PMLD LINK

sharing ideas and information

Promoting inclusion: transforming lives

Winter 2017

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GUEST EDITORIAL

Promoting inclusion: transforming lives

Our warmest welcome to the Winter Issue of PMLD Link. As you may remember, our last issue featured a call for contributions on inclusion and transforming lives, the central theme of PAMIS' conference in June of this year. At this event, PAMIS launched 'Profound', a film produced and directed by the amazing production team at August Pictures. The film is deeply real and moving as it challenges our assumptions and definitions around the word 'profound'. It promotes 'profound' as deep, wise, intense and expert. People with PMLD are recognised as educators and teachers in communication, compassion and care.

Attracting more than 200 national and international delegates, the conference had a strong focus on inclusion. With a focus on PMLD, many presenters shared their expertise in education, life transitions and emotional wellbeing. Extending these themes to practical considerations, the conference provided opportunities to discuss how our physical, environmental, cultural, creative and social spaces can be designed to promote inclusion. We wanted to parallel the focus of the conference, with this issue and I am sure you will agree that the following contributions, some of which are from conference presenters, share a wealth of insight.

As I read through this month's contributions, our first article is written by the wonderful Scottish Storyteller Ailie Finlay. She has a passion for play and has been working for many years in developing innovative and creative ways of including people with PMLD in play activities, regardless of age. Her contribution has useful guidance on how to modify traditional childhood games for this group. In addition, Lynsey Robinson and Joanna Grace introduce us to their recent project, which values the person with PMLD as co-authoring partners. Following the theme of storytelling, our latest contribution from Karen Bunning, Nicola Grove and Jane Harwood shares an interesting perspective on how Storysharing® can influence lives in meaningful ways. Our very own Maureen Philip shares her passion for storytelling too, and introduces us to a variety of stories that aim to engage people with PMLD with stories derived from the oral folktale tradition. With more of a research focus, Joanna Grace and Andrea Silva assess the usefulness of storytelling guidance, which has implications for practice.

On the theme of transition and change, Marion McArdle, mother of Laura, shares her story of separation and the impact of this on her daughter's health. My own contribution aimed to support Marion's story with some important messages from research about embodied emotion and dysregulation. I really felt that these messages were further extended in Christina Vasileiou's article on 'Embodied Humanity'. In addition, Dianne Cantali describes her recent review of primary to secondary school transition and applied this to the needs of people with PMLD. She highlights the value of technology as a supportive tool. A comprehensive article on technology by Chas Mollet and Leonie Elliot-Graves features exciting and innovative ways of including people with PMLD in creative activities. Perhaps related to this, Roney Lee challenges us to consider the accessibility issues of our environments. Finally, Naomi Rosenberg reflects on years of visits to classrooms offering suggestions on what best enables individuals with PMLD to learn – some very valuable ideas for those who are new to this work.

It has been an absolute pleasure to co-edit this issue with Annie Fergusson and Jill Davies. We thank all of the contributors and hope you enjoy the final edition of this year.

Hannah Young
Guest Editor from PAMIS, leading on this special issue of PMLD Link

The 'Profound' film can be accessed by visiting www.pamis.org.uk and clicking 'PROFOUND' tab on the navigation pane.

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Traditional Childhood Games for Children with PMLD

Ailie Finlay

A scene from my childhood:
One child (the ‘wolf’) stands facing the school wall.
‘What’s the time Mr Wolf?’ yell all the other children who are lined up at the furthest end of the playground.
‘It’s one o’clock!’ says the wolf.
All the children take one step forward.
‘*What’s the time Mr Wolf?’* they yell again.
‘It’s eight o’clock!’
All the children take eight steps forward.
‘What’s the time Mr Wolf?’
‘It’s dinner time!’ yells the wolf, ‘and I’m going to eat you up!’ The wolf turns and turns and chases the children who all run away shrieking as loud as they can.

When I think of this game I remember the fluttery feeling in my stomach as I waited for the inevitable moment when the ‘wolf’ would suddenly turn around and start to give chase. And I remember the joy of running away and shrieking! Perhaps you remember ‘What’s the Time Mr Wolf?’ as well, or perhaps you have different memories. Maybe you remember hiding in a cupboard while somebody clomped round the house yelling: *‘Ready or not here I come!’ Or your memories might be of the simple delights of ‘tig (or ‘tag’) – you’re* *it! (Or the slightly more illegal delights of 'kiss, cuddle or torture!')*

For me the emotions that go with these games are some of the most vivid memories of my childhood. These feelings were my starting point when I began adapting traditional games for children with PMLD. I wanted these children too to be able to experience the excitement, hilarity, suspense, cheekiness and almost-but-not-quite-real fear that comes when playing these games.

I have been working as a storyteller with children with additional needs for a number of years, developing and telling interactive multi-sensory stories. I use a lot of traditional folk tales in my work. Over the years I became increasingly interested in the intersection between traditional games and folk tales. I discovered that folk tales often contain similar structures to traditional games, and traditional games often contain strong elements of tale-telling in them. In my work the lines often became blurred; stories became games and games became stories.

I began to think more about this whilst telling tales at the Friendship Club run by PAMIS in Fife (Scotland) for families with a member with PMLD. I have worked at the club regularly over a number of years. I wanted to include games there in the same way I did in my other work. I wanted the children to experience these quintessential childhood feelings. I also knew that the best way of fostering friendships between children is to encourage them to play together, so I began to think about how I could use traditional games with children with very complex additional needs.

Traditional games were in many ways very suited to using in this context. Firstly, the language of traditional games is very inclusive. Recently I overheard the following exchange:

Child [Clapping and chanting fast, demonstrating a clapping game to an adult]: *Dom, dom, dalee, see see alelee, mini, mini makara, mini mini alelee*
Adult: *What does it mean?*
Child: *I don't know.*
Adult: *Is it in a foreign language?*
Child [shrugs]: *Maybe…*

The child's shrug sums up their attitude to the language of play; meaning is very often secondary to the joy of the sound, rhythm and rhyme. This makes these games perfect for children who may struggle with meaning, but can relish the sensory experience of the words. Everyone joins in and the children with PMLD are surrounded and bathed in the sound of the song:

The wind, the wind, the wind blows high
The rain comes scattering from the sky
or delight in the rhythm and rhyme of:
Olinka, bolinka, Susan solinka, olinka, bolinka, Bob

Another benefit of traditional games is that they have very definite rules, but within those rules allow a certain amount of wildness. Every child likes to go a wee bit wild now and again; to careen around yelling loudly, to roll on the floor giggling. Children with PMLD should have these opportunities just like any other child, but for safety reasons in a group setting the wildness needs to be more controlled than the common free-play rampage. Within the clear boundaries of a traditional game children with PMLD can enjoy silliness and exuberance just like their peers. They can blow raspberries at 'the wolf', or hide from the giant with some friends under a piece of fabric, and giggle and giggle and giggle.

Interestingly from my experience it is not necessary to understand the rules of a game in order to enjoy playing it. Anyone who has witnessed a younger sibling at a birthday party joining in with musical statues or pass the parcel, laughing uproariously whilst very definitely not getting the rules can vouch for this.

Traditional games also give us the welcome chance to celebrate each and every child. For children who may be amongst the most marginalised in society this is especially important. So we form a ring and sing:
Bee, baw, babbity, babbbity, babbity
Bee, baw, babbity
A lassie or a wee laddie

and choose a lassie or a wee laddie to come into the centre. 'Hurray!' for them 'Hurray that they are here!' we say.

Or we help a little witch put on her woolly shawl and witch's hat and cower from her as she scares us all. '*Hurray*!' for her, '*Hurray for the little witch*! Hurray that she is so scary!' Everybody gets their chance to be in the middle of the ring, to be the hero, or the scary one, or the baddie. Everybody gets a cheer!

With all these benefits in mind I set about creating a small repertoire of traditional games for children with PMLD. It was not always simple to work out how to do this. Many traditional games involve chasing, racing, seeking, wrestling… But by concentrating on the feelings of the games I was able to work out how to make them work. My starting question was always: how does this game make a child feel? And then: how could a child with PMLD experience the same feeling?

Sometimes different sensory props need to be included to make a game work. In a game that relies on visual clues (for example the game Red Rover where children are allowed to 'come over' to safety according to the colours they are wearing) we may need to provide fun tactile props. In a game that creates excitement through speed (for example Duck, Duck, Goose where the 'goose' has to run around the circle very fast) we may need to think of a different way of creating similar suspense; the 'goose' could remain still but be covered in a large piece of silk for example. Sometimes games need to be simplified right down, one simple sequence of action and suspense can be picked out and used. Adults involved need to approach the games with gusto, to ham it up rather than spectate from the sidelines.

I will now return to the 'wolf' and finish with a scene from a recent Friendship Club games session:

The 'wolf' (an adult) is in the middle of the circle, wearing large furry mitts.
'*What's the time Mr Wolf*?' asks everyone in the circle.
'*It's three o'clock*!' says the wolf and takes three steps forward.
'*What's the time Mr Wolf*?' everyone yells again.
'*It's six o'clock!*' says the wolf and takes six steps forward. It is clear the wolf in now heading for one particular family group. They huddle together laughing…
'*What's the time Mr Wolf*?'
'*It's twelve o'clock*!' says the wolf and takes twelve steps towards her 'victims'. They huddle and giggle even more. The child in the middle who is in a wheelchair is laughing louder than anyone else.
'*What's the time Mr. Wo*lf?' everybody asks, louder than ever.
'*It's dinner time!*' yells the wolf, '*and I'm going to eat you up!'* The wolf runs towards her 'victims' making mock fierce roars and 'getting them' with her furry mitts. All is laughter and friendly chaos.

Contact details

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To download some adapted games: http://www.flotsamandjetsam.co.uk/inclusive-games.html

Appointment of a Development Officer

PMLD LINK has received a grant from a charity to enable the Trustees to engage a freelance worker to act as a Development Officer. The core purpose of the role is to increase the number of stakeholders subscribing to the PMLD LINK journal and website. Increasing the number of subscribers to the journal will benefit a greater number of people with PMLD. Also, PMLD LINK is entirely dependent upon donations and subscriptions to maintain the journal and website. In recent years associated costs have increased significantly and it is hoped that this initiative will ensure the continued existence of PMLD LINK. It is a particular aim to bring PMLD LINK to the attention of many more organisations, especially service providers of all kinds for children and adults with PMLD.

It is expected that the person appointed will advise the PMLD LINK Trustees on the development of a marketing strategy and promotional materials. It is envisaged that increasing subscriptions will involve the use of modern computer technology. The person appointed will use social media technologies and develop website materials to publicise the journal and website as well as contacting organisations directly via e-mail and mail shots.

This is a part-time freelance post. The person appointed must be able to work from his/her own home or other base and must have ready access to the Internet and e-mail facilities. It is expected that, on average, the time commitment will be for the equivalent of one day per week on average (or approx. 300 hours during a 12 month period). Extension of the post beyond 12 months will depend upon whether PMLD LINK can access further grants. The person appointed will be self-employed and must be responsible for their own tax returns, insurance, etc.

Interviews will be held in early 2018. To get a job description, person specification and other details, please email: rob.ashdown@ntlworld.com or write to Rob Ashdown, 15 Cliff Gardens. Scunthorpe, North Lincolnshire, DN15 7PH. For informal discussions contact Rob Ashdown.

Storysharing® for Inclusion

Karen Bunning, Nicola Grove and Jane Harwood

We all need to have friends, to feel part of a community, and to have a voice in making decisions that affect our lives. This can be a real challenge for people with PMLD and their families (Hughes, *et.al*., 2011; Reinders, 2008). Clement and Bigby (2009) found that staff and families often had different ideas of what inclusion meant, and that some staff felt that the people in their care were just too different to be included in society.

A major barrier is of course the perception of communication difficulties of people with profound and complex needs, and how these impact on everyday participation with friends and in civic life. Communication skills are critical, whether for a topical discussion, networking, first time encounters, or the sharing of news with people who matter in your life. In each situation, it is the skill of narrative, storytelling, that connects individuals (Fivush et al., 2011) and makes sense of experience (Lambrou, 2014). The stories capture significant, 'reportable' events that hold meaning and interest for both the teller and the listener (Labov & Waletzky, 1997). We also know that telling your story is one of the best ways of changing minds and reducing prejudice. This is because when you hear a story – as distinct from a set of facts - the empathetic, feeling part of your brain kicks in and influences you in subtle ways (Svoboda, 2015).

In 2002, Grove (2002) was working in a day centre for people with PMLD. She noticed that staff continually recounted tiny stories about what they had been doing during the day - funny, surprising, or even anxiety provoking. As soon as two staff members were together, storytelling was inevitable. The stories were told ABOUT the people who attended the centre. But they were never told BY them, or WITH them. You might say this is obvious - people with PMLD don't talk, so how can they tell stories? Well it turns out that they absolutely can - as long as you adopt the appropriate perspective, and the appropriate tools. Over the last 15 years, the charity OpenStorytellers has been developing and refining an approach that enables everyone to take part in the telling of stories, called Storysharing® (Grove, 2014). The emphasis is placed on social participation and emotional engagement, rather than developing well-formed narrative structure. Outcomes have included an improved balance in the contributions of supporter and individual, a greater focus on the high point of the story rather than the factual events, and increased expression of feelings through the use of expressions, gestures and vocal sounds (Bunning et al. 2017). From the start, community participation and inclusion has been a real focus of what we do.

Storysharing for friendship

We noticed early on in our work that when people exchanged stories of personal experience, the barriers between them fell away. A lady who had lived in a village all her life recalled the floods of her childhood, and one of our members had experienced the same event. Together they reminisced excitedly. The same thing happens when people with PMLD share their stories - Linda shows a rose and opens her mouth while a staff member uses coconut shells for horse hooves - and we all feel shock at how her favourite flower was eaten. We laugh about it with her, and what was at first rather an upsetting event becomes one to tell and retell with friends. Horses also featured in a story told to his peers by a child with autism who had experienced a frightening event. The teacher was unsure if he would want to tell this story, yet he persisted. His teacher notes , "this was a really good way of dealing with an emotion that he wasn't sure about - and we weren't either". When he subsequently came to class with a story about getting back on the horse, his pride and pleasure were shared by everyone, further validating his resilience in the face of challenge.

Storysharing and decision making

Children learn to participate in society first by being included in family discussions which often arise out of personal experiences, and they take those skills into the classroom. For youngsters with special needs, two critical places for decision making are annual reviews and school councils. Storysharing enables students to be included in decision-making processes concerning their lives by bringing significant stories to their annual reviews. Co-narrated anecdotes about real things that have meaning for the young person can be powerful and pertinent; very different from a list of points being read from a sheet of paper on their behalf.

When we began in one school, a senior manager commented "..at the moment, the students' voice is only a very, very small fraction of the annual reviews. We have to listen to the parents, get through the paperwork, and problem solve....and hear what the class teacher has to say". We saw that often attending a review may be deemed too stressful for the young person. Providing appropriate support isn't just about making information accessible; it's about supporting genuine, valid contributions from the student.

In a PMLD class at Exeter House School in Salisbury, we worked with a teacher and two non-verbal pupils who prepared stories together for their annual reviews. Their teacher said "I've got to know the children and, it's helped me understand them and know them as people … For our students, these stories are age appropriate and its personal. It gives them a voice - a lot of them don't have expressive communication to say things important to them".

S's story, about a new bath installed downstairs in her parents' house, was significant not only because she loved the fragrant jacuzzi bubbles, but because as she was leaving school it meant her parents could continue to care for her at home.

Storysharing encourages repetition, which helps to build confidence, memory, and recall. We use all the young person's communication toolkit to support his/her contributions. Familiarity with the story invites increased participation through interaction.

At Threeways School in Bath, P brought a story to his annual review. His teacher says:
"He loved it and I felt he really grasped that to make it funnier for the audience he needed to emphasise that 'mummy tried to do it anyway and got very wet!'. It was a positive experience all round, P shared his story with real animation and pride. It was great to see, and his mum and dad were really enjoying seeing his confidence. P really felt like an equal member of the team".

Here we also developed work with the school council. Grove and Chalmers (2014) describe how a boy with PMLD, supported by a peer with a hearing impairment, told his story of how the noise of chairs being stacked led to spasms, with a knock-on effect on his health and comfort. This powerful contribution led to a rethink by youngsters who were at first unwilling to take responsibility for changing their habitual rush to leave the dining hall.

