PMLD LINK
sharing ideas and information

Training and Development

Spring 2021

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Cover picture of Isaac Archibald and one of his support workers, Becky at PMLD Link's 2019 Raising the Bar conference. Sean Kelly photographer

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GUEST EDITORIAL

Training and Development

We are delighted to present this bumper issue on the theme of Training and Development. When we put out our call for submissions we didn't anticipate that we would receive articles which spoke to all of the issues we highlighted but we have done! Janet Gurney and Anne Laney, Verity Sowden, Sarah Clayton and Eleanor Gibson have written about the challenges and unexpected rewards of moving their training and development activities online. Catherine De Haas has written about her experiences of providing training and consultation in partnership with her daughter Johanna, and invites readers who may have done something similar to join a conversation about people with PMLD as trainers. Catherine's article chimes with Sandra Archibald, Becky Downey and Esme Brown's article about developing the team of workers who support Sandra's son Isaac. Sandra shows how good training and development can give workers 'the energy to care deeply'.

Two articles seek to invert – or subvert – traditional ideas of training in health and social care. Rachel Wright writes about the parent-led workshops training practitioners to work with rather than for families. Sheridan Forster writes on the Hanging Out Programme, which she calls 'the 'un-training approach to communication' and raises important questions about the role of culture in supporting engagement with people with PMLD. In another challenging article, based on a study of the use of multisensory rooms, Jo Grace unpicks the fascinating question of why some people may seem to have an instinct for how to work with people with PMLD (they 'get it') while others need more focused training and support.

Training for teachers and teaching assistants is another theme within the issue and we have four excellent articles which look at different aspects of this, including initial teacher training and training on the use of an assessment e-book (from Nancy Beesley, Rob Ashdown and Iain Chatwin, Jackie Saha and Neil Mullen).

As well as articles on training and development, this issue also includes updates on important current research studies – the Seldom Heard project and the Coronavirus and people with learning disabilities survey – as well as further inspiring articles showing how the Core and Essential Service Standards are being implemented in diverse areas of practice (from Gerald Wainwright, Julie Calveley, Sarah Hall and Martin Goodwin).

We would like to thank all of our contributors and look forward to continuing the conversation about training and development in future!

Guest Editors: Rachel Hughes, Annie Fergusson, Michael Fullerton and Rob Ashdown

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Training at a distance: In the Zoom instead of the room

Janet Gurney and Anne Laney

Us in a Bus has had to develop radically the way it delivers its training and other services during the pandemic. Here, Janet describes the development of on-line workshops and Anne describes how she has been developing the way Us in a Bus can continue to offer consultancy and mentoring in the practice of Intensive Interaction from a distance. They explore the advantages and disadvantages of using Zoom for training.

Janet Gurney writes:

Twenty years or so ago, Us in a Bus was grappling with the issue of how best to offer support staff a training workshop which could enable them to feel more confident and equipped to build relationships with the people they were supporting. We had been using Intensive Interaction for a decade by then; we knew that this approach was a wonderful way of engaging and connecting with people who found this a challenge because of a range of complex needs. But what was it that needed to be at the heart of a workshop in order for it to be of the most use to the people we wanted to attend it? My colleague at the time, Laura Blake, came up with the word "congruence"; it was a lightbulb moment and has been at the heart of how we have tried to offer and develop training ever since.

For us, congruence meant finding the link between what support staff were expected to do, and how they were supported themselves. As a rookie care worker in the 1980's I can remember being told to "Treat the people you support with respect and dignity" and silently wondering to myself "Yes of course. But how?" The feelings of inadequacy when trying to help someone do something they didn't want to do in the first place, when we didn't share a method of communication let alone a shared purpose, were real, and I'm pretty sure, not unique to me! So, if our training workshop was to help support staff feel more able to express their respect in their work, we needed to make sure we were expressing it through our training. The training principle we decided to use as our foundation was 'experiential learning' – broadly defined as the process of learning through experience and reflection.

Over the following 20 years, I've had the pleasure of meeting thousands of people (including family carers, teachers, support workers, personal assistants) on my 'Introduction to Intensive Interaction' workshop, sharing theory and practice, learning from each other, sharing encouragement, reflecting on what we've done and planning what to do next. At the heart of each workshop has been the intention to engage as genuinely as possible with as many participants as possible. And then, bang… here's Covid 19 and we can't deliver face-to-face training anymore.

