

PMLD LINK

sharing ideas and information

A wider view

Winter 2022



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26 More than words

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GUEST EDITORIAL

A wider view

Welcome to the Winter 2022 journal. Firstly, we want to thank all the contributors to this general edition. It is always very exciting waiting to see what articles arrive for our journals without a set theme. A general edition allows us to understand the reality of what is of current importance for readers - the latest, pressing topics, what's new or helping push the boundaries in the real lives of people with profound and multiple learning disabilities (PMLD) and everyone involved in their lives.

Contributions to this issue of PMLD LINK continue to demonstrate the enthusiasm and passion to share innovative practice, thinking and relevant research. It keeps the focus firmly centred on what is important, the people with profound and multiple learning disabilities themselves. Although this is a collection of articles with no particular theme, you'll quickly recognise there are common threads that overlap and interweave items. We explore the sheer joy music can bring – but sometimes that happens in quite unexpected contexts, where 'activity boundaries' are blurred. Music can enrich the lives of people with PMLD in many ways and their music can be celebrated. The Hidden Word Project describes how it allows people with PMLD to immerse themselves in different sound worlds and how music engages them to be creative artists. Music also has a valued place in therapeutic interventions promoting relaxation, communication and wellbeing. The joy and confidence of a whole-body experience is described when music is used within hydrotherapy by Liquid Vibrations. Want to know what happens when music is used to accompany rebound therapy? That's included here too!

The many benefits of rebound therapy are discussed in this issue, but we hear from some practitioners who are being extra creative -in one article we hear that Staffordshire County Wide Specialist Opportunities Service use airbeds – yes, lilos! What a versatile and affordable way to provide this activity. Louise Molineux goes on to tell us how they valuably incorporate storytelling within their airbed rebound sessions and shares an example, to try ourselves. The importance of stories continues elsewhere in this issue, with articles about the significant role they can play in day to day lives. Lauran Doak discusses the use of Pictello, a story telling app and how it can be used to evoke memories and make connections. Nina Martinez reflects on her own storytelling experiences with that of her newer role, as a funeral celebrant, to help her to make accessible end of life celebrations. Naomi Hewardine shares how a sensory story enabled her group of college students to access the LGBTQ+ TV show, Heartstoppers.

Making sure people with profound and multiple learning disabilities have a voice and are heard, is another common topic for PMLD LINK – and this edition is no different. In several articles passionate writers and practitioners describe communication beyond linguistic codes. Innovative ideas such as Sheridan Forster's, Hanging Out Café, where the focus is on inclusivity and interaction takes place in a relaxed atmosphere. Another article explores how we can reflect on the impact of Intensive Interaction and the challenge of 'measurement', in turn helping us to reflect of the importance of how, and which, data we collect. We pose other, thought-provoking questions for readers, including the ethics around including people with profound and multiple learning disabilities in research or in them having a public or online presence.

As always, we try to bring you the latest relevant news, including some updates on Changing Places toilets across the four nations of the UK. All our regular features follow on - reviews, useful publications and resources and our information about future events and courses.

It has been a pleasure for our volunteer editors to create this Winter journal and we really hope you enjoy it. If you feel inspired to contribute to future journals, please don't hesitate to get in touch. You can find out in this issue, what's planned for Spring 2023 on page 48 or online: <https://www.pmlmlink.org.uk/the-journal/future-focus/>

Guest Editors: Wendy Newby, Michael Fullerton, Maureen Phillips and Annie Fergusson

Contact Us

Subscriptions

PMLD LINK
Caerludd, Cilgerran,
Pembrokeshire, SA43 2SN

info@pmlmlink.org.uk

Production

Paul Bramble
Email: info@pmlmlink.org.uk

Website: www.pmlmlink.org.uk

Twitter: @PMLDlink

Facebook: @PMLDLink

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Fantastic folk: exploring traditional music with some really fantastic folk

Peter Burgess

Fantastic Folk was a pilot project developed by Fantastic Journeys. Fantastic Journeys was set up by Rose Gordon (a dance practitioner) and I in 2021. We are constituted as a social enterprise. The aim of the organisation is to enable children with additional support needs to access music, dance and storytelling.

We had lots of experience of running workshops for children with a wide range of needs. We often found that the children with Profound and Multiple Learning Disabilities (PMLD)/Complex Support Needs required more support in order to participate. Our experience was that it was hard to keep a group session running and provide this more intensive support. We also found that the children with higher support needs required more time to engage in the activities.

Out of this frustration came the vision for a discrete music club for children with PMLD/Complex Support Needs. We decided to apply for a small grant, with support from Creative Black Country, to run a pilot

project. I recruited multi-instrumental Madeline Norris to work with me on this project.

At our first planning session, we talked about whether anyone had explored traditional American and English folk music with people with PMLD/Complex Support Needs. I wondered whether what we were doing was completely new. We were two traditional folk musicians with a passion for connecting with children with PMLD/Complex Support Needs. Both of us had experience of supporting children with learning difficulties and disabilities but hadn't tried anything quite like Fantastic Folk.

The project

The project was based around the following concepts:

1. All children are able to participate in music making.
2. We, as musicians, need to create a space where the children are able to participate.
3. We will use an interactive approach that responds to what the children can contribute, and through their contributions, make music, in the moment, together.



Madeline and I knew each other really well and played in a band together. The instruments we decided to use for the project were acoustic guitar, square neck resonator guitar, fiddle and accordion. We wanted to deliver to small groups of children, with a maximum of four in each group. Each session was an hour and we delivered a total of six sessions over three delivery days. Each delivery day had two groups, and the children were invited to all three delivery days.

What happened

As the children arrived, we welcomed them with improvised playing by Madeline on fiddle and me on square neck resonator. We welcomed each child and sang a "getting ready" song. After this the children took part in a "hello" song which used the folk tune "Jesse James." Each child was sung to individually and was given space to play an instrument (either a real percussion instrument or a virtual instrument on the iPad) or use their voice to make music. The musicians responded to the sounds the children created using rhythm, volume and repetition of musical motifs. This interactive approach seemed to be very popular. After the first week, we decided to split the group into two for part of the session. Madeline and I worked with two children each, encouraging them lead the interactions. The children enjoyed our take on Morris Dancing.

We had a large piece of material (like a Morris Dancer's hanky) which we wafted over the children's heads, whilst Madeline played the Morris Tune, "St. Anne's Reel" on the fiddle. We played with the tempo and volume and wafted the material accordingly. Connecting the music with the movement of the wafting material seemed to work really well and prompted lots of positive responses. Our multi-sensory story was based around the popular sea shanty "Wellerman". The ship, the Billy 'O' Tea, set sail with the children on board and had various adventures. The activities for the story included; pulling up the ship's anchor (Using rope especially adapted with small, jingle bells); going fishing (but we could only find musical instruments in the sea!); visiting the beach and digging for sea shells (exploration of a sensory tray with sand and sea shells); and sailing through a storm (the children were fanned and had their hands sprayed with water). We sung the song at the start of each part of the story to signify that a new activity was about to take place. Throughout the story we continued to respond to the music the children were making using our voices or any other instruments that were at hand. Finally, we sung a "goodbye" song to the Northumbrian folk tune "Blow the wind southerly."

We organised the sessions in the same way each week in order to develop a predictable structure. We always started with the getting ready music and hello song. We always ended with the same goodbye song.

What we learnt

We found that the children really responded to the music. They were interested in our playing and singing. We were responsive to their playing and vocalising. We listened to them and followed their lead and created new music together. We found that the children really enjoyed this and over the sessions we spent more time responding to the music the children made with instruments or their voices.



The children were also interested in the instruments we were playing. The accordion was particularly popular and some of the children enjoyed pressing the buttons and

keys as Madeline played. The guitar was also popular and one child wanted to hold it for the whole session. The following week I brought a second guitar with me for that child to hold. I tuned it to an open tuning so that he could play and make music in one of the keys we were playing in.

A couple of the children came with their brothers. We hadn't planned to accommodate siblings and were initially unsure how this would impact the session. We did not want the focus to be taken away from participants by noisy siblings. However, we found that the siblings really enjoyed being with us in the session and liked taking on the role of helping their brother/sister to take part. Some of the families commented that they hadn't had an opportunity to attend an event for the whole family which was focused on the child with PMLD/Complex Support Needs. This unexpected factor enriched our sessions. We came away from the pilot project with a commitment to taking into account the role of siblings and how we can include them, whilst ensuring the focus isn't taken away from the child with PMLD/Complex Support Needs (see table below Feedback from Families) .

Conclusion

We thoroughly enjoyed delivering Fantastic Folk and found that each child was able to participate when we listened to them and what they were doing. As the project progressed, we found that the most satisfying

part of each session was the interactive approach to creativity. This approach focused on making music together in a playful and genuinely collaborative way. It is this ethos that we will take with forward with us as we plan for future music sessions with children with PMLD/Complex Support Needs.

Biography

Peter Burgess is Co-founder of Fantastic Journeys CIC. Peter has 16 years' experience of supporting people with a range of Additional Support Needs. He has a PGCE (PCET) specialising in Learning Difficulties and Disabilities from the University of Greenwich. He also has an M.Ed. in Severe, Profound and Complex Learning Difficulties and Disabilities from the University of Birmingham. In addition to running Fantastic Journeys, Peter works at a college for young adults with PMLD in Birmingham. Peter is also a multi-instrumentalist and currently performs with folk and bluegrass band The Bearwood Bandits.

Contact Details

fantasticjourneycic@gmail.com
Fantastic Journeys CIC deliver music & movement workshops specialising in working with children and young people with additional needs

Feedback from Families'

Answers
Opportunity to enjoy a different style of music with my child. Meeting the other families and having a consistent group to get to know during the sessions. The musical story part was a particular hit with my son - we liked the very sensory props and the consistent story theme between weeks. Great to have a small group so each child's little ways could be learnt so well and remembered each week - sessions were really well personalised.
XXXX has loved making music. His brother YYYY has really enjoyed joining in and helping XXXX too. It has been lovely watching XXX engage and communicate together as a family. It's also lovely to see the other children participating. It's great for him to have something he enjoys so much that is out of school because there are so few opportunities for him.
XXXX enjoyed using the iPad and playing with various Instruments.
She is happy, she enjoyed everything.
Continue with more sessions – so beneficial for him to get out.



Hidden Worlds

Rosie Rushton

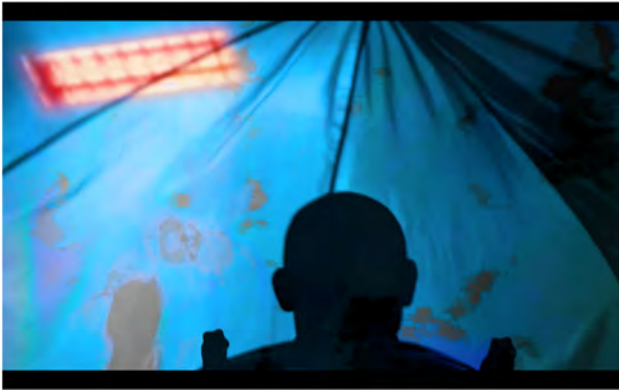
Hidden Worlds was a six-month collaboration between artists with profound and multiple learning disabilities (PMLD) and world musicians.

Exploring the hidden sound worlds of people with PMLD, the Hidden Worlds project commissioned three new audio-visual artworks, with the aim to develop these with, by and for people with PMLD.

The collaboration process

Throughout the project three sound worlds were explored. Selected for their relevance to the experiences, background, and cultures of the artist with PMLD involved, the project explored the sounds of English folk music, South Asian song and dance, and Western Africa, in particular Senegalese music. The collaborative process was developed to enable the artists with PMLD to become familiar with, and immersed in each sound world, before working in collaboration with professional musicians. In this way the artists with PMLD had the opportunity to develop familiarity and responses to the specific musical characteristic connected to each artist, before meeting them, and creating a sound world together. These introductory sessions were delivered by a core team of music facilitators who are familiar and experienced in making music with people with PMLD. The process of collaboration is outlined below.

1. The facilitation team met the artists, both the artist with PMLD and the expert world musician. The musician and the team explored key musical elements related to the sound world and the musical and creative skills and abilities of the other artists.
2. The facilitation team worked creatively to make these musical elements accessible, relevant, and engaging to the artists with PMLD. Considering the sensory elements involved within the theme.
3. The facilitation team worked alongside the artists with PMLD to introduce and explore the sound world together. New ideas and creations began to emerge.
4. Artists with PMLD and expert musician/s met. Musical and creative opportunities were facilitated, created, and recorded. Excerpts of these were shared with all artists.
5. Creative contributions and compositions were worked together with visual imagery to generate a new composition. These were shared with the artists.



It was important to the Hidden Worlds team that these new commissions were shared using an accessible and interactive platform. The team discussed the lack of presence of people with PMLD on the internet. There seemed to be websites 'about' people with PMLD, very little trace of anything 'by' or 'for' them. Working with a web-designer the Hidden Worlds site is intended to be used by people with PMLD, featuring content created by, with and for people with PMLD. After the initial development stages the website was shared with people with PMLD and their families to explore together and feedback to the Hidden Worlds team. The final site includes minimal written text and is designed to be navigated using three button options. It is best accessed using a tablet or iPad.

Reflections

Throughout the project the team shared their perceptions of creativity, and what this meant or may look like for people with PMLD. Philosophising about this, we debated the similarities between the creativity of artists with PMLD and that of free improvisors. Free improvisation is a form of improvised music without any rules beyond the inclination of the musicians involved. The in-the-moment freeness of the responses and initiations of the artists with PMLD meant that the music generated through project was spontaneous, instinctive, and irreplicable. Free of rules beyond the understanding and perceptions of each individual, regardless of disability. Viewing the project through this lens the contributions and roles of all the artists were equitable. Each artists' individual contribution was integral to the sound worlds created.

Although it may not always have been the intention of the person with PMLD to create music, just as it may not always be the intention of a musician producing sound, if we, the listeners, received it as music, as a creative contribution, that in turn validated it as such. Music, and more broadly creativity, was viewed as the relationship between the intention of the creator and the intention of the listener. The Hidden Worlds facilitation team plan to explore this understanding in further projects and future work.

Conclusion

The aim of this project was to explore the hidden sound worlds of people with PMLD, capture these sounds and share and release them into the wider world. The new tracks generated from the Hidden Worlds project and the interactive site can be found at www.hiddenworlds.uk.

The project is grateful to all the artists, supporting staff and creators involved.

Hidden Worlds was funded by Arts Council England and delivered in partnership with Victoria College, Birmingham, and Big Top Musical Adventures.

Any feedback on the site, the commissions, or this article is gratefully received.

Contact details

Article written by Rosie Rushton
info@bigtopmusic.co.uk

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Musical hydrotherapy: combining the therapeutic benefits of music and aquatic body work for children with complex needs

Alice Walton

The therapeutic benefits of music therapy and aquatic body therapy on children with profound and complex needs are well documented. But what would happen if children experiencing aquatic therapy were also able to listen to – and feel the vibrations from – specially composed music under water? For almost a decade now, our small charity has been working with teachers, therapists and practitioners in special needs schools across the UK to demonstrate that Musical Hydrotherapy can help children with profound disabilities to experience deep relaxation, increased motor and sensory skills, increased vocalisation, improved wellbeing – and sheer joy.

Liquid Vibrations was launched in 2013 by sound artist and composer Joel Cahen and Adele Drake, the founder and former CEO of Drake Music, a pioneering music and disability charity. Adele had made the connection between the properties of underwater sound perception and its potential benefits to children with special and complex needs.

In Musical Hydrotherapy, speakers are placed within a hydrotherapy pool and sound is heard through them when any part of the head is placed in the water. The vibrations travel through the water and stimulate the inner ear directly, and so the listener perceives the sounds as if they are heard from inside their head. The result is an all-body experience of sound that is incredibly detailed and immediate: despite being in a public space, the listener feels as though they are inhabiting a very private space, an almost womb-like environment. The vibrations can also be felt inside the body when it is in close proximity to the speakers. When this is experienced alongside WATSU-based body therapy (see note at end), the participants enter a deep state of relaxation.

"I just kind of drift away... it feels so good for my back. It's just one day a week but it feels good for days afterwards." Student at Victoria Education Centre, Poole.

"All classrooms without fail reported a sense of calm, a serenity in the students, which lasted into the following days. Some parents have reported better sleep, help with breathing, better digestion." Sophie Prichett, Head of Swimming, Victoria Education Centre, Poole.

For the children themselves, the pleasure of the experience can take many forms. At St Ann's School in Hanwell in March this year, a young non-verbal boy cried



out in clear joy as his severe neck spasm was released and his spine was able to align. At Victoria Education Centre in Poole a student that was described by his teachers and parents as "constantly on the move" and frequently agitated, fell asleep in the water during his final session. Ella, a pupil at Marjory McClure School in Bromley, used to be very afraid of water and insisted on wearing armbands and also had to be held at all times, but her Musical Hydrotherapy experience has given her the confidence to float independently and without water aids or assistance.

Musical Hydrotherapy remains at the core of our programme today, and our philosophy is to enable schools and residential homes for children with complex needs to embed our practice into the heart of their curriculum. We train teachers and learning assistants to deliver Musical Hydrotherapy themselves and then provide ongoing support. We offer bursaries to help purchase the underwater speakers and equipment, we create free classroom teaching resources to help non-specialist music teachers to bring listening therapy and creative music-making into the classroom, and we are helping to build networks of schools using our practice to support each other and share ideas.

We are also developing new programmes to complement our core pool work. Our Music Production module helps 13-19 year old learners to use technology to compose, record, produce and present original music that is then used in Musical Hydrotherapy sessions. It has been wonderful to see students creating their own sounds, experiencing them underwater alongside the relaxation and wellbeing benefits of the pool-based activity - and then sharing their music with family and creating something for their peers to benefit from in their own pool sessions. We are now looking at ways to help schools - with and without their own pools - to create classroom-based listening therapies to promote similar relaxation and wellbeing effects.

"Our staff team reported that it was some of the best training that they had ever received". Julia James, Headteacher, Bedelsford School, Kingston.

We are always keen to introduce our work to new schools and communities – where possible we welcome teachers to observe our sessions locally, and we offer taster days. We're also trying to find ways to make connections with the wider local PMLD community as well as with special schools.

There is plenty more that we could say about what we see when we watch children with PMLD experiencing Musical Hydrotherapy, but it's probably simplest to give the last word to a pupil from Valence School in Kent in May this year:

"The music feels like rainbows inside me".

Contact Details

Alice Walton

Email: alice@liquidvibrations.org.uk

To find out more about the work of Liquid Vibrations, view film clips at: <https://www.liquidvibrations.org.uk/testimonials>

For more information about Musical Hydrotherapy or any of Liquid Vibrations related programmes, visit www.liquidvibrations.org.uk, follow on Twitter (@LiquidVibratio1) or Facebook (@liquidvibrations) or email the Artistic Director Joel Cahen: joel@liquidvibrations.org.uk

Note

Watsu® is a form of hydrotherapy which involves stretches, massages, and acupressure in warm water. The term Watsu® comes from the words "water" and "shiatsu." Shiatsu is a type of traditional Japanese massage that uses acupressure to promote relaxation. In Japanese, shiatsu means "finger pressure." https://www.healthline.com/health/watsu#_noHeaderPrefixedContent

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

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

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

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

Rebound therapy with improvised musical accompaniment

Phil Tomkins

This article describes how the use of appropriate improvised music to accompany rebound therapy sessions on the trampoline can lead to more active engagement and enjoyment by children and staff alike.

