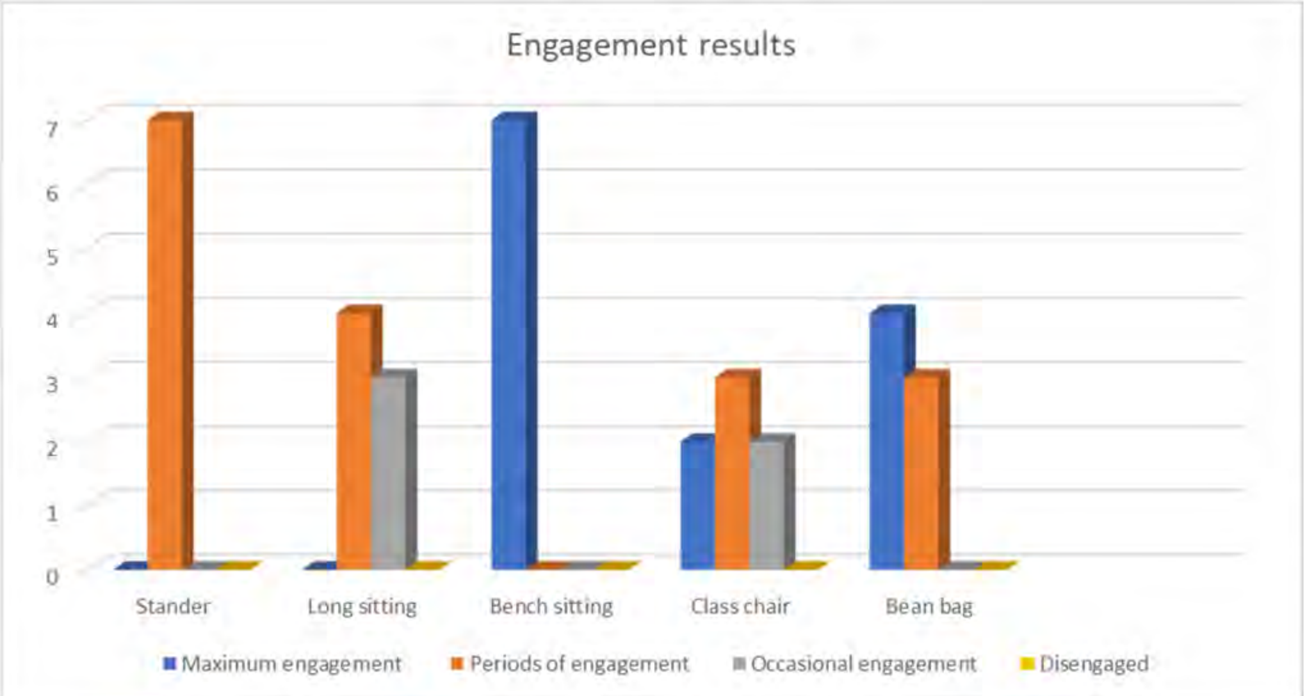

Chart 1: Engagement scores in each piece of equipment.

position, and it is perhaps for this reason, that they were not always engaged. The fact that they were prompted into action physically on the bench appeared to go hand in hand with being mentally alert and in a state most compatible with engaging in the learning process.

The bean bag provides no physical support, and its use is designed for comfort and relaxation through reduction in muscle tone. It was noted throughout the process that when an activity on the bean bag involved participation from an adult, the learner's level of engagement was higher than when they were encouraged to participate in an activity unaided. While in this position, an adult is not restricted in how close they can physically get to the learner, which can be the case with bulky pieces of equipment. This physical closeness appears to have alerted the learner to maximum level of engagement. With removal of the close physical proximity, the level went down.

The results, therefore, indicate that levels of engagement for this particular learner, are affected by postural management. Close analysis of the findings has revealed that attention should be paid to what type of postural support is being offered and when (without compromising on a 24hr postural care plan), and to plan learning activities accordingly. The effect on engagement caused by the balance between comfort and stimulation is apparent. The limited support but low level of discomfort provided by bench sitting provided this learner with optimum state for maximum engagement. High level of comfort and maximum support provided by class seating seemed to reduce the potential to reach maximum engagement. This information can be used in planning when to use each piece of equipment and what sort of activities to use when in them. For example, a highly stimulating and alerting activity may be beneficial when in class seating, new tasks could be introduced when bench sitting and fully interactive activities could take place on the bean bag. The class team involved in this case study, also felt it would be useful to consider using the same approach adopted with the other pupils in class, a process which has now begun.

It is important to note that these results are specific to one child. The same case study using the same audit tool with a different child, but personalised to them, may provide results that offer a different set of conclusions. With regards to the multidisciplinary element of this case study, professionals involved, both in health and education, have a renewed joint-goal of enhancing the quality of outcomes for children in our setting.

Conclusion

In my opinion, further enhancement of the quality of provision in schools for children with PMLD who require 24hr posture care, will develop through embracing a multidisciplinary collaborative approach that listens too, and values the input of the whole team around the child. This case-study has provided evidence of such collaboration and has created an intention to use its findings to influence future practice within the setting in which it took place.

Moving forward, further research has found that some education staff have called for enhanced training and input around posture care, citing for example, lack of time to implement it as a barrier to its use (Robertson et al, 2016). Perhaps future studies similar to this, that highlight the link between positioning and engagement could go some way to removing those barriers by encouraging a higher level of understanding of postural care equipment as an educational aid rather than an educational obstacle, and go some way to creating environments where teaching and therapy aim to be 'complementary rather than competing' (Lacey, 2001:136).

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Summer 2020, Vol. 32 No. 2 Issue 96

I like to MOVE it

Lowri Williams and Leigh Wharton

The MOVE Programme is an activity based practice that helps disabled children and young adults gain independent movement. It uses the combined approach of education, therapy and family knowledge to teach the skills of sitting, standing, walking and transitioning between. The aim of the MOVE Programme is to offer these movement opportunities to disabled people, opening up and transforming the world around them and creating an accessible, interesting and educational world full of opportunity and choice (MOVE Europe, 2020). The MOVE Programme was developed in the early 1980s by a special education teacher, Linda Bidabe (Lambert M, 1998).

