PMLD LINK

sharing ideas and information

Fun

Summer 2022

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Cover picture from the article by Jane Godfrey and Julie Calveley

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GUEST EDITORIAL

Fun

What is fun? What do we mean when we use this little word? And what is fun? Well an awful lot actually it seems. As Jill Goodwin points out the word ‘conjures up images of laughter, activity, joviality and noise - being together in a lively or boisterous way’ (see page 10). But fun can be of a quieter kind in a less active, but equally companionable way. Lucy Garland says that ‘fun should be at the heart of everything and that it has the power to change hearts and minds’ (see page 7). But Neil Mullen reminds us that, although play and fun are important for their own sake, they can also lead to progress in cognition, improvements in mental health, and increased wellbeing (see page 45). Similarly, Maureen Phillip says ‘….when we work together, we learn together, and the outcome is fun and more inclusive for everyone. Learning and development doesn’t always have to be onerous or heavy it can be fun’ (see page 18)

A key message is the need to take painstaking care when planning activities and being flexible. As Melanie Nind says (see page 47), we would surely all agree that we would like to foster laughing together, being companionable together, sharing fun-filled interactions with the people but, do we consciously create environments that permit these or do we rely too much on chance and seizing moments that present themselves?

We all differ in what we find fun. Who would have thought that Isaac Archibald could find fun in an emergency hospital setting (see page 5) or that Helen Fitchett could create pockets of fun during night-time care routines (see page 6). Thinking outside the box is crucial to providing fun activities.

Equally important are: knowing the person well, knowing what they might enjoy and what they definitely wouldn’t; taking time to sit and play with them and be uninterrupted by anything else that is going on around; and always being attentive to the person’s responses looking for signs of like and dislike and requests for more or to stop. This is illustrated well by Jane Godfrey’s descriptions about how she interacts with her 13-year-old son Joel (see page 2).

We have wonderful contributors to this issue of PMLD Link who show children and adults being playful and having fun and how these can make life better for them. We feature theatre performances, movement, music and art activities and events, festivals, and a wide range of activities in schools and adult settings. Sit back, read and enjoy. Have fun and be inspired !

We have had so many great contributions that we could not fit them all into this issue and the others will appear in our Winter issue.

Guest Editors: Maureen Phillip, Bella Travis and Rob Ashdown

Contact Us

Subscriptions

PMLD LINK
Caerludd, Cilgerran,
Pembrokeshire, SA43 2SN

info@pmldlink.org.uk

Production

Paul Bramble
Email: info@pmldlink.org.uk

Website: www.pmldlink.org.uk
Twitter: @PMLDlink
Facebook: @PMLDLink
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Using Joel's Fun Experiences

Jane Godfrey and Julie Calveley

This article is based on a conversation between Jane Godfrey, parent to 13-year old Joel, and Julie Calveley, learning disability nurse and director of NAC Wellbeing, a not-for-profit organisation dedicated to the emotional wellbeing of children and adults with severe and profound intellectual disabilities. We wanted to reflect on the place fun has in Joel's life; what is fun for him, how having fun is supported and whether there are times when fun is not what is wanted or needed.

After a Google Search, we agreed on a broad definition of fun as 'enjoyment, amusement or light-hearted pleasure that is often associated with play and playfulness'.

Some of the things Joel finds fun

People engaging in 'proper play'

Joel loves people playing with him, properly playing. You know, having that time to sit and play and be uninterrupted by anything else that is going on around whilst reading his responses. He has different kinds of signals that tell us 'I like this', 'I don't like this' and 'I'm feeling excited'. For example, when excited his legs will go out, he will beam a big smile and laugh.

I think for Joel it is about the tone of voice that you use. If I was just to use a plain tone and present him with a toy, I don't think I would get the same response. We use a sing song tone of voice, higher pitched, really playful and happy. I think that goes a long way.

He does like this little game where I'll give him a cuddle and say 'Oh lovely Joel'. He will turn his head away and then turn back to say 'more'. He will do that over and over. We end up laughing about playing the game and him wanting this cuddle more and more.

The rainstick

Joel loves his rainstick, which is really bright and colourful (see photo). I think we recognised quite quickly that there was something about the rainstick that he particularly liked and I wondered if it was the definition of the beads going down and then all of sudden the sound stops and it goes quiet and it is like ‘How can I make it work again? What can I do?’ So by giving him that opening, that opportunity to do it again, do it more, he soon learnt ‘When I vocalise, I get more, and I like it, it is fun’.

Now, ten years on, you only have to show him the rainstick and he beams a big smile, like ‘I know how I am going to play this and I know I can make it do more for me’. So there seems to be something about Joel being able to make things happen, with the rainstick and other ‘cause and effect’ objects and games.

Movement

When we used to go to the gym a wonderful manager came up with the idea of trying one of those trolleys that mechanics use to go under cars. We put padded cushions on it so Joel could learn to scoot across the gym on his tummy. He did not like being on his tummy initially but when we gave him a crawling motion - by doing and saying ‘bend, push, bend, push’ with his legs - he learnt how fun it was to move around the gym. He was having fun but he was also exercising. Because he can’t move for himself, when you give him movement that gives him some sort of comfort and pleasure, you can see it; he stills and is comfortable and relaxed. His whole body changes.

Trampolining

Oh my goodness, little did we know what his reaction would be when we first put him on a trampoline. At first, he was small enough to be held. When the practitioner put him in her arms and jumped up and down on the trampoline, he screamed with delight. It was so lovely to see. We had no idea that was how he was going to respond when we initially did that. I think, being restricted with movement, then to have somebody help him have that movement was something that Joel found so delightful.

I can imagine it would be like if you are a person who loved going on the thrill seeker rides at the fairground. So every week we built in the trampoline, almost as a reward, after his exercises at the gym ‘You have done so great, let’s go on the trampoline’. He would scream with delight and laugh. He loved it.

Eye gaze games and reading

Joel likes popping bubbles and is learning to read stories by eye pointing to a word, which causes the device to read it out loud and for an accompanying picture to be shown. When he sees the eye gaze machine coming towards him, his legs will go up and you can see that he becomes really animated and excited. Now that is work, that is hard work. But it seems that for Joel it is also fun. Joel starts to read the story and gets responses from us as well as the device, like clapping and cheering ‘Well done, you’ve done it’.

Going out in the car

He loves going out in the car now and squeals with excitement. When we put him in his wheelchair, he is picking up on cues and knowing what is coming next. Going out is fun for Joel because he loves looking around. He has naturally got these amazing observation skills. You can see how he is taking it all in, what is going on around him and almost trying to work out what people are saying to him and what is going to happen next.

Music

I think music is a really big one for Joel. He has music therapy and music for wellbeing sessions and we do a lot of music with him at home as well. We have taught him how to put his finger out so that he is able to join in playing instruments. He is starting to realise that if he relaxes his hand enough he can do it. We are saying ‘Joel is doing that’ so that we can support him to recognise that he is making the sound.

Familiar toys and new experiences

Our house is so full of lots of toys that I can’t get rid of because Joel recognises them and when they are brought out he smiles with delight. His beaming smile shows ‘I know what this toy is going to do’. He is actually also quite comfortable with certain changes and new experiences too, it is just when something is absolutely brand new that it is difficult for him to manage.

Joel’s Top 10 of Fun

1. Music - listening and supporting Joel to play. Vibration is always valuable here too!
2. Movement - Swing, ijoy ride (exercise machine), trampoline.
3. Stimuli - rainstick, sensory toys.
4. Interaction with people - chatting with a jolly voice, with tapping, touch etc.
5. Going out in the car.
6. Stories - from books with an adult, or Joel reading from eye gaze himself.
7. Going to holiday club - social time with neurotypical children.
8. Mr.Tumble / in the night garden on the t.v.
9. Cooking with all the smells and joining in with the whole process.
10. Massage, reflexology and reiki.

Times when fun is not what is wanted or needed

Sometimes Joel will also say when he has had enough of playing. It might be that he is bored with what he is playing, and so we offer something else, but if he repeatedly rejects a variety of options, we know that he probably does not want to play anymore.

When Joel is feeling distress, discomfort, pain or anxiety he just might not be wanting to play at that time. I think that sometimes we can read him quite quickly and understand that he didn't want to play. He will tell me through the way he makes eye contact with me. It is really quite specific, almost kind of 'I am not feeling this at the moment'. So just reassuring him with my voice and holding his hand is a really big one for him. Fun can be a distraction, but we comfort first. The first thing you go to is a natural cuddle.

If we see he is in pain, we don't use the sing song tone of voice, or if we see he is in discomfort, we are with him on that one 'Oh, I think you are feeling a bit rubbish', or 'I think you are feeling pain or sad'.

He doesn't cry very often so we have to pick things up in a different way. This is where the tools that NAC have created for recognising pain and emotions, states and feeling are useful (available as part of their 'Promoting Emotional Wellbeing' course). For example, his muscle tone can be quite tense, and this is recorded as possibly being pain, but that it could also be anxiety. Reading the context is crucial to interpret what is happening for Joel.

Offering him a drink when he is not feeling quite right is really important for Joel. When we went to music for wellbeing for the first time, I offered him his cup and asked 'Would you like a drink?' and even though he was feeling what he was feeling - all those emotions that were obviously going on for him - he still managed a smile, which told me that he did. So once he had a drink we just waited for him to settle and calm. I guess it is like all of us, when we feel upset and overwhelmed, we need time for composure, and he is no different than that.

Perhaps it takes us to be in a certain psychological and physiological place to actually be able to enjoy light-hearted pleasure. If we are having to deal with anxiety or pain that could be hard because we are experiencing something a lot heavier. Sometimes just being calm and content is where we need to get to. Fun might come later, or even another day.

Having an inner confidence and composure not to feel pressure to make someone be seen to have fun, smile and laugh is crucial, because there is so much more to a rich and rewarding emotional life than just fun. In order to know who we are and to feel a sense of belonging people must be able to express and share their most authentic self (Brown, 2021). Those moments of connection where other feelings, such as sadness, anxiety, overwhelm, loneliness, grief, calm (to name just a few) are shared are just as valid and necessary for wellbeing and a good quality of life. However, with its association with positive affect and increased social bonding (Reis et al, 2017), for Joel and many others, experiencing fun is certainly an important component of a satisfying and fulfilling life.

For more information on the course referred to in this article: 'Promoting Emotional Wellbeing' go to: https://learning.nacwellbeing.org/courses/emotional-wellbeing or contact julie@nacwellbeing.org

Contact Details

Julie Calveley, learning disability nurse and director of NAC Wellbeing
https://www.nacwellbeing.org/contact/

Jane, Rich and Joel Godfrey can be contacted at richjanegodfrey@gmail.com

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Jane's Top Tips

- Use a sing song, higher pitched, playful, happy tone of voice, and being very jolly.
- Making things happen is fun - allow opportunities to make things happen!
- Fun is great for learning and developing skills.
- Simple games can be really fun.
- Familiarity and repetition are fun as well as new experiences, if introduced sensitively and when ready.
- Observe for when ready to move on to something different or more challenging.
- Allow sufficient time to process and settle, especially in new environments.
- Think about sensory needs and optimum distance and volumes of you, toys and objects.

Hospital happiness – despite our concerns

Sandra Archibald

Isaac in a hospital bed, mid-clap and gazing happily into the camera with a big smile on his face.

Yesterday...All my troubles seemed so far away...

After three bad coughing nights and a next day visit from a truly incompetent GP...

We end up in hospital for tests...

Where Isaac belies my concerns with a show of extreme good health and humour!

'What cough?' He seems to say, smiling, clapping and gazing warmly at the medical staff. Delight in being wheeled along corridors and into lifts!

Never thought we'd see the day when a fun outing was a visit to the hospital...It's all about perspective!

Contact Details

Sandra Archibald, Isaac and Isaac's team are always keen to connect with others – do follow them on Facebook and check out Isaac's blog:
https://www.facebook.com/IsaaacArchibald
https://acollectivecare.wordpress.com/

Connect with us on social media

twitter

facebook

Remember to tag us on social media ~ @PMLDlink

Twitter: @PMLDlink

Facebook: PMLD Link

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

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

Finding Pockets of Fun

Helen Fitchett

In my role as a Family Support Worker, I work the night shift.
I administer medication.
I reposition to prevent pressure sores and for comfort.
I record observations.
I change pads, bedding, pyjamas.
I administer feeds.
I keep an eye on monitors.
I watch and wait in case anything does not go to plan.
But most of all I promote sleep.

So where is the time for fun?

The answer is simple, any snippet of time can be turned into fun time. The early morning wake ups, late nights when not quite ready for sleep, the middle of the night mad half hour. The early morning wake up is the most fun, the other two are for relaxing interactions which are to encourage that sleep – massages, gentle music, story massage.

Early morning is the best time, fresh from sleep, wide awake, spontaneous, simple.

One young man I care for loves a game we play which locates the parts of his body. I will start by saying ‘where’s your right arm/left leg/chest?’ while tickling it and making a silly noise (he does love a silly noise!) I will then ask, ‘where next?’ and he will respond by lifting an arm or leg and I’ll tickle that one saying the body part and making the same silly noise. Sometimes he becomes still and has a look of anticipation, so I’ll tickle his chest or cheek, to be rewarded with a sudden burst of laughter.

Spontaneous, early morning discos are a firm favourite – obviously we must wait for a respectable hour but once that comes, the gloves are off! Out of tune singing, silly dance moves – they all come out to play.

Stories are another place to find pockets of fun. Changing voices, noises to emphasise actions, puppets, physical actions both large and small, textured fabrics and items to represent parts of the story.

To have fun in this way, it helps to have built a mutual knowledge and trust in each other as they are usually crazy, mad pockets of fun-filled laughter but equally, having fun will help build trust in each other.

I like to find fun in the spontaneous and don’t care too much about planning as I like to see which direction it naturally takes.

Contact Details

Helen Fitchett BA (Hons) is a Family Support Worker, CCT, Royal Derby Hospital

Email: helen.fitchett@btinternet.com

Fun and Fire Songs

Lucy Garland

When I heard that the topic of this issue of PMLD Link was FUN, I was filled with excitement. ‘Fun’ is one of the core principles of Frozen Light - although we often talk about it as ‘Joy’. It is something I think is often overlooked by society in general, something seen as not as important as work and daily chores, but at Frozen Light we believe that fun should be at the heart of everything and that it has the power to change hearts and minds.

Our shows are a fun-filled extravaganza. They take audiences with PMLD on an emotional narrative journey but each sensory interaction is filled with fun. The question we ask of our audiences is ‘What can we find within this sensory item that brings you joy, how can we find fun together?’

The answer to this question often surprises us. Smell a mushroom? No thanks; Put it on each of my fingers to make a miniature finger umbrella? Yes! This! Of course, there is always the option for an audience member to say no, but the offer of fun is always there.

At Frozen Light we are in a privileged position that we can create a space focused on having a good time. We know it is an honour to have this job and want to share this fun with audiences up and down the country.

In May 2022 we were lucky enough to finally premiere a show which brought fun to not only audiences and performers but to a 35-strong choir as well. Fire Songs was dreamt up in 2019. It came from a desire to explore the sensory properties of singing with audiences with PMLD. In our shows we have always used singing, especially singing an up-close individualised name song to each audience member. This singing is usually performed by 3 performers in 3 part harmony. It is a moment in all our shows which never fails to connect with an audience member, a moment that seems to reach down into a space of intrinsic humanity. With Fire Songs we wanted to ask the question: What does it feel like if more than 3 people sing to you, what about if a whole choir sings your name?

In September 2019 we worked with two groups of people with PMLD, one adult group and one school group, to explore this question. We brought in 15 singers and shared songs, sounds and vocal noises with the groups and we collaborated with them to discover what worked and what didn't. We initially explored just singing but realised that adding sensory objects and one-to-one interaction gave our audiences a more meaningful way to access the singing.

But aside from the show, Fire Songs had another goal. To create the choir for the show we designed the project to work with a different choir at each location the show is performed. The idea behind this was to bring two groups from the same community (the choir and the audience with PMLD and their carers) together to share in a joyful choral experience. The project isn't about the choir doing a concert for an audience, it is about the choir and the audience sharing an experience, one where the choir get as much from being with the audience as the audience get from listening to the choir. At its core is a desire to bring people together to enjoy spending time with each other and to meet each other on a level of openness and honesty. It is a show with a real belief in the power and beauty of humanity and connection.

Fire Songs takes place in the round, the choir and the audience of six people with PMLD and their families/ support staff all sit together in a large circle. In the centre of the circle are 6 large triangular tables which come together to form a large hexagon. Throughout the show the tables move to the audience, lids open and magical sensory things appear from secret drawers and compartments. Four performers engage with the audience with warm blankets, burnt wood, mirrors and light up vibrating moons.

We were all set to perform in May 2020, and then the pandemic hit. Fire Songs was put away in a shipping container and the long wait began.