Rebound Therapy - the therapeutic use of the trampoline for children and adults with special needs - has greatly increased in popularity since its introduction in the 1960's and is widely used in special schools in Britain, Europe and the United States. The aims of the sessions vary enormously: addressing high or low muscle-tone, encouraging appropriate balancing responses and proprioceptive awareness, working towards independent movement, choice-making, engagement, building self-esteem and more. Most of the programmes are drawn up by physiotherapists or occupational therapists and are tailored to the needs of the individual. My own interest was aroused whilst reading Music Therapy, Sensory Integration and The Autistic Child by Dorita S. Berger, an American music therapist who wrote about playing live music to help with an autistic child's trampolining programme. She suggested that among other things, the music, by involving a large part of the pupil's conscious brain, allowed a more autonomous and relaxed response to the trampoline's movements.

After reading about her intervention, I approached one of the teachers at the special school where I work to see if my own improvised music might add to the experience of Rebound Therapy for the children in her class.

It was fairly obvious from the start that it did, and that music reflecting the rhythms and the mood of the sessions was adding something significant to their experience. When asked "How does this compare with previous sessions without music?" the teachers and teaching assistants involved were consistently positive in their responses. Staff felt that they themselves were more relaxed and engaged when there was music, and they saw that the children were too.

Initially I played on a keyboard alongside the trampoline, but gradually introduced other instruments - viola, hand-drums, auto-harp etc. I began to work musical structures into the programmes where appropriate, reinforcing movement sequences with musical markers, emphasising turning, lifting or bridging with clear musical patterns, sometime using spoken or sung cues. The children often responded directly to the musical phrasing and were

better able to anticipate movements when they were accompanied by familiar and predictable musical sequences than when no music was present.

I introduced a winding-down time at the end of each session in which the child and facilitators lay and bounced gently together while calming music brought the session to a relaxed end.

Music seems to work in different ways in these sessions. For the children who are very physically challenged - many of whom also have visual impairments - music acted as reassurance as they moved on the trampoline, providing a predictable framework for their movements. For autistic children presenting with distressed behaviour it can provide a safe structure and act as a bridge between the child and the session's facilitators, encouraging more meaningful engagement during the session. For other, active, ambulant pupils the music can greatly enhance and extend their participation in and enjoyment of rebound therapy sessions. It seems to have caused a genuine shift in the nature of the sessions, transforming them from a series of sometimes routine exercises on the trampoline into mutually enjoyable, shared musical experiences.

Examples:

S.H. was a seven-year-old with quadriplegic athetoid cerebral palsy. His rebound programme was partly occupational therapy - based and partly physiotherapy-based. It began with deep-pressure relaxing massage and continued with stretching, sitting, and head-raising. The music for his session worked in a number of ways. At the beginning the learner relaxed more easily, seemed less distracted by his own involuntary movements and was able to lie with his hands by his sides unaided for a significant length of time. For much of the rest of the session, during which he sat up, I played a hand-held instrument (a recorder or a hand-held drum) directly ahead of him at the end of the trampoline, which encouraged him to raise his head towards the source of the sound.

J.R. was an older child with hemiplegic cerebral palsy. He had a particular affinity with music. Since the introduction of improvised music to his programme he rarely refused, was visibly relaxed during difficult stretching exercises and could often be heard vocalising quietly in time to the music. At the end of his session he would sit quietly, waiting for the relaxation music. He was often reluctant to leave the trampoline afterwards.

D.S. was a physically able 10-year old with autism. She had become aware of the sequence of exercises in her programme and would often prompt the rebound facilitator by signalling the next exercise. She would go through her programme by herself, relying on musical cues alone to start, stop, change, turn etc. The music helped her to extend the time she spent bouncing independently, and she relaxed visibly in the winding-down time.

D.P. was a teenager with very poor sight and little intentional movement. His physiotherapy-based programme was essential for maintaining the mobility he had, but the exercises were often uncomfortable for him. The music, which followed the rhythm of his exercises precisely, clearly engaged and relaxed him and allowed him to concentrate less on the difficulty of the exercises and more on the accompanying music.

Contact Details

Phil Tomkins Music Therapist
Swansea
Email: philip.tomkins3@ntlworld.com

Summer Issue 2022 – A correction

In the last issue of PMLD LINK, the article 'Being with: creative fun' (*PMLD LINK* No 102, p. 10) was incorrectly attributed. The author was, in fact, Jill Goodwin, who is an artist and researcher. That article was based on Jill's work as Researcher in Residence at Oily Cart. The editors have corresponded with Jill, who was very understanding, and have corrected the online copy.

Since then, a new report from Jill Goodwin and Ellie Griffiths, Artistic Director for Oily Cart, has been made available. "Being With' in Sensory Theatre" investigates what can be learned from people with different perspectives and grapples with the difficult questions that arise in Oily Cart's work.

The report focuses on the theatre experience for audiences who experience the world in radically different ways and looks at how sensory shows can create equal opportunities for all theatre goers. The authors also consider the areas of language and labelling and agency and personhood and offer some clarity and suggestions.

The authors hope that this research will be of interest to anyone who works creatively with disabled children and young people who experience the most barriers to access.

There are also three short films that introduce the key findings of the report and you can see the report's authors in conversation with Miss Jacqui one of the report's contributors.

The report is available online at: <https://oilycart.org.uk/resources/being-with-in-sensory-theatre/>

Contact details for Jill Goodwin:

Email: jillkgoodwin@gmail.com

Website: <https://jillgoodwinphd.wordpress.com>

Rebound therapy: exercise and fun on a trampoline!

Callum MacKinnon

Bounce OT (bOunceT) is a social enterprise delivering a range of Occupational Therapy (OT) services, based in Scotland. Our vision is for everyone to be able to do the things they want, need, or have to do. Similarly, our mission is to improve the quality of life and participation in meaningful activities for children and adults with disabilities, and their family carers.

As the name of the organisation might suggest, a huge focus of our work is delivering inclusive rebound therapy sessions. In my experience, rebound therapy is either hugely popular - or not known about at all. The benefits of this therapeutic activity can be obvious, especially when seeing the smiles on people's faces as they take part, or when hearing direct feedback from parent carers. However, a lack of research into this intervention leaves room for doubt and confusion about its accessibility, and benefits.

What is rebound therapy?

Let's look at some facts about this intervention:

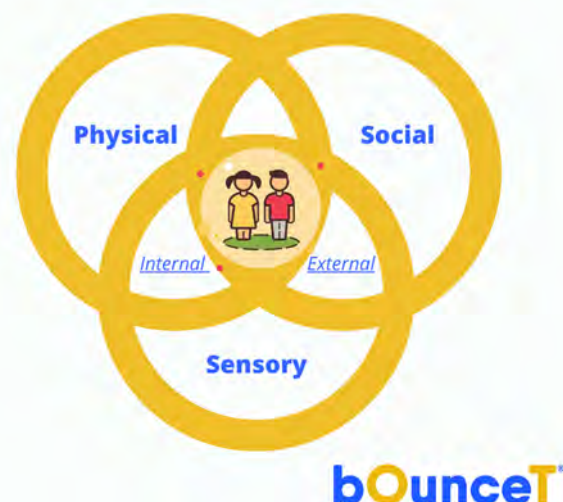
- In the UK 'rebound therapy' is a descriptive term which means the therapeutic use of a trampoline (Intellectual Property Office, 2013). Think of this as an intervention that a wide range of people, from various professions, are trained to deliver in their workplace or in the community with the people they support.
- There is not a regulatory body for rebound therapy, and there is not one mandatory training course to certify people in rebound therapy (ASA, 2016).
- Rebound therapy is not a registered trademark (Hayward-Giles, 2016).
- This intervention is commonly used by professionals across Education, Health, and Social Care settings.
- Research mainly across PHYSIOTHERAPY has enabled rebound therapy to grow an evidence base and become implemented in various services across the public and private sector.
- Rebound therapy is often used alongside other interventions like HYDROTHERAPY.
- The Chartered Society of Physiotherapists (CSP) special interest group 'Rebound Therapy Association for Chartered Physiotherapists' acts as a benchmark for best practice in rebound therapy.

- There are some suggested contraindications to participating in rebound therapy - like pregnancy, dwarfism, detachable retinas and a atlantoaxial instability (AAI) screening .

Rebound therapy and Occupational Therapy

Despite OT's not regularly using rebound therapy in practice (or having a special interest group like CSP) OT's are experts in activity analysis and finding the 'just right' challenge for people. OT's often support children and adults living with profound and multiple learning disabilities (PMLD) to access meaningful sensory experiences, and therapeutic play opportunities. Also, as bOunce OT is a service independent from the public sector we have more flexibility to offer different, more diverse, services. It was a no-brainer to set up an activity-based service that was different to anything else in my local area at the time.

The approach we take to measuring outcomes and progress in rebound therapy is by following our 'Physical, Social & Sensory' model. For example, considering physical development, social and communication skills, and sensory regulation.





To stay compliant with best practice, we make sure to keep the principles of OT at the core of what we do, and how we do it. We call this being ‘occupation centred’ and ‘occupation focused’. As a result, typically goals for rebound therapy are not solely about skills like ‘improving eye contact and develop communication’ – or ‘increase stamina/ duration of activity’. Instead, we work with the person with PMLD, and their family, to ensure participation [in their meaningful activities] leads the way we make playing on a trampoline purposeful. Additionally, we seek to complete joint assessments with other professionals to be as consistent as we can, combining multiple therapeutic benefits into one session. For example, link in exercises from Physio, and communication strategies from Speech and Language Therapy into the play.

This is slightly different to other rebound therapy sessions provided by different services and professionals, who might only have the capacity or skills to measure physical or educational outcomes.

The benefits – that we know to date

Although there is a lack of empirical research into rebound therapy, it is still widely accepted that this is a beneficial intervention - especially for those living with PMLD.

The main benefits include:

1. Having fun! This is always overlooked and under rated.
2. **CARDIO-RESPIRATORY** fitness – parent carers have commented this is one of few activities that can increase the individual’s heart rate and physical activity levels.

3. Prevention of coughs and colds – especially in winter months when there are reduced opportunities to even go outside/ for walks.
4. Improved bowel movements – from participating in physical activity
5. Altered tone - low and slow bouncing can help to reduce tone in those with hypertonia (high tone). This is another ‘safe’ way of getting individuals out of their chairs for a full body stretch (even without touching them/ doing hands on physio).
6. Improved balance – coordination and vestibular skills.
7. Improved sensory awareness (proprioception). Movements on the trampoline stimulate the joints, skin and muscles.
8. Stimulating movement and sensory regulation – the mixture of bouncing roughly and intensely, compared to soft and slow, can bring your senses ‘up’ (hyper) and ‘down’ (hypo).
9. Improved communication & social skills – especially when participating in play and different games during time on the trampoline.

Feedback from parent carers

“The activity on the trampoline not only stimulates the cardiovascular system, but also provides significant mental stimulation at the same time. It’s fun for C - it’s one of the few times I see him laugh!”

“K loved her rebound therapy sessions. She loved being bounced with her imagination taking her on a roller coaster or on horseback (her favourite things).”

“J has been getting great physical exercise – it is one of only activities he is able to access, and is actually interested in participating in! His mental health is getting better too as a result. His dad and I get a short break too, we really need it.”

The barriers

As mentioned, some people still have no idea what rebound therapy is, or how it can improve the health and well-being for children and adults living with PMLD. This will only be resolved once there is further clarity across both research, and marketing of services, about what this intervention is - and why it should be used more often.

Unfortunately, many parent carers have commented they cannot access learning opportunities about this intervention – for them or the paid staff supporting their child. The limited occasions when they can is only to complete a formal training that’s too expensive and designed for schools/other professionals. Furthermore, trampoline parks and leisure centres do not let parent

carers - or paid care staff – facilitate playing on a trampoline without this formal qualification. Often this is about liability for using the heavy equipment and being trained in the set up/take down of the trampoline, instead of what therapy is happening during the activity.



Finally, there are some contraindications that cannot be compromised on when considering if rebound therapy is a suitable intervention for individuals with PMLD – but keeping abreast of research and evidence from across the field is necessary. Too many children and adults are being denied access to rebound therapy on unfair grounds. One common example is that individuals who have had surgery on their spine cannot participate in rebound therapy. There is research within Physiotherapy to highlight that with clearance from a medical professional, and risk assessments in place from a Physiotherapist, having surgery or a spinal rod should not be a barrier to accessing this intervention.

Conclusion

Rebound therapy is clearly a valued intervention by many as it is a fun opportunity to try a new activity, whilst improving the health and well-being of children and adults with PMLD. However, it is still not commonly used by professionals across learning disability services – or by parent carers, and paid carers, in their community. This is due to various factors, but mainly confusion around what rebound therapy is, and its accessibility.

Recommendations

Services delivering rebound therapy should:

- Continue delivering 1:1 and group sessions, and encourage multidisciplinary team working with other services and professionals – e.g. between sectors, and Education/ Physiotherapy/ Occupational Therapy.
- Continue providing training to staff in workplaces - enabling rebound therapy to be practiced in more places, by more people.

Create opportunities for parent carers to access reduced cost training. This will allow parent carers and paid care staff to lead therapeutic play on a trampoline at home, or in the community. This could be a different learning experience to formal training for workplaces (that require strict risk assessments and policies).

- Liaise with trampoline parks and leisure centres to make rebound therapy more accessible (e.g. formal training to their staff, health promotion).
- Partner with Universities to provide student placements and explore research opportunities to initially define the intervention, then measure its impact both quantitatively and qualitatively.

Contact Details

Callum MacKinnon is a Specialist Occupational Therapist for bOunceT

Email: callum@bouncet.com

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Using air beds to promote wellbeing and fun

Louise Molineux

Our Staffordshire County Wide Specialist Opportunities Service supports adults with complex needs and profound and multiple learning disabilities (PMLD). To engage and support our customers' health and wellbeing we aim to create opportunities and activities which not only benefit them on a physical, emotional, and sensory level, but also provide a way of connecting and having fun together. The ingredients of one such activity includes the use of an inflatable camping air bed, tailored air bed stories designed to incorporate a range of movements as well as other various props used to create sensory experiences.

Why use air beds

Practically speaking, air beds are an invaluable sensory item; they are lightweight, quickly inflated and deflated, making their storage and setting up relatively easy. Air beds can be used vinyl side up to maintain safe hygiene practice. Whether you choose to use an air bed in the day room or classroom it is up to you. During holiday season it could add an element of fun to any camping trip!

Practicalities

We use a double-sized mid-priced, self-inflatable air bed, although a single bed could be used. The deeper the air bed the better as this supports safer manual handling and posture. There is always a risk of punctures but the beds do come with puncture repair kits. To reduce the risk of a puncture happening: remove shoes; do not stand on the air bed; avoid using heavy or sharp props; be aware of debris on the floor and consider whether the air bed need to be positioned on top of mats.

Before you carry out this activity, I would advise you to have a play, and experience the air bed for yourself. You will soon establish what feels good and what does not. Explore the various ways in which the air bed can be moved and used, practise the tempo and depth of the movements, be creative!

Preferably, the activity requires 2 to 3 staff; one on either side of the bed, and, depending upon the activity or individual, one could support the feet. We place padding/cushions down either side of the air bed to protect staff's knees.

Please be person centred - follow care plans and seek advice and support when needed. Observe and record responses, including likes and dislikes. Monitor throughout so that they can experience the best out of the activity.



The benefits and outcomes

This activity offers various physical benefits. The physiotherapists who support our service, recognise that the air bed activities promote movement as well as supporting postural care, skin integrity and pressure management. The movements of the air bed can be a great way of maintaining one's health, by freeing trapped wind, easing constipation and for some easing chesty conditions.

The air bed promotes sensory engagement, with or without the use of additional props. For instance, additional movements and sensations can be created by positioning the person on top of a fleece/ blanket, or

parachute. Also, the fabric can be used to rock the person from side to side, to move limbs, or used to enfold and wrap around the person or their limbs. In general, the air bed activities and movements are a great way to stimulate the vestibular and proprioceptive systems. Parachutes can be used in a different way to a fleece or blanket as the fabric can be moved at varying speeds and intensity around the individual to convey the story.

Besides these sensory systems the spoken rhythmic verse of the stories, the sound effects created on the bed surface, and sensory props also engage the auditory and tactile systems. Some air bed stories are devised to incorporate a range of sensory experiences and shared as you would when sharing a sensory story.

Ultimately, we find that this activity reaches and activates a person's sense of joy and fun. It not only releases feel-good hormones, but the shared fun also promotes social bonding.

Andrew



Andrew has a limited range of physical movement and has a windswept posture. As such, Andrew has limited opportunities to access and experience the joys of self-created movement. When on the air bed Andrew is free to rock and move his body, the air bed responds and increases the sensations of his movements.

Whilst on the air bed Andrew laughs and makes his happy sounds. Even before the story starts Andrew anticipates what will be happening by gleefully rocking his body and bouncing down on to the surface of the bed. Throughout, Andrew laughs and giggles, only slowing to listen and process the sounds and sensations. These are created by the tapping, swirling, or pounding sounds over the bed's surface. Each time there is a change of movement Andrew shakes his head from side to side and giggles.

Sometimes a Bluetooth speaker or microphone are placed on the bed for Andrew to hear and feel the vibrations of the music, this adds to the sensory joy of the activity. Opportunities to move his body are so important in terms of Andrew's physical, physiological, and emotional health, and wellbeing.

Jane



Jane uses a wheelchair with modular seating. She finds comfort in rocking her body. Jane raises her arm when she rocks as this intensifies these rocking movements. When on the air bed Jane will become still and appears to focus on the sensations of the bed movements. As far as words and stories go, Jane likes the gentle rhythmic rhymes of Julia Donaldson stories. The air bed stories are enjoyable as they too rhyme.

Narrative	Actions
<p>We're going on a journey up to Cannock Chase.</p> <p>We're going on a journey, up to Cannock Chase</p>	<p><u>Use Alternate walking hands</u> <i>Both staff coordinate and match each other's walking rhythm. Using a slow steady beat in time to the rhyme walk hands up and down the bed. Leave a gap between each line whilst the rhythmic beat continues. Repeat as often as you like. Ensure the rhythm and flow is maintained, to hold the space and create continuity.</i></p>
<p>Kicking through the leaves, we walk on Cannock Chase</p> <p>Kicking through the leaves, we walk on Cannock Chase</p>	<p><u>Silver blanket or hands focus on their feet</u> <i>Use hands / silver blanket to create a slow steady beat and sounds over and around their feet.</i></p>
<p>Deers run and jump over Cannock Chase</p> <p>Deers run and jump over Cannock Chase</p>	<p><u>Alternate running hands</u> <i>Increase the tempo of your hand beats and then administer one firm slap down on the word 'jump'. Leave a small 2 second silent gap to build anticipation then repeat</i></p>
<p>Walk to Pottal Pool over Cannock Chase</p> <p>Walk to Pottal Pool over Cannock Chase</p>	<p><u>Alternate walking hands</u> <i>Slow steady tempo using your hands to walk up and down the bed. Leave a gap between each spoken line whilst the rhythmic beat continues Repeat as often as you like. Ensure the rhythm is maintained whilst holding the space.</i></p>
<p>Jump into the boat whilst on Cannock Chase</p> <p>Jump into the boat whilst on Cannock Chase</p>	<p><u>Hands together Bang</u> <i>Big bang on 'jump' then rhythmic walking hands</i></p> <p>Repeat</p>
<p>Sail through the water whilst on Cannock Chase</p> <p>Sail through the water whilst on Cannock Chase</p>	<p><u>Under bed rocking</u> <i>Gentle lift of the bed. Place hands just under the bed and create a movement or a rocking motion. Alternatively swirly hands over the surface of the air bed. Or use both movements alternately.</i></p>
<p>Jump out of the boat back in Cannock Chase</p> <p>Jump out of the boat back in Cannock Chase</p>	<p><u>1 x Open 2 hands together Bang</u> <i>Big bang on 'jump' then rhythmic walking hands</i></p> <p>Repeat</p>
<p>Feeling very tired whilst on Cannock Chase</p> <p>Feeling very tired whilst on Cannock Chase</p>	<p><u>Open hand walk</u> <i>Gradually slow the tempo</i></p>
<p>Time for us to go, goodbye Cannock Chase</p> <p>Time for us to go, goodbye Cannock Chase.</p>	<p><u>Open hand walk tapping</u> <i>Gentle slow rhythm and tempo, fade out until it stops. Whisper/quiet voice on 'goodbye Cannock Chase'.</i></p>
	<p>Still hands</p>

Jane prefers a gentler experience of the air bed stories; she appears relaxed and happy throughout and will drift to sleep after or during the activity.

