

PMLD LINK



sharing ideas and information

Ideas and Insights

Spring 2020



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Cover picture from Lucy Williams article

GUEST EDITORIAL

Ideas and Insights

We know it is a difficult and uncertain time at the moment and our thoughts are with all of you. We want to praise both NHS workers and those working in social care, education and other services for people with PMLD. We are hugely grateful for the work you are doing to support people with PMLD and all of us at this time.

We hope you enjoy this Spring issue of the journal. We have had a wealth of articles covering a range of topics, which we want to share with you. So we have decided to make this a general issue. We hope the ideas and insights from families and practitioners will inspire you, and their personal experiences – whether challenging, joyful or both - offer you something to reflect on.

There are articles exploring Intensive interaction, on valuing a person's communication and the role of important objects from Mark Barber and Graham Firth, Sheridan Forster, Anne Laney, Andrea Ricci and Magdalena Jordan.

Pat Thomson has looked at the practice and guidelines of sensory storytelling and Pete Wells gives us a detailed step-by-step guide to delivering one. We hear about sensory songs from Bev Cullen, creating community through song from Eleanor Gibson, and we hear from Susannah Crump's family about the wonderful experience she had sharing sensory experiences with people with PMLD. In another piece, Shibden Hall is brought vividly to life as we read about the rich sensory experiences Gerard Wainwright and the young man he supports shared on a visit there.

Lucy Williams talks about her son Thomas and their family, sharing how difficult it is for her to think about the future. In Mike Ormian's article he shares the profound impact that a personal health budget has had on his daughter Rebecca's life. The photo of Rebecca says it all!

We also have two thought-provoking poems – one from Pat Graham, a family carer and another from Jo Fitch, a teacher. We have an article on play for children with PMLD from Helen Fitchett, a reflection on the meaning of independence from Sara Davis, and an article about 'Skiggle' from Christine Singleton (you will have to read it to find out more).

This issue is dedicated to Jeanne Carlin, our friend and colleague at PMLD Link. She will be much missed by us all. We start with an Appreciation of her.

With very best wishes from us all at PMLD Link

Rob, Jo, Maureen and Bella

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An Appreciation of Jeanne Carlin

The PMLD LINK Editorial Team

We are deeply saddened to share the news that our dear friend and colleague Jeanne Carlin died on Friday 31st January after a period of illness. Jeanne died peacefully, surrounded by people who loved her.

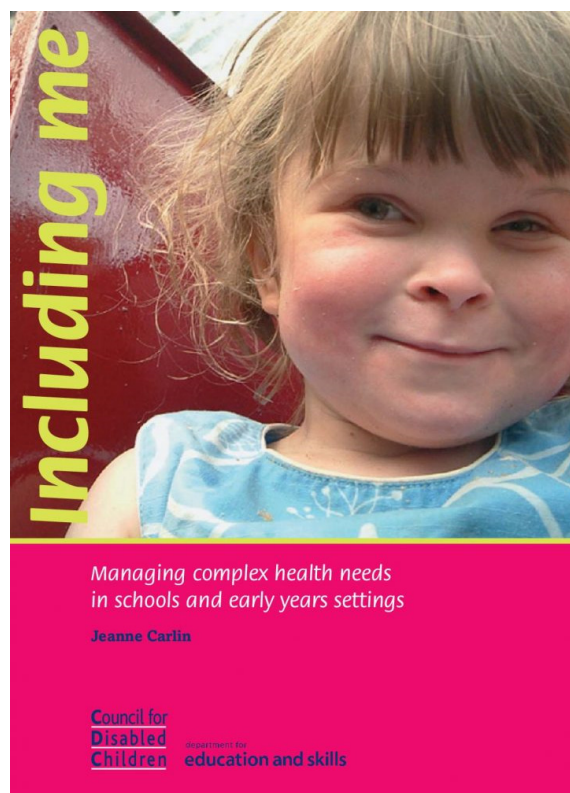


Jeanne was a much valued member of our Editorial Group from 2012, a trustee and the current chair of our charity PMLD LINK. Indeed, Jeanne was involved in editing the Winter 2019 issue of the journal when she became unwell. It was a huge shock to hear how ill Jean had become as many of us had seen her presenting at the Raising the Bar conference in Birmingham in November, sharing the innovative work they were doing in Hull. It is no surprise to hear that Jeanne faced the discovery that her death was to come quickly and unexpectedly early with the same skills and values that she lived by; and she even planned her final blog with a friend (www.peterhay.online/post/a-day-out).

Jeanne's interest and passion in this area of disability stemmed very much from her passionate devotion to the causes of equality and inclusion reinforced by the experience of being a parent of a young woman with PMLD. Jeanne was central to the team of family, carers and professionals who have tirelessly worked providing a good quality of life for her daughter Erica. Jeanne qualified as a social worker in 1990. She initially worked in child protection in the former unitary authority of Humberside and then moved in to children's disability services in Hull and the East Riding of Yorkshire. In 2001 she left full-time employment to become a freelance Disability Consultant.

Jeanne remained a strong advocate for social care and social work and used her public voice to draw attention to the highly skilled support provided by the social care staff in Erica's care home.

Jeanne was an accomplished writer. Three important examples of her published work resonate with us in particular. In 2005 Jeanne authored the handbook called *Including Me* published by the Council for Disabled Children. This was developed to provide schools, early years settings and health providers with practical advice to develop policies and procedures to ensure that children with complex health needs can access education and child care. In 2015 she was a co-author for an updated version called *Dignity and Inclusion* published by the National Children's Bureau. Jeanne was also the lead author for *The Raising our Sights How to Guide 2: Clinical Procedures* published by Mencap and the PMLD Network in 2013. This guide was produced in recognition of the fact that the number of disabled adults who now require clinical procedures has increased significantly during this century. It makes strong pleas to services and commissioners to develop services so that they can be accessed by these adults as is their right.





Jeanne sharing with Sue Thurman the management of the PMLD LINK stall at Raising the Bar 3 conference in Autumn 2019

Jeanne was not just an accomplished author; she was also an effective campaigner for equality and rights for disabled people. Although she formally retired as a Disability Consultant eventually, Jeanne continued actively to contribute and campaign in the disability field. She was a regular user of social media using Facebook, Twitter (@JeanneCarlin) and blogs (sandwichcarer.blogspot.co.uk) to share information, raise awareness and promote campaigns. She was a representative for the national partnership TLAP (Think Local, Act Personal) which aims to transform health and care through personalisation and community-based support (www.thinklocalactpersonal.org.uk/News/Jeanne-Carlin).

Jeanne worked closely with her local Learning Disability Partnership Board in Hull and, as a member of a vigorous PMLD subgroup within it, campaigned to secure: a specialist doctor in learning disability services with a background in general medicine and palliative care (a first for England); training in non-verbal communication for residential care staff; recognition from the local CQC (Care Quality Commission) that inspectors need to pay particular attention to the safeguarding of individuals with PMLD; clear guidance about who is responsible for providing and funding consumables (including gastrostomy tubes, feeding connectors, gloves, etc.) for individuals with PMLD and complex health; and better understanding of who are the actual adults with PMLD living in her city of Hull – where they live; what they do during the day; who funds their services, the age of their carers etc.

Jeanne was a warm, wise and caring person. Jeanne contributed immensely to the work of the PMLD LINK team bringing to bear on our work her enthusiasms and personal insights as a carer for 40 years. Despite her legitimate outrage with inequalities and barriers created by UK social, governmental and legal systems, she always dealt with people fairly and sensitively and with good humour. Through creativity and being resourceful she was able to bring out the best even in difficult situations. Jeanne had an ability to speak truth to power in a way which brought people on side.

Jeanne was a creative person - in particular, an amazing needlewoman. One of us still has a beautiful playmat Jeanne made for their son when he was born. Jeanne's creativity and needlework were evident in her quilt making and she generously used her skills to make quilts for young people leaving care, taking care to meet their individual needs, through the project Quilts for Care Leavers – Quilty Hugs. Another of us gave her a piece of batik fabric and she created something bespoke for a young person of African heritage.

Jeanne Carlin, far from retired, was a disability consultant, carer, disability activist, fond parent and grandparent. Jeanne leaves an incredible legacy that has, and will continue to improve many people's lives - in particular, individuals with PMLD.

Our thoughts are with husband Les, daughters Erica and Linzi, family and friends.



Why I'm scared I won't bury my child

Lucy Williams

No parent should have to bury their child, but we've known since Thomas was a matter of days old that he isn't expected to live beyond early adulthood. For a few days we were actually told he'd only live a few months, then a neurologist's analysis of his MRI scan revealed it was not so drastic as that. We spent 5 days though holding and looking at our baby believing he wouldn't survive the year. I've never known pain like it. I understood the feelings behind self-harm that week, the thought that maybe physical pain could take away the emotional pain (I didn't try it). I can therefore anticipate what it may be like when the time comes.

We've been told now that Thomas is life limited, that his life will be shorter than it should have been due to his conditions (Polymicrogyria, Microcephaly, Congenital Cytomegalovirus -CMV- and calcium deposits on the brain). Nobody has given us any time scale, the only guide we have is the knowledge that he qualifies for care at the local children's hospice, which is for children who aren't expected to live beyond 25 years old.

Thomas is currently 8 years old and we're so lucky. He is remarkably healthy given his conditions. The polymicrogyria and microcephaly are serious brain conditions that have left him profoundly disabled in every respect. Yet he doesn't currently suffer seizures. I know parents of children with epilepsy and it looks such a frightening thing to have to deal with. As every year passes and Thomas remains seizure free, I breathe a sigh

of relief. I don't know how much I can relax though and if there's still a chance he could develop them. For now though, it's a trauma we don't have to deal with.

Thomas is very healthy in other respects. Not being mobile means he doesn't run around and exercise his heart and lungs like healthy children. He also lies flat a lot more than healthy children. Children like Thomas are therefore more at risk of infections, particularly chest infections. As he has reflux Thomas is also at risk of aspirating (vomit and saliva going into his airways) which can cause issues such as chest infections. He's only had one chest infection in 7 years though and wasn't too ill. The last overnight hospital admission due to illness was for bronchiolitis when Thomas was under a year old and many healthy babies get that. He is quite remarkable. Thomas' good health though leaves me in the paradoxical situation that I'm terrified I'll die before him.



He's so healthy it's so hard to think of him dying in the next few years so what if I and my husband go first? We're only in our 40s now but who knows how healthy we'll remain and how long Thomas continues to do so. Then there's obviously the chance of sudden events like accidents.

I have absolutely no idea what would happen to Thomas if something happened to my husband and I. We have wills prepared and my parents listed as guardians for Thomas and his older sister. We made our wills when he was a baby and were advised to add a Letter of Wishes to go with it. This isn't legally binding but gives your preferences for things like care for your children. I have only just done it though because I didn't know what to say. I have just tackled it with my parents who have reassured me the children can live with them. I was so scared of talking about it for years, as I was afraid they'd say they couldn't do it as they couldn't cope. I would have totally understood if they did but I still didn't want to hear it.

Having these thoughts and feelings recently has prompted me to seek advice and review our wills. I've been advised we need at least one other guardian, someone of our generation but I can't think of who I can ask. As I said above it's a massive responsibility for

anyone, especially for those who have their own children and responsibilities even if Thomas didn't live with them, so I don't know who to ask at all. Imagine how difficult it would make a friendship if I ask someone and they said they couldn't do it. Whilst I'd understand, I'd feel awful for having asked them. So, it's on hold because I don't know what to do.

The biggest fear is therefore both my husband and myself dying but even if it was just me that's scary too. I'm Thomas' main carer. I'm the one who deals with all the professionals, who does the research on methods of communication and so on. My husband works away with a long commute so whilst he is wonderful with Thomas (and Thomas loves his Dad so much) he is less involved and less aware of everything. He'd have to give up work and take it all over but dying with me would be tonnes of information. I'm sure my husband would be more than capable, but I know how lost he'd be for a long time. I don't know how much Thomas would be aware. He certainly recognises us and has his favourite people, but I don't know if he'd notice if I was gone. In some ways that's a blessing I suppose. In others it breaks my heart. I haven't forgotten my daughter here. I just can't bring myself to think about the effect on her in any circumstance. It breaks me.

This whole thing is something that comes to me occasionally, but I've forced it into a box and I daren't open it. I know when I've lifted the lid on it, it hurts so much that I have to force the feelings back in and put the box away. I therefore find myself in a situation where I am terrified I may not bury my own child, because the alternative seems so much worse.

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Metamorphosis: A Personal Health Budget, and a life transformed

Michael Ormian

In my dictionary ‘metamorphosis’ is defined as: ‘a *change of form, substance, appearance, character...by, or as if by, magic: the marked change that some living beings undergo...*’

On 8th May 1969 my daughter Rebecca Mary Ormian was born, and I was there to witness her arrival. Sadly, the birth did not go well; it was a protracted labour and it was clear that things were not good. When Rebecca was delivered she was not breathing, and she was a worrying colour. She was rushed off immediately for emergency treatment, and eventually was returned to my wife and I looking a little more like the baby we wanted. Once we got her home we began to notice things that were different to the way our other babies had developed. Her head was always turned to one side, her limbs did not move freely, and she had a pronounced double-squint. Other signs that things were not normal led us to visit our GP and within a few months we had entered the frighteningly unknown world of disability: hospitals, tests, injections, scans, biopsies, consultants, fear, worry, and sleepless nights. Eventually Rebecca’s disabilities became apparent: suspected neuronal migratory disorder, intractable Lennox Gastaut epilepsy, profound intellectual and multiple disabilities, spasticity, inability to walk or weightbear, no verbal communication, lacking mental capacity etc. However right now, we are happy to report that Rebecca will soon be celebrating her 52nd birthday. She lives in her own wheelchair-friendly bungalow, right next door to us, and she has 24/7, 1-to-1 support from a wonderful, dedicated team of support workers. Rebecca’s package of care is fully-funded by NHS Continuing Healthcare.

Prior to October 2017, Rebecca's support workers were recruited and employed by a major healthcare provider who totally failed to see Rebecca as a person, and provided at best, an ineffective ‘baby-sitting’ service. Rebecca became more and more depressed; she didn’t want to get up and was always angry, bored, and frustrated. She tore at her hair and hands, and ground her teeth incessantly. A support worker told us that “she was at war with herself”. Her family felt helpless, and we were at an all-time low.

As parents of a disabled person, we have always held the view that ‘knowledge is power’, so when we heard of NHS Personal Health Budgets (PHBs), we had to investigate. What we read gave us hope – here was a way of taking the control out of the hands of impersonal



‘Big Business’, and using that control to bring about a better quality of life for Rebecca. It took us more than 18 months of PHB form-filling and dealing with apparently ill-informed, and ill-equipped, ‘professionals,’ but on 16th October 2017 Rebecca’s Personal Health Budget was approved. We knew that the responsibility for its success would bear heavily on the family, but we could not think of a better way of ensuring Rebecca's health and wellbeing. There was one thing we had already decided we would not do. We definitely did not want to be an employer; however, we did want to be able to select, interview and recruit Rebecca's support team. Quite by chance we came across Solo Support Services, a third-party, community interest organisation, and they were happy to help us by advertising for, and employing, the staff we selected. Definitely, a burden lifted! Solo is now employed to hold Rebecca’s Budget and provides a range of administrative and legal services for Rebecca, for which they are paid a monthly management fee from the PHB.

Before the PHB we were expected to use the documentation provided by the agencies delivering support (and there were quite a number over the years). Because we needed to keep detailed records of many aspects of Rebecca's life, such as diet, seizures, weight, medications etc., we wanted to design our own robust, but simple administrative documents that would provide that essential information. Solo Support worked with us to ensure the data collected would meet the needs of both parties.

As parents we are fast approaching our eighties, and we feel the need to step back a little from our current high level of involvement. Solo now employs Amanda, one of Rebecca's sisters, as her Service Manager, which relieves us of some of the burden, but also reassures us that direct family involvement will continue when we are no longer around.

Although we are not their formal employer, we feel strongly that the family must take the lead in the way in which Rebecca's support team delivers her care. The Personal Health Budget allows the team to be paid to attend six-weekly team meetings. The team is encouraged to jointly formulate the agenda, and to participate fully in the discussions and decisions. It is at these team meetings, (fortified by cakes and coffee), where plans are made for identifying and achieving the PHB outcomes required by our Clinical Commissioning Group.

Every month Amanda produces STAR News, a colourful and upbeat report of what Rebecca has been getting up to (STAR, by the way, stands for 'Super Team Around Rebecca', and they are indeed Super).

Rebecca has a wheelchair-accessible vehicle which allows her to sit alongside the driver and it transports her to all manner of exciting activities. The team has autonomy over how they, and Rebecca, spend their day, and Rebecca is doing some amazing things; ten-pin bowling, pantomime, cinema, singing group, exercise to music, adult LD club, steam rallies, motorbike nights and...she is also a 'lady that lunches!' As mentioned earlier, Rebecca's life before the PHB was dire in the extreme – because there was nothing to get up for, she would stay in bed for days. She lost many of the skills she had laboriously acquired over the years, and remained passive and totally disinterested in life in general.

The title at the top of this story is 'Metamorphosis?' I could have used the word 'Transformation', but whatever word I use, there is absolutely no doubt in my mind that Rebecca's life has changed beyond recognition. In the first few weeks with her new PHB team, we could see our Rebecca re-emerging. We said she was coming from a very dark place, back into the light.

From the outset our STAR team saw Rebecca as a lovely person and they set about giving her a lovely life. Within weeks she was laughing, smiling, playing again. She has learned how to pick things up and let them drop, open and close doors, turn lights on or off (more than one support worker has been plunged into darkness when Rebecca switches the toilet light off!).

For years Rebecca would sit with her head down, shutting out the world. Now there is a rapid realisation that things are happening around her, and she loves to watch the wind blowing the trees outside her window. She has discovered birds, and aircraft, and flowers, and sunshine. The greatest pleasure for me is to catch her at a quiet moment, just looking at things – I am always reminded of Rebecca's favourite story 'The Hungry Caterpillar' – Rebecca has certainly turned into a most 'Beautiful Butterfly'.

Every day we are reminded of all of the wonderful things that are happening to Rebecca: they can only happen because she has a Personal Health Budget. We had to make the PHB work, and it has certainly been, and continues to be, hard, challenging work – but the rewards are actually beyond description.

Would I recommend a Personal Health Budget for somebody with PMLD? The answer would have to be: YES, but you must know what you are getting in to; so be warned – it's a huge responsibility and definitely not for the faint-hearted. Could you cope with record keeping, administration, and financial issues? Can you argue your corner with the professionals, and be unafraid to press hard for the needs of your family member? I suppose the greatest downside to Rebecca's PHB is the amount of time we have to give to ensure that her life is as good as it can be, and that our own self-imposed high standards are always maintained. In my darkest moments I have sometimes asked myself "when will my life begin?" But I already know the answer – I just can't have my cake and eat it!