Fast forward to 2022 and after much consulting with our audience panel and families of people with PMLD we decided that now was the time to bring back Fire Songs. After two years apart the offer of connection seemed more poignant than ever and people were definitely up for having some fun! We worked with the Thetford Singers and also put together a Frozen Light choir in Norwich and together the two groups became our Norwich Fire Songs choir. After lots of rehearsals, cups of tea, practising in living rooms and church halls and a fair amount of lost voices (mainly on my behalf) and laughter, Fire Songs was ready to go. We premiered it at Norfolk and Norwich Festival 2022 to sell out audiences.

Luckily Fire Songs achieved everything we hoped it would. It is a very different show for Frozen Light but one that feels incredibly full of joy. It is warm and nurturing whilst really feeling like a festival spectacular. There are surprises at every turn. But the biggest triumph for us was the profound effect that the show had not just on the audience but on the choir. Many of the choir members were people who had never met anyone with PMLD before and they were moved by the connection they felt with the audience. They truly understood that it wasn't us and them, that there was no hierarchy in the room, it was an hour of sharing. Here are some quotes we collected from choir members post the show:

> *"Seeing this audience as individual people who are valued is extraordinarily important"*
> *"As one of the songs says, we are US together. I very much felt that"*
> *"I can honestly say that taking part in this project was life enhancing and something that I will remember for the rest of my life"*
> *"It was a "coming together" more than a traditional performance with delineation between audience and performers"*
> *"It brought me so much joy - one of the best musical experiences of my life"*

But one of the most fun things to evolve from Fire Songs was completely unplanned and led by the choir and audience together. Following the joyful final song where we clap and throw confetti the show ends, we all bow and then Tom (the composer) and Alfie (one of the performers) reprise the song as the audience leave… or so we thought! But on the first show both the choir and audience started spontaneously dancing together, the fun, joy and the warmth of the show wasn't ready to end, both parties seemed to need to spend time together informally and revel in the experience they had shared.

The choir learnt so much from all the individuals with PMLD and many commented on the increase in their wellbeing from sharing a space and experience with the audience. Alongside our audience having a fabulous time, which was the ultimate aim of the project, we also hoped that the choir would learn from audiences with PMLD how to have fun in the moment and share in joy, and boy did they learn that!

Contact Details

Lucy Garland, Co-Artistic Director, Frozen Light

www.frozenlighttheatre.com
www.frozenlighttheatre.com/currentshows/firesongs
Email: info@frozenlighttheatre.com

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Being with: creative fun

Jill Goodwin

The word 'fun' conjures up images of laughter, activity, joviality and noise - being together in a lively or boisterous way. Even if we are not actively participating in it ourselves, the positive energy of boisterous activity can often be enjoyable to be around. In this article however, we focus on a quieter kind of fun as we explain how Oily Cart made a show designed to bring people together in a less active, but equally companionable way.

Space to Be was the artistic outcome of Dr Jill Goodwin's Researcher in Residence role with Oily Cart. During the residency we discussed the challenge of being with a disabled person whose body is still and who may show only very small responses to what is going on around them. We know how this apparent passivity can sometimes cause companions to become louder and more active, as if to compensate and try and 'break through' the stillness. With Space to Be we chose to think of a disabled child's stillness as an invitation to stop 'doing' and simply 'be' together in the sensory moment.

Created during lockdown in the Covid-19 pandemic, Space to Be was designed as a touring show that could be delivered by post to families who were shielding. Families were sent five boxes and instructed to open one a day, so that the story/family experience (connected by an audio track; see Note 1 below) built up over the week. We wanted parents and siblings to join their disabled family member in a language-free space of 'being' rather than 'doing'.

The show was made in 2020 (during the lockdowns) and was delivered to family homes in the form of five packages. Each package contained a unique sensory experience, on the theme of outer space, carefully crafted to bring families together with the disabled child at the centre. Each family member was invited to take the name of a fictional star (with its own characteristics and properties) and the Space to Be experiences encouraged them to create their own stories from the lines that link these stars, the family's unique constellation. It was important to the team that each creative experience placed the disabled young person at the centre of their relational constellation with a view to creating moments of mutual enrichment for all.

The first package was designed as a solo experience for the adult/carer alone, aimed at bringing them into a more sensory headspace. This included an immersive binaural soundtrack played through a set of high quality headphones, an eye mask and a mini handheld sculpture designed for touch exploration. This element of the show received a lot of positive feedback from parents, for example:

> *"it was really moving and very strong and unique. So I want to thank you for thinking about the carer first..."*

The second package included a double-sized deep blue velvet pillow that had a speaker embedded at each end, and a velvet blanket embroidered with stars linked into constellations by lines of stitching. The soundtrack included various voices repeating the simple phrase "you and me" in stereo (see Note 2 below). It provided a powerful experience for some people:

> *"....almost like a connection, like we were both experiencing this in exactly the same way and getting the same level of enjoyment out of it ... It was just like this really intense sharing of an experience"*

In our research prior to developing the show, the families we consulted with all spoke about how difficult it was for them to find things they could all enjoy together, and how important that was to them. The third and fourth Space to Be experiences therefore involved siblings and/or any other members of the family. The third package contained silver tins, each containing a wrist torch and a tessellated mirror sheet that threw reflected light patterns onto the walls and ceiling. Each tin played a soundtrack that could be listened to separately, or brought together to form a layered piece of music. The fourth package contained an audio resonator box designed to be placed on the lap or under the feet of the disabled child. By stretching and pulling on lengths of fabric to create a star shape, other family members could change the sounds and increase the intensity of the vibrations within the resonator. The final Space to Be package contained a mini 'planetarium' tent with a starlight projector and a musical soundtrack that included the sounds of real stars in the galaxy.

> *"Deep, meaningful, powerful and profound experiences which were new to us as a family and were very special"*
> *"It was amazing! And it was lovely being able to see all of the family being able to access and enjoy the same activity!"*
> *"It felt so special to have a beautiful experience that connected us all"*

Space to Be was experienced by 164 young people and 150 parents/carers in 70 different homes around the UK. The show is now being redeveloped for use in hospitals and hospice settings based on feedback we received from parents about how the show fostered valuable moments of connection, and made them feel seen and appreciated during covid isolation and the strain of life in lockdown.

Notes

Note 1: https://soundcloud.com/oily-cart/sets/space-to-be/s-i7DiKT36daT?utm_source=clipboard&utm_medium=text&utm_campaign=social_sharing

Note 2: https://soundcloud.com/oily-cart/box-2/s-Fc6yAh1NED5?in=oily-cart/sets/space-to-be//s-i7DiKT36daT

Note 3: For video of families enjoying 'Space to Be', go to: https://www.youtube.com/watch?app=desktop&v=srbDLkLa9HM

If you would like to read more about Space to Be, or about Jill's time as Researcher in Residence with Oily Cart we have written an in-depth report titled 'Being With in Sensory Theatre' that can be found on our website: www.oilycart.org.uk.

Contact Details

Dr. Jill Goodwin is Researcher in Residence at Oily Cart
Email: jillkgoodwin@gmail.com; website- https://jillgoodwinphd.wordpress.com

Curiouser and Curiouser: multi-sensory theatre for performers with profound and multiple learning disabilities

Heather Molloy

'*She is accepted and valued for what she brings to this world. She has found her place in it and is confident, capable and proud of herself and her friends.*' (Jacqui Law, Parent of participant).

The idea for a multi-sensory theatre group emerged from a moment of pure joy following a sneak preview of the film where PAMIS musicians and their music practitioner Fiona Sharp performed their song 'Silver Lining' as part of a multi-sensory story adaptation of Dunja Jogan's book 'Felix After The Rain' at the Edinburgh International Book Festival 2020.

Despite the many difficulties and tragedies of the coronavirus pandemic and lockdown restrictions, this amazing group of musicians and their families worked hard to produce a beautiful piece of music which would be performed before an international audience, making them truly visible in a way, that had it not been for the pandemic, we might not have seen. This was not a performance being delivered to a group of people with PMLD. They were the performers. And, what a performance it was! It was a piece of work that they rehearsed for weeks before the recording. For them it was a way of accessing the book and then conveying the message of the book to others.

It's something we already knew they could do because they are our best educators, but it was the catalyst to developing our multi-sensory storytelling and performance troupe in Dumfries and Galloway.

Alice in Wonderland was the first story we chose to adapt, and Grove and Phillip (2022) describe perfectly why in their chapter on Literature and Legends from 'Storytelling, Special Needs and Disabilities'. They say 'This story offers a multi-sensory, multi-faceted adventure that is colourful, varied and full of amazing characters, which makes it a safe and fun way to explore people and emotions.

Each week the group would begin with the same warm-up – a journey down the rabbit hole and into

Wonderland. To facilitate this a hoop was placed in the centre of the space and one at a time performers would move inside the hoop and have it lifted, or lift it themselves, over their bodies. Each week this would develop as performers added sound effects, vocalisations and actions, making this integral scene their own.

The project was planned to begin with a series of workshops where participants were able to explore each scene and place themselves in the shoes of each character. This would then be built into a script/ performance.

The Caterpillar, for example, blows bubbles (instead of smoking a hookah) and performers blew the bubbles, and had bubbles blown around them, both inside and outside our venue. This then translated into the final production when the cast blew bubbles around the audience in the auditorium.

As they took part in the workshops, the performers were demonstrating and recognising their sensory likes and dislikes which helped them to understand the impact on the audience and choose which part they would like to play.

This process also helped us as practitioners to learn from the performers and adapt the script which grew organically and was co-produced.

For many of the families involved in this project, this was the only safe and in-person activity following the lifting of restrictions and gave much needed fun and respite.

One of the parents, who regularly attended with her son, commented ‘I have to say that these sessions were a life saver for my son and myself as we were desperately looking for social connections at that time when there was very little opportunities that we could access.’ A benefit we hadn’t anticipated during planning was the level of support this provided for family carers. Spending time together during the sessions lessened feelings of isolation.

Another integral element to this project, and our aim to make this an important opportunity for bringing the community together, was to collaborate on the final production with external organisations. By doing this we were also able to widen participation for those more comfortable in familiar settings. We initially reached out to three local partners; Paragon Music and two of Dumfries and Galloway Council’s Activity Resource Centres (ARCs). Throughout the process we were delighted by the enthusiasm of all the facilitators to make this happen no matter what.

As the workshop phase came to an end, the decision was made to make a multi-sensory movie. At that time, we felt it would be safer and release some of the pressure from a live performance (we could have as many takes as we needed). This allowed the two Activity Resource Centres (ARCs) the creative freedom to develop scenes for the production to meet the needs of their members and work at a pace that suited them, and it was a pleasure to see the unique way that everyone contributed to the production. The staff and cast at the ARC in Castle Douglas decorated a large indoor space like the Mad Hatter’s tea party which stayed up for several weeks and brought everyone together. When they were ready, we were able to go along with the video camera and film their scene, complete with costume, props, and a musical number! At the ARC in Dumfries, the Jabberwocky was created through sensory artwork and then taken to their outdoor space for filming. Paragon Music’s wonderful musicians provided an enchanting musical composition that represented the laughing flowers and perfectly represented the absurdist nature of the novel.

Once the movie had been edited, a multi-sensory screening was planned and an audience invited to watch the movie on the big screen at the Dumfries Baptist Church Centre with the cast providing live demonstrations of the sensory stimuli.

Two performances took place in November 2021 and 127 tickets were taken. We chose the Dumfries Baptist Church Centre as a venue because of its fantastic facilities, including a fully accessible Changing Places toilet. We held the event in their main auditorium but were also provided with additional rooms as quiet spaces should they be needed.

We were delighted when several schools brought pupils and one of the local learning centres chose to use the film to create a curriculum around the film for the rest of their school term.

Following the success of the film another one was planned, and in February of this year work began on a multi-sensory adaptation of The Wizard of Oz. Once again, we were pleased to welcome Paragon Music and the two ARCs as partners in the project and we are looking forward to a live performance later in the year.

It was fantastic to see how creating the multi-sensory performance of Alice in Wonderland supported so many people and provided a purposeful and meaningful activity for the community involved, for several months. The film is a celebration of how community came together to include everyone in the making of this wonderful film and through the creation of the film they learned the story but most of all they had fun! The audience loved every minute of the film and had fun too with the sensory elements that accompanied the film showing on the day.

Link to film: https://www.youtube.com/watch?v=_ScvYI0vju4

Contact Details

Heather Molloy is PAMIS Programme Lead in Dumfries and Galloway.

Email: heather.molloy@pamis.org.uk

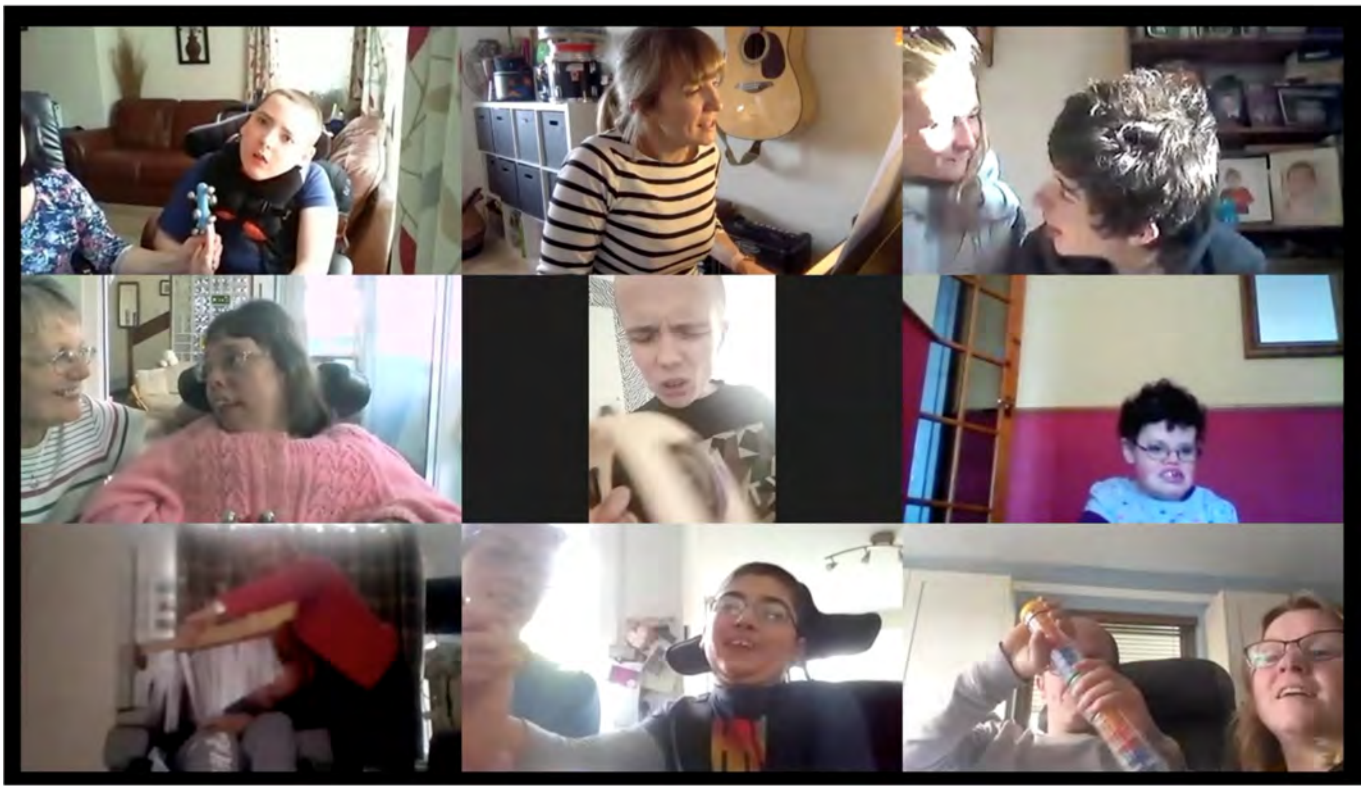
Get Involved

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

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

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

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



Festivals and fun

Maureen Phillip

Let’s weave our way through the fun of festivals and what they offer people with profound and multiple learning disabilities. Festivals can be wonderful places that provide people with the opportunity to step out of the everyday and enter another realm for a few hours or days. Festivals offer families the opportunity to spend time together in a setting where there is something for everyone. Festivals can also be overwhelming and busy for some people but for those who are comfortable and happy to step into the festival fun, a wonderland of adventure awaits them. Festivals take place all year round and a varied seasonal festival programme offers opportunities to explore a wide variety of experiences.

PAMIS and the Scottish festivals

Thanks to grant funding, and at the request of families, PAMIS (promoting a more inclusive society), has worked with a number of Scottish festivals over the last few years to support them to have an inclusive programme of events that can be enjoyed by the whole family. A wide variety of experiences, such as The Edinburgh International Book Festival, Wildhood, the award winning children’s festival in the grounds of the beautiful Tullibole Castle in Perthshire, The Folklore Festival, The Wild Goose Festival and Nithraid Festivals in Dumfries and Galloway and many more. Each festival not only brings its own unique experience to people with profound and multiple learning disabilities (PMLD) but it offers the festival organisers and participants the opportunity to learn from people with PMLD about what makes the festival a truly inclusive experience for everyone and what is required to make sure no one is excluded.