I was dismayed by the prospect of delivering training on-line, and very resistant to giving it a go. But my good colleagues at Us in a Bus were impervious to my reluctance and together we looked at ways forward. Our incentive was the understanding that lockdown was having a disproportionate impact on the lives of people with learning disabilities and complex needs – people living in care homes, families with children unable to attend their school, teachers grappling with providing distance learning, early years outreach teams trying to reach out without being able to visit, etc..

So, I have continued to offer the 'Introduction to Intensive Interaction' workshop, through Zoom, pretty much in its original format but paying as much attention as possible to ensuring that the level of engagement is maintained. There are hurdles - 'reading the room' can be tricky; who am I 'losing'; who has got something to say but isn't confident about saying it; who doesn't agree but isn't saying so? All of that is a familiar part of face-to-face training too, of course, but on Zoom, the face is all we have! We miss the body language, the whisper, the glance. And then there are participants who choose not to turn on their cameras, sometimes for very good reasons (they don't have a camera), sometimes less so (they've popped out to do the shopping). It's really hard to include people who aren't 'there' (metaphorically and/or physically) and I have to sometimes consciously remind myself to reset my Respect button!

Getting group discussions going is also a challenge for the same reason – the micro relationships that can be nurtured in the training room are that much harder in the training Zoom and people are just a little slower at letting themselves relax into conversation. The Breakout Room button on Zoom has been a great help in getting those small conversations going that can feed into a group discussion. I've noticed I have to guard against the slide into lecturing rather than facilitating; if I am hearing too much of my own voice, I realise it's time to ask a question or have an impromptu mini-break.

Despite these differences, the feedback over the last 10 months has been amazingly encouraging; participants have consistently commented on how much more interactive the workshop was than they were expecting. Recent participants have had this to say:

Vicky Rose (SALT Assistant)

'I recently took part in the Us in a Bus online workshop for Intensive Interaction. Information was sent through with a link in plenty of time and written information and a video link attached to read and watch before the course.

The training was led in a very clear and precise way at a perfect pace to allow plenty of time for discussion and questions. It was so good to split into breakout rooms and have discussions with others from all over the country with a wealth of experience to share through their work in care homes, schools or parents of children and adults with communication difficulties. Being online did not hinder my learning or enjoyment of the course in any way as it was so well planned and executed.

Having recently started a job as a speech and language therapy assistant and due to Covid not being able to shadow fellow members of staff easily this course was absolutely invaluable to me. The course content gave me the foundation information that I needed to begin to support families through my job and has helped me to feel more confident to do this.'

Julia Brown

'The zoomed workshop was interesting, interactive and very practical so that I felt well equipped to go away and try things with my profoundly disabled brother who has ABI [acquired brain injury] and is diagnosed as minimally conscious. It gave me one of those lightbulb moments, that it was about learning to speak his language and pick up on the cues he is already giving. I realised that I had gone about it in a similar fashion to going abroad and just talking to everyone in English - but loud and slowly, expecting them to communicate in ways I can understand, instead of learning to speak some French, or whatever, and then being able to communicate in the same language, even if it's a bit stumbling. I felt as though I was taken right back to basics with a clear path to follow. Very exciting.

It didn't matter that the group was all on zoom - we still had some great chats and I felt very supported and part of a bigger group, not just sitting there on my own.
My brother seems to respond well to the things we have tried and we have seen increased vocalisation - obviously everything has been curtailed with Covid, but as we emerge I am heading right back there to start again.

Anne Laney writes:

As Janet has expressed, the fact that face to face contact in almost any scenario has not been possible during the Covid 19 pandemic, has created high levels of anxiety in all areas of society. Baroness Sheila Hollins in her speech to the House of Lords on 23rd April 2020 highlighted this and stated that:

"People with learning disabilities will need an increase in support to recover their confidence, meaningful occupation and friendships when lockdown ends. Can the Minister say what will be done to reverse the harm done by the loss of familiar support during this period, which for many will have been complicated further by other traumatic losses?"

Recognising that potentially, now more than ever, people with profound and multiple learning disabilities and complex needs may be at risk of social isolation and reduced well-being has contributed to the urgency of our thinking about how mentoring and consultancy in Intensive Interaction can be delivered via remote services. (Us in a Bus have incidentally, worked hard to resume some face to face and zoom sessions, our bread and butter income stream, and details of how we have embraced Zoom in this capacity are available on the www.usinabus.org.uk website).