There is a myriad of information on the internet – just make sure it's current and reliable. Here are some websites that may help your research:

- People Hub www.peoplehub.org.uk
- Beacon - for Continuing Healthcare information www.beaconchc.co.uk

And we would also be happy to answer your questions. We are pleased to be able to share Rebecca's success story with you. With hard work and dedication, a better life is always possible.

Contact Details

Mike and Julie Ormian are Rebecca's parents.
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Being All Right

Pat Graham

There are days when I wonder what's wrong with me
There's not really anything much you can see
But it often catches me quite unawares
When I'm out shopping or drying my hair.

It's not contagious but I've not found a cure
Just one of those things that you have to endure
I do smile a lot but behind the façade
At times I just feel so unbearably sad

What is this dire condition I hear you say
You seem to have managed to hide it away?
You worked hard all those years and now you've retired
What about those arty new skills you've acquired?

You've changed your lifestyle, you eat quinoa and grains
You're seen beachcombing for hours, even in the rain
You've been known to write poetry on the train
Oh! For goodness sake you've become such a pain

So anyway... back to the point. I've digressed.
That's just displacement, is what Freud would have said
Why is it so hard to say what's still hurting?
Classic behavioural avoidance coping!

I was stunned to learn, my malaise has its own name
It turns out chronic sorrow's the name of the game
Just a few words will tell all you need to know
Guilt about yesterday and fear for tomorrow

I could tell you about the thoughts that haunt my nights
Pondering the imponderables; the fears and the doubts
About the things I didn't do, but should have done
And the things that I did, that I shouldn't have done

I wonder whether it might be all about guilt
And how to be forgiven for our perceived fault
But no one else thinks that we've done anything wrong
So we'll have to forgive ourselves all on our own

But hang on a minute. Just listen to me
Life hasn't all been doom, gloom and misery
So much has been lost but much more has been found
So many silver linings I could recount

Only Lauren thinks that my singing's great music
Or laughs at my dancing and other daft antics
My food's not fine dining but she eats every crumb
She can only say one word, but that word is Mum.

Would I change anything? Well of course I would
But that line of thought does no one any good
No; that's not a route that I want to go down
We'll just do our utmost to make this life count

Lauren is a person with a mind of her own
Life's an adventure; a journey to the unknown
So who cares if her label is PMLD?
She'll always be my bairn and that's all right with me

Contact Details

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Editors' note

Pat Graham is the parent of a 30 year old with
PMLD and has written a number of poems. Pat says
that this particular poem was inspired by a friend
who is still bereft more than 20 years later about the
loss of her daughter who had a disability and got her
thinking about how it feels to care for someone with
PMLD.

Intensive Interaction: Is it an intervention or an aspirational cultural norm?

Mark Barber and Graham Firth

Intensive Interaction is now practiced in a wide variety of settings, from early intervention departments in special educational settings, to facilities that provide care and support for people experiencing late stage dementia. Since the approach emerged in the 1980s, the teams of practitioners that have developed local cultures of good practice in these settings often comprise over-lapping generations of staff; while some may clearly remember the closure of the long stay institutions in which many people with intellectual disabilities lived, others will have never experienced cultures of support prior to the emergence of Intensive Interaction and the variants of the relatively recent positive approaches to supporting people who have severe social or communication difficulties.

Currently, Intensive Interaction supports the social inclusion of a very broad range of learners, service users and/or clients. While the approach emerged in the large residential ‘hospital’ settings in which people with a diverse range of needs were then housed, it is safe to say that it is used to support a much more diverse population now. While we would see this as positive progress, it can raise questions about whether aspects of Intensive Interaction practice change as the nature of the support provided adapts to accommodate the needs of the person being supported.

Intensive Interaction ‘Communities of Practice’ (Lave and Wenger, 1999; Barber and Firth, 2019) have been seen to range from established Intensive Interaction communities, some made up of accumulated generations of practitioners, others of pioneering ‘first’ practitioners, essentially creating their space within established and sometimes resistant cultures. Whichever they are, insights gained from the process of editing contributions for a book on the delivery of Intensive Interaction internationally (Barber and Firth, 2019) seem to support the notion that, while policies and organisational structures can be used to embed a counter cultural initiative into the fabric of a service or school, it is the commitment of the people who are prepared to go the extra mile – to go to work once they have arrived home, that actually ensures that Intensive Interaction cultures have been embedded, grown and then spread.

Fidelity and practice principles

As authors and providers of professional development, we hope that our confidence is well founded in saying that if we were to watch different people supporting a person through Intensive Interaction, while we would be able to appreciate the personal interactive styles of the ‘more skilled communication partner’, we would also expect that the

fidelity of the Intensive Interaction approach would be very apparent in the nature of how they respond to and socially engage with the person with a social or communication impairment.

People with a social or communication impairment or complex intellectual disability don’t ‘do’ Intensive Interaction, it is the person supporting them that ‘does’ it. There is certainly no conceptual chasm between using Intensive Interaction in a social context with an aged adult, or in a school with a young child. The spark of energy might well be brighter and more obviously playful with an 8-year-old than a 68-year-old, but the shared and mutually developed structure of the interaction would likely be embedded in the same principles.

The teacher would probably not see their primary role as supporting the 8-year old’s ‘quality of life’, but nor would a carer for someone with late-stage dementia, necessarily be focused on being the fuel for sustained activity in the older person’s ‘zone of proximal development’ (Vygotsky, 1978). But both practitioners would be alert to the growing familiarity of the shared narratives of easy companionship and nuanced exploration of the ‘what if’ possibilities of sustained social exchange. Both practitioners would be hopeful that their responses might occasionally result in ‘aha’ or springboard moments of more profound connection and learning. However, getting practices to this point in an organisation or service that supports people with intellectual disabilities, sometimes takes on the organisational equivalence of a sustained military campaign.

Intensive Interaction; a ‘social’ intervention?

Fundamentally, Intensive Interaction sits within the paradigm of a ‘social’ rather than a ‘medical’ model of support. Rather than being curative or restorative in

nature, supporting a person using Intensive Interaction essentially removes barriers to their inclusion. This can be achieved by focussing entirely on supporting the person to express their existing, but possibly latent communication abilities, in the responsive context described by Firth (2009) as a social inclusion model of support.

Where person-led, 'taskless' and purely social conversations are the cultural norm that characterises interactions between the staff in a setting and those who receive their service, there is no great need for Intensive Interaction. Sadly, however, for the moment, this description is usually an aspiration rather than a true picture. In most services for people with intellectual disabilities, Intensive Interaction is not the routine or automatic way you 'approach and support someone with a communication or social impairment', it is an 'implemented strategy'; it is therefore an 'intervention'.

So, if Intensive Interaction is seen as a social communication 'intervention', what identifies it as this?

Identifying Intensive Interaction as an intervention

The observation that, 'the worst thing that can happen in Intensive Interaction, is that the person being supported will have a great time', makes redundant the consideration of whether Intensive Interaction is an intervention, a manner of support, or just a way of sociably being with someone. However, when the approach becomes a technique, or 'different' or 'more considered' than common behaviour, questions arise such as, "Who is it appropriate for?" and "How is that decided?"

While the cohort of people supported using Intensive Interaction is identified via a range of routes and rationales, the practice of Intensive Interaction occurs largely as an intervention and usually in a separate or distinct context, serving an identified cohort. People supported through Intensive Interaction are commonly and variously identified by processes of elimination of the alternatives, by referrals within services, through pragmatic and cognitive assessments, through their behavioural attributes, or their clear rejection of the communities in which they find themselves. There is no clear or formalised path to the decision to use Intensive Interaction. While there may be advantages to non-prescriptive approaches in deciding when Intensive Interaction is an appropriate response or strategy, there are also complications.

We would conceptualise Intensive Interaction as an approach which is appropriate for an identifiable or self-announcing cohort of service users, customers, clients and/or learners. In a climate where agencies that

respond to the educational, health and social needs of people with intellectual disabilities are increasingly pressured by the merchandised and quasi 'therapeutic' interventions marketed to them, this inevitably leads to an 'in/out' discussion and allocation process, i.e. 'Where is the point at which Intensive Interaction is not the best (or even 'least worst') approach to support learning and/or social inclusion?' How can we respond to such questions?

The alternative view of Intensive Interaction as an intervention presents it as a 'process': a process of adjusting the (usually verbal) idea of a 'conversation', so that it includes whatever it is that the person who we are supporting is currently doing or is interested in, 'no matter how idiosyncratic the behaviour' (Nind and Powell 2000). Within this paradigm, the support adjusts with the interactive preferences and interests of the service user or learner. While this interactional style ensures that it 'is not the skills of the person with a communication or social impairment that enables them to interact, but the skills of the partner who supports them' (Barber, 2002), it also suggests that the interaction might just as easily settle on sharing the exploration of a blade of grass that a person has just found, as it might on the rhythmical sounds of a sentence in a treasured book that a person enjoys.

While the playful imitation, dramatic hesitation and synchronized attunement might identify the interactive support provided to the person with the blade of grass as Intensive Interaction, the fidelity of the approach would be less easy to identify, but no less present, in the support provided to the person enjoying the cadence of the sentence in the treasured book. Playing with words and sentences is likely to look more like the collaboration of a facilitative playmate than the person using closely linked movements with grass to create social interest.

In both situations the practice is focused on removing the barriers to the person's inclusion by focussing entirely on supporting them to rehearse and express their existing but sometimes latent communication abilities to their maximum extent. Just as crucially, both situations actually announce themselves specifically to the observer as Intensive Interaction because of their lack of focus on any predetermined or concrete outcome. More than any other identifying aspect, the more skilled partner's focus on 'the process' rather than the outcome, identifies the use of Intensive Interaction to the observer. Supporting social inclusion and subsequent communicative development to emerge from activities that are open-ended and led by the person, '... rather than from activities that drive toward preordained descriptions of them' (Hewett, 2012), separates Intensive Interaction from all of the other approaches which aim to effectively support and fuel a person's social engagement and learning journey.

Intensive Interaction as an intervention rather than an expectation

Given that Intensive Interaction aims to reduce and even remove the challenges of communication and social engagement for the person with the difficulty, how will their support be organised across a staff team or service? It may be that from an organisational or administrative perspective, Intensive Interaction benefits from being seen as an intervention rather than an assumed or expected cultural norm. Implementing an intervention knowingly, i.e. with consideration and planning over time, will often result in Intensive Interaction becoming an integral and culturally established practice that follows the person along their journey to improved social connectedness.

Recognising that Intensive Interaction is not an intuitive practice is useful in the process of raising awareness within a service or school where there are aspects of practices that may continue to build, rather than remove barriers for the people they support. Professional development opportunities, that create awareness of how support and/or teaching can be provided through practices that do not create the barriers that the service is intending to remove in the first place, are crucial. Until the preferences of the service user or learner clearly shape the manner in which their support and/or teaching is delivered, there remains a constant need to discuss and identify the barriers that impede progress and wellbeing.

Within organisational settings supporting a wide range of needs, that require active consideration to match practices with the needs, preferences, emerging strengths or learning styles, identifiable 'Communities of Practice' (Lave and Wenger, 1999) are a vital pool of experience and cultural knowledge. The reflective practices that occur within and across a 'Community of Practice' should ensure the continuity of an approach that contributes to the development of the self-esteem and emotional wellbeing of supported individuals and imbues them with the control and self-possession that identifies them as successfully included.

In such a supportive, practice focused body as a 'Community of Practice', Intensive Interaction can be adopted, developed and sustained in the longer term, and thus become embedded as the organisation's cultural norm to the undoubted benefit of the individual, the carers or staff team, and the positive productive capacity of the organisation itself.

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“Favourite things” ...the gateway to connection

Anne Laney

Many of the people we support have a favoured object, which seems to have particular importance or significance to them. They may hold it, flap it, mouthe it, or seek it out with determination. As we become increasingly aware of the impact that sensory processing has on people’s ability to engage with the world, and how they may use these things to alleviate anxiety and establish their sense of self, we become increasingly aware of how important it is to work with them to explore how these items of safety can become gateways to shared engagement.

Often, when we begin to build our relationship with people, and sometimes for a considerable time, people are reluctant to share or be parted from their favourite thing. And, we must ask ourselves, why should we expect them to? They may serve a vital role in how they make their lives work. The impact of not having access to them can lead to them feeling adrift, anchorless, unsettled, and in some cases, provokes huge anxiety. Of course there is sometimes a simpler explanation for why someone is so focused on something they are manipulating. It may be that the object is, to them, just more interesting, exciting or predictable, than people have proved to be.

When used creatively, with Intensive Interaction at the core of the process, favoured equipment can form the foundation of strong and trusting relationships. Sometimes the object eventually becomes superfluous as the relationship grows and the person discovers, and explores, how human connection can be as fulfilling and pleasurable as time spent with their favourite possession.

Us in a Bus began working with Rebecca when she was in her final year of school. We have been fortunate to follow her through her attendance at two further education colleges, with home visits during school/college holidays. This case study sets out our journey with her, and illustrates how Intensive Interaction can play a role in supporting people to gain confidence to communicate and to express their wants and needs, establishing resilient and adaptable qualities that will hopefully extend to other areas of their lives.

Our initial sessions with Rebecca were spent exploring her range of vocalisations, in conjunction with her preferred objects. At the time, these were tactile books which she explored with her thumbs predominantly, saying “feel it, feel it” frequently and with great enthusiasm. We quickly established several things:

- These books formed a safety net for Rebecca. Feeling the books (or often the carpet, or sofa) seemed to provide a sort of “reset” for Rebecca’s sensory world. Perhaps when she was experiencing interaction that was becoming too intense? Often an increase in unexpected or unfamiliar sensory or social contact creates an overload of sensation that becomes uncomfortable and necessitates regulating in some way. People are incredibly skilful at knowing when and how to do this but the methods may look strange to others.
- We were not allowed to be in charge of the books for anything other than a short period of time, although she was willing to hold them out to us for us to feel.
- Rebecca seemed to enjoy our echoed and mirrored responses to her suggestion we “feel it”.
- When we responded by embellishing her words slightly, she became more interested, especially if we used alliterative words.
- This interest often developed into laughter, especially when we left large spaces and waited for her to say her next word before we responded.

We also noticed how frequently Rebecca looked closely at our mouths as we were echoing her sounds and words. Over time, we came to think that she was becoming increasingly aware of the connection between how our mouths looked and what the sound was. She occasionally seemed to ‘test out’ a shape and then utter a variation of a word.

We spent many weeks exploring her books, feeling them when directed by her; always handing them to her when asked; creating daft stories about the characters; exploring the tactile concepts as widely as we could. We

established a trusting relationship with her with Intensive Interaction at its heart, within which we responded reliably, always following her lead and encouraging her to control our interactions.

After some discussion, we agreed that offering some alternatives to her “feely” books would be a way of testing Rebecca’s level of attachment to, and interest in equipment. We also thought that our objects would offer her opportunities to expand her experiences and potentially spark her curiosity.

We chose a variety of items that were all visually appealing, interesting for tactile exploration and some of which made musical sounds. Placing them all in a large, red, plastic bucket, we proceeded to encourage Rebecca to explore the items however she wanted to. We followed her lead as she twirled ribbons around her fingers or poked her fingers into the back of bricks. We used all her vocalisations, repeating and often embellishing with alliteration and playfulness. A good example of this is our joint focus on “The ball with the bell that goes bing”.

Rebecca often used the word “bing” and even more frequently “boing”.

We supplied a ball that happened to contain a bell. The articulation of the sentence above was ours, but its content was Rebecca’s. The rhyming was us, responding to Rebecca’s expressions of pleasure when we suggested words that would fit. The fact that the sentence (together with close focus, eye contact, laughter and physical exploration of the ball) provided the basis for an interaction that lasted for 20 minutes illustrates so many things about fundamental communication skill acquisition. Repetition is good. Actually it’s more than good, it’s vital. Operating within a relaxed and unpressured environment maximises opportunity for concentration. Creating fun and laughter is motivating. Having the confidence to be led entirely by the person you’re with, without making demands, is an incredibly successful way of actively exploring how they can have a positive influence on others. These interactions provide the ideal environment for encouraging expressive language, and treating these expressions as communicatively significant, maximises the possibility of them becoming intentional and meaningful.

Gradually, the “feely” books became almost superfluous. They were still present, but Rebecca rarely chose to access them except occasionally when a new member of the Us in a Bus team visited. This added to our thoughts that they acted as a “safety” net for her.

We consciously began to take less equipment with us, in the hope that Rebecca’s need for the safety net of

“things” would be replaced by her recognition that we were, in fact, more interesting than equipment and could provide the same level or consistency of response but in a slightly different way. In the same way a fluffy book felt the same each time she rubbed her thumb over it, we could be similarly reliable and consistent each time she vocalised. The responses from Rebecca were reassuringly reflective of our hopes. She did indeed seem to consider us - the Us in a Bus practitioners - as a stable, consistent alternative to things. She did not demonstrate any desire (and therefore presumably need) to calm her internal processing systems by “feeling” and “fiddling”. Our time together became entirely based on an exploration of how we could maximise the social and wonderfully warm connection we had established.

For the last year, we have been visiting Rebecca at the college she attends.

We take no equipment with us and spend time continuing to investigate how Rebecca can build upon the confidence she has gained, to both initiate communication with us, and persevere to make herself understood. Her vocabulary is increasing and she is linking words together to form sentences. She is exploring concepts such as “taller and shorter” and most exciting of all is spontaneously inviting turn-taking and sharing, both of which are significant developments in her understanding of the social world and communication. The clearest example of this developing awareness of other people, was illustrated when she carefully took a bracelet off the wrist of my colleague.



She explored it carefully, handed it back to her, looked at her, smiled, gently took it back again and then passed it to me. We sensed she had a real understanding of fairness. She seemed to want to ensure we had equal access to this thing. This is a significantly more advanced communication tool than the very definite holding on to her favourite things from when we first knew her. On a very recent occasion, she welcomed a brand new practitioner with the most welcoming manner, almost affectionately drawing her into our space. She seemed to be saying “come on in, the connection’s fine”.

To finish, a quote from Rebecca’s mum which we think illustrates that all we hope for Rebecca is happening.

“She is doing really well at college and really benefiting from the sessions she has with "Us in a Bus". She is much more aware and lets us know if she wants to do a particular activity or go to another room etc. She will gently nudge you on the arm, which is really great as she has always had such a placid nature. It is so good that she is not content to just let people ignore her, as this can happen as she is such a happy young lady”.

Possibly one of the most pleasing aspects of our journey with Rebecca is how her family reflect upon the changes in her. They describe everything that we hope will happen. An increase in self-esteem that translates into having the confidence to express wants and desires, the motivation to connect with others (because people are interesting after all) and, most importantly, the recognition of the role of Intensive Interaction in this process. It offers a genuinely effective tool for supporting people at times of transition, and ensures that the person, the essence of who they are, remains the focus as they run the gamut of education and life skill acquisition.

In the words of Oscar Hammerstein II, a songwriter and director of musical theatre, “I simply remember my favourite things, and then I don’t feel, so bad”. We must always remember the importance and significance of people’s favourite items. Intensive Interaction gives us the perfect way to become someone’s favourite thing, opening to them the possibilities and excitement of venturing out of their safe inner world, into our stimulating and social one.