Each of the festivals mentioned here provides a variety of wonderful experiences for people with PMLD and their families and each one could fill a book on their own, but I hope this article gives you a flavour of what festivals offer for those who enjoy attending them. Not only do they provide entertainment, they provide learning experiences, improved mental health and well-being, social interaction and connection and they are fun. The hidden treasure in watching the interaction between people and their environment is a reminder not to make assumptions about what each individual enjoys. Every festival offers a different experience, and each person enjoys it in their own unique way. So let’s begin the festival journey...

Some of the festivals

At Wildhood, the award winning children’s festival at Tullibole Castle in Perthshire, people with PMLD enjoy an outdoor experience with the whole family, safe in the knowledge there is something for everyone and that they can attend together as a family. There are multi-sensory storytelling sessions, story walks, stories beside the story tree as well as adapted games alongside all the other activities on offer at a festival, and of course Obama brings accessibility and joy to everyone. Obama is a pony who loves to come along and spend time with children and young people at the festival. He takes them to the inaccessible wild, hidden parts of the festival. He brings happiness and joy to everyone and is an integral part of this festival. Obama brings along Kate and Simon Mulholland, to help him on the day and together they are, Inclusive Countryside Access. This wonderful team camp over at the festival, ensuring that everyone enjoys the magic of Wildhood and that no one misses out and of course Obama has fun too. Wildhood takes place in June and is a festival that celebrates nature and the outdoors. Spending time here under the trees beside the river offers time and space for observation and reflection.

One young woman accompanied her mum and dad along the riverside. They stopped to listen to a story and then to chat to other people along the way. From her wheelchair the young woman watched the sunlight dance through the leaves on the tree and she smiled. Along the riverbank some children were fishing with their nets identifying water bugs, tadpoles and water fauna using the charts supplied by the RSBP in the tent nearby. The young woman tilted her head slightly to catch their chatter and laughed to herself as she listened to their conversations. It is wonderful to catch moments of natural, uninterrupted connection and personal communication moments that bring such obvious pleasure to someone. She sat contented by the

riverbank, obviously enjoying being in the moment and listening to the chatter of the children as they played. Wildhood offers something for everyone and of course the PAMIS mobile changing places toilet, The PAMILOO, ensures that everyone can have a carefree time at the festival. (For more about the festival and Pamiloo go to: https://youtu.be/HgS4Ts8IdSI)

Other festivals that people enjoy celebrating are The Wild Goose Festival and The Nithraid Festival in Dumfries and Galloway. Both these festivals celebrate nature, creativity and place.

Wild Goose Festival takes place in October and is inspired by the migratory route of the barnacle geese between Svalbard and the Solway estuary. The festival celebrates the journey of these geese and the connection that people have to the environment. It is supported by Dumfries and Galloway Council and Traditional Arts and Culture Scotland – TRACS. This festival is very much a community event where individuals and community groups come together to participate in the festival. The Stove Network facilitates this family friendly festival through an innovative programme that includes art, literature, multi-sensory storytelling, nature walks, talks, films and creative events. People with PMLD have enjoyed the migratory story by accessing the festival online as well as through active participation in creating art for display at the festival.

In 2020, COVID meant the planned live performance had to be cancelled at the last minute but the migration story was captured in dance and filmed alongside the narration of the story. Boxes of stimuli to accompany the story and the film were delivered to the homes of people who wanted to attend the festival to enable them to participate from home. People accessed the film online and enjoyed the experience from the comfort and safety of their own homes. In 2021 people with PMLD enjoyed hearing the story, learning about the migration of the geese then creating artwork for display at the festival. 2022 will see live, in-person events that continue to evolve and enhance the experiences of people with PMLD and allow them to experience the festival along with everyone else in their community.

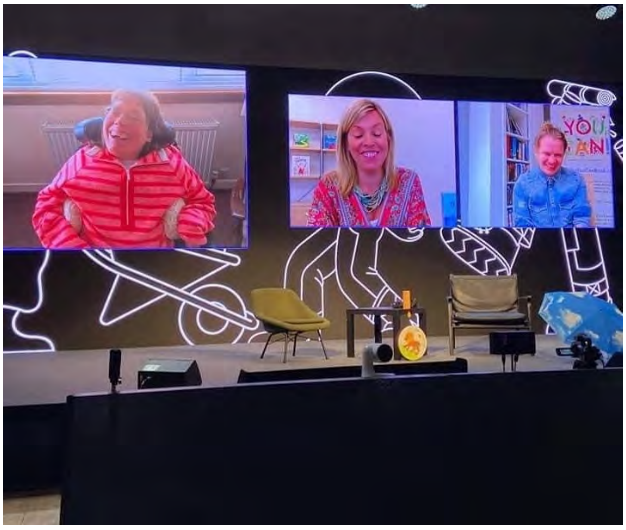
The Nithraid Festival is a festival that celebrates and explores the River Nith. The river connects people, places and communities. As it winds its way from source to sea you can feel the stories, folklore, myths and legends waiting to reveal themselves and be told. These stories are captured by PAMIS's Heather Molloy and turned into multi-sensory versions that enthral audiences with PMLD and enable them to be a part of their community celebration and part of their cultural heritage. They experience the excitement of being part of the mythical landscape that the stories of the river reveals and as Heather captures them they are brought alive for people with PMLD and so they too play a meaningful part in this community event.

Thanks to The Stove Network these festivals offer people with PMLD opportunities to connect to place, to be a part of their community, to experience festivals that are fun and that connect them with their heritage, nature and the environment. They learn so much at the festivals while having fun. The Stove Network is an award winning arts and community project in Dumfries. The Network believes the power of art, community and creativity helps us to understand the world and empowers us to make the changes necessary to make a fairer world for everyone.

Folklore and Book Festivals

Literature, stories and picture books feature a lot in the lives of people with PMLD. Stories help them interact, connect and make sense of the world. It is no wonder that festivals involving books and stories are very popular. For several years now PAMIS has worked alongside families and book festival organisers to ensure that people with PMLD are included in their events.

Working alongside authors preparing and delivering inclusive book events that enable people with PMLD to experience the atmosphere of a book festival and access and interact with books in a way that is meaningful for them, is a joy. James Carter, Dunja Jogan, Alexandra Strick and Steve Anthony, Philip Ardagh and Anne and Steve Brusatte are some of the authors that have worked alongside people with PMLD, their families and PAMIS to make their events suitable for this group to enjoy at the Edinburgh International Book Festival. It has been a wonderful, varied and ongoing journey that has enabled people with PMLD to experience the fun and excitement of a book festival.



Oral stories and history told through folklore and legends are also much enjoyed by people with PMLD too. “Greatly inspired by the area’s rich legends, compelling history and sweeping “mythical landscapes” they decided to build on the inaugural support for community-led tourism to make it an annual event with a programme of storytelling, art, tours and trails throughout Upper Nithsdale”. This quote from the Festival of Folklore defines what the folklore festival in Dumfries and the surrounding area aims to do. Again, working alongside the organisers and contributors to help adapt their programme and ensure that it could be enjoyed by people with PMLD, Mary Wood from Mostly Ghostly and Heather from PAMIS worked together to adapt a local story, The Sanquhar Fairies. They created an interactive and inclusive experience complete with a downloadable resource pack. Live craft workshops were accessed to help create items to bring the story to life from people’s own homes. Work continues on expanding this in the local community and PAMIS are currently looking at working together with Mostly Ghostly to create regular inclusive tours. Mostly Ghostly are award winning creators of a unique range of ghost and local history tours.

The process of creativity allows and supports an exploration of the self and often takes us on a journey of discovery that leads to deeper awareness and understanding of our personal stories and our own life journey. Working alongside people with PMLD on their creative journey is a privilege and honour that often leads to deeper understanding of their personal story and how they interact and engage with the world around them. Given the time the space and the right environment people with PMLD can enjoy and participate in the world just like anyone else. Profound means, deep, wise, understanding, learned and they are, if only we took the time to listen. PAMIS stands for promoting a more inclusive society and together with people with PMLD, their families and their communities, we take our combined wisdom out into the world to make it a better place.

I hope this meander with me through some of the festivals helps to demonstrate that when we work together, we learn together, and the outcome is fun and more inclusive for everyone. Learning and development doesn’t always have to be onerous or heavy it can be fun. Who would have thought festivals would be pathways to learning and development. The fun of the festival can continue long after the event, it all depends on how you view the experience and how you build on what the experience offers. The resources developed for the festivals can be accessed and adapted for use anytime, sometimes on the festival’s learning site and always on the PAMIS website (https://pamis.org.uk/creative-arts/festivals/).

I hope you’ve enjoyed this festival journey.

Contact Details

Maureen Phillip is the Creative Director for the Scottish charity PAMIS. She is also an Editor for PMLD LINK

Email: maureen.phillip@pamis.org.uk

Ambient Jam Collective
Moments from Goldsmiths Centre for Contemporary Art

Ambient Jam is a 30-year old unique dance and music improvisation programme arising from long term collaborations with adults and young people who have profound and multiple disabilities. Ambient Jam is hosted by Entelechy Arts which is a charity based in Lewisham, South East London.

From November 2021 to October 2022, working with Goldsmiths Centre for Contemporary Art (CCA) in New Cross, London and contemporary performance artist Roland Carline, Entelechy Arts has given the public access to be part of and experience Ambient Jam. This new collaboration is part of a year-long residency within the art gallery.

At an Ambient Jam session, people can stay as long as they like and leave when they want to. The Ambient Jam Collective suggest taking the time to acclimatise even simply sitting with eyes closed and it is even OK to fall asleep. They welcome using the ambience of the improvisation to rest and decompress and taking part by improvising through vocalisation, stillness, movement, and drawing. People can choose where they go, watch from a distance and move around. Ambient jam artists guide people through the improvised experience.

Ambient Jam events are open and accessible to people of any age from 0 to over 100 and to disabled people and those with PMLD. All the events are wheelchair accessible.

Here are some photos from one session at the CCA and comments from some of the participants.

“What a beautiful session that was. Thank you for gently and warmly welcoming us in. This work is incredible. Felt myself sing into my body and be super present. Need

more of this.” Rachel Gildea, Blink Dance Theatre.

"What a wonderful afternoon at CCA it was. I'm looking forward to the next one. The beautiful flower of a soul, Lizzie, enjoyed herself more than usual". Lauren Longhurst, AJ volunteer and Heart n Soul artist.

"On arrival, I was walking up to the building and became transfixed by what I could see through the windows from the street. It was like looking at a tableau whose floor stretched across several windows, like a platform or podium placing all who were standing, lying or moving on it each and every one at the same level. The quality which reached out to me through the glass was of the people inside being profoundly absorbed in and by their relations and relationships new or longstanding and each all almost imperceptibly moving and behaving with unity. I could have stood there all day. Inside, it seemed to take some time for me to acculturate, acclimatise and tune in as relations and processes seemed in train, in balance and I would do well to find and sense the 'ground' before I entered in a meaningful way. I saw the familiar presence of Carol and I was able to introduce myself and to the unfolding Ambient Jam this way - by sharing touch and gentle to and fro improvised contact. Finally, I felt at home." Aladin Aladin (audience member).

Rebecca Swift, Creative Director for Entelechy Arts and founder member of Ambient Jam adds: “Ambient Jam is a fulcrum that draws together different energies, stories and people, who would not normally connect, with the intention of exploring how we can be together and what the emergent story is when we are. The collaboration with Roland Carline is one of equal exchange between him, our artists, musicians, members and volunteers, and the ensemble. Roland has allowed himself to undergo a journey and be changed by everyone and become part of the Collective. In turn, he has allowed everyone's identities and emerging stories within the Jam, to inform sensory sculptural ideas that permeate the immersive landscape, enabling the Jam’s playground feel. As an artist, he brings with him a tremendous celebration of the ordinary. He responds with a vital sense of mischief to what the improvisation is about in terms of its playfulness, the surreal and its jester qualities. Working with Goldsmiths CCA is an amazing opportunity and also nourishment for the ensemble to work with an artist who not only ‘gets it’, but also wants to reflect on what is already happening, relishing the chance to play and include everyone. Ambient Jam is a coalescence of everyone’s needs and acknowledging this creates equity.”

Contact Details

For more information contact Rebecca Swift, Creative Director, Entelechy Arts
Email: info@entelechyarts.org

For further information on Entelechy Arts go to: https://entelechyarts.org/

For more on Ambient Jam Collective go to: https://entelechyarts.org/projects/ambient-jam-collective/

Inclusive Folk Arts

Emmie Ward

Inclusive Folk is a three-year project run by the English Folk Dance and Song Society (EFDSS) with funding from John Lyon's Charity. The aim of the project is to introduce young people with learning disabilities to traditional folk music and dance. We host fortnightly Folk Unlimited sessions and festival days at EFDSS' folk arts centre, Cecil Sharp House in Camden, and deliver workshops around Northwest London. We also make freely downloadable resources, sharing ideas of songs and activities from the project.

Folk music is often unfamiliar to the young people we work with and it comes with history and traditions that can be complex to learn about. A good starting point is with the stories in folk songs about working life or changing seasons that people can still relate to. After all, who would have thought sea shanties, sailors' work songs from the 19th century would capture everyone's imagination on TikTok in 2020?

The Universal Declaration of Human Rights (article 27) states that everyone has "the right to participate in the cultural life of the community" with the implication that we should all have opportunity to engage with the cultural expression of others and benefit from our shared cultural heritage. Learning about British folk arts is a great way to start exploring the cultural heritage of our diverse communities, making connections between shared traditions, and creating rich musical mashups.

The songs we teach our groups come from the aural tradition where you learn music by ear. Songs have repeating lines, easy tunes, call and response, nonsense words, simple verse, chorus structures. All these techniques make songs quite easy to pick up and join in with.

Cecil Sharp, the notable collector of English folk song and dance, claimed that in the mid-19th century every village in England was 'a nest of singing birds'. It used to be an ordinary part of life to be singing around the home, in the pub, at work, and in the school playground. There was nothing unusual about it and at most celebratory gatherings, everyone was expected to contribute something.

Sensory Songs and experiences

Folk music has so many themes that inspire interesting sensory experiences such as work, magic and myths, nature, and romance. We had lots of fun when we did a theme about coal mining. There is a wealth of folk music, song and dance associated with coal mining with tales of hardship and strong characters.

For this theme we made a soundscape representing the sounds of the machines and tools. We shone a torch underneath black cloth draped over our heads to re-create a sensory environment of being underground.

Songs like 'What Shall we do with the Herring's Head?' are great as a sensory song. This is a humorous song from traditional fishing communities about things you can do with a herring and it's rich with sensory imagery. Sensory stories and songs give people who may not communicate with language, the opportunity to share in the journey of a story by appealing to senses beyond language alone.

Below is a video link to our sensory song 'What Shall We do with the Herring's Head?' We adapted it so that it covered the senses of taste, touch, sight, sound, and smell. https://youtu.be/UUiYjwSZmC0

This song is traditionally a cumulative song so that every verse builds up the list of each part of the fish. However, you might want to start with only a couple of verses to avoid too much information. You could sing each line or it works just as well chanted rhythmically. If you wish you could expand the verses and activities to also include the vestibular and proprioceptive senses, as we have done in the outline of the song lyrics and sensory ideas to go with it.

In other songs we have also used Makaton signs to support the meaning of the story. You can see examples of this in our video for the song Hopping Down in Kent. https://youtu.be/H8Yf4b5DnKQ
If you want to use Makaton signs as part of the sensory story of the Herring's Head, you can include the sign for "fish" in the chorus: hold your hand with palm facing the chest while waving the fingers and moving the hand across your body, like a swimming fish.

Lyrics and activity outline for "What Shall we do with the Herring's Head?"

What shall we do with the herring's head (point to head)

Turn it in to loaves of bread! (slice of bread - taste)

Chorus:
Of all the fish that are in the sea the herring's the king of the fish for me
Bunka do di li do bunk a do di li. (clap hands or do Makaton sign for fish)

What shall we do with the herring's tail? (point to legs)

Turn it in to ships and sails (fabric-touch)

Chorus (clap hands or do Makaton sign for fish)

What shall we do with the herring's eyes? (point to eyes)

Turn it in to a light that shines. (torch-vision)

Chorus (clap hands or do Makaton sign for fish)

What shall we do with the herring's belly? (point to belly)

Turn it in to something smelly (any scent-smell)

Chorus (clap hands or do Makaton sign for fish)

What shall we do with the herring's fins? (point to arms)

Turn it in to baking tins. (Bang on baking tin with wooden spoon-sound)

Chorus (clap hands or do Makaton sign for fish)

Optional extra verses to include vestibular/ proprioceptive senses.