We have continued to receive enquiries for input from organisations and individuals. It has always been an expectation before agreeing any longer term mentoring, that participants have an understanding of the theory of Intensive Interaction (have attended one of Janet's training workshops) and have been beginning to explore how it can enhance the relationships they have with those they are supporting. We have tentatively agreed proposals for face to face delivery "at some point in the future". This does not however address the fact that support is needed now. People are struggling. The necessity for alternatives to community participation, activities and visitors is acute and unless attended to may result in untold, difficult to reverse damage.

When broken down, the key points our mentoring and consultancy services provide are:

- Opportunity for us to guide Intensive Interaction practice
- Trouble shooting and situational unpicking
- Recommendations and advice regarding setting up supportive systems within teams.
- Confidence building and demonstration.
- Motivation and enthusiasm.

Biting the bullet, we have tentatively held several pilot Zoom mentoring sessions, to test how well the technology supports what is, or perhaps has been, a process dependent on demonstration and observation of person to person interactions. We have learned the following:

- Preparation is vital. Unless attendees have explored an interaction and have either positive moments they want to share, or questions that have arisen, conversation may end up generalised and unfocused. There is a place for this sort of support too, but best use of time (and therefore money) requires discussion within clear boundaries.
- It is easy, possibly easier for attendees who are slightly less confident in their practise to engage with us on Zoom. Perhaps because there is less pressure. Perhaps because of how our emotions and levels of nervousness are connected to how we process sensory input. We are increasingly aware of how this impacts those we support. It would be true to say it is likely to impact us all in some way. A face on a screen may be less intimidating than an in person presence.
- When attendees come with specific questions connected to experiences they have had, the discussion is rewarding and effective in trouble shooting and unpicking.
- It is more difficult for us, as mentors to “read” those we are mentoring. Images on screen are small and distant. Sound is often poor. We need to ask more questions about the mentees thoughts and feelings to get a clearer sense of what is going on.
- The technology does not allow quick, spontaneous, two-way interaction and is often stilted. For this reason, it is less easy to comment on “live” interactions. This is not unsurmountable but requires recognition that any “in the moment” guidance is not possible.
- Enthusiastic and motivational conversation is easy and may constitute the most positive aspect of delivery of mentoring in this way.
- The necessity for follow up sessions must be built into proposals and delivery. There is a tendency for Zoom session invitations to become overlooked and the importance of proposals stressing consistency and commitment from mentees and organisations is paramount. Although a flexible technology, remote delivery is open to being unintentionally abused. Care must be taken to ensure the professionalism of all aspects are maintained.
- Provision of questions or video by attendees/ mentees prior to the session, makes best use of time and even greater use of expertise of mentors.

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The congruence so fundamental to the ethos of Us in a Bus and described by Janet is equally relevant for the mentoring services we offer. The process of ensuring this is ongoing. Balancing the requirements of support teams learning to use Intensive Interaction to deepen the relationships they have with those they support, and the responsibilities of organisations to support those team members is always a craggy path, and one that during face to face mentoring we devote considerable time to. Exploring how formal Feedback constitutes part of this support process is something we consider vital to the total mentoring “package” and which we hope will translate to remote discussion with ease.

Recognising that these slightly altered services are of value, and therefore potential income generators, is important. The knowledge and experience behind their delivery is not lessened because the method of delivery is different. Balancing the elements of this has been a challenge, but one that we are confident the outcome of will enable us to continue to support as many people as possible to explore the enjoyment and effectiveness of using Intensive Interaction in this way.

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For details about on-line workshops (contact Janet at janet@jg-training.co.uk or visit http://usinabus.org.uk/events/book-on-a-workshop/)

Training practitioners to work with rather than for families

Rachel Wright

In the last year, the country has been turned on its head. Many things we once thought were important are no longer a priority. Our values have been honed, our world has shrunk, and we’ve all got used to living in a different way; whether it is wearing a facemask to pop into Sainsbury’s, infection control procedures at school, therapy sessions over Zoom or using our newfound lingo such as social distancing, isolation and PPE. It seems everyone on the planet has had a glimpse of the transformation that occurs in the life of a family who loves someone with profound and multiple learning difficulties.

When my eldest son was born my life went off on a completely different trajectory – and not one I had chosen. I started using clinical jargon as a mother tongue. As a nurse I knew the terms but now I was using them about my son in our kitchen. Our world shrank to miles from the nearest medical establishment, and it was the professionals around us who controlled our world with their life-changing decisions.