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This article has previously been published on the Us in a Bus Website.

Further information

If you want to read more about how we encourage each other to develop our practice and raise our standards, spend 99p and have a look at Chapter 8 of *Delivering Intensive Interaction Across Settings: Practice, Community and Leadership*.

E-Book edited by Mark Barber and Graham Firth, from <https://amzn.to/3eJmnW6>

Now Communication

Sheridan Forster

Thousands of adults with severe and profound intellectual disabilities are now, through the NDIS (The National Disability Insurance Scheme – Australia’s funding scheme for people with disabilities), having access to speech pathology services. In many ways this is new territory for therapists. Experienced therapists are being flooded with referrals and new therapists are entering the field.

For many therapists, the traditional way of working may have been to examine present skills and recommend the next level of complexity. There is a logical impetus to work towards expanding a person’s communication repertoire and teach symbolic systems which will be more easily understood by partners. Particularly with the rise of electronic communication systems, devices are recommended with the hope that partners will model the systems rigorously until the person can then use it both for comprehension and expressive communication.

What is sometimes missing, however, is a deep examination of what the person understands now and what they express now. What a person does now is their “now communication”. It is how they connect, share, and relate to the world and people around them. It is their strongest neurological network.

Speaking neurologically, what a person does while they are sitting by themselves tells us much about their understanding – what they are doing by themselves is where their attention is focused. It may be tiny movements of fingers, shaking of a foot, sucking movements at their mouth, rhythmic rocking. Some movements may be voluntary, some involuntary but triggered by particular conditions. These movements are the textures that permeate the person’s day, either with a connection to the environment outside of the person’s body or mediated by internal factors. If we are sincere about interacting with a person, then these movements are part of the language that we must use with them.

Firstly, let’s consider what the person understands. Understanding what a person understands necessitates a grasp of the person’s sensory functioning. The more severe a person’s cognitive impairment, the greater the likelihood that they will experience sensory impairments, though, sadly the more likely their sensory impairments will not have been diagnosed. Unfortunately too many people may have not accessed assessments of vision and hearing, and those who have may have findings of “non-compliant with testing”, “not assessable”, or a polarised diagnosis of deaf or blind versus hearing or seeing. Few will have a quality low vision assessment that addresses

what the person can see, the colours, the settings, and the distances which best enable them to use the vision they have, and avoid painful visual stimuli like glare or particular colours. Few will have hearing aids, a description of which ear functions best, or a diagnosis of hyperacusis (heightened sensitivity to particular sounds) and its distressing affect when the person is in particular auditory environments.

Subsequently, our assessments of what a person can understand requires creative problem solving. We examine the person’s responses to sounds, including our voice, at different positions, pitches, and volumes. We watch the person’s responses to sounds, from turning, leaning, or attempts to cover their ears either with their fingers or through self creation of sounds that can block out external sounds. We watch for how the person uses their eyes: looking at people across the room or only when a person is sitting next to them. Their response to colours: reds, yellows, fluorescents, bright on dark on an iPad, light tracking in a darkened room, or light gazing (all giving some clues around potential cortical vision impairment).

Most importantly we examine how the person responds to our, and others’, engagement with them. What do they respond to: words, tone of voice, presence of a person, touch of a person? Do they demonstrate anticipation in an activity, memory of an action? Do they smile on your smile, laugh with your laugh, or demonstrate fear or indifference? If you ask them, “can I sit down?” and gesture to a spot, do they minutely nod, shift their posture, or demonstrate tensing muscles? How close will they accept your presence – a gaze from across the room, two metres away, on the couch, sitting with knees together? A deep curiosity for what a person may or may not understand is needed. For some people, with the possibility that they understand speech, you may preface your assessment with “I have just met you and I want to learn what you understand and how you express yourself; you can learn about me too”.

We need to accept, with seriousness, that we need to communicate with the person in a way that they can understand; to not do so compromises shared meaning.

It is inauthentic. For some people, this means our first language directed to them needs to be impressions on their skin at different body parts - firm, soft, quick, tickly, slow, tiny, broad, clapping, tensing - a rich language of sharing of the feelings of life. Some will need a rich language of non contact gestures such as pointing, along with our face expressing happiness, frustration, tiredness, shared excitement. For others, single words with gestures will be their way of understanding; acknowledgement is needed that a multiword sentence may result in many words floating into the air and the words that land at the person's comprehension may not be the ones intended (e.g. "don't hit Santa" may only be understood as "hit").

Our next challenge is to see how the person expresses themselves. Again, we observe the movements that the person makes when alone. What is their face expressing, their hands, their feet, their torso, their sounds. Often the expressions are best translated not into words, but word qualities: languid, excitable, considered, heightened, restless, attentive. In presence with a partner, what expressions do you see: leaning in proximity, reaching, retracting, caution, lingering gaze, smile, lip smacking, pointing, eyebrow raising. We look for any signals indicating levels of arousal. For some people, in parallel to typical infants, turning away, grasping hands together and wringing, may be used to reduce a feeling of being overwhelmed in an interaction. They are signals for a partner to slow, soften, and wait for reengagement, but are too often interpreted as signals for the partner to leave the person alone.

Everyone is expressing themselves in some way. Their moves and stillness are all expressing a state of being. We need to observe with our eyes, ears, and touch senses to capture the expressions that can share a meaning about what the person is thinking or feeling in the present moment. Much like the act of mindfulness, we need to be aware of all that is happening now.

Sometimes the way a person expresses themselves can best be seen by looking at a video recording of an interaction. Transcripts of interaction, describing the moves beyond words, allow the dialogue to be observed. Watching the video, in different ways, allows you to change your lens for meaning. Watching without sound will reveal another story. Watching in slow motion will illuminate how two people are responding to each other microscopically; the proposition of who initiated and who responded will become blurred. As a therapist, you can write down this transcript to help other people see what you are seeing, and explore alternative interpretations to what you see, including acknowledging when you are not sure what a person is expressing with particular movements or sounds. Setting this scene of curiosity and willingness to be right, wrong, and explore alternative

interpretations is an essential stepping stone in quality planning, goal setting, or supported decision making.

Combining an understanding of a person's comprehension and expression lays the foundation for an authentic conversation with the person using what they can do. Feelings can be shared and heard, expanded or softened. To be shown that you've been understood by another person is the blossom of a flower: "I express my feelings and my partner shows me they've understood (or tried to understand) by repeating my feeling in the same way".

To respond to a person's feeling by only using words, for example the person laughs and you say "You're happy" may be a speckle of meaningless word dust to the person. But for you to laugh back, lands on the person's brain: "I can hear my partner knows what I know".

The same is true for expressions of sadness, pain or frustration. It is important to hear and let the person know you've heard their expression before being tempted to try to change their state. For example, a person growls, grasps their chest and writhes suggesting possible reflux – you can respond by making the same sound to let them know they are heard. You will often find that people will gaze towards you or pause if you repeat their action, showing that they have noticed you noticing them.

In the area of mental health we know that validating a person's feeling is essential. To have your feelings ignored, invalidated, leads to feelings of isolation, exacerbation of the feeling, and fails to support a person in developing their resilience or problem solving for responding to the feelings. Holding someone's hand, metaphorically, with the feeling, allows you to meet the person where they are, and gently guide them to a resolution – even if that resolution is that pain, frustration, anger, and sadness happen, they will know they are not alone in those feelings.

Topics of "How about we do this with our hands", or "Let's drop these objects" form the basis of turn-taking and anticipation. Often our perception of whether a person is truly understanding turn taking is at first tentative; "I'm not sure if they do understand it... but we go with it", admits its exploratory nature. Simple sharing or games build rapport and a desire to be with another person.

It is essential to acknowledge that turn taking is only possible if two people have access to the same behaviour. You can not turn take in a clapping hand if one partner cannot move their hand. You can not turn take in a song if one partner has no voice. But if you both have access to a movement or sound, then you have

what is needed for a turn taking interaction – subsequently using what you’ve observed about what the person can already do is needed, is the starting point, for this mutually imitative engagement.

Unfortunately, what is missing from many of our service systems and communication interventions is the essential ingredients of two people who want to authentically engage with each other.

Here lies the challenge in assessments and interventions for adults with severe and profound levels of intellectual disability – two people who want to authentically engage with each other.

Our assessment reports need to take the ingredients and spell out the recipe. The recipe for authentic engagement with a person with the most complex communication needs is rarely obvious. It is rarely an adaptation of an old family favourite that you’ve used for years. It is a thoroughly unique combination of understanding what the person understands, being receptive to every expression that the person makes, creating a bridge of sharing meaning using these ingredients.

Every time we meet a person, they already have a language. The sad thing is, too often, others are failing to use their language with them. Others are often trying to pull the person to use a different language, perhaps speech or pictures. Second language learning is of value; don’t get me wrong. But failing to use the person’s now communication, even as a foundation for building their second language, leaves the person in a communicative abyss. Alone. Not understood. Not shared.

Our reports and interventions need to teach partners the person’s rich now communication. The reports and interventions need to give permission and overcome systemic barriers that may try to stop us from using the person’s language. Our reports, interventions, and interactions need to acknowledge the complex ethical issues, and the dynamic way that we need to explore how to be with a person authentically where there will be points where we are unsure of meanings or what the right thing to do is. People with severe and profound intellectual disabilities are complete people now, they are communicative and relational now... we need to be willing to meet them.

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Being with a 'Sensory Being'

Susannah Crump

The following piece was written by Susannah Crump, by a mindfulness practitioner, about her experience of sharing sensory experiences with people with PMLD. It offers a nice outside perspective on some of the joys we are all familiar with. Sadly Susannah passed away recently. Her friends and family said that she had told them all about her experience and the profound positive effect it had on her. They are all keen that her words are shared.

I had spent time with a teacher and her 6th form tutor group before joining her and assistants for a Tacpac (music and touch) session for learners with PMLD. I loved it. Most striking was the quality of the relationships between staff and students. I witnessed the depth of understanding and prizing of each student. This demonstrated to me the staff's trust in the uniqueness and potential of each student and the commitment to ways in which this could be honoured and developed. This underlined for me the fundamental nature of relationship and the richness of the experience and learning that flows from relating in an attentive, open, respectful way.

As I write this I see the room of 'sensory beings' in my mind's eye:

*The teacher greets them, each and every one.
Respect and care embodied.
Holding them. Looking into their eyes.
Their being.
Each one, unique and precious.
Allowed to be.
All welcome here.
Enfolded in love.*

*As the music begins, J's face lights up.
He rolls his head, and around and around.
Is he feeling the music?
Letting it swirl in his body as it rises and falls in pitch and volume?
Or am I imagining this?
Delight on his face.
He rocks and claps.
Yes, he is responding to the music. This is sensory-being in front of my eyes.
The staff are attending to other children who need hoists and cushions.
My gaze is drawn to J.
I feel warmth spreading in my body and I am grinning, I realise, as I watch him.
He doesn't look at me.
He is experiencing the music and I am at a distance yet feeling it with him.
Delighting in his delight.*

And now his attention to the music and involvement in it seems to fade away. The music continues and he becomes still and his face less animated.

I am reminded of my own experience of practising mindfulness - it is much like this. When I direct my attention to listening to music, or to my body in movement, or to my breath, I focus for a while and notice details of my experience and notice how I respond. Sooner or later my attention fades or wanders or is caught by something else.

Now I am invited to work with A. She has bare feet and I take off my shoes and sit on the floor, facing her.

She is not looking at me, but at the screen and I see the side of her face.

We have only just met and I ask her if it's okay for me to work with her. She seems to look at me for a moment or two then back at the colours and shapes moving on the screen. What does she see? What does she hear? I don't know.

What do any of us know about what another sees or hears?

The instruction is given to stroke A with the furry fabric. I choose to rub her arms with it. How is she responding? I have read that a firm touch may be more acceptable than gentle touch and I try to keep my strokes firm and in time with the music. A seems to accept this. I move the cloth onto her leg, her ankle and bare foot and wonder how this feels to her. Her foot arches slightly. I press the cloth firmly onto her lower leg as I prepare to move it to her back. I rub from the outside of one shoulder across her upper back to the outside of the other shoulder. And repeat. As I stroke back and forth from shoulder to shoulder, A sits still. I notice the bare skin on the very uppermost part of her back and notice myself questioning how the furry cloth might feel for A, touching this bare skin. I move the cloth there, turning and looking for any signs this is unwanted. And how about her neck? She moves her head a little more as I touch the back of her neck with the fabric. Her face? I

touch the furry cloth to her cheek and she moves her head away. "Not yet", she seems to be saying.

So I return attention and stroking to her shoulders and the middle of her back and arms and legs and feet. I hold one of her hands and rub the cloth on the back of it. What are her hands saying to me? I don't know. I notice the softness of her skin, her long fingers and thumb grasping my fingers.

And now the music is stopping and I add a little pressure and firmness to my final stroke.

I look into A's face and she holds my gaze for some seconds.

And now, new music and chopsticks. Chopsticks! I feel tentative. I attempt to play on A's arms, legs and feet and back and shoulders. Tapping. I remember the finger tapping I have done on my own head (as a warm up in choir and as part of a mindfulness practice). The pleasant memory encourages me to tap gently on A's head. Is that okay I wonder? Her head is steady as I do this. I think it's okay. I tap on her hands and she takes one of the sticks from me then drops it. What is she saying? Our eyes meet. I pick it up and tap again.

The time comes for the dry kitchen sponge with one side rough, one side soft. I notice images and memories in my mind of scrubbing the inside of pans. I feel an urge to "test" the rough side on myself before stroking A with it. To my surprise the rough side does not feel as rough as I imagine. In fact my sense of touch doesn't register "rough"-only my eyes do. My sense of touch registers pleasant. I feel more confident in stroking A with both sides, each in turn.

Faster, more rhythmic music starts for the next item- a small paint roller. A's face and body become alert. Is that a smile? She lifts her arms a little and rocks her trunk from the hips and her face becomes more animated. I feel excitement rising in my chest and my body starts mimicking hers and I feel as if I am doing a seated dance with her, rolling the roller rhythmically on her arms, legs and back.

Now I am given some warm water and a small bath sponge. I register the temperature of the water as I soak and squeeze the sponge. I "squelch" on A's bare legs and feet, on her hands which open and close as I do so. How will this feel on her face, I wonder? I touch the sponge to her forehead and she keeps her face steady as I move to dabbing cheeks and the back of her neck. She meets my gaze. I dry her face and her neck and her feet. I feel very tender towards A and to those small soft feet, a little cool to the touch, though the room is warm. My hands are warmer and I feel the urge to place them firmly on her

feet. And I do and she sits as she has done throughout, with her legs crossed, one foot under the other.

So now I am given a soft fleecy blanket. "For swaddling" I am told. I put the blanket around A's shoulders, wishing it would reach a little further down to cover those feet. I reach my arm around her, keeping the blanket in place and I keep my arm around her shoulders as I sit by her side. The music is gentle, and A begins to sway away from me and back, away from me and back. As she sways back she rests her head on me and I am touched. A warmth and tenderness arises in my heart area and spreads to my chest and arms. As she sways away and back, I look into her eyes and she looks into mine. No words needed.

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Editors' Note:

In this piece Susannah uses two terms that are often used by Joanna Grace: 'sensory-being' - the enveloping of natural presentness and awareness in an unfolding sensory moment; and 'sensory beings' - people whose experience of the world, and meaning within it, is primarily sensory.

Grace, J. (2017) *Sensory-Being for Sensory Beings: Creating Entrancing Sensory Experiences*. Abingdon: Routledge

The “My Bags” project

Andrea Ricci and Magdalena Jordan

We all carry our personal items with us at all times. We keep them in the wallet, handbag, rucksack, in our pockets etc. They have various relevance and different importance to us, but we need to have them with us always. Objects and personal possessions create the sense of reassurance, they are small yet precious extensions of our lives. They are part of us and of who we are.

And there is where “My Bags” come from. “My Bags” are small bags used to carry personal items important to and for the individual. Inspired by the work of Joanna Grace and The Sensory Projects, we have observed that people we support don’t necessarily carry personal objects with them. But why? We know for sure that all of them have unique and exciting interests, hobbies, likes, dislikes, which undeniably can be associated with and embodied by personal objects – objects that can be put together in the bags... MY BAGS! “My bags” that can become a good starting point for an introduction, be fantastic ice breakers, conversation starters, as well as communication boards and somehow three-dimensional support plans.

People we support have selected a number of objects that are precious to and for them. That could be because they are super sensory, fun or dearly loved, they bring back the memories, they are reassuring, they are soft, loud, make funny noises, they smell good or because they are the best crisps ever!

We also included photos and objects of reference as they empower and enrich “My Bags”. So for example we have got photos of people, places, vehicles, symbols. They also can be put together to create a conversation related to the object loved or chosen by the person. All of them can create the link between the person and the outside world.

“My Bags” is a simple yet powerful tool which could be the way to show an interest and the way to tell the person: “I am here and I want to know everything about you”.

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Deconstructing Doris!

Pete Wells

When I was asked to write a story about springtime for the glorious PMLD Link magazine my mind raced with visions of the countryside, teeming with new life, newly hatched chicks, ducklings and beautiful springtime flowers. Naturally, before long, these idyllic scenes had morphed into the image of a frustrated duck sitting on a football waiting for it to hatch, as the more sensible thoughts in my head often do! Using a variety of balls with my students in the classroom is a great way of developing hand eye coordination, observation, motor, tracking and turn taking skills, so it felt like a nugget of an idea for a story. And lo, the idea for Doris the Dozy Duck was hatched!



Doris flounces in at a flabby set of twelve rhyming couplets, yikes! However, as the reader of the story, YOU are in command, so feel free to remove a couple of erroneous lines if that suits your learner(s) better. Also, please don't think you have to read the story as written (though the singsong nature of the couplets may suit your learners well). If there's too much language, feel free to summarize each part of the story - for example, the first lines could be chopped down to "Doris Duck has lost her egg!" the second could be "A fox took the egg!" and so on. As long as you're consistent in your delivery, Doris won't mind how you tell her story!

Knowing that you're free to cut down on the story, it's worth thinking about how you're going to deliver the lines and use your props too; is there one storyteller or many in smaller groups? Do you have one set of props or many, to ensure wait time is reasonable and engagement not compromised? If you are limited with props, then a 'round robin' approach to telling the story may be beneficial (i.e. one group starting before another so props are available to different groups at different times).

Last thing before we start, it's good practice to have a routine before your story, if you are in a structured setting. This could be an object of reference, a particular aural cue, positioning of students, a sensory trail or a particular location – a consistent approach to the start of story time will get your learners cued in and ready!

So, with your learners in position, the lights down and your screen fired up (there's a switch-adapted, animated version of the story in the 'Free Special Stories' section of my website at sensorystoriespodcast.com) let's break down the story of Doris the Dozy Duck. Please note, there are multiple ideas for props for each line, please choose the ones that work best for your learners!

So here we go – several ways in which I would tell this silly little story. I hope it's useful, and above all, enjoyable for you and your learners!