Civic inclusion

Storysharing has been used by OpenStoryTellers to promote active citizenship and civic participation. One example is the nationwide campaign against withdrawal of mobility allowance for people with disabilities in residential homes in 2011. Our company ran a public meeting specifically for people with PMLD to tell their MP stories of how they used this money and what it meant to them, using karaoke, art and drama. We were not telling the stories FOR these individuals - they were up front, showing props, photographs and of voice output communication aids. The MP, then in coalition, voted against the measure. Other projects we have run include sensory town planning; general election hustings, and an active citizens programme (Grove et. al., 2014).

In conclusion, we know that sharing personal experience stories is one of the most effective ways of forming and sustaining relationships, breaking down barriers and combating prejudice, and enabling marginalized voices to be heard in ways that can be revolutionary. The techniques we use to support active narration by people with PMLD are simple and cheap (though we won't deny that a Big Mac really does help!). Conversational practices that put people in passive roles (for example, rhetorical questions "You went to the circus, didn't you?") can be very entrenched, and take time and training to shift, but when that shift comes, the benefits are remarkable and long-lasting.

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The latest film showing Storysharing in action can be viewed at https://www.youtube.com/watch?v=B8V5iBeGGJs

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The Spirit of Stories

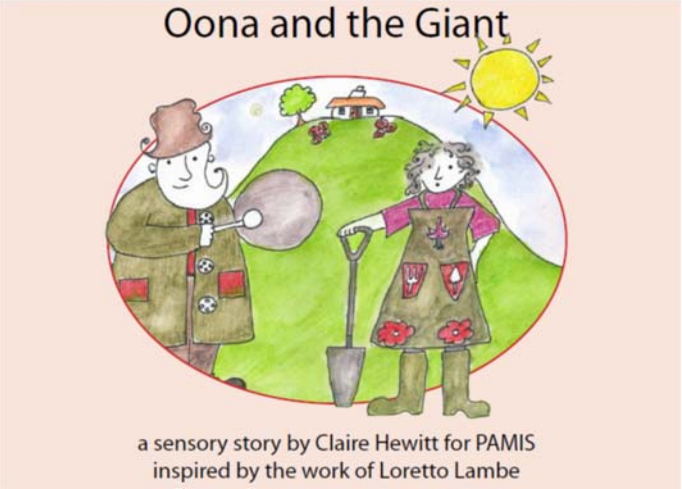
Maureen Philip

Stories are everywhere, they are all around us every day. Every one of these stories is waiting for someone to pick up the thread of the story and begin weaving tales. Stories are engaging, educational, empowering, healing and transformational. At PAMIS, Spirit of Stories, the threads of people's stories are carefully picked up and sensitively woven together to create a trust and understanding that nurtures a natural desire to value and share individual stories. They are versatile and fun, but an overlooked learning resource.

For people with PMLD multi-sensory storytelling is a way of supporting interaction and engagement. It is a fun way to enhance communication and gain a better understanding of how to be with others. It is a fantastic resource that enhances understanding of people with PMLD. Storytelling enables individuals with PMLD to be both the storyteller and the listener depending on the situation.

In this article I would like to briefly share some of the ways that storytelling can help us better understand and relate to people with PMLD. I would like to share with you how stories can support education, engagement and understanding for a wide variety of people, from students to support staff and people with learning disabilities.

Creating a multi sensory story for an individual is both rewarding and educational. To create a story together with someone with PMLD is like opening a Pandora's box of information that supports and facilitates a deep connection with that individual. Firstly, there's the identification of the story - whether it be a fun story about a life event or a sensitive topic such as going to the toilet. Next is the information gathering stage. Gathering information from key people who know the person you are writing the story for will help you to better understand the person. This includes preparing a detailed profile of the person the story is intended for, and should include information such as how they like to communicate, and what their sight and hearing is like. These conversations unlock a wealth of information that helps the design and development of a meaningful personal story, as well as provide information that will facilitate connection and communication.



Personal stories developed in this way are also fabulous learning resources. Everyone loves a story about themselves and there is something very special about the one to one connection with someone with PMLD when you work in this way with individuals who like the individual attention. There is always a new discovery. People also love to share stories and sharing a personal story or experience with a group is also empowering and fun for someone with PMLD.

Multi-sensory stories created from the rich oral storytelling culture also offer the opportunity for people with PMLD to engage in their cultural heritage. Again, these stories can be told individually in small groups or developed as a performance. There is no right or wrong way and there is nothing more exciting than to see people with PMLD and their peers enjoying a storytelling session together.

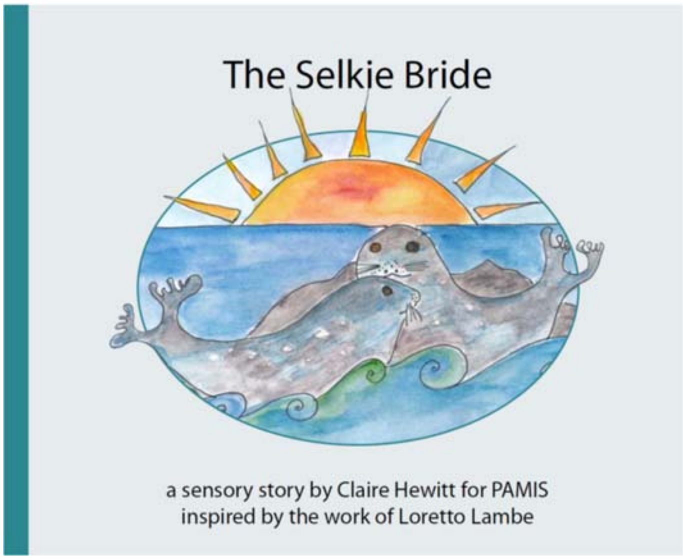
Storytelling brings communities together too. In partnership with Tayberry, a Social Enterprise in Dundee, PAMIS have trained people with learning disabilities to become multi-sensory storytellers. The Tayberry Tales storytellers tell stories in schools, day services and they have performed at the Edinburgh Fringe Festival. Being able to design, develop and tell stories, has helped build their confidence, given them focus, a purpose and skills that are valued and respected. The course was undertaken at the University of Dundee and the student storytellers attended two days a week over a five-week period, along with their supporters. The supporters undertook the course together making the course a co-produced learning experience that has been further developed by those who undertook the course. One young man won a Fellowship award for his storytelling with individuals with PMLD, following the course. Undertaking the course at the University also benefited the participants from a personal development point of view. They gained improved social skills and confidence by mixing with students on campus and over lunch. The storytelling became a learning experience in self-development, team work, understanding each other, working together and understanding how to engage with people with PMLD.

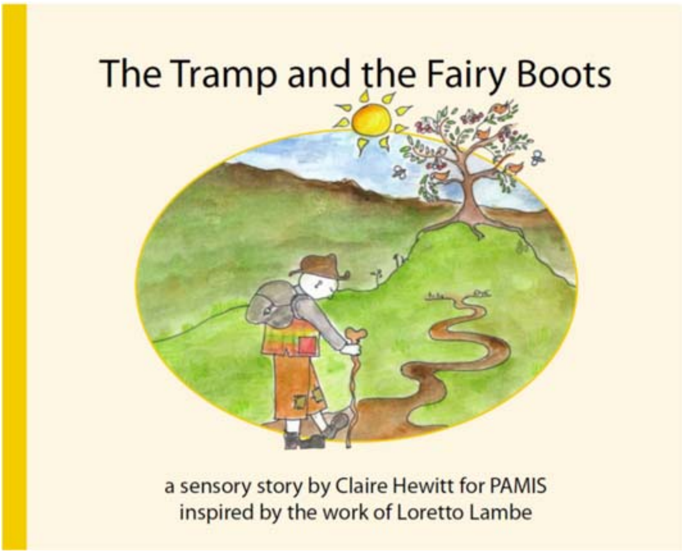
Storytelling books by PAMIS

The cultural stories developed by PAMIS from the oral storytelling tradition, in memory of the former Director of PAMIS, Loretto Lambe, have been designed to be inclusive and encourage people to begin to think about making their own stimuli by getting everyone involved in the stories, from art groups, to sewing and felt making sessions as well as shopping trips to look for sensory items to accompany the storytelling. The stories become a stimulating and exciting way of connecting communities and involving everyone. In the resource there are three storybooks, a book about the PAMIS journey with multi-sensory stories. The resource was designed, developed and illustrated by Scottish Storyteller Claire Hewitt in partnership with PAMIS and supported by Genie Dee. Each book has ideas at the end on how to make your own stimuli. These books can be purchased from PAMIS.

Digital passports

Life story work is another important aspect of the work undertaken with storytelling at PAMIS. The PAMIS Digital Passports have been instrumental in facilitating the sharing of personal stories in a digital format that is flexible and adaptable in the way it enables people to develop their own stories using video, audio, text and pictures to help them tell their story. These stories can be used to share information with support staff, medical staff, educational staff and with students. The passports have been adopted by adult day services in Angus as a way of informing people of the service they provide. In the passport the story of the service and how it supports everyone who attends the service is conveyed in picture, audio, video and text. The story of the service offered in the three Angus centres is brought to life in the passports and everyone is involved in its development. The services are going to continue to develop the passports for everyone attending the service. Each person will be enabled and supported to create their own Digital Passport that will demonstrate their life at the service. This will be shared by the individuals at reviews and meetings, thereby empowering people to create, develop, tell and share their own story.





Continuing on the theme of life stories and Digital Passports I would like to share how working together with families to create a medium like the Digital Passport helps to facilitate support during difficult times, not only for the person with PMLD but for those family members supporting them. To take the time to listen to someone's story and to record it on paper or on a Digital Passport format is incredibly healing. Family carers spend so much time caring for their son/daughter/grandson/granddaughter that they have little time to themselves or for their own story. Working with family carers on their stories offers them the time and space to feel listened too, to reflect and in many cases to dare to voice their inner thoughts out loud. There is something very powerful and healing about getting your story heard and recorded. The process of having someone record it for you and take time to listen and respond is time that carers rarely get. Working with carers in this way to capture and record their stories and the stories of those they care for in a resource like the Digital Passport is another valuable resource. Not only does it offer the opportunity for an individual to be listened too, it also offers the opportunity to help people designing and delivering services to fully understand and appreciate the lives of people with PMLD and their families and to create holistic services that consider and appreciate everyone's story. Stories like these, offer the opportunity for healing, understanding, involvement, learning and development, education and so much more. We just need to take the time to listen.

"There is no greater agony than bearing an untold story inside you."
— Maya Angelou,

Information about Digital Passports can be found at: http://www.pamis.org.uk/digital-passports/

PAMIS Stories, inspired by Loretto Lambe:
Oona and the Giant
The Selkie Bride
The Tramp and the Fairy Boots
For more information on these go to http://pamis.org.uk/news/news/remembering-loretto/

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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 Rob Ashdown (rob.ashdown@ntlworld.com).

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PMLD LINK
sharing ideas and information

Refining the guidance for sensory storytelling with individuals with PMLD: a move towards improved research and practice

Joanna Grace and Andreia Silva

Guidelines for the creation and sharing of sensory stories have been relied upon by research teams evaluating the use of sensory stories. The guidelines were not originally meant for use in this way and their application in research could perhaps be leading to some confusion in the findings. Having people research sensory stories is a wonderful thing and we want their research findings to be as useful to us as practitioner as possible. To this end we created a set of refined guidelines for sensory story sharing, which we hope are better suited for research and for practice. We tested these guidelines by following them with a new group of sensory story recipients. Our results show that following the refined guidelines successfully elicited the increased responsiveness of participants characteristic of effective sensory storytelling, which indicates that these refined guidelines are valid.

Sensory stories

Sensory stories are concise narratives told through a combination of spoken language and sensory experience. Sensory stories have a rich history in being used as a tool for communication with individuals with profound and multiple learning disabilities (PMLD) (Lacey 2006; Taylor 2006; PAMIS 2002; Watson 2002; Deonarain 2010; Fuller 2013; Park 2004; Young et al. 2011; Young &Lambe 2011).

Developing communication through sharing sensory stories

Sharing a sensory story with an individual with PMLD enables the storyteller to convey meaning through sensory experience as well as spoken language and receive comment through the responses and reactions of the individual with PMLD, and in so doing: enter into a conversation. Told consistently overtime sensory stories can be used to develop emergent communication skills and foster engagement with the world (Penne et al. 2012; Brug et al. 2012; PAMIS 2002; Taylor 2006).

Existing guidance

Guidance exists concerning the creation and use of sensory stories e.g. PAMIS (2002), Fuller (1999). This guidance has previously been used as the basis for research, e.g. Brug et. al. (2012), Penne et al. (2012). The guidance was produced with the aim of helping facilitators create and share sensory stories successfully, it includes prescriptive suggestions and detail that make it unsuitable as a research tool. For example both PAMIS and Bagbooks state that the sensory experiences in a sensory story should be attached to a firm board. Whilst there are obvious benefits to a board, it's page like quality representing a typical book and the provision of a high contrast background to make a visual experience more accessible, it is not necessary for something to be attached to a board in order that it be a good sensory experience. Story creators in the Brug et al. (2012) study found not attaching stimuli to a board were deemed to have created the stories incorrectly. We feel that research could be improved by focusing on a set of core principles in the creation and facilitation of sensory stories. A set of core principles would enable research to discriminate between the important therapeutic benefits of sensory storytelling and differing presentation preferences that whilst valid are not essential to ensuring these benefits.

The book *Sensory stories for children and teens with special educational needs* (Grace 2014) reviews the literature on sensory stories and gives guidance for the creation and sharing of sensory stories. This guidance is summarised below:

Creation:

1. Stories should be concise, ideally told in under ten sentences although more can be used if suitable to the person experiencing the story.
2. Each section of the story should be accompanied by a strong sensory experience, this is one that is of high interest to the targeted sense (what is of interest will vary between experiencers) and also relevant to the section of the story.
3. Over the course of the story creators should aim to address as many of the seven sensory systems (visual, tactile, gustatory, olfactory, auditory, proprioceptive and vestibular) as they can. The particular needs and interests of the individual with whom they plan to share the story should be taken into account.

Sharing the story:

1. Facilitators should read the story text and share the related experience clearly, aiming to do this in the same way each time they share the story.
2. Facilitators should allow time for reactions and responses.
3. Facilitators should refrain from adding extra language to the story in order to keep the experience of the story consistent and allow the experiencer to focus on the experiences.
4. Ideally facilitators should know the person they are sharing the story with and be aware of their sensory abilities and preferences.
5. Facilitators need to prepare for sharing a sensory story thoroughly, ensuring all resources are ready for use before the story begins.

Past research (Brug et. al. 2012; Lambe & Hogg 2013; PAMIS, 2002; Park 2004; Penne *et. al*. 2012; Taylor 2006; Watson 2002; Young *et al*. 2011; Young & Lambe 2011) has used increased responsiveness in individuals experiencing a sensory story as a significant indicator of effective sensory storytelling. We did a small study to see if following the refined guidelines above would also elicit increased responsiveness.

The study

The study took place in a residential care facility in Castelo Branco, Portugal. Six adults with profound multiple learning disabilities, were involved in one-to-one sessions of multi-sensory storytelling. The participants were aged between 21 and 47. All of the participants have cerebral palsy, visual impairments, epilepsy and cognitive impairments. An adaptation of the story "Two people made me" from the book *Sensory stories for children and teens with special educational needs* (Grace, 2014) was used with all participants. The story was created in accordance with the guidance given above and included 12 sensory stimuli encompassing the seven sensory systems.

Permission was sought from the participants' parents and carers for them to be involved in the study and also from the participants themselves through observation of their behaviour: any participants showing signs of not wishing to be a part of the sessions would have been withdrawn. This situation did not occur; all participants displayed visible signs of enjoying the sessions.

Three storytellers were involved in the research. Silva was the prime storyteller and two other storytellers acted as backup for times when she was unavailable. Silva works regularly with the participants and is familiar with their sensory abilities and preferences.

The story was shared daily from Monday to Friday for two weeks (10 sessions). The story was shared in the same room each day, this room was empty, free from external noise and visual clutter.