In those early months as a parent, I very quickly found a gap existed between the ‘parent’ me and the ‘nurse’ me. In the intensive therapy unit watching my son not breathe I glanced fearfully at the monitors, knowing what they meant (silencing alarms when nurses didn’t come). I noticed how different nurses spoke to my husband and I when they knew he was a doctor and I a nurse. It wasn’t so much that they used more medical jargon – although that did happen – it was the difference between being spoken at and worked with. It is a pattern I continue to recognise.

When I published my memoir, ‘The Skies I’m Under’, I was surprised by the response from professionals who simply said they had no idea what carers go through behind closed doors. I guess it shouldn’t have been a surprise because, before my son was born, I had no idea either. When the stories of families land on the ears of practitioners, eyes and hearts appear to be physically opened to a different reality. No matter how much these stories throb with the heartbeat of our lives, they never quite give justice to the reality we live. However, after a recent course on ‘Communication and co-production with relatives and carers’, one delegate commented, “You have changed my viewpoint and practice from this moment forward.”

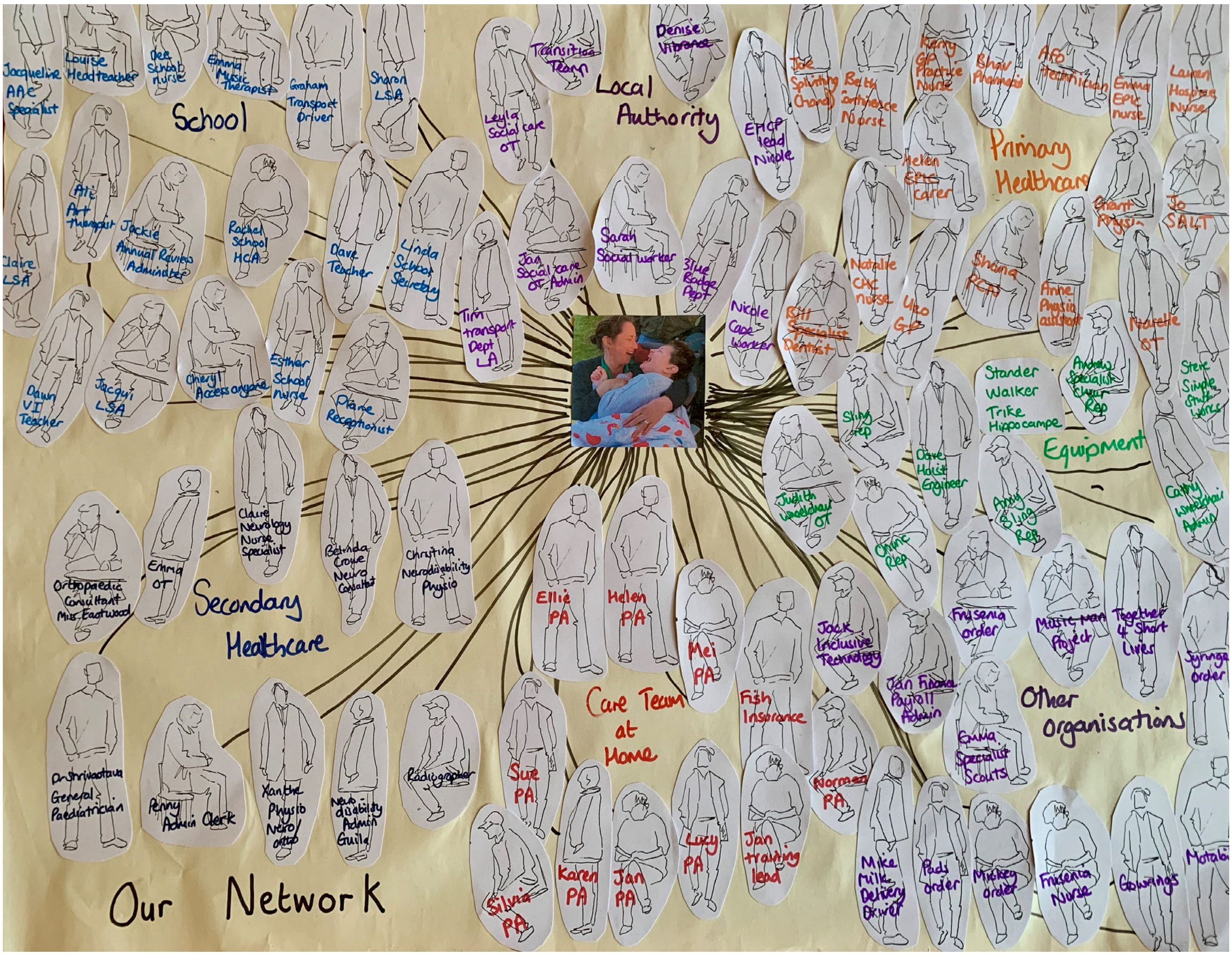
Practitioners might be an expert in their field, top of their game and the best in the business but the single most important thing for the parent juggling to care for someone with profound and multiple learning difficulties is the way those practitioners communicate and work with them.