Ysgol Ty Coch Special school was first introduced to the MOVE Programme in June 2017. Several members of staff attended MOVE senior practitioner training together with Greenfields School, Merthyr Tydfil and members from Cwm Taf Morgannwg University Health Board paediatric physiotherapy and occupational therapy departments. We learnt all about the MOVE principles which includes the six MOVE steps. These steps are;

- Assessment - Where is the individual now?
- Goal Setting - Where does he/she want to get to?
- Task Analysis - What skills are needed to get there?
- Prompt Measurement - What support is currently required?
- Prompt Adjustment - What support will be needed to achieve the goal?
- Teaching the Skills - How do you ensure the individual reaches their goal?

In September 2017 the MOVE Programme was implemented at Ysgol Ty Coch for children with functional movement difficulties. Since introducing the programme, we have seen many benefits for our pupils with profound and multiple learning disabilities. These include a reduction in barriers to learning through enabling pupils to be in optimal positions for learning: accessed sitting, or standing, and moving. MOVE helps our pupils to live a healthier and happy life.

At Ysgol Ty Coch our children are empowered to be as independent as possible. We provide the support and equipment for them to have a fully inclusive school day. Below is an example of how we integrate the MOVE program into the day of a child with PMLD.

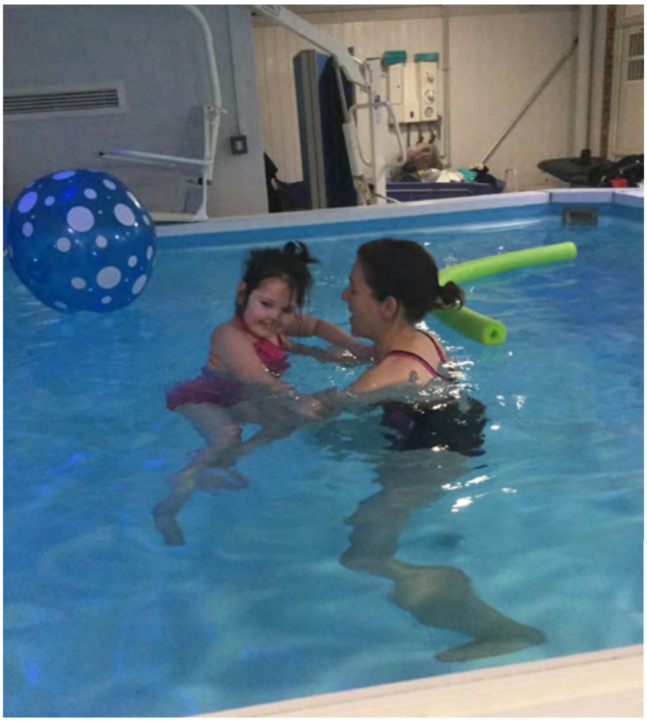

FIGURE 1 : Hydrotherapy session

During warm water experiences Pupil A is encouraged to move her arms and legs independently with support, placing movement at the centre of her learning. This activity is fun and motivating for Pupil A and encourages functional mobility.

FIGURE 2 : Personal care / wellbeing

Pupil A is actively engaged with drying her own hair. This is a purposeful activity to encourage movement opportunities throughout the school day .

FIGURE 3 Cooking session

Pupil A enjoys our weekly cookery sessions. To do this activity effectively, she needs to be in the most optimum position possible. This position also aids her posture and digestion and motivates her to complete the activity which is part of our everyday curriculum.

Figure 4 Exploring different tactile experiences

Pupil A is engaged in exploring different tactile objects and is in the optimal position to do so. As you can see Pupil A is thoroughly enjoying herself!

We have noticed a considerable impact on our pupils lives such as increased independence, better quality of life, inclusion, able to join in with activities and more time for family centered activities.

"Every child deserves a champion—an adult who will never give up on them, who understands the power of connection and insists that they become the best that they can possibly be." - Rita Pierson (YouTube, 2013)

MOVE fits into Welsh Government's 'A Curriculum For Wales'. It identifies the child's greatest needs and it aligns it with the most appropriate pedagogical approach. You can then gauge the impact of this approach through pupil development. The sole aim is to help children enjoy school and acquire key skills that they will need to become active citizens in today's 21st-century society, regardless of any disability. Our strategic aims at Ysgol Ty Coch are ambitious and are rooted in providing the very best for our pupils. These aims are:

1. Promoting the highest quality individualised teaching and learning.
2. Investing in staff - aiming to put world class people in front of our learners.
3. Unconditional support for parents/families - seeking 24hr curriculum.
4. Celebrating difference within the local, regional, national and international community.
5. Enhancing the physical environment - promoting equality of access.

Graham Donaldson's vision to teach 'what matters' resonates loudly with us! For a lot of our pupils at Ysgol Ty Coch, movement is paramount for them to be able to learn. As movement is paramount to enrich their lives we aim to train the parents and caregivers of all our pupils to enable a 24 hour MOVE curriculum. More recently, key members of staff undertook MOVE Trainer Training in 2019. Upon our return to school we felt empowered and couldn't wait to implement what we learned.

We have found the MOVE Programme to be a common sense approach which empowers people to help children with complex disabilities to learn to move, teaching functional skills of long term importance to be motivating and purposeful for that child. This enables children to lead more inclusive meaningful lives rather than being passive participants who are unmotivated .

We started with an Initial cohort of 6 pupils and over a two-year period 100 % of pupils in the initial cohort made progress in each of the MOVE Programme motor milestones and 33% of pupils graduated from the MOVE Programme. Not only have we noticed the difference of the impact of MOVE for the children, we have also seen the impact on their families and the staff at Ysgol Ty Coch.

Some of the benefits that both school and families have experienced are:

- By working on head skills such as raising the head to midline, it has enabled pupils to use a EyeGaze system with more precision for communication and for participating in online activities of their own choice. They have been able to transfer these skills from school to home environment.
- Social benefits, by being in an upright position it has provided pupils a new perspective of the world. Parents have noted how more alert and aware their children are of their surroundings.
- The MOVE programme has enabled children and their families to lead more inclusive, healthy, happy and meaningful lives
- The impact on staff to provide as many meaningful movement opportunities as possible during the school day.