A few things to think about before actually telling the story. Firstly, think about what version of the story you're going to tell and how? One of the (mercifully few) rules of sensory story writing is to keep things brief and to distill information right down to its very essence. Some say that the golden rule is to keep sensory stories to ten sentences but, as you can see, the very verbose Dozy

Dozy Doris Duck and her Missing Egg

By Pete Wells

Dozy Doris is a dizzy duck, running around in a terrible flap!
Because she's lost her new laid egg! Cor blimey! Fancy that!

(Explore Duck toy/feathers/duck whistle)

But Doris' egg, it has been stolen! By a wily fox named Greg!
Whose very favourite dinner, is freshly laid duck's egg!

(Explore plush fox/puppet, anti-static duster or taste egg mayo)

Doris searched all around the duck pond! And on the short-sighted armers!
It's not next to his tractor! Not under the straw in his hay barn!

(Hide items (but no egg) in a box of Hay/water/Orbeez, interact with toy tractor)

Doris' egg's not by the pig sty, nor by the bed of springtime flowers, Dizzy
Doris is in a tizzy, she's been searching now for *HOURS*!

(Smell flowers/flower scent/explore compost/vestibular jaunt!)

It's not under Daisy's udders! Not in the short-sighted farmers ditch!
Then dozy Doris spots a spotty egg! Next to the football pitch...

(Feel marigold/changing glove filled with warm water or introduce football)

Is this Dozy Doris's egg? The dizzy duck can't really tell!
It looks very, very, *VERY* big! With black spots on a bouncy shell!

(Bounce football)

"I don't remember pushing *THAT* out!" Said Dozy Doris with a gasp!
Before she promptly sat on it, waiting for it to hatch!

("I don't remember pushing that out!" on BigMack/ Tap head / practice gasping)

The short-sighted farmer saw a football! But did not see a duck!
He kicked the ball with all his might! What rotten, terrible luck!

('Kick' football)

Poor Doris flew straight through the air, then landed with a splat!
Right on top of Greg the fox! Cor blimey! Fancy that!

(Duck whistle, slide whistle)

Greg the fox let out a mighty howl! Then ran off, not looking back!
And as Doris sat upon her egg... its shell... began... to crack!

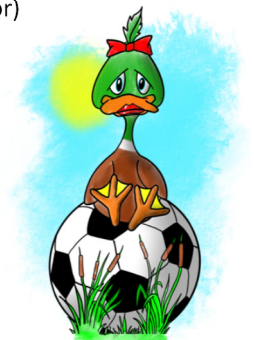
(Foxy toy/puppet. Large plastic egg)

Out flopped a ball of feathers, two webbed feet and orange beak,
"Mamma!" cried the duckling, kissing Doris on the cheek!

(Feathery cat toy/feather duster, damp sponge on cheek, "Mamma" on single switch communicator)

Now Greg the fox stays away from Doris Duck, he's scared she'll squash
him flat!
And Doris and her duckling are very happy. Cor blimey... Fancy that!

(Hugs/massage)



Line 1	
Dozy Doris is a dizzy duck, running around in a terrible flap! Because she's lost her new laid egg! Cor blimey! Fancy that!	Explore Duck toy/feathers/ duck whistle.
<p>Let's start by introducing Doris the Duck! Visually or physically exploring a duck toy would do the job nicely here. However, you should be careful to ensure that your prop does not confuse. It should feel like a duck. So for our most complex learners, a rubber duckie would be too confusing! A plush duck will do, and if you can get one that makes a sound when squeezed, then that's even better as it promotes functional exploration and gives your listener a little gross motor work out! I ordered a 16cm Mallard which does six realistic quacks when squeezed for around £8 from Amazon. It's great, however sounds like the operatic Fortuna Imperatrix Mundi from the Omen films, which I must admit is scaring me a bit!</p> <p>Some learners may appreciate playing with some feathers here, which are great for throwing, transporting, tracking and blowing, if your learner is able.</p> <p>Alternatively, duck callers are very cheap (£4 for two on Amazon) and, forgive the pun, a hoot! They make a great sound which students can learn to anticipate. If your learner is able to blow, then by all means, let them have a try! If not, try recording you duck caller on a BigMack or single switch communicator of choice.</p>	

Line 2	
But Doris' egg, it has been stolen! By a wily fox named Greg! Whose very favourite dinner, is freshly laid duck's egg!	Explore plush fox or puppet/anti-static duster or taste egg mayo.
<p>Again, a plush toy or puppet will work a treat here! Remember to be animated with the toy, taking the fox in and out of the learner's vision, playing peekaboo and allowing the student to grab for the toy. Again, there are some great ones online, including a 45 cm beauty for £2 from Wish.com!</p> <p>If you don't want to use a toy, then you can simulate Greg's bushy tail with an anti-static duster. This will be great for a wily tickle and can look very stimulating, especially under UV light...</p> <p>Another idea would be to taste some 'egg mayo' sandwich filler here. This is nice and mushy for our learners and can be a real tasty treat! Of course, if your students have made the egg mayonnaise in a previous lesson, then that's all the better! I often place gustatory items at the end of a story to make a pleasurable shared experience that forms the basis of your plenary – however, a little munch at the beginning of a story can really motive your learners right out of the gate!</p>	

Line 3	
Doris searched all around the duckpond, and on the shortsighted farmer's farm! It's not underneath his tractor, or in the straw in his hay barn!	Hide items (but no egg) in a box of Hay/water/Orbeez, interact with toy tractor.
<p>An excuse for a rummage in some nice, soft hay or playing with some water now! Water play is great for developing fine and gross motor skills and hand-eye coordination through actions like pouring, squirting, scrubbing, stirring and squeezing, if our learners have the mobility. Try hiding some stimulating items in the water (or a tray of Orbeez water beads) and let our learners have fun exploring different textures and temperatures. Alternatively, a box of hay with stimulating hidden items can be fun – just remember not to hide an actual egg in there!</p> <p>Over the years, many of my lovely learners have been fascinated with toy cars and things with wheels, so a nice tractor to explore and drag across their tray may be fun for some learners here...</p>	

Line 4	
Doris' egg's not by the pig sty, nor by the bed of springtime flowers, Dizzy Doris is in a tizzy, she's been searching now for HOURS!	Smell flowers/explore soil or compost/vestibular jaunt around the learning space.
<p>Smell is a super important sense which is linked to some pretty emotional and powerful areas of the brain. Smell is linked to memory, strongly influences our flight or fight response and is ace for adding emotion, drama or tension to a tale. It's also great for encouraging pre-verbal communication. When crafting your own sensory stories, please be sure to remember to include some pleasant smells! It's easy to regularly pull out the stinky fish, blue cheese or seven day old underpants, which always get a great facial reaction - but remember we want our stories to be fun and enjoyable, so please be mindful to be sensitive with props and try and use some more pleasant smells. Offer a range of contrasting smells too, this promotes choice making and independence and can help learners choose their lunches and toiletries in time. Our smell for this story is flowers, which can be a couple of real, ideally contrasting smelling bouquets of flowers or, more realistically and financially sensible, some flower smells – these can be deodorants, candles or, from my favourite company Aromaprime, a couple of vortex cubes (they do lots of floral smells, from roses to honeysuckle to wallflowers). Remember, offering a choice of smells is good practice and great for promoting choice.</p> <p>Alternatively, you can make like Doris and explore some soil or compost here. The nice, cool muck can be great fun for exploring, especially if you hide some favourite, stimulating items within! Nice links to horticulture here too.</p> <p>An often-overlooked sense is the vestibular sense, which is key to balance and movement. If your learner is able, then why not have a little jaunt around your learning space, looking for Doris' pesky missing egg? As with all of these suggestions, you'll have to use your professional judgement here - we don't want to lose, overstimulate or confuse learners here, so this certainly won't be for all!</p>	

Line 5	
It's not under Daisy's udders! Not in the short-sighted farmers ditch! Then dozy Doris spots a spotty egg! Next to the football pitch...	Feel marigold / changing glove filled with warm water or introduce football.
<p>A good old changing glove or marigold filled with water has been representing the humble cow's udder for as long as I can remember! Wonderfully stretchy and durable, I have many learners who enjoy a good squish of a rubber glove! To add stimulation, you can add glitter, beads or other items, providing you aren't going to confuse your audience.</p> <p>You may choose to introduce the football here. Balls are great for our learners – they feel and smell great, come in different sizes, small movements can bounce around the classroom and they're great for promoting coactive exploration, turn taking and partnership working, if that's where your learner is at...</p>	

Line 6	
Is this Dozy Doris's egg? The dizzy duck can't really tell! It looks very, very, <i>VERY</i> big! With black spots on a bouncy shell!	Bounce football
Here you really can explore your football – squish it, track it, bounce it. Have fun!	

Line 7	
“I don’t remember pushing THAT out!” Said Dozy Doris with a gasp! Before she promptly sat on it, waiting for it to hatch!	“I don’t remember pushing that out!” on BigMack/ Tap head / practice gasping.
<p>Ho ho ho, my favourite line here! Students can deliver line this using your (hopefully) often-used single switch communicator! We’ve come a long way since the humble BigMack – try using a BigMack Step-by-Step with levels. This means you can have a range of appropriate sounds or break up a sentence, encouraging multiple presses. With a levelled BigMack, you can have store sounds on different ‘levels’ – so that brilliant “Quack!” you found on the internet before the lesson can be stored on level 2, so you’re not scrabbling around google mid-story trying to find it again. Of course, your ‘Good Morning’ song or whatever will be stored on level three, and always will be, meaning you can use level one for grabbing sounds on the go. Of course, your BigMack (or other sound switch) is going to help with those wonderful cause and effect skills, promote intentional communication and be a tremendous way to fart when the headteacher walks in the room...</p> <p>You may also want to tap your own, or your learner’s, head a couple of times with your finger here and say “I don’t remember pushing THAT out!” in your best, Oscar winning Sir John Gielgud voice. Of course, you’d try to get your learner to vocalise this too, in any way they can. Note: Some of you may work in a setting where there is a no touch policy and this would be frowned upon. In this case, may I suggest you blow a large raspberry at the boss, shove your resignation up their nose and go and work somewhere that understands the importance of human interaction and common sense as quickly as possible?</p> <p>I love getting my students to vocalise during my stories. However, for the vast majority of my learners, spoken word is unmanageable so I firmly believe that any kind of vocalisation from them is a meaningful, exciting bit of script or dialogue in my story. So try to perform your most theatrical gasp and, if appropriate, invite your listener to mirror it. Capturing and replaying the tiniest noise from our learners can be extremely powerful and can certainly contribute to the beginnings of real meaningful communication.</p>	

Line 8	
The short-sighted farmer saw a football! But did not see a duck! He kicked the ball with all his might! What rotten, terrible luck!	‘Kick’ football
<p>It’s time for anarchy in the classroom as you get your listeners to hoof the football any way they can! This can be great physiotherapy and help with proprioception as the learners try to concentrate on areas of the body they may not usually see, and try to move those extremities. Of course, many of our learners will have little to no movement in the legs so some help from an adult would be much appreciated here! Stretching and elongating tight muscles and connective-tissue is of huge benefit to many of our learners and will form the basis of much of their physiotherapy programs.</p> <p>Though the short-sighted farmer kicks the ball, it is not a life-and-death matter that your students have to kick - they just have to move the ball any way they can. Obviously, for not so little Jimmy who enjoys listening to his sensory stories in his standing frame, it would be impossible, some movement of the ball using any extremity is what we’re after here.</p>	

Line 9	
Poor Doris flew straight through the air, then landed with a splat! Right on top of Greg the fox! Cor blimey! Fancy that!	Duck whistle, slide whistle
<p>Fixating and potentially tracking Doris the duck as she soars through the air is potentially what we're after here! Tracking is a difficult skill, involving all kinds of complex processes and reasoning skills which many of our learners simply won't possess yet. However, if they do, tracking is vital and forms the basis of several huge blocks of development. Be sure to be aware of any visual impairments your students may have. The field of vision may be limited in some so you have to know the sweet spots of where they can see! Tying some fishing wire to your duck can be a great effect as the flight path can look somewhat more realistic and the students can reach out and bop Doris like a great quacking piñata!</p> <p>An alternative route to telling this part of the story lies in the good old swanee whistle! Myself, and many of my learners, love a good slide whistle – it certainly is the most deliciously suggestive of musical instruments. They are great for practising blowing and breathing techniques and also hand eye coordination as students attempt to pull the slider. If this is too much for your student, then a slide whistle noise on your BigMac will suffice!</p> <p>You may want to bop a skin drum here too, as Doris lands with a splat on Greg the fox! This can be another great excuse for co-active working as one student operates the swanee whistle then another bangs to the drum. We are talking high-level interaction here but in some classrooms, we are not asking the impossible!</p> <p>Finally, your learners may want to actually physically squish Greg the fox with your Doris toy, and why wouldn't they, the egg stealing twerp!?! We need our students to practice their play skills in a variety of contexts and sensory stories are a great place to start!</p>	

Line 10	
Greg the fox let out a mighty howl! Then ran off, not looking back! And as Doris sat upon her egg... its shell... began... to crack!	Foxy toy/puppet. Large plastic egg
<p>Again, interaction with your fox toy or puppet can be useful here, getting young Greg to disappear peekaboo style. You may also want to record his mighty howl on your single switch communicator of choice.</p> <p>Rather excitingly, it is at this moment that Doris' egg begins to hatch! Cor blimey, fancy that! There are many large plastic eggs on all the usual online cheapy stores, a quick look sees them for less than £2 on eBay, so they're fairly easy to source. Obviously, these eggs are great for hiding things in and promoting functional exploration by our students as they try to get those pesky eggs opened! Once your student has the egg open, you can proceed to the penultimate line of the story...</p>	

Line 11	
Out flopped a ball of feathers, two webbed feet and orange beak, "Mamma!" cried the duckling, kissing Doris on the cheek!	Feathery cat toy / feather duster, damp sponge on cheek, "Mamma" on single switch communicator).
<p>Here, you can buy a little duckling or choose to get creative as you and your learners make your own little sensory bundle of feathers! There are some great toys for cats out there which are simply a bundle of feathers on a pole and line. These make great little ducklings, especially if you stick on some orange card on for a beak and a couple of webbed feet. Your listeners can interact with this little bundle of feathers bringing the miracle of a new life to your learning space!</p> <p>Again, you may choose to record a cute "Mamma!" onto your high-tech augmentative communication aid of choice – please note, you don't always have to use a single switch communicator, try using an iTalk2 to record "Mamma!" on one switch and "Dadda!" or a raspberry, pig snort or whatever you jolly well like on the other. This introduces the important skill of playing with two switches to your learner and offers some real choice making.</p> <p>The little duck gives Doris a well-deserved kiss! To replicate this, try using a nice, soft, baby sponge dipped into some warm water which is then pressed gently on the cheek. This can feel lovely – exactly like a kiss from Katy Perry herself, and I'm speaking from experience here!</p>	

Line 12	
Now Greg the fox stays away from Doris Duck, he's scared she'll squash him flat! And Doris and her duckling are very happy. Cor blimey... Fancy that!	Hugs/deep pressure/massage
<p>Bah, I like the "Cor blimey... Fancy that!" motif and would have liked to have got it in more times, but as I said earlier, this story is very long as it is.</p> <p>I always make my last line leads to an extended activity, for example a massage, musical activity or party, to encourage interaction and act as a good old-fashioned plenary. During this time of contemplation, be sure to sit with your exhausted learners (remember, they've just helped deliver a baby!) giving a relaxing massage whilst chatting about the story you've just shared.</p>	

Contact details

Pete Wells has been a Special Storyteller for over twenty two exciting years His innovative, interactive special stories, are well known for their interactive, multi-sensory content.

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You can find an animated version of the story in the 'Free Special Stories' page of <https://sensorystoriespodcast.com/>. This will allow your learners to tell the story using switches.

Sensory storytelling

Pat Thomson

First take one black sheet. Add some pink icing, a space blanket, a flashing light, some smelly aftershave and the sounds of raucous market traders.

These were the instructions for a sensory story I wrote for a group of learners with PMLD. Grace (2015) describes a 'sensory story' as a story which has words and sensory stimuli to represent the words of the story. Both the words and the stimuli are of equal importance. The title of my story was 'A trip down the local market'. This was a perfect subject as I have seen children from school there, and the variety of market stalls gives endless sensory possibilities. Grace and Silva (2017) suggest a story should provide sensory stimuli for as many senses as possible. In this story the senses of smell, hearing, taste and sight were stimulated, as the children explored the music, toiletries and hardware stalls and stopped off at the local cake shop.

Like many teachers I love writing and telling sensory stories and have used them in different settings with children with a range of needs. I was a self-taught sensory storyteller who learned my practice first from my teaching assistant, and then from other colleagues and books on the subject. I wanted to improve my practice, so for the research project for my Open University degree I looked at using sensory stories with a group of learners with PMLD aged 2-8 years.

For my study I read about the origins of sensory stories. The first sensory story was told by Chris Fuller (Fuller 2013) a teacher who told a story using sensory cards to a group of learners in the 1990's. Her idea took off and she wrote guidelines to support teachers who were new to sensory storytelling. Her guidelines were developed by the voluntary group Promoting a more inclusive society (PAMIS) and gave instructions on writing and presenting stories. When I began my project, I knew nothing about the guidelines. Like the teachers Preece and Zhao (2015) interviewed for their research, I did not use guidelines, nor did I think there was a right way or a wrong way to tell a sensory story.

In 2000 a government paper (DfE 2000) noted that sensory stories were used widely but there was no research to show their value. After this date research was done into the use of sensory stories and researchers used the existing guidelines in their work. They developed the guidelines and added new ones, and Grace and Silva (2017) redefined the guidelines for practitioners and researchers.

For my research project I wanted to know how the guidelines could be used to encourage attentiveness and anticipation with a small group of learners.

I chose the following guidelines to promote attentiveness:

- To know the learner's preferences
- To give them time to respond to stimuli
- To present active stimuli
- To provide a personalised learning environment
- To know the learner's reactions to stimuli.

I chose these guidelines to promote anticipation:

- To adhere to the words of the original story in the storytelling
- To repeat the story.

I worked as a volunteer with the learners 1 day a week, so I did not know them as well as the class teacher. In an interview she gave me the information I needed to put the attentiveness guidelines in place, such as how the individual learners respond to stimuli and their preferences. Using the information, I wrote individual stories and I planned to tell the story twice a week for 5 weeks. I kept diaries to record the learners' responses and I made a video recording of my storytelling.

The evidence from the diaries showed that throughout the 5-week period all the learners reacted to the stimuli in the expected way and showed signs of attentiveness. I concluded that the guidelines I chose encouraged the learners to be attentive during the storytelling sessions. What was interesting in the findings was that the learners were most interested in the active stimuli. They all seemed to enjoy exploring the icing and the space blanket with their hands and tracking the flashing light under the sheet. In the conclusions to their research, Ten Brug et al (2015) recommend using active stimuli so that learners can participate fully in the story session. They suggest practitioners find new ways to present stimuli to make it more active, such as using a switch.