Assessment

During the story sharing sessions the participants responses were observed and tallied against the checklist of the types of responses that could be reasonably expected during sensory storytelling sessions. To view the checklist and graphs detailing our findings please visit http://ow.ly/wUMg30g4i2k and click the download at the bottom of the page.

Checklist

Looks at the stimuli: The participant looks (however briefly) at the stimuli.
Initiates movement: The participant moves in response to some aspect of the story - any intentional movement should be counted.
Touches the stimuli: The participant touches the stimuli.
Manipulates the stimuli: The participant makes an effort to explore the stimuli manually.
Discontinues stereotypic behaviour: The story experiencer pauses their stereotypic behaviour, this can be interpreted as attention to the story.
Vocalises: The participant makes vocal sounds in response to the story.
Changes facial expression: The participant changes their facial expression in response to the story.
Smiles: The participant smiles. [This condition was included because it was known that several of the participants are able to smile in response to stimuli.]
Anticipates: The participant indicates in some way (e.g. through expression, movement, sounds) their expectation of the next section of the story.

Significant observations about behaviour, mood, interaction with the storyteller, or other responses were registered at the end of each session in the comments section of the checklist. The assessment was made for all sessions and all participants. Each session took between 20 and 30 minutes with the variation being due to the differing response times of the participants.

Discussion

The participants responses increased over time suggesting that the guidelines followed supported their ability to respond. This increase in responsiveness over repeated tellings of sensory stories is in line with what other research has found (Bruget al. 2012; Lambe& Hogg 2013; PAMIS, 2002; Taylor 2006; Watson 2002; Young et al. 2011; Young &Lambe 2011) indicating the suitability of the guidelines for effective sensory storytelling. The particular strength of these guidelines from a researcher's point of view is their focus on the core components necessary for successful sensory storytelling.

During this study we noticed other factors that we believe are of interest:

Storytelling environment: The clarity of the telling in this study was significant and potentially unusual as in many settings stories are told in busy environments with a lot of decoration or through traffic of people. In this study the stories were told in a plain room and were simply the words and the experiences, nothing else. The responses from the story experiencers were equally as clear. We feel that this uncluttered telling, with no extra words, no additional prompting, no visual distraction or auditory interruption, aided the story experiencers in their ability to process the information from the story and respond to it.

Influence of the storyteller: The prime storyteller was a critical component in the increased responsiveness of participants over time. On occasions during the research the prime storyteller was unavailable to run the daily sensory storytelling sessions and one of the backup storytellers shared the story with the participants instead. Although the backup tellers were well prepared and presented the story in a similarly clear manner to the prime storyteller they received less responses during their sessions, indicating that the benefit of maintaining a consistency of storyteller as well as a consistency to the delivery of the story itself.

Demonstrating higher level skills: It is notable that some participants demonstrated their ability to anticipate the story after several repetitions. Had they not had the opportunity to experience the story repeatedly they would not have been able to demonstrate their ability to anticipate. This example highlights the importance of repeated tellings for the development of literacy skills in individuals with PMLD.

Enhanced social interactions with the storyteller: One notable additional observation made over the course of the study was the effect the story telling sessions had on the relationship between the participants and the prime storyteller. After three repetitions participant A took the storyteller's hand and used it to interact with the stimuli. After four tellings participant M took the storyteller's hand and after five tellings made eye contact with the storyteller. Over the subsequent tellings the frequency of eye contact and the duration of the eye contact increased. This observations show how sensory storytelling sessions could enhance social interaction and strengthen the bonds between the participants and the storyteller.

Conclusion

We have presented a refined set of guidelines for the creation and sharing of sensory stories. The responses of participants in this study increased over time indicating the suitability of the guidelines for supporting effective sensory storytelling. We suggest that these guidelines are particularly suited for use in research because of their focus on the core components necessary for successful sensory storytelling, reducing the risk for research results to be obfuscated by non-essential practitioner advice. Our observations also reinforce previous findings regarding the importance of consistent repetition when sharing sensory stories.

Contact details

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Silva, A. Occupational therapist and practitioner in a residential care facility for adults with learning disabilities in Portugal.

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Separation and Health

Marion McArdle

Our daughter Laura was born with Down's syndrome 34 years ago and when she was a year old she suffered severe brain damage following a heart operation which means she now also has cerebral palsy and many other complex needs. Despite this, Laura is happy and enjoys life, especially when her health is good. In fact, even when she's not well she always manages a smile and never ceases to amaze us all at her unwillingness to be miserable or to complain.

Maybe this is partly due to her knowing she is loved and feels safe because she always has someone who knows her well beside her all the time. If she doesn't have that person with her she may feel vulnerable and become very anxious especially if she's in a strange environment.

This is particularly true in a hospital where many strange people are touching her and giving treatments such as injections, or struggling to get blood from her tiny veins. Having someone whom Laura feels safe with means that she will be more relaxed and feel reassured that the person she trusts is with her.

In the past five years Laura has had two emergency hospital admissions with suspected chest infections. I am grateful that Laura came home about five weeks later clear of any infection. However, each of these hospital experiences led to Laura almost losing her life. In my opinion, this was due to a lack of understanding by the hospital staff of just how essential it is to Laura's health for her to have someone who knows her well with her all the time.

As well as making Laura feel safe this also allows Laura to have someone to speak on her behalf, advising on many important issues for Laura such as her communication, how to move her safely, and how to position her so that her body is supported in the best way to alleviate her postural problems. Laura's posture problems are unique and cannot be assessed by guessing. For example, whilst being treated for a chest infection Laura was positioned in the usual way for a typical patient. We tried to explain the consequences for Laura's health if she was positioned in the usual way, including her right lung being squashed. Unfortunately, this often fell on deaf ears.

During these two hospital stays we were often asked to leave Laura alone with the staff. I presume this was so that they could get on with their job without me getting in the way. This may have been for short periods but that would be enough to cause stress, fear, anxiety and all that goes with that for Laura. Furthermore, if Laura had to receive any treatment during this time which was uncomfortable, painful or frightening in any way she would certainly suffer extreme anxiety.

What I observe when Laura is anxious, upset or frightened is increased muscle tone, which leads to muscle spasms and seizures. I also see her scoliosis worsening, bowel problems and a state where it is difficult to communicate with her. Her mental health can be affected which can then go on in turn to affect her physical health. These are just some of the symptoms which are obvious to me but I'm sure doctors may be able to observe the effect on other symptoms such as blood pressure, oxygen saturations etc. This distress not only prevents Laura from getting better but it can also make her much worse. This is what I strongly believe happened in these hospital visits.

On one occasion, I was asked by a nurse to leave Laura's room so that the doctor could come to take blood from Laura's groin area. The nurse explained that the doctor would be nervous if I was watching and since the procedure was going to be particularly uncomfortable for Laura, the doctor might struggle to get it right. Surely that was an obvious instance of when a reassuring parent would have helped Laura! Eventually they agreed when I said I wouldn't look at what the doctor was doing but would stand back as long as I was in the room to talk to Laura to reassure her I was there.

Laura was admitted on both occasions as an emergency and was taken to hospital by ambulance and by the time we arrived at Accident and Emergency I didn't think Laura was as ill as the medics thought but I wasn't sure and so had to err on the side of caution and allow Laura to stay in the hospital. Since the staff believed Laura was very ill with a chest infection, they acted very promptly and without a lot of consideration for her comfort. They were trying their best to save her life. They didn't have time to consider some of the things I was saying. I imagine they probably saw me as a caring parent who wanted to comfort her daughter. I tried so hard to explain the consequences of aggressive nursing or treatments but it was mostly in vain.

On a ward in the first hospital I was asked by nurses several times every day to stand outside Laura's room whilst they did something to Laura. I cannot stress enough how much harm I believe this would have done to Laura. My heart breaks every time I think of how much she must have suffered.

On a Friday after about a week in the first hospital I was told that Laura may not survive the weekend. I begged with all the strength in me for the doctors to do everything possible to make her better. I told them that if Laura died then I would also die, and Laura has two sisters who also needed me. They then said that they would throw everything they had at Laura and hope that she would pull through. Perhaps up until that point they may just have seen Laura as a patient with multiple and complex needs and might have presumed that she had a poor quality of life.

In the second hospital, as in the first, Laura's anxiety was escalating fast. Then the drug, Baclofen, was withdrawn as it was deemed to be unsafe for Laura to be given it orally because of the risk of aspiration. Baclofen is a muscle relaxant which Laura had taken for most of her life. If this drug is to be withdrawn it must be done very gradually as withdrawing too quickly will likely result in the patient suffering dreadful withdrawal symptoms including hallucinations. Laura was on the maximum dose allowed for this drug and yet it was suddenly stopped. I don't have any words to describe what I saw Laura suffering.

Despite our pleas for Baclofen to be given to Laura, by whatever means, it was several days before she was given any. By that stage Laura was needing more than Baclofen to relax her state. We could see that Laura was never going to get better until her anxiety was greatly reduced. Every day we asked if Laura could be given something to relieve her anxiety and reduce her tight muscle tone but doctors feared this might compromise her breathing. They were concentrating on what they believed was a severe chest infection.

Laura continued to get worse until one day the doctor told us that Laura may not survive the next two hours. I then asked if they could now give Laura something to relieve her anxiety. After all, if they believed that she was about to die, (which I disagreed with), then what did they have to lose by giving her what we had been asking for all along. They agreed and after giving her something to relax her, within hours we saw much improvement.
We celebrated that evening in the hospital canteen. We were now convinced she was going to get better.

Laura came home from hospital physically much weaker than she ever was and I doubt whether she will ever regain her full strength. Her swallow was weakened and she now is fed through a tube going straight into her stomach. A couple of weeks following discharge from each of these hospitals Laura's hair fell out. This was probably due to the anxiety and stress which Laura's body had endured. Fortunately, after about six months Laura's beautiful hair started to grow back in again.

There is no doubt in my mind that Laura suffered greatly in these hospitals mainly due to the lack of knowledge and understanding by the medical staff of the important part a parent or carer can play in a patient's recovery. Laura was often denied the benefits of this throughout her hospital stays and I believe her health suffered greatly as a result.

I'm hoping that soon all doctors and nurses will fully realise what a valuable medicine there is in allowing a parent or carer to be an equal partner in making someone better.

Separation and Health: In Response to Marion's Article

Hannah Young

Separation and loss from loved ones is painful. Having a learning disability certainly contributes a layer of complexity to that experience, which may add further confusion and pain.

The current article is based on my recent PhD thesis entitled Reflections on the Loss Experiences of People with Profound Learning Disabilities: Promoting Sensory Therapeutic Practice (Young, 2017), which I presented at the Promoting Inclusion: Transforming Lives conference in June of this year. There I met Marion McArdle, a mother of a woman with PMLD who gave me incredible encouragement, after what was my first public sharing of my thesis. I was nervous, because I talked a bit about neuroscience and I did not want to appear to be reductionist. On the contrary, the parents and professionals felt that the content truly reflected what they had intuitively sensed about people with PMLD and their experiences of separation. Marion and I decided that we wanted to share our dialogue with PMLD Link readers. Therefore, alongside Marion's (McArdle, 2017 - pages 15 and 16 of this issue) shared experience, I will focus on body-based responses to separation and highlight the importance of this for considerations of complex healthcare. A brief article, since I intend only to support Marion's story with some observations from the academic literature.

Separation Responses

In a recent literature review (Young, 2016a), we find that only a small number of studies have reported on the loss reactions of people with PMLD. These include crying, searching for the person who has died, challenging behaviour and self-harm. If we were to extend this review to include studies of other forms of separation, we would find some additional studies revealing several physiological insights. Chaney's (1996) study, for example, demonstrated changes in heart rate, blood pressure, respiration rate and body temperature when the individual was removed from their home environment and caregiver. In addition, Shewmon, Holmes & Byrne (1999) report a range of behavioural and physiological observations of children with hydranencephaly to brief separations from their mother. One of these cases involved a young boy requiring hospitalisation for airway obstruction. The mother's soothing was directly regulating her son's oxygen saturation levels; if she withdrew her voice, oxygen saturation destabilised. Marion's (McArdle, 2017) article is a further contribution to this body of literature, highlighting fragility of health under conditions where she and her daughter were unnecessarily separated for important – but distressing - medical treatment.

Bowlby's (1980) Attachment Theory can help us make sense of the many behavioural reactions we can observe in dependant individuals separated from their caregivers. Crying and searching are innate responses to bid strongly for the caregiver's proximity. Self-harm may be attempts at reducing the distress experienced during these separations (Janssen, Schuengel & Stolk, 2002). In cases where bids for needs to be met are not heard and sensitively matched with a response from the caregiver, despair and detachment may follow. We may see this more so in people with PMLD, who often have limited ways of attracting the attention of their caregiver and to communicate their needs effectively. These final stages of separation responses can manifest in what is called a 'physiological shutdown'; a survival mechanism to conserve the body's energy (e.g. by being quiet and withdrawn), reducing the likelihood of further loss and danger (Panksepp & Biven, 2012).

Regulating Care of Complex Needs

It is a concern to read that Marion has been asked to leave the room as her daughter has undergone medical treatment. It would have been entirely appropriate and supportive for her mother to be present during these procedures, especially given the fragility and complexity of her daughter's health, but also given the regulatory power of Laura's mother to maintain physiological stabilisation. As can be evidenced above, small changes in the mother's availability can lead to serious dysregulation, of even breath itself. Separation is therefore a withdrawal of key regulators. We know that parents of people with complex healthcare needs are incredibly knowledgeable caregivers. Care and support for people with PMLD requires great skill and sensitive attunement. Pawlyn and Carnaby (2009) provide a thorough review of epilepsy, nutrition, dysphagia, postural care, moving and handling, epilepsy, sleeping, communication, toileting and medication. This patterned

-repetitive care will certainly play a role in regulating mental and physical health. The regular nature of care – and let us not forget the place in which that care takes place - may be crucially important for the sense of wellbeing and safety, resulting in dysregulation if minimally disrupted (Young, 2016b).

Conclusion

Medical care will face significant challenges in treating people with PMLD if caregivers are not valued for their skill, knowledge and attunement. I understand more now about the inherently affective and body-based nature of relationships between caregivers and people with complex health care needs. Caring for their every-day needs is fundamental to their survival, and the person providing that care is a direct bio-behavioural regulator of their emotional and physical existence. We should listen to the neurobiological narrative that tells us how our bodies are interdependently linked to those we love and who make us feel loved. This is not to reduce painful experiences, such as separation, to some quantifiable measure, but to emphasise the fundamental and body-based nature of emotion, which can lead to a better understanding of care for and being with people with PMLD.