We are continually inspired by all our MOVE pupils and their families and are driven to open up more experiences and opportunities for them. We are a school that likes to MOVE! Whether it is within the class area, in our playgrounds and garden or out in our local community.

Contact details

Ysgol Ty Coch is a 3-19 maintained special school in Rhondda Cynon Taf.
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Twitter @Leighwharton

Finding out more about MOVE
www.enhamtrust.org.uk/move
Twitter @MOVEProgramme

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Barriers and possibilities in researching PMLD: reflections by a University Tutor

Helen Bradley

As a tutor on the Masters in Education (MEd) programme in severe, profound and multiple learning disabilities (SPMLD) at the University of Birmingham, my students work with people with SPMLD whose age range encompasses very young children to young adults in college and care settings. The students are drawn to the course because they want to extend their knowledge and understanding, and influence practice. One of the mechanisms to help students develop and apply knowledge is a series of assignments followed by a small scale study and then a dissertation. A number of students follow a similar programme at undergraduate/BPhil level. This is the context to my reflections on the issues the students face when carrying out research projects with students with profound and multiple learning disabilities (PMLD) and some of the barriers they may need to navigate.

This article will focus on research concerning children and young people up to the age of 16. A subsequent article will reflect on the special ethical issues that arise when children reach the age of 16, because research then needs to be compliant with the Mental Capacity Act (DoH, 2005) which stipulates that participants over the age of 16 should consent for themselves if they have the capacity to make an informed decision. If deemed not to have capacity, then additional arrangements must be put in place. This particular aspect of the research process further adds to the complexity of research with people with PMLD.

Our students often come to us with a good understanding of the fact that children and young people with PMLD are a complex, diverse and marginalised group. This is reflected not only in the struggle schools and parents often face in order to obtain services, but also in research. One potential barrier that often discourages students from picking particular topics is that so little relevant research exists on their chosen topic. In general, students conducting research are expected to demonstrate a knowledge of their field through their awareness of past research. Where there is no body of research, students can worry their work would not meet this aspect of the requirements.

The lack of relevant past research is particularly an issue when they are interested in finding information from research carried out in classrooms. The situation appears even more difficult where the students are college tutors and the learners have PMLD. Students often express surprise at how little is known about mental health, happiness and well-being in individuals with PMLD. The best way to support peer interaction remains another under researched area (Field 2019). It is really important for these students to be supported to address under-researched areas because that is how knowledge progresses and an evidence base established.

Where students try and find research that actively tries to engage participants with PMLD and capture their voice, they may uncover a number of difficulties with this process. Some researchers (Nind, 2009, Boxall, 2010 and Simmons and Watkins, 2014) have encouraged the use of innovative approaches for example using observation, interviewing stakeholders who know children well, using technology and total communication approaches. It is pleasing to see the students experiment with these ideas in their own projects.

In choosing a research project, the students need to be mindful of ethics and to follow the British Educational Research Association [BERA] (2018) guidelines. Essentially ethical guidelines encourage the pursuit of knowledge without doing harm to the participants, who may be the children themselves, teaching staff, other professionals and family members, usually but not exclusively mothers. Participants' anonymity needs to be protected throughout. Many of our students are teaching staff and have to balance the need to carry out small scale projects with the need to fulfil their duties as teachers, teaching assistants or other professional responsibilities. Students wishing to carry out observations quickly find out how challenging this can be in busy classrooms. Other areas of care include being mindful that a child does not miss out on essential activities while being part of the research/intervention and is not stressed or distressed by it or otherwise disadvantaged. The children involved in the research are, by definition, at very early cognitive stages and communication is likely to be pre-intentional or early intentional and so they cannot meaningfully consent to taking part or to having their data used. Where children are under sixteen, their parents or carers can consent to the child's participation. However, researchers also need to be aware of behaviours which may signal that the child is comfortable with any aspect of their involvement.

The researcher needs to be mindful of the often fragile health of the children and young people. Sadly, children may become ill or die during the course of a project. This can be a child that is the focus of an intervention or may be a child in the same class or school and the emotional impact of such a situation cannot be overlooked when trying to collect data. One parent recently told the student that she wanted the data that had been collected to be used because it was important to the family that what had been learned was not lost. Recently there have been some studies by students which focus on children with life limiting and life-threatening conditions and these have provided valuable insights into this group, for example, James (2019).

The issue of poor health has an impact for students who are interested in doing single case studies. Where children are complex and unique so that comparative group studies may not be appropriate, an in depth study of a single child provides valuable insights. However, from the point of view of the student, it may be a disincentive to research short term educational interventions as the child may need to have unplanned time away from school for medical care.

Another potential barrier to short term projects that involve an intervention is that the children and young people may need many repetitions and adaptions to techniques before changes in learning or behaviour are demonstrated. Students need ingenuity in researching and developing very sensitive tools that will pick up changes can be very time consuming.

One popular research method is to gather the views of parents and other family members and some people are very generous with their time and expertise. However, students need to be aware that parents themselves may be stressed and vulnerable and they may be required to provide some signposting to support if participating in the study raise issues for them. For example, if researching poor sleep, the student may need to be mindful of the impact of this on parents and make some suggestions about places they can go to seek help. It is very clear when listening to the students discussing participant recruitment, that some parents are easier to reach than others, though it is likely all parents have important views. Some parents may not speak English as their first language or experience literacy difficulties so all documentation explaining voluntary involvement and informed consent needs to be written with care, offering phone call support where appropriate. It is important that parents understand they can withdraw consent . They may need to understand that every learner can access any group intervention being offered even if they do not want their child to be one of the focus children whose data is used. It is my impression that access to translation services varies markedly between schools and colleges. Some parents do not reply to school communications and this is the group of parents whose views and experiences are likely to be overlooked in research projects. It may also mean that consent cannot be obtained for children under sixteen to participate in projects or for their data to be used.

Where parents do participate, it is really important that they are thanked and offered some sort of summary of the findings at the end. Interviews and questionnaires should involve questions that are not leading, but gentle and respectful. Where the views of parents about current practice and opportunities for improvement are sought, this is likely to demonstrate the importance of the parental voice. This approach may hopefully encourage parents to participate in future research and recommend the process to other families. If they give their time and then learn nothing about the findings or potential impact of the research, they may be less likely to contribute in the future.