The guidelines I used to promote anticipation, repeating the story and sticking to the words of the story were not so successful. The learners showed no signs of anticipation. I was unable to tell the story 10 times as

planned because the learners were frequently absent from school. Learners only heard the story 3-7 times which was not enough as researchers recommend reading a story 10 or 20 times. In their studies Grace and Silva (2017) and Penne et al (2012) repeated the story 10 times and Ten Brug et al (2015) read the story 20 times. In future I intend to tell a story once a week over a whole term which means learners could hear a story up to 16 times.

In my storytelling I found it difficult to adhere to the words of the original story. The video recordings showed I used between 67 and 215 extra words in sessions at the beginning of the research. During stories I responded to the learners' vocalisations, gave verbal prompts and chattered constantly. When I made a conscious effort to stay quiet the number of extra words dropped to single figures in sessions at the end of the study. In future I will try to remain quiet throughout story sessions so the learners can focus on the words and the stimuli.

In my practice in the future I will use the guidelines I used in the study and experiment with new ones. A guideline from Grace and Silva's (2015) list that I could try, is to have all the resources ready at the beginning of a story session. In 2 of my sessions I forgot resources and although this did not interrupt the flow of the story it would have been better to be prepared at the beginning. My research study was small scale so my results cannot be generalised. However, I hope that teachers who work with similar learners might find my study interesting and consider trying out the guidelines in their practice. My original aim to improve my practice has been achieved. I will continue to learn more about sensory storytelling in my bid to write - in the words of a child I once taught - 'the best story ever!'

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Sense-ational songs

Bev Cullen

I have over 25 years experience of teaching music, both in the classroom and as a visiting curriculum and instrumental teacher. I have taught music to all ages from 6 months to adult, working in both the mainstream and SEND sectors. I currently deliver music in two local SEND primary schools, linking to their creative curriculum as much as possible. I am also a licenced Makaton Tutor, one of the first trained to deliver the 'Using Makaton with Singing' training.

Last year I attended 'The Sensory Story' training, run by Joanna Grace at Oakwood School. After being blown away by the ideas in this training, and a chat with Joanna afterwards, I came up with the idea of Sensory Songs in my music sessions.

I had the perfect opportunity to try this out during Oakwood's 'Sensational' topic, which encourages the pupils to explore and learn about their senses.

Song Choice

The book Music Express (Hickman et al, 2012) offers the song 'What can you see?'. The song is about the seaside and each verse focuses on a different sense. Living in the West Midlands, many of the pupils with PMLD would never have experienced the sights and sounds of the seaside, so I set out to make this as close to the real thing as I possibly could.

Resources

The song refers to the sea, seagulls, salt in a shell, stones and ice-cream. I set about the challenge of finding/making resources that could enable the pupils to experience each of these things within the school setting. I decided to focus on a different verse of the song, and therefore a different sense, each week. Each week, we repeatedly sang the words of the focus verse many times, whilst the pupils explored the resources.

Week/Verse 1

'What can you see? I can see the patterns of the waves on the sea'.

Staff: waft a long piece of blue material over the pupils; work 1:1 with pupils to move the tiny ball bearings in ocean drums; explore the movement of water (coloured with blue food colouring to make it easier to see in clear plastic tubs). On the screen I had a YouTube clip of ocean waves playing quietly.

Each pupil responded differently to the different resources. All the pupils enjoyed the shared experience of looking up at the material as we sang. They smiled and one vocalised along with us. One boy particularly liked

the ocean drum, holding it and playing it independently... although it sounded like stormy seas rather than a gentle



lapping of the ocean waves!

Week/Verse 2

'What can you hear? I can hear the seagulls when they're flying near'.

Staff: vocalise seagull sounds whilst moving cut out seagulls over pupils' heads; use VOCA (Voice Output Communication Aid) e.g. BIGmack switch with recorded seagull sounds on. On the screen we watched a YouTube clip of seagulls from 'Finding Nemo' and seagulls at the seaside.

The staff really got involved this week and enjoyed pushing the wheelchairs around, pretending to be seagulls...the pupils laughed. The more they laughed, the more we made the sounds, and the more we made the sounds, the more they laughed. This could have quite



happily gone on for all afternoon – I’m not certain who was having the most fun.

Week/Verse 3

‘What can you smell? I can smell the salt that’s hiding in the shell’.

Various size shells had been donated by another school. Into the shells I put dried Sea Vegetable Condiment e.g. Green Nori Sprinkle, that was available in our local health food shop, and some ground sea salt (available from most supermarkets). Each shell was sprayed with water to enhance the smell. On the screen I had a YouTube clip of ocean waves lapping over shells.

Staff modelled sniffing the shells and encouraged pupils to do the same...although many of them opened their mouths to taste it so be very careful with this!



Week/Verse 4

‘What can you feel? I can feel the stones moving under my heel’.

Thankfully we’d recently had our garden landscaped and had gone for beach style aggregate and still had some unused in bags. This was put into boxes for pupils to touch and feel. Staff took pupils shoes and socks off and put their feet into the boxes. The YouTube clip this week was a man walking across a very pebbly beach. It was interesting watching the pupils to see who found this relaxing, or ticklish, and who withdrew their feet very quickly.



Week/Verse 5

‘What can you taste? I can taste my ice-cream, couldn’t bear to let it waste’.

Sadly, we didn’t get to this verse, but following what I had seen Joanna Grace do in her training, I had got vanilla food flavouring (available from most supermarkets) to dilute in warm water and a pipette dropper to place one drop onto each pupil’s tongue so that they could experience the flavour (I don’t have access to a fridge/freezer in my lessons, so didn’t feel that I would be able to provide the full experience on this one!). I had found a YouTube clip of an ice cream van playing ‘I do like to be beside the seaside’ to introduce our tasting session.

I know that the staff were looking forward to this week in the hope of getting an ice-cream!

At the end of the project we would have had one week with all the resources available to recap on all the senses, but as you all know, life in school at the end of the summer term, with end of year rehearsals and performances, things don’t always go to plan! Many thanks to Oakwood School for being supportive in letting me try out new ideas in these sessions.



Extension/ Development work

This project could also be used to introduce pupils to communication symbols to be used on a communication aid e.g. Makaton symbols on the MyChoicePad App.

Each week as you sing the song and explore the resources, introduce the pupil to the relevant symbol. After two weeks give them the choice of which sense they would like to explore again by showing them two symbols. The pupil may respond by smiling when shown one symbol or turning towards their preferred option. (You know the children that you work with best, and how they show you their choices). As they become familiar with two choices, you can build up to three, four or five choices...as I said before, you know them best and how many choices are best for them.

I hope that this article has given you some inspiration to explore sensory songs for yourselves and the wonderful pupils we all work with and care for. If you want to contact me at all regarding this idea or Makaton training, please email me with the subject reference Sense-ational Music or Makaton with Singing.

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Websites

The Makaton Charity: <https://www.makaton.org>

Joanna Grace: <http://www.thesensoryprojects.co.uk>

BIGmack switches are available from <http://www.inclusive.co.uk/ablenetbigmack-p2039>

MyChoicePad <http://www.mychoicepad.com/>

Resources

Hickman, S., Nicholls, S. and Scott, P. (2012). *Music Express Early Years Foundation Stage: Complete music scheme for Early Years Foundation Stage*. Second edition London: A&C Black

11 hrs. Healing Sea #1 - No music - Gentle ocean waves - Soothing sound of ocean <https://www.youtube.com/watch?v=CYXG9rG0Jf0>

Mine mine mine (Finding Nemo) <https://www.youtube.com/watch?v=p-3e0EkvIEM>

Seagull Sounds <https://www.youtube.com/watch?v=IP7K8tf6kT8>

1 hour Sea Shell Sounds <https://www.youtube.com/watch?v=Ers2blQjY4&t=506s>

Walking on Stones and Rocks in the Beach - ASMR Sounds Moment
<https://www.youtube.com/watch?v=-1rUCe87kyA>

Ice cream van playing 'I do like to be beside the seaside'
<https://www.youtube.com/watch?v=kHuh16yUXpY>

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

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

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

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

'Singing Sangha'

Creating community through song

Eleanor Gibson

For a couple of years now, a small group of us – around 6 small humans with PMLD and 3-5 bigger humans - have been singing together. We began with the challenge of setting up a 'sacred singing' group with children, who were only just beginning to vocalise, and the work has developed since - through and with and alongside the different children and adults who have engaged with it.

For the first session, nervous about engaging children, I took tubes to vocalise down, feathers to blow, and an idea that we would need 'tricks' to facilitate engagement. It very quickly became clear that what the children most wanted was the closeness of another human being; whether this was to make eye contact, to enjoy touch, to share vocalisation or to feel vibration. Another surprise was how much the adults enjoyed the session and that they have really valued it as a nourishing place and time in the week since.

The session developed a predictable structure: we began with an extended 'Hello', improvised by the adults with the support of a recorded backing loop. We spent enough time with each child to make eye contact and sometimes physical contact, such as touching their chest to reinforce the connection, or stroking or squeezing arms or legs to calm or engage. Any sounds or mouth movements made by the child were supported. This was sometimes by imitation or sometimes by a translation of movement into sound: for example, tongue movement might be interpreted by a vocalising adult as 'lalala'.

From this beginning, with everyone fully welcomed, we sang a range of simple chants, from vowel sounds to chants drawing on different faith traditions. We kept the words simple e.g. Ambe Ma, Om Namah Shivaya, Allah Hoo, Amen; supported by an Indian-style harmonium. One chant would feature drumming, with each adult holding a resonant drum, so that vibrations as well as sound could be felt. Drums would be shared with children if they showed an interest. At times the speed and quality of the music would be dictated by the gestures or movements of the children. The session finished with each child being sung to again in an affirmative 'blessing'.

Early on, my questions centred around: Yes, it's a lovely session, but what are we actually doing? Is there any learning going on? And later I was asked by others: What is your aim for the session? What do you want the children to get out of it?

The simple answer to the latter two questions is that singing has been such a big and important part of my life that I want everyone to have the opportunity to experience it. I am quite evangelical about singing! I think even for those who don't [yet] vocalise, there is much to be gained from being in a 'sung' environment. Being in a choir, in the middle of a gathering of singers, can be a wonderful experience on many levels even if we are not singing ourselves. In our current culture, we are very focused on what singing sounds like and there is little attention paid to what singing FEELS like.

Two other questions occur to me: What does singing feel like? Why do I feel so alive when I sing? And it is in answering these questions that I believe we will find the answers to those first original questions (What are we doing? and What learning is going on?).

With our new group this term, the session has become less faith-based, but I believe it retains an implicit spirituality. The beginning and ending of the sessions remain the same. Wordy chants have been replaced by vowel-laden soundscapes supported by a drone (a note or chord continuously sounded). The rhythmic element is supplied by an upbeat improvised vocal loop that invites participation. Adults and children are specifically invited to co-create, to 'make it up'; and the music is structured to allow and support this. Adults are encouraged to support children's vocalisations and mouth movements as before.

The session has taken on a greater sense of immediacy, of 'present-moment-ness'. We aim to optimise sensory input (which might look different for each child) by giving opportunities for close body contact, as well as eye contact and closeness to the source of sound. These factors also maximise the opportunities for connection and co-regulation: as early learners, our youngsters may not yet be skilled in regulating their own feelings.

Through co-created music and touch we invite them to co-regulate with us. Mirror neurons get to work: through our actions and song the children have an opportunity to

experience what it feels like to sing, to be connected through singing, to feel calm, to feel joyful, to feel.

It is early days for this new format, and there is much to be discovered and enjoyed...

We are holding space

We are holding a particular space where all of everyone present is welcome and where wellbeing is nurtured within the container of the music. There is enough consistency to give the space a structure in time - a beginning, middle and ending. There is enough humanity to ensure support for pupils in the space we are opening and holding. It is something akin to Donald Winnicott's 'transitional space' where play happens and where transformation is possible (Winnicott, 1971). We adapt our presence and our vocalisations to the pupils – sometimes matching, sometimes amplifying, sometimes echoing, sometimes countering - in a dance akin to early infant-carer communication. James Rhodes in a 2016 TED talk describes music as 'a language we are all fluent in'. Some current research says that singing – vocal melody – develops before language. Whilst some of our pupils may never develop conventional spoken language, this language of the emotions is always open to them, and we are ready to listen.

We are tuning in

We are sharing space, time, breath, pitch, rhythm, resonance, action and gesture. In order to be fully responsive, we need to be fully present. This means the adults tuning in to their own feelings and sensations at the same time as tuning into the children. We try not to interpret what is happening (except perhaps afterwards, when we might speculate on the reasons for particular responses) but we are highly alert to sound, movement, gesture, eye contact, mouth movements. The improvised soundscape means that it can be calibrated to match a rhythm which may be overt – such as a waving arm, a vocalisation, a rising and falling of breath - or may be implicit, such as a sense of high or low energy or alertness in the group.

We are inviting relationship

As we respond to the sounds and movements of the children we create relationship moment by moment. It is a time to 'be' when they can learn more about themselves; who they are and who they might be. There is a focused opportunity to experience through the senses: particularly looking, listening and touch. There is time to 'just be' with us. We are hanging out, with singing and silence to help us stay in the moment. There is relationship with the wider world through the singing traditions we invoke. Occasionally there is the sense of a world beyond knowing, when silence descends and we are all caught in a moment out of time.

We are creating community

Singing has always created community, indeed, that may have contributed to its evolutionary purpose. 'Human singing is unique, no other creature begins to synchronise the rhythm, or blend the pitch, of its utterances with that of its fellows in the way that human singing instinctively do. '...everything about human music suggests that its nature is sharing, non-competitive' (McGilchrist, 2009, p.123). Science tells us that when we sing together our bodies produce oxytocin, known as the 'bonding hormone', alongside other 'feelgood' hormones.

We are supporting growth

We have seen different aspects of development in different children. For example, increases in vocalisation, more variation in vocalisation and musical development: accurate pitching and engaging with the musical structures. We have seen interaction: eye contact, reaching out, turn-taking and 'chatting'. We have seen sensory development: discrimination of voices and development of preferences. We have seen an increase in action and engagement showing a sense of agency: reaching out for the drum and vocalising to initiate a song. We have also seen physical development: rolling over during the session and afterwards, as if the singing somehow stimulated the desire and strength to move.

Where is the spirituality?

‘There are ten levels of prayer, and above them is song’ (Hasidic teaching).

When we are singing, we create a threshold into another world. We move out of the language-based place in our heads and into a more sensory, intuitive space. The repetition in the singing offers a kind of container to go deeper and deeper into this space: a space that is inside ourselves and in the relationships between us. We open to the best of human intelligence, but also perhaps to more-than-human intelligence. In the words of Briony Greenhill: 'We can feel and sing our own deep inner truths, and through that, come to know them.' (Greenhill, 2020)

We are making it up as we go along; tuning into our intelligence, creativity and intuition, as individuals and as a group. We become a resource for each other, creating a moment-by-moment soundscape; a repository for who we are, for the energy in the room, for who the children are; playfully creating a world where all of each one of us is welcome. Is that not divine?

When we're singing, we're in the moment; we are singing from our hearts (the goal of many spiritual and meditative traditions). In improvisation we are opening to breath, to inspiration, to not knowing...to waiting, and

to silence. Those who have joined us for a singing session have been moved by the experience; when we sing together, we are definitely more than the sum of our parts. Our voices reach high and low, sometimes evoking other worlds, expanded time and space. It is a treasured time of the week...

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A very special job!

Jo Fitch

How do you do that job? So many people ask,
I don't think I could do it, I couldn't complete the tasks!
I couldn't do the toileting or give emergency meds,
I couldn't reposition them to sleep safely in their beds.
How can you continue when they become so poorly?
It must be so difficult and affect your heart? Surely?

Oh yes, my job, it certainly affects my heart,
I'll tell you all about it, if I can find a place to start!
My job, you see, it's more than just a job to me,
It's about the amazing people who every day I see -
Fighting constant battles with a smile upon their face,
Knowing that you're helping them win their individual race.
They invite us into their world with a glance or a smile,
A very special place that we can share with them a while.
It's a privilege for me that I get to share my day,

With amazingly special people learning through a sensory
world of play,

It makes my day worthwhile and fills my heart with pride,
To be part of this amazing world and join in on this ride.

When sad times come, and tears are shed, our hearts do feel
the pain,

But there's always a little spark that stays alight through all
the rain.

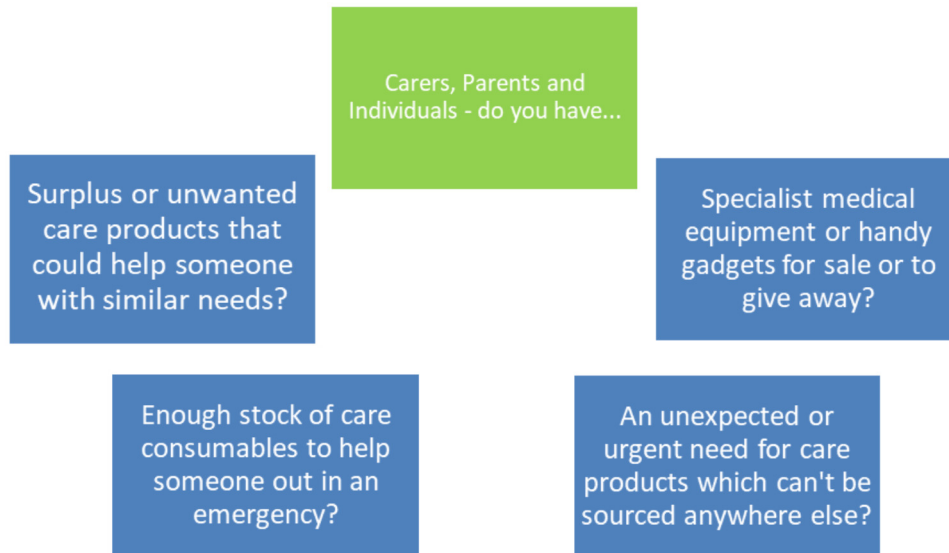
For we know we are lucky that we can feel so affected.
We get to love and care, so hearts cannot be protected.
It isn't for the money but something better that we earn,
Their smiles, their happiness and the love that is returned.

I am honoured to have been chosen for this special job of
mine,

One in which the important things are fun, love, care and
time.

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Skiggle

Christine Singleton

My name is Christine. I am a wife; I am a daughter; I am a mum and I am a special needs mum. Due to medical complications, my son Will came into my husband’s life and mine with severe Cerebral Palsy and a profound complexity of additional needs. Sixteen years on, he is a brother to two sisters and is a young man whose journey and way of life inspired my creation of Skiggle (www.skiggle.co.uk).

My journey as a mum through this special needs world often feels like a whirlwind: it is calm and is as full as that of the life of any mum, and then before I have time to blink, the winds pick up and often I can’t see or hear anything for the chaos! The wind comes in extreme circumstances when within a split second I have to call 999 to have Will taken to hospital; it comes as medical staff come to take Will down for surgery.

And it comes as a part of my family’s everyday life as we pack to go away on holiday. Navigating my way through this packing process is where Skiggle began. After packing the normal things that every family needs - clothes, food, and the buckets and spades - and then everything that Will needed, including medication, continence products, syringes, breathing equipment, slings, portable hoist, indoor supported seat, tracheostomy, splints, the normal ton of extra clothes for the inevitable mishaps and the kitchen sink - we set off for our few days away.