For those who prefer to sit whilst on the bed

For those who can sit up the movement of the bed is great for building core strength and balance. They can explore their movements and how these impact upon the air bed. One person used to sit and rock from side to side on the air bed.

The Stories

A range of stories which incorporate rhythmic rhyme and motions/actions have been created with the air bed in mind. The tempo, rhythm, stops and starts all add to the adventure. With the repeat telling of the stories, individuals have become familiar with the stories and in turn anticipate their favourite stories, movements, and actions.

Sometimes we add props and other sensory experiences, such as music or silver blankets over feet to simulate kicking up of leaves. The stories can be developed further by incorporating names or things that are familiar to them. We have a story entitled 'Cannock Chase' which is our local beauty spot. Ideas for story telling are available from the Sensory Projects and Story Massage. Please see an example of an air bed story on the next page.

'Going to Cannock Chase'

Prepare the air bed and environment

- Place a fleece/fabric/parachute on top of the air bed. Place padding on the floor either side of the air bed.
- Collect all the required resources. For this story you need a crinkly silver survival blanket or similarly crinkly material (to create the sound of the dry leaves).
- 2 staff members are required, 1 staff member either side of the bed.

To conclude, the air bed provides an affordable, versatile activity. The activities can be used in a more constructive way or as a general hang out time together. It offers a range of physical and sensory experiences, at the same time promoting wonderful interactions, and ultimately a fun way to spend time together.

Contact Details

Louise Molineux is Senior Day Service Officer for Cannock Specialist Opportunities

Email: louise.molineux@staffordshire.gov.uk

Useful Websites

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

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Using the Pictello App with young people with profound and multiple learning disabilities (PMLD)

Lauran Doak

I recently led a research study funded by the UK Literacy Association involving young people with learning disabilities and digital story making. I chose to use Pictello, an App made by AssistiveWare, which is available on iOS and Android. It allows users to create their own personalised digital story about any topic using their own photos, videos, typed text and audio recording. Virtual pages can be ‘turned’ with a swipe of the touchscreen, with switch access, or by having the App control the story as a slideshow. Amongst study participants I was delighted to have two young people with PMLD – ‘Matthew’ and ‘Eve’, and in this article I’ll focus on their experiences with the App.

In this study, families had twelve weeks to explore Pictello with their young person. There were no rules, no compulsory topics or formats: young people and their families could do anything which seemed engaging. Overall, I wanted to create a very ‘open-ended’ research project and to remain curious about what might happen. A family member took part in an interview at the start and end of the project, and families also updated me with weekly email ‘diaries’ to tell me about their progress. Families made home videos of their young person engaging with the App, and I also collected their Pictello stories for analysis.

Matthew

Matthew is a nine-year-old boy with profound and multiple learning disabilities (PMLD). Matthew’s mother Laura supported him to take part in the study. At the beginning of the study, Laura described how Matthew enjoys sharing robust colourful board books, ideally with sounds or textures to explore. Reading together is a positive experience for both of them: ‘it’s good one to one time ... we just have a little snuggle and have a little read’. (To read more about Laura’s thoughts on PMLD and literacy, to start talking phonics is crazy’: How parents understand literacy in the lives of children with learning disabilities, Pedagogy, Culture & Society (Doak, 2021)).

The first Pictello story, My Lockdown, celebrates activities Matthew did at home during COVID-19 lockdown. Laura described this as ‘very much a learning experience for both of us’. For instance, Laura initially experimented with the synthesised voices available in Pictello but concluded that recording a familiar voice would be more engaging. Matthew’s reaction to My Lockdown seemed mixed, showing more engagement with pages that featured close family members. The

second story, Love You, was a compilation of short videos of various family members explaining why they love Matthew. Matthew appeared moderately interested in videos featuring very close, familiar relatives but less so with more distant relatives. Laura reflected that perhaps future stories needed to be more centred on Matthew’s perspective and sensory embodied experience of the world: ‘that was all part of the learning really, about what he needed from the app, not what I needed from it’.

The third story, Daddy’s Birthday, marked a turning point in Matthew’s engagement. This story was narrated by Matthew’s younger sibling who was keen to be involved. The topic was chosen because of Matthew’s intense interest in one page in My Lockdown story about this birthday. The story featured an audio recording of the family singing Happy Birthday, Matthew’s favourite part of the celebration. Laura noted that ‘he’s definitely responded better to that story’, with giggles every time the song started.



Matthew's fourth story, A Visit to a Castle, was described by Laura as 'probably the most successful story'. Here, Laura foregrounded small sensory details which seemed important to Matthew: the sound of geese honking, the shade of the trees overhead, the taste of ice-cream, his ambivalence about the jiggling sensation when his wheelchair was pushed over cobblestones. Laura incorporated fun sound effects: for example, she read the line 'I don't know if I like it!' in a shaky voice to evoke the jiggling feeling. Matthew seemed highly engaged – giggling at the geese, maintaining eye contact with the screen and reaching to touch the iPad. Laura reflected that this story could be used as a celebration of happy memories, or it could function as a kind of cue or digital object of reference to prepare for a future visit. Initially, Matthew was positioned upright in his standing frame for Pictello time, a position he associates with schoolwork. However, by this point Laura realised that a more relaxed posture snuggled up with an adult on the sofa – which is how Matthew normally shares books - was more conducive to engagement.

The final story – Haircut Day! - built further on the idea of a story as a digital object of reference. This story used minimal words, with most pages containing only an image and a recorded sound effect to represent each stage: for example, splashing water, the electric hair clippers, the snipping of scissors. Matthew finds haircuts stressful, and Laura hoped that with the story 'we can give him advance warning of what's going to happen'. Matthew appeared engaged but had a serious expression throughout and there was a slight frown when the electric clippers sounded. Whilst this type of story is not as intrinsically enjoyable, it could be a useful cue if shared just before a haircut: 'the more he watches it, the more he will understand and he will link the two events'. Summing up her Pictello experience, Laura reflected that a trial-and-error process had enabled her to fine-tune stories to maximise Matthew's engagement:

'We just had to find what works for him, and how Pictello works for Matthew. Every time we've done a story, it's got better, and he's responded more positively to it as we've made changes. So yeah, it's definitely been a journey.'

Eve

Eve is eleven years old and also has PMLD along with a range of complex health conditions. Eve was supported by her mother Anna to take part in the study. Anna described how much Eve enjoyed sharing books which rhyme throughout or with a musical element. Eve enjoys books which are very familiar to her and appreciates a sense of build-up or anticipation to a main event. Anna described how Eve is primarily engaged by sound (rhyming, music, sound effects) rather than visual or tactile features of a book.

As with Matthew, some experimentation was needed to maximise Anna's engagement with Pictello. Based on prior experience, Anna wrote Eve's Pictello stories in rhyming format. The first story, Eve's Garden, explores features of the garden that Eve enjoys such as the trampoline, swing and playing with her dog. The story features photographs and the text, which is narrated by Anna, rhymes throughout. Home video suggested some engagement although also some impatience, with Eve swiping the screen repeatedly before narration had finished. Like Matthew, Eve did not respond well to the built-in synthesised voices in Pictello so all stories were recorded by family. As Anna explained, 'the intonation on them isn't how we would do it and that was very important'.

The second story, My Favourite Things, was also a mixed experience. This story featured objects and places of particular interest to Eve such as her musical keyboard, her iPad, and going to McDonalds. Originally the story contained mostly photos with one video. Noting that Eve was engaging well with the video, Anna then inserted further videos and this had a positive effect on engagement: 'it helps her to connect the name of each object or activity with its action'. Eve's engagement with this story was still moderate with a lot of repetitive screen tapping. Anna reflected that this might be because it wasn't a structured 'story' with progression but more of a 'list', and also because it wasn't yet sufficiently familiar.

A third story, A Trip to the Beach, was a rhyming story with many photos of the family enjoying a day out together. As with the previous story, Anna felt that the rhyming script worked well, perhaps because 'I then am a bit more animated in my delivery, so the follow on from that, is she enjoys it more'. She also hoped that the photos of a happy family day



would evoke happy memories for Eve. Eve showed moderate levels of engagement with this story, although again she sometimes swiped the screen repeatedly whilst the narration was still playing. However, Anna observed that this story became more engaging over time with repeated readings, as Eve responds well to familiarity.

By far the most successful Pictello stories for Eve, however, were digital adaptations of her favourite storybooks. Anna created three Pictello adaptations of Eve's favourite books: Don't Wake the Bear, Hare by Steve Smallman; Peace at Last by Jill Murphy; and My Shadow by R.L. Stevenson. These involved taking a picture of each page of the book and recording the accompanying narration in the way it would normally be read. It was interesting to note how books are deeply embedded into a storysharing experience for Eve: for example, Peace at Last is typically read by Eve's dad and so he recorded his voice for the Pictello equivalent. Eve's level of engagement appeared much higher with these storybook adaptations. Her screen swiping was more spaced allowing time for narration to finish: as Anna commented 'the minute she tapped, she was waiting, because she knew some of the story was coming'. Eve consistently smiled at certain key points like the word 'Pop!' in Don't Wake the Bear, Hare. Anna noted that whilst the Pictello versions would not replace live story sharing with Eve, this new format gave Eve autonomy: 'I think she was quite proud that she was telling herself it really. Look what I'm doing, I can do it myself, being in control of it'. Anna also welcomed that Pictello made the family story sharing experience exportable to other contexts: 'if she's ever staying elsewhere, in respite or whatever, if she's got those stories, and it's got our voices with the familiar stories it's perfect'.

In summary, Anna commented that Pictello has 'got a bit more to it' than the usual cause-and-effect sensory Apps which are often recommended for learners with PMLD:

'It gives them some independent activity, choice making, and I think it would give the opportunity for progression, because you can simplify and complicate things as much as you want'.

Conclusion

These findings suggest that story making Apps such as Pictello can be relevant to the lives and literacy practices of young people with PMLD. Pictello stories can celebrate past achievements or events, evoke memories and connections, consolidate cause-and-effect understanding through page turning, and provide reassurance and comfort in settings outside the family home. They can also be used as a kind of digital object of reference which can provide a cue that something is about to occur. The main challenges encountered by parents were the initial technological issues, such as

learning to transfer photos and videos between devices, and learning to use the features of Pictello itself. However, both Laura and Anna were positive about continuing to use Pictello in the future.

Top tips for using a story making App with a young person with PMLD

1. Experiment with different postural positioning arrangements for optimum comfortable engagement with the iPad screen.
2. Experiment with different ways of physically operating the story: switch access, direct touchscreen operation or slideshow (story plays automatically).
3. Consider whether sound or visual effects are likely to be equally important to your learner or whether one will take prominence, bearing in mind any sensory impairment.
4. Experiment with making different types of stories to find what your learner finds most engaging.
5. Experiment with different formats: photo or video (or both)? Recorded narration or in-built voices? Include music or sound effects? How much text (if any)?
6. Stories may need repeated many times to build familiarity before they become engaging.
7. Write stories which reflect the world as experienced by the young person – which sensory details of an event catch their attention?
8. Consider the purpose of the story – is it to celebrate and remember happy memories, or a form of digital object of reference to provide a cue for forthcoming events? Or something else, like a family photo/video album or digital adaptation of a favourite storybook?

Contact Details

Dr Lauran Doak, Senior Lecturer in Special & Inclusive Education, Nottingham Trent University
Email: Lauran.doak@ntu.ac.uk
Twitter: @LauranDoak

Heartstopper sensory story

Naomi Hewerdine

If anyone has been around teenagers recently, they will have heard of “Heartstopper”. The show, based on graphic novels by Alice Oseman, aired on Netflix in April 2022. It is about two high school boys Charlie and Nick, who meet, become friends, and fall in love.

At Bridge College we felt that it was important to give our Sensory Learners access to this type of story. Many people still wrongly assume that the whole area of sexuality and relationships is irrelevant if you have a learning disability – it isn’t. In fact, autistic people are statistically more likely to be LGBTQ+ than neuro-typical people, so the themes in Heartstopper are even more relevant to our students.

So how do you go about translating a story that is a graphic novel and a TV show into a Sensory Story? We followed the advice from Mencap and Sensory Projects and summarised part of the story into about a dozen sentences. Our story is book one, or covers episodes one to four. Pages from the graphic novels and stills from the show were projected on a screen using PowerPoint.

We focussed on the two main characters Charlie and Nick. They were represented with clothing, smells and sounds. We incorporated switch work into the part of the story where Nick invites Charlie to a party, and the students turned on disco lights. We used songs from the soundtrack such as Baby Queen’s “Colours of You” to move the story along.

Students who use communication devices were able to narrate parts of the story, others could join in with single phrases or a doorbell sound on BIGmack switches. We even recreated the iconic rain umbrella scene by borrowing a watering can from our horticulture department!

The students have been really engaged and are loving getting to know the characters. As staff, we have loved telling this story, though we have got achy shoulders from wafting the multicoloured parachute. We will carry on telling Heartstopper in our Citizenship lesson, and during Pride Month, because whatever your ability or orientation, everyone needs the opportunity to be loved and be love.

Contact details

Naomi Hewerdine, Speech & Language Therapist.
Email: hewerdine@googlemail.com

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Many thanks for your support.

What if?

Nina Martinez

What if something happens to you unexpectedly?
What if you are too scared to talk to somebody?

What about if your nearest and dearest do not have the ability to share your thoughts and wishes?

Whilst funerals are no doubt sad occasions, I don't believe they have to be full of sorrow. A funeral is a celebration of a person's life - their loves; their journey; their life story.

I am a storyteller and passionate about telling stories. I have worked in this field for many years creating accessible and meaningful stories for people with profound and severe learning disabilities and those with autism and I thoroughly enjoy sharing these stories with them. More recently, I have turned this passion for storytelling towards telling people's life stories when I trained as a celebrant. Four years ago, I went on to train to become a Funeral Celebrant and I'm now proud to be a member of Fellowship of Professional Celebrants.

I've now decided it is time for me to extend and combine these two sets of experiences and roles, with the aim of making these celebrations of lives more accessible to people with profound and multiple learning disabilities (PMLD). This could be their own life stories or the story of someone significant to them who has died.

In the role of funeral celebrant, it is a true privilege to walk alongside bereaved families in creating a unique

and special service that truly reflects the life of the person you love. It is so important to listen carefully with kindness and understanding as you hear about their loved one so together we can create a service to reflect their personality; one full of warmth, humour where appropriate and one filled with love.

I would be very interested to hear from readers about your experiences, whether it be about the challenges you have faced or overcome in these sensitive situations – or the successes you have achieved in making a funeral service inclusive and meaningful to our loved ones with profound and multiple learning disabilities (PMLD).

I fully appreciate death and dying is a daunting subject but in turn, it is one we must think about. I look forward to hearing from you.

Contact details

Nina Martinez , Storyteller and Professional Celebrant, based in North Kent, close to London boroughs of Bexley, Bromley and Greenwich
Email: ninamartinezcelebrant@gmail.com
or via Facebook: Nina Martinez Professional Celebrant.

Connect with us on social media



Remember to tag us on social media ~ @PMLDlink

Twitter: @PMLDlink

Facebook: PMLD Link

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

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



Hanging Out café is a success

Sheridan Forster

The Hanging Out Program (HOP) is an approach and attitude to being with people with severe and profound intellectual disability (or anyone really). Originally, it was about committing to spending 10 minutes with a person, giving your full attention and engagement, and making brief notes about it. This year we extended HOP to a two hour Hanging Out Café in collaboration with AGOSCI for International AAC (Augmentative and Alternative Communication) Awareness Month in October, 2022.

Too often people who do not use voice or communication books/boards or devices, miss out on attention and engagement. In the alternative and augmentative communication community there is some argument whether people who don't use symbolic systems are included as AAC users. With knowledge of this, I alongside with AGOSCI (the Australian group focusing on people with complex communication needs) decided to run an event that would directly target the people most likely to miss out: people who did not use any formal means of communication, but lots of unique ways that we were willing to explore "how do I need to be, in order to be with you?"

We set about creating a single Hanging Out Café event for people who did not use and did not seem to understand speech, alongside experienced communication partners, and people interested in spending time with this group. We booked a venue, set a time (worried over the time crossing over when "shift-changes" often occur for staff), and set about advertising.

Finding experienced communication partners to come along was the easiest task. People who knew about HOP and knew me, immediately signed up. The other groups were not so easy...

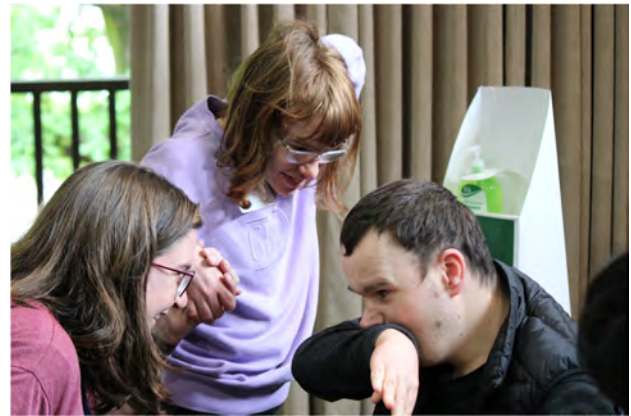
But how do you bring together people who require someone else to make the choice for them to join in? The first person with a disability to be signed up was a sibling of a speech pathologist who knew about HOP. The next few came from speech pathologists who spoke to families and encouraged them to sign up.

The challenge then hit when I distributed fliers to service managers, service contacts, service newsletters, group home door stops... I was faced with the difficulty of the distance between the person who would benefit from the Hanging Out Café and the hurdles inherent in organisations. A flier to managers could not be assured to get to houses; a flier to a support worker could not be assured to get to the house supervisor who might not make the decision to sign up to something and allocate a support worker, particularly if they did not know who was “on shift” on the day (essential signing up the support worker as well). Unfortunately, no easy solution was found. A few more people came along after I knocked on the door and sat down and chatted to the service manager the day before the event, and I highlighted who and why they may enjoy the event, as they asked the question “so... what exactly will be happening?”.



For some people, it is difficult for them to imagine someone who they perceive as “nonverbal and doesn’t communicate” to be signed up to a social event focusing on communicating with a whole new group of people. Some staff may perceive the person as not interested in interacting and label to person as “wanting their own space”. Overcoming this sort of thinking presents another challenge.

Nevertheless the day came. I had deliberately prepared no activities; I wanted people to informally interact with each other with no pressure on how to interact (but rules to be mindful of anything perceived to be, such as personal touch). It wasn’t an event to teach any of the participants about any theories or knowledge about interactions, although I did have a handful of fliers (e.g., AGOSCI, PMLD-Link, NAC, Sensory Stories, Changing Places Australia). I planned food, packed up the coffee maker.



Surprisingly, I had to fight the urge to bring “equipment/sensory materials/switches/and stuff”. While I knew all these things could be used in interactions, I resolved to set up interactions in an equipment-free way. I wanted people to experience great interactions without special equipment, just like might happen if a person was waiting for an appointment or going to a café.

As the time arrived and I set up my own sensory equipment (aromatherapy, half room lighting, open doors to fresh air) solely for my own regulation, people began to arrive and the magic happened!