What shall we do with the herring's mouth? (point to mouth)

Turnaround from north to south (turn around with support-vestibular)

Chorus (clap hands or do Makaton sign for fish)

What shall we do with the herring's gills? (point to side of face)

Show them all our roping skills (tug on a piece of rope together-proprioceptive)

Chorus (clap hands or do Makaton sign for fish)

Moving on from experiencing the herring's head as a sensory song, you can play a different instrument, rhythm or vocal sound for each verse.

Here are some tips from our sessions on how to support someone to play an instrument

- Think about where the instrument is in relation to the person and experiment with different placements.
- Hold the instrument for them or place it on a table to free up their hands, or offer a beater to hold in their hand.
- Sound makers can be placed where involuntary movements may brush against them and make a sound e.g. bells tied to arm of wheelchair or wrist or dangling from a hoop held close by.
- If the individual cannot use their hands to play an instrument, they may be able to use their elbow, chin, knees or feet etc.
- Give them time to explore the instrument in their own way and at their own pace, perhaps in a sensory way i.e. smelling and touching.
- Try a wide range of instruments to see which are the easiest to play and which are the most enjoyable.
- It can be tiring or hard to maintain concentration playing an instrument. Encourage building up playing skills but be sensitive to cues from the individual that they need a break.
- iPads can be used to great effect as accessible instruments using a number of free and low-cost apps. We use GarageBand and ThumbJam, but there are many more options.
- BIGmacks are switches that can record speech, music or any sound. They are easy to use and a simple way of enabling people to contribute sound.

Contact Details

Emmie Ward is the Lead tutor for Inclusive Folk at the English Folk Dance and Song Society

e-mail: emmie.ward@talktalk.net

For more details about Inclusive Folk go to: https://www.efdss.org/learning/young-people/inclusive-folk

Note - all photos copyright EFDSS. Photographer Brian Slater

Resources

If you are interested in seeing some of the resources created by Inclusive Folk, which contain songs and more ideas from our sessions, here are the links to the resources which are freely available on the EFDSS' award-winning Resource Bank, along with many more: www.efdss.org/resourcebank.

Songs of May: using folk arts in inclusive settings (PDF & audio)
https://www.efdss.org/55-resources/learning-resources/9884-songs-of-may

Songs of London Life: using folk arts in inclusive settings (PDF & audio)
https://www.efdss.org/55-resources/learning-resources/10248-songs-of-london-life

Herrings and Hops (video & supporting PDF)
https://www.efdss.org/learning-resources/10329-herrings-and-hops

For more information visit: www.efdss.org or contact: education@efdss.org

Wobble – Slide – Stretch!

Claire Graham

WOBBLE

Whether you can grip the giant bungee or someone close to you is holding it; explore how it bounces and wobbles. Move it close to your body, feel the pressure as the elastic becomes taught. If you can, stretch your arms and let the bungee become saggy and lose. Can it bounce and touch the floor; can you feel it on your feet? On your legs? Can you bounce to the beat of the music?

Benefits to explore: Proprioceptive input, vestibular input, cause and effect, turn taking, intensive interaction, linking movements to songs and rhymes.

SLIDE

Yellow, blue, red green; see the colours twist and turn. Can you slide the bungee to touch and feel each different colour? Move it slow… move it quickly! Slip and slide the bungee over tables or over your lap. You can even use it as a tool to move other items. Stop a ball from rolling off the table by having a bungee border. Slowly move the bungee closer to you and then reach to the end of your finger tips to grab the ball.

Benefits to explore: problem solving, tactile input, visual stimulation, fine motor skills, gross motor skills, play and fun!

STRETCH

Feeling strong and mischievous? See how far you can stretch the bungee. If you have a strong grip, see if you can hold it while a friend spins and bouncing inside the bungee “walls”. Count down 3...2...1... PING! Let go and see where it lands. Can you hear the noise it makes; did you feel the pressure release through your fingertips? Hold the whole bungee on your lap, is it heavy? Can you hear the thud as you push it off onto the floor?

Benefits to explore: Auditory input, team work, social skills, anticipation, curiosity, humour, strength and grip.

Contact details

Claire Graham is Activity Coordinator and Founder of Inclusion Un.LTD
Email: Inclusion.un.limited@outlook.com

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

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

The PMLD Standards are available on the home page of the PMLD Link website: https://www.pmldlink.org.uk/

An article may be found in *PMLD Link*, Vol. 30 No. 1, Issue 89 (Spring 2018), pages 2-5. ‘Raising standards - a clarion call to meet the challenge!’ by Annie Fergusson, Joanna Grace, Michael Fullerton and Thomas Doukas

Reflexology therapy supporting emotional wellbeing

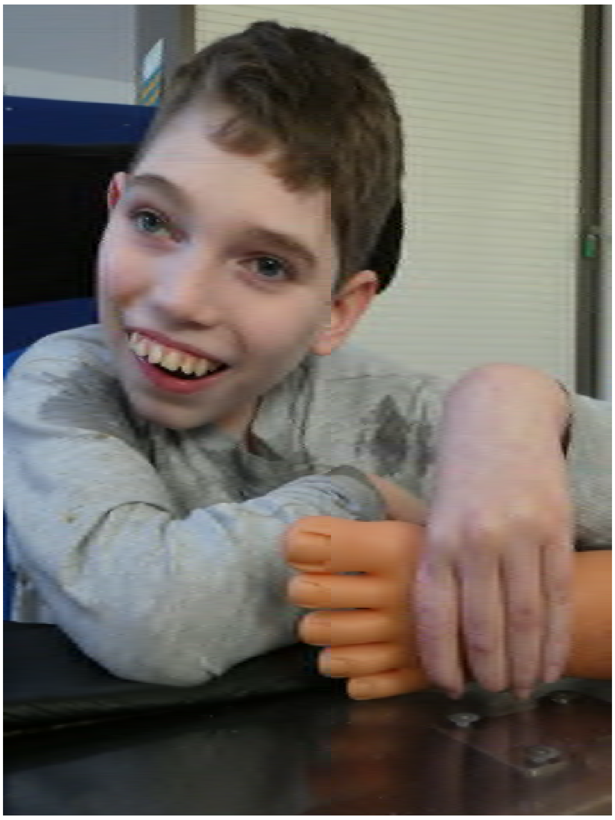
Lorraine Senior

An invitation from Fred and Lorraine to enjoy a little playfulness and relaxation during reflexology therapy supporting emotional wellbeing.

Being anxious can bring many difficulties that impact how a person copes throughout the day. The enjoyable sensory experience and specific delivery of the positive touch of reflexology may reduce both physical and mental difficulties attributed to anxiety. It may also help with wellbeing, with regulation and with coping better during the school day and beyond.

Meet Fred

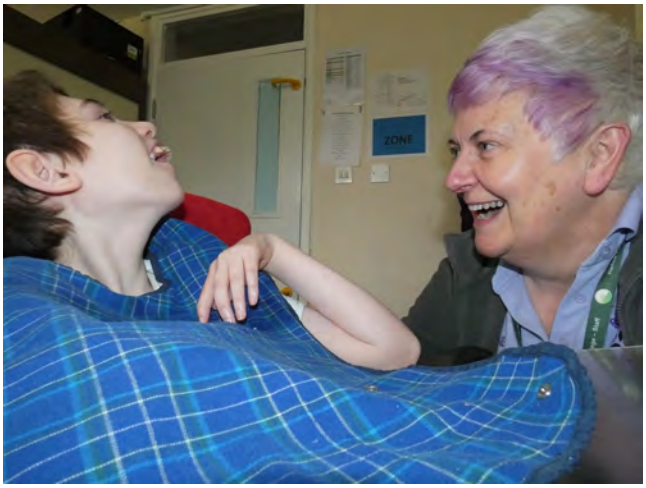
Fred doesn't use words, he communicates with sounds, with objects, with his movements, noises and gestures. Even his stillness has a valuable meaning. It is so important isn't it that we allow him the opportunity to have his say and goodness, he has a lot to say!



Supporting emotional wellbeing

Some communication challenges and heath difficulties also bring frustration, fear, anxiety, anger, and sadness. Here at Harlow Fields School, I am privileged to invite young people to receive the positive touch of reflexology therapy. Although I may address some specific highlighted health issues through my therapy sessions, the main intention is to support emotional wellbeing, hopeful that using purposeful touch and having fun in the therapy room will reduce stress, ease tension and anxiety that may have an impact of how a person manages within the classroom environment.

I have used my experiences and training as a Reflexology Therapist and as a teacher supporting young people of all ages with diverse and complex needs, to create a supportive framework and a unique method of delivery of touch for reflexologists to use in 1:1 timetabled therapy sessions during the school day. I share my work and framework through an accredited training course for reflexologists who are looking to develop their therapy work in this area; along with supporting staff, with the Functional Reflex Therapy (FRT) Rainbow Programme. The Programme introduces a simple structured relaxation reflexology activity through the colours of the rainbow for staff to use within the classroom. This training does not replace the valuable work of a qualified reflexologist but supports staff through providing skills for them to use in the classroom at a time that is right for them and their pupils and supports the role of the qualified reflexologist.



Nurturing touch

All nurturing touch has an important role to play in connecting us with ourselves and to other people and the world around us. Such a sensitive sensory form of communication, when delivered with kindness, can calm, reassure, lower stress and ease anxiety. We offer much of this already through our positive touch activities in the classroom.

Why reflexology?

What is reflexology? Is there a difference to other lovely touch activities and why does it have many benefits during the school day? Reflexology works on the principles that certain areas of the feet and lower leg, hands and forearm, face and ears correspond to zones, areas, organs of the body. Reflexologists apply skilful techniques and movements with varying pressure to encourage a change within and throughout the body within specific systems and/or organs and/or areas of the body. The techniques are delivered with real purpose and can address many issues. My sessions may include a small amount of support for issues highlighted by parents which are often digestive and sleep issues, but reflexology can be accessed at any time, evenings weekends etc. So why offer it during the school day? Young people are invited to receive reflexology therapy with the intention of encouraging relaxation to help them feel good and be in a better frame of mind for learning and to cope with the activities throughout the day.

Repetition and rhythm, allowing time, brings reassurance

The method of delivery of my reflexology – the sensory experience - is always repetitive and rhythmical. Through receiving movement to specific areas and receiving something nice, as the body relaxes it is encouraged to release many supportive happy hormones. Of course all hormones are important but for me the delivery of reflexology during the school day is important as the release of oxytocin helps the body to calm. It may also help a person to regulate their emotions, to be able to focus and concentrate on the activities within the classroom. It is important that everyone participating in the session feels relaxed but also that they remember the session as being enjoyable and they have had some fun.

I use a variety of reflexology techniques depending on how Fred presents on the day. These are delivered to different parts of the foot and/or hand. I am mindful that different areas of the skin can be sensitive and I gather information from my touch in different ways, but as already mentioned, the 'method' of delivery is important. Mechanoreceptors react to any movement on the surface of the skin and there are slow and quick acting receptors. There are differences depending on whether it is non-hairy skin (found on the palms of hands and the soles of the feet) or hairy skin (found on the forearm and lower leg), so a combination of techniques with this information in mind is very supportive. But importantly, the beginning of the therapy session and the ending of the therapy session are always delivered in the same way to Fred to support him to be as aware as possible of the beginning to our work together and when I am bringing it to an end.

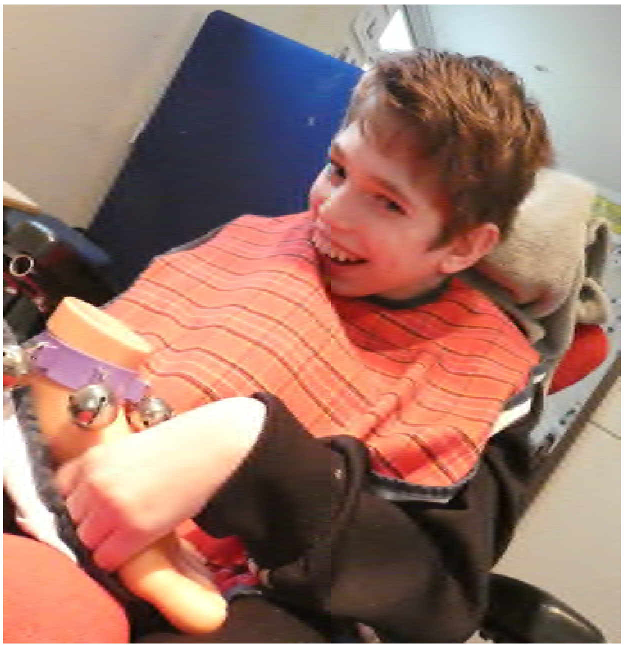
A non-invasive positive touch activity

Sometimes socks are on, sometimes socks are off, sometimes I work just the feet, sometimes I work just the hands, sometimes I work the hands and feet one after the other, sometimes I work the hands and feet synergistically. (Synergistic reflexology is a term introduced by Lynne Booth, creator of Vertical Reflex Therapy, tutor and reflexologist. It involves working the same reflex on the hand and the foot which may accelerate the body's response to the intention).

Sometimes Fred decides he would like to receive touch on just his feet, sometimes on just his hands or sometimes he asks for both.

I use the FRT framework to support my reflexology. It is called 'functional' because it has a specific aim and purpose and considers more than just the touch of the reflexology. I carefully develop meaningful ways of using methods of communication to enhance awareness and understanding of the activity of what is going to happen and carefully watch for any response/ indication that he does not want me to continue.

The FRT tool kit for Fred contains a towel for him to feel, a little pot of balm that I can rub onto the back of his hand when I meet him in the classroom, a hand and foot model that often has some bells attached which he enjoys shaking and banging on his tray or some textured material. He usually however responds best to my voice as I tell him it is time for reflexology and ask him if he is ready for the sweep - using my voice to signal sweeping uuuuup and sweeping dooooown. If it brings a smile or a giggle, I feel reassured he is ready. Sometimes I need to wait a while as he thinks about it, which is important to do. We do not leave the classroom until Fred has let me know that he is ready.



Communication, respect, and the unique delivery of the touch is the key, allowing the body time to feel, to become familiar with, to bring an awareness to self, to become comfortable with (or not) and to have time to gather the information of my touch, to process and respond.

When young people are referred for reflexology, I always begin with observation in the classroom. Working alongside Fred and staff helped me to begin to understand how I could best communicate in a meaningful way. It allowed him a little time to begin to get to recognise me and my voice and for me to make sure I could involve him as much as possible in any decisions and choices. Consent to take part in this activity and to receive reflexology belongs to Fred.

I am not working with labels or names of conditions, but it is important and very helpful to have background information from the family and staff with official diagnosis of conditions and more ongoing up to date information, of medication and health issues. It may be necessary and helpful to discuss any concerns with members of the team around him and this helps me to adapt my work and/or my approach. It is also important to provide parents and carers with information about the sessions and to receive initial consent that they would like their child to have the opportunity to attend the sessions. But ultimately, I am very mindful that consent is ongoing, and as I have mentioned, Fred has control of that.

It is surprising what the body can do for itself when general areas are encouraged to be calm, and the mind and body can begin to relax. Perhaps reduce discomfort, ease pain, ease digestive difficulties, reduce spasm, calm the mind, and increase the feel-good factor.

Key points

- Being respectful, of consent and preference, offering an invitation to receive touch
- Making my communication meaningful
- Using multisensory stimulation at transitions to help support Fred’s understanding of what is happening next
- Allowing time to prepare and to feel the touch
- Raise awareness through touch to be more aware of limbs and increase his sense of self
- Supporting him to make choices
- Give him a little responsibility and place consent within his control
- Raising self-esteem
- Having fun and saying thank you and sometimes if I am lucky, along with giggles and smiles I get a nice hug too.

Thank you for allowing us to share a little snippet of our fun and smiles with a combination of structure, repetition, and rhythm of relaxation reflexology therapy on the timetable during the school day.

Along with all the other very valuable therapies and activities that we should have available for and accessible to our young people, how amazing it would be if ALL schools had a qualified reflexology therapist as part of their multidisciplinary team using the Functional Reflex Therapy Framework to bring a consistency and recognisable professional package through reflexology to support emotional wellbeing (and much, much more).

Contact Details

Lorraine Senior is a Reflexology Therapist who works with young people of all ages with diverse and complex needs.

Email: info@functionalreflextherapy.co.uk
Website: www.Functionalreflextherapy.co.uk

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FUN-damental

Delyth Williams

People with profound and multiple learning disabilities (PMLD) are unique individuals with different needs and a multitude of ways to have fun. Having fun can have positive biological effects, releasing dopamine and reducing stress levels and improving sleep patterns. Having fun with a communication partner allows us to connect with others and build positive social bonds.