We were having a brilliant time, but suddenly I realised that I had forgotten to pack a box of enteral milk feed; feed that Will is reliant upon and imminently needed. What do we do now? I rang the out-of-hours doctor who assured me that she would be able to get me the feed we needed. However, three hours later she informed me that she had been unsuccessful and that our “only option

was to either drive home or put Will into a regional children’s hospital!” So as to avoid unnecessary risk of infection, we felt our only option was for one of us to leave our family and drive home.

This experience gave my husband and me reason for thought; if only there was a warehouse that stored everything you could possibly need, open and accessible any time of the day or night. But where would this be located, as no one location would be suitable for all? Then, we had a light bulb moment... many of the people who have additional needs have a supply of stock at home whether it’s in the garage, shed or a spare room. Someone somewhere could have almost certainly helped us, they could have lent us some feed to tide us over, and we could someday have returned the favour. With the help of a small group of volunteers, I consequently established Skiggle. It is a UK based not-for-profit service and aims to stand as an online platform dedicated to helping the families of the disabled, by creating a network of members who can offer vital medical equipment to other members when in need. I established it for other families and individuals either caring for disabled persons, or living with a disability themselves, to help each other, via our unique cloud-based SOS solution system, in unforeseen moments of

need by offering their surplus products (for example, breathing apparatus, specialist food and continence products) to the carers, families or individuals themselves who may have found themselves needing of something specific that is not immediately and easily accessible. The hope is that as the community grows, families will be saved the heartache and stress of being in the situation that we found ourselves in, simply because the wind picked up.

One of our current members experienced the same heartache and contacted us after using the SOS service:

"I was away on holiday with my family, 5 hours away from home, when I realised I'd not packed enough FreeGo Giving Sets for my son. I was so stressed and distraught (tears running down my face), that my partner offered to drive the 10 hour round trip, through the night, to go and get them! My son would have suffered without feed for that long though. I rang my friend to see if she could help me - she said, "Send an SOS on Skiggle". I sent one within a few minutes, once I'd composed myself, and a lovely lady came to my rescue! I would have been completely lost without Skiggle! Thank you so much! I'll definitely be using it again."

The SOS service does not just need to be used if you forget something on your holiday. It can be used when item(s) are required immediately, whether you are at home (your stock delivery might be late, or incorrect items have been sent to you), on holiday, or on a day out, as without it/them your daily routine will be seriously affected. Examples are:

"Desperately in need of a couple of size small Tena nappies (or similar). Our son has had upset tummy due to a viral infection and we are going through our allocated supply too quickly. We are going to run out. Please help."

"My daughters feeding tube has cracked. I am on a day out with her. To fit Enfit syringes."

An unsuitable SOS however is one that requests items that are wanted/needed for longer term solutions, bulk buying, information purposes, or to advertise products/companies:

"I am looking for a wheelchair for my niece who has ABI. Where should I go?"

"I create toys for children with disabilities. Please message me for more details."

If your message does not meet the SOS brief, Skiggle is also home to a free online Marketplace at www.skiggle.co.uk where the items you need may also be sourced. The Skiggle marketplace is strictly regulated, and is a space where you can buy and sell products relating to disabilities (in line with Skiggle's terms and conditions), and offer free excess products to other

families in need, rather than throwing them away.

My design for the marketplace came from constantly being told to throw products away when I no longer needed them, or could not use them. I am constantly rotating the stock that comes through for Will and topping up his cupboards after a delivery. It is not uncommon upon these occasions for me to receive a stock order for the month to find that I am in receipt of incorrectly supplied items. I make my regular phonecall to the ordering team to say that I've been sent items that Will doesn't use, and I get the usual reply: "Just throw them away!" Every time I am lost for words. Could you imagine if I threw away all of the items pictured, how much it would cost the NHS?



An item that I have received incorrectly before now is Will's enteral feed. I did our family food shop a couple of weeks ago for rest of my family, who all eat regular food, and it came as no great surprise when me when the bill totalled over £200. I began to wonder, how much does Will's cost? The difference is astronomical! Over a 12 month period, the food shops for the rest of my family totals approximately £2,400. Will's specialist feed costs £19,200! How can we ever be asked to throw it away?

I find this wastage of the NHS really upsetting, and so I hope that the marketplace will ultimately reduce the amount of surplus product that ends up in landfill. Please note however that you cannot sell NHS supplied consumables; the idea is to prevent waste, not profit from erroneous deliveries! Let's all do our bit to save our wonderful NHS and the environment. If you would like to get involved or learn more, please visit www.skiggle.co.uk or send a message on Skiggle's Facebook page. Skiggle has recently been awarded charity status.

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Play for children with PMLD

Helen Fitchett

Play should be a fundamental right for all children. However children with profound and multiple learning difficulties (PMLD) are a minority group who are often on the fringes when it comes to social interactions, including play opportunities. Play for children with PMLD is not likely to look the same as play for a typically developing child, as more interventions will be required, resulting in play being adult-led rather than a child-led activity, which is more commonly observed.

The style of children's play generally develops through three distinct phases: solitary, parallel and co-operative play (Lindsay and Lam, 2017). However, children with PMLD are likely to need adult support to maintain solitary play, with few progressing to parallel play and an even smaller number advancing to a point where they will co-operate with their peers in play. Play is a vital component to all areas of children's development, including decision-making, social and life skills (Kilburn and Mills, 2019; Lindsay and Lam, 2017). Research suggests that children progress through the various stages of development in the same order, albeit at different rates. Children with PMLD are likely to progress at a much slower rate, potentially reaching a plateau and not progressing any further. Amongst children with physical disabilities, studies have shown the children who engage in play more frequently have a higher level of determination to complete tasks (Lindsay and Lam, 2017). It must be remembered that children cannot be lumped into a single group whose needs, and desires are presumed to be the same (Kilburn and Mills, 2019). Everyone will have their own preferences as well as needs, to assist with their development.

Sensory play is important for children with PMLD; but it does not have to be the dominant feature. The five senses are hearing, sight, smell, touch and taste. Not all types of sensory play are enjoyed by all children; some children do not like different noises, some are not happy when expected to touch different textures, especially if they are wet or sticky. It is therefore important to listen to the child and accommodate their likes and dislikes. But if a child has a deficiency in one sense, then it is crucial to encourage stimulation of other senses further. For example, if a child is blind, you may want to over stimulate the sense of smell or touch to compensate for the lack of vision (Orr, 2003). Many blind people will come to understand their environment based on the smells and sensations they get in different places as their other senses over develop.

Children with PMLD will often engage best with toys that have an immediate reward, for example switch toys or robotics (Lindsay and Lam, 2017). The reasons for this are

because they are more easily adapted to individual need. In addition, children with multiple disabilities often find even a single movement takes a lot of energy. This means they will be easily distracted from the activity if the toys response is not instantaneous.

Incidentally, physical play is often omitted from a child with PMLD's repertoire, as this group are fragile (Orr, 2003). On the contrary, research suggests that physical play, especially rough and tumble, is an important aspect of assisting children with balance and understanding proprioception, or the perception of how the body moves, how it is all connected and the reaction or feeling on other parts of the body when touch or movement happens in a specific area (Macintyre, 2010). Rough and tumble has been studied in primates as well as humans, suggesting that it is in fact a behaviour which is inbred into our psyche rather than a learnt behaviour (Jarvis, 2019). This type of play offers a distinct set of behaviours, some of which are human specific but are consistently found in both Western and non-Western cultures (Jarvis, 2019). Evidence from studies of rats suggests that the areas of the brain which improve social interactions, the amygdala and frontal lobe, have increased neural connections after engaging in rough and tumble, highlighting the importance of such play (Jarvis, 2019). Considerations and allowances must be made for children with PMLD when undertaking rough and tumble play due to their unique and individual needs. However, this aspect of play should not be disregarded due to the advantages discussed above.

Play opportunities can be sought out for children who have PMLD, although this will be adult-led, rather than a product of their own imagination. Listen to the wind blowing the leaves in the trees or along the ground; if you can get close to overhanging leaves, feel the way they tickle your skin as they blow; listen to and feel the crunch of fallen dead leaves; feel the textures of different stones, tree bark or play equipment. A good way to promote play development, as well as other areas of expansion of cognitive development, is through storytelling especially if it is undertaken in a physical way.

The physical environment may need some adjustment; however, it will not be practical to completely re-arrange a room to permit a certain game to be played. Small adjustments like changing the seating or providing softer flooring may be enough to allow particular children to join in (Hewitt-Taylor, 2008). This may be an easy solution if the changes can be permanent or are simple to do. Sometimes protection needs to be applied each time play is undertaken. For example, if protective cushioning needs to be put down outside, this will need to be taken inside to avoid it being damaged due to inclement weather. Research by Papatheodorou (2007, cited in Kilburn and Mills, 2019) suggests that better outcomes for children with learning difficulties are achieved by paying specific attention to the individual child, their learning styles, the learning environment and the teaching styles used. However, results are mixed, and outcomes tend to improve more significantly in those children with a milder learning difficulty than in those who have a more significant impairment.

Some children may have issues which are personal to them. For instance, the presence of scoliosis could mean they can only lie in certain positions, require specialist support or tolerate sitting in an adapted chair for a set amount of time. This can make social interaction and concentration challenging. Another child may have restricted movements, meaning resources must be very close, or in a specific position in relation to their body, to allow them to interact with them. Certain conditions will mean that an activity cannot be tolerated for any length of time. A child with a respiratory condition may enjoy running around playing with their friends, but due to their illness this exertion can only be executed for a short time, isolating them from their peers (Hewitt-Taylor, 2008).

Many children with PMLD will require the use of additional medical equipment for some or all of the day. This may include but not be limited to a ventilator, oxygen, feed pump or saturation monitor. Manoeuvring this extra equipment as well as a child with potentially limited mobility or who is non-mobile adds its own complications. Often children with PMLD will need medical or personal care routines to be upheld at certain times of the day and this may impact on the time available for play. Therefore, when addressing play opportunities, these things need to be taken into consideration.

There are some specific areas of play where precaution or prevention of using certain products is highly recommended. Approximately 5% of children and adolescents with epilepsy are photosensitive, so flashing lights, flickering screens and certain patterns should be avoided if they are found to be a trigger (Epilepsy Society, 2019). However, the incidence of this lowers

once adulthood is reached. Playing with dry sand, water or glitter when a child has a tracheostomy should be done with extreme caution or avoided if possible. This is because the tube is open and the tip sits just above the carina where the trachea divides to each of the lungs (Macqueen et al., 2012). Therefore, the child is at risk of aspiration and consequently infection within the lungs, resulting in increased respiratory problems.

While it appears that there are a lot of things to be taken into consideration, play with children who have PMLD can be a real joy, for the care-giver as well as the child because even the smallest achievement in this group of children will seem like a huge milestone which has been overcome. An important factor to consider is the child's own likes and dislikes, even a child who is non-verbal can communicate their preferences. The most important thing to remember is that it is every child's right to be given opportunities to engage in play activities and to have lots of fun in the process.

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Towards Independence

Sara Davis

“Towards Independence: don’t you think that’s ableist?” asked my colleague pointing to the school motto in big words on the wall. “It’s not like our students will ever be independent.” “I have to think about it,” I said, and do every Monday-Friday at 8:45 when I see it in big blue lettering. ‘Living Independently’, by which we usually mean living without parents or caregivers, is the goal for a handful of the students at my specialised high school, but isn’t on the cards for people with PMLD. Does this motto leave them out?

Maybe independence is an ableist fantasy. What pride some people take in saying, “I don’t want anyone to have to wipe my bottom!” as if wiping their bottom is the thing that they are most proud of. Yet none of us are truly independent: we all require technology and other people. Isn’t it a very arbitrary line between me needing someone to grow my food, drive it to the supermarket, and often cook it, and a person needing someone to lift the spoon to her lips?

Then I heard disabilities rights professor Catherine Frazee (Professor Emerita at Ryerson University, Toronto) explain her understanding of independence as a disabled person herself -- it isn’t merely doing things with no one helping but having agency to make decisions. Her wheelchair, for example, affords her a great deal of independence. As do support people who assist her in fulfilling her choices.

Remember how a few years ago, there was so much concern about phones? Millions of people were dependent upon, ‘addicted’ to phones, and then no one was. A phone went from being a problem to being a very useful tool when a critical mass of people started using them. Being dependent upon something seems to be what using something is called when the majority of people don’t use it.

Why is it I describe myself as having interests and things I like, but when my student plays with a musical toy with an enthusiasm and joy we cannot imagine, people say he’s dependent on it and ‘stimming’ and their first thought is how to control it and take it away? What if him making a choice to enjoy what he likes to enjoy is not him being dependent upon it but being independent to do what he wants to do? A wheelchair makes someone independent because it does their bidding to support them, and the same can be said of a support person, perhaps especially when they are supporting someone with PMLD, who has many barriers to executing their decisions.

“But I don’t want to be a tool like a wheelchair or a toy”, one might respond. It feels ugly. It feels dehumanizing. But support workers are the ones being paid, and doing stuff someone wants done in exchange for money is pretty much the definition of a job. Sometimes it is hard on the ego not to be needed at the moment, and I think that’s often behind the complaint that “he’s in his own little world”, enjoying his toy. When people have choices, sometimes their choice won’t be to interact with me. My ego has to be independent of him for validation. And we need to accept the goal really is for his ego to be independent of me, and not to need a constant reassurance of ‘good job’.

Of course, people still need guidance at times. A technology can’t increase someone’s independence if they don’t know how to use it, and with every person and with every technology, there was a point where we didn’t know what it could do. People with PMLD often have learned not to interact with things they haven’t been invited to use. And people need to learn successful ways to interact with people, which may also feel awkward for some people before it feels liberating.

By seeing that independence is not a lack of a need of others or of technology but the freedom that can be enjoyed with the support of people, I see that for students with PMLD, the goal is indeed to move Towards Independence.

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Exploring Sensory Realms A visit to Shibden Hall

Gerard Wainwright

M is a young man with profound and multiple learning disabilities. He has cerebral palsy and uses a moulded wheelchair to support his posture. He does not use spoken language, pictures, symbols or sign language to communicate. His communication and understanding of his surroundings are through his senses. I have known M for about a year and during that time we have learnt a lot together. Halifax, the town where we both live, has recently become well known as the home of Anne Lister, following the drama series about her life 'Gentleman Jack'. I wanted to support M to understand more about this fascinating part of our local history, so we planned a visit to Shibden Hall, the ancestral home of the Lister family and immersed ourselves in the Regency period of Anne's life.

It's easy to forget how some people are excluded from experiences we take for granted, and that the word 'accessible' can be quite misleading – it's about much more than ramps and handrails. For M to fully engage with and get the most out of the visit it was important to create an immersive experience which focused on the five senses of sight, smell, sound, taste and touch. To really bring it all vividly to life in a way that was meaningful to him and which he would understand and enjoy.

The language of the senses

We often rely on what we see over and above our other senses. Because we understand language, we sometimes lose the ability to take notice of our other senses, the sound of the breeze in the trees, the smell of wood polish on the oak panelling, the touch of the fabrics of that era - silk ribbon, coarse wool, the cool feeling of brass buttons... All so resonant of the Regency period. If we can understand a Tour Guide or read a brochure, how much of this do we miss out on? How more impoverished our experiences can sometimes be? Which is why I believe I've learnt such a lot from spending time with M. He's given me the gift of experiencing the world in a different and ultimately more fulfilling way. Such an awareness of all our senses can truly enhance our everyday life and experiences.

Evocative scents

M does not eat orally, he has all his fluid, food and medication given through a tube in his stomach. This does not necessarily exclude him from the world of taste. Our tongues only register five basic tastes – sweet, sour, bitter, savoury and salt. All the other flavours come from our sense of smell. To enhance the trip M was offered a range of scents to evoke aspects of the visit to the Hall. Herbs are very reminiscent of Anne Lister's era. We took small amounts of thyme, rosemary, mint and



parsley and used these to bring the kitchen at Shibden Hall to life - along with the clanking of the pots and pans, the sound of the crackling fire to cook the roast, the distinctive odour of a burning candle... In the garden we smelt the wildflowers which are native to the Hall, such as Cow parsley, daisies, tea roses and English lavender. Smell is connected to the part of the brain associated with memory and is very powerful at bringing feelings to mind so can intensify our other senses.



A different view

M's favourite position is to lean out of his wheelchair and look up to the sky. I think that's partly why he's such an optimistic and inspirational person - he's always looking up! Because of this he sees and experiences the world in a different way to those of us that look down, or simply ahead. In the Hall he was fascinated by the ancient brass chandelier and its many twinkling and illuminating lights, which seemed to bounce off the polished wood panelling and shimmer on the shiny surface of the furniture. Equally, sat out in the grounds he seemed mesmerised looking up into the late summer leaves of the trees, catching the dappled



sunlight as it danced in and out of the shade. These moments can be quite magical but are easily missed if we are not attuned to people with profound and multiple learning disabilities. We have so much to learn from the people we support, and I think we are in danger of forgetting that sometimes. The best relationships are a two-way process, if we can work in partnership it's so much more rewarding for both sides.

Creating opportunities to touch

Touch is often discouraged in museums and Stately Homes. We are used to being denied the experience of feeling the objects which are often too valuable to be handled. With a little planning a small selection of items which are resonant of the time can be put together. M was encouraged to touch an old leather-bound bible, to stroke the cracked binding and feel its smooth pages. To trace his fingers across the delicate curves of a bone china cup and saucer. We also had a needle and thread, lace, a silk scarf and peacock feather. For M touch is not just about the ends of his fingers, he relished the feel of the smooth fabric and the feather against his cheek. Warm, cool, wet, dry, rough, soft, hard... there are so many tactile opportunities to be explored. For a fully immersive experience and to be truly sensory touch is extremely important and a very direct way to interact with the environment. Our visit to Shibden Hall and the world of Anne Lister was an adventure in sensory realms. But what I've learnt from M is that all aspects of our daily lives can be enhanced and enriched by utilising the language of the senses.

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Raising the Bar: 2019 Conference

Readers will be aware that PMLD LINK has now organised and promoted an annual PMLD LINK conference for three years running. PMLD LINK has used the conference to present the Core and Essential Service Standards for Supporting People with Profound and Multiple Learning Disabilities (Doukas et al, 2017), together with innovation and excellent practice in the support of children and adults with profound and multiple learning disabilities. The conferences have been popular and well-attended. The PMLD Standards (Doukas et al, 2017) are free to download from <http://www.pmlmlink.org.uk/resources/#pmld-standards>

PMLD LINK regrets that the 2020 conference will have to be postponed due to the current Coronavirus epidemic in the UK. However, rest assured that PMLD LINK will organise another conference when this can be safely done. Here are two interesting reports from Elly Chapple and Jo Grace on the 2019 conference that could not be included in the Winter 2019 issue.