Six people with intellectual disabilities came along, with three family members, four support workers, and a speech pathologist. Three “experienced interaction partners” spent time with everyone. Families and support workers mingled with each other and their supported people. Many different forms of communication were used. The means of communication were broader than anticipated with a number of people understanding and using some speech, and those who had them pulled out their iPads with ProLoQuo2Go and LAMP to support conversations. Some people showed their support workers and families what they could do with the help of these ways of communication. There was body language, muscle tension, sounds, smiles, touch, wiggles, jiggles, and shakes, walking (and me knee walking to matching the height of one lady), being guided in and out and all around the room, eyes looking at



people, places, and sometimes away. There was “talking” hands, feet, noses, snuggles, sounds, words, and pictures. There were questions, comments, aghast joy, and at times a little reserved confusion. There were poems shared, stories recited to familiar delight, and a duet of “So Long, Farewell” as one woman headed home.

The unanticipated outcome was how everyone interacted with each other. The curiosity of individuals to wander off and look at another person, the delight in seeing the pictures on someone else’s communication device, the trips to the coffee bar with other people, and the occasional clambering around and over other people as individuals led where they wanted to go. Even the exploration of the neighbouring art exhibition at our community venue.

The event was a great success. A family member commented, “I can see in the future that the Hanging Out Café, with its relaxed atmosphere will be a fun and easy environment for all who attend to learn from and look forward to”. An experienced partner stated that it was “A perfect way to spend a Saturday afternoon, making some fabulous new friends, hanging out in the moment”. The photos capture what our folks who do not use words or symbols (or use minimal or unclear words/symbols) say.

The first of many!

Contact details

Sheridan Forster is a practising Speech Pathologist and researcher with a special interest in adults with profound intellectual and multiple disabilities

Email: sheri@sheridanforster.com.au
Website: www.sheridanforster.com.au

Sheridan runs a number of communication-focused Facebook groups including one for HOP: Hanging Out Program) <https://www.facebook.com/groups/334617066670161>

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More than words

Gerard Wainwright

If good communication is more to do with listening than talking to truly understand, we need to be open to hearing others in a different way. I support people with profound and multiple learning disabilities (PMLD) who are non-linguistic – in most cases they don't use speech or words to communicate. Sometimes I hear it said that a person with PMLD can't communicate and my heart sinks. If you take the time to deconstruct that statement, what it truly means is that the person saying this doesn't understand the other person's communication. This is an entirely different premise; one based on revoking responsibility and blaming our inability to comprehend on the other person – the opposite to listening.

But perhaps it goes even deeper and belies an ignorance of what communication truly is. Albert Mehrabian's 7-38-55 Communication model (World of Work Project, no date) asserts that only 7% of the meaning of feelings and attitudes takes place through the words we use in spoken communications, while 38% is through tone of voice and the remaining 55% takes place through body language (specifically our facial expressions). There was a time when we all communicated effectively without speech; we used a language of gestures, sounds, touch; a way of understanding and being understood which was pre-verbal. We were expressive in a much more immediate and intuitive way that didn't rely on or require words – in our early life this is how we bond with our carers, explore, and learn. But as we develop, many of us learn

not to communicate in this way, effectively forgetting what we previously intuitively understood.

This can lead to us being dismissive of non-linguistic communication, as if it is somehow inferior to spoken and written language - to words. The codes hidden in the marks on a page or screen, in the sounds we learn to make; a language which is not always inclusive. Developing speech, learning to read, are considered significant milestones in our development. These form such a key part of our identity, our social status and ability to prosper but this is not shared by people with PMLD, who overall do not develop these skills, which can lead to us distancing ourselves, 'othering', setting ourselves apart and subconsciously or otherwise not identifying with the person. This negative view is



supported by the lack of visibility of people with PMLD who are underrepresented in the media, tv, social media and everyday life (Aspis, 2020).



In my thirty-year career as a learning disability nurse, the emphasis has been biased towards getting non-linguistic people to fit into our often well-meaning but misinformed way of thinking. Attitudes need to shift. The practitioner-client relationship is based on a power imbalance, on a conviction that we have the answers and the people we support are reliant on our help, on us changing them to fit in with our belief systems. We now know this is not only unrealistic, but it is ignorant, presumptuous, and systemic of an approach which should have no place in our relationships with people who have PMLD and do not communicate through words.

The almost universally accepted primacy of words - spoken and written - to convey information and meaning is rarely questioned. But the true meaning is often elsewhere. The reality is we only take in a fraction of what's said. Our interactions don't have to be wrapped in linguistic code, the true meaning of our relationships exists beyond this, at a different and much deeper level. People with PMLD often have the gift of living life in the moment, possessing mindfulness. Indeed, it could be argued that non-linguistic people with PMLD have little to learn from us but conversely there is so much that we can learn about how to communicate effectively from

them. Jo Grace explores this approach in her insightful book *Sensory Being for Sensory Beings* (Grace, 2018) which provides powerful insights and practical advice about enhancing communication through sensory means with people who are non-linguistic.

A recent study highlighted the positive impact that those supporting people with PMLD experience when making a meaningful connection with the person which is not reliant on spoken language - "during these moments, they experienced joy and emotional nourishment, which contributed to their job satisfaction and gave them the energy they needed to continue the intensive work." (Bloomer, 2022)

Surely our primary motivation when supporting people with profound and multiple learning disabilities should be to listen before being heard. We are in a position of privilege; we not only have a platform but also an obligation to meaningfully engage with and learn from the people we support and to present a positive narrative and highlight the abilities, gifts, and achievements of people with PMLD in a way that enhances their position within our lives, communities, and wider society.

Contact Details

Gerard Wainwright is a Registered Home Manager for Heatherstones which is part of St. Anne's Community Services
Email: Gerard.wainwright2@st-annes.org.uk

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Objects of reference: misused and misunderstood

Eleanor Kay

Through a series of questionnaires and interviews, this study explored how communication partners use Objects of Reference (OoR) with Learners with profound and multiple learning disabilities (PMLD) aged twenty-five years or younger. Participants' anecdotal evidence demonstrated that Learners can use OoR when a small number of familiar and recognisable objects are used consistently, but a lack of understanding about the use of OoR leads to a confused and disjointed approach from communication partners.

Objects of Reference (OoR) are physical objects which represent a person, place, action or concept. People use them to convey or receive information without needing an understanding of traditional communication means (such as spoken word, symbols, signing or pictures). For individuals with PMLD, meaning is often conveyed by current experience (Grace, 2018); using OoR can provide a way to communicate which is not dependant on immediate experience. This allows the individual to be informed of something before it happens rather than being unaware until it is underway, for example, a person can be told that it is time to brush their teeth rather than having an object suddenly thrust into their mouth. The use of OoR has been studied in previous research, briefly outlined in the next section.

Previous Research

Seminal work by Jones, Pring, and Grove (2002) shows that adults with PMLD can receive and convey information from and to communication partners when objects are index rather than abstract objects. An abstract object is an arbitrary representation with no resemblance to what it represents, whereas an index object has a functional and integral link to the experience (Brum, 2016); this close link between object and activity

supports the awareness of a means-end relationship for learners at a pre-intentional level of communication. Continuing with the toothbrushing example, an index object could be the person's toothbrush, whereas an abstract object could be a set of comedy wind-up dentures. This study explored the use of index and abstract objects by families and practitioners, the design of which follows below.

Research Design

In this 2022 study, participants from a secondary special school and via the PMLD Conference were invited to participate in the study. Practitioners from the school were also invited to participate in semi-structured interviews, and delegates from the PMLD Conference were invited to complete an online questionnaire. Two separate questionnaires were used to consider the different experiences of professionals supporting Learners with PMLD and their families. Fifty-four participants completed questionnaires (forty-one practitioners and thirteen families), and four participants were interviewed (a Headteacher, Teacher, Teaching Assistant and a Speech and Language Therapist). The breakdown of relationships and professions of the participants is shown in the tables below:

Practitioner Questionnaire	
Profession	Count
Activity co-ordinator	1
Consultant	1
Early Years Complex Needs Practitioner (Portage)	1
Higher Level Teaching Assistant	6
Senior Leadership Team (class-based)	5
Senior Leadership Team (not class-based)	1
Speech Therapist	1
Teacher	21
Teaching Assistant	2
Trainee Teacher	2

Family Questionnaire	
Relationship	Count
Father	4
Mother	7
Respite carer	1
Sibling	1

Figure 1: Questionnaire Participants

The following section identifies the findings this research produced and includes anecdotes from participants.

Research Findings

The research uncovered three principal findings: learners with PMLD can use OoR effectively; theory about the use of OoR is misunderstood; and there is a lack of communication and consistency between practitioners and families. The findings are evidenced and discussed below.

Finding 1: Children and young people with PMLD can use OoR effectively

Participants reported that when objects were relevant to the individual with PMLD, OoR could be used to support their understanding of what would happen next. Some learners could also use OoR to make requests and communicate needs to practitioners. In the following anecdotes regarding two different teenage learners, the objects used were index objects closely related to the activity in question:

(...) when we get in there, she refuses to get out of her wheelchair because it's like her safe haven, but if you show her a pad and open it out on the bed then she will move (...)

(...) she had four things: a shoe, cream, hairbrush and a pad. And she was at the stage after two years where she could get the shoe to show she wanted to go for a walk.

In some respondents' anecdotes the objects were limited in number, were index objects and were individualised to a learner's experience. However, many respondents repeatedly identified the OoR system as a tactile timetable or symbolic communication system, with objects identifying each lesson, activity or concept a learner may experience. When children and young people with PMLD are presented with OoR incorrectly or inconsistently, their ability to use the system will be compromised. The Speech and Language Therapist interviewed summarised the effect of presenting many objects rather than a small number of index objects:

(...) we're then presenting loads of things to these young people who actually cognitively and in terms of their sensory processing aren't able to understand that level of objects that are all very similar (...)

Finding 2: The use of OoR is misunderstood

Participants generally identified an inconsistent approach to using OoR and a misunderstanding of what objects are appropriate for use with learners with PMLD. This has led to frustration amongst practitioners who believe OoR has greater potential for use with individuals with PMLD:

People view them as a way of communicating without language and add to them, standardise them, etc, in ways that render them meaningless to the very vulnerable and marginalised population for whom they are intended.(...) They should be inherently personal, intimate to that one individual's experience. Any standardising destroys their power and potential.

Practitioners identify with concepts of OoR in various ways, interpreting the system based on a confused and inconsistent approach. The following excerpts demonstrate this:

The OoR were designed by a previous teacher. I have since added sessions and changed the timetable. The curriculum has also been redesigned, so they [are] no longer relevant to the finer details of our day.

[We] have a general box of objects but it's specific to our young people depending on what they access in the curriculum during the day.

One practitioner, unaware that OoR are not intended to be standardised, commented that the irrelevancy of some objects rendered the system unusable: This response highlights a lack of understanding

Some are not suitable for most, such as a cup for a snack when the child is fed via gastric tube.

surrounding the need for objects to be functionally linked to what they represent and relevant to the individual using them (Brum, 2016; Jones et al., 2002). A situation in which a learner with PMLD is presented with an object with no relevance to their experience should not occur if objects are individualised to each user.

Some practitioners also reported using abstract objects for choice-making, which the learner has no common use of or experience with.

(...) we might use a clock [and] a soft toy to say, 'Do you want more time to do this or do you want to play with that?'

In the above quote, an abstract object, a clock, is used to represent more time for an activity; however, this requires an understanding of the concept of time passing and its representation by a clock and an understanding that selecting this means the individual will get more of the original activity, not the clock itself. That is a complex cognitive leap for a learner whose experience of the world is primarily a sensory one experienced in the present moment (Grace, 2018).

Misconceptions about the use of OoR and what objects are suitable can lead practitioners into a cycle of incorrect implementation, abandonment of the system and reuptake without remedying their gaps in knowledge. This cycle is expressed in the following diagram:

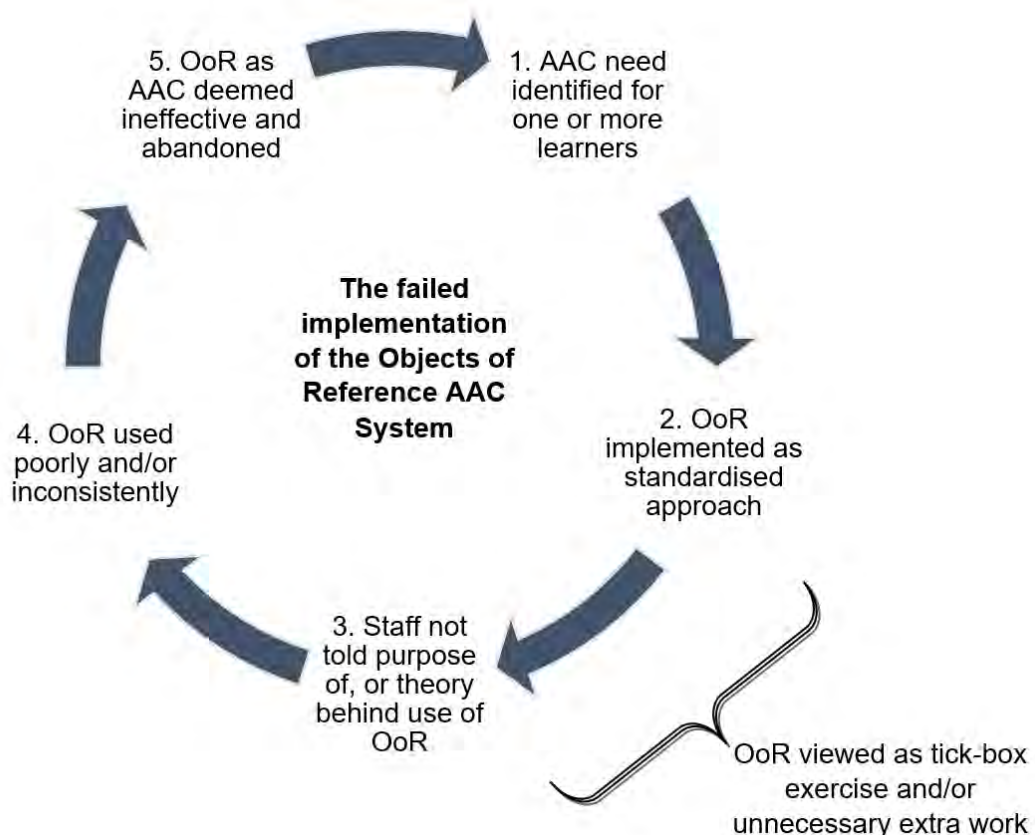


Figure 2: The failed implementation of the Objects of Reference Alternative and Augmentative Communication (AAC) System

Finding 3: There is a lack of communication between practitioners and families and a lack of consistency in approaches

One participant expressed frustration when they successfully implemented the use of OoR with a learner, only for it to be discontinued after two years:

(...) we used the Objects of Reference really well in school to reassure her of what was happening, and mum was using them at home as well, (...) and we used them for the two years really well. (...) Then she moved to another class, and they dropped it. (...)

Families reported that they often felt as though practitioners working with their children did not include them in communication matters. As a result, families may be marginalised, leading to inconsistent approaches to communication which can reduce the learner’s ability to convey and receive information. One parent stated that practitioners did not involve them even in assessments for AAC:

I did not get to meet my child's Speech and Language Therapist. We were never invited to meet them when they were assessing our daughter.

The following excerpt details how one parent who used OoR with their child at home found that practitioners were reluctant to use the system in school.

I was the person that formulated my daughter's Communication Passport, produced the objects of reference and created the resources for school and home. (...) I shared all this knowledge with her school too but I never felt that we had a full team approach unfortunately. It felt [like] parents were kept at arms length.

Where parents are willing and able to work with practitioners to support their child's communication, this should be encouraged and facilitated to ensure the best outcome for the learner with PMLD.

Conclusion

This research examined the use of OoR with learners with PMLD. It has revealed three significant issues relating to the use of OoR. Firstly, whilst learners with PMLD are capable of using OoR, this is significantly affected by their communication partner's ability and willingness to offer appropriate opportunities. Secondly, a lack of understanding and training regarding OoR hampers their effective use by practitioners. Finally, when families want to use OoR, some practitioners do not communicate routinely with them, impacting their ability to work together in a parent/practitioner partnership. Implementing OoR effectively can make a confusing world clearer for learners with PMLD and open up the world of the linguistic communication partners with whom they share their lives.

Contact Details

Eleanor Grace Kay
Email: ellegracekay@gmail.com

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Reflections on developing an outcome measurement tool for use with people with profound and multiple learning disabilities within an Intensive Interaction service

Sarah Webster & Jules McKim

Intensive Interaction (II) is a technique for interacting with someone who is at an early stage of communication development, with the primary aim of making interactions meaningful and enjoyable for them. Based upon the principles of infant-caregiver interactions, II also aims to support, through direct experience, the learning of the “Fundamentals of Communication” (FOCs), such as the use of eye contact and turn taking (Nind and Hewett, 1994, Hewett and Nind, 1998); Intensive Interaction is used within our service to improve the quality of interactions people with learning disabilities, usually with profound and multiple learning disabilities (PMLD), have with their supporters, including relatives and carers. Supporters are trained in the theory and practice of II by our II Specialist Care Co-ordinator. Supporters learn to allow the person they support to mostly lead the interactions. The use of the approach is supported by mentoring visits along with paper and video record-keeping.

Why do we need to measure outcomes of II?

Outcome measures are used to determine the impact (if any) an intervention has had. They are helpful to assess whether a person’s needs have been met and to facilitate reflection. They are also used to assess the effectiveness of a service or intervention for auditing and service development purposes.

Goldbart and Caton (2010) reported that “there is reasonable, and growing, research evidence and practitioner support for Intensive Interaction”. Despite the strong promotion of II in learning disability services, it has also been argued there is limited methodologically sound evidence for the efficacy of II with people with PMLD (Hutchinson and Bodicoat, 2015). This can partly be attributed to the complexities of seeking the views of people with significant communication difficulties. Using outcome measures with people with PMLD who are unable to tell us themselves about their experience is reliant on staff picking up on cues from the person. Calveley and Hewett (2017) state that there should be no set objectives for II because it is process-focused; the interaction is the outcome. As Firth and Barber (2011) argue, meaningful social interaction is a fundamental human need, regardless of potential additional outcomes. However, some observable outcomes will often occur over time when we focus on the process, such as more use of eye contact and greater tolerance of sharing physical proximity (Firth and Barber, 2011). Based on these considerations, we identified the need to measure outcomes to demonstrate the positive benefits

of the interventions we provide to the service users referred to us.

What did we do?

We started trialling an “II Outcomes Reporter” drafted by Calveley and Hewett (II Institute, 2017) to “record progress made as a result of II”. This fifteen-page proforma allows practitioners to record observations relating to four developmental domains: social; cognitive; emotional; physical and sensory. Domains include learning outcomes that closely resemble the FOCs with examples of behaviours given. For example, “smiles with or at people more” is a behaviour that could be indicative of learning “enjoying being with other people” within the social domain. There is additional space to include “Observations Prior to the Start of II” as a baseline to later compare with. The tool strongly emphasises the use of video recording to illustrate behaviours and skills, and to measure frequency and duration.

An Assistant Psychologist and Trainee Clinical Psychologist trialled the II Outcomes Reporter for use within our service with the supporters of three service users. They provided feedback on some of the challenges and benefits they experienced. Their feedback suggests the measure helped guide supporters’ reflections on observable communication skills and abilities of the person supported, however the number of examples and boxes meant it took a long time to interview supporters. Conscious of time pressures and the numerous demands

supporters have, they were unable to complete each section of the tool, concluding the tool was too detailed for use within our NHS service. They also found supporters needed considerable assistance to interpret some of the concepts, such as 'sense of self' and 'self-esteem' within the 'emotional' domain. This raised some potential validity concerns. Overall, the feedback highlighted the need for a shorter, simpler version to be developed for use in our service. Based on the original draft, the measurement tool was reduced to two pages.