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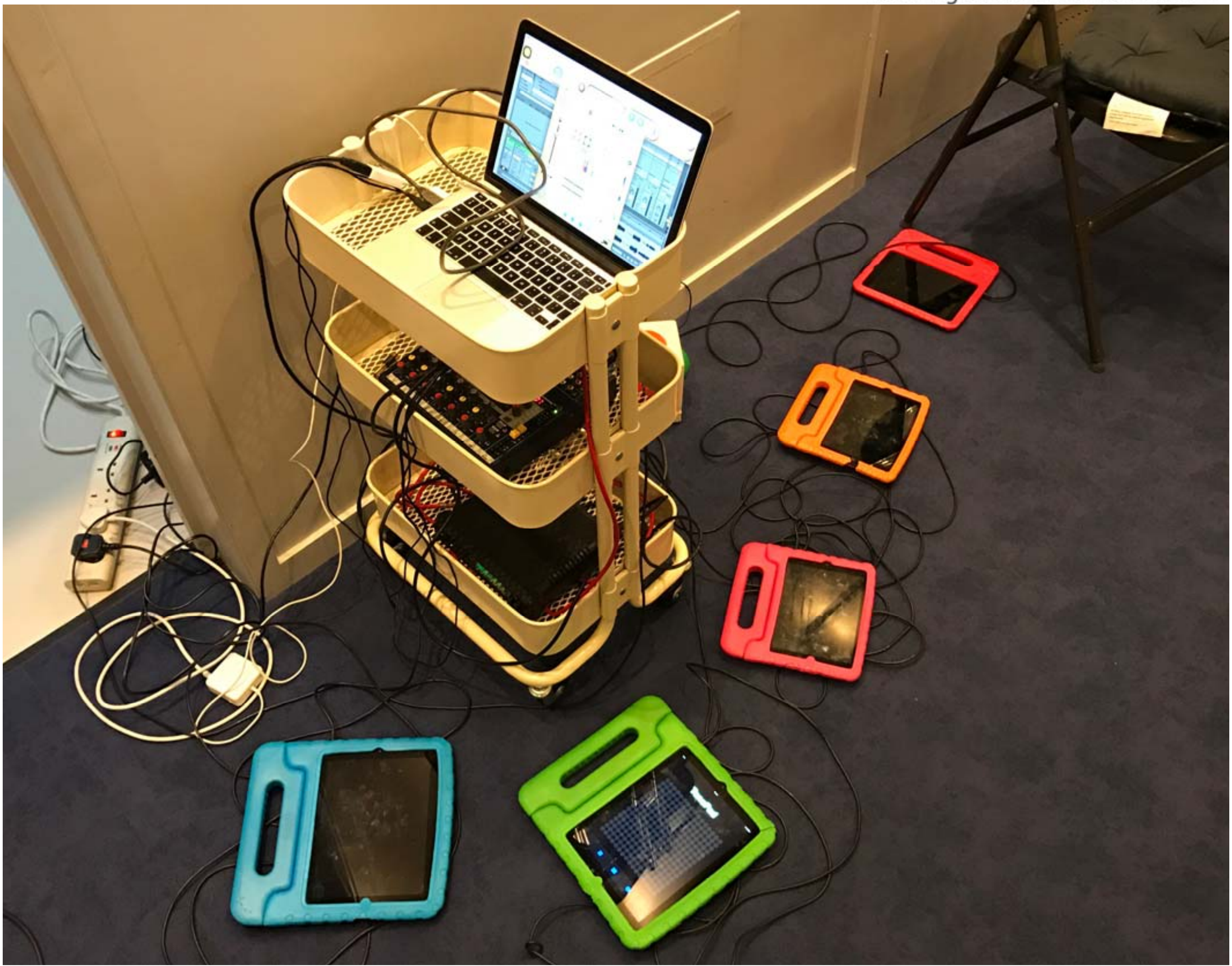


Picture above: iPad orchestra: here each iPad has a different app that makes sound through touch and movement. Participants can choose from different sounds, sound effects and instruments.

Assistive Creative Technology at Wac Arts

Chas Mollet and Leonie Elliot-Graves

At Wac Arts we believe that the creative arts are uniquely placed to offer participants with PMLD situations where they work independently and are in control, where they have powerful sensory experiences and, where they can work and interact with peers on an equal level. To this end we have developed Assistive Creative Technology (ACT) projects that enable us to include our participants with PMLD in the creative activities we develop.

What we do at Wac Arts

Wac Arts delivers a range of creative arts and media projects for young people and adults with disabilities. We use innovative technology including Touchboards, Soundbeams, Skoogs, Beamz and specialist software in order to include even the most isolated or hard to reach participants in our creative work. We often adapt existing technology by creating what we call Assistive Creative Technology (ACT) systems combining programmed software and hardware peripherals such as the Microsoft Kinect or Nintendo Wii accessories. Our practice focuses on delivering fun activities that bring the participants together and give them ownership over the process and the outcome. Previous projects include themed soundscape creation, digital orchestras, painting with sound and digital group games. In our practice we have high expectations to deliver inclusive projects and enable all participants to engage in the process equally.

Wac Arts and Participants with PMLD

In many of our projects we work with participants with PMLD and this challenges us to stretch our capacity to work inclusively. There are two key factors that present this challenge. Firstly, people with PMLD often experience even higher levels of isolation than other people with disabilities due to unique challenges in communication and high care needs. They are often limited to interactions with their carers, with their peers being either unwilling or unable to interact with them fully. This can cause loneliness and lack of stimulation for people with PMLD. It can also have serious effects on those around them who may often underestimate the things those individuals can do and the richness they can bring to a group setting. This challenges us to find activities and use ACT to ensure participants with PMLD can engage in the same activities and performances as the rest of the group. Secondly, people with PMLD often experience difficulties with their motor skills and this can prohibit them from using conventional musical instruments and technology such as computers, iPads, sound mixers and cameras. This challenges us to find new ways to engage participants with PMLD in activities that do not require significant physical strength or highly developed fine motor skills.

Drumming Activities with Inclusive Groups

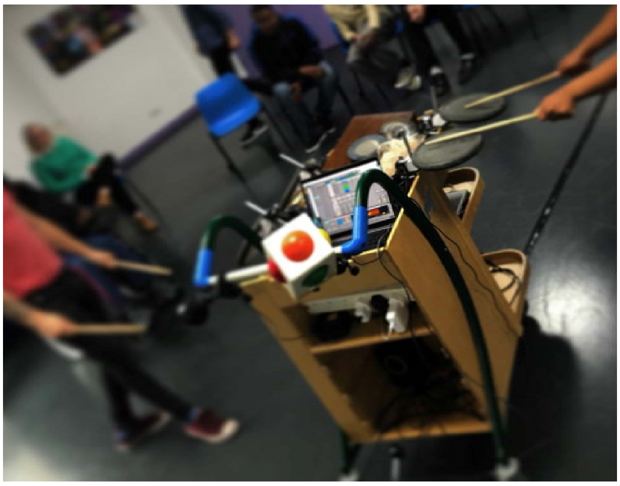
We have found that drumming projects enable us to work inclusively. They have been some of the most successful projects in bringing a diverse group of participants together and we use them to build strong team work between young people with PMLD and the rest of the group. Circle drumming with Djembes and percussion brings a group together united by rhythm, sheer fun and the exhilaration of playing in unison as part of a large ensemble. It creates a unique pulse that affects each young person and fully engages their sense of sound and feeling. This is a rich sensory experience that is equally felt by all participants (whether they have PMLD or not) and sweeps everyone up in its rhythm. With the wide diversity of needs in our disability groups, the use of ACT is paramount to ensure all are included equally and can contribute to the group's dynamic. For those group members who have physical impairments ACT items (such as the Skoogs, Soundbeam or Mogees) can turn even tiny movements into sound, via a computer and amplified PA. The technology can also produce visual projections (colours/shapes) in response to the movements which further enhances the affect the participant's movement has.

Another powerful tool is combining the use of ACT with participants who are more-able. For example, we often pair a participant with PMLD playing a sound via the Skoog with another student who controls the timbre and pitch of the same sound, using an iPad. This unifies the two participants and they play together creating the final sound. This allows young people to collaborate in unique ways that are accessible to both and do not rely on conventional methods of communication.
Despite the possibilities that technology offers in supporting participants with PMLD to engage, the success of the projects rely on the facilitator's ability to promote those individuals' important role and musical contribution to the rest of the group and to ensure they are given space and time to express themselves. The way the technology is incorporated and utilised can have extraordinary effects on the sound being produced. Hitting a drum could be done through the slightest movement and could produce a whole range of different sounds and images depending on the choices the participant makes through the software. Being able to make choices about the sound and music they produce is essential in establishing a young person's presence in the group and validating their role as musicians within this group. The use of funny sounds can be an excellent tool for enabling the whole group to enjoy themselves, become friendlier and accept each other. However, it is also the responsibility of the facilitator to explain to the group that each participant will interact in different ways, both to the others in the group and with the instruments and technology being used. It is crucial the other participants understand these differences so they can appreciate and give time to the alternative approaches being employed within the workshop.

Our use of ACT and innovative drumming workshops have allowed us to successfully remove elements of isolation and enable other young people to become more eager to engage, and assist those with PMLD both in and then outside the sessions.

Interactive Music Projects with young people with PMLD

Soundscape projects work particularly well with groups comprised entirely of people with PMLD. With the soundscape projects we usually begin with a theme chosen by the group (such as animals, the jungle, London). We then collect sounds relating to the theme from online sound banks or record our own sounds within the group. Once the sounds have been collected we use ACT to allow the participants to play and modify them, for example by moving in front of a Soundbeam, wheeling over different switch pads or gently tapping the Skoog. This allows participants with PMLD to exercise high levels of control and choice about the final outcome. This collection of sounds are then played back and modified by the group creating a full soundscape. This soundscape can be pre-recorded and added to a multi-sensory installation that includes visual, tactile and olfactory stimuli. The soundscape can also be played live as part of a performance or installation.



Through the use of ACT in such projects we can clearly define each participant's interactions and that means we can more easily evidence each individual's unique contribution, responses and engagement. As ACT offers a unique way of engaging each participant, we are unlimited in the sounds and styles we can create within each project. Over a period of time we trial different ACT configurations with the individuals to ascertain a best-fit approach in terms of unassisted performance, enjoyment and communication/engagement with the group as a whole. When all members of the ensemble have been assigned ACT that works for them, the group can begin exploring ways of playing together, often led by the facilitator and with assistance from carers where necessary.

Though these projects can be immensely successful in engaging participants with PMLD in powerful creative work, it is important to consider some key factors in running such a project successfully. Firstly, choosing soothing sounds that are harmonious together is often preferable as opposed to loud unexpected sounds. This is because young people with PMLD are often unable to pre-empt loud sounds and this can make them uncomfortable with loud volume levels. Secondly, any opportunities to utilise the participants' existing communication methods should be employed for the best possible experience and interactions. This is because a project will be more successful if the structures it uses build on existing skills and familiar methods that will allow participants with PMLD to really extend and develop their skill set whilst being comfortable and confident within the process.

One PMLD label does not fit all

In all the projects we have run with participants with PMLD we have seen a huge difference in each individual's interests, capabilities and needs. This means that getting to know the individual participant well is absolutely necessary to design an appropriate and effective process and actually a diagnosis of PMLD on its own does not offer enough information about the best way to approach working with them. When engaging participants with PMLD we assess two key practical elements in order to produce a bespoke ACT support structure:

- Is the participant a confident communicator? Can he or she make their choices known either verbally or through other means?

If communication is the biggest concern, then we shape our ACT to support the participant to communicate their views or to use the technology independently without needing to communicate to others what he/she chooses to do. Technology such as the Soundbeam and the Skoog offer participants an opportunity to make and modify sounds using their body, movement and wheelchairs without needing to explain what they have chosen to do and why:

- In what ways does this participant move and what movements are more natural/easier for them?

If mobility and movement are the biggest concern then we focus on adjusting our ACT to pick up on even the slightest movement so that even participants with the most limited movement can participate equally in the project.

Of course, in any project, the participants with PMLD are likely to present challenges in both communication and mobility but working through their capabilities and the potential presented by the technology we use allows us to create the most appropriate and targeted support structure for each individual. Throughout our work however, we have found that the biggest challenge is working with participants with very limited communication. In such cases the facilitator has to advocate sounds and decisions on behalf of the participant with PMLD but is often unsure if the participant is in agreement with these choices and if they are enjoying the process or not. Working with teachers and carers who have established relationships with the participants helps us understand their likes and dislikes, and note positive and negative body language signs that it would normally take time to fully grasp for each individual. There are no shortcuts to understanding the individual participant holistically, yet working through the arts is an invaluable process for new discoveries both for practitioners and the participants themselves. However, working closely with the people who support the individual with PMLD can often be as significant as the technology we use in helping us understand and work with our participants with PMLD.

Conclusions

Our conclusions are that ACT provides the creative assistance necessary for people with PMLD to be fully included in creative arts work in a way that offers them equal access, choice and control and an opportunity to interact and work with peers. At Wac Arts we challenge ourselves to continually increase our inclusiveness and our participants with PMLD help us learn more about how to do this. Through our successes so far we have found that it is as much the ACT we use as our approach to using it that makes a project successful, and getting to know the individuals we work with is a lengthy and invaluable process. Though we offer specialised ACT projects and training, we are also confident that other practitioners, teacher and carers can find new and creative ways to engage more fully with people with PMLD through the creative arts.

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Inclusion from the start of every design: universal design approach

Roney Lee

In modern societies we see many buildings and public facilities attempt to be making the built environment more “accessible” to meet the standard and expectation of today’s society. What many people might not realise is that sometimes the so called accessible design was not made to be inclusive at all but merely to tick boxes.

Some very unthoughtful designs include ramps that require a few stairs to get to them, or have a dangerously steep slope, accessible routes that lead you to an extremely narrow space with a very heavy door, or even that lead nowhere. Everyone knows immediately that that these designs are not inclusive at all, but how about those designs that are “accessible” but not “inclusive”?

The majority of accessible design today offers some functionality, allowing people with different needs to have a certain amount of accessibility. However, the problem is that such accessibility is not always available for people to access, or only partially accessible. It is not uncommon to find buildings that have an accessible entrance but once you are in the building, no other accessible facilities can be found. Wheelchair-users could find it easy to enter a building but then, not have access to the rooms inside it. People with PMLD and their parents or carers might be able to physically access a building or facility but because there are no Changing Places toilets, they cannot visit for long. Public transport options are rarely accessible throughout the whole journey without having the wheelchair-user or their parent/carers needing to ask for assistance from members of the public to have the accessibility that they were supposed to have.

It is simply not enough. Inclusion is not being achieved by these perfunctory designs. The real catch is people might think that such an “accessible design” is already enough to promote inclusion believing that this enables them to continue to enjoy a barrier-free life.

So, what is the problem here? And - where does this problem come from? Why is it not enough even when people have attempted to make reasonable adjustment to create a more inclusive environment for people with PMLD or other disabilities that these adjustments are not sufficient or do not tackle the holistic issues of inclusion?

The problem lies in the root of every design. The approach of many designs currently has been trying to add on accessible elements to an original design that had not taken account of people’s differing needs. This top-down approach will always miss out something crucial because it is easy for them to ignore the details if it the design does not start with people’s needs first and then incorporate the perspectives from people with differing needs. It also encourages a boxes-ticking attitude and that’s why the ridiculous designs mentioned above happened in real life! Such a checklist approach might work for adaptations to existing buildings but it should no longer be used for new designs.

Design nowadays should be to design for all; something universal rather than designing for more able people and then subsequently adding on the necessary “accessible” elements.   Accessible design might be about siting an additional, accessible door next to the main entrance for people with disabilities and wheelchair-users. However, universal design is about making the main entrance accessible for everyone!

The definition of Universal Design (UD) is “The design of products and environments to be usable by all people, to the greatest extent possible, without adaptation or specialized design.” (NC State University, 1997).

There are 7 principles of Universal Design:

1. Equitable Use – e.g. Provide the same means of use for all users; avoid segregating or stigmatising users
2. Flexibility in Use – e.g. Provide choice in methods of use; provide adaptability to the user’s pace
3. Simple and Intuitive Use – e.g. Eliminate unnecessary complexity; provide effective prompting and feedback during and after task completion
4. Perceptible Information – e.g. Use different modes (pictorial, verbal, tactile) for redundant presentation of essential information
5. Tolerance for Error – e.g. Provide fail safe features; provide warnings of hazards and errors
6. Low Physical Effort – e.g. Minimise sustained physical effort; minimise repetitive actions
7. Size and Space for Approach and Use – e.g. provide adequate space for use of assistive devices or

personal assistance; make reach to all components comfortable for any seated or standing use (National Disability Authority,2014)

One of the good examples of Universal Design in real life is automatic sliding doors that are wide enough to let everyone get in and out easily, instead of putting an "accessible" door next to a rotating door in the middle of an entrance.

Universal Design is not an abstract concept but a practical design strategy focusing on usability (Lid ,2014). However, Universal Design has not been widely accepted by the architecture community, let alone putting the concepts into practice – people are sceptical of the utopian nature of UD, regarding it as simply a set of good attentions rather than scientific and necessary to be taught in architectural education (Heylighen,2014) . It explains why we rarely see many designs nowadays in our society that are truly inclusive.

This article aimed to increase awareness of this concept and thus to usher in a change in building, environmental, product and other design. Nothing is perfect but we need to start discussing how we can incorporate new concepts to try to make things better (from the start) and discard the old thinking that stifles inclusion.

Future research is still needed to empirically test the implementation of UD and we need to remember that there isn't always a quick fix for the problems we face nowadays in our society. But to promote inclusion and transform lives, I believe Universal Design can play a crucial role in it.