Reflections

I had the honour of attending the latest Raising the Bar event at the University of Birmingham. Last year, I had shared our journey to #flipthenarrative and been inspired beyond words by the focus of the people attending on the day to will the change in attitudes towards those within our society who may need our help the most. People with Profound and Multiple Learning Difficulties (PMLD) are often missed within our daily view, and as the whole view is critical to all of us developing as humans, their presence and being is key to everyone understanding themselves more.

The work that Annie Fergusson, Joanna Grace, Michael Fullerton and Thomas Doukas have put into ensuring these people have a voice should be highly commended and followed. I know they would all say that's not necessary, but they as a four took it upon themselves to raise the bar in our human view and ensure that everyone has a seat at the table. The Core and Essential Service Standards for supporting people with profound and multiple learning disabilities (PMLD) that they have created and shared widely are a must for everyone to read across education, health and social care – indeed life.

I attended with my reflective Studio 3 head on this time to listen and learn. In our busy world, sometimes being part of the background is essential to understand what we are doing daily. In fact, I'd go so far to say it's a critical part of our understanding developing further. Really taking the time to reflect upon things develops our sense of our own states of stress, well-being, empathy and the understanding we afford to others, whose journeys differ to our own. In his book, *The Reflective Journey*, Professor Andrew McDonnell really focuses our thoughts on what we need to be truly empathic and reflective practitioners, or indeed human beings. As Andy says, 'If we are part of the problem, we are part of the solution'.

A theme that ran throughout the day was the message that people are not what we always assume, and often

we aren't listening or reflecting enough. It sounds simple, but listening to the parents that shared their stories, there was a commonality around the often lack of understanding of what their child could do, who they were and what we should expect. Sally Phillips (@sallyephillips) shared poignant thoughts that resonated with so many on the day – how we could #flipthenarrative around the public perception of people who are seen as different, because those walking with them know how amazing their life is: 'Being in the world of learning disability can give you a whole new understanding of life. 'You think you've gone down a snake but actually you've gone up a ladder and the board was the wrong way round.'

The way we reflect as humans about others really is key to unlocking our understanding further, and seeing the world through enriched human eyes, hearts and minds. Jo Grace says that, 'A person's ability to communicate is not dependent on their being able to master certain skills, it is dependent on our ability to listen and communicate responsively'. This is further highlighted within Standard Five. Jo Grace echoes the same message Andy gives throughout his book – that often it is about what we bring to the table, and how we respond that will inform the next step of the journey. The relationship we have with those we support, or live with and love, and our awareness of our own state within that, is critical to understanding the human connection that can thrive. When we remain conscious about how much we affect a situation with our responses, be those verbal or non-verbal, we see things differently.

Although my own daughter started out life being termed PMLD, she later lost this label, and I've thought a lot about what that meant and why. I often think the drive to understand something we do not, via an individual's presentation – which is often how our children are seen - in medical appointments or during 'assessments', the whole context of their being isn't captured. There can be many assumptions made due to the presentation of certain 'behaviours' which take us down one route, but we may have then missed critical information which was

available had we remained reflective and curious. This starkly reminds us to be more human, and remember that those we are trying to understand are too. In Ella's case, missing the vital information that she was Deafblind meant that assumptions replaced reflective considerations about her behaviour.

Mark Gray, who was the first person to see Ella for who she was, also presented on the day, reminding us about the importance of sensory loss and how that changes our understanding of communication, informs our view of 'behaviour' and presents situations that we need to be far more aware of to support our fellow humans well. Instead of connecting the dots about Ella's visual and hearing impairments, the focus became about her behaviour, because that was what was seen first, rather than the whole human she is, or asking 'why?' That loss in both senses meant that the world did not make sense, unless she was supported to learn experientially by working with her, not doing to her.

Our sense and understanding of who we are, and who others are, is linked to our feelings of acceptance by one another in shared spaces. Do we belong? Professor Melanie Nind from the University of Southampton Education School discussed the importance of belonging during her talk, and our societal view of what this actually means. Often, we are excluding those who are perceived or assumed to be 'too impaired' or, to term it differently, those who we do not yet know enough about.

Being reflective about our understanding of who people are and their being in this world should not just focus on behaviours that challenge, but also our ability to see more than we did upon first glance. When your practice is reflective habitually, you will find that the world is not as it was originally. It is such a simple thing to do, yet it can be inordinately difficult to reframe our view and reflect, connect, listen and see more. Once we have more information and have considered where we sit within the view – our societal view, our 'norms', our experience – we stretch. In doing so, fellow humans that perhaps we viewed through one lens, become absolutely 'worthy of moral parity', as Eva Feder Kittay discussed, like anyone else. In essence, she states that what we then see is 'the environment of inclusion: of welcoming many sorts of bodies and minds, seeing the world as enriched by this diversity, and embracing the possibilities as well as the challenges'.

Alison Pettitt's talk will stay with me for a long time. She described painfully the journey that they had taken with their son, and the danger of not listening to parents who know their child, nor being reflective about why someone's behaviour is changing. In her son's case, his behavioural changes were due to inordinate levels of pain. He screamed daily in agony, but this was referred to

as 'behaviour' and therefore his physical distress was ignored. After two years, his family were finally heard, and the few people who made a huge difference saw him as a whole person, recognising his distress. By working together with the family, his life and theirs was changed for the better.

Sally Phillips echoed the need to listen more, and shared that her son will play video games to block out pain, but to someone who doesn't know him, this can be interpreted very differently. These stories drove home the critical need for our human reflective practice that encompasses the whole human view, listening not just with our ears but working with those who have the relationships and understanding that we have yet to gain. I'm reminded of something Dr Tim O'Brien (@Doctob) shared recently: 'Listen' is an anagram of 'Silent'. When someone is distressed, listen. Sometimes you don't even need to talk. You can just be present and listen. Be there for them.' Our ability to listen comes in so many forms, and when we really attune ourselves to the people we are trying to understand, the door is opened wider, furthering our understanding of one another. Observing and listening are key to our understanding. Connection is opening the door. It was a day that brought about so many differing views, conversations and reflections. A day that put humans first and assumptions last. The depth of understanding what we are about and how we are together in the shared space was quite overwhelming, and the rich diversity of thought and discussion created many links to so many things we face. It's a reminder to remain committed to our reflective journey as human beings, to focus our efforts on understanding what we do not, and to continue to strive to see beyond a societal lens that is not yet stretched enough to encompass all of us and give everyone an equal seat at the table.

It was also a poignant and uplifting reminder that we can do that - we will do that – because humans are hard wired for change and we can re-frame our view. We can be better, and we were made for continuous development and improvement. This isn't something that is solely for those we support in life. It is for all of us to remember that the lessons our fellow humans teach us every day are key to our own reflective, human journey.

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This article originally featured as a guest blog for Studio III and is reproduced here with their kind permission. <https://www.studio3.org/post/raising-the-bar-and-reflections>

Aiming for the highest of standards

Professionals and parents came together at the UK's only national event focusing on people with profound and multiple learning disabilities. The Great Exhibition Hall at Birmingham University buzzed with excitement, as 200-plus exceptionally passionate people flooded it with one mission in mind: to raise the bar with regards to what best practice looks like for people with profound and multiple learning disabilities (PMLD).

The Raising the Bar National PMLD Conference is the only national UK event focusing on the support of this group of people. It brought together speakers, exhibitors and delegates from across the UK and beyond to inspire and promote good practice. Their tool for this bar raising? A document written by a dedicated group of people that describes in 13 bullet points what this care might look like – Supporting People with Profound and Multiple Learning Disabilities: Core and Essential Service Standards – which was first issued in 2017.

The hope is that services and settings that host people with PMLD will use the document as a tool to guide their provision and that those inspecting such settings might use it to judge how they are doing. Unlike other events, this was not just professionals talking to professionals or parents to parents, it was not just education, just adult care, just the medical world – it was everyone working together for a common goal.

Seeing the whole person

On the main stage, Andrea Sutcliffe, outgoing head of the Care Quality Commission and newly appointed chief executive of the Royal College of Nursing and Midwifery, began the day calling for more learning disability nurses and underlining how much people matter. She was followed by family carer Jeanne Carlin who told delegates: "Consultants saw my daughter organ by organ – it was only when they began to see her as a whole person that her life was saved." She spoke about developing a holistic approach to care for her daughter Erica.

From Australia, Sheridan Forster, a researcher and speech pathologist, challenged the room with the notion of subtle ableism hidden in presumed competence. Forster was closely followed by Professor Melanie Nind, famous in the PMLD world for her role in the development of intensive interaction, talking about the importance of belonging.

By this point you would be forgiven for thinking the full content of the day had been covered, but that was just the first hour of an extraordinarily packed programme of keynote speeches and interactive workshops. Like the

organisers of the event themselves, the speakers worked in a voluntary capacity and the whole day operates on a not-for-profit basis. It is not a job for anyone and it is not for making money – it is solely for Raising the Bar. Everyone there and the many people following the event through social media – its hashtag #RtB3 trended in the top 100 hashtags in the UK on the day – are working towards a common goal of a better future for people with profound and multiple learning disabilities.

Creative powers, strong stories

In the afternoon, delegates were joined by actress and comedian Sally Phillips, who lent her celebrity status to raise the profile of the standards. Inspirational presentations were given by Frozen Light, who discussed how they created high-quality immersive theatre, and Rachel Wright from Camp JoJo, who talked about the lengths they go to enable people with complex disabilities to enjoy a camping trip. I told delegates about my award-winning Sensory-being Project, which sees people with profound disabilities meaningfully co-designing sensory resources with designers.

All gave us glimpses of how high the bar could be. Parent Emma Murphy and adult care professional Erren Wheatland showed how rich the lives of people with profound disabilities could be if they were provided for correctly. As Murphy showed us photo after photo of her son, "happy little Hugh", she reminded us that she has had to repeatedly argue for his right to life and justify that his was a life worth living.

The images of adventure, joy, engagement, connection and community stood in stark contrast to Alison Pettit's presentation about her son Timmy. Failings in provision for Timmy meant that when he developed a rare disease, his daily cries of agony went unheard for two and a half years, dismissed as "behaviour". Pettit and her wife fought desperately to be heard but lost the right to care for Timmy, were reported to social services for talking to him about his impending death and were, ultimately, unable to protect him from a painful feeding regime that authorities at the time insisted was in his best interest. Pettit stood alone at the lectern, her voice was clear, brave and unwavering, while those listening struggled to keep their emotions under control. The bar must be raised. Together we will raise it.

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<https://www.cl-initiatives.co.uk/aiming-highest-standards/>

REPORT BACK

Intensive Interaction Support Group

The South East Regional Intensive Interaction Support Group met at the Us in a Bus office on Jan 29th 2020. We aimed to respond to the following direct question:

How do we maximise the impact of Intensive Interaction when working with people with pmlD, especially when they are dealing with additional sensory complications? For people who do not move their bodies much, do not vocalise and cannot see adults mirroring them.

Having such a wide variety of practitioners (teachers, lay therapist, speech and language therapists, day service support staff, Us in a Bus practitioners) meant that we were able to tackle this question from several angles.

Initially we recognised that it was necessary to acknowledge the importance of understanding what the purpose of using Intensive Interaction with someone is. Purpose is usually based around supporting someone to feel listened to, valued and important and the recognition that these things form a vital part of their wellbeing. As this forms part of much legislation it goes without saying that finding ways to meet these needs is both desirable and necessary. Intensive Interaction therefore goes a long way towards meeting legislative criteria. On this occasion the person who had raised the query felt that they hadn't yet formed a relationship with their student. Intensive Interaction was listed in their paperwork as a key technique, but because they weren't sure what Intensive Interaction looked like for someone with such sensory complications, it hadn't been pursued that far.

From an Intensive Interaction perspective the obvious thing to suggest as a way of responding to someone who can't see or hear is to add an element of touch to the interaction. On this occasion this was complicated by the fact the young person uses touch prompts for daily tasks and there was a concern that she would become confused.

We discussed using an olfactory cue, perhaps wearing the same fragrance or a jam jar with fragranced fabric inside (to contain it) as a way of indicating that something different was about to occur. Finding the balance between trying to alter or expand the expectations the young person felt when she received a touch cue, against the usefulness and necessity of the touch cues is important. We also discussed using breath/breeze as a sensory cue, as well as a response to her

breathing. Matching tempo and style would give her the message she is being noticed. It may take some time to establish this and we also spoke about making use of the moments when she is most alert, to maximise potential connection. These moments of greater alertness happen after she is given a touch cue, she sits up and is "ready". We discussed being bolder in these moments.

Another thought was to use alternative touch methods. Perhaps using squashy balls placed against her shoulder/knee. This would be different enough from the touch cues to hopefully support her to recognise the difference and open up channels for fun.

We had quite a detailed discussion about the possibilities of using shoulder to shoulder touch, squashing in as a response to something (her breathing initially), perhaps even doing this when she is out of her chair. The most important point, which kept returning, was being courageous enough to spend time with someone "being". To an observer this may look very limited, but tuning in and making yourself available, giving someone 100% of your attention, is an excellent way of reinforcing their sense of self. It's an equally excellent way of forcing ourselves to notice things that could become bridges of connection between us and that which may be lost in the bustle of day to day life.

This is a brief account of the content. The following is a list of possible responses to a rhythmic 'happening' that Us in a Bus had previously compiled for a coaching session. We distributed it on this occasion too as a resource list.

How many ways can you respond to a rhythmic manipulation of an object?

- Clapping our own hands. Quiet, loud, which bits of hand, proximity to person, tempo (vary it).
- Clapping the person's hand. Intensity, speed, length of contact, style (gentle or playful)
- Tapping. On different appropriate body parts. On chair, bag, pillow, adapt to what you know of the person....eg not loud if someone sound sensitive. Choose a part of the body that moves/ take into account people's sight/ hearing/ sensory profile.
- Squeezing. As above, know your person, but don't be afraid to try things. Choose where to squeeze by which body part they are moving moving/ considering sensory world.
- Pushing into joints/ fingers particularly.
- Pressing, explore sensory aspects of this.... Head/ shoulders/feet
- Shoulder to shoulder.
- Blowing, with or without sound. Against/close to appropriate bits of body.
- Rhythmic sounds. Lips smacking, tongue clicking, vocal sounds. Same variations as above. Volume,

- proximity, speed, pitch, intonation.
- Share the object
- Imitate movement by shaking arms/ hand/ body. Variations. Freeze/ pause
- Move their chair rhythmically or not.
- Using breath to match rhythm...or a fan. Explore proximity.
- Often providing a steady rhythm on a drum or by tapping constantly creates a predictable and safe environment that enables people to process their senses and emotion more effectively, calming them enough to enable interaction.

Anne Laney, Us in a Bus

SUBSCRIPTIONS

Subscription Rates

UK Individual £25.00
UK Organisation £35.00

EU/Overseas Individual £32.00
EU/Overseas Organisation £45.00

The journal remains the only UK journal focussed on the needs of children and adults with PMLD. Thank you for your support for it.

Subscriptions are for 12 months from the point of subscribing. You will receive 3 issues of the PMLD LINK journal. During this period you will have access to the members' page of the PMLD LINK website (www.pmlmlink.org.uk) which allows you to access downloadable versions of back issues from the last three years. Subscribers only can access these. Other older issues are in the public domain of the website.

In order to access the members' page on the PMLD LINK website, you need a Username which is your e-mail address and a Password. You will be sent a link to your personal website account and you can create/reset the password.

We have a limited number of copies of back issues remaining which are available at £5 per copy so may be able to provide you with copies of issues that you may have missed.

If you have any queries, please do not hesitate to contact Rob Ashdown (PMLD LINK Treasurer) via info@pmlmlink.org.uk

In the Next Issue Summer 2020 What matters?

It's an understatement to say we are writing this in times of uncharted territory, where all we know and have largely taken for granted has been swept aside. However, what we see to balance the uncertainty and fear is a spirit of great generosity and resourcefulness. People familiar with the people we love and support have been popping up from everywhere to share their talents and creativity as a way to promote wellbeing and resilience amongst our community – particularly for those with profound and multiple learning disabilities. Thank you!

In light of this abundance of positivity, we invite you to step out even further and share these valuable insights, your ingenuity, those whacky or creative talents (many previously hidden or 'untapped') through the pages of our PMLD LINK journal.

Our Summer issue is another open, un-themed edition to allow all your contributions to demonstrate what matters, what works and perhaps even shines a spotlight on the unexpected and inspirational! Let's lift our spirits as we celebrate the good things that have been happening even during such a difficult period in our global history.

PMLD LINK's volunteers are always ready to help – just get in touch. We look forward to articles, news items, stories, events ... and whatever else we should know about and share. Over to YOU!

Guest Editors, Summer 2020 Issue
Sue Thurman, Martin Goodwin and Annie Fergusson

Please send all contributions by **5 June 2020** to any of the editors

annie.fergusson@outlook.com
Sue@thurmancc.co.uk,
lmartin1978@icloud.com

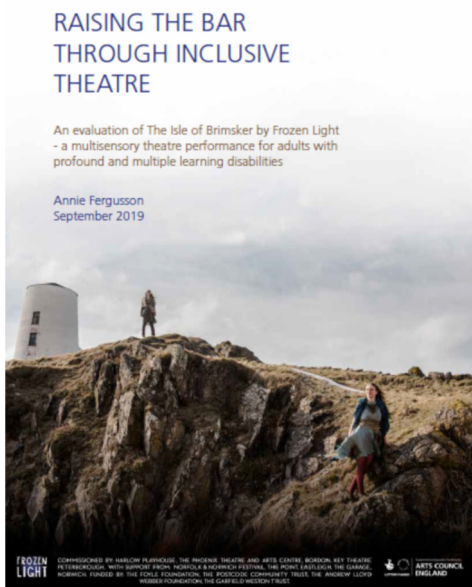
or info@pmlmlink.org.uk

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

BOOK REPORTS

Raising The Bar Through Inclusive Theatre

Frozen Light are a small performance arts company dedicated to providing high-quality theatre in mainstream arts and theatre venues, for people with PMLD. It has made available a 70-page evaluation report of The Isle of Brimsker - a multisensory theatre performance for adults with PMLD. This report was undertaken by Annie Fergusson, as an independent reviewer, at the invitation of Frozen Light. Annie is a member of the PMLD LINK



editorial team. The review process gathered together contextual information, theatre-visit observations and the views of a wide range of stakeholders. Once collated, this information was analysed for common themes and then mapped against the PMLD Standards. This quality assurance framework focusses specifically on people with PMLD both in terms of outcomes for the individual with PMLD as well as the key actions of any provider of services. The PMLD Standards may be downloaded for free from the PMLD LINK website.

Annie Fergusson found a wealth of high-quality evidence from the work of Frozen Light to support every aspect of the PMLD Standards. In particular, she ascertained that the positive benefits to Frozen Light's audiences with PMLD were consistently perceived and supported by every stakeholder group involved in this review. These outcomes for the audience was attributed to the creative and well-informed theatre design by Frozen Light and their high quality delivery. Frozen Light's person-centred practice was seen as cutting edge. The benefits and influences of Frozen Light's innovative models of working

with the wider arts and disability communities are comprehensively documented in Annie Fergusson's evaluation report.