Other important sources of information are the staff teams in schools and colleges. Again, care needs to be taken because many staff members have very high workloads and questionnaires, interviews and focus groups if not used with care, can add to multitasking that these staff members have to manage. It is important for some projects to make sure a range of voices is heard. Teaching assistants, learning support staff, school volunteers and transport staff may have important views and experiences which may be very different to those of teachers and tutors. Sadly, it is likely that high workloads in special schools and specialist colleges may act as a deterrent and mean that important viewpoints are not accessed. Students do not offer incentives to participation (financial or other), so are dependent on goodwill and on the participants being given clear information on the potential benefits of the research.

Research with children and young people, their families and the teams that support them, is time consuming but valuable and every effort should be made to disseminate the findings in an effective manner to both participants and other stakeholders. It is important that the full implications of the findings are carefully considered. These could be implications for practice but often they are indicators for future research and policy.
Given the scarcity of research in this field, I would always encourage students with suitable projects to consider submitting their work for publication or presenting at conferences. Their literature reviews alone often highlight important and worrying gaps in our state of

knowledge so if they can do anything to contribute to the our knowledge base, then this may impact positively on future students who are inspired to follow in their footsteps.

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In the Next Issue Winter 2020

Raising Our Sights: 10 years on

For the next issue, we would like you to help us mark 10 years since the Raising our Sights report (2010), by the late Professor Jim Mansell.

As many of you will be aware, this was a specific review of services for adults with PMLD, commissioned by the Department of Health. Through good practice examples, Professor Mansell wanted 'to illustrate both what is possible and what policy obstacles have to be overcome.' He made a series of recommendations that aimed to make sure people with profound and multiple learning disabilities and their families get the support and services they need, and do not miss out on opportunities for more choice and control over their lives.

The review looked at all areas of people with PMLD's lives and covered topics such as individualised and person-centred care, treating family as expert, quality of staff relationships with the person and advocacy, communication, health, housing, further education, day activity, employment, wheelchairs and more.

The review looked at all areas of the lives of people with PMLD (10 years on). You may want to share your family's experiences, focus on specific topics or look back at the recommendations in Raising our sights and share your reflections about progress and priorities for change going forward. As well as articles – please also send us your comments and reflections, however short . We can gather these together to create an item. To read or revisit the 2010 Raising our sights report https://www.mencap.org.uk/sites/default/files/2016-06/ Raising_our_Sights_report.pdf

Guest Editors- Bella Travis , Maureen Phillip and Annie Fergusson

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For more about writers' guidelines or sharing photos;
http://www.pmldlink.org.uk/get-involved/
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REPORT BACK

Sibs – A day for adult siblings, Manchester

I've only recently discovered Sibs (my older sister Alison has Down's Syndrome), and I was really looking forward to making my first connection with the charity at their Adult Sibling Day. I am so grateful Sibs went ahead with the event on 14 March which, as we now know, was held shortly before the UK went into lockdown. My experience of the day and knowing how Sibs uniquely understands how we, as adult siblings, are coping in this current situation, is somehow making the stresses and strains a little bit more bearable. I can't visit my sister for the time being and that's hard, but with Sib's support I know I'm not alone.

As for the event itself, for the first time in my life I was meeting fellow adult siblings and realising we all shared the same experience: wow! Describing growing up with a disabled sibling to someone who has non-disabled siblings, I have often found difficult to articulate, but here I was in this lovely hotel conference room filled with people who just “got it. Finally, I felt none of my usual awkwardness.

I was particularly moved by the personal stories related by adult siblings Prakesh and Joe. All the speakers throughout the day were insightful and knowledgeable. I was very grateful to Liz Wilson from Dimensions who afterwards gave me some really helpful advice on my Appointee role. The day finished with a relaxing mindfulness session and a chance to stay and socialise at the close. I finally headed off home armed with plenty of food for thought and useful information to further explore.
Thank you for a great and supportive day, Sibs!” Helen Davis, sibling

Sibs are a charity who work to support siblings of all ages. To find out more https://www.sibs.org.uk/

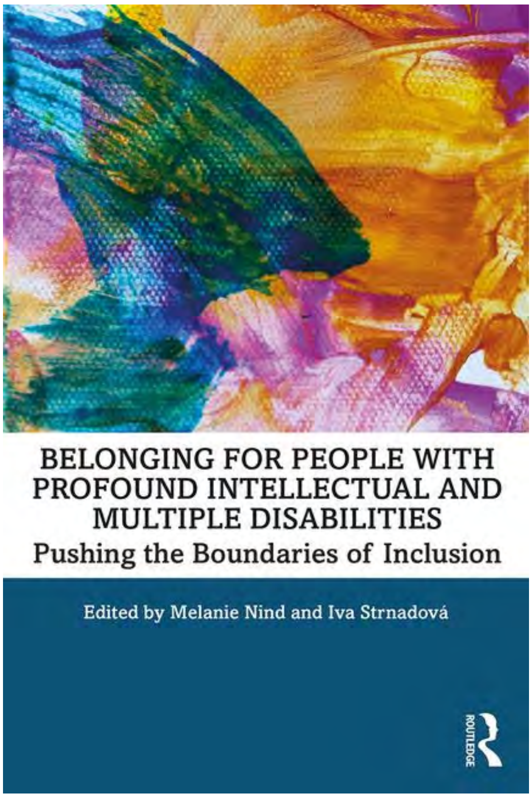
BOOK REVIEW

This new publication had an international online launch in July. Both editors, along with a number of chapter authors, presented via video livestream to a large audience from Australia and UK.

Belonging for People with Profound Intellectual and Multiple Disabilities: Pushing the Boundaries of Inclusion

Melanie Nind and Iva Strnadová (Eds). (2019). Belonging for People with Profound Intellectual and Multiple Disabilities: Pushing the Boundaries of Inclusion. Abingdon: Routledge. 218 Pages. £29.99. ISBN 978-0-367-20295-8

Link: https://www.routledge.com/Belonging-for-People-with-Profound-Intellectual-and-Multiple-Disabilities/Nind-Strnadova/p/book/9780367202958



I recommend this book to people who have an interest in children or adults with profound intellectual and multiple disabilities. It is particularly relevant to teachers, scholars and postgraduate research students. I believe it will also provide interesting and engaging reading for students and professionals working in health and social care.