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Moving to Secondary School for Children with Profound and Multiple Learning Difficulties: a review of the literature

Dianne Cantali

This article explores some of the existing literature relating to children's transition between primary and secondary school, primarily focusing on the move for children with profound and multiple learning difficulties. Recommendations for future research are also considered.

In the existing body of literature relating to transition from primary to secondary school, there is little academic literature which focuses specifically on the needs of children with PMLD. There is a small body of existing literature relating to children with special-educational needs (SEN) making the transition from primary to secondary school.

The literature review forms part of the wider review of literature on primary to secondary school transitions which was undertaken as part of the author's doctoral studies. The author was previously a teacher for children with severe and moderate learning difficulties, and autism, in a specialist teaching service.

What the literature is telling us

The literature broadly agrees that preparation for the forthcoming transition is essential and that planning should include working with the child to ensure that all their needs are met. Strnadova & Cumming (2014) and Davis, Ravenscroft & Bizas (2015) recommend that a child-led model of transition planning should be followed. Figure 1 below shows the characteristics of effective transitions suggested by Davis, Ravenscroft & Bizas (2015).

Much of the literature agrees that for children with additional support needs, an enhanced transition can be beneficial (Lithari & Rogers, 2017; Jindal-Snape, 2016; Chambers & Coffey, 2013; Jindal-Snape et al., 2006 and Maras & Aveling, 2006), with Lithari & Rogers also discussing the need for 'careful transitions', in which support from the child's support network including peers, family and professionals, together with resources and services provided, is 'interdependent' (p.271).
In research that has elicited children's views, this has almost always highlighted the need for educators to have training in the child's specific additional needs so that

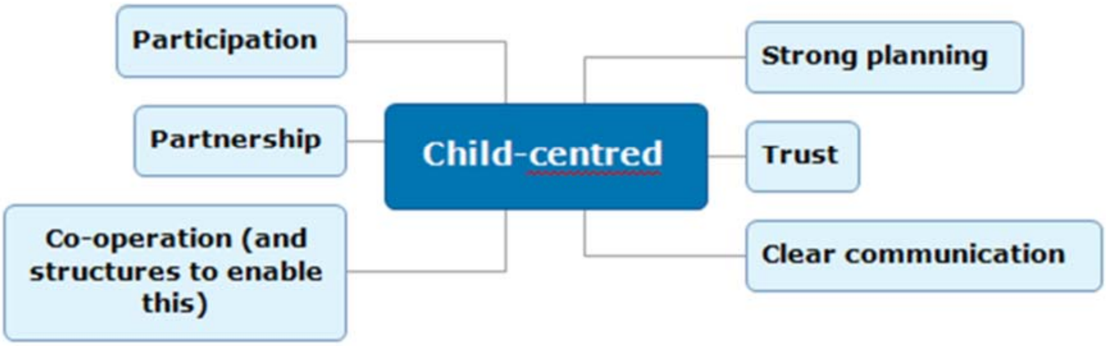

Figure 1: Characteristics of Effective Transitions from Davis, Ravenscroft & Bizas, 2015, p.37).

they have a good awareness of the needs and how to meet them (Foley, Foley & Curtin, 2016; Hopwood, Hay & Dyment, 2016; Hanewald, 2013; Topping, 2011). Educators also recognise there is a need for training, both formal and informal, with Hopwood, Hay & Dyment (2016) suggesting that for teachers to support children adequately, they themselves need to have received support.

The existing research also considers parental experience and the role of educators in supporting children's parents and the family. Peters and Brooks (2016) and Scanlon et al. (2015) both comment on the need for professionals to understand the experiences of parents and families, and there is a need for effective communication between all members of the team around the child. This ideal of shared working within a team also underpins good practice and policy, for example Getting It Right For Every Child (GIRFEC) (Scottish Government, 2012).

The use of published resources to support the transition, for example the pupil passports in the BILD Transition Toolkit (Broderick and Mason-Williams, 2008) and the social scenarios in Black Sheep Press (2016) 'Talking About Secondary School, have been used by the author to support transitions of children with additional support needs, and she has found that personalising these to meet the specific needs and context of the child being supported makes these more effective and engaging for the child. The use of technology to support the transition is discussed by Chambers and Coffey (2013) who suggest that this is an appropriate tool to use, given that many children are already using technology in their everyday lives.

Recommendations for future research

Overall, the existing literature gives a picture of a positive experience for most children as they make this transition. Most children see moving to secondary school as part of growing up. They look forward to going to their new school and experience excitement and anticipation around this life event (Foley, Foley & Curtin, 2016; Topping, 2011; Lucey & Reay, 2000). For some children, it can take longer for them to settle into their new school (Foley, Foley & Curtin, 2016) and some may experience heightened anxieties, particularly those who are on the autistic spectrum (Mandy et al., 2015; Hannah & Topping, 2012), for whom Mandy et al. describe the transition as a 'substantial challenge' (p. 2). Recommendations for future research

Further research into the educational transitions of children and young people with additional support needs, and particularly those who have PMLD, is recommended, particularly as there is currently a 'dearth of literature' (Hughes, Banks & Terras, 2013, p.31) in this area.

There is much good practice in schools, both in the United Kingdom and further afield, and there should be consideration of how to share this more widely. It is also recommended that further research should also consider the wider impact and experience of the transition on the child's family and on their educators.

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IN THE NEXT ISSUE

Winter Vol. 30 No. 1 Issue 89

Raising the Bar

Do you have any stories to share?

If so, contact the Guest Editors:

Jo Grace, Michael Fullerton, Thomas Doukas and Annie Fergusson

sensorystory@gmail.com

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More information on page 41

Co-authoring sensory stories with individuals with PMLD

Lynsey Robinson and Joanna Grace

The Sensory Trust and The Sensory Projects have been collaborating on different projects for some time, but this was our most ambitious to date. On the morning of National Multi-Sensory Story Telling Day on the 22nd September we set out to meet forty young people with PMLD in the hope that we could enable them to co- author a sensory story. We did not know whether this would be possible but by the end of the day we were able to perform the story the young people had authored.

Introduction

The Sensory Trust and The Sensory Projects both have a history of collaboratively creating stories and in recognising the creative talents of people with PMLD, but neither outfit had attempted to combine the two. In planning this project, we drew on insight gained from a Sensory Trust heritage project in which secondary school students from an ARB unit worked with a professional writer to co- author a story about a surfer . To test our theory, that individuals with PMLD are capable of authoring their own stories, we contacted Mayfield Special School in Torquay to see if they would allow us to work with their students for the day. Being a forward-thinking school and understanding the creative abilities of their students, they said yes.

Preparation

We gathered a loosely themed set of sensory stimuli focused on six senses: proprioception, tactile, olfactory, vestibular, visual and auditory. We also had options for gustatory experiences to offer to those for whom these would be accessible. Examples of our stimuli included rubber gardening gloves which were very popular for promoting proprioceptive awareness but also had interesting tactile and olfactory properties, and a bowl of compost with things hidden inside to discover which offered tactile stimulus and a visual reveal.

Each stimulus was presented in a canvas bag with accompanying guidance notes for facilitators. The purpose of these notes was to encourage novel exploration of the stimuli, and also to support the facilitators in seeing responses through fresh eyes. We wanted people to watch the response as it happened, not know in advance what the person they were supporting thought or felt.

Also with each stimulus was a simple recording sheet that asked facilitators to record physical and emotional responses to stimulus, e.g. turned head away, seemed to dislike it, or reached out and seemed excited (of course actual responses were more complex than these). We were very clear that we did not want facilitators creating story text, their role was purely to record the expression of the student authors.

The Creative Process

**For the rest of this article we shall refer to the students with PMLD as authors, this reflects how we worked on the day. In calling them authors throughout our time with them we publicly acknowledged our belief in their ability.*

The day began with close to eighty authors and facilitators gathered together. We set the scene by sharing a sensory story co-authored with a group of scientists: The Birth of a Star (which is available from The Sensory Project's website) and explaining that today those present were being invited to co-author a story. The authors then came and worked with us in smaller groups throughout the day, with each group spending around twenty to thirty minutes with us.

During the writing sessions authors explored the sensory materials with facilitators in a rotation that saw each writing pair having a few minutes with a resource before passing it on to their neighbouring pair. Responses, both emotional and physical, were recorded to be analysed and fed into the main story at the end of the day. We joined in with explorations and watched what was happening in the room, this also gave us a sense of the story being created.

> The exploration of the soil was consistent in wanting to uncover something beneath the surface, to dig, to move it, to change its shape.

The focus and concentration in the room was palpable. Staff at the school observed that it was good to have a specialist day where the focus was on the abilities of the students with PMLD rather than them having to fit in around the edges of an event. We were amazed with how each student gave their attention to the different stimulus. Themes began to emerge through similar responses but we were also pleased to see many individual voices coming through with different and unusual reactions. At times being in the room felt like waking on the edge of a dream and we were left reaching to articulate what we had just felt and experienced.

> When exploring the sound one author and his facilitator were doing this beautiful dance from side to side, there was a rhythm and symmetry to their movements, wrapped up in a joyous exchange!

A few of our authors could speak one or two words but we did not have an author present who could meaningfully generate the text of the story. The words were our part. Following the sessions, we analysed the responses and noted down our own observations. We discussed between us what we had felt. The task for us, was very much to put the words to a story already there. The essence of the story: the sequence, the emotional journey, the events – was dictated to us by the authors in the room. Our conversations were simply about how best to phrase it so that our words represented what they had told us.

The groups entered the hall with feelings of uncertainty; both the authors and facilitators seemed on edge. As the process of authoring unfolded each group became focused and calm. Events such as digging through earth and flowers and discovering treasure or wrapping oneself up and sleeping with petals against one's face happened spontaneously, and in one group a light wind turned into a song. Some responses were completely counter to what we had expected to happen, in particular the disgust at the smell of the basil plant. For us putting the story into words it was a race against time as the final gathering of the day approached, but the story itself was very much there.

We ended the day by sharing the story altogether twice. The feeling of achievement in the room was immense. The school plan to go on to share their story at other events, and we want to share it here with you too.
As a test run for this process the day was a success. There is still plenty of room for development and The Sensory Trust and The Sensory Projects continue to collaborate to this end.

Mayfield thoughts by Luana Winston, PMLD lead, Mayfield School.

Our learners had a wonderful time on national multi-sensory storytelling day, welcoming our visitors and sharing our interactions. As a department with a massive focus on interaction and communication, it was brilliant to welcome visitors for whom that focus resonated. I wasn't certain how much success we would have creating authors of my learners', but I was excited to see what Jo and Lynsey had in mind.

Beginning the day with one of Jo's customary sensory stories was a delight and whilst an audience of forty is not customary for PMLD practice, the story had as much impact as it would have had on a one to one basis. Our learners were grabbed by the initial 'bang' and followed the motions and props of the story with gusto. It was beginning to become clear that our learners were keen story-listeners and confidence grew in the aims of the day.

> One author plucked a leaf from the basil plant held it to their nose and then disregarded it. In a conversation that saw the facilitator retrieve this leaf and use it to gently beat a rhythm on a plastic chair the author re-engaged with the smell, bending their head to the chair to explore it further and repeating their initial turning away from the odour.

I had prepared some complimentary activities for classes to undertake in their rooms while each group took their turn to become authors with Lynsey and Jo. The props prepared by our storytellers were exciting in their novelty which led the children into some lovely and unusual responses. What emerged was a series of responses from four groups of children who told the story not only of their experiences with the individual props but also with the unusual set up of the day and the activities. Many initially felt a sense of unease at the new activities to one of calm exploration, touching on heightened periods of super-stimulation and surprise. Watching one learner delicately smell and handle the individual petals of the chrysanthemum whilst another pulled the petals from their stem, sprinkling them and watching them fall. The individuality of response led to each verse of the resulting story matching a mood and emotion that was recognisable in the children and young people.

Ending the day in the hall for a collective reading of our co-authored story was a great close to the event. Watching the recognition as learners re-encountered items that they had explored earlier and the enlightenment this promoted was a fantastic end to a spectacular day. However, that is never the end of the story, the comments and anecdotes shared by staff members from the department were a pleasure to hear and solidified our judgement that the day had been a resounding success. Perhaps this is just the beginning of our co-authors' writing careers!

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Any information about potential grant applications and any donations are welcome. Currently, PMLD LINK needs money to support its '*Far and Wide Project'* which aims to communicate with potential new subscribers to bring these services to the attention of families and carers, adult day centres, residential homes, and small self-help organisations that are harder to reach, as well as to schools and other charities.

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Garden Story by Mayfield School

Joanna Grace and Lynsey Robinson

Dark and overgrown, what is this place? My heart beat quickens gathering pace.
Sound of a heartbeat, pat out onto your chest.

The wind whips wildly around and about, churning up leaves and throwing them out
Create the feeling of wind

Urgh, yuck, blurgh what a smell! The heady scent makes me feel unwell.
Smell of a fresh herb. Basil.

I'll dig it up. Fetch a spade. Destroy its roots. I'll be obeyed.
March, stamping feet loudly.

Push and pull, wobble back and forth. Jiggle wiggle until it comes out of course!
Wiggle all or parts of your body.

The wind works with me, I'm calmer now, I know I'll get all this work done, somehow.
Whoo sound of the wind calming into ooo ooo, oo oo oo and repeat.

I lie down to sleep on soft earthy ground.
Wrap yourself up, either in blanket or just with your arms around yourself.

Wrapped up tight as petals fall all around.
Feel soft flower petals

All things bright and beautiful, all creatures great and small.
Sing this song

Garden Story

A sensory story is a narrative told through your senses.

You will need –
Story text, a board or fan to make the feeling of wind, a fresh herb to smell, your arms to wrap around you or a blanket, soft petals of a flower, the words to all things bright and beautiful.

Delivering the story

Before you begin

Practice. Run through the story without an audience to make sure you know how it goes and how you want to deliver it. This will help you feel
confident in delivering and give everyone a better experience.
Make sure you have all the props needed for the story within reach and ready to go.
Make sure everyone is in a comfortable position and can hear and see you. Everyone is close enough to you that you will be able to deliver the different sensory stimuli of the story to everyone taking part.

For the story

Take your time! Make sure everyone gets to experience each sensory stimulation for each section of the story.
Once you have finished a section put the prop back so you are ready to focus on the next section.
Try to be as enthusiastic as you can when delivering the story!
If you have time run through the story several times. Repetition, anticipation and remembering are important.
Consistency is important, repeat the story in the same way each time you do it.
The story can be delivered to individuals or to groups, you can spend more time on different parts depending on who you are working with. Think about how best to tailor the experience.

Have fun!

PMLD LINK
sharing ideas and information
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Old Man Big Hat
The Limitations of a subject based curriculum for semi-formal learners

Naomi Rosenberg

Thirty years ago, as a young teacher of the deaf I visited children with complex needs in special schools as a peripatetic teacher. At first I was bewildered. I could support the staff and parents, hearing aids, advise about acoustics in the classroom make observations concerning the children's responses to sound but had no training in how to teach children with such complex learning needs. I soon realised that I needed far more time than was allocated for each child; that I had to simplify and simplify again; and that I needed to make my interactions very explicit and clear. I had to learn about epilepsy and cerebral palsy (CP), a range of genetic conditions, mobility, vision and our other senses. It became clear to me that these in combination with each other and hearing loss has a massive impact on children's ability to learn and communicate.

I did however, know a great deal about child language development and my impulse was to communicate through play as you would a baby or toddler, but trying to do so in an age appropriate way. Making clear distinctions seemed to be the key to understanding and communication. Provide a stimulus and then stop. Observe response or lack of. Ask and sign if the child wants more. Child may bang their tray, or kick or wriggle or vocalise. Then repeat stimulus. I still had a lot to learn.

These were the days before the National Curriculum was imposed on special schools with no guidance as to how to deliver it, which came little by little. Mostly staff were muddling through with the children’s education and focussed on their physical needs. But there was great freedom. Freedom to experiment and to enjoy music, dance, fairy lights and CD mobiles, holographic paper wrapped round tubes and made into shakers. There were Sherborne movement and swinging in hammocks with dappled sunlight through the trees, aromatherapy and Dance Massage. Sound Beam and sensory rooms and switches were just starting.