The report provides developmental pointers for Frozen Light but just as importantly it shows how theatres, dramatists, personal supporters and others need to do more to ensure that there is truly inclusive performances for people with PMLD. In that respect, the report has implications for many besides being a good example of how the PMLD Standards may be used by organisations to evaluate their work.

Do check this report out. The full report may be downloaded from Frozen Light's website: <http://frozenlighttheatre.com/evaluation-report>

Title: Disabled children: a legal handbook (3rd edition)

Edited by: Luke Clements

Published date: 16 Jan 2020

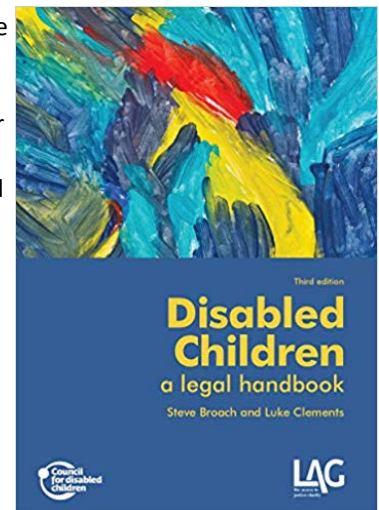
ISBN: 9781912273188

Publisher: Legal Action Group

Page count: 720pp

Price: £50.00

This is a guide to the legal rights of disabled children, young people and their families in England. The law is complex and frequently misunderstood by those who have duties and responsibilities towards them. Many families also lack essential information about legal matters which substantially affect their lives and about the ways the law might be used to assist them.



The book explains what public bodies must do to support disabled children and that which they may do.

Contents: understanding disabled children's lives – legal fundamentals – children's services – education – health – housing – decision-making – carers – equality and non-discrimination – transition to adulthood – remedies – welfare benefits

IN THE NEWS



Dave Hewett Awarded OBE

We were very pleased to hear that Dave Hewett has been awarded a well-deserved OBE in the New Year's honours list.

Dave has been working with people who have special needs since the 1970s. During the 1980s, he was the principal at Harperbury Hospital School in Hertfordshire and led the team that instigated and developed the Intensive Interaction approach. After the first publications and the demand for seminars and conferences, he resigned his headteacher post and dedicated himself to the dissemination of Intensive Interaction in all services nationwide, through continuously speaking at conferences, giving seminars, publishing books, articles and training materials. He has gathered together a team of colleagues who now make up the Intensive Interaction Institute and his work is no longer in the UK alone but takes him around the world to other countries.

Dave says that the news of the award was a bit of a shock. He regards this as an award for Intensive Interaction rather than himself personally. On his Facebook page he says:

“This thing is for all of you who put in the tough days, day after day, making the approach work, generating progress with your people, changing their lives. All of you who work with reluctant and unimaginative organisations, constantly arguing your case for the approach, demonstrating its worth. It is for all of the

sleep-deprived parents and families who make contact with us, who may see some of their hopes and aspirations for their child starting to come about and who help us to tell other parents about this simple, beautiful thing. It is an award to the joyful human spirit that exists, we all know, even within the most reluctant-seeming communicators, strong, lovely people who can gradually blossom and flourish in their new-found, wonderful social world.”

“Finding Harmony” campaign

World-renowned six-part harmony group The King's Singers have chosen the Oxford-based Soundabout Inclusive Choir to become ambassadors of their new Finding Harmony campaign, raising awareness of the power of music to bring people together.

As part of the campaign, the King's Singers will be running workshops with the choir, and singing together in a collaborative performance alongside two other Finding Harmony ambassadors. Unfortunately Soundabout group sessions have been cancelled for the time being due to the need to restrict the spread of coronavirus

Created in September 2018, the Soundabout Inclusive Choir brings together singers of all ages and abilities. Many of its members have never been able to join a choir before.

Finding Harmony was coined by The King's Singers as the name for their mission – to use singing as a tool to find unity in a divided world.

For more information contact Clare Cook – clare.cook@soundabout.org.uk

Website: <https://www.soundabout.org.uk/news/the-kings-singers>

Making a plan for emergencies

Together Matters has produced a timely update of its information and template to make an emergency plan. An emergency plan sets out the best way of supporting your relative and should contain the information that helps to stop an emergency turning into a crisis. It can be downloaded for free including a rewriteable version.

<https://www.togethermatters.org.uk/resources-and-information/>

Update to rapid COVID-19 guideline on critical care

Revisions to NICE Guidelines now give those with learning disabilities and autism, equal access to critical care. NICE has reported that it has updated their rapid COVID-19 guideline on critical care in response to concerns raised by patient groups about its application.

Find out more here: <https://bit.ly/2WIRqeb>

Funding For Children's Hospices

Funding for Wales' two children's hospices is said to be reaching "crisis point" and there are calls for more public funding to stop them cutting respite care for families. See, for example, the BBC News report at https://www.bbc.co.uk/news/uk-wales-51728944?ns_linkname=wales&ns_campaign=bbc_wales_news&ns_source=twitter&ns_mchannel=social

The Welsh hospices get on average less than 10% of their funding from the Welsh Government, lower than for other UK countries. The Welsh Government said it was discussing funding needs with hospices. Funding for children's hospices in Wales - which comes from local health boards rather than a central grant - has not been reviewed since 2009.

The two children's hospices in Wales, Ty Hafan near Cardiff and Ty Gobaith near Conwy, rely on public donations to survive. But they say uncertainty around funding affects their ability to plan services. Due to the financial strain on the Ty Hafan hospice, the charity said it had been forced to prioritise families with immediate need - so respite care to families has been cut in half. This change ensures that the hospice can meet the clinical end-of-life demands alongside the respite care.

More details were broadcast on Wales Live at 22:30 GMT on Wednesday 4th March on BBC One Wales and are available on the BBC iPlayer. <https://www.bbc.co.uk/iplayer/episode/m000g2sh/bbc-wales-live-201920-04032020>

Legal action on Human Rights

Learning Disability England (LDE) reported that in February the Equality and Human Rights Commission (EHRC) wrote to the Health Secretary, Matt Hancock, starting a legal challenge over the failure to protect the Human Rights of people with learning disabilities and autistic people.

LDE believes that it is important that the rights of these people is being championed through this legal challenge. You can read LDE's statement here: <https://www.learningdisabilityengland.org.uk/news/legal-action-on-human-rights/>

The Government department had 14 days to respond to this letter. They offered to suspend the legal process for three months if the department agrees to produce a timetabled action plan detailing how it will address issues such as housing and workforce shortages at both national and regional levels. You can read more about the letter on the EHRC website: <https://equalityhumanrights.com/en/our-work/news/health-secretary-faces-legal-challenge-failing-patients-learning-disabilities-and>

Temporary changes to Care Act as a result of Coronavirus

Due to the additional pressures being placed on the social care system by the pandemic, the Government has made temporary changes to the Care Act 2014 via a new Coronavirus Act 2020. The new powers are intended to support local authorities in prioritising those with the most pressing needs by introducing 'easements' which are supposed to be temporary reductions or delays in the services they offer. However, these changes can only be made in response to unusual pressures on the local systems. Local authorities are still supposed to take reasonable steps to ensure that people with learning disabilities and their families get the support they need. Mencap has published guidance about these changes and their possible impact. The Q&A section covering people's rights and appropriate responses to various scenarios.

More details can be got from the Mencap website: <https://www.mencap.org.uk/advice-and-support/health/information-about-coronavirus/coronavirus-changes-care-act>

A review of the CQC's regulation of Whorlton Hall

In the summer of 2019, following a televised BBC Panorama programme showing abusive care of people with learning disabilities and/or autism in Whorlton Hall (an independent hospital in the north of England), the CQC (Care Quality Commission) commissioned an independent review of its inspections of Whorlton Hall. Professor Glynis Murphy was appointed to conduct the review and her report was published by the CQC on 18th March.

The CQC had been heavily criticised by the media and others for failing to spot abuse in Whorlton Hall. This independent review of CQC actions over several years recognised that the CQC had followed its procedures, but there were a number of reasons why it was unable to detect the abusive behaviour of staff.

Professor Murphy's report has made a number of recommendations which echo many of those made previously, for example, in the Serious Case Review after Winterbourne View. The six recommendations to CQC are to:

- Displaying data, for each service inspected, in a user-friendly way, including on abuse allegations, complaints and concerns
- Using only unannounced inspections, including evening and weekend visits, and not signalling upcoming inspections
- Working with other relevant agencies when it receives abuse allegations, safeguarding alerts and whistleblowing events and recognising that they are probably the tip of the iceberg
- Hold in-depth service user interviews (without staff from the service that is being inspected) and train inspectors in alternative and augmentative communication methods
- Where there are indicators that a service may be at risk of failing its service users, conducting inspections that allow more time for observing and interviewing service users, as well as staff surveys
- Not registering or allowing expansion of services that are very isolated, in unsuitable buildings and have out-of-date models of care and deciding how best to alter those that are already registered

As Professor Murphy states in her report, 'Certainly, the families of people with learning disabilities and/or autism, as well as professionals, will be watching CQC closely to examine improvements in its methodology over the next few years.'

The report is available from the CQC: <https://www.cqc.org.uk/news/stories/cqc-publishes-independent-review-its-regulation-whorlton-hall-between-2015-2019>

Frozen Light - new show for arts festivals

Frozen Light has announced Fire Songs as its new show for arts festivals for audiences with profound and multiple learning disabilities. Fire Songs has been composed by Thomas Johnson and has been co-commissioned by The Garage and Norfolk & Norwich Festival.

Fire Songs is an immersive sensory sound experience for audiences with PMLD, performed in collaboration with a local choir. Frozen Light will work with a different local choir at every festival it visits to create an immersive sensory shared choral experience for audiences with PMLD. The show provides an hour of original music interwoven with sensory experiences in a new kind of production from Frozen Light.

For more details visit: <http://frozenlighttheatre.com/current-productions/firesongs>

Online postural care booklets

The charity Pamis reports that the postural care booklets produced by NHS Education for Scotland on behalf of the National Postural Care Strategy group are now online.

These booklets have been created in light of the current COVID-19 situation reminding people that, if someone has a movement difficulty and is having trouble breathing or is reducing social contact, altering their position frequently throughout the day might help them from becoming stiff and sore.

These booklets are for anyone who has difficulty with their movement so please share with anyone that might find them useful.

<https://learn.nes.nhs.scot/28190/coronavirus-covid-19/resources-for-other-new-staff>

RESOURCES

Case Law Directory

The Council for Disabled Children (CDC) provides a case law digest service which offers updates on the latest judicial decisions affecting disabled children and young people and those with SEN.

CDC's case law digest service provides information about the latest decisions affecting these children and young people. The digests provide a description of the case, the implications for children young people and their families, and how professionals might need to change their practice as a result of the judgement.

Some of the cases deal with fundamental issues of human rights, such as the judgment of the Supreme Court concerning when disabled children are considered to be deprived of their liberty in health and social care placements.

These updates are intended to provide general information. They cannot and do not provide advice in relation to individual cases.

<https://councilfordisabledchildren.org.uk/our-work/social-care/policy/case-law-directory>

Special journal issue on relationships of people with developmental disabilities and their siblings

The journal "Research in Developmental Disabilities" published in February 2020 (Volume 97) a special issue on sibling relationships in developmental disabilities. The issue, edited by Dr Katie Cebula (University of Edinburgh) and Dr Hanna Kovshoff (University of Southampton) includes research studies exploring a range of issues concerning the lives of children and adults with developmental disabilities and their siblings – from playing together, to feelings of school belonging, to relationship quality. The volume can be downloaded from: <https://www.sciencedirect.com/journal/research-in-developmental-disabilities/special-issue/106X577CZ7Z>

Summaries of the articles are included can be found on the Sibs website at: <https://www.sibs.org.uk/research/>

Standards for Health and Social Care Records

The Professional Records Standards Body (PRSB) creates standards for health and social care records.

More people than ever are living with long-term conditions in the UK. As a result, there has been a national drive towards providing patients with long-term, personalised care plans.

The PRSB worked in partnership with the Royal College of Physicians Health Informatics Unit and the North West London Collaboration of Clinical Commissioning Groups to develop the digital care and support planning standard, so care plans can be effectively shared between patients, carers and all the health and care professionals involved in that person's care.

The new standard for generic care planning, including end of life treatment, will contribute towards the creation of a more joined-up care system. The standard can be viewed at: <https://theprsb.org/standards/dcsp/>

The PRSB also presents a video giving Matthew Prosser's story. This shows how digitalised care and support plans could change the future of care for people living with long-term health and care needs: <https://theprsb.org/matthew/>

Another great offer from Richard Hirstwood

An introduction to multi sensory learning - a FREE online training resource with text, video, infographics, reflective practice and a quiz for you to check your learning. This was launched in November 2019. Have you had a look? <http://ow.ly/qhPu50yoYMK>

This course is effectively a taster for a full online learning package due to be launched in Spring 2020. Further details about courses included in this bundle, pricing and how to buy can be got from: <https://hirstwood.com/contact>

Changes to the Routes for Learning materials

As part of a wider reform of curriculum and assessment arrangements in Wales, practitioners and experts have been working together to update the invaluable Routes for Learning materials.

In April 2019, an amended Routes for Learning Routemap was published. An advisory group has been updating the Routes for Learning guidance to enable practitioners to assess learners with PMLD and identify how to support them in developing their learning.

Updates of the assessment booklet and exemplification videos and case studies have also begun.

The intention, as stated in January this year, is that the full suite of Routes for Learning materials will be finalised and published in summer 2020 but, presumably, there will be slippage due to the coronavirus epidemic.

More details are available at:

<https://hwb.gov.wales/curriculum-for-wales/routes-for-learning>

Make and use a Resonance Board

If you have not seen this YouTube video yet check it out. It contains some helpful information about how to make your own resonance board quite cheaply. Anne Cheesebrough and Helen Potter explain the value of resonance boards and how to introduce children to one. They show how to 'risk assess' activities and suggest a range of possible activities.

<https://www.youtube.com/watch?v=Xsa8w82xPsQ>

Resources Available Online During Lockdown

What is amazing and uplifting during the current health crisis is the incredible generosity and ingenuity being shown to support folks with PMLD. PMLD LINK's own Facebook Page has received posts from people sharing their talents and ideas with activities and interactive sessions online. Their work is fabulous - and seemingly without any expectation for anything in return. So many have created resources and videos.

The PMLD LINK editors have been in touch with quite a few of the people who have been sharing in the hope that they will share them through future issues of the journal too. In the meantime check out PMLD LINK's Facebook page.

SHORT COURSES & CONFERENCES

In this section we would normally advertise a range of courses, seminars, and other events that might be of benefit to the family members and professionals supporting children and adults with PMLD and, sometimes, people with less severe learning disabilities. Inevitably, the requirements for social-distancing and the vulnerability of many people with disabilities mean that we cannot publicise any course with any degree of certainty that it will occur as originally planned.

However, we do feel it is important to remind people of the various training providers who have advertised in PMLD LINK and have contributed in one way or another to our community. Even if they cannot offer face to face courses some have available digital options. So here is a list, not exhaustive and in no particular order, of regular and relevant providers together with their website details. We suggest that you regularly visit their websites to see what may be on offer. We would welcome suggestions for any additions to the list and we will provide an update on courses in the Summer issue due out in July.

The Seashell Trust is a charity which is dedicated to providing a creative, happy and secure environment for children and young people with complex and severe learning disabilities which include little or no language abilities
<http://www.seashelltrust.org.uk/events/training-development>

Us in a Bus is a charity which offers practical workshops for individuals, groups and organisations about Intensive Interaction'
usinabus.org.uk/events/training-dates

The Story Massage Programme combines the benefits of positive touch with the fun and creativity of words. The charity offers a range of courses.
(<https://www.storymassage.co.uk/training>)

The Social Care Institute for Excellence (SCIE) aims to improve the lives of people of all ages by co-producing, sharing, and supporting the use of the best available knowledge and evidence about what works in practice.
<https://www.scie.org.uk/training>

The Goldsmith Centre offers training courses relevant to people with complex disabilities; including postural care, specialist seating and sensory engagement.
<https://thegoldsmithcentre.com>

Simple Stuff Works also offers products and training designed to help people manage postural care and is associated with the Goldsmith Centre
<https://www.simplestuffworks.com>

The Intensive Interaction Institute is dedicated to providing training and a range of publications and videos from accredited trainers in Intensive Interaction
<https://www.intensiveinteraction.org/training>

EQUALS is a charity committed to supporting the work of schools and parents/carers of pupils with with SLD/PMLD through provision of curriculum materials, guidance, workshops and conferences
<https://equals.co.uk>

Sensory Spectacle aims to create a better awareness and understanding of auditory, visual, tactile, smell, taste, proprioceptive and vestibular difficulties. It offers online courses as well.
<https://www.sensoryspectacle.co.uk/>

The Sensory Projects seek to show how with the right knowledge and a little creativity people can use inexpensive items as effective sensory tools for inclusion. It has a useful list of links to explore that could be handy for people as they home educate their children.
<http://www.thesensoryprojects.co.uk/covid19-resources>

Concept Training is a group of experts who aim to provide training to help people to better understand those with special needs and learning disabilities. They are currently delivering their courses via live video conferencing <https://www.concept-training.co.uk>

Hirstwood Training has a team of consultants whose mission it is to share the best sensory approaches to breaking down barriers to learning for all learners. Aside from face to face training there are also online training packages and free taster courses. <https://online.hirstwood.com>

Together Matters helps in a number of ways including provision of training for support staff and/or managers on supporting people to have a good life as they get older including a set of resources they have developed published by Pavilion Publishing <https://www.togethertatters.org.uk>

Learning Disability England (LDE) exists to make life better with people with learning disabilities and their families. LDE offers an effective and representative voice of people with learning disabilities. It campaigns actively and provides information services, including webinars, resources and currently a coronavirus hub for sharing information and resources about the virus. www.learningdisabilityengland.org.uk/

PAMIS is the Scottish charity supporting people with profound and multiple learning disabilities - their families, carers and professionals. PAMIS are currently adapting their learning and development resources so that they can be delivered where possible online or virtually. For more information please contact Fiona Harper at PAMIS – f.k.harper@dundee.ac.uk <http://pamis.org.uk/>

SENSE is the charity supporting everyone who is deafblind and people living and working with them. It offers a range of resources and training, notably intervenor courses. <https://www.sense.org.uk/get-support/housing-and-individual-support/individual-support/>

Rebound Therapy training has been offered by its originators for many years and is now offering online courses. <https://reboundtherapy.org/courses>

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

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

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

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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.
- 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.
- 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 tweets for us on @PMLDlink follow for ideas and information.
- 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, and now works as a professional advocate and involvement worker for an advocacy charity. She uses creative and arts-based approaches including music, sensory storytelling, and intensive interaction. Becky is also passionate about raising awareness and expectations, to build high quality support that is truly person-centred.
- 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

Disclaimer: Views expressed by contributors to **PMLD Link** are their own and do not necessarily reflect the policies 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.pmlmlink.org.uk

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