1. Seven rows based on the FOCs (for example "can attend to an interaction") with four columns to score the FOC at the start of the intervention ("time one") and later ("time two") and provide "comments" for each time. Scoring ranged from one (never) to five (always). Coupe O'Kane's (1998) Communication Before Speech levels of communication for 'social organisation', 'mutual gaze' (eye contact) 'turn taking and social interaction', were also included in this table. Although the original reporter only gave space for observations, coding was added to the adapted tool to aid quantitative measurement of change (although we are very aware that communication skills cannot be reduced to a number).
2. The second page included a "service audit" about processes around II such as training and record keeping. There was also space for 'comments' about the general aims and hopes relating to the II intervention, which could include improving the person's communication skills or increasing the quality and quantity of interactions. This page also included Brazelton and Nugent's (1995) 'The neonatal behavioural assessment scale' levels to score a person's physical contact preferences.

Alongside our adapted FOC tool, we used the Mood Interest and Pleasure Questionnaire-Short Form (MIPQ-S) as a quality-of-life measure.

Reflections

An "outcome measure questionnaire" was produced to ask supporters for feedback about their experience of completing the outcome measurement tool. The questionnaire also asked for qualitative feedback to help assess whether the quantitative measures were capturing change perceived to have occurred by supporters. Between November 2020 and October 2021 five supporters were interviewed using the tool, the MIPQ-S and the outcome measure questionnaire by an Assistant Psychologist within our service. The tool was adapted three more times, based on feedback on the implementation of the tool to clarify questions and restructure for clarity. Understanding the terminology used, such as, 'attends to another person' proved to be confusing for some supporters. The wording was adapted to provide context for scoring.

Feedback in the outcome measure questionnaire indicated more positive change than the tool was suggesting. In order to work out if the FOC tool was capturing positive changes we looked at quantitative data from the five interviews conducted. In total, 43 questions were asked from the FOC questions (9 questions x 5 people, minus two questions which were not applicable to one service user). Overall, 42% of questions were scored the same on follow up as baseline, 39% showed a negative change and 19% showed a positive change.

Although the FOC scores did not necessarily reflect "progress", staff reported positive changes in the person they supported. For example, some reported seeing more eye contact from the person they supported, however their scores on the FOC tool showed a reduction. This may have been because:

- staff were pausing and tuning-in more to the person they were supporting and were noticing things more (because of the II training). It might be that they originally thought someone used eye contact during interactions more than they actually did, because the quality of interactions was not as good,
- they were not noticing originally, and therefore rated them higher at baseline.

Staff feedback showed they found the tool a helpful way to reflect on the person they had been doing II with. We reflected that by measuring outcomes, support staff may value the impact of the approach more. However, we also felt the need to make it very clear during training that II is process focused not outcome focused and had some concerns that focusing on measuring outcomes in this way might make some staff more directive in their interactions.

There were some practical challenges to supporters completing the questionnaires including, for example, staff time, their availability and shift patterns. Based on detailed feedback we have now developed a two-page tool that can be completed by the wider team. This revised tool condenses the measures into one two-page form, so supporters have less to complete. We have also made a separate, service audit form to be completed by the manager (where applicable) which includes questions about the general aims and hopes of the II intervention (and the progress of these). Having observed that the qualitative feedback presented a much more positive outcome than the quantitative questions, we have included an open question for supporters to provide any other comments they wish to add.

It is worth noting this work was completed when social distancing restrictions were in place during the pandemic so interviews with staff were held virtually. One supporter reported that they would have preferred to complete the outcome measure in person somewhere

quieter because they were in the busy home that the person they support shares with others. It could be that the context of completing outcome measures virtually, and during a pandemic in which services were under a lot of pressure, could have affected some of the responses.

Conclusions

Although interaction is the outcome of II, our service needs to measure outcomes to demonstrate that we are providing a good and effective service. The contrast between the results of the quantitative FOC tool and qualitative feedback gathered as part of the outcome measure questionnaire demonstrates the challenge of capturing complex outcomes, especially from people who are unable to tell us themselves. Our work so far, in line with the literature, suggests II does support positive outcomes but that their measurement is problematic. Below are some comments from supporters to demonstrate some of the perceived positive benefits II has had on the lives of the people they support (names have been changed to protect confidentiality):

"It has made Mary feel important. It has benefitted Mary a lot because she always craved attention. She now knows staff are there to respond to her. Her vocabulary is growing . . . It has given Mary some power. Staff respond differently to Mary repeating herself knowing that she is trying to start a conversation or tell them something."

"I think it has helped staff think about how they communicate with Adam which in turn benefits Adam".

"It does refocus her and gives her a more positive way of interacting and meeting her sensory needs."

A recent piece of II work outside of this outcome measure development work captured the following narrative outcomes to help illustrate some of the positive changes thought to be linked to II by supporters:

"I was amazed at the level of engagement". Care Service Co-ordinator

"He uses more eye-contact and smiling during interactions in general. Everyone's noticed the change in Dennis". Support Worker

"He no longer 'ends' sessions by pushing partner away". Support Worker

"He is spending much less time lying on the floor". Support Worker

"In my opinion Dennis has become quite social. So much so that when the builders were in making a

real racket Dennis was sat in his chair right in the doorway watching what was going on. Previously he would have been disturbed by having strangers in his house." Care Service Co-ordinator

It is hard to envisage how some of these outcomes could have been measured by any quantitative outcome measurement tool. Despite and as well as the quantitative outcome measurement within the tool there is still an important role for capturing qualitative data. We are continuing to work on adapting and fine tuning our outcomes measure with the intention of developing a tool that clearly captures outcomes and demonstrates the benefits of II in the lives of people with PMLD. With thanks to Rebeka Laczik and Holly Banfield who trialled the first outcome measure with supporters and gave feedback. Thanks also to the supporters who gave their feedback about completing the outcome measure.

Contact details

Sarah Webster, Assistant Psychologist & Jules McKim, Intensive Interaction Specialist Care Coordinator, Oxford Health NHS Foundation Trust
Emails: srwebster9@gmail.com
jules.mckim@oxfordhealth.nhs.uk

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Share their picture, say their name Is it safe to share photos of people with profound intellectual and multiple disabilities online? The ethics of being presented to the online world.

Jo Grace

This is Harry, working with me on the Sensory Being project. In the image with him is one of the design team who collaborated on the project with me that year. The photo shows you Harry's opinion on this work. Harry died shortly after this photo was taken. His parents had previously given consent for me to share the image in conjunction with the project. Aware of their grief I wondered how they would feel now about me sharing Harry's image. I got in touch and asked if they were happy for me to continue sharing pictures of Harry. They told me to continue sharing and asked me to say his name when I did.



In the years that have passed since Harry's death I've shared his smile and said his name to hundreds of people. The old adage about a picture speaking a thousand words is true. Images like this are so powerful. This picture shows Harry as a communicative person, as a person responding socially, as a person enjoying their work. It also shows Harry as a person with profound disabilities, but not as a passive person – as people with profound disabilities are often assumed to be, but as a dynamic, active, participating-in-life person.

When people see this image, they meet, in a small way, Harry, and in a small way, something of what it is to be profoundly disabled. This picture is an act of advocacy, it changes perceptions, challenges stereotypes, and most importantly it spreads joy – for everyone's first response on seeing it is to smile.

I'm sitting at my desk. Those of you who've known me for a while, either through my publications here or for my prolific presence online, will know I've long been a bit of a research geek. Well it has caught up with me and here I sit in the midst of my first year of a PhD. I am studying Identity and Belonging for People with Profound Intellectual and Multiple Disabilities at the University of Southampton. Harry's picture is on my mind, as right now the task at hand is to complete my ethics application. I must have passed the ethical approval process at the university before I can commence my research.

The form I must fill in to justify the ethical nature of my research asks how I will keep those who take part in the research with me anonymous. The ethical process is incredibly complex, and I desperately want it to be

finished so I can get back to collaborating with my friends with profound and multiple learning disabilities. The simplest thing for me to do would be to tick the boxes that say I will not say their names and I will not share their photos. But I cannot bring myself to do it.

Over the past decade I have collaborated with lots of people with profound disabilities, but there have been two groups of young people who I've returned to time and time again, doing first one project and then another. When I leave I always joke with the adults who support them that I'll be back soon enough, like a bad penny, with a new creative way to disrupt their daily life and bring a colourful sensory chaos into their school.

The parents and carers of the young people with profound disabilities that I work with give their consent to the young person's participation in my work, and give me consent to share photographs of them in relation to that work. (Of course not everyone gives permission for photos to be shared, so there are young people I work with whom you never see, but in the main everyone gives consent).

I share our work as it unfolds. This does a number of things:

- First of all it gives parents/carers a window into what we are up to. This has never happened, but were a parent to see in the photos I share that their child looks bored or worried, for example, by the work, they could get in touch and let me know.
- It gives families a way of celebrating and sharing the work that their children are doing. These children are often looked at as incapable, people may view them primarily through a lens of all the things they cannot do. Imagine family friends thinking "oh it is so sad your child cannot walk, cannot talk, cannot, cannot, cannot..." My pictures are about what they are doing, what they can do, how genuinely useful they are to my work. The families re-share these images celebrating the achievements of their young person in just the same way that they might share another child's exam results or swimming certificate.
- It puts these young people, and through them a representation of profound disability, online.

Yes, I share these images on social media...I can feel the shudder from people who do not use social media, or who use it but only at the greatest distance they can maintain. I fully understand the disdain people have for social media, there is a lot wrong with the online world. But regardless, or rather regarding that but continuing open eyed, it remains a social space. In many lives it is THE social space.

A long time ago we might have gone down to the market square to socialise, to buy goods, to sell wares, to hear the news, to meet people, to flirt and connect. And yes, when in the market someone might have picked our pocket, or shoved us roughly, and someone we disliked and disagreed with might have owned the square. Bad things can happen in the social space. Removing oneself from the social space can protect you from the dangers of being there but it does so through exposing you to a different danger, the danger of being isolated.

A long time ago people with profound disabilities would not have been brought to the market square. They would have been hidden out of sight, in the home, in institutions, or more awfully still doctors advised families to let nature take its course and they were removed from life itself.

Visibility matters.

When we see difference we consider it. When the general public sees a person with a profound disability they realise more easily the need for ramps, lifts, accessible toilets and so on. When the general public sees difference they get used to it, they learn about it, they become curious, prejudice is slowly dissolved.

Many of us live online, and currently people with profound and multiple learning disabilities are hidden from view in the online world.

My current ethics conundrum is an extension of paternalistic notions that say that we must keep them 'safe' in this way. That it is 'safe' to not share the photo and 'dangerous' to share the photo. I think it is a lot more complicated than that.

What are the dangers? The dangers are the same for any photo online, it could be taken and used in ways we did not intend. I think the danger we think of first is the risk of ridicule.

Yes, if we share images of disability people may laugh at them. There are two options to solve this problem: we could not share, so not risk the laugh, or we could share and challenge the laugh. The first is a cowering response, the second moves to change the world for the better. I believe that sharing images, like this one of Harry, does good in the world. Harry's advocacy in life and in death is contributing to a world where people have a little more understanding of disability and of who these people might be and what they can do.

It is a brave act to share an image online, to step out of your house and be seen in the market square. There are risks involved. But I am personally so grateful when people do it. I am reminded of the C S Lewis quote from

his book *The Four Loves*:

“To love at all is to be vulnerable. Love anything and your heart will be wrung and possibly broken. If you want to make sure of keeping it intact you must give it to no one, not even an animal. Wrap it carefully round with hobbies and little luxuries; avoid all entanglements. Lock it up safe in the casket or coffin of your selfishness. But in that casket, safe, dark, motionless, airless, it will change. It will not be broken; it will become unbreakable, impenetrable, irredeemable. To love is to be vulnerable.”

The online world is a messy imperfect place full of noise and showcasing, but sift through it and there are moments of beauty, moments of raw expression, moments of connection, humanity and truth. I want

people with profound and multiple learning disabilities to be a part of this world, known and seen by this world, and I very much hope the ethics committee I must sit before will grant me permission to share their pictures and say their names.

Contact Details

Joanna Grace is a Doctoral Researcher, Sensory Engagement and Inclusion Specialist and founder of The Sensory Projects.

Jo PhD studies are funded by the Economic and Social Research Council (ESRC) through the South Coast Doctoral Training Partnership
Email: sensorystory@gmail.com
Website: www.TheSensoryProjects.co.uk
Twitter: @Jo3Grace

Advice About Legal Issues

PMLD LINK is run by only a handful of volunteers working in their spare time to produce the journal and maintain the website. We are parents, carers, teachers and workers in services and have a good range of collective experience and knowledge. However, none of us have legal expertise and only one or two, mainly through family experiences, have had to deal with service commissioners and providers.

As a result, PMLD LINK, as currently organised, does not have a campaigning role and has no capacity to support individuals in their dealings with organisations. PMLD Link can really only offer its journal and its Facebook page and twitter account as a means of sharing information.

If you ever need advice and support for dealing with a particular issue relating to someone with PMLD for whom you have a concern, we would advise that the obvious start is your MP. There will be some entitlements to support for you and/or the person with PMLD as constituents.

Next, you might contact Mencap's national learning disability helpline. Go to the website where there are details about making contact via phone, webform or email: <https://www.mencap.org.uk/advice-and-support/our-services/learning-disability-helpline>

As regards legal advice, there are some other potential sources for general legal advice:

(1) Access Social Care: Legal Network. This service (previously called the Legal Coalition Network, then hosted by Mencap), is now on an independent footing. They work with families to find solutions to situations. For referrals go to: www.accesscharity.org.uk/need-help. Complete online form to start the process or phone 02476978903

(2) Another organisation is CASCAIDr - <https://www.cascaidr.org.uk/> run by Belinda Schwer who offers regular webinars, templates & other free resources to respond to issues where the Care Act is not being upheld.

As regards NHS complaints, you can make a formal complaint to the service provider and/or commissioner. If you do this and are not happy with the way your complaint has been dealt with and would like to take the matter further, you can contact the Parliamentary and Health Service Ombudsman (PHSO) which makes final decisions on unresolved complaints (<https://www.ombudsman.org.uk/making-complaint>) or phone 0345 015 4033. Unfortunately, due to the coronavirus (COVID-19) outbreak, there has been a pause in the investigation of new and existing complaints. Hopefully, this service will be reinstated soon and there can be no harm in initiating a complaint.

What constitutes ‘ethical’ research for people with PMLD? A call for reader responses

Ben Simmons, Stuart Read, Anne Parfitt, and Tanvir Bush

In this paper we discuss what constitutes ethical research for people with profound and multiple learning disabilities (PMLD) We describe the work of university ethics committees and suggest that people with PMLD and those involved in their care and support have not been given due consideration in mainstream research ethics regulations. Readers are invited to share their thoughts about what an ethical research project looks like for people with PMLD.

What is research?

Whilst the meaning of ‘research’ has been debated, it is commonly defined as the process by which we develop and share new insights of relevance to society (HEFCE et al., 2011, OECD, 2015). These insights are vast in range and might include discoveries such as about how the brain works, the development of pharmaceutical treatments to improve mental health, and the advancement of technology in neonatal incubators. Such medical research is high-profile in the UK, and the public imagination is captured through calls for donations (e.g. through cancer research TV adverts) and celebrations of drug trials in the media (e.g. the Guardian’s 2022 article describing the latest Alzheimer’s drug hailed as ‘historic moment’).

Medical research is important, but it is just one field of inquiry, and universities serve to develop insights into a range of topics that can benefit society. For example, social science research can evaluate approaches to improving how hospital staff communicate with patients who cannot use speech, or develop insights into parental opinions on controversial topics such as sex education in special schools. Humanities research can uncover the historical reasons why people with learning disabilities were placed in institutions, while arts research can produce artefacts that tell stories about disability activism. Regardless of the topic being explored, all research is bound by principles of ethics. But, what does it mean for a project to be ethical?

What are research ethics?

The word ‘ethical’ is sometimes used in our society to indicate whether or not something is morally right. For example, businesses such as shops and restaurants sometimes claim to ethically source their products. This can mean a number of things. It can mean that the products are not tested on animals, that the people who

make products have fair working conditions and are not victims of modern slavery, and that the creation and transportation of products are environmentally friendly. The reputation of some high street businesses revolves around the extent to which they are ethical – ethics are the core of their ‘brand value’.

UK universities pride themselves on conducting ethical research, and each project has to be approved by a Research Ethics Committee before data collection begins. Whilst the process can vary from project to project, it typically involves a researcher writing an ethics report that outlines the design of the study (e.g. who will be involved, how the data will be collected, analysed and stored, how risks to participants will be mitigated, etc). The job of a Research Ethics Committee is to decide whether a project can go ahead, or whether it should be modified to satisfy research regulations. This is an important process as it serves to ensure that all projects minimise risk of harm to both participants and the researcher.

The need for research ethics approval emerged against a backdrop of – quite frankly – dreadful studies that showed little care for the lives of participants. Textbook examples of unethical research include the Tuskegee Study which investigated the long-term effects of untreated syphilis on 600 African American patients. During the Tuskegee Study, diagnosis and treatment was deliberately withheld from the patients so that researchers could study the progression of syphilis over time (CDC, 2021). Examples such as this led to the creation of formal scientific ethical guidelines such as the Belmont Report (1978), and over the last forty years a plethora of regulations and guidelines have been published to minimise harm during the research process.

How are research ethics contested?

On the surface, research ethics appear straightforward. The principle of minimising harm to research participants intuitively feels like the right thing to do. However, when we scratch beneath the surface to examine real world examples, we realise that ethical decisions are complex and problematic. For example, informed consent is often seen as a benchmark of an ethical project. Informed consent means that the participants know exactly what they are signing up for, that they can read and understand a research project information sheet (which may consist of technical or legal jargon), and consent to participate by signing a form. Whilst some participants are very capable of reading and signing such documents, it is not altogether clear how people with PMLD can participate in this process. For people with PMLD under the age of 16, a parent or guardian can sign a consent form. Even though this may satisfy a university's Research Ethics Committee, it completely overlooks the wishes of people with PMLD. For researchers who deny that people with PMLD have any perspective on participating in projects, this may not be an issue, but for others who seek to honour the agency and experiences of people with PMLD this is simply not good enough and dehumanises the 'participants' of research. An alternative model is to seek what is known as 'assent', that is, to honour the expressions of approval and agreement provided by people with PMLD during the research process, even though they cannot legally consent to participate. However, whilst informed consent is almost universally acknowledged as a benchmark of ethical research, the processes by which we seek assent is neither regulated nor universally acknowledged, resulting in inconsistent ethical practices.

What the example above demonstrates is that a cornerstone of ethical research – seeking informed written consent – is not a process which all groups can participate in. Does this mean that research should only include participants who are literate? Should research focus only upon those who have the privilege of being fluent in written language? We argue that this would result in a narrow body of knowledge that only reflects privileged groups. As readers may recognise, this problem extends beyond people with PMLD. It might, for example, exclude people whose first language is not English, or parents without a university degree who are less familiar with the jargon of higher education. One solution to the problem is to simplify the language used in project information sheets and consent forms, such as through use of 'easy read', accessible materials. While simplifying language may go some way to redressing barriers, it still leaves unaddressed how people with PMLD can participate in the process.