The book has adopted the internationally accepted term ‘intellectual disabilities’ within its title. Readers be aware authors use the terms intellectual disabilities, learning disabilities and also learning difficulties. Despite these terms in the context of this book they refer to the same people (defined on page 1).

The book explores how individuals approach people with profound intellectual and multiple disabilities within education, research and across the wider community. The book is structured into three parts ‘Belonging in education’, ‘ Belonging in research’ and ‘Belonging in communities’. Each part explores and challenges policy, legislation, social provision and social and cultural development drawing on contemporary research and personal insight.

The contributing authors, each an expert in their field, include family members of people with profound intellectual and multiple disabilities alongside respected researchers and practitioners from a variety of educational and clinical backgrounds present a vivid multinational story. The inclusion of fellow traveller accounts brings a personal richness to the book.
The book begins with its dedication to a wonderful lady Johanna de Haas. Johanna was an immense source of inspiration to all who knew her and a key member of the social history of learning disability community at the Open University.

The structure of the book lends itself to either be read from cover to cover or by dipping into one section or chapter at a time. Whichever route you choose I would urge you to start by reading chapter one and then perhaps chapter eleven.

The contributing authors provide an opportunity for us to scrutinise our practice and how we nurture relationships with others really does push the boundaries in how we approach people with profound intellectual and multiple disabilities.

In summary, this highly readable book provides real examples of how boundaries to inclusion of people with profound intellectual and multiple disabilities have and are being pushed. It challenges us to individually and collectively reshape boundaries to inclusion.
I encourage you to push against the boundaries and shape the future.

#Belonging #PIMD #PMLD

Jillian Pawlyn. Registered Nurse (Learning Disabilities)
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IN THE NEWS

Oily Cart update

Oily Cart are a theatre company who specialise in creating sensory theatre made for and with children and young people with PMLD. We exist to serve our audiences and artists and are aware of what a distressing time this is for many of the families we work with and have huge respect for. We are sending out our love and solidarity.

Over the next 18 months we will take our inclusive theatre onto streets and into homes, making as much noise as possible to ensure that our young audience and their families are being heard now and as things transition to the 'new normal'. We will use our resources to respond to what families tell us they need. Shielding should not affect anyone’s right to creativity, their right to connection and their right to play.

To kick off this new programme, we're very excited to share 3 interactive, creative ‘Sensory Sessions’, inspired by sensory moments in our show ‘Jamboree’. Making Shadows, Colour and Movement and Making Noise can be enjoyed individually or all together. The Sensory Sessions was made in collaboration with families during lockdown, and are designed to be used at home and in other settings.

We have also created a private Facebook group especially for families with a young person who has PMLD. We would love you to join us there for sensory ideas and activities, resources from other relevant organisations and to have your say about what you need from Oily Cart at this time. We want to hear from you and your young person!

You can join the Oily Cart Families Facebook group here https://www.facebook.com/groups/OilyCartFamilies/?source_id=151594858186715

Samir, Frankie and Brad from Campaign 4 Change present at the Learning Disability England (LDE) Conference

The planning and thought that goes into co-ordinating events for people with Profound and Multiple Learning Disabilities (PMLD) is something that often gets overlooked. Every step must be considered, and every eventuality thought of. Months of careful consideration and contingency planning for every possible occurrence are essential in order to ensure the smooth running of every event.

Samir El-Ziftawy, Francesca Dunn and Bradley Crittall, 3 members of the self-advocacy group, Campaign 4 Change, were asked if they wanted to facilitate a workshop at the Learning Disability England Conference in February 2020. This event would present its own unique set of hurdles and would require participation from Samir, Brad, Frankie and their staff team.
The conference was a great way to raise the profile of Campaign 4 Change, but more specifically the work that Samir, Brad and Frankie are doing to raise awareness of the issues and barriers faced by people with PMLD. Ironically, taking part in this it came with barriers of its own! The LDE conference venue didn't have a fully accessible Changing Places Toilet . However, the LDE team planned well and there was one nearby, in Manchester Central Library - so people were able to use the loo (very nice loos too!).
Samir, Frankie and Brad met up a few times before the conference with Mary Woodhall, another member of Campaign 4 Change. They wanted to explore what to include in their workshop and how to present it in the most inclusive way. They decided a film would be a great way to show what they wanted to say, alongside some PowerPoint slides which Mary and the staff team could help to explain. Samir volunteered to be the one to change the presentation slides, and so, a new wireless touch-switch was purchased.

As part of the presentation, Campaign 4 Change made a short film entitled 'We Are People' demonstrating the ways in which people with PMLD are just as much 'people' as those without disabilities. The film was created on a very tight schedule but involved a lot of planning - interviewing health professionals, arranging appointments and going out and about, as well as just being spontaneous, and adjusting to last minute changes. The journey to the conference, from Brighton to Manchester, was also one needing meticulous planning. The long-distance journey meant an overnight stay was necessary. Whilst Frankie, Brad and Samir are frequently supported to go on days out, nights away have been far less common, and require an extra level of planning and risk assessment.

For the journey itself, there were quite a number of things to consider. Our transport needed to accommodate three larger-than-normal wheelchairs, suitable Changing Places toilets en route for the personal care needs of Samir, Brad and Frankie had to be identified and mapped out beforehand and these stopovers also had to coincide with feeds and medication

regimes. During the journey, to distribute pressure and maintain good skin integrity, staff made frequent use of the tilt mechanism on wheelchairs. We also needed a backup driver too, for such a lengthy journey.
Finding a suitable hotel was a challenge. It had to be wheelchair accessible and there had to be at least a 6 inch gap between the bed and the floor for mobile hoist access. The rooms also had to be close to each other or at least on the same floor to ensure staff could assist and provide support.

In a more obvious vein, the hotel had to be walking distance from the event - just in case things didn't go as planned and we had to return to the hotel.
Hiring a mobile hoist presented its own challenges too, despite only needing it for one night, the minimum hire time and charge was one week. This meant the budget would only stretch to one hoist, shared between Frankie, Brad and Samir. This meant that transfers taking about 30 minutes each time, had to be well planned too.
The overnight element of the event presented its own challenges. Bed safety was very important; minimising the risk of falls, a make-shift sleep system was used (as agreed with the physio prior to the trip), as well as monitoring at night. This involved the use of assistive technology so that staff could be called for assistance if needed. Reflux and aspiration had to be managed without the use of an electric profile bed, as well as respiratory health, which was managed by taking a nebuliser, Bipap and suction machines. Extra enteral feeds, medication and water flushes were packed to allow for any delay or holdup.