The Multi-Sensory Impairment team in what was Avon, came into being in 1992 and I was invited to join. I dropped my mainstream schools and could focus on working with the most difficult to reach deaf children, those with autism and PMLD. It was an exciting time, with a passionate team leader, Sally Silverman, and an outstanding group of creative colleagues. We cherry-picked great working practices that we observed and shared them, along with our ideas, out to schools and we did lots of training days. We wrote articles for magazines and spread our enthusiasm for a multi-sensory play based curriculum. We studied 'Vision for Doing' and formed relationships with specialists like Flo Longhorn and we contributed to and published 'Information Exchange' a grassroots magazine for parents and anyone working with sensory impaired children with PMLD.

Then the Literacy Hour and the Numeracy Hour came into special schools with the National Curriculum and later all the other subjects followed. It was and still is a challenge to make subjects relevant and meaningful to semi-formal learners. Time for play and sensory exploration was and still is squeezed. Time for enjoying music, communication and massage diminished.

There were positives though. It was a really creative time for teachers because they had to spend an hour on literacy and an hour on numeracy every day. For this they had to invent new activities and resources and stretch the limits of what literacy and numeracy means. Fantastic sensory stories and dramas evolved. We made our own books with textured pages, scented pages, or simply plain coloured pages. We realised that mathematical concepts can be explored at sensory level - Long/Short, Fast/Slow, Heavy/Light. Counting and adding are pretty meaningless to children with PMLD. One, two and lots is more than most will understand, but stretching a Slinky to make it longer and longer and letting it spring back to short is relevant. Making dots and lines with white or fluorescent paints in UV light is relevant. Feeling a big melon or pumpkin in your lap and comparing it with a similar sized ball is relevant.

All was well and good. We were offering the children a new range of stimulating activities and learning experiences but then all the subjects were introduced with a more rigid curriculum and targets, assessments, P levels, subdivided P levels and recording evidence not overall but for every subject. Experienced teachers of children with PMLD know that their students cannot climb up a ladder of progress in the way most children can. They make some progress, then tend to plateau. It doesn't mean that they can't learn, but it is a more horizontal progress as they encounter new experiences and stimuli and sometimes one of those lateral experiences help join up some neural pathways and some vertical progress is made. Sadly, many children in this cohort have life limiting conditions and some have genetic syndromes where their learning, speech, mobility, vision and hearing will inevitably deteriorate. Many will have long periods of absence from school due to illness, being in hospital, and lots of appointments.

I have argued for years that it is dreadful to impose subject based targets and P levels for these individuals. I have had so many discussions with teachers, head teachers, the Sensory Support Service about this. All think it ridiculous but all play the game. The impact of this is that the children are set up to fail. The teacher is set up to fail and we give false expectations to parents and others working with the children. The teacher is under huge pressure to show that their input has been effective and will often stretch the reality giving some 'evidence' that the child has gone up a notch or two. When the next teacher gets that child they soon realise that the child has not made those advances and has to reset the starting point. The sheer amount of time and energy spent on the administrative task of logging evidence for every subject is massive. You have to ask yourself what is the point?

We have to accept that these wonderful human beings who we love and cherish will never be independent in this world. They will all need a lot of support, albeit to a greater or lesser extent. So what is really important to that person? Here is my list in no particular order that I am sure you could add to:

To be happy and have a sense of self-worth
To not be in pain
To receive the right care with drugs, physiotherapy, medical interventions
To not be scared or anxious.
To be given dignity in personal care
To have relationships with family, friends, teachers, teaching assistants and carers.
To have a simple communication method that is understood by the above.
To have accessible technology, functioning and consistently used - hearing aids, communication aids, switches, computer eye gaze, vision aids, tablets…
To be as mobile as possible
To have opportunities to choose.
To not be bored -range of activities that are accessible, motivational and fun.
To be clued in to what is happening

To have a routine and a chance to understand what will happen next.
To feel included and valued in a group.
To be able to do favourite things often.
To have a good learning environment
to love and be loved.

I observed an awful history lesson once. It was about Isambard Kingdom Brunel. I was supporting a profoundly deaf boy with CP. He was one of the more able in the group with a working knowledge of over 300 symbols in his communication book and a more extensive understanding of BSL signs he's unable to make himself due to his CP. The teacher rattled through who Brunel was, his engineering achievements and I could see the children did not have a clue. A picture was handed out for the children to colour in. All that J could do was scrub a pen over the picture and with my help access 'old' 'man' 'big' 'hat' in his communication book. I'm sure that J won't remember that lesson and it wouldn't be on his important list. Wearing hats and looking at each other in a mirror would be a more relevant, fun experience with opportunities for communication and perhaps a new word/sign/symbol to increase vocabulary.

Life is not divided into subjects -everything impacts on everything else. I believe topics are more useful and holistic in education and spark off a creative flow of ideas. For example, See Figure 1 on opposite page.

What have the children learnt from this Egg Topic? Probably nothing about the reproductive system of birds - but maybe a concept of 'bird' with the opportunity to watch, hear and touch a chicken. Maybe the word, sign or symbol for an egg. But they've explored big and little eggs with chicken and quails eggs. They've explored warm and cold eggs in their hands and stroked on skin. They've used visual tracking skills watching eggs roll and spin. They've had taste experiences and maybe shown a preference for boiled, scrambled or chocolate eggs. They've explored the texture of scrunched eggshell and dabbled in the raw egg to make eggy bread and laughed when the old lady in story keeps dropping them. They've become familiar with the chicken song and the rhythm of the egg shaker. They've painted eggs, foraged for nest making materials outside and explored those grasses, leaves and moss. They've enjoyed snuggling in cosy nests of duvets, cushions and teddies.

Fun, motivational activities create communication with lots of simple repetitive language that may be learned and retained. The children have had lots of opportunities to look and listen, to feel and to smell and taste and be fully involved in the activities. This is all good for feelings of self-worth, happiness and being part of something so positive for their mental health which may lessen unhelpful or harmful behaviours.

Good experienced teachers know what level their students are at and how to pitch their teaching at the right level for each individual, practising what is known and gently extending that. They know what is accessible to one is not for another. They extend knowledge to the classroom team so they can help with that access. They know how to provide a good environment that is conducive to learning, paying attention to noise levels, visual and physical clutter and trying to minimise it. No one can focus and learn in a chaotic noisy place full of distractions. This is an area where there is often great room for awareness and improvement.

Obsessing about levels, targets and evidence gathering is really not important. Do you think the child would put these on the list of what's important to them? It is the quality of communication and dedication to keeping all the technology functioning and consistently used. It is providing meaningful activities that are accessible and motivational. It is having routines so the children can feel secure and understand what is coming next but has some flexibility to enjoy being outside in nice weather or having a 'Surprise' slot for something new, fun or relaxing…

Try to put yourself in the child's shoes and imagine how they are seeing, hearing and experiencing their time at school. This will help you to make your teaching relevant, accessible and meaningful. Then work on the environment, not to make it pretty (although that's nice), but to make it easier to focus and concentrate. Those should be the priorities for a great teacher. That with a big dollop of laughter and warmth, music and all forms of creativity, expressive faces and voice.

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Naomi is a teacher of the deaf for children with complex learning needs, a volunteer for Sense, a multi-sensory consultant and trainer for Hirstwood Training, and initiator and trainer of Dance Massage and maker and trainer of Clonkerboards - resonance boards.

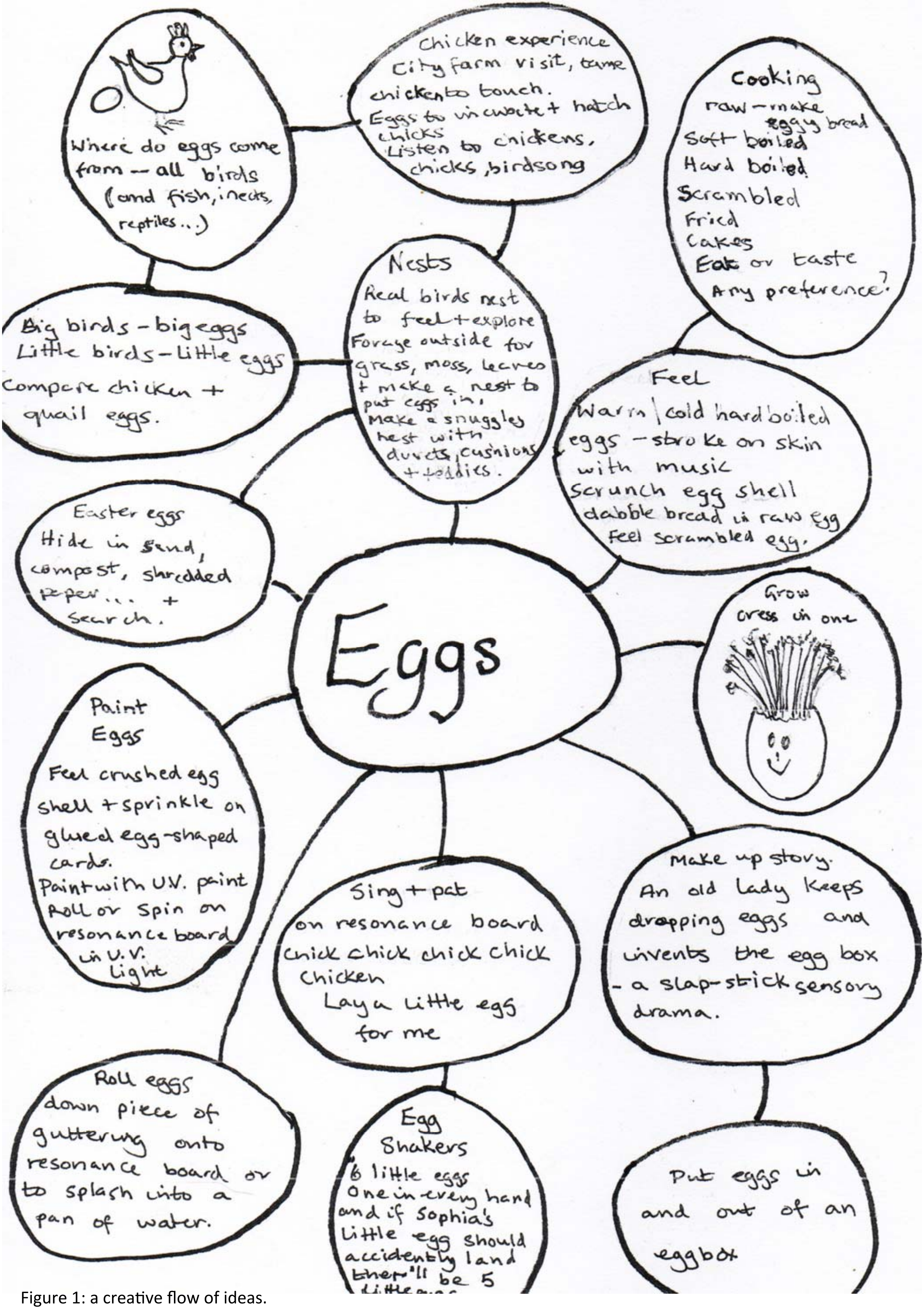

Figure 1: a creative flow of ideas.

A new Sensory Story from Pete Wells

My Funny Family

Storyline:	**Suggested Props!**
I have a funny family; brothers, sister, mum and dad, All living under just one roof, we drive each other mad!	
My Mum is always shouting, “Wake up! Eat up! Get to bed!” “Pick it up! Put it down! Wait! Hurry!” Until it hurts my head!	(BigMack nagging!)
I think Dad lives in the toilet, he spends hours there each day! Making strange noises and stranger smells, it's best to keep away!	(Smell egg)
My brother is disgusting! He put a snail upon my head! And a spider in my pyjamas, and a frog inside my bed!	(Feel frog/spider/slime)
My sister is a poser, she takes selfies all day long! She plasters her face with make up, and her perfume smells too strong!	(Take selfie/smell perfume)
Baby Gilbert is a cutie, his mouth always has a bubble! He giggles and throws his baby food and gets in so much trouble!	(Taste/smell/feel baby food. Blow bubbles.)
Grandpa Jim is hard of hearing, and finds it hard to see, But Grandpa Jim can always find me, and share his sweet toffee.	(Smell/taste toffee)
Granny Annie keeps losing her glasses. She searches the sofa and under her bed, And none of us dare tell her, that they're perched upon her head!	(Glasses on head & mirror)
My dog, his name is Woofles, he really has great taste, He likes to jump up on my chair and lick dinner from my face.	(Lick with wet flannel)
Our cat’s called Mr Whiskers, he bring us gifts to show he’s nice, Like mangled birds and half a butterfly, rotten fish and poor dead mice.	(Smell tuna/feel feathers)
But more important than all Mum’s shouting, Dad’s smells and tricks from bruv, My house is a place of laughter, of hugs and kisses and LOVE.	(Massage)

Pete Wells is the Deputy Head Teacher of Percy Hedley School in Newcastle (despite being a proud Sunderland lad!) and has been writing special stories for over twenty years, the old codger! Be sure to visit his site at http://www.petewellssensorystories.com/ or contact him at petewellssensorystories@gmail.com

FROZEN LIGHT BLOG

Tour Reflections: Working with Venue Marketing Teams to Develop an Audience

So it's been over six months since our mammoth UK-wide, 47 venue tour of HOME ended, and over two months since we returned from the Edinburgh Festival Fringe, performing for the second year running at The Pleasance. We're at a very exciting stage at the moment, having begun the rehearsal and development phase for our next show. The creative team spent two weeks at Ovalhouse and Stratford Circus Arts Centre in September working on exciting new concepts for the next production and will continue to develop the show with more rehearsals during November at The Garage, Norwich and at the New Wolsey Theatre, Ipswich – so watch this space! Meanwhile, I (Administrator Zoë) have been reflecting on my role liaising with the marketing teams of each of the 47 venues during the HOME tour in Autumn 2016 and Spring 2017, in order to sell the show to our audience with Profound and Multiple Learning Difficulties (PMLD). This was the first time I had been involved with a Frozen Light tour, and my first time working on audience development, this is what I learnt:

Keep in Close Contact

At first I was worried about phoning too often, leaving too many voicemails or emails, but I quite soon realised that being in close contact with the marketing team at each venue (or whichever team or individual had been tasked with our show) is absolutely imperative for a number of reasons. Because our audience of teenagers and adults with Profound and Multiple Learning Difficulties is such a specific and under-engaged group within the arts, we are passionate that they are the main priority for venues to target. Maintaining a good dialogue with venue staff around three months before we were due to visit a tour venue worked best in ensuring that the venue team were entirely clear on exactly who our audience with PMLD are, to make sure that they get priority. After all, it is entirely for them that we make the show. The other reason that close contact between us and the tour venues was incredibly important was due to the small capacity of our shows. Because our shows are designed for six people with PMLD and six carers, support staff or family members, we have to keep a close eye on who those tickets have gone to. For people with PMLD, a trip to one of our shows is very often the first time they have been to live theatre in their community, and guidance from Mencap states that a lot of the anxiety around this can be eased by having a very small number of audience members. Frozen Light do supply a training video and handouts to answer questions that may come up a lot when marketing and selling our shows, so as long as venues watch and read them and we maintain a clear conversation and help them with any questions they may have about how to market and sell our shows, we can make sure people with PMLD coming to our shows have a positive and meaningful experience.

Direct Target Marketing

We completely appreciate that especially if it is the first time we have toured to a specific venue, it can be difficult to know where to find our audience and how to reach them. I think that this speaks to a larger problem within our society about the lack of visibility in the community of people with PMLD, which is something that through our commitment to touring to mainstream arts venues we're trying to change – but that's a blog for another day! One of the earliest conversations I would have with venue teams would be about any existing relationships they may have with people with PMLD and their families or carers in their local community. Some venues had really strong links with local special schools, day centres or residential homes, either through us touring to that venue with a previous show or through other accessible work they have programmed in the past. If venues didn't have these existing links, I would research nearby special schools, day centres, residential homes and other places where our target audience could be reached, and pass this information onto the venue for them to target. The main challenge in this area was talking through just how different the approach has to be when reaching our audience with PMLD versus reaching another audience group. A lot of the usual channels of finding audiences or publicising shows that marketing teams use don't work for our shows, simply because our audience don't 'live' on Facebook or Twitter, and because of the lack of events in the community that are accessible to people with PMLD, their family members and carers won't often won't pick up a theatre brochure and expect to find an accessible theatre show on offer. The best ways to connect with our audience is through a direct phone call to a school or centre, or the activities co-ordinator for a residential care group or parents forum. In the past some venue staff have even had face-to-face meetings with some schools, bringing along our Visual

Stories and Pre-show Guides with them to help talk about the show. We offer to help with the direct contacting as much or as little as the venues need it. Establishing those personal relationships over the phone (or even in person) with potential audience bases can be incredibly useful to venues not just in order to sell tickets to our shows, but to help them maintain these audience links for future accessible shows that the venue may programme.