Research ethics become even more complex when we take into account the different philosophical positions that inform debate. One branch of ethics is 'deontological ethics', which means that there are universal ethical principles or rules for everyone about what is right and wrong. Informed written consent is currently one of these rules - everyone should be able to read information and decide whether or not they want to participate in research. A contrasting position is consequentialist ethics. Consequentialism holds that we should not follow general rules (an ethical code of conduct), but instead design studies based on whether or not they will result in good outcomes for the groups under investigation. If people with PMLD were participating in research then the research should benefit the participants directly, or people with PMLD more generally. A third ethical position is relational ethics. According to Ellis (2007) relational ethics requires that researchers are not objective in their research but act from their 'hearts and minds' (p. 3), that they acknowledge interpersonal bonds and take responsibility for actions and their social consequences. Research informed by relational ethics 'recognizes and values mutual respect, dignity, and connectedness between researcher and researched, and between researchers and the communities in which they live and work' (Ibid, p. 4). This kind of research has been influential where participants are judged to be vulnerable, or in contexts where the responsibility of caring is already prioritised, such as nursing research (Hammersley and Traianou 2012). Instead of prioritising informed consent, which is an agreement that takes place before the research takes place, relational ethics suggests that researchers maintain a good relationship with participants during and after the research. What these different philosophical positions on ethics ultimately demonstrate is the complexity of ethical decisions, and how researchers should be mindful of a range of issues that cannot always be prescribed in advance. For people with PMLD, it means we have to consider not simply formal rules, but the perceived benefits of the research as well as the relationships that develop during the course of a project. Given the lack of research about what constitutes an ethical project for people with PMLD, we invite readers to get in touch and help shape ethical debates.

Call for reader responses

As a research group, we agree that all research projects should obtain research ethics approval and minimise risk of harm to participants and society at large. However, research ethics guidelines are typically created by universities and professional bodies rather than the research participants themselves. In other words, academic organisations decide what constitutes an ethically or morally right research project, at the expense of listening to people who are the actual subjects of research (i.e. the people being researched). Modern

research ethics takes the non-disabled experience to be the norm, and by doing this, devalues the interests of the people who are the subjects of research, including people with PMLD. We wish to flip the narrative here. We call on readers to think about what would constitute an ethical research project for people with PMLD and those involved in their care. As a research team, we cannot abandon university ethics, but we can enrich it by creating a code of practice that reflects the values of the communities we engage with, such as people with PMLD. We invite readers to engage in this debate and we welcome emails on the topic. What do you think an ethical PMLD research project involves? What should we do to make a project more ethical, and what should we avoid? Is it enough to simply minimise risk, or does all research involve an element of risk? If you have any questions, suggestions, disagreements and comments, please get in touch with us - we welcome all opinions on this controversial topic.

Contact Details

Dr Ben Simmons, Reader in Inclusive Education and Disability Research b.simmons@bathspa.ac.uk
Dr Stuart Read, Research Fellow s.read@bathspa.ac.uk
Dr Anne Parfitt, Research Fellow a.parfitt@bathspa.ac.uk
Dr Tanvir Bush, Research Fellow t.bush@bathspa.ac.uk
We Are The People research team, School of Education, Bath Spa University

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Get Involved

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

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

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

For more information contact info@pmldlink.org.uk



Changing Places Toilets - updates from across the UK

Changing Places - Fully accessible toilets and personal care facilities

Karen Hoe

Over 250,000 people with disabilities that severely limit their mobility, including those with profound and multiple learning disabilities (PMLD), cannot use standard accessible toilets. People may be limited in their own movement or mobility so need equipment to help them or they may need support from one or two carers, either to get on the toilet or to have their continence pad changed. Standard accessible toilets do not provide changing benches or hoists and most are too small to accommodate more than one person. Without Changing Places toilets, the person with disabilities may be made to sit in wet or soiled pads, or they may be put at risk, when families (or paid carers) are forced to risk their own health and safety by changing their loved one on a toilet floor, – or they simply have to go home to get changed.

To find your nearest registered

Changing Places Toilet on our UK-wide national map, check our website <https://www.changing-places.org/find> (PLEASE NOTE THERE IS NO OFFICIAL CHANGING PLACES TOILETS app)

Latest news for England

We were delighted to secure £30 million in new funds from the Department of Levelling UP to install over 600 more Changing Places Toilets across England. MDUK (Muscular Dystrophy UK), are the Changing Places delivery partner managing this grant programme, working with over 200 local authorities to support them with this new installation programme. In line with the research undertaken for MDUK by RiDC (Research Institute for Disabled Consumers), new facilities will be prioritised for the following venues:

- Public parks and open spaces
- Tourist attractions including historic properties, seaside resorts and zoos
- Cathedrals
- Museums, theatres and galleries
- Shopping malls
- Libraries and public buildings

To find out more about this programme visit:

<https://www.changing-places.org/local-authority-funding/ps30-million-investment-to-provide-changing-places-toilets>

Guide to installing a Changing Places toilet

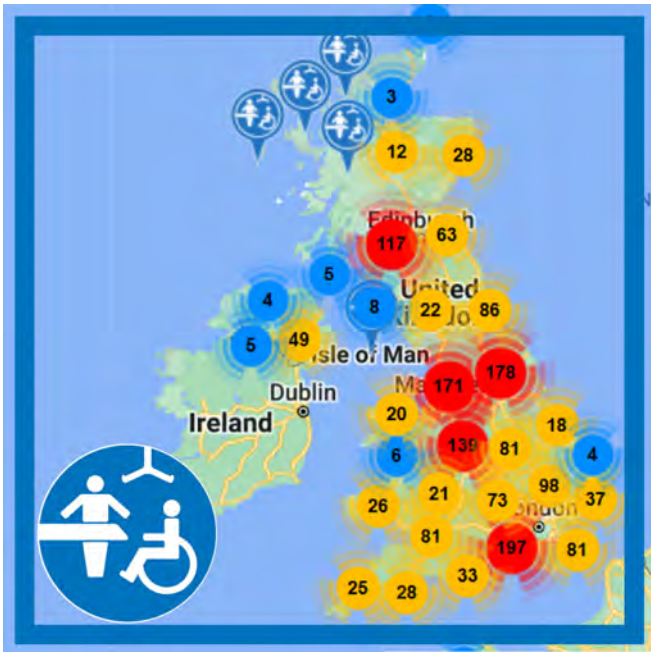
We have a practical guide available which details all the legislation, duties and guidance on specifications required to meet the building regulations standards when building a Changing Places Toilet (nb: this guide applies to England).

<http://toiletmap.s3.eu-west-1.amazonaws.com/content/Changing%20Places%20a%20Practical%20Guide.pdf>

Keep up to date with Changing Places news in our online newsletter, 'Engaged'

Contact Details

Karen Hoe, Changing Places National Manager
Email : K.Hoe@musculardystrophyuk.org
<https://www.changing-places.org/>



Changing Places Toilets A Scottish Perspective

Fiona Souter

The campaign for Changing Places toilets (CPTs) in Scotland has been going from strength to strength. PAMIS are co-chairs of the UK Changing Places toilet Consortium having co-founded the campaign over fifteen years ago. Our work includes providing a free enquiry and advisory service for venues, community members, families, professionals and architects across Scotland to help with planning, design, equipment advice, risk management and ongoing maintenance of a facility. We administrate the Changing Places toilet UK website (<https://www.changing-places.org/>) and interactive map and register all new CPTs.

We are delighted to have over 250 CPTs in Scotland now. This number will be hugely boosted following a recent Scottish Government announcement that a dedicated £10 million fund will be established to ensure a robust network of these life changing and essential

facilities is available across the country. This financial commitment follows on from legislative changes around Scottish Building Standards as well planning legislation.

In 2013 the Scottish Building Standards Division worked with PAMIS, to introduce a specification for CPTs into the Scottish Technical Handbooks. The specification would promote consistency when building owners elected to install a CPT in their building as it would outline the essential feature. However, the installation of these facilities remained voluntary and solely at the discretion of the developer.

By 2018, the number of available CPTs in Scotland was still less than 200 and there was a need to do more to increase provision. A public consultation was launched in February 2019 and ran for three months. The response to the consultation was overwhelmingly positive with over 1000 responses in total, the highest response to a public consultation that Building Standards Division has received.

Following the consultation, the Non-domestic Technical Handbook was amended and a new clause, 3.12.13, was added to cover CPTs. This change covers CPTs in large retail, assembly and entertainment buildings, hospitals and schools with community facilities. The revised Technical Handbook came into force on 1st October 2019.

The UK is now considered a world leader on CPTs, with other countries having now introduced the same or a similar mandatory provision through building standards.

Also in 2019, an excellent opportunity arose to review planning legislation and cross party support was gained to amend the Planning (Scotland) Bill with Mary Fee MSP and Jeremy Balfour MSP both playing an instrumental part in achieving the amendments and successfully taking this through committee. Scotland are again the first country in the world to legislate in this way and in order to gain planning permission for certain types of new buildings at least one CPT must be installed.

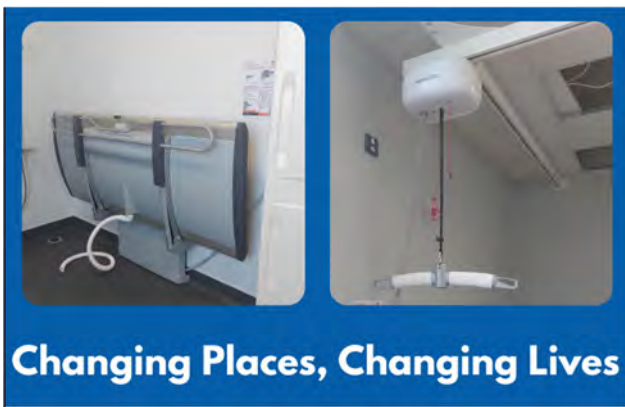
- a) as a school, college or university,
- b) as a community centre, sports and leisure centre, or similar public building,
- c) as a hospital or other facility for the provision of health services,
- d) as a retail outlet,
- e) as a cultural centre, such as a museum, concert hall or art gallery,
- f) as a stadium or large auditorium,
- g) as a major transport terminus or interchange,
- h) as a motorway service facility,
- i) as a conference or exhibition centre,
- j) as a restaurant or café,
- k) as a public house or nightclub.

The Changing Places toilet Consortium is currently updating the key publication to support the design and planning of CPTs, The Changing Places Practical Guide. This document is freely available on the website and contains all the information to install a gold standard Changing Places toilet. If you are interested in joining our equipment focus group which is supporting the publication amendments then please get in touch with us by emailing: changingplaces@pamis.org.uk

Contact Details

Fiona Souter is Inclusive Communities Director, PAMIS

Email: changingplaces@pamis.org.uk



Changing Places toilets in Wales

Rob Ashdown

The Changing Places (CP) campaign is calling for CP toilets to be installed in all major public places. Its website is the place to register new CP toilets and has an interactive map of all CP toilets that have been registered (<https://www.changing-places.org/>). The total number of active toilets registered so far is 1738. Looking at the map about 60 are registered in Wales. So, what is being done to encourage the development of CP toilets in Wales?

The Petitions Committee of the Senedd considered a long-standing petition that “The Welsh Government can and must do better than the current situation and make Changing Places toilets Compulsory for Large Public Buildings”. At the Committee’s meeting on 16/03/2021 the petition was closed in light of the upcoming election and the consideration given to this issue to date.

In Wales, all planning policy is covered by the document Planning Policy for Wales (2002) with supplementary guiding documents called Technical Advice Notes. The Welsh Government agreed an amendment to the Technical Advice Note (TAN) 12 which states that all those seeking permission to build new and public commercial buildings are encouraged to include in their plans, accessible CP toilets in addition to standard accessible toilets. Although not a firm requirement for new public and commercial builds, it is at least an endorsement of good practice. The current state of devolution means that the powers to make them a pre-requisite to being granted planning permission is not devolved to the Assembly. However, assurance has been given that when such powers are devolved, further amendments will be made with regard to Changing Places toilets.

Under the Public Health (Wales) Act 2017 each local authority within Wales is required to publish a local toilets strategy. The information is included in a National Toilet Map which shows public toilets, toilets in public buildings and some toilets owned by businesses (<https://gov.wales/find-toilets-open-public>). It shows the type of toilets at each location such as baby change facilities and CP toilets. You do not have to be a customer to use any toilet listed on the map.

In February 2021, the Welsh Government published for consultation a draft policy on CP toilets and baby nappy changing provision (<https://gov.wales/changing-places-toilets-and-baby-nappy-changing-facilities>). This made plain that the Welsh Government wants there to be more CP toilets. It set out a three-pronged strategy:

1. Every local authority must write a plan for toilets in their area, and find out the need for CP toilets and say how they plan to meet that need. There is an emphasis on considering how existing public toilets might be improved.
2. Building control bodies should check that the new planning guidelines are followed in all major new builds.
3. Planning Policy Wales is the document which says what people need to consider when planning changes to public buildings in Wales (<https://gov.wales/planning-policy-wales>). The intent is that the guidelines should be amended to say that any large new public building, or a public building being significantly extended, must have a CP toilet. The aim is to have CP toilets in places like shopping centres, sports and leisure centres, public spaces in hospitals, buildings used for entertainment or meetings, hotels that have public events and schools that are open to the community.

CP toilets are not cheap. The consultation documented

estimated that a CPT can cost between 47 thousand pounds and 64 thousand pounds. Also, it recognised that business owners may lose some space in their building and this may have an impact on places like shops, where they need selling space. But it argued that having a CP toilet will help businesses get more customers and more people into their buildings.

Arguably, last year's elections and the Coronavirus pandemic and other pressures have had a huge impact on development planning but Planning Policy Wales has not been updated at the time of writing, although the amended Technical Advice Note 12 does at least encourage the inclusion of CP toilets in new builds. On a positive note, in May of this year, the Welsh Government's £2.9 million Brilliant Basics capital fund was published and it does include funding for a few more CP toilets at tourism locations in Pembrokeshire, the Brecon Beacons and Flintshire.

Contact Details

Rob Ashdown
Email: rob.ashdown@ntlworld.com



Changing Places Updates in Northern Ireland

Michael Fullerton

Statutory guidance which came into effect in June this year (2022) makes it a requirement for Changing Places toilets to be provided in certain buildings commonly used by the public. The guidance applies to new buildings and existing buildings where there is material change of use. Changing Places guidance will include buildings used by the public as follows:

- Assembly, entertainment and recreation buildings with a capacity of 350 or more people
- Shopping Centres/Malls or retail parks with a gross floor area of 30,000m² or more
- Retail premises with a gross floor area of 2,500m² or more
- Leisure and sports buildings with a gross floor area of 5,000m² or more
- Hospitals and primary care centres
- Cemetery and crematorium buildings

<https://www.finance-ni.gov.uk/news/changing-places-toilets-must-be-provided-new-public-buildings-murphy>

Further details: <https://www.finance-ni.gov.uk/>

Access recent issues online

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

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

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

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

A limited number of printed back copies are available at £7 (inc p&p). Contact info@pmlmlink.org.uk

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

A survey of the views of special school staff about the value of singing in music for students with SLD and PMLD

Kat Skeavington

This article is based on research undertaken in part for the M. Ed degree at the University of Birmingham. The focus of the study was ‘Staff views of the benefits of Music involving singing for those with SLD and/or PMLD’.

The overall purpose of my research was to reflect on the benefits (if any) of Music involving singing for learners with severe learning disabilities (SLD) and/or profound and multiple learning disabilities (PMLD). and how we can help to reduce barriers and provide support for students and staff. Current musical research has few studies that include the valuable perspectives of staff who work in UK special schools for students with special educational needs and disability (SEND). I predicted that staff members, who worked with the students and knew them very well should be able to make a reasonable judgement about their learners’ reactions/responses to music involving singing as stimuli. Therefore, my research project sought to help fill this void by utilising the reflective views of staff. I hoped that my research might also disprove the misconceptions of a perceived lack of communication between those with SEND – especially those who communicate without words – and neurotypical people who speak through music, singing being a bridge to communicate.

Objectives

I aimed to answer the following research questions:

1. What are the views of staff in UK special schools about the benefits (if any) of music involving singing?
2. What factors currently support singing in the classroom?
3. What barriers do staff encounter when promoting singing in the classroom?
4. What support do staff feel they need?

Methodology

This research started with a literature review and a proposed, happiness audit tool for staff to measure the responses of a learner with profound and multiple learning disabilities (PMLD) to Music sessions (Skeavington, 2021). I searched for relevant literature using terms such as ‘music’, ‘singing’, ‘song’, ‘choir’ in relation to (severe learning disabilities (SLD), PMLD, SEND, ‘autism’ and/or ‘autistic’ and ‘learning disability’). There were very few results.

After a pilot study to test validity of a questionnaire, a Qualtrics online questionnaire was advertised via social media sites for people teaching learners with SLD, PMLD, and SEND. It was also posted to a Masters students’ discussion board, to recruit staff in UK special schools involved in Music. All posts gave the research area title, the eligibility criteria and a hyperlink to the questionnaire.

Results

Results were analysed on the basis of completed questionnaires only. After data cleanse, 24 completed questionnaires were analysed. Both quantitative and qualitative data were exported from Qualtrics as a raw data set. A range of between 10 and 15 questions were answered by each respondent with the mode being 14 questions for 13 out of 26 respondents.

The quantitative data including ‘other’ text comments was analysed via a ‘coding and constant comparative method’ as suggested by Thomas (2017). Automatically generated visuals were exported from Qualtrics, but then replicated automatically using Microsoft Excel changing colours to monochrome patterns. This data This revealed important quotes key themes and trends and outliers/paradoxes were noted. As a final stage key theme mapping was produced as graphics. A selection of the results are reproduced on the next page (see Table 1 and Table 2).

Conclusions

The majority of respondents perceived music involving singing to be of a high level of importance to their learners with SLD and/or PMLD. They also reported that these learners enjoyed music. Respondents’ views showed that they perceived music to aid these learners socially, impact positively on their well-being, and helped to improve their alertness.