In ‘Born at the Right Time’ communication and co-production training, we use the term ‘vulnerability labyrinth’ to describe the early experience of parents of children with complex needs. It’s a way of defining what happens when a life-changing trauma occurs; whether it is a diagnosis, accident or birth. Firstly, you find yourself in the eye of a storm with everything happening around you. The only option you have is to keep putting one foot in front of the other, gleaning whispers of hope from the quiet words of professionals uttered in busy corridors. I’ve been part of that storm as a nurse in a resuscitation room and I’ve watched it unfold as my husband gives mouth to mouth to our son while I call 999.

Then comes the invasion. Initially, it’s in the acute setting as medics rush around but as the dust settles in swoop the multi-disciplinary team with appointments, therapies and suggestions. It can even permeate as far as your neighbour’s hairdresser’s nephew who read an article in the Daily Mail and has some really useful advice. But what all this leads to is a vulnerability labyrinth experienced by carers who no longer feel in control of their family’s lives. The vulnerability labyrinth is built on the language, systems and power imbalance of professionals and policies which all contribute to relatives and carers feeling powerless and isolated.

As a parent carer I am placed at the centre of a network of professionals. Having sat down one day last summer and worked out exactly how many people that included, I can tell you it is more than eighty practitioners, professionals, therapists, administrative staff and engineers.

This image on page 6 depicts exactly why I firmly believe that training practitioners in communicating and working well with families is the single most powerful training they can experience. Every single practitioner who sees a parent differently, creates a more positive connection and wants to really hear the family’s priorities and perspective, and does so with the numerous families they work with.



Communication and co-production training acknowledges the vast network of already established relationships and focuses on strengthening and oiling each one with connection and collaboration. Making that network of people work well with families of people with profound and multiple learning disabilities makes a difference to their lives every day – several times a day.

Imagine the impact if every time a parent picked up the phone, read an email or spoke to a professional they felt that they had been heard and respected and as though everyone was on the same team. And the same is true vice versa. Communication is a two-way street which is why 'Born at the Right Time' provides professional training and parent workshops helping parents understand their own story and emotional landscape while helping them connect with others – including professionals. It would turn the world of families and professionals upside down – and for the better.

Talk of the incessant fighting carers need to do or the necessity to be a 'warrior parent' would be redundant language. The time and energy spent on driving stakes in the ground, handling conflicts and going to tribunals, could instead be spent working together to bring about the best kind of life for people with profound and multiple learning difficulties. Now that would be an exciting world.

In every walk of life, we are often tempted to present a single version of ourselves and we only see a snapshot of the lives of families of people with profound and multiple learning disabilities. Stepping back and seeing the full story of those who love people with profound and multiple learning difficulties is a deep dive under the surface of the iceberg. 'Born at the Right Time' training goes further though; by using research and best practice it equips practitioners with the strategies and practical steps to work with rather than for families. It is the magical combination of people's stories and research data which has the potential to drive life-giving, transformational change.

Contact Details

Rachel Wright – Founder of 'Born at the Right Time', author, qualified nurse, and parent.

For more information on 'Born at the Right Time' training visit www.bornattherighttime.com, email admin@bornattherighttime.com or call 01702 963019.

Are other families or professionals working alongside people with PMLD to train staff?

Catherine de Haas

I would like to write this article as the start of a conversation with the readers of PMLD Link and their networks. I used to go to the Social History of Learning Disability (SHLD) Conference at the Open University in Milton Keynes, with my daughter Johanna. The conference attracts a mix of family members, advocates, practitioners, academics, from undergraduates to professors and people with learning disabilities, many of whom have experience as working as co researchers, within the fields of inclusive research or life story work.