However, despite the extensive planning, and the many barriers faced by Samir, Brad and Frankie and the staff supporting them, the event was a complete success and really worthwhile. Our workshop, entitled 'Making a profound difference together' was exceptionally well received. The whole trip was filled with fun and some unforgettable memories for everyone involved.

Nevertheless, it clearly demonstrated that as accessibility is generally poor for people with a physical disability and wheelchair users, simply accessing the community takes considerable planning. Going forward, people with PMLD need more Changing Places toilets, installed conveniently in all large precincts, parks, music arenas, football stadiums, supermarkets and motorway stations. Accessible hotels, with specialist beds, hoists and showers need to be more commonplace, as well as the availability to hire specialist equipment at affordable rates (i.e hiring a hoist at daily not weekly rate).

Hopefully, as more people become aware of the everyday problems people with PMLD face, our society and amenities will adapt to suit their needs, and not the other way around.
Watch our short film, "WE ARE PEOPLE" https://www.youtube.com/watch?v=8hS2WK5l7t0

Contact details:
Email: C4C@achievetogether.co.uk
c/o Elmi Terjavjainena
Co-production & Involvement Partner, Achieve together

Follow Campaign 4 Change on social media:
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www.instagram.com/campaign.4.change
https://www.youtube.com/channel/UCpLursghxn0gfMmeHmxtblw

Exciting developments will lead to more Changing Places toilets

On Changing Places Awareness Day 2020, the government announced that changes will be made to legislation to make Changing Places toilets mandatory in all new, large public buildings in England. Adding to that, extra funding will be made available to install Changing Places toilets at 37 motorway services stations. This announcement was made on 16 July, by the Ministry of Housing, Communities and Local Government and the Department for Transport.

For more about Changing Places toilets and an interactive UK map of toilets
http://www.changing-places.org/

Staying in touch with the PMLD community through podcasts

Frozen Light has started a podcast aimed at staying in touch with the PMLD community in the age of coronavirus. We have been interviewing people who care and support people with PMLD as a way to document people's experience and ensure that people with PMLD are not forgotten during this moment in history. To listen you can find the episodes at www.frozenlighttheatre.com/podcast or on any other podcast platform, please do rate, review and subscribe.

We are also trying to work out when it may be safe for us to tour our sensory theatre again and when our audience with PMLD may feel safe enough to visit a theatre venue. We would love to hear your thoughts and opinions about this so please do get in touch at info@frozenlighttheatre.com

Removal of safeguards for children in care

On 23rd April, the Government introduced a Statutory Instrument which removed a large number of legal protections from children in care: Statutory Instrument 445, also known as The Adoption and Children (Coronavirus) (Amendment) Regulations 2020. The changes include the following:

- Care planning safeguards do not apply to disabled children in short break settings until the placement has lasted more than 75 days.
- The duty for social workers to have six-weekly contact with children in care has been removed
- Six-monthly independent reviews of a child's care are no longer mandatory
- Care standards relating to the skills and knowledge of staff have been weakened in children's homes
- Twice-yearly Ofsted inspections of children's homes are no longer required
- Monthly independent visits and reports on children's homes are no longer mandatory
- Fostering services are no longer required to report infectious disease to Ofsted

These changes were implemented without consultation and have been widely criticised by key individuals and organisations within children's social care, including the Children's Commissioner, the Care Leavers' Association and the British Association of Social Workers.

"I do not believe that the changes made in these regulations are necessary – except perhaps for some clarifications (in guidance) about contact with children taking place remotely during the lockdown.

Children in care are already vulnerable, and this crisis is placing additional strain on them – as most are not in school, less able to have direct contact with family and other trusted professionals, and facing the challenges of lockdown and anxiety about illness – all on top of the trauma they have already experienced.

If anything, I would expect to see increased protections to ensure their needs are met during this period.

"I would like to see all the regulations revoked, as I do not believe that there is sufficient justification to introduce them." Anne Longfield, Children's Commissioner for England, 30 April 2020

The organisation Article 39, which campaigns for the rights of children in care, has been leading a campaign against S.I. On 10 June, the then Shadow Education Secretary Rebecca Long-Bailey MP led a motion to annul the Regulations, which was defeated by 260 to 123 votes. Article 39 subsequently applied for permission for an expedited judicial review of Statutory Instrument 445. This was granted on 26th June on the grounds that:

- the Department for Education failed to consult before making the changes to children's legal protections.
- the Regulations are contrary to the objects and purpose of primary legislation, particularly the Children Act 1989.
- the Education Secretary, Gavin Williamson MP, breached his general duty to promote the well-being of children in England.

The hearing will take place on 27th and 28th July.
For more information, please see the Article 39 website: https://article39.org.uk/scrapsi445/

An article with more detail on the implications for disabled children's short breaks is available on the Special Needs Jungle website: https://www.specialneedsjungle.com/coronavirus-changes-to-childrens-social-care-implications-for-disabled-childrens-short-breaks/

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 2020/21 academic year.

Pupils will now be assessed using five areas of engagement:

- Exploration
- Realisation
- Anticipation
- Persistence
- Initiation

The standards and testing authority advise that the areas of engagement:

'allow teachers to assess pupils' engagement in developing new skills, knowledge and concepts in the schools curriculum by demonstrating how pupils are achieving specific outcomes' (Gov.uk)

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

Gov.Uk The Engagement Model. Accessed from: https://www.gov.uk/government/publications/the-engagement-model Accessed on: 17th June 2020

Obituary for Gill Kennard (1946-April 2020)

Founder, development & training manager of Signalong for over 20 years

Many of the readers of PMLD Link will have crossed paths with Gill over the years as she built up Signalong, developed resources and undertook training for Signalong across the UK and beyond. It was originally based on British Sign Language, adapted to meet the particular signing needs of special people. It is held in high esteem as an alternative and augmentative key-word signing communication method especially for special children and adults.