Case Study: Joseph (AKA Joey Bear)

Meet Joseph, otherwise known as Joey Bear. Joey has quadriplegic cerebral palsy, cystic fibrosis and epilepsy. He loves to have fun and will clearly indicate his joy with raucous laughter that has everybody around him in stitches. Here are some of the ways Joey likes to have fun:

The Great Outdoors

A lot of our learners with PMLD enjoy the great outdoors. Whether it's experiencing the elements or, as Joey is here, enjoying a sensory forest school activity, the outdoors is a naturally rich learning environment that facilitates activating the main 7 senses easily. For example, Joey loves nothing more than a walk on a blustery day or whizzing around on an adapted bike. In the image Joey is enjoying exploring a range of different types of leaves in a forest school session. Those with a keen eye may also spot that he has some soot on the end of his nose from smelling fire. Fire is not only an enjoyable sensory experience it helps to keep our learners warm meaning they can access the outdoors whatever the weather.

Dressing for the part

In my experience with humanity, dressing up is like Marmite - you either love it or you hate it. I love it and so does Joey (it's probably why we've always got on so well). Some face paint or a silly hat and a mirror and Joey is fully on board. He even finds it hilarious when we show him how he's managed to get chocolate pudding all over his face. In this picture Joey is enjoying being sorted into Hufflepuff House for our Harry Potter sensory story (something else we have in common). He loves a bit of drama so dressing up for a story was the perfect activity for Joey and as you can see, he more than rose to the occasion. This provided a lovely social bonding experience that we could enjoy together as a group.

Animal friends

Joey just adores animals, usually the creepy crawly kind, but he kindly makes an exception for our gorgeous school guinea pigs Patch, Eric (pictured) and Norman. I have observed myself in Joey and his classmates an increase in communication skills, such as talking back when the guinea pigs squeak. The pupils in the class also showed more coordinated limb control when caring for our furry friends. Joey is also lucky enough to have his own dog as well who is a bit of a cheeky devil, much to this young man's amusement.

Favourite Shows

This next one is universal. Staring at the goggle box is so popular there is a whole programme focused on it. Joey loves cartoons such as Beauty and the Beast and the Simpsons (he definitely identifies with Bart). We found this a great way to encourage him to engage in physio activities, such as lifting his head when lying prone over a wedge, as the noise and bright colours entice him to lift his head and look. Just like everybody else, what Joey would like to watch can depend what mood he is in. However, this then presents another communication opportunity as staff can question Joey and he can flash that gorgeous smile as an indicator when we get it right.

Making Music

Oh what a great big drum and Joey can definitely play it! Using favourite musical instruments is not only fun it gets those limbs moving. In this session Joey enjoyed hitting the large drum with his beater (supported by the wonderful Sarah). He started off slowly tapping the drum but quickly sped this up and was banging as loudly and quickly as he physically could, hysterically giggling the whole time. He also enjoyed reaching up to bang the chimes, especially when we made a game of "no more" or not doing it again. What can we say? He's a natural rule breaker. This activity was clearly enjoyable for Joey but it also afforded the opportunity to get his limbs moving in different directions and loosen up those tight muscles. It also allowed us to develop his wicked sense of humour in a social context by giving him joke rules that everybody knew would be broken.

In conclusion

What staff have observed in Joey's case is that when he is having fun, he is alert and engaged in the world around him. On days where he is having fun he will eat well, his muscles will be less tense and he will show less visible signs of discomfort. Fun enables him to build bonds with those that care for him and allows him to engage with his immediate environment as fully as possible. Having fun and truly experiencing pleasure and joy is one of the easiest and greatest experiences we can facilitate for our learners.

Contact Details

Delyth Williams is a teacher at Dee Banks Special School in Chester

Email: dwilliams@deebanks.cheshire.sch.uk

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Let’s have fun!

Sarah Parkes

Fun is defined as ‘enjoyment or playfulness’. As a teacher of pupils with PMLD, having fun is central to what I do! This short article explores three ways in which we have fun in school, within an early years PMLD class for pupils aged between 3 and 7 years old.

As an early years teacher, I use a play-based approach to learning; learning which is encouraged and fostered through play and playful interactions. Play is nurtured through carefully planned opportunities, designed to support pupils to develop their own play and explorations. Individualised play opportunities are planned, based on thorough knowledge of individual pupils taking account of hearing and visual impairments, and physical difficulties. Relationships are also central to having fun, with strong staff-pupils relationships facilitating playful interactions.

Luckett et al (2007) proposed that play is internally motivated, pleasurable, voluntary, flexible and spontaneous. This article outlines three ways in which we have fun; being messy, playful intensive interactions and fun within the environment. These activities have been selected as:

- They are regularly chosen by the pupils
- Pupils demonstrate sustained concentration when participating in them
- Pupils display high levels of intrinsic motivation
- Pupils are motivated to communicate (lots of requesting for ‘more’)
- And of course, their smiles and laughter show just how much fun they have!

Being messy!

This can be through wet media such as paint, gloop, custard, water, angel delight, shaving foam, baked beans, jelly or whipped cream! Dry media such as shredded paper, rice, flour, glitter, porridge oats, lentils or sand can be used. Messy play can also be incorporated into cooking as pupils explore and help mix the ingredients.

Messy play brings many benefits, such as sensory stimulation as pupils’ sensory perceptions are heightened (Beckerleg, 2009). It also develops fine and gross motor skills, creativity, communication skills, social skills and provides opportunities for relaxation and mindfulness.

My observations of pupils engaging in messy play include a beautiful observation of a pupil who reached out to grasp my hand and pull it into the messy tray, inviting me into his play! I have observed pupils request ‘more’ and become ‘lost’ in their explorations. For example, a pupil who swirled bubble mixture in a tray for 20 minutes, observing the bubbles change shape. Using one messy tray between two pupils fosters interaction as pupils watch each other explore (or splash each other with the messy media!). My pupils love being messy!

But note that, when engaging in messy play, it is important to consider those pupils who are sensitive to different textures, and those with allergies and food intolerance.

Playful Intensive interaction

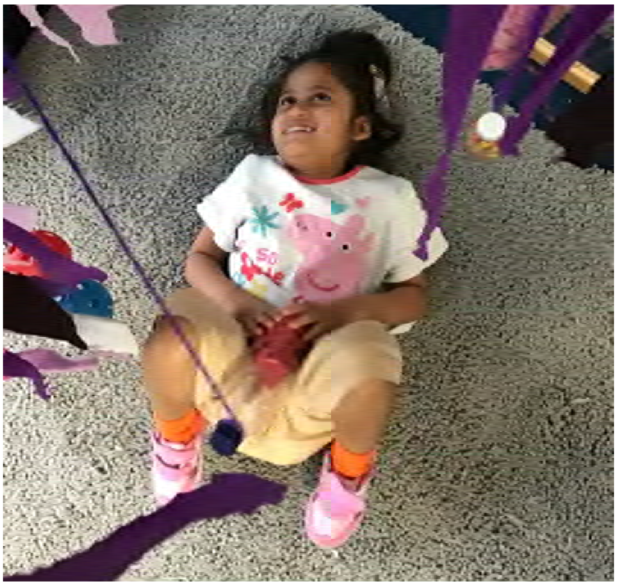
Intensive interaction does not only develop communication skills, it is lots of fun and is a firm favourite in our class! Pupils enjoy engaging with adults and many respond with smiles and laughter as their gestures and vocalisations are copied (please see www.intensiveinteraction.org for further information)! Intensive interaction takes place 1:1 with a pupil, and also as a group session. Intensive interaction sessions have contributed to the close relationships staff have with the pupils, and our group sessions have cultivated lovely responses from the pupils as they notice each other within the group. One pupil has begun to copy his friends' actions!

Fun with the environment

It is important the classroom creates playful and fun opportunities for the pupils, fostering creativity and also independence. As Beckerleg (2009:27) stated 'many thinking or cognitive skills are learnt incidentally through our response to our environment'. Below shows a range

of home-made areas/resources which the pupils have fun with! Here is our rainbow. It is central to our choosing area. Pupils enjoy spending time under the fabric, reaching to find exciting objects hidden inside!

Pupils also enjoy exploring a range of mobiles. The current favourite mobiles are the phonics mobile with a range of sound making objects attached, a maths mobile which includes a range of different sized objects, and also a shiny objects mobile! These have been effective in encouraging the pupils to 'reach/stretch/grasp', supporting their physiotherapy programmes.



Reflection

Having fun is central to learning. Pupils need to have secure relationships with the adults around them, be motivated to engage and interact with their environment, and have opportunities to lead play and playful interactions. I have discovered attentiveness, knowing the pupils well in order to respond to their intentional communication clues, a sense of humour and a creative approach to the curriculum aid this!

'Play is a hugely important part of everyone's life. It is, simply, fun. We learn best when we are enjoying ourselves. We want to do those fun activities again and again' (Anderson, 2022, 2)

Contact Details

Sarah Parkes - Teacher of pupils with PMLD in Bristol, with a special thanks to the pupils and families in Bumblebee Class.

Email: sarah.parkes@bristol-schools.uk

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Musical fun with a virtual festival

Bev Cullen

Last year the schools I support were invited to take part in a virtual Summer Festival, Summer Fest ’21, organised by Walsall Music Hub. The idea was for each school to work on songs and music relating to summer. Work would be videoed and submitted to the Hub, where they would be edited into a Virtual Festival to go live on their YouTube channel.

The PMLD department at Old Hall School chose the Singing Hands version of the song ‘Here Comes The Sun’ for us to work on.

Each week in our music lessons, the staff and myself would sing and sign the song (using Makaton signs), whilst the children watched and listened to us and the video on YouTube.

I took in different sized and textured soft toy suns for the children to explore whilst listening to the song. You can see how much Lily and Eliza enjoyed looking at them, holding them and cuddling them.

On another week, I took in small disco balls and a torch. The children looked up at them as they represented the sun’s rays. They explored sheer yellow material and looked at the lights through the material. Lily was fascinated by this and stretched her hand to touch the lights. All of the time, the song is being played in the background.

We found as many yellow instruments as we could for the children to explore, touch, hold, play and listen to whilst the song was played.

In between each music lesson, the children explored lots of yellow sensory activities with their class staff e.g. moving their hands in custard; painting with yellow; exploring yellow lights in the sensory room. Each time, the song was played in the background.

The children were photographed and videoed having fun exploring yellow items whilst listening to the song. Their video can be found here: https://youtu.be/3erjxHZgWYc?t=2350

We're looking forward to seeing this year's Summer Fest '22. It premieres at 7pm on Thursday 14th July on Walsall Music Hub's YouTube Channel.

I hope that this article has inspired you to put on some music to listen to whilst exploring instruments and sensory items related to the song/music. Music is a beneficial shared activity for yourselves and the wonderful pupils we all work with and care for.

Contact Details

Bev Cullen is a self-employed specialist music teacher working in the Walsall area. She is a lMakaton Tutor and delivers the 'Using Makaton with Singing' training

Email: bcullenmusic@outlook.com

Further Information

The Makaton Charity: www.makaton.org

Walsall Music Hub https://www.youtube.com/c/WalsallMusicHub

Old Hall School https://www.oldhallschool.co.uk/

'Here Comes The Sun' – Singing Hands
https://www.youtube.com/watch?v=uPhMyKAeYyw

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Fun and why it should be funded

Helene Abbiss

Fun – defined as simple enjoyment, amusement or lighthearted pleasure - is commonly viewed in relation to play and leisure and therefore separate from work, learning and daily tasks. Hence the perception that may exist for some that fun is an indulgent extra within service provision. Yet it's such an important part of what it is to be human – we all seek fun. Being human too, people with PMLD are no different in their need for fun from anyone else.

At Parity for Disability, fun belongs within effective service provision and is considered integral to social connection, learning and development. It is funded as an essential part of what we do.

"In funding fun, you start with the activity you want funded and ensure the fun element is there," Parity's Executive Director Alison Cooper *says. "It's about finding the fun, not funding the fun. The fun bit actually doesn't cost."*

Our services currently support 54 adults with multiple disabilities (called students), the majority of whom are people with profound and multiple learning disabilities (PMLD). In developing meaningful activities tailored to each student, we see fun as essential to participation, connection and learning and to meeting people's social and psychological needs. Fun is proven to have beneficial biological effects such as the release of dopamine, and to promote relaxation, connection and communication. We don't think of fun as a separate pursuit divorced from essential daily activities. Staff must build fun in so that students are able to fully engage and therefore achieve the outcomes they want and need. Very few of the activities that the students undertake would be effective if our staff did not look for and recognise the fun within them. "*It comes down to knowing the individual really well and understanding what each person finds fun*," Alison says.

Staff make sure the fun aspects are there or support the person to bring the fun aspects out, and let them lead. If a student finds noises funny, they use it as motivation. For example, amusing noises can be recorded onto talking tiles and switches, and the noise on each used as a reward or an incentive to press. With interactive technology like eye controlled devices, staff photos can be programmed to pop up for a student to 'throw' custard pies at using their eyes.

While always recognising that people need space to express difficult emotions too, communication techniques and approaches benefit from playfulness. In developing activities involving choice-making, staff adapt these to reflect the student's personality and preferences, and they can easily infuse them with humour and whimsy. Intensive Interaction is often about having fun. "*You're being heard and listened to, but it's done in that jolly, playful manner,*" Alison says.

Someone who operates mainly on a sensory level will experience the fun through the senses that they use. There are the fun sensations, as with the student who loves going over speed bumps, the student who can spend hours with a hand dryer and the student who likes going up and down in lifts. Anything a student finds fun can be built into activities, like developing an understanding of cause and effect, or encouraging the student to indicate a positive response, which allows them to take more control over their everyday life.

Art activities, of course, are full of sensory elements and students with PMLD will participate through a playful approach, using the skills and movement that they have. Staff might fill a bottle with paint and then support the student to pour it in their own way onto a canvas on the floor or adapt a paintbrush and support them to splat paint onto a large piece of paper.

Dressing up, along with slapstick elements, helps staff to capture and hold students' attention, and stimulate the senses with colours and movement. Staff dress up as superheroes, clowns and circus performers, Tweedledum and Tweedledee! Students are unlikely to pay attention to, or benefit much, from a soberly delivered science experiment. But a staff member that students know well, uncharacteristically dressed in a lab coat and goggles and supporting them to touch, smell and see new experiences, will provide stimulation and entertainment. On top of this, there's all the fun of the reaction from those around them when things go wrong!

Which raises another important benefit of fun for the students: the sense of belonging that comes from people having fun as a group. People laughing together will automatically feel a sense of connection. At a corporate accessible sports day organised with Parity for Disability's students and staff, which included an obstacle course and a match with a giant football, we observed everyone experiencing a great deal of fun. The group, and its wide range of abilities, enjoyed a day full of engagement and connection.

Staff training should emphasise the fun element and ensure participants understand that because of all the benefits for people with PMLD, adding fun adds to the value of the activity. Fun conceals the recital and repetition of information that can make learning or performing necessary daily tasks tedious.

A student finds a Murder Mystery activity entertaining, using his senses to find clues in a tray of spaghetti, and participating in the group

"*If everything's earnest, it's dull. People don't get as much out of it,*" Alison Cooper says. You can't let fun go out of your service because you're worried about it not getting funded. Ensuring interactions have meaning, with spontaneity and joyful moments, should be seen as part of someone's job.

When arguing for the funding of different elements by local authorities, we aim to help funders recognise and understand the role that fun plays in meeting each student's needs. We're able to explain the theory behind the way we develop activities at Parity for Disability. Referring to established approaches and to influencers, such as Jo Grace and Julie Calveley, provides credibility. In persuading our funders, we work hard to maintain an understanding of local, regional and national priorities.

For example, policy and planning has a focus on making community provision as accessible as possible, and involving everyone. In her book Fun and Games: Practical Leisure Ideas for People with Profound Disabilities, Judy Denziloe points out the importance of leisure pursuits (or fun) (Denziloe, 1994). The PMLD Core and Essential Service Standards (Doukas et al, 2017) refer to fun within Standard 4: Social and Community Life, noting that it's about 'thriving and not just surviving'. Item 8 says that there is evidence that it's happening when "*Each person is supported to participate in social and leisure activities personalised around perceived and known interests and choices and that provide recreation and are fun*" (Doukas et al, 2017, p.33). As we found with our corporate sports day, fun facilitates increased engagement with others in the community for people with PMLD, and more opportunities to experience the wider world. This ticks a box for local authorities charged with ensuring their communities are inclusive and can meet everyone's needs.

Day Service Manager Darren Shergold and Senior Key-worker Ian Hoole, along with other staff members, dressed up in different costumes for live, remote 'Fun Zoom' sessions during the January 2021 lockdown. As well as performing music and reading stories, they came up with slapstick activities like throwing an egg back and forth standing further and further apart, until the egg was dropped and broke.

It's been vital for us to build and maintain awareness and reputation within the field of community provision. Providers can do this by joining networks and forums, including Valuing People groups where they exist, participating in relevant conferences and meetings whether remote or in person, and connecting with influencers and decision makers as far as possible. Take opportunities to speak. You want to reach a level of awareness where the people you meet are saying, 'We *know you, you are so good'*.