Johanna had extremely severe cerebral palsy. She had epilepsy, visual impairment, learning difficulties and was a wheelchair user. We both really enjoyed going to the conference and went for a few years together. We had experience of doing presentations together before we went for the first time. We had joined Flo Longhorn, as guest speakers at a number of her training days (Note 1). We were motivated to try going to the SHLD conference, because we were interested in the theme, which was friendships and people with learning disabilities. We really wanted to share our experiences of making friendships in our community.

When we got to the conference we spoke together - with Johanna interjecting her point of view or reactions to my voice, with facial expression, body movements and vocalisations. I felt that in common with many people with physical disabilities Johanna's understanding of conversation exceeded her ability to express herself. I have very limited evidence of this though. I argued a few times with professionals that my feeling that she had some verbal understanding wasn't just wishful thinking. Sometimes she laughed first at a verbal joke. It was something that we didn't intend to be funny but when she pointed it out, with her own amusement, the rest of us joined in with laughter. However, people with PMLD are subject to other people's narratives or stories they make up about them. I suspect that there was a variety of responses to her part of our presentations. I once watched another person with PMLD use facilitated communication to speak. I felt he was being attributed thoughts that weren't his own, however I didn't know him, so was I showing my own prejudices? These experiences made me careful not to interpret Johanna's reactions as we were speaking. I left the audience to draw their own conclusions about her contribution.

Although we were nervous about speaking, the audience were so lovely. The delegates could not have been kinder when we finished talking - they came and made friends with us. We felt we had found a new community of people who shared our interests. Some of those friendships continue to thrive. The Open University and the other delegates did all that they could to make the experience accessible to us too. People understood that at times my co presenter, Johanna, might not be able to take part due to an event like a severe epileptic fit.

Our involvement with the SHLD conference led to Johanna and I being invited to take part in the inclusive archive project with Sue Ledger and Liz Tilley, of the Open University, and to the contribution that we made to the book 'Belonging for People with Profound Intellectual and Multiple Disabilities' (Nind and Strnadova, 2020). In a chapter in this book we describe, using multiple voices, the experience of belonging in our community. In a later chapter, Sue, Liz and I build a case for why participation in history and heritage matters to people like Johanna.

Sadly, we are no longer able to work as co-presenters. Johanna died in 2019. Looking back, I am very proud that we were able to have these experiences together. As a team we were able to alter the way our audience regarded PMLD, we opened up possibilities.

I said I wanted to write this article as the start of a

conversation, as I believe that there are other people who are able to present as a team to an audience. Indeed, there may be teams of presenters elsewhere. Who are you and what are your experiences of presenting together? What support would you need to be able to tell your story to other people? Maybe you have already given your story to the 'Surviving through Story' website (https://www.survivingthroughstory.com/) which tells the stories of people with learning disability during the pandemic, or the 'Open Story Tellers website (www.openstorytellers.org.uk/), which is a community arts charity which supports people with learning disabilities and autism to tell stories?

Sadly, the SHLD Conference is unable to go ahead this year because of the pandemic. However, the 'Surviving through Story' website is a place where families could experiment with presenting in pre-recorded format (either video, or a written piece or through photos, art and so on). The Open Story Tellers website has a Thalis for Tales fundraiser which asks for people to send their lockdown stories on a postcard. They would absolutely welcome people getting in touch with them via email or their Facebook page. In addition, they are just about to launch tickets for their upcoming online show where the storytellers are telling the true story of a young man with learning disabilities who lived in the 1700's - Peter the Wild Boy, as a theatrical performance. This disability history story may be of interest to you (Note 2).

I have recently been accepted by the University of Southampton to study a PhD to explore belonging with young people with PMLD. The focus of my research will be to discover what will happen if families, alongside their children with PMLD, are given the opportunity to:

- share stories about belonging with each other
- discuss barriers to belonging
- discuss strategies that have helped them to form links to their community
- be asked about their preferences and needs with respect to expanding a sense of belonging to their own communities
- and were asked what might help this to happen?

In the meantime, before my period of formal study starts, I will be interested know what other families are doing to inform professionals and their communities about their life experiences. Please let me know what you are doing or could do with support via the editors of PMLD LINK.