From the beginnings of Signalong, Gill was ably assisted by her husband Mike Kennard, who was the Chief Executive and company secretary. Between them and a devoted team, they built up a wide range of resources, high quality books, training and in-depth cooperation with families and carers.

Gill developed Signalong with the strong belief that vocabulary should be led by the needs of the user and what they wanted to express, not the dictate of others. I certainly found this out when I was trying, without success, to find explicit signs and symbols on sexuality for a book I was writing. I was overwhelmed with the enthusiastic help I received from Gill. She continued to remain passionate about signing, communication and special people even after her retirement.

On a personal level Gill was a great friend, lively, full of enthusiasm in everything she undertook, the devoted wife of Mike and loving mother of Jane.

Rest in peace Gill

By Flo
Longhorn

RESOURCES, ACTIVITIES AND INFORMATION

Responding to the Coronavirus lockdown

As if by magic, our wonderful ‘PMLD Community’ responded immediately to the unexpected challenge created by Covid -19. Out of nowhere many generous individuals, groups, charities and professionals spontaneously sprung into action offering to share their talents and expertise. Without doubt this evolving collection of information, ideas and resources a will remain as a positive legacy of the coronavirus.

Our collection here is by no means exhaustive. It goes a little way to reflect the regular posts from our social media platforms where we strive to share inspirational ideas and signposting to relevant information and advice. This listing complements the article by Amy Perkins on page 10 , the catalogue of activities collated by The Sensory Projects http://www.thesensoryprojects.co.uk/covid19-resources and the creative and quirky generous contributions from sensory wizards like Pete Wells (page 35) and Sarah Hall (page 36).

Webinars, Podcasts and Covid information:

Surviving through story: This group have offered a series of live and recorded training webinars, a growing body of real life ‘stories from lockdown’, valuable resources and practical advice on story- sharing. Facebook: Surviving through story and www.survivingthroughstory.com. For more about their work read their article on page 2

Pamis: Webinars. Current recordings on moving and handling and using digital passports to deliver postural care. http://pamis.org.uk/news/news/postural-care-gets-digital-watch-our-webinars/

Simple Stuff Works: Complex Care in Lockdown- advice and support on postural care. A series of informative webinars offering clear and practical advice on postural care, for those caring for people at home. https://www.youtube.com/playlist?list=PLx7Dyp1wZw_v90WLWexpbBGrp8SLhk_Ag&feature=share and www.simplestuffworks.co.uk

Learning Disability England (LDE): Coronavirus Hub. A source of information, webinars, resources and platforms for connecting people. https://www.learningdisabilityengland.org.uk/what-we-do/keeping-informed-and-in-touch-during-coronavirus/
St Giles school in Retford has devised COVID 19 guidelines for special schools. The operational guidance details adjustments to premises and practice in working with pupils with a range of disabilities and particularly, PMLD. https://pbs.twimg.com/media/EaU0atoXQAIR_X6?format=jpg&name=large

Frozen Light: Podcasts and Sensory Resource Kits. A growing library of podcasts, created to stay in touch with the PMLD community during the time of corona virus. Sensory Resource Kits of previous theatre performances to use at home, as an alternative offer to their live multisensory shows,. http://frozenlighttheatre.com/

Activity sessions, ideas and resources:

Sensory Spectacle: A whole treasure chest of daily online DIY sensory activities available via Facebook: Sensory Spectacle. Their website and YouTube channel have an abundance of resources, videos and information. www.sensoryspectacle.co.uk

Jensory Ideas: Engaging, interactive, sensory activities suitable for learners of every age. Jen Steptoe has created a huge bank of activity ideas and resource lists from the thirty-plus sessions she presented throughout lockdown. From September, Jensory will offer a weekly video on Saturdays, with a monthly theme. These sessions will still include the messy, sensory and musical activities plus ideas for sensory boxes and Sensology-style sessions! In her videos Jen also offers some valuable information on how to use specialist approaches and strategies to support the additional needs of people with PMLD. Facebook and Instagram: Jensory Ideas; YouTube channel: Jensory

Starfish: A series of simple but insightful reflections were posted on this Facebook page to support families caring for their relatives with PMLD at home during the early weeks of lockdown. Peter Blaker shares valuable knowledge, helpfully illustrated by some great photos of meaningful activities in better times. Facebook: Starfish

Pamis: Virtual Activity Programme. An online programme to support wellbeing through activities at home. http://pamis.org.uk/news/news/virtual-activity-programme/ The programme was designed to support engagement in multi-sensory stories, music therapy, drama, movement and art- inspired activities. Most activities have downloadable resources, some also have supporting video recordings. A wealth of ideas and resources from specialists in the field.

pamis
promoting a more inclusive society
Sensory Inspired Art Activities
Created for PAMIS by Caroline from Making SENse Creative Services LTD

This example was created by Caroline Hill from Making SENse Creative. She recorded videos for every art activity, still available via: https://www.facebook.com/sensorycreativeMakingSENse/

Bag Books: Live and interactive sensory stories! Nina Martinez, the fabulous storyteller, uses the wonderful Bag Books props to lead you through a host of interactive stories old and new, Access via Facebook and YouTube. Some free stories and DIY ideas on their website www.bagbooks.org

Story Massage Programme: Regular live and recorded follow-along massage stories on Facebook and Vimeo https://vimeo.com/storymassage. Familiar stories and nursery rhymes are made into hands-on massage stories, demonstrated on Emmanuel the teddy bear by founder Mary Atkinson. Mary has created some free story resources - simple text supported by massage stroke symbols. www.storymassage.co.uk/

Collar & Cuffs Co: A plethora of creativity and resources! One of their Covid-specific project includes a suite of sensory stories to support people with a broad range of needs in processing their experiences of the Covid-19 pandemic and, specifically, the mental health challenges of living in Lockdown. The suite, called 'Strings & Things', comprises 6 stories plus Story Massages, accompanied by original songs and sound effects. They use the very simplest of resources to ensure barriers to participation are minimised. It's immensely hard for some families, residential settings, early years settings and schools to be able to access resources at the moment, so almost everything that's needed is made from strings...and things! . These resources are free to download. http://www.collarandcuffs.org/covid-19-projects.html

Oily Cart: This long-established theatre company have partnered with the Institute of Imagination for their Inclusive Virtual Imagination Hub. Oily Cart are delivering free sensory workshops this August, exploring sound and music, and bringing stories to life!