Establish a Plan

Working on the audience development for the HOME tour has taught me how important it is to know who your main contact at each venue is, and to establish a collaborative plan together. For the majority of venues, I had a main contact (usually a member of the marketing or creative learning team, depending on who was in charge of targeting audiences) that I would liaise with over potential audiences and sales figures. Looking back, when first speaking to my main contact, I would've established a much clearer plan with some venues in terms of who is going to be doing what, and our expectations of when we'd like the majority of tickets to be sold by. Selling our show can be a very different experience to selling any other show, due to specificity of our audience, and particularly if we haven't toured to that venue before or if the staff we've previously worked with has changed, it can mean creating a lot of audience relationships from scratch.

For us, an ideal audience development liaison between us and a venue would be us sharing our knowledge with the venue of local audience bases, places we've had enquiries from or had audiences from before, talking through the capacity of our shows so it is clearly understood, and then the venue teams doing the direct contacting themselves. We are always happy to help as much or as little as venues need it, and if venues need a little more help from us in terms of the direct contacting, this works much better when we know in advance. When organised, collaborative plans are established specifically with our audience's needs in mind, I've seen first-hand how huge the demand for tickets can be, and how in a matter of days our shows can go from half-full or less to sold out with a waiting list.

During the tour of HOME, we worked with over 20 venues we had never toured to before, and so many others we had been to in the past but toured to for more days than we had before. It was fantastic to see how enthusiastic so many of the venue staff were about our work, and how they really got behind what we do. We can't wait to work with many of you again during the next tour, and together continue to reach local audiences with Profound and Multiple Learning Disabilities.

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To read their blogs go to http://frozenlighttheatre.com

Connect with us on social media

@PMLDlink on twitter

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Join in with the #pmldchat conversation focused on making a positive difference to the lives of people with PMLD.

See you online

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Choice Support's Safe Touch: Re-introducing and Re-educating in Embodied Humanity

Christina Vasileiou

July 2017, the Choice Support organisation presented the findings of their research project, "Safe Touch", a collaboration between Leonie Elliott-Graves, Ph.D. candidate and visiting lecturer at Goldsmiths University of London, and Dr. Thomas Doukas, Head of Inclusive Research & Involvement at Choice Support. The event gathered audiences from diverse settings of work with people with learning disabilities, PMLD and SEND.

It had particular relevance for these areas, but also opened up a significantly broad scope of interest for all people who generally engage in other areas. The initiative aimed to highlight the importance of touch in the practice of supporting individuals to raise awareness on the use and benefits of this. It ultimately aimed to re-educate supporters and service users in aspects of safety, but also of caring, support and genuineness as essential to practice. A useful set of guidelines, which "explore new and creative ways of using touch to foster communication, support care, and develop strong relationships", was provided and widely disseminated (Choice Support, Safe Touch Guidelines, 2017)

Touch and the Lived Body

There is no such thing as a body that stands on its own. Being alive means that we perceive, interact and communicate with the world and others, through the surface of our bodies, through our skins. Bodies can only be conceived as 'in relationship' with other bodies, engaging in these relationships primarily through touch. For Aristotle, touch is the first sense, the one that contains all the other senses. It is "the sense one cannot live without, the sense that human beings have just for the sake of being, whereas other senses, Aristotle suggests, we have for the sake of well-being" (p. 62, Manning, 2007). Touch though, always operates in excessiveness; touch goes beyond the limits of our bodies and crosses the other's physical boundaries. It is through our embodied excessiveness that we understand the world and others, and come into relationship with them.

An Embodied Practice: Touch in Supporter's Practice

Working with people with PMLD and SEND means that first and foremost you work with your body. The body is the tool, the means through which you communicate with others. We practice, therefore we participate with and through our bodies. We are present, looking and been looked at, touching and being touched. However, in a world that strictly worships rationality over the uncontrollable excessive "flesh", how can we find comforting and supporting touch in our practice? The Safe Touch event brought us into a re-education and re-conception of what it means to communicate through touch: of how we can physically enrich our practices, and ultimately, of being more human, more of ourselves in the contexts of our work. Safe Touch provided a platform for a reflection and understanding of how much touch is involved in our practices within these environments. It was indeed very interesting that the findings stressed the importance of bringing more caring and communicative touch into practice, showing how this can tremendously affect the way that both service users and practitioners experience the provision of care. The guidelines explicitly demonstrated how touch helps to enhance communication and trust between service users and supporters and also to promote feelings of calmness and contentment. What is more, the project made explicit how the arts can re-train us and our bodies into understanding what safe, respectful, caring, and communicative touch is. This ultimately helps people to feel valued, as their presence is acknowledged on an intellectual, emotional and a physical level.

Lack of Touch: Ethical and Political Reflections

The presentation of the research on physical interaction in these contexts, highlighted a rather gloomy aspect of our work: how neglected human, warm, communicative touch is, and how it is overpowered by the normative, (self) monitored touch which operates within boundaries and regulations. This explicitly echoes the repentance and Western "panic" about this "excessiveness" of our human expression. However, touch is a crucially important part of our lived experience. I also find that this can also be alarming for the ethical and political connotations it may have, particularly for the work in PMLD and SEND settings.

Little touch or lack of touch can be related to the ways that particular bodies and physical interactions may be marginalised, not only out of fear of abuse but also for hierarchical reasons. It is therefore, crucially important for us as practitioners to self-reflect on our practice and wonder whether we want touch deprived practice? And, what is more, to identify the reasons for this: do we want touch deprived care for the sake of monitoring and "safety"? What are the physical "borders" we may be raising and policing, and what understandings and transcribings of alterity may these borders perpetuate "in order to be certain that we do not reach over that border to touch another who is not our-selves"? (Manning 2007: 69) .

Last but not least, how do all these help and support the development of our people?

Conclusion: Touch as Self-Knowing

Touch can be seen as a radical leap towards the embodied democratisation of our societies: an embodied resistance on prevailing ideas of power and agency. But I would also add that engaging in touching others safely and respectfully, and monitoring this as part of the development of our practice, can offer us another valuable gift: that of self-reflection and checking-in with the self, which ultimately may lead to a better, deeper and more genuine relationship to ourselves and our practices. After all, as Erin Manning argues it is "the skin of another [that] will always lead me back to my own skin" (2007: 66). It is through this kind of shift in performing our practices, in experiencing the others' bodies that we can generate shifts in the ways that we experience our own selves.

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REPORT BACK

Raising the Bar conference and launch of the PMLD Standards

Wow, what a day! Families, once side-lined by 'the experts' took centre stage side by side with practitioners who share a determination to raise the bar so that a 'PMLD' label can no longer be confused with a 'no hope' label.

The speakers each described good practice and placed it firmly in the grasp of ordinary people and families, and the child and adult services that support them to live well. Jonathan and his mum's campaign to make sure everyone has the chance to become literate set the bar high at the beginning of the day reminding everyone that 'we haven't yet found a way to communicate' is not the same as 'there is no way to communicate.'

The standards have the remarkable quality of being both person centred and straightforward to evidence by those inspecting services. An invaluable resource for Ofsted, CQC/CSSIW and internal reviewers who might not be quite sure of what good might be at both organisational and individual levels. Of course having written standards mean that families and advocates can simply describe the standard of support they want and work in partnership to achieve a great life for the person.

These practical core standards are the result of visionary thinking and collaborative effort. Thank you to everyone involved. I'm looking forward to putting them to good use!

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In the Next Issue

Raising the Bar

Hello all. In the next issue ~ Raising the Bar: Spring 2018. On the 24th of November the new Core and Essential Service Standards for Supporting People with Profound and Multiple Learning Disabilities were launched at our Raising the bar conference. We hope this document will be a powerful tool for change in the quality of care people with PMLD receive. You can download it for free from www.pmldlink.org.uk

In our next issue of PMLD LINK we hope to offer a clear introduction to these standards, illustrating how they drive improvement and positive change across Education, Health and Social Care for people with PMLD, their families and others involved in their care and support. We are keen to receive submissions from those who presented or attended the Raising the Bar conference, and we would also like to receive submissions from any reader, relating to the standards themselves:

- How do you plan to respond and meet the standards in your setting?
- How have you gone about effecting positive change – eg in the care received by the people/person you support or, perhaps in the training and professional development opportunities available to your staff?
- Do you have a novel or innovative way of meeting one of the standards? Or, tell us about the challenges to making progress towards a particular standard.

The standards for organisations cover: leadership; quality; staff development; physical environment; communication; health and wellbeing; social, community and family life – we would be interested in submissions on any of these topics. The standards for individuals cover: communication; health and well being; meaningful/quality relationships; social and community life; meaningful time; and transitions – we would be interested in submissions on any of these topics.

We are particularly interested in forward facing submissions, e.g. from professionals about how they plan to effect change, and from family carers about the change they hope for. Please get in touch if we can help in any way. We look forward to receiving your contributions!

Jo Grace, Michael Fullerton, Thomas Doukas and Annie Fergusson, Guest Editors

Please send contributions by 19th March 2018 to sensorystory@gmail.com

Supporting people with profound and multiple learning disabilities

CORE & ESSENTIAL SERVICE STANDARDS

New PMLD Standards launched in November

SUPPORTING PEOPLE WITH PROFOUND AND MULTIPLE LEARNING DISABILITIES CORE & ESSENTIAL SERVICE STANDARDS

The aims of the Standards are to support in ensuring people with profound and multiple learning disabilities, children and adults, have access to consistent high-quality support throughout their lives, when supported by any service provider. The ambition is that these Standards will be adopted nationally.

The standards outline key objectives and principles that should be evident across all education, health, and social care services. These should be adopted by commissioners and providers of services, ensuring families and other key stakeholders have awareness of these standards.

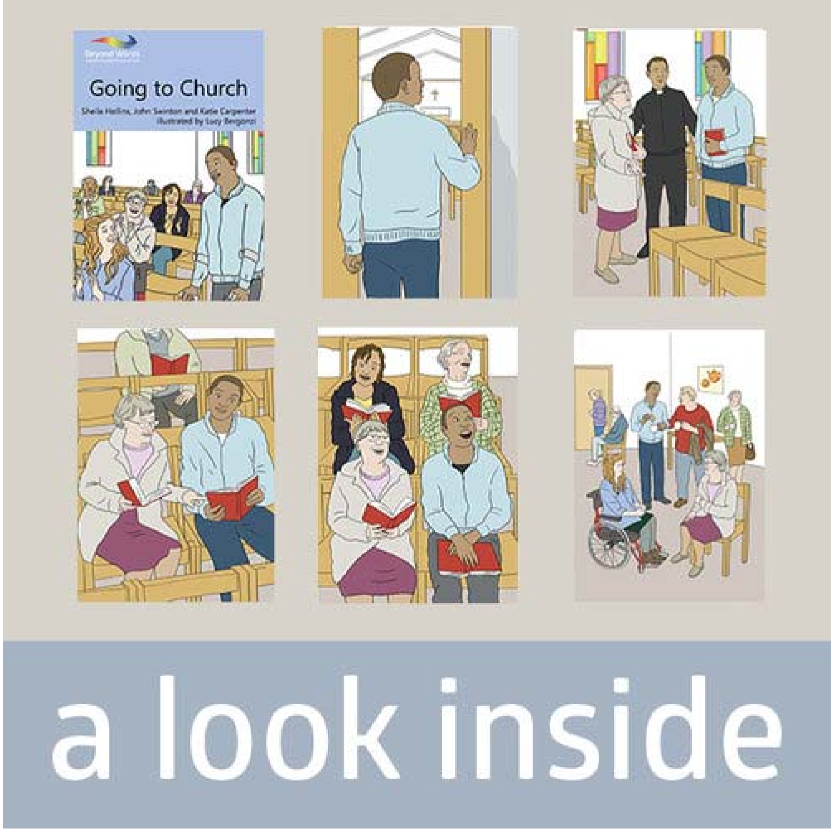
Families and other representatives should be clear, from the outset, of what level and type of standards to expect for the person they represent and advocate for.

Free to download from http://www.pmldlink.org.uk/

Homepage (scroll down to image) AND from Resources section (Commissioning tab)

PMLD Link are proud to be involved in these quality standards as a means of improving the lives of people with PMLD, their families and those who work in the field. Our intentions are to focus on the positive impact and potential of these standards in the forthcoming issues of PMLD Link.

REVIEW



Title: Beyond Words: Going to Church

Author: Sheila Hollins, John Swinton, Katie Carpenter. Illustrated by Lucy Bergonzi

Media: Book (ISBN: 978-1-78458-090-2)

Available: Full range of books available at: www.booksbeyondwords.co.uk

Price: £10.00

Funded By: Books Beyond Words (independent charitable publisher)

'Beyond Words' has a 25 year, award winning history of producing books for adults and young people who find pictures easier to understand than words. The lead author and founder (Baroness Sheila Hollins) first created picture books to enable her teenage son, who had a learning disability, to gain an understanding of events that were happening in his life. Now with a team of authors and advisers, 'Beyond Words' have created a broad range of books to tackle personal and social topics such as healthy living, relationships and bereavement to name but a few. Clear, full colour illustrations not only tell a story but encourage readers to develop their own understanding and remove barriers that young people with learning difficulties face when making decisions about their lives. The latest book, entitled 'Going to Church', helps people with limited reading ability to explore aspects of a church community.

This book and others in the series would be useful for adults and young people who already enjoy accessing story books and can engage in discussion with a supporter about the subject of the book. It is therefore perhaps better suited to those with moderate to severe learning difficulties.

Whilst this may not be appropriate to use directly with individuals with PMLD themselves, it could provide a valuable resource to help open a conversation and focus the discussion with the church community.

The book itself is A5 in size and is closer in appearance to an adult fiction book as opposed to the larger children's fiction formats that we sometimes see. Although the external appearance is perhaps more suited to the target audience, those with visual impairments may require a larger format. The illustrations are clear, colourful and offer lots of interpretation for discussion. A suggested storyline to supplement the pictures is printed in the back to assist if required. The suggested story line follows a young man called Alan, who despite initial anxieties, joins a local church community. The book also provides some insightful written guidance for families and support workers around such issues. Perhaps more notably, the book also includes detailed advice and practical tips for church communities about how to remove barriers to inclusion.

As a teacher of young people with learning difficulties, families will often ask for advice about personal and social issues. For students who access and enjoy stories, this book and others in the extensive range, are ideal in facilitating an understanding and discussion around such issues. The insightful and practical guidance coupled with an accessible story to use with members with communication difficulties also make this a useful book for church communities to add to their collections.

Reviewed By:
Rob Emery. Key Stage 4 Teacher, Phoenix School, Peterborough

The Government's Response to Rochford Review Report

In the Spring Issue of PMLD LINK (Vol. 29 No. 1 Issue 86), there were articles by Richard Aird and Martin Goodwin about the Rochford Review Report on assessment of pupils working below National Curriculum expectations. The Report was followed by a period of Government consultation (https://www.gov.uk/government/consultations/primary-school-pupil-assessment-rochford-review-recommendations) and then in September, the Government published an Equalities Impact Assessment (https://www.gov.uk/government/publications/primary-pupil-assessment-rochford-review-impact-assessment) which took into account comments made by respondents to the consultation and looked to see whether there were negative implications for any particular groups of pupils if the Rochford Review Report recommendations were implemented. The impact assessment outcomes persuaded the Government that there should be a year of pilot studies before making any firm regulations about assessment for these pupils.

So the pre-Key Stage 1and 2 Standards recommended in the Rocford Review Report are to be trialled for assessment purposes (https://www.gov.uk/government/publications/interim-pre-key-stage-1-standards; https://www.gov.uk/government/publications/interim-pre-key-stage-2-standards). These will have greater implications for the wider group of pupils with SEND and are likely to be used with only a handful of pupils with more severe learning difficulties in many schools. Once tested and confirmed, these could become permanent in the school year 2018-19.