With the cost of living crisis, demonstrating need when trying to secure funding from Grantmakers, trusts and foundations is paramount. Yet the people reviewing the applications are human too and highlighting the fun in applications will help someone who may be ploughing through their 100th application of the day to engage and want to support your activity.

For these two audiences (people in the field of community provision and grant funders) the emotional argument is as powerful as the practical argument. Stories and photos of people with PMLD having fun, smiling, and interacting with others drive home the fact that they are human too and their needs can be successfully met in similar ways, with the right knowledge and expertise.

Local authority funders, of course, may appear much harder to reach in this respect, due to lack of opportunity to meet people with PMLD and lack of training to properly understand their needs. Indeed, in the case of NHS continuing healthcare, the medical model of disability seems to persist. (While the medical model is a helpful way of understanding illness and loss of function, disabled people have largely rejected it in favour of the social model which promotes the idea that social and physical environments can and should be adapted to accommodate people in order to improve their quality of life and opportunities.) This lack of understanding may be the single biggest challenge to funding and sustaining good provision. For Parity for Disability, repeated engagement, reiterating the message over a period of time, has helped.

In a perfect world, all funders would experience 'goosebump moments' and be moved by pictures of a person with PMLD fully participating and laughing along with somebody else. Everyone deserves their needs to be met, everyone's needs can be met, people with PMLD are no exception and funders should fund the fun.

Contact Details

Helene Abbiss is the Community Support Director at Parity for Disability.

Based in Farnborough, Hampshire, Parity for Disability runs three specialist day services.

Email: helene@parityfordisability.org.uk

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Camp Jojo is the epitome of fun!

Ellie Byfield

Camp Jojo is a small charity based in Essex, that provides accessible camping weekends for children with complex needs and their families. The weekends are jam packed full of fun. This includes a trip to the beach, music around the campfire, talent shows and much more!

Camp Jojo aims to provide all the equipment and support that families need to make camping not only achievable, but enjoyable too! Our motto at Camp Jojo is, 'Everybody Can' and we are passionate about families sharing new experiences and making life-long memories! Our volunteers have a blast too and become part of a very special community.

For more information about attending Camp Jojo with your family, volunteering or donating, please visit www.campjojo.org.

You can also follow us on Facebook or Instagram.

There is a video showing activities from Camp Jojo 2021 and comments from volunteers and family members on the website. Camp Jojo ran for four weekends throughout the summer of 2022 in July and August. The camps were held at Ivy Farm, near Colchester.

Contact Details

Ellie Byfield is the Operations Manager for Camp Jojo
Email: campjojoinfo@gmail.com

The use of mindfulness to increase the well-being of individuals with PMLD

Dylan Crimmins

In September 2021, I began my Initial Teacher Training (ITT) at Cardiff Metropolitan University. This was the first year that the University offered student teachers the opportunity to complete their teaching practice within a Special Educational Needs school. I was given the absolutely fantastic opportunity to undertake my teaching practice within a class catering for pupils with profound and multiple learning disabilities (PMLD).

Teachers are required to be reflective and evaluative in their practice, to develop and improve (Pollard, 2014). This is certainly a view instilled in student teachers by the University. As part of this, I reflected on my personal teaching philosophy. Prior to commencing my ITT, I worked in a residential care home for children with autism. My role focused on the development of the individual's independence, and the maintenance and furthering of their well-being. This has transferred over to my personal philosophy as a teacher, where I have a passion to increase the well-being of pupils.

This philosophy led me to researching the practice of mindfulness, and the potential benefits it could have for the pupils in my class. Mindfulness is the practice of paying attention to the present moment, non-judgementally. It is recommended by the NHS as one way of improving mental well-being (NHS, 2019a). Mindfulness has increasingly gained interest within education (McCaw, 2020), and has been shown to aid relaxation and reduce levels of depression, anxiety and stress amongst pupils (Dunning et al, 2019).

There is limited research evidence examining the impact of mindfulness among individuals with PMLD. However, there are a number of studies testifying to the effectiveness of mindfulness among individuals with 'mild' intellectual disabilities (for example, Idusohan-Mozier et al, 2015; Jones and Finch, 2020). An important theme that arose from these studies was the idea of adaptation. Appropriate adaptations can make mindfulness accessible. There are a number of ways in which adaptation can be made, including simplification of language, use of concrete activities, use of materials at a developmentally appropriate level, and being flexible in delivery (Thompson Prout and Browning, 2011). The experiential and skills-based practices of mindfulness are easily adapted and applicable for use with individuals with PMLD (Robertson, 2011). This led me to develop this resource (see next page), which outlines three adapted mindfulness activities for use with individuals with PMLD, providing they appear to consent to participate.

I have used these activities on a number of occasions with my pupils, both inside and outside the classroom. Pupils engaged well and were visibly more relaxed after the activities, compared to the start. Support staff also benefitted from the activities, and enjoyed the interactions with pupils that the activities gave them. I believe it is most important to note that, pupils enjoyed the activities, especially the supported body scan. Pupils laughed, smiled, vocalised happily and gave and maintained eye-contact. Enjoying activities and having fun is also recommended by the NHS as a way to become happier, and improve well-being (NHS, 2019b).

Prior to researching mindfulness and designing these activities, I knew very little about mindfulness and the benefits that it could hold for increasing an individual's well-being. Neither did I know about the enjoyment and happiness these activities would bring. On reflection, I believe that the use of mindfulness holds considerable benefits for individuals with PMLD.

Contact Details

Dylan Crimmins was a PGCE student at the time of writing. He was part of the first cohort of students to be placed in a special educational needs school.

Email: dylanaacrimmins@gmail.com

The following text is taken from the resource developed by Dylan for sharing ideas about mindfulness.

Mindfulness
3 Mindfulness Activities for people with PMLD

SUPPORTED BODY SCAN
A body scan focuses attention to different parts of the body as you scan head to toe. Touching, pressing, and squeezing different parts of the body can help a person to become aware of themselves as a whole, as well as aiding relaxation.

Start by sitting comfortably at the person's side, and gain their consent, and communicate what is about to happen.
Slowly work your way around the person's body, increasing the pressure of your touch and squeezes as much as is appropriate and safe for the person. Move from each finger, up the hand, wrist, forearm, elbow, upper-arm, shoulder, down to the chest, ribs, stomach (only rest the weight of your hand on the ribs and stomach), thigh, knee, lower-leg, ankle, heel, inner and outer foot and the toes. Then swap to the other side.
Give the person time to process and notice any changes in their body.
End the body scan by communicating to the person that the scan is finishing.

GUIDED BREATHING
Mindful breathing can be calming. If the person you are supporting has any breathing difficulties, seek advice from a health professional before proceeding.

Start by regulating your own breathing. Let your breath flow as deep down into your stomach as is comfortable, without forcing it. Breathe gently and regularly, in through your nose and out through your mouth.
You can share the space so that the other person can sense your breathing. If appropriate, you could place your hands on the person's upper chest and/or stomach to draw attention to their breathing. If possible you can try sitting back to back with the person, so they can feel your breath and you can feel theirs.
Be vigilant for all communication signs, and any signs of distress of discomfort throughout this activity, discontinue if necessary.

5,4,3,2,1 SENSORY EXPLORATION
This technique can help people to focus on the present moment and promote relaxation. This activity can be used to recognise stimulus that is immediately present, or stimulus can be provided.

Start by communicating to the person you are supporting what you will be doing. You will be guiding them through exploring their senses.
Acknowledge and name 5 things you can see, and draw the person's attention to them. Choose between big and small items.
Name 4 things you can feel and draw their attention to them, for example the wind, or the ground beneath your feet.
Name 3 things you can hear and draw their attention to them, for example a clock ticking, or the birds in the trees.
Name 2 things you can smell and draw their attention to them, for example freshly cut grass, or provide a stimulus such as vanilla extract.
Name 1 thing you can taste, this could be that morning's toothpaste, or provide a stimulus such as honey. If nil by mouth, a hand massage with a nice smelling cream can be a perfect end to this activity.

TIPS
Before starting the mindfulness activities make sure the person is comfortable and ensure there is little to no distraction or chance of being interrupted.
If you wish you can complete these activities alongside calming music, however make the music the same each time activities are completed.
Always ask for consent at the start of any activity involving touch, and be aware of any signs that consent has been withdrawn, and discontinue.
It is important to record how the person was before, during and after the activities. Include signs of comfort, discomfort, pleasure and displeasure. Make sure what are you offering is well-received, and does not cause any distress, discontinue if necessary.

For further guidance see www.nacwellbeing.org/guidance/mindfulness/

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Access recent issues online

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

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

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

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

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

Everything you need to know about hats

Sara Davis

I smile proudly during Akbar's graduation photos– he's the first student I've seen through his high school career and I remember how challenging those first school photos seven years ago were. I sing his favourite song and am rewarded with eye contact. Click! And that's a keeper.

A new staff member puts the mortarboard on his head and he immediately takes it off. She coos and pleads, but he's having none of it and is getting annoyed. He's telling us "No" as politely as he can and I know if she gets more forceful about it, so will he.

"Akbar doesn't like hats," I say.

"Oh just for a second…"

"You're refusing, that's ok," I say to Akbar and let him hand me the hat. "You're all done."

I happily text his mom that we got some nice photos, but none with the hat.

"Akbar doesn't like hats," she replies.

"You know, he puts his hat on when he's cold and takes it off when he's hot. I think Akbar has learned what he needs to know about hats," I text.

"Exactly!"

Maybe there aren't a lot of times teaching students with profound learning disabilities when we can say we're all done with a skill. But it is still important to think about what the finish line will probably look like.

Maybe a skill won't be complete in a traditional way. Some people will wear hats when the occasion calls for it because fitting-in and following the social expectations about hats is important to them. And some will not. I am reminded of the photos where everyone has a birthday hat except my dad.

Some people will never fully complete toilet training, to give a more important example. I have run across objections to teaching some of the steps when there are steps that are unlikely or even impossible to accomplish: "But will he ever be able to tell us he needs to go?" "But if she only goes when we sit her on the toilet, that's not really being toilet trained". But each step can improve a person's life. Learning even just a few steps makes diaper changes more predictable, interactive, and pleasant, and does much to protect a caregiver's back. A few steps mean less time being wet. One doesn't need perfection to save thousands in supplies over the years. And, as sad as it is to have to think about it, each step reduces opportunities for a potential abuser.

One of my students is visually impaired and he knows how to eat with a spoon and a fork, but often chooses not to use them. New staff will always want to remind him to use a utensil, or to feed him with one. But I think that, like Akbar has learned about hats, he's learned what he has to learn about utensils. He always uses a spoon for pudding and ice cream and needs no reminder then, but usually abandons his fork when eating his hot food. But it is quite practical for someone who uses his lips to explore to want to touch food with his fingers first to know its temperature and texture before it goes to his mouth. Table manners that make a good impression at a fine dining table may be valuable to me, but don't seem to be as valuable to him as unscorched lips. Maybe he's just all done.

Teaching is a gift– we give our students the best we have, what we hope will improve their lives the most. But like any gift, once it's given, it's no longer ours, it belongs to them, and they might not choose to use it the way we would.

UPDATE!!!!

Akbar did wear his cap at the graduation ceremony, surprising all of us!

But Akbar has always been full of surprises. His family was very surprised when their Sikh guru told them to give him this Muslim name. When they found out at prenatal screening that he has an extremely rare chromosomal abnormality, no one could tell them what that would mean. Again, they saw the guru, who this time said, "All you teach him, you will teach him with love."

This should be a motto for all special education teachers, but it surprises me how it applies particularly to Akbar. When people are frustrated or distracted, when there's an edge to their voices and a subconsciously clenched jaw, they lose him. Many times, he's seemed to know my mood better than I did.

I know some people will say, "See! He could do it! You should have had higher expectations!"

But choosing to wear it for the occasion is a higher expectation than expecting him to relent under the force of a stronger will. We'll never have all the information he has about how uncomfortable it is to him and the cost of wearing it. Lots of people will have harmful behaviours or sweat in discomfort instead of removing their hat: they don't know they are allowed to take it off or they don't know removing it will make them feel better.

So maybe Akbar surprised us by keeping it on because we had proven to him that he didn't have to. By letting him take it off during photo day, maybe I built trust. Because we weren't afraid of disappointing his family, maybe the edge of fear in our voices was removed. He knew he didn't have to wear it to make us happy or to make his family love him. Through love, Akbar learned one more thing about hats.

Contact Details

Sara Davis is a Special Education teacher at Parkholme School in Brampton, Canada.

e-mail: sara.davis@peelsb.com

PMLD LINK
sharing ideas and information

Summer 2022, Vol. 34 No.2 Issue 102

Fun for Learners with PMLD

Neil Mullen

A simple Internet search for fun and engaging activities for learners with profound and multiple learning disabilities (PMLD) alerts and signposts parents/carers, professionals and volunteers to a plethora of research, books, activity packs and resources within seconds. Fun activities such as bubble play, sensory stories, adapted technology activities and accessible activities within the community are highlighted and can be accessed to create memorable and lasting fun memories. However, is there more to these activities than just creating fun? Are there deeper developments taking place?

Within a school or home context, some fun activities can be seen as just that (often by those who have not worked with them) but these often have additional facets to them. Fun activities often provide lots of enjoyment, laughter and engagement but do provide other benefits too. It must be noted though that one individual's fun maybe another's less enjoyable activity. The key to providing fun activities is about knowing the learner well, using what you know about the learner to think what they may enjoy and what they definitely wouldn't! It is crucial that the person supporting the learner is attentive to their enjoyment and fun within the activity. Also, in this instance, there must be a debate as to whether the activities are fun in themselves or whether the people supporting the activity are making it fun.

Imray and Hinchcliffe (2014) highlighted that engaging activities may not only lead to developments in learning and more interactions with key staff, but also bring a sense of belonging to the individual themselves. These activities have the potential to promote fun in both home and school environments and also lead to progress in cognition, improvements in mental health, and increased wellbeing.

Meeting needs both inside and outside of an educational context can provide fun activities alongside these additional benefits. Simmons and Watson (2014) highlighted that fun activities provide crucial opportunities to enter the world of learners with PMLD, enabling supporters to further understand preferences and choices. Songs, dedicated sensory activities (parachute, sensory bubbles) or technological apps provide opportunities for fostering expression of preferences, increased awareness and anticipations, as well as promoting interactions with key individuals within their lives – most often parents/carers/volunteers. These activities can become part of routines within home and school environments, and associated with key supporters. They can become much loved aspects of their lives. More importantly, activities that are based in the community provide more fun opportunities as they progress into adulthood and no longer have access to settings like those in schools.

Anderson (2022) also suggests that engaging and purposeful play is not only fun, but it develops deeper learning (cognition), improves mental health (through interactions/awareness of activities) and their own wellbeing (improved lifestyle). Wells' (2020) sensory stories podcasts highlight the additional benefits of fun activities. His sensory stories can promote awareness of intentions (within stories), acceptance of new experiences and potentially new sensory preferences. These stories are widely used and are great fun but it is likely they also bring benefits in relation to cognition and communication. Additionally, Flo Longhorn (2022) has a vast array of activities, apps and resources in this area to use with learners with PMLD.

Venturers Trust is a website that highlights adapted technology resources, websites and apps. See also, for examples, CENMAC (2018) and iPad apps used by Briarwood School in Bristol (Briarwood, 2018) that can be used by both parents/carers and professionals to engage and work with them. This type of web-based resource not only provides the link to technologies and aids but also shows the benefits that each one has. Adding to the fun these apps/websites (Ikidz pro, firework) and resources (sensory bags) provide, there are the additional benefits of developing fine/gross motor skills, cognition developments as well as activities to engage also.

My own experiences of fun activities for learners with PMLD support my view of the additional benefits of these activities. From my work as voluntary sports coach to my work as a lecturer, fun activities are initially the hook that engages and allows parents/carers and professionals various opportunities to explore their world and this can be used to articulate their preferences and meet their needs. Indeed, fun activities can also benefit these learners in terms of mental health and wellbeing as well as furthering development of relationships with supporters. Indeed, the supporters of learners with

PMLD can themselves benefit in terms of their own wellbeing and mental health through enjoyment of supporting with the fun activities.

A critical and important point must also be made about fun activities for learners with PMLD and inclusion in activities involving the wider community of learners. Davis et al (2004) highlighted that factoring in time for activities for all learners with SEND (special educational needs and disabilities) fosters increased interactions with others, wellbeing and benefits for mental health. I have seen first-hand in my work as a teaching assistant supporting learners with PMLD and other learners with SEND together at lunch/break times that such opportunities to engage with fun activities can foster these benefits. These inclusive activities may take place not only in more formal settings (schools/colleges) but also in community settings (social care settings/ community groups).

There is much enjoyment to be had in sharing/providing these fun experiences which foster developments in learning, supporting mental health and wellbeing. Watson and Corke (2015) highlighted this in their work on supporting playfulness through play – their key focus was on providing fun, engaging, playful and out of the ordinary activities that provide new experiences.