Table 1: Positive Factors: Music sessions involving singing that went well and how they knew

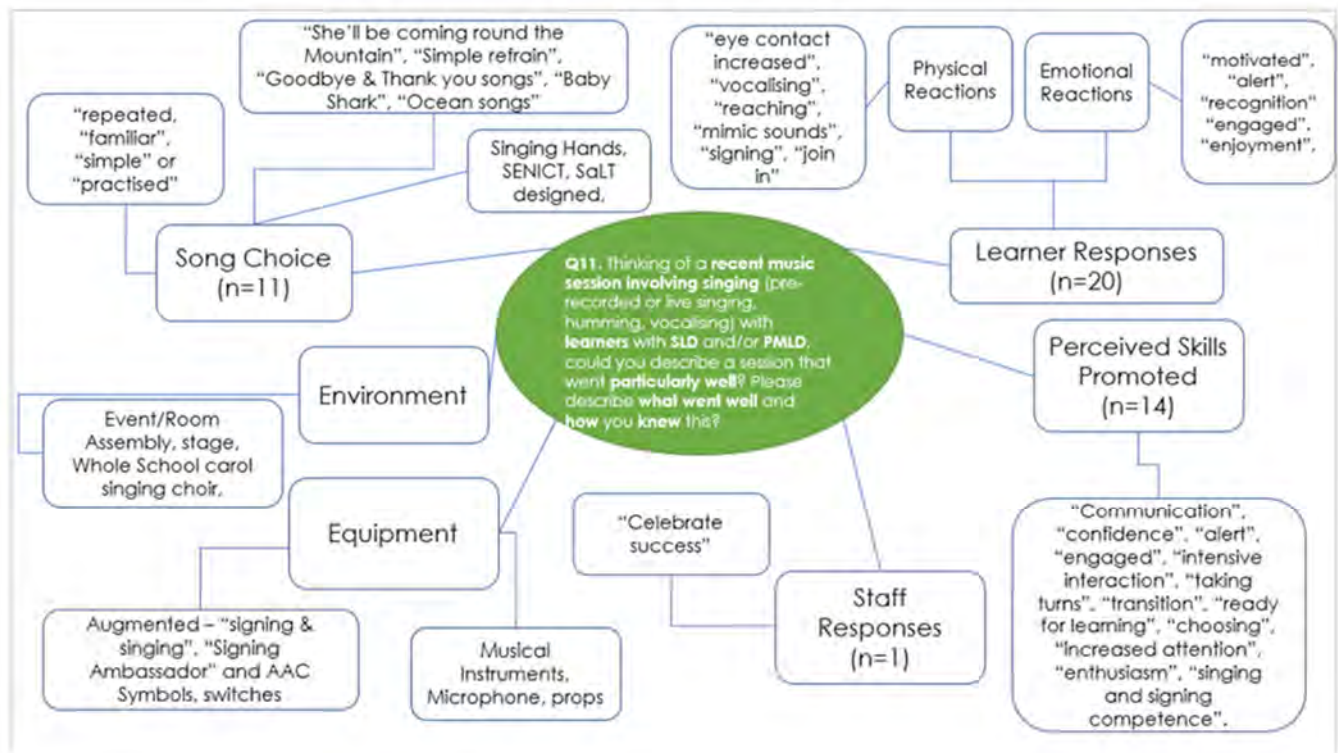
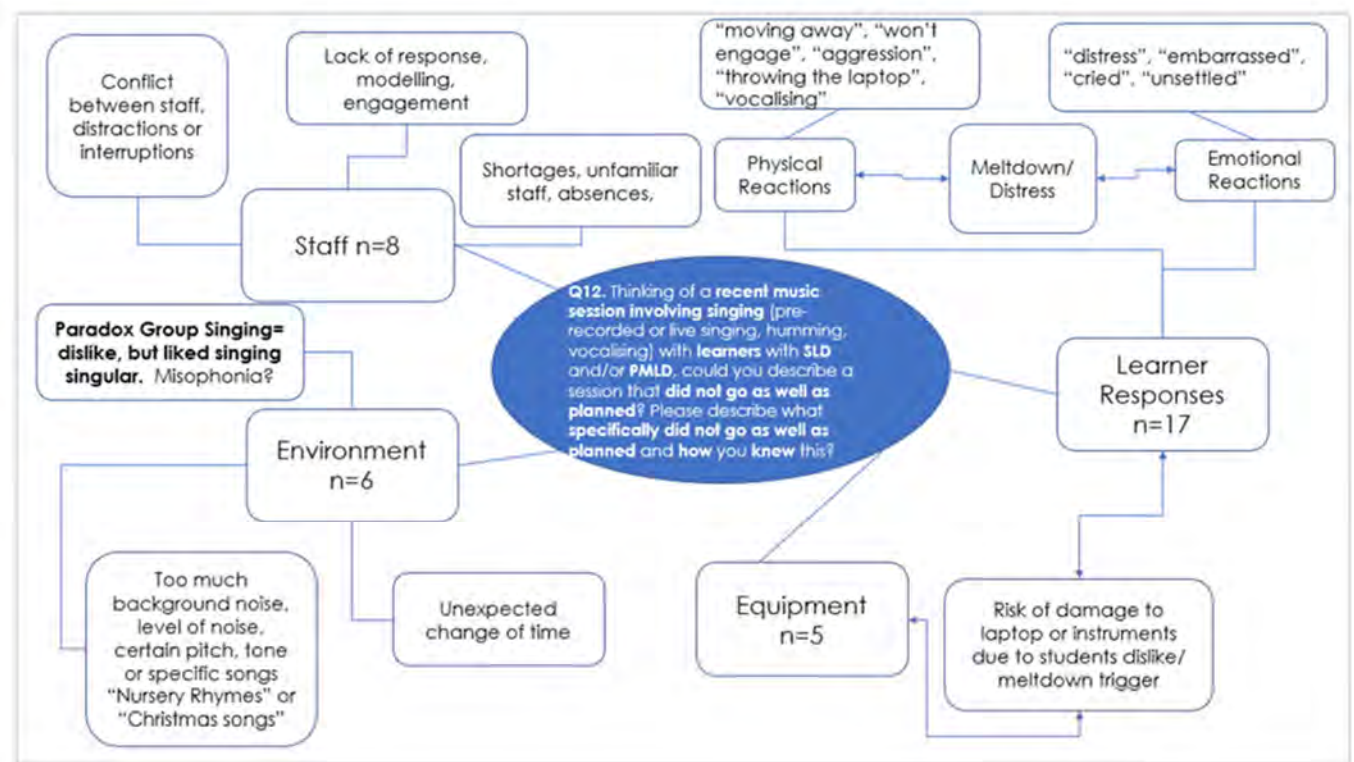


Table 2: Negative Factors: Music sessions involving singing that did not go so well and how they knew



This research supports much of the literature that I reviewed yet contradicts the lack of music-specific study in the government literature reviewed, much of which fails to recognise the powerful perceived benefits of music to learners as evidenced by these staff members who knew their learners very well. Future research might benefit from a 'mixed methods' approach, to include semi-structured interviews to allow more depth of questioning than the questionnaire. It would be good to research parents' and carers' views of music involving singing, and also research into preference of different genres, pitches, group singing, "signing and singing", Makaton etc.

Contact details

Kat Skeavington is an author, teacher and early career researcher. She's a final year student at University of Birmingham studying for Masters in Education: Severe, Profound & Multiple Learning Disabilities

Email: KXS036@student.bham.ac.uk

A summary of findings is available online. All respondent views have been anonymised in this summary which can be found at:
https://www.canva.com/design/DAFPG9OZdwQ/mubkJRsmBK6Lfr8kpL7b-A/view?utm_content=DAFPG9OZdwQ&utm_campaign=designshare&utm_medium=link&utm_source=publishsharelink

Acknowledgements

I wish to thank all those who answered my research questionnaire. Also, thanks to tutors, Helen Bradley and Dr, Lila Kosyvaki for their guidance. My love of music was inspired by my Mum and led to a lifetime love of music and singing which I try to promote in my work with my students who do not use words - we do not need them; the music and the smiles speak volumes.

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Doukas, T., Fergusson, A., Fullerton, M. & Grace, J. (ed.) (2017), *Supporting People with Profound and Multiple Learning Difficulties: Core & Essential Service Standards*. Available at: <https://www.pmlmlink.org.uk/wpcontent/uploads/2017/11/Standards-PMLD-h-web.pdf> (Accessed:12/02/2022).

Skeavington, K. (2021), 'Enhancing quality for those with PMLD by using a happiness audit tool for MOLF music sessions'. Assignment for Enhancing Quality Level M 25064, MEd (Post-graduate taught Year 2) in Severe, Profound & Multiple Learning Disabilities, University of Birmingham. Unpublished.

Thomas, G. (2017), *How to Do Your Research Project: A guide for students*, 3rd edn. London: SAGE Publications Ltd.

**For a full list of references please email:
KXS036@student.bham.ac.uk**

In the Next Issue

Our Spring issue of the PMLD LINK journal next year has the specific theme of Personal Care. For our purposes here, personal care means anything that carers do which is of a personal nature. These tasks are personal to the child or adult with profound and multiple learning disabilities (PMLD) and will probably include bathing, showering, applying creams and lotions, providing medication, dressing, toileting (including continence management and general laundry), meal preparation and support with eating, drinking and nutrition (including tube feeding), and other day-to-day activities to sustain a consistently good quality of life in the comfort of their own home or in whatever out-of-home services they access. So many people with PMLD have severe physical disabilities and they will require hands-on physiotherapy, massage, mobility training and 24-hour postural care to maintain their physical health. These individuals often have quite complex health needs requiring very detailed health plans that must be consistently followed by all of their carers, including routine and emergency invasive medication and other interventions.

Too often parents and other family members are seen by services providers as the main deliverers of personal care but a whole-system response is key. Campaign groups down the years, and supported by the PMLD 'core and essential service standards' (Doukas et al, 2017) have insisted core and essential service standards, have insisted on the need for collaborative, multi-disciplinary and multiagency working, as well as skilled informed responses from education, leisure, health and social care services, in partnership with the person with PMLD, their family, and those who provide day-to-day support.

The Editors of the Spring 2023 issue would be pleased to receive information about how individuals and/or organisations work to ensure that personal care is tailored to meet individuals' specific requirements. Contributions about training of carers to offer discreet and professional personal care would be of great interest too. Also, how can a continuous service be delivered by the same familiar faces when so many organisations experience staffing issues. Finally, how can personal care activities be integrated into the normal practices and day-to-day routines of organisations and families so that they are not seen as a distracting chore or 'bolt-on'? Personal care activities can offer so many opportunities for learning independence, thinking, communication and social skills after all.

We do realise that many of our readers have a story to tell but do not consider themselves as writers. But the Editors are keen to involve new writers and 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.

Of course, your article need not be about personal care at all. Do you have anything you wish to share that relates to the lives of people with PMLD? It could be something you alone have experienced, it could be a piece of action research you have carried out, it could be something that has helped you and your family that you think might help others.

We also welcome shorter items about new resources, books, websites, events, courses, and news in general so please let us know about these too.

All contributions by Monday 27th February 2023 please.

The Spring 2023 issue editors are Michael Fullerton, Maureen Phillip and Rob Ashdown.

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



REPORT BACK

Involving Everyone Photography Exhibition

by Annie Fergusson

During 2022, professional photographer/artist Rachael Munro-Fawcett partnered with Inclusion North on their Involving Everyone project, to share the lives of people with profound and multiple learning disabilities and their families, living in the North East of England.

The Involving Everyone project was developed from an awareness that this group of people are often not seen and not heard in our communities. That there is often little focus on their quality of life and that they are not always seen as equal, valued citizens. The photography project, facilitated by Rachael as 'photographer in residence', was an important part of this work and the exhibition, a wonderful culmination of the many strands to this work. I was really fortunate to be invited to attend the exhibition launch in October. I joined the individuals who took part in the photography project, along with their families, friends and supporters at The Word, in South Shields, to celebrate the project and this wonderful body of work.

Rachael Munro-Fawcett created her digital photography exhibition, as an opportunity for people with profound and multiple learning disabilities to be more visible, to share their personal stories and what is uniquely important to them as individuals, but also, to offer others a better understanding of what life is like.

The digital exhibition comprised many components including still images, video footage and some audio description offering insights into everyday life in their homes and in local communities. Rachael's camera focused on whatever was of significance to each individual, at given moments in time or in differing

contexts – for example to portray the rich diversity and importance of relationships, being out and about in nature, solo music-making on a keyboard or with an African spin-drum, flapping and tearing paper, exploring that favourite rainbow slinky, mutual pleasure from hair being brushed or simple moments of silence and contemplation. An audio commentary accompanied this visual imagery. For me, this combination was a powerful way to share how people filled their lives, what (or who) was important to them. The voiceover simply gave clear descriptions of exactly what was seen, without comment or interpretation. It genuinely valued each individual for who they are, and perhaps, what they themselves perceive to be of value.

The digital exhibition included a collection of images taken by six individuals with profound and multiple learning disabilities. These artists had taken part in accessible photography workshops facilitated by Rachael and Inclusion North, using iPads and switches. Each single photograph by these artists with profound disabilities, in my eyes, would stand up admirably against work in any exhibition. This stunning collection of images were collated into a separate, paper copy 'zine' for the exhibition.

The exhibition and the launch event itself were a real celebration for all attending. It was fantastic seeing the artists enjoying their artistic acclaim. Family members (many of whom had featured in the exhibition) commented on how emotional they felt– so rare to come together with other families and guests and share such proud moments. This wonderful exhibition by Rachael Munro-Fawcett, is a great testament for genuinely, Involving Everyone.

It is hoped this digital exhibition may be shown to a wider reach in 2023, following it's time at The Word. Look out for updates in our next journal or on social media. This project was funded by the North East and North Cumbria Integrated Care System and Arts Council England.

For more information

Rachael Munro-Fawcett, photographer and to view images from the exhibitions: <https://www.rachaelmunrofawcett.co.uk/involvingeveryone> <https://www.instagram.com/rachaelmunrofawcett/>

Involving Everyone project, Inclusion North and updates on this exhibition in 2023: <https://inclusionnorth.org/our-work/involving-everyone/>

Contact details

Annie Fergusson, PMLD LINK
info@pmlmlink.org.uk or
annie.fergusson@outlook.com

IN THE NEWS

Positive funding news for the Sensory Theatre Sector!

In November Arts Council England announced the 990 arts organisations that it will be funding from 2023-2026, these organisations are known as 'NPO' (National Portfolio Organisations). This means that these organisations will receive guaranteed regular funding for the next 3 years. It is the first NPO funding round since the Arts Council had launched its 'Let's Create' strategy which focuses on a future where the creativity of every individual is valued and has access to a range of high quality cultural experiences.

It was a fantastic day for Sensory Theatre makers who make work for audiences with profound and multiple learning disabilities, a demonstration that the Arts Council has heard that for the sector to thrive and flourish that organisations must receive regular funding in order to plan for the future. Oily Cart and Bamboozle who were both previous NPO's have continued to be funded in this round, and Bamboozle have received an increase in their funding. Frozen Light, Blink Dance and Second Hand Dance are all new additions to the portfolio.

There are many more theatre companies and individuals making sensory based theatre, some of which are funded by the arts council on a project by project basis, and some individuals doing amazing work who are not Arts Council funded at all, but we're excited by a future where there is a huge diversity within the Sensory Theatre sector, and where audiences with profound and multiple learning disabilities can access theatre and arts, where they want it and when they want it. An increase in regular funded organisations in this field is a wonderful place to start!

For more on the work of these theatre companies:

<https://bamboozletheatre.co.uk/>
<http://www.blinkdancetheatre.org/>
<https://www.frozenlighttheatre.com/>
<https://oilycart.org.uk/>
<https://www.secondhanddance.co.uk/>

FREE mindfulness course for adult sibling carers

Are you an adult sibling carer of someone with a learning disability? Would you like to step out of automatic pilot, reconnect with your body and find new ways of coping with difficulties? Then this FREE mindfulness course from Be Mindful could be for you. This project is being led by the University of Warwick, Sibs the charity for brothers and sisters is one of the project partners.

To find out more or sign up, see the link here. <https://www.sibs.org.uk/bemindful/>

Sibs – adult sibling support groups

Are you an adult who has grown up with a disabled brother or sister? Would you like to meet others who just 'get' what life as a sibling is like? You're not alone. Join a support group today. <https://www.sibs.org.uk/support-for-adult-siblings/adult-sibling-support-groups/>

Oliver McGowan Mandatory Training Update

A new e-learning module has been launched, following a two-year trial involving over 8300 health and social care staff across England. Everyone in health and social care should complete the eLearning no matter where they work, and what tier of training they need to complete.

From the 1st July 2022, it has been a requirement for CQC registered service providers to ensure their employees receive learning disability and autism training appropriate to their role. The Oliver McGowan Mandatory Training on learning disability and autism is the standardised training that was developed for this purpose and is the governments preferred and recommended training for health and social care staff. This requirement is set out in the Health & Care Act 2022 and the Secretary of State is to publish a Code of Practice in 2023.

The Oliver McGowan Mandatory Training on Learning Disability and Autism - eLearning for healthcare (e-lfh.org.uk)

Reasonable Adjustments in Health Services

NHS England has published a web page on reasonable adjustments in Health Services for disabled people focusing on specific adjustments for people with learning disabilities. There are several videos and links to help both people in the health service as well as people with learning disabilities. You can find the web page here:

<https://www.england.nhs.uk/learning-disabilities/improving-health/reasonable-adjustments/>

Dimensions' research inspires first-of-its-kind toolkit to improve access to healthcare

Research from social care provider Dimensions, on improving health centre accessibility, has formed the basis of a ground-breaking toolkit launched this week to help GP practices improve the design of their buildings and physical environment for people with disabilities and other conditions.

The toolkit looks to support GP surgeries and health centres to adapt to the needs and reasonable adjustments of people with disabilities, dementia, neurodiversity and anxiety.

The 'Designing for Everyone' kit was commissioned by primary care building specialists Assura and written by the Association for Dementia Studies (ADS) centre at the University of Worcester, in partnership with the NHS Worcestershire, Worcestershire County Council and Dementia UK.

This 'Designing for Everyone' toolkit forms part of the Dimensions #MyGPandMe health equality campaign and suite of resources.

Download the Designing for Everyone guide, summary assessment tool, and full assessment tool at: <http://www.dimensions-uk.org/designingforeveryone>

Download Dimensions 2019 research report Building Better Together: <https://dimensions-uk.org/wp-content/uploads/Building-Better-Together-Dimensions-Assura-report-web-final.pdf>

UK Coronavirus and people with learning disabilities study - new participants from ethnic minority groups needed for Wave 4

For Wave 4 of the Study, the research team want to hear from new participants from ethnic minority groups who live in England.

In Waves 1-3 of the study about 1 in 10 people they talked to were from ethnic minority groups. They want to increase this.

They want to interview 100 new people with learning disabilities from ethnic minority groups who live in England.

They also have an online survey for family members or paid carers of people with learning disabilities (including those with profound and multiple learning disabilities (PMLD), who would not be able to take part in an interview with one of their researchers.

Take part here: <https://warwick.ac.uk/fac/soc/cedar/covid19-learningdisability/wave4newparticipants/>

Learning Disability England and PMLD LINK are the research partners for England. For more, including easy read information and videos from people with lived experience: <https://www.learningdisabilityengland.org.uk/news/latest-news/coronavirus-and-people-with-learning-disabilities-study-can-you-help/>

Training launched for new advanced level Learning Disability Physician/ Practitioner roles

Health Education England (HEE) commissioned the Royal College of Physicians (RCP) to undertake the development of a specialist training programme to meet the medical needs of adults with a learning disability. The training programme consists of two modules leading to a post graduate certificate. We are pleased to report that PMLD LINK and a number of families were involved in helping shape this training.

The training programme is designed for doctors, nurses and allied health professionals working at a senior level and caring for people with a learning disability within their role. It will enhance their skillset and to address a number of cross cutting themes. This is key to enable practitioners to provide high quality and person-centred care for adults with a learning disability. The training programme has been developed and will be delivered with the input of experts by experience. The first module has been developed by RCP and Edge Hill University and is due to start in February 2023.

This training is key to enabling practitioners to provide high-quality and person-centred care for adults with a learning disability: <http://ow.ly/y7qz50LN0hA>

RCSLT Guidance on Learning Disabilities Consultation

The RCSLT (Royal College of Speech and Language Therapists) is updating its guidance on learning disabilities. They are seeking feedback from people with learning disabilities and their families/carers on the public information in their guidance, (including some Easy Read information). This consultation is collecting views via an online survey until 11 December 2022. We hope to bring news of this updated guidance in the Spring issue.

You can view the draft guidance: bit.ly/3U039Pu

Signers Speaking Up

Nicola Grove & Kathy Howery

Historically, "AAC" always included signing. But now it seems to refer to communication aids and technology. So signing and gesture can get left out, or seen as inferior. Sign may not be mentioned on AAC websites, many therapists may not know enough about its use. This means that this modality is not valued as it should be.

In 2023 we want to change this situation. We are passionate about using sign and gesture creatively, as part of Total Communication. We want to set up some panels of Experts by Experience, who use sign and gesture and can speak up for why it is so important to include in AAC. We are working with colleagues in Australia, Canada, the US and the UK.

Do you know anyone using Key Word Sign as one of their main forms of communication, who might like to take

part? They can do so in small ways, by showing what they can do. They can be supported by family members, friends and advocates, or professionals. We are especially keen to hear from families about the questions we should be asking.

Contact: drnicolagrove@fastmail.net - add 'SIGN' in the email subject line.

Free energy and water advice to disabled people

Scope is offering free energy and water advice to disabled people, helping them to manage their energy and water needs.