As regards pupils assessed currently as being at P-Levels P1 to P4, commonly (but somewhat inaccurately) viewed in schools as pupils with PMLD, the Government has agreed to finance a pilot in 2017-18 of the Engagement For Learning Framework (ELF) developed by Professor Barry Carpenter's team. The Rochford Review Report recommended that there should be a statutory duty to use the ELF to assess progress in cognition and learning in a way that reflects the needs of each individual pupil. The Government has taken on board that the ELF is relatively untested with these pupils and may not assess all aspects of cognition and learning that are of interest and importance. Also, cognition and learning is not the only critical area of development. Hence, the need for a pilot. Also, school accountability remains important to the Government and the pilot study outcomes will be used to decide whether ELF assessment outcomes should be reported to the Government and what format any such reporting might take. Any final decisions will be made so that any changes will take place in the 2019-20 year. In the meantime, schools are encouraged to continue using the P-scales for reporting progress and may continue to use them even if they are eventually dropped by the Government as seems likely.

The implications are that schools should start to familiarise themselves with the interim pre Key Stage Standards and the ELF. However, they do not have to ditch their own preferred assessments so tools like Routes for Learning and MAPP. In all probability it would be a good thing if individual schools did their own pilot studies during this year, since the standards and the ELF are likely to be recommended for adoption albeit with possible modifications.

Interested readers might like to engage with the Engagement4Learning website set up by Prof. Carpenter and his team (http://engagement4learning.com). This provides links to the Rochford Review Report and to the latest versions of the ELF tools and related documents. The website also has several interesting blogs including two by Richard Aird which will be of particular interest to people working with pupils with PMLD. Some reading of the material on this website seems an excellent place to make a start and then progress to more detailed examination of the ELF. Professor Carpenter's team also offer training opportunities.

IN THE NEWS

The Whiteboard Room is back!!! Free interactive resources

I have some exciting news... The Whiteboard Room is back!!! A number of years ago I collected lots of excellent interactive technology resources that special school teachers had created for their learners to use in a number of ways - interactive whiteboards and plasma screens, laptops and computers or personal tablets and iPads. We put them together in The Whiteboard Room website for anybody to use.

About 18 months ago the site disappeared when our host went offline and a valuable resource appeared to be lost. However Equals has come to the rescue by offering to host the Whiteboard Room on their website. It is now up and running again – please go to and take a look. Now! http://www.equals.co.uk/whiteboard-room

For PMLD LINK readers in particular there is a great 'PMLD' Resource Folder. The creative resources include a number of wonderful sensory stories by Pete Wells and some motivating cause & effect games and targeting activities from Alison Collins and myself.

We want to add more resources - so if you have created a PowerPoint or other shareable resource for
learners please let me know!

Sally Paveley (The Bridge School,
London) sally.paveley@thebridge.islington.sch.uk

Quality Checking Health Checks for People with Learning Disabilities: A way of finding out what is happening locally

This brief audit tool is an update of one published by the Learning Disabilities Observatory (then known as IHaL) in 2011. It is designed to support practices, primary care liaison staff, health facilitators and others to improve the uptake and quality of annual health checks (AHCs) and thereby reduce the health inequalities experienced by people with learning disabilities. The audit tool (based on six simple questions) can be used by GP practices and those providing support to GP practices to:

- identify good practice and encourage services to improve their practice further
- establish whether health checks and primary care services are provided consistently across a geographical area
- monitor progress
- embed key 'reasonable adjustments' within primary care

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/647512/Auditing_health_checks_tool_for_people_with_learning_disabilities.pdf

Us in a Bus. 5 Top Tips about Intensive Interaction

The Us in a Bus team have written some Top Tips for those practising Intensive Interaction. This has certainly stretched our imaginations as every time we think we've narrowed it down, another one pops up and demands to be let in. So to keep this exercise inside the realm of possibility, we have assumed that the Top Tips are for people who already know the basics of Intensive Interaction and want tips for focusing and developing their practices.

http://usinabus.org.uk/what-we-do/intensive-interaction/

Inclusive multi-sensory storytelling

Join Scottish storytellers Claire Hewitt and Ailie Finlay who along with Maureen Phillip from PAMIS and Lorna Strachan and some of the Tayberry Tales storytellers from Tayberry Enterprise for a development day of inclusive multi-sensory storytelling at the Scottish Storytelling Centre in Edinburgh on 24th February 2018 . The day will be rich and varied in content. Come along and immerse yourself in the smells, sights, sound and taste of sensory stories that will indulge and inspire your senses and imagination. Throughout the day you will have the opportunity to hear and create sensory stories that promote inclusion, learning and development, engagement and connection and you'll have fun. Further details will be available soon and can be found in the Scottish Storytelling Centres programme of events 2018. The day will include sharing stories from the beautiful resource created by Claire Hewitt and Maureen Phillip in memory of Loretto Lambe the founder of PAMIS. Hope to see you there.

PMG Conference 2018 – Call for Papers

Posture & Mobility Group (PMG) is currently accepting abstracts to present free papers, breakout sessions and/or poster presentations at the PMG Conference 2018.

PMG Conference 2018 – Call for Papers
The event is taking place Monday 23rd – Wednesday 25th July 2018 at Manchester Central. Abstracts must be submitted by 5pm on Monday 22nd January 2018. PMG's annual conference provides an educational programme, industry exhibition and networking events for professionals working in the field of posture and wheeled mobility.

The majority of our delegates are occupational therapists, physiotherapists, rehabilitation engineers and clinical scientists working within the NHS wheelchair services or for manufacturers/distributors of posture and mobility products; with a smaller, but significant, number working in other NHS departments, the charitable sector, for local authorities, or independently.

Our event focuses on the posture and mobility needs of wheelchair users and, therefore, abstracts should be relevant to professionals working in this field. Popular subjects include pressure care, 24-hour postural management, special seating, electronic assistive technology and powered mobility. Case studies and research-based presentations are both welcomed, and we accept abstracts from all sectors as long as they are evidence-based with a clinical focus.

Before submitting an abstract, please read the guidance. To submit an abstract, please complete our online form.

For more information about PMG, go to: www.pmguk.co.uk.

People are dying from chronic constipation, in 2017, in civilised societies like the UK, Australia and New Zealand

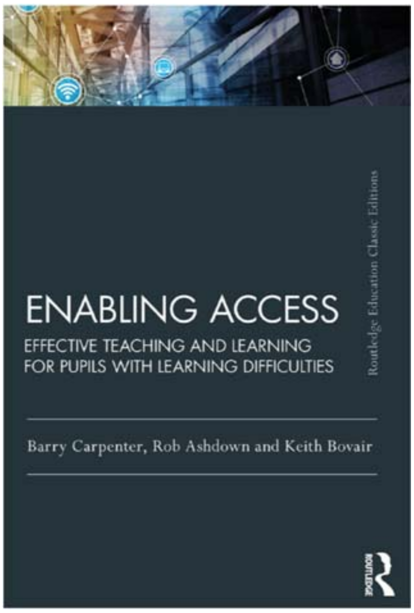
In her role as a William Chrurchill Memorial Trust Fellow (#WCMTLD), George Julian is currently exploring first-hand how deaths of people with learning disabilities are investigated in Australia, New Zealand and Canada, with a focus on the involvement of bereaved relatives and families. She discovers harrowing commonalities to the UK, where people with learning disabilities are dying not from the consequences of their disabilities, but from treatable health conditions (such as constipation) – their deaths could have been prevented with access to quality healthcare.

George illustrates some staggering statistics from the CIPOLD Report (2013) in her poignant craftivism shown below.

Read George's blog - http://www.georgejulian.co.uk/churchill/ @GeorgeJulian #WCMTLD

RESOURCES

Enabling Access Effective Teaching and Learning for Pupils with Learning Difficulties



ENABLING ACCESS
EFFECTIVE TEACHING AND LEARNING FOR PUPILS WITH LEARNING DIFFICULTIES

Routledge Education Classic Editions

Barry Carpenter, Rob Ashdown and Keith Bovair

Routledge

Edited by Barry Carpenter, Rob Ashdown and Keith Bovair

Published September 2017 by Routledge. 408 pages. Available in e-book, hardback and paperback. Paperback price is £32.99.

Routledge has reprinted the second edition (2001) of this successful book as a 'classic edition'. This edition has a new appraisal of the contents from the editors, but it is a virtual reprint of the edition from 2001. So you do not need to buy this classic edition if you already have the 2001 book. However, if you do not have it, then you will find this new edition very useful. The various contributors raise debates, illustrate effective teaching ideas and discuss strategies for providing a high-quality education for pupils with severe and profound and multiple learning difficulties. The book also discusses how to involve family members and the learners themselves in planning to meet their needs and interests through appropriate activities and considers issues surrounding empowerment of learners and the professional development of the workforce. Of course, there have been curriculum developments and important new legislation since 2001 but most of the content remains highly relevant to readers today. This book has proved its value for students and lecturers in higher education, and for teachers, support staff, and other professionals in all educational settings in the UK and abroad catering for these learners.

Loretto's Stories

PAMIS have developed a multi-sensory story resource created in memory of their founder, Loretto Lambe. This resource consists of 3 sensory stories:

- Oona and the Giant
- The Selkie Bride
- The Tramp and the Fairy Boots

There is also a CD with recordings of the full stories, songs from the stories and an extra song for variety.

The last two pages of each story book offer suggestions on how to make and use sensory stimuli to use with the stories which will make the stories come alive for people with profound and multiple disabilities.

They all come together in an illustrated jute bag.

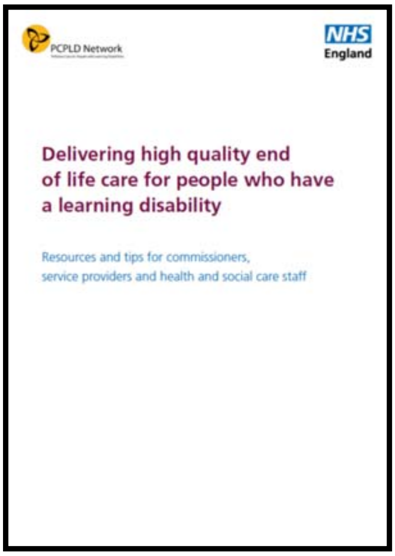
To preview video clips of the stories and to order http://pamis.org.uk/news/news/lorettos-stories/

*Read Maureen Philip's Storytelling article about these resources on page 8.

Delivering high quality end of life care for people who have a learning disability

Resources and tips for commissioners, service providers and health and social care staff

This guide has been developed to support commissioners, providers and clinicians to reduce inequalities in palliative and end of life support for people with a learning disability.



PCPLD Network

NHS England

Delivering high quality end of life care for people who have a learning disability

Resources and tips for commissioners, service providers and health and social care staff

SHORT COURSES & CONFERENCES

January

Title:	Sensory stories
Date:	8th
Location:	Leicester
Provider:	Joanna Grace
Contact:	http://jo.element42.org/training

Title:	Rochford Review - Recommendations
Date:	19th
Location:	London
Provider:	Hirstwood
Contact:	www.hirstwood.com

Title:	Profound And Multiple Learning Difficulties
Date:	25th
Location:	London
Provider:	Concept
Contact:	info@concept-training.co.uk

Title:	Sensory stories
Date:	26th
Location:	Newham
Provider:	Joanna Grace
Contact:	http://jo.element42.org/training

February

Title:	Implementing a non-subject specific curriculum for pupils with severe and complex needs, functioning at P4 - P8.
Date:	2nd
Location:	Manchester
Provider:	Hirstwood
Contact:	www.hirstwood.com

Title:	Sensory stories
Date:	16th
Location:	Walsall
Provider:	Joanna Grace
Contact:	http://jo.element42.org/training

March

Title:	Sensory stories
Date:	9th
Location:	York
Provider:	Joanna Grace
Contact:	http://jo.element42.org/training

Title:	Implementing a non-subject specific curriculum for pupils with severe and complex needs, functioning at P4 - P8.
Date:	2nd
Location:	London
Provider:	Hirstwood
Contact:	www.hirstwood.com

Title:	Sound sensory engagement
Date:	15th
Location:	Leicester
Provider:	Joanna Grace
Contact:	http://jo.element42.org/training

Title:	Sensory engagement for mental well being - Birmingham - 16/3/2018
Date:	16th
Location:	Birmingham
Provider:	Joanna Grace
Contact:	http://jo.element42.org/training

Title:	The Big Autism Play Day!
Date:	16th
Location:	London
Provider:	Hirstwood
Contact:	www.hirstwood.com

April

Title:	Sensory engagement
Date:	9th
Location:	Long Eaton
Provider:	Joanna Grace
Contact:	http://jo.element42.org/training

May

Title:	Develop your sensory lexiconary
Date:	11th
Location:	Plymouth
Provider:	Joanna Grace
Contact:	http://jo.element42.org/training

Title:	Develop your sensory lexiconary
Date:	18th
Location:	Bristol
Provider:	Joanna Grace
Contact:	http://jo.element42.org/training

June

Title:	Sensory stories
Date:	15th
Location:	Mansfield
Provider:	Joanna Grace
Contact:	http://jo.element42.org/training

PMLD LINK
sharing ideas and information

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About Us

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

Rob Ashdown	Former teacher of pupils with severe and profound and multiple learning difficulties and special school Headteacher.
Jeanne Carlin	Retired Disability Consultant and a parent of a young woman with PMLD.
Helen Daly	Mum to a young Adult with PMLD, previous career in Further Education for 20 years - including Curriculum Team Manager for Inclusive Learning and Developing an Improving Choice Programme for people with Complex Needs. Currently involved in carers groups in the Eastern Region, Learning Disability Partnership Board and associated projects.
Jill Davies	Jill Davies currently works for Oxleas NHS Foundation Trust as a community nurse specialising in mental health in people with learning disabilities.
Ann Fergusson	Annie is a senior lecturer in the SEN & Inclusion team at the University of Northampton, teaching on undergraduate and postgraduate courses relating to severe, profound and multiple learning disabilities. Her research interests relate to person-centred working, meaningful participation and the voice of the individual in promoting positive mental health and wellbeing. She works one day a week in a special school with a role for training and looking at impact. Annie has a brother with a learning disability. She is a family member of the Learning Disabilities Mortality Review Programme Advisory Group.
Michael Fullerton	Michael the Director of Quality and Clinical Care with CMG, 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 PMLD. Michael co-hosts the @PMLDChat Twitter chats.
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. Martin has experience of working in play and leisure, education, residential and advocacy.
Joanna Grace	Joanna Grace is a sensory engagement and inclusion specialist. She is the founder of The Sensory Projects which are run on the principle that with the right knowledge and a little creativity inexpensive items can become effective sensory tools for inclusion. Joanna co-hosts the #PMLDChat Twitter chats.
Rachel Parry Hughes	Lecturer in Social Work, Goldsmiths, University of London, researcher in the field of profound and multiple learning disabilities
Becky Loney	Becky has a background in running creative services for adults with PMLD within the voluntary and statutory sector and she established the Lambeth Mencap Carousel project. Becky is passionate about intensive interaction and sensory storytelling, and spreads the word by training staff teams in high quality activities and creative approaches.
Wendy Newby	Deputy Headteacher at The Shrubberies School, Stonehouse, Gloucestershire. This is a school for students with Severe and Profound Learning Difficulties
Sue Thurman	Former NHS Speech and Language Therapist for adults with learning disabilities with a particular interest in PMLD. Now writes and trains about communication and is a Registered Intermediary assisting vulnerable witnesses to communicate at police stations and courts.
Bella Travis	Policy Lead, Mencap
Hannah Young	Hannah completed her PhD studies on the loss experiences of people with PMLD. She is Researcher for PAMIS, a Scotland-based charity supporting families of people with PMLD, and has led a number of projects that aim to enhance quality of life for this group. Her experience also includes teaching, training and digital developments. Hannah acts as Welfare Guardian for her brother.

Disclaimer: Views expressed by contributors to **PMLD Link** are their own and do not necessarily reflect the polices and opinions of the editorial team

PMLD LINK
sharing ideas and information

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

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