It appears there is much more to a fun activity than you might think!

Contact Details

Neil Mullen has taught in a variety of schools, colleges, community and voluntary organisations. He currently teaches Post 16 learners with special educational needs and disabilities for DurhamLearn.

Email: nmullen1988@yahoo.com

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Do they find it fun?

Melanie Nind

I remain committed to the partnership between British Journal of Learning Disabilities (BJLD) and PMLD Link (see Nind, 2021) that works to ensure that work published in BJLD about the lives of people with profound and multiple learning disabilities is shared with readers of PMLD Link. This is about widening the impact of the papers, provoking dialogue and stimulating more research that 'stands alongside' (citing BJLD's Diversity, Equity, and Inclusion Statement) not just people with learning disabilities, but people with profound learning and multiple disabilities.

Enacting this partnership strategy is good for me as editor-in-chief of BJLD as for each issue of PMLD Link I am prompted to trawl through our back catalogue of BJLD articles to see what is important to share or what connects to the PMLD Link theme. It continually reminds me of how little research we publish that stretches to those whose disabilities make them harder to include and who continue to experience lack of belonging in research.

As an originator and early researcher and proponent of Intensive Interaction (Nind and Hewett, 1994) I was chuffed that my search in BJLD for papers with 'fun' and 'profound' in them threw up a paper about Intensive Interaction and specifically this quote from an Intensive Interaction practitioner:

We just ignore that age appropriate thing, and we just find out 'is it stage- appropriate?' … does it meet this person's needs? Do they find it fun? (Firth, Glyde and Denby, 2021, p.123)

The paper is about the decision making processes of 13 experienced and trained Intensive Interaction practitioners using the 'dual process theory' that they move between 'conscious, internally articulated and controlled thinking' and 'intuitive, unconscious and seemingly automatic thinking' (p.119). The latter is a kind of 'cognitive shortcut' that enables us 'to unconsciously process information and make decisions based on that information, whilst simultaneously applying those decisions in our current actions' usually when 'we are immersed in, and mentally attuned to, a familiar and predictable situation' (p.119).

While Firth and colleagues note that 'Learning ways of enjoyably "being with" another person' is one of the fundamental principles of Intensive Interaction, the paper is not really about fun and they make little other mention of it. Nonetheless, this snippet of data illustrating the conscious decision to ignore one discourse (we must be age appropriate in our interactions) and override it with another (stage appropriateness is the important thing) is interwoven with more intuitive thinking about the importance of fun. Who doesn't want to find ways of laughing together, being companionable together, sharing fun-filled interactions with the person(s) with profound and multiple learning disabilities in their family or working lives? But do we leave this to chance and intuition or do we consciously create an environment that fosters this.

Fun came into McKim and Samuel's (2018) paper presenting case descriptions of people who 'used challenging behaviour and received Intensive Interaction support'. Like Firth et al (2021) they cite the principles of Intensive Interaction including 'mutual enjoyment' and describe one woman becoming more relaxed, vocal and smiley through use of fun, enjoyable social interactions/ Intensive Interaction. However, their finding that Intensive Interaction should be used at the initial assessment within Positive Behaviour Support so that immediate and important improvements can be made to the person's social and communication experience, was based on experiences with people whose learning disabilities were not profound.

My conclusion from all this is that we need more research into the how we engender fun in the lives of people with profound and multiple learning disabilities and the added value of doing this. This is not to discount the point powerfully made by Goodley and Runswick-Cole (2010) that play and fun are important for their own sake, and not just for assessment, intervention or therapeutic goals. It is more to say that, as Watson (2020) (and I am sure this issue of PMLD Link) shows, playfulness and fun are within the capabilities of people with profound and multiple learning disabilities and can make life better for them. Standing alongside them involves seeking to understand this as best we can.

Contact Details

Melanie Nind, University of Southampton, Editor-inchief, British Journal of Learning Disabilities

e-mail: M.A.Nind@soton.ac.uk

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In the Next Issue

We already have some excellent articles which we could not include in our Summer issue for space reasons. We thank our writers for their forbearance and look forward to seeing their fine contributions in the Winter issue. However, we are now asking you wonderful people to contribute more to go with these.

We would welcome more items on the theme of ‘Fun’ since this has proved so popular. Also, we are wanting to include some information about Changing Places toilets (CPts) and are keen to have any contributions from across the UK on this important topic. Are there sufficient CPts in your area or nation to support travelling to fun activities?

However, the Winter issue of the PMLD LINK journal will be a general issue without any specific theme and we would welcome contributions on any topics.

We welcome submissions from anybody. The Editors are keen to support new writers and will provide help for those who want it. To see our Guidelines for Writers visit the ‘Get Involved’ pages on our website www.pmldlink.org.uk

Don’t forget to think about photos. The Summer issue has loads and they really help bring articles to life. So, if you have any really good photos, please share them.

We would be pleased to receive short texts that suggest ideas or convey useful information or even just photos with a caption. We also welcome shorter items about new resources, books, websites, events, courses, and news in general so please let us know about these too.

All contributions by Friday 21st October please. Many thanks in advance!

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

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

UNIVERSITY OF BIRMINGHAM | DEPARTMENT OF DISABILITY INCLUSION AND SPECIAL NEEDS

Are you looking to make a real difference to people's lives? Would you like to become a specialist in your field?

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- Severe Learning Disabilities/Profound and Multiple Learning Disabilities

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IN THE NEWS

Launch of ARC England Learning Disability Research Unit

ARC England (Association for Real Change) is a membership organisation dedicated to supporting learning disability and autism service providers. It has launched the ARC England Learning Disability Research Unit to provide more and better research data for the sector.

The COVID-19 pandemic shone a spotlight on the social care sector and exposed the lack of timely and robust data and poor understanding that have hindered its development for years. It is hoped that this research programme will allow new insights into the size, value, structure and dynamics of the sector, identifying best practice and innovation and providing a knowledge base to inform business planning and shape future policy making.

The development and content of the research programme will be guided by a Research Steering Group that will also provide core funding for the initiative. The Group, chaired by ARC England, is formed of a cross-section of care providers and stakeholders and met for the first time this month to confirm research priorities for the first 12 months. Amongst the new research projects being discussed will be a quarterly 'CEO Confidence Index' that will help track the health of the sector across a range of key indicators. The Steering Group will also act as a forum for discussing sector-wide issues and agreeing joined up solutions.

Current ARC England Research Steering Group members include Community Integrated Care, Digital Social Care, Learning Disability England, Lifeways, Linkage, Log My Care, Macintyre, Marr Procurement, National Autistic Society, National Care Forum, Real Life Options, Ridouts, VAT Solutions, Wilf Ward Family Trust and Windward Day Services.

Sam Clark, Learning Disability England, has commented: "Learning Disability England is supporting ARC England Learning Disability Research Unit as a member of the Steering Group as we want to help generate data and information that will support all our members' lived experience be understood and recognised to bring about the change we need for everyone to live a Good Life."

ARC England has also set up a new Research Fund for individuals and organisations wishing to support this initiative. All donations will go towards increasing the scope and efficacy of the research programme.

For more information and enquiries, contact Liz Collins at the ARC England Press Office on 01246 555043 or email liz.collins@arcuk.org.uk.

The PMLD Conference III from the Sensory Projects

The third PMLD Conference from the Sensory Projects will launch online on the 18th September at 10.00, with on demand access until the end of October. There will be over 20 presentations to watch, all focused on making the world a better place for people with PMLD. Joanna Grace of the Sensory Projects urges you to think of it as 'your very own PMLD Netflix!'

Hosted by Joanna online in a private Facebook group, this conference will feature a wide range of presenters including people with PMLD. All the presenters have one thing in common: they want to see the world change for the better for people with PMLD. Delegates will have access to presentations on demand until the end of October.

The speakers' presentations will be uploaded as videos to the conference page in four waves during the day on Jan 22nd along with additional content. Presentations will remain available to view until February 28th.

Tickets cost £5.98 and can be got from Eventbrite at: https://www.eventbrite.co.uk/e/the-pmld-conference-iii-tickets-253593674507

Purchasing a ticket will entitle you to join the private Facebook group dedicated to this event. This group is the virtual room in which the conference will be held. Those inside the room will be able to view the presentations, those outside will not.

Once you have purchased a ticket please request access to The PMLD Conference III Facebook group immediately. You will need to provide your ticket number in your request. If you delay requesting access, you may experience difficulties getting into the event on time as Facebook only allows 50 people in per day.

For more details contact:
thesensoryprojectsofficeteam@gmail.com

Involving Everyone – Photography Project

Inclusion North is working with photographer Rachael Munro Fawcett to capture stories of people with a profound and multiple learning disability, appreciating the joy and value they bring to the people and communities around them, whilst also recognising barriers and challenges faced.

The exhibition includes not only photographs and film of the individuals themselves, but also images they have taken through the inclusive photographic workshops they participated in with Rachael.

The Involving Everyone exhibition is taking place at The Word – National Centre for the written word, South Tyneside, from the 22nd October for 8 weeks. This is an opportunity to demonstrate storytelling and information sharing in a different, creative format. The exhibition will be accessible for everyone, with a changing places facility also available in the building.

For more information about this project contact Kirsty.morgan@inclusionnorth.org or Rachael.Munro-Fawcett@inclusionnorth.org

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The Disabled Children's Partnership's response to *Right Support, Right Place, Right Time*

By Stephen Kingdom

The Disabled Children's Partnership (DCP) is a campaigning coalition of more than 100 organisations that fights for better support for disabled children and their families. As with all organisations and coalitions working with disabled children and those with special educational needs, our focus in recent weeks has been on Right Support, Right Place, Right Time – the government's Green Paper on reforming the Special Educational Needs and Disability System.

There are parts of the Green Paper we welcome: in particular the ambition for better early intervention; for a more inclusive mainstream education system; and for parents not to have to battle to get support for their child. However, we are concerned that – far from realising these goals – some of the proposals in the Green Paper will actually make it harder for families to access support, and that too often the focus is on saving money, not improving support. The proposed National Standards – as described in the Green Paper – could undermine existing statutory protections. Proposals on school choice may make it harder for parents to secure the right place for their child; and the proposal to make mediation mandatory will put an extra barrier in place for parents seeking redress through the Tribunal. The Green Paper also suggests a system of national tariffs and funding bands to allocate resources, which we think is incompatible with an individualised, needs based, system. And finally, the Green Paper does not say enough about accountability. The problem with the system at the moment is not the legal framework, but that there is a lack of accountability when statutory agencies, including local councils and the health service, do not meet their legal duties.

We have raised these concerns with government and with politicians from across the political spectrum. This included hosting a virtual Parliamentary event where MPs and members of the House of Lords heard directly from parents and young people. And we have also sought to make it easier for parents to send their views to the government. The official consultation response form is long (22 questions), complicated, not user-friendly, and even then doesn't cover some crucial issues. We focused down on key areas in the Green Paper and produced six simple questions for parents and others to answer – and we got the government to agree to accept these as a full part of the consultation process. At the time of writing – a couple of days before consultation closure on 22 July – more than 1,600 people have submitted their views using our questions.

Following the closure of the consultation period, we will continue to press the government to ensure their reform programme genuinely does improve the lives of disabled children and their families.

For more information about the Disabled Children's Partnership and to get involved, go to https://support.disabledchildrenspartnership.org.uk/

Publication of Sixth LeDeR Report

The sixth annual LeDeR report was published in July. Some changes have been made to the format of the annual report, including: more graphical presentations of the data and findings in a visual format; the inclusion of infographics with key take away messages of the main findings; and a focus on making findings easy to understand and interpret.

A total of 3,304 deaths of people with a learning disability were reported to LeDeR during 2021. This includes 208 deaths of children aged 4-17 and 3,096 deaths of adults aged 18 – 98. A proportion were selected for focused reviews that looked in more detail about the life and death of the person and lessons that can be learnt from their care.

It is hard to be sure how many people who died would be regarded as having PMLD but they would have been a minority. Data on long-term health conditions show that approximately 1,100 of these people had long-term health conditions, the most common being epilepsy, cardiovascular conditions, sensory impairment, mental health conditions and dysphagia. The greatest hazard was associated with having epilepsy.

This year's report found a number of things:

People with a learning disability continue to have a much shorter life expectancy than the wider general public, with 6 out 10 dying before age 65, compared to 1 out of 10 for people from the general population. Those with epilepsy and from minority ethnic backgrounds were more likely to die younger.

The most common cause of death based on death certificates during 2021 was COVID-19. The estimated excess deaths during 2021 compared to pre-pandemic years was double that of the general population. Being vaccinated significantly reduced the likelihood of dying of COVID-19.

Approximately half of all deaths of people with a learning disability was deemed to be avoidable, compared to less than a quarter for people from the general population.

The full report and easy read version and infographics are available online at: https://www.kcl.ac.uk/research/leder

NHS England has also published the fourth annual LeDeR Action from Learning report and easy read version, which describes some of the work being undertaken across the country by the NHS to reduce health inequalities and premature mortality amongst people with a learning disability. There is also a document that details useful resources and links. These are available online at: https://leder.nhs.uk/resources/action-from-learning-reports

Coronavirus Study – Wave 4

In previous issues of PMLD LINK, you will have read about the outcomes of *The coronavirus and people with learning disabilities study*. This project tracked the experiences of people with learning disabilities through the COVID-19 pandemic. The project workers interviewed about 500 adults with learning disabilities directly and surveyed a further 300 family members or support workers of adults with learning disabilities who could not take part in an interview.

The researchers have announced that they have been given some more money to talk to people with learning disabilities and their carers again for a fourth time to find out how people and families are managing as the UK recovers from the COVID-19 pandemic. They plan to go back to people in late summer/early autumn 2022. They are calling this 'Wave 4' of the research. They will be going back to people who have taken part in previous waves.

They also have funding for two additional pieces of work in England: 1) to gain views from a sample of adults with learning disabilities from minority ethnic communities (100 interviews and 50 surveys); 2) to carry out in-depth qualitative case study research with up to 20 people with learning disabilities about their journeys through the pandemic.

For more details go to:
http://covid19learningdisabilities.co.uk/

Easy Eye Care - information for the learning disability community

Following a successful launch in Learning Disability Week, the Easy Eye Care pathway is now live in Lancashire and South Cumbria, alongside Greater Manchester and Cheshire and Merseyside. The service provides regular eye care for people with learning disabilities and for autistic people and includes:
a longer appointment or several shorter appointments if needed; a pre-appointment form About Me and My Eyes to be completed and given to the optometrist;
the person receives a plain English Eye Test Results form after the appointment.

For the full list of practices in the North West go to: www.seeability.org/sites/default/files/2022-07/NW%20Easy%20Eye%20Care%20optoms%20for%20database%20PDF%20-%2029.6.22.pdf For more information, please contact Steve Kill at s.kill@seeability,org 07738 040307.

The SeeAbility website (www.seeability.org/optometrists) allows you to search the charity's database of optometrists and dispensing opticians who have said they welcome people with learning disabilities. Some are accredited to provide the specialist Easy Eye Care service. Search your town or postcode and use the filters to find a suitable optometrist near you. If you represent a practice and would like to sign up to the database or have any queries, please email: eyecare@seeability.org.

A requirement for staff to have learning disability training

All health and social care providers registered with the Care Quality Commission (CQC) must ensure that their staff receive training in how to interact appropriately with people who have a learning disability and autistic people.

The requirement was introduced by the Health and Care Act 2022. It is expected that a Code of Practice outlining the content, delivery and ongoing monitoring and evaluation of training is expected next year. The mandatory training is named after Oliver McGowan, whose death demonstrated the need for health and social care staff to have better training. The CQC has produced statutory guidance which is available at: https://www.cqc.org.uk/guidance-providers/regulations-enforcement/regulation-18-staffing

The guidance makes it plain that providers must provide sufficient numbers of suitably qualified, competent, skilled and experienced staff to meet the needs of the people using their service. Staff must receive the support, training, professional development, supervision and appraisals that are necessary for them to carry out their role and responsibilities. They should be supported to obtain further qualifications and providers must give, where required, to the appropriate regulator to show that the staff meet the professional standards needed to continue to practise.