The service is open to any disabled person or households where 1 or more disabled people live, in England or Wales

Their expert advisers can help and talk you through a wide range of topics related to your energy and water needs, including:

- managing energy and water debt
- changing your meter
- energy and water efficiency
- accessing benefits, grants, and trusts
- free fuel vouchers (conditions apply)
- contacting or complaining to your supplier
- understanding your gas and electricity bills
- understanding how to use your heating systems
- support registering with the Priority Services Register 2

Contact: <https://www.scope.org.uk/disability-energy-support/>

Priority Services Register as power cuts loom

Contact for families with disabled children, are encouraging anyone caring for someone with disabilities and those who rely on medical equipment, to sign up to the 'Priority Services Register' ahead of possible power cuts this winter. By contacting your energy supplier directly to join their register, you will get priority support in an emergency — some may arrange heating and cooking facilities too. Read more about the Priority Services Register, where to get help with energy and household bills and other cost of living advice on Contact's website: <https://contact.org.uk/>

PUBLICATIONS AND RESOURCES

Scottish Learning Disability Observatory film: Reducing child deaths from chest infections

A short film aimed at health and social care workers and educators, carers, and families of children and young people with learning disabilities. The film shares evidence about the avoidable deaths of children and young people with learning disabilities and highlights key areas where awareness and action are needed:

- Postural Care
- Swallowing Problems
- Vaccinations
- Healthcare Information

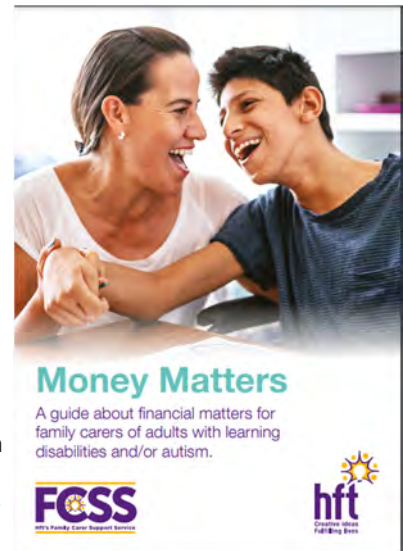
For more information about this project, this film or other SLDO work, contact: sldo-info@glasgow.ac.uk

HfT family Support Services resources available free to download, paper copies for families Money Matters guide

This guide is for family carers of an adult with a learning disability and/ or autism who may need to support their relative with their finances.

Supporting another person with their finances is far from straightforward. It requires a good understanding of the Mental Capacity Act, and the options available if your relative is found to lack capacity to manage some or all of their finances. Whether you, as the family carer, manage their finances as a Lasting Power of Attorney or Deputy,

or their benefits as their Appointee, there is a lot of responsibility and administrative work involved. You become the main point of contact for everything finance related. Dealing with finances is particularly difficult when coming to terms with the death of a relative, especially when they didn't have a Will, as is the case for many people with learning disabilities. The aim of this guide is to provide practical information and key considerations relating to these matters.



Contents

- Chapter 1: Disability benefits
- Chapter 2: Appointeeship
- Chapter 3: Lasting Power of Attorney
- Chapter 4: Deputyship
- Chapter 5: Banking
- Chapter 6: How can we best prepare financially for my relative's death?
- Chapter 7: How can I remember my relative in my Will?

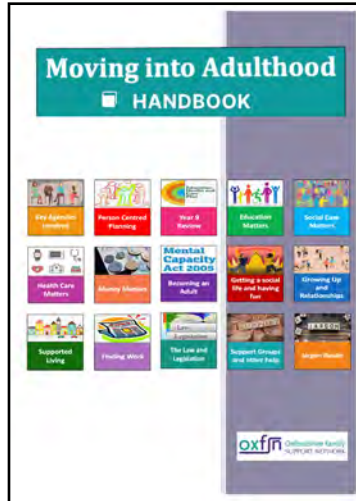
This guide was written by the Family Carer Support Service, which is made up of family carers and people who consider themselves allies to family carers and their relatives. It has been reviewed by a range of professionals and family carers, who are referenced in the acknowledgements.

<https://www.hft.org.uk/our-services/family-carer-support-service/fcss-updates/money-matters/Care-Act-guide>

The Moving into Adulthood Handbook

This new transition resource has been designed by OxFNS (Oxford Family Support network) as a guide for family carers of a young person aged 14-25 with a learning disability and/or autism with an Education, Health and Care Plan. This resource however also offers some valuable information whatever the age of the person you support.

Each chapter focuses on one of fifteen different areas, providing an overview of what you need to know as you and your family member navigate your way through the moving into adulthood stage. It is designed as a user-friendly, dip-in and out resource.



Free to download:
<https://movingintoadulthood.oxfsn.org.uk>
Contact OxFSN: info@oxfsn.org.uk

The cost of caring report features research from Family Fund's four quarterly family polls, from September 2021 to June 2022,

Report available: <https://www.familyfund.org.uk/news/the-cost-of-caring>

Podcast: The Skies We're Under

A podcast by and for parents of people with complex disabilities. It's about the weather not always what we predicted or want. Author of 'The Skies I'm Under' and nurse, Rachel Wright has authentic, funny and sometimes swearsy conversations (her description!) with fellow parents about a different kind of parenthood. Rachel says, "It's for all of us trying to get from one end of the week to the other, whilst bridging the gap between the life we expected and the one we are living".

Season 1 podcasts covers topics such as Diagnosis, Epilepsy, Feeding, Self-care, Guilt, Holidays and much more.

Season 2 of The Skies We're Under podcast comes out early 2023. Rachel is currently asking for topic ideas and volunteers to join her podcast conversations. Contact Rachel admin@bornattherighttime.com or Twitter/Facebook: @bornatRightTime

Access podcasts: <https://www.bornattherighttime.com/the-skies-we-are-under-podcast/>

The Cost of Caring report

New research by the Family Fund shows that UK families raising disabled, or seriously ill, children and young people are now facing serious financial jeopardy and struggling to survive, due to the scale of the cost-of-living crisis.



"The cost of caring" polled 4,264 families with a disabled child or seriously ill child, to find that nine in 10 families are struggling, or falling behind on their regular household bills and many are forced to forego living essentials such as food, heating, basic furniture like beds, flooring, washing machines and fridges, to try to make ends meet. The new report highlights the, now, unsustainable strain on families raising disabled and seriously ill children and young people, as they try to cover sky-high costs on top of severely reduced incomes due to intense caring responsibilities, three times higher costs to look after a disabled child and critical levels of debt.

Last year, Family Fund Group delivered over 170,919 grants and services, worth over £37 million, to families on low incomes across the UK.

A suite of free activity programmes to support access to technology

Ian Bean is a well-known expert when it comes to technology for anyone with additional access needs. Followers of PMLD Link on social media may have seen our recent post about his interactive online Advent Calendar.

One of the many valuable resources on Ian's website is this suite of free to download programmes. SEN Switcher is a collection of fifteen programs, each carefully designed to teach a specific level of switch skills from experiential (purely for enjoyment - needs no actions from the individual) through to early scanning skills. Although the programs were written in 2002, they still provide motivating opportunities for learners to develop and practice these important access skills
<https://www.ianbean.co.uk/sen-switcher/>

PMLD Sensory Thematic Units



Practical resources to support developing a sensory curriculum for learners (aged 3-19)

The Council for the Curriculum, Examinations & Assessment (CCEA) have developed these thematic units to support teachers in delivering a vibrant and motivating curriculum for learners aged 3–19 with profound and multiple learning difficulties (PMLD). These units are aligned with the Northern Ireland Curriculum.

You can use them to enhance the learning experiences of this unique group of learners and deliver all aspects of the curriculum at a level appropriate to your learners' cognitive ability.

The Thematic Units include:

Activities

- These activities adopt a process-based interactive approach with the aim of best supporting learners in acquiring, practising and establishing the early skills of communication and active involvement in everyday experiences.

Resources

- printable information pages and worksheets for learners and/or teachers.
- whiteboard resources which can be used for display and some can be used interactively.
- music files in MP3 format which have been numbered as those included on the Thematic Units (PMLD) Music CD.

<https://ccea.org.uk/learning-resources/pml-d-sensory-thematic-units>

Sensory Story Collection

A collection of all the sensory stories published on inclusiveteach.com. A sensory story is one that serves to activate each of the senses to encourage engagement in a range of learning situations. There is a range from simple engagement to knowledge recall, memory, communication, vocabulary development, social skills, literacy, movement and so on. Each has a

different purpose. This may be to calm, to share experiences, purely to encourage joint attention or interaction.

<https://inclusiveteach.com/sensory-story-collection/>

PMLD Dance

Enriching lives with Dance for people living with PMLD. By artists for artists, the website brings together PMLD Dance Professionals to share approaches, knowledge and resources to enrich dance experiences for people living with Profound and Multiple Learning Disabilities. Together we explore, question, develop and inspire our practice - and each other - to ensure people with PMLD experience and enjoy dance regardless of the challenges that they face.

<https://pml-dance.org/home-1>

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COURSES, CONFERENCES AND EVENTS IN 2023

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

January		Title: 5-Day Intervenor Course (MSI) Date: 23-27 January Location: Ely, Cambs Provider: Highfield Ely Academy Contact: srowe@highfield.cambs.sch.uk
Title: Mindfulness Through the Breath and Body for People with Profound Disabilities Date: Starts 3 Jan 2023 (weekly sessions over 5 months) Provider: NAC Contact: julie@nacwellbeing.org https://learning.nacwellbeing.org/mindfulness/		Title: Intensive Interaction Date: 24 January Location: Online Provider: Concept Training Contact: info@concept-training.co.uk https://www.concept-training.co.uk/pml-training-courses/
Title: 5-Day Intervenor Course (MSI) Date: 9 – 13 January Location: Exeter Provider: In Focus Contact: mgarrett@InFocus-charity.org.uk Tel: 01392 454329		Title: 24-hour Postural Care from Cradle to Grave Date: 26 January – 9 March Location: online Provider: Born at the Right Time Limited / Simple Stuff Works Contact: admin@bornattherighttime.com https://www.bornattherighttime.com/disability-training/
Title: Developing the PMLD curriculum for learners aged 16-25 (Pts 1/2) Date: 12 January + 14 February Location: Online (zoom) Provider: Natspec Contact: transform@natspec.org.uk https://natspec.org.uk/events/developing-the-pml-curriculum-for-learners-aged-16-25-session-one-2/		Title: Sensory Learning: a guide for support staff with Richard Hirstwood & Carol Allen Date: 26 January Location: online Provider: Hirstwood Training Contact: lois@hirstwood.com https://hirstwood.com/virtual-courses/
Title: Parenting a Child with Complex Needs Workshop Date: 17 & 24 January Location: online: Provider: Born at the Right Time Ltd Contact: admin@bornattherighttime.com https://www.bornattherighttime.com/disability-training/		Title: PMLD-Developing Creativity through Music and Movement Date: 26 January Location: Online Provider: Concept Training Contact: info@concept-training.co.uk https://www.concept-training.co.uk/pml-training-courses/
Title: Communication and Co-production with Relatives and Carers Date: 18 January Location: online: Provider: Born at the Right Time Ltd Contact: admin@bornattherighttime.com https://www.bornattherighttime.com/disability-training/		Title: Technology to support sensory learning - with Richard Hirstwood & Carol Allen Date: 27 January Location: online Provider: Hirstwood Training Contact: lois@hirstwood.com https://hirstwood.com/virtual-courses/
Title: Fire Songs Date: Performances 20-22 January Location: The Lowry Theatre, Salford Provider: FROZEN LIGHT theatre company Contact: Lowry Box Office:0343 208 6000 https://thelowry.com/whats-on/frozen-light-fire-songs/		

February		Title: Date: Location: Provider: Contact	Rebound Therapy 9 -10 March Edinburgh ReboundTherapy.org info@reboundtherapy.org
Title: Date: Location: Provider: Contact	Rebound Therapy 6 - 7 February Devizes, Wiltshire ReboundTherapy.org info@reboundtherapy.org	Title: Date: Location: Provider: Contact	Equals National Conference – Different or Differentiated 10 March London Equals admin@equalsoffice.co.uk
Title: Date: Location: Provider: Contact	Engaging PMLD Learners - A Responsive Classroom 8 February Online Concept Training info@concept-training.co.uk https://www.concept-training.co.uk/pml-training-courses/	Title: Date: Location: Provider: Contact	Rebound Therapy 13 -14 March Pentre, South Wales ReboundTherapy.org info@reboundtherapy.org
Title: Date: Location: Provider: Contact	Sensory Topic Planning - with Richard Hirstwood & Carol Allen 9 February & 2 March (Pt 1&2) Online Hirstwood Training lois@hirstwood.com https://hirstwood.com/virtual-courses/	Title: Date: Location: Provider: Contact	The River performances 13 -31 March Bespoke by arrangement Bamboozle Theatre Company To register interest: jade@bamboozletheatre.co.uk
Title: Date: Location: Provider: Contact:	24-hour Postural Care: Hands on training for the postural care workforce 23 February & 23 March Online Born at the Right Time Limited / Simple Stuff Works admin@bornattherighttime.com	Title: Date: Location: Provider: Contact	Intensive Interaction 15 March Online Concept Training info@concept-training.co.uk
Title: Date: Location: Provider: Contact	24-hour Postural Care Family Course 23 February – 23 March Online Born at the Right Time Limited / Simple Stuff Works admin@bornattherighttime.com	Title: Date: Location: Provider: Contact:	Rebound Therapy 16 - 17 March Bromsgrove, West Midlands ReboundTherapy.org info@reboundtherapy.org
Title: Date: Location: Provider: Contact	Intensive Interaction 23 February Online Concept Training info@concept-training.co.uk	Title: Date: Location: Provider: Contact:	Intensive Interaction 23 March Redhill, Surrey Us in a Bus info@usinabus.org.uk
March		Title: Date: Location: Provider: Contact:	Conference: Celebrating past, present and future 23 March Betchworth, Surrey Us in a Bus https://usinabus.org.uk/conference-23-2/
Title: Date: Location: Provider: Contact	Understanding and responding to difficult behaviour- with Clive Smith 9 & 23 March (Pt 1&2) Online Hirstwood Training lois@hirstwood.com https://hirstwood.com/virtual-courses/	Title: Date: Location: Provider: Contact:	5-Day Intervenor Course (MSI) 27 - 31 March Cwmbran, Gwent Sensory & Communication Support Service sencom@torfaen.gov.uk

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

Title: Date: Location: Provider: Contact:	PMLD-Developing Creativity through Music and Movement 29 March Online Concept Training info@concept-training.co.uk https://www.concept-training.co.uk/pml-training-courses/
Title: Date: Location: Provider: Contact:	Engaging PMLD Learners - A Responsive Classroom 30 March Online Concept Training info@concept-training.co.uk https://www.concept-training.co.uk/pml-training-courses/
April	
Title: Date: Location: Provider: Contact:	The River Performances 17– 28 April Bespoke by arrangement Bamboozle Theatre Company To register interest: jade@bamboozletheatre.co.uk
Title: Date: Location: Provider: Contact:	Fire Songs Performances 25-26 April The Civic Theatre, Barnsley FROZEN LIGHT Theatre Co. Civic: 01226 327000
May 2023	
Title: Date: Location: Provider: Contact:	Fire Songs Norfolk & Norwich Festival Performances 27-28 May The Garage Theatre, Norwich FROZEN LIGHT Theatre Co. Festival Box Office: 01603 531800
Title: Date: Location: Provider: Contact:	The Lost Feather: A Sensory Storytelling Session 29 May – 16 July Touring Oily Cart To express interest: alison@oilycart.org.uk
July	
Title: Date: Location: Provider: Contact:	The 2023 Super Sensory Lexiconary! 13-14 July Birmingham The Sensory projects https://www.eventbrite.co.uk/o/the-sensory-projects-9788075245

<p>Us in a Bus (https://usinabus.org.uk/what-we-do/#training)</p> <p>Us in a Bus offers workshops on 'Intensive Interaction' run by Janet Gurney. For more information, including costs, please contact admin@usinabus.org.uk or telephone 01737 823310.</p> <p>Make Intensive Interaction part of people's daily lives. To discuss your specific needs contact Anne Laney: anne.laney@usinabus.org.uk.</p>
<p>The Sensory Projects (www.thesensoryprojects.co.uk/conferences-training)</p> <p>The Sensory Projects offer: In person training days, workshops and conference presentations. Online study courses and workshops. Live online training days, workshops and conference presentations. Consultancy services are also available.</p> <p>For online study opportunities visit The Sensory Projects Online College.</p>
<p>NAC (www.nacwellbeing.org)</p> <p>NAC provides online and in person courses and consultancy to support the emotional wellbeing of children and adults with severe and profound intellectual disabilities.</p> <p>Including: Trauma Promoting Emotional Wellbeing Emotional Regulation Depression and Low Mood Bereavement, Loss and Grief</p> <p>New course starts 3 January 2023, weekly over 5 months</p> <p>Mindfulness Through the Breath and Body for People with Profound Disabilities https://learning.nacwellbeing.org/mindfulness/</p> <p>Contact: julie@nacwellbeing.org</p>

Story Massage Programme (www.storymassage.co.uk)

Story Massage offers online training courses and easy to access resources. These are for those wishing to use the Story Massage Programme at home or work. You can study at your own pace. You have full access to the online course materials for 6 months.

Contact: 07899813659 or info@storymassage.co.uk

Pamis (<https://pamis.org.uk/services/training>)

Pamis offers face to face courses, events and other training and development opportunities for family, paid carers and practitioners.

Contact: fiona.harper@pamis.org.uk to book or make enquiries

Postural Care – Simple Stuff Works & Born at the right time
(<https://www.simplestuffworks.com/training>)

A range of opportunities and CPD accredited modules, including:
Introduction to 24-hour postural care (half day workshop)
24-hour postural care: Hands-on training for the workforce
24-Hour Postural Care: Getting to the Core of the Problem

Contact: admin@simplestuffworks.co.uk

Born at the Right Time (www.bornattherighttime.com)

For 2023, a host of new courses are being launched, from entirely on-line courses to be completed at your own pace to in-person advance practitioner events.
See website for more details

Hirstwood Training (<https://hirstwood.com>)

Range of online, on demand opportunities including:
Creating inspiring sensory classrooms
Sensory Impairment and Sensory Loss
Sensory Resources

Contact: lois@hirstwood.com

Learning Disabilities Speech and Language Therapy-HWHCT

Speech and Language Therapists in the Community Learning Disability Teams across the Herefordshire and Worcestershire NHS Health and Care Trust have developed some new, free training, in line with the RCSLT 'Eating, Drinking, Swallowing Competency Framework'.

Level 1 and 2 eating and drinking training is available to the general public through their FREE online e-learning - <https://www.hacw.nhs.uk/mealtime-matters>

For updates follow <https://www.facebook.com/LDSL.T.HW/>

EQUALS (<https://equals.co.uk/training-from-equals/>)

EQUALS provides FREE Online Training for Members covering a range of topics including: the Engagement Model of assessment, teaching learners with Profound & Multiple Learning Difficulties, and EQUALS Pre-Formal PMLD Curriculum

For further information please contact Paul Buskin at paul@equalsoffice.co.uk

PCPLD Network (palliative care for people with learning disabilities) (<https://www.pcpld.org/events> and conferences/)

PCPLD makes available free webinars as well as making past webinars available as recordings. They also offer podcasts.

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

Name of Subscriber:

Address:

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

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

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

I/we have set up a standing order for £ with our bank starting on

I /we have paid using PayPal through the PMLD Link website

Date:.....

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

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

Gift Aid Declaration	
Name of Charity:	PMLD LINK
Details of donor:	
Title	Forename(s)..... Surname.....
Home Address:.....	
.....	
..... Post Code:.....	
I want all subscriptions and donations that I make from the date of this declaration to treated as Gift Aid until further notice	
<i>You must pay an amount of Income Tax and/or Capital Gains Tax at least equal to the tax that the charity reclaims on your donations in the appropriate tax year (i.e 25p for each £1 you give on or after 6 April). If you are unsure whether your donations qualify for Gift Aid tax relief, refer to help sheet IR65 on the HMRC web site (www.hmrc.gov.uk)</i>	
Date

STANDING ORDER MANDATE (Send to *your* bank)

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

The sum of: £.....

Commencing: and thereafter annually until further notice

Account to be debited:

Account No.

Signature(s):

Date:

About Us

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

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

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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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