To book, you must live in or go to school in Brent, Barnet, Harrow, Camden, Kensington & Chelsea, City of Westminster, Hammersmith and Fulham or Ealing. https://ioi.london/whats-on/

FEEL Theatre: Sensory Circus Online - an interactive, ultra-violet-inspired on their website! You have the option to watch 3 different videos of glow circus and choose whichever piece of music you'd like watch along with via their Spotify playlist (or other songs on YouTube or any other music platform of your choice!) There is a free downloadable resource of UV-inspired activities to try at home.
https://www.feeltheatre.co.uk/sensory-circus-online?fbclid=IwAR36TkMXphMAJ3Xu_mQdqViuSif8g2ybb4a02caWi5nt9z9SHjgmsxpDUZc

Flo Longhorn: Apps Updates. Flo has recently created some new updates on apps that may be suitable for individuals who have very early skills in accessing apps on iPads, tablets or mobile phones. The listed apps have all been researched online and are currently available, both for iPads and (in many cases) Android tablets. The updates valuably include links to informative YouTube video clips. Download the updates www.flopublications.com/index.php or sign up to the mailing list for the next update flopmld@gmail.com

Soundabout: Musical interactions, offered across the week through their Facebook page and YouTube channel .

Hello Songs (9:30am Mondays - Fridays) A daily singalong to start your day. Learn a new song each week - for people of all ages with PMLD and their families.

Little Soundabout (10.30am Mondays) Online interactive music-making sessions and tutorials for parents/carers of children with PMLD in the early years (0-5.)

Soundabout Live! (2pm Tuesdays and Saturdays) Interactive music-making sessions with a new theme each time for people of all ages with PMLD and their families.

Soundabout Life (11:30am Thursdays) Online interactive music-making sessions and tutorials for parents/carers of young adults with PMLD (18-26.)

Soundabout Inclusive Choirs – Oxford (all ages) and Youth Choir (Under 18s) Wiltshire (3.30pm alternate Sundays). Currently all sessions take place online but will be in person once COVID restrictions are lifted. People with PMLD and their families living in/around Oxford or Wiltshire. Zoom invite will be sent via email once registered. www.soundabout.org.uk/

Big Top Musical Adventures CIC: Interactive and engaging live sessions have been offered since March and provide a fantastic archive to revisit at your convenience. Africa is the current theme for musical adventures. Big Top invite you to join Rosie & Dom for this latest series of videos exploring the sounds of Africa. These sessions are devised to support families to explore in a multi-sensory and musical way and were created to cater for the processing times of people with complex needs. Resource lists and alerts via Facebook, Videos on their YouTube channel.

Self-care for adult siblings, a new eBook has been created by Sibs. This UK charity is dedicated to supporting siblings of disabled children and adults. Adult siblings play a vital role in supporting their disabled brother or sister and their parents. Many siblings receive little acknowledgement or support, and few recognise the impact of their sibling role on their own needs and wellbeing. In response to this, the eBook was produced by and for adult siblings who have grown up with a brother or sister who has a lifelong disability.
It includes:

- common topics and questions from adult siblings
- ideas for self-care
- tips and experiences from other siblings

Download a free copy: https:// www.sibs.org.uk/support-for-adult-siblings/ebook-for- adult-siblings/

EVENTS

Palliative Care of People with Learning Disabilities Network (in place of the annual conference)

16 September 2020 Webinar: 'End of life care for people with learning disabilities … Are we prepared?'
To book: https://www.pcpld.org/events-and-conferences/

Training from Rachel Wright, Born at the Right Time

10th September 'Communication and co-production with relatives and carers in a changing world' with Rachel Wright
19th October 'Bridging the Gap: Reimagining Communication and co-production with families in a Post-Covid world' with Rachel Wright, Sarah Clayton and Lucy Parr
25th November 'Communication and co-production with relatives and carers in a changing world' with Rachel Wright
Book via Eventbrite. For more information email: training@bornattherighttime.com www.bornattherighttime.com

Creative events from Collar & Cuffs Co.

12th September 2020 - The Brain Hug Symphony - part of All In The Mind digital arts festival,. A free sensory participative video session, signed in Makaton plus accompanying resource pack, all about co-regulation www.aitmfestival.com

November - December 2020 - Strings & Things: commissioned by Mainspring Arts, programmed for Together 2020 Disability Arts Festival, a series of free sensory stories with original songs designed to support with the emotional and mental health impact of living through Lockdown and the Covid-19 pandemic. https://www.mainspringarts.org.uk/strings-and-things-sensory-stories

October 2020 - House: part of the We're All Bats Listening Arts Channel https://www.wereallbats.co.uk. A series of 4 sensory signed participative video sessions exploring the sounds of home, building feelings of safety, connection and belonging. Subscription to channel required, available from October 2020

Intensive Interaction Institute

September 15th Intensive Interaction General Introduction Day Birmingham,
November 13th Intensive Interaction General Introduction Day, Bushey, Herts
December 15th – 17th Intensive Interaction Coordinator Course (Block 1), Bushey, Herts
Details and application form: www.intensiveinteraction.org

August - Inclusive Virtual Imagination Hub

free sensory workshops live in or go to school in Brent, Barnet, Harrow, Camden, Kensington & Chelsea, City of Westminster, Hammersmith and Fulham or Ealing.
https://ioi.london/whats-on

Oily Cart
August 2020 - Inclusive Virtual Imagination Hub
Free sensory workshops.
Information and booking : https://ioi.london/whats-on

PMLD LINK
sharing ideas and information

PMLD LINK

Subscription for 12 months

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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.
Ann 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 Clinical Director 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, Rachel is a researcher in the field of 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 an independent advocate, an involvement worker and a LeDeR Reviewer for the Learning Disabilities 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	Deputy Headteacher at The Shrubberies School, Stonehouse, Gloucestershire. This is a school for students with Severe and Profound Learning Difficulties
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	Policy Lead, Mencap

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sharing ideas and information

PMLD Link is a journal for everyone supporting people with profound and multiple learning disabilities.
Visit www.pmldlink.org.uk

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