PUBLICATIONS AND RESOURCES

Holiday Information Guide

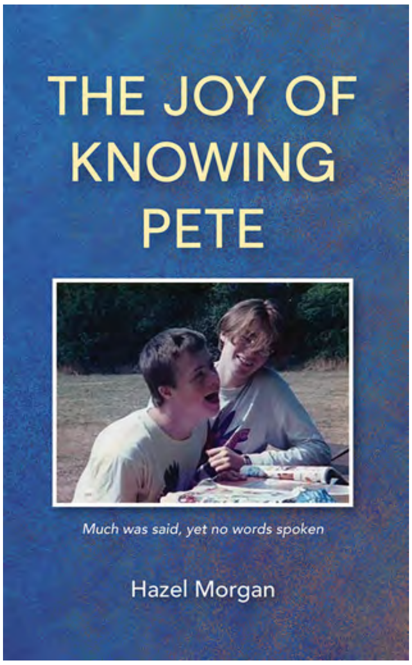
Hft is a long-established charity supporting people with learning disabilities. Hft's Holiday Information Guide is packed with information to help people with learning disabilities and those closest to them choose an accessible, disability-friendly holiday. The sections in the guide include: Useful advice, General guides and information, Tour operators, Places to stay – UK, Places to stay – abroad, Specific-interest holidays, Insurance, Funding and grants and Resources specifically for family carers. Please note that the guide uses the words of the organisations listed and also contains adverts from some providers. Full contact details are provided.

You can request a copy by post via:
Freephone: 0808 801 0448
Email: familycarersupport@hft.org.uk
You download your free copy at:
https://www.hft.org.uk/our-services/family-carer-support-service/fcss-updates/holiday-information-guide/

The Joy of Knowing Pete: Much was said, yet no words spoken

Title: The Joy of Knowing Pete: Much was said, yet no words spoken
Author: Hazel Morgan
Publisher: YouCaxton Publications (https://www.youcaxton.co.uk/pete/)
Published: May 2022
Paperback: 120 pages
Price: £11.99
ISBN: 9-781914-424526

Hazel Morgan looks back on the teenage years of her younger son who had Down's syndrome and profound and multiple learning disabilities describing his positive influence on those he met in his short life, while including some reflections on more recent government policies.



Peter never used words but still made a profound impact on the lives of his family, friends and those he met. His individuality, love of music, his friendships and his determination all shine are explored in this book: his home, his surroundings, his schools, his church membership, his outings, his holidays, his three months in hospital following severe strokes and his final months in a Sue Ryder home.

This is Hazel's second memoir about Pete. In her first book, Through Peter's Eyes, she captured his life up to the age of eleven. Peter's death shortly before his nineteenth birthday prompted Hazel to change career: she had taught for many years in secondary, further and higher education and subsequently became a Co-Director of the Foundation for People with Learning Disabilities, then part of the Mental Health Foundation, overseeing research and projects.

The Kippford Mermaid

Title: The Kippford Mermaid
Authors: The Arts End of Somewhere
Publisher: Curly Tail Books (https://curlytalebooks.co.uk/)
Cost: £12.99 (all proceeds go to PAMIS)
ISBN: 9781999633677
Pub Date: July 2021
Page: 28

Based on a traditional Dumfries and Galloway folk tale, The Kippford Mermaid has been written and illustrated by The Arts End of Somewhere, an arts collective based in Dumfries. The book tells the story of a drowning sailor rescued by a beautiful mermaid. This tale of love and tragedy has been written and illustrated alongside multi-sensory activities that help the story come to life for people with profound and multiple learning disabilities (PMLD) and their families.

The book is designed to be interactive and contains instructions for how to use easily available props for multisensory story telling. There is also a resource package which can be downloaded from the PAMIS website. There is an explanatory video about the sensory story, which also shows members of the group demonstrating how they tell it.

For details of how to buy the book and to see the video, go to: https://learning.edbookfest.co.uk/resources/the-kipford-mermaid-a-multi-sensory-story-created-by-the-arts-end-of-somewhere/

The Arts End of Somewhere is a group of people who have additional support needs. They came together to learn about multi-sensory storytelling in May 2019. Since then, they have formally become PAMIS Volunteers and research, write, and develop multi-sensory stories with people with PMLD in their community.

SPLASH study

This research by Caroline Tbaily into the benefits of hydrotherapy for adults with profound and multiple learning disabilities (SLD/PMLD) has been published recently. Caregivers (paid/unpaid carers, health/social care professionals and family members) of adults with severe, profound and multiple learning disabilities were recruited through public advertising. Participants were asked to attend a virtual semi-structured interview and complete an online questionnaire.

It was found that caregivers of adults with SLD/PMLD believe that hydrotherapy has an impact on physiology, such as tone, range-of-movement and function, but also on other physical-health areas, such as seizures, bowels and chest infections. There were also impacts on mental health (independence, choice and social inclusion) and other social implications (alertness, communication, developing support networks and rapport/trust with existing caregivers).

In other words, hydrotherapy doesn't solely impact on the biomedical needs of adults with SLD/PMLD. These findings show caregivers experience hydrotherapy to impact in many different biopsychosocial ways. Future studies should consider quantitively measuring the impact of the main themes, e.g. seizure frequency, hospital admissions, constipation, quality-of-life, carer-burden and communication.

The SPLASH Study has gained unique insight into the experiences of a population currently underrepresented in research literature. The full SPLASH study is now freely available here as set out in Caroline Tbaily's Master's thesis: https://eprints.bournemouth.ac.uk/37282

Skip to pdf page 94 for the conclusion, or pgs 128-131 for the full catalogue of themes that were found!

The Impact of COVID-19 on the Mental Health and Loneliness of People with a Learning Disability

As restrictions in England lift following a period of worldwide turbulence caused by the Covid pandemic, Mencap has produced research aimed to gather insight into the impact that this pandemic has had on people with a learning disability in England with specific reference to mental health and loneliness.

During the analysis, several themes were identified that relate to people with a learning disability's experiences of loneliness and mental health during the pandemic. These themes are: relationship with loved ones, isolation and lockdown, negative effects on mental health, discrimination, bullying and understanding of learning disability.

Of particular note is that parents of people with profound and multiple learning disabilities felt the majority of people rarely understood the reality of being a carer (p12):

"Understanding someone with complex needs is difficult, it's hard work and people just don't understand how it affects the family, you donate your life to that situation."

Also, during the pandemic, some parents and carers of people with profound and multiple learning disabilities who usually lived in services talked about decisions they had made to care for their loved one at home during the pandemic. Safety of loved ones was a key concern driving such decisions. A few parents and carers emphasised the challenges of these increased caring responsibilities (p.5):

"I brought [my daughter] home because I was concerned about staff going in and out... It was hard work, but it was worth it to keep her safe. She wouldn't have coped being in hospital."

Even as England removes all remaining restrictions as part of the government's 'Living with Covid' plan, understanding these and other longer-term impacts is vital to ensure people with a learning disability are appropriately supported.

The report is available at: https://www.mencap.org.uk/sites/default/files/2022-05/LONELINESS%20ENGAGEMENT%20FUND%20REPORT%20A4%20MAY%202022.pdf

COURSES, CONFERENCES AND EVENTS IN 2022

Many training providers are still not running face-to-face or in-house training courses, but there are some excellent online training opportunities available. It is suggested that you visit the websites of regular and relevant providers as listed in the Winter 2020 issue.

September	
Title:	Intensive Interaction Training – one day
Date:	1 September
Location:	Online
Provider:	Us-in-a-Bus
Contact:	info@usinabus.org.uk
Title:	24-hour postural care from cradle to grave
Date:	7th September – 19th October
Location:	Online
Provider:	Born at the Right Time/Simple Stuff Works
Contact	Email:admin@bornattherighttime.com https://www.eventbrite.co.uk/e/337135129247
Title:	Kidz to Adultz Scotland
Date:	8th September
Location:	Royal Highland Centre, Edinburgh
Provider:	Disabled Living
Contact:	Tel: 0161 214 4592. Email: info@disabledliving.co.uk
Title:	Five Day Course for Intervenors
Date:	12th – 16th September
Location:	Chadsgrove School and Specialist Sports College Bromsgrove
Provider:	Jenny Fletcher, NatSIP and University of Northampton
Contact:	Email: sgribble@chadsgrove.worcs.sch.uk Phone: 01527 871511
Title:	24-hour postural care: Hands-on training for the postural care workforce
Date:	15th September – 13th October
Location:	Online
Provider:	Born at the Right Time/Simple Stuff Works
Contact	Email:admin@bornattherighttime.com https://www.eventbrite.co.uk/e/337217666117
Title:	The PMLD Conference III
Date:	18 September (launch day; presentations avail. > 31 Oct)
Location:	Online
Provider:	The Sensory Projects/Jo Grace
Contact:	https://thepmldconference3.eventbrite.co.uk
Title:	EQUALS Regional Curriculum and Assessment Conference
Date:	30th September
Location:	Queens University, Belfast
Provider:	EQUALS
Contact:	Email: admin@equalsoffice.co.uk https://equals.co.uk/conferences-2/
Title:	ACPPLD Annual Learning Event 2022
Date:	26th and 27th September
Location:	Hilton Hotel, York
Provider:	ACPPLD Association of Chartered Physiotherapists for People with Learning Disabilities
Contact:	https://acppld.csp.org.uk/
Title:	Depression and Low Mood: Supporting Children and Adults with Severe and Profound Intellectual Disabilities
Date:	29th September
Location:	Online
Provider:	www.nacwellbeing.org
Contact:	julie@nacwellbeing.org
October	
Title:	Five Day Course for Intervenors
Date:	3rd - 7th October
Location:	Chalvey Community Centre, Slough
Provider:	Jenny Fletcher, NatSIP and University of Northampton
Contact:	Email: bev@chalveyeyc.slough.sch.uk
Title:	Introduction to 24-hour postural care for healthcare professionals
Date:	5th October
Location:	Online
Provider:	Born at the Right Time/Simple Stuff Works
Contact	Email:admin@bornattherighttime.com https://www.eventbrite.co.uk/e/347876165977
Title:	EQUALS Regional Curriculum and Assessment Conference
Date:	Friday 7th October
Location:	Melland High School, Manchester
Provider:	EQUALS
Contact	Email: admin@equalsoffice.co.uk https://equals.co.uk/conferences-2/

Title:	Sensory learning: a practical approach for support staff
Date:	13th October 2022
Location:	Online
Provider:	Hirstwood Training
Contact:	Email: lois@hirstwood.com or https://hirstwood.com/
Title:	The importance of messy play
Date:	14th October 2022
Location:	Online
Provider:	Hirstwood Training
Contact:	Email: lois@hirstwood.com or https://hirstwood.com/
Title:	EQUALS Regional Curriculum and Assessment Conference
Date:	Friday 14th October 2022
Location:	Wilson Stuart School, Birmingham
Provider:	EQUALS
Contact:	Email: admin@equalsoffice.co.uk https://equals.co.uk/conferences-2/
Title:	Five Day Course for Intervenors
Date:	24th – 28th October
Location:	Queen Elizabeth High School, Carmarthen
Provider:	Jenny Fletcher, NatSIP and University of Northampton
Contact:	Email: SADurbridge@carmarthenshire.gov.uk
November	
Title:	24-hour postural care from cradle to grave
Date:	2nd November – 14th December
Location:	Online
Provider:	Born at the Right Time/Simple Stuff Works
Contact	Email:admin@bornattherighttime.com https://www.eventbrite.co.uk/e/375141788187
Title:	Communication and co-production with relatives and carers in a changing world
Date:	23rd November
Location:	Online
Provider:	Born at the Right Time
Contact:	E-mail: admin@bornattherighttime.com https://www.eventbrite.co.uk/e/271077489067
Title:	Kidz to Adultz North
Date:	Tuesday 1st November Manchester Central
Location:	
Provider:	Disabled Living
Contact:	Tel: 0161 214 4592. Email: info@disabledliving.co.uk

Title:	Five Day Course for Intervenors
Date:	14th – 18th November
Location:	Mary Elliot School, Walsall
Provider:	Jenny Fletcher, NatSIP and University of Northampton
Contact:	Email: postbox@mary-elliot.walsall.sch.uk
March 2023	
Title:	"Celebrating past, present and future" Us in a Bus 30th Birthday Conference
Date:	23rd March 2023
Location:	Hartsfield Manor, Sandy Lane, Betchworth, RH3 7AA
Provider:	Us-in-a-Bus
Contact:	Us in a Bus conference Tickets £85 from https://www.eventbrite.co.uk/e/the-us-in-a-bus-conference-2023-celebrating-past-present-and-future-tickets-337145600567

Frozen Light Events

Fire Songs will be at bOing! International Family Festival in Canterbury - 27th and 28th August
Night Out In Nature will be at Blickling Hall, Norfolk - 28th September - 1st October
2065 goes back on tour in Autumn 2022:

16th - 17th September - Brentwood Theatre, Brentwood
21st -22nd September - Blackwood Miners Institute, Blackwood
23rd - 24th September - Chapter Arts Centre, Cardiff
27th - 28th September - Galeri, Caernarfon
3rd - 5th October - Fisher Theatre, Bungay
6th - 7th October - National Youth Theatre, London
11th - 12th October - The Pavilion, Porthcawl
13th - 14th October - The Met, Abertillery
17th - 18th October - Ffwrnes, Llanelli
19th - 20th October - The North Wall, Oxford
24th - 25th October - Tobacco Factory, Bristol
27th - 28th October - Tramshed, Woolwich

For more details contact
info@frozenlighttheatre.com

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

Us in a Bus training – online workshops

'Introduction to Intensive Interaction' training sessions by Janet Gurney
Dates: 11th January and 6 June 2022 - 9.00-3.30 pm, via zoom.
£50 per person or £25 family carers
Download a booking form; http://usinabus.org.uk/events/book-on-a-workshop/
Send this to: info@usinabus.org.uk, or call on: 01737 823310
The Caldwell Autism Foundation is funding £25 bursaries for these online workshops.
To apply email: admin@usinabus.org.uk

The Sensory Projects – online

Each option begins at the start of each month, and delegates have three months to complete their studies.

- Ambitious and Inclusive Sensory Storytelling.
- Sensory Engagement for Mental Wellbeing.
- Exploring the Impact of the Senses on Behaviour.
- Multisensory Rooms: Myth Busting the Magic.

*these can be broken down and studied as three separate workshops.

- Creating Sensory Accessibility
- Sensory-being: Mental Wellness for People with Profound Disability
- The ‘Get it’ Question

www.TheSensoryProjects.co.uk/online-college for more information or to enrol

NAC – online courses

Available as on-demand and bespoke options:

- Supporting Children and Adults with Severe and Profound Intellectual Disabilities Affected by Trauma
- Emotional Wellbeing for Children and Adults with Severe and Profound Intellectual Disabilities

Contact: Julie Calveley - julie@nacwellbeing.org
https://learning.nacwellbeing.org/lp-courses

Story Massage Programme – online training
Available at all times.
Contact: Mary Atkinson, 01243 779600 or info@storymassage.co.uk
www.storymassage.co.uk

Pamis – online courses

Understanding Communication & Behaviour
This course runs regularly throughout the year
Contact: fiona.harper@pamis.org.uk to book or make enquiries

Postural Care – Simple Stuff Works & Born at the right time – online

A range of opportunities and CPD accredited modules, including:

- Introduction to 24-hour postural care (half day workshop)
- 24-hour postural care: Hands-on training for the workforce
- 24-Hour Postural Care: Getting to the Core of the Problem

Contact: admin@simplestuffworks.co.uk https://www.simplestuffworks.com/training/

Hirstwood Training – online, on demand courses – some free!

Huge range of opportunities including for example:

- Cheap and cheerful
- Creating inspiring sensory classrooms
- Sensory Impairment Sensory Loss
- Sensory on a shoestring, and portable sensory environments
- Sensory Resources
- The senses and learning

Contact: lois@hirstwood.com or https://hirstwood.com/

University of Roehampton
London

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University of Roehampton in partnership with Sounds of Intent Charity and Services for Education, Birmingham

For more information please contact Professor Adam Ockelford
a.ockelford@roehampton.ac.uk

https://www.roehampton.ac.uk/postgraduate-courses/music-and-children-with-special-needs-sounds-of-intent/

PMLD LINK

Subscription form

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

Name of Subscriber: ……………………………………………………………………………………………………

Address: ………

………

Telephone No. ……………………………… **e-mail:** ………………………………………………………………….
(this email address will be your username for your website account)

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

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

I/we have set up a standing order for £ with our bank starting on …………………………….……
I/we have paid using PayPal through the PMLD Link website

Date:……………………………………

Please send this form with payment to: PMLD Link, Caerludd, Cilgerran, Pembrokeshire, SA43 2SN

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

Gift Aid Declaration

Name of Charity: **PMLD LINK**

Details of donor:

Title …….......Forename(s)....……………………………….Surname……………...…………………………………......

Home Address:.....…………………………………………………………………………………...………………........

……

……………………………………………………………………………..………Post Code:………………………...…

II want all subscriptions and donations that I make from the date of this declaration to treated as Gift Aid until further notice

You must pay an amount of Income Tax and/or Capital Gains Tax at least equal to the tax that the charity reclaims on your donations in the appropriate tax year (i.e 25p for each £1 you give on or after 6 April)

Date ………../……………../……………..

STANDING ORDER MANDATE (Send to *your* bank)

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

The sum of: £………………

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

Account to be debited: …………………………..…………………………………………………………………

Account No. ………………………………………

Signature(s): ………………………………………………………………………………………………………

Date: ……………………………………………

About Us

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

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

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