Contact Details

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References

Nind, M. and Strnadova, I. (2020) (eds) *Belonging for People with Profound Intellectual and Multiple Disabilities*: *Pushing the Boundaries of Inclusion*. Abingdon: Routledge

Further Information

1. Flo's books are now available as a free download on line https://sites.google.com/view/flolonghornsensorybooksfreedow/home

2. Trailer of Peter the Wild Boy. - https://www.youtube.com/watch?v=hZiu2zdqqQs&feature=youtu.be

Why MOVE is needed now more than ever: ensuring disabled children aren't left behind in the wake of COVID-19

Verity Sowden

The MOVE Programme (MOVE) is an activity-based framework that is used to teach the skills of head control, sitting, standing, walking and transitioning between. MOVE can be used with anyone who has not yet learned these skills, regardless of age or disability, but is most commonly used with young people with PMLD. MOVE Europe is the charity that coordinates MOVE across the UK, and every year we train schools and therapy teams to deliver MOVE for the disabled individuals they support.

2020 has been no different despite all challenges. COVID-19 has had a significant impact on young people with complex needs, so it has been a priority for MOVE Europe to adapt our services for online delivery. This has ensured that we not only reach more children who could benefit, but also ensure that the settings delivering MOVE and the young people using it continue to achieve great outcomes.

Why we're needed

MOVE is currently used in 137 schools across the UK, enabling 1,137 disabled young people to improve their independent mobility skills; however evidence obtained from our schools shows that the disruption that COVID-19 has caused to the school routine, therapy support and medical care has resulted in many disabled young people plateauing or regressing in their physical skills. 93% of our schools have reported that multiple lockdowns have negatively affected their students' mobility, and this is reflected in our latest figures. In 2019, 818 children using MOVE gained or maintained mobility skills and 48 children learned to walk independently, whereas in 2020 those figures dropped dramatically to 549 and 24 respectively.

We know from talking to education and physiotherapy professionals across the UK that MOVE will be an important tool to overcome the impact of COVID-19. MOVE is a highly effective, holistic and collaborative programme which has helped to bridge therapy and education gaps, and will support children to recover, and continue improving, their mobility skills going forwards:

"For pupils who need postural management and a physical activity programme, lack of school routine has had wider implications…The MOVE Programme will be vital in helping them to regain movement skills before it is too late."

Neuro Physiotherapist, South Wales

"MOVE will be so important in schools going forwards as a lot of our children and families have been shielding for many months…Children, parents and class teams need to be reminded of what they can do and what their movement potential is, so they continue to build, not lose, their skills."

Teacher and Middle Leader, London.

How we've adapted

Looking back at March 2020, our services looked very different to how they do in March 2021. At that time, we routinely travelled throughout the UK delivering our training and support services in-person. Because of this, when COVID-19 became a serious public health issue and we were faced with the prospect of school closures, redeployment of physiotherapy teams, and our team working from home indefinitely, we were concerned about the negative impacts this would have on thousands of disabled children. Every change and adaptation to MOVE Europe's training and support services has been made with these young people at the forefront of our minds.

When COVID-19 hit, we pivoted quickly and moved our immediate focus to support services. Knowing that some education and therapy professionals would be spending less time in school, we utilised this break in routine to provide development opportunities and a wealth of home resources free of charge. Throughout the first national lockdown, we delivered a series of webinars based around areas of MOVE that our schools told us they needed support with, which enabled them to continue developing their MOVE knowledge and provision despite not being in school. 314 people attended these webinars from schools across the UK and responded very positively:

"It generated a lot of chat between us and our MOVE Action Plan has already been amended in response."

Hob Moor Oaks School, York

"Thank you for all the things you are doing. It's nice to know someone is there for us right now."
Oaklands School, Edinburgh

In addition to forging new means to support our schools virtually, we adapted our training courses to be effective when delivered online. This has been an immensely positive change as it has enabled schools to continue accessing training despite COVID-19 restrictions and has also mitigated barriers such as staff release time and travel costs. Online delivery has ensured that we continue to have a positive impact on the lives of disabled children already using MOVE, as well as reach more young people who could benefit. Since the pandemic began, 248 professionals from 50 organisations have accessed our online courses, and have given us great feedback:

"What a brilliant start to our introduction to the MOVE family! Absolutely fantastic! Can't wait for our next session!"
St Giles School, Nottingham

"The course was delivered well, and I feel the programme will be of benefit to many of our students in the future."
Icknield School, Andover

By developing a more comprehensive support offering and the option of online training, we have opened up more avenues through which we can make MOVE accessible to schools, which will result in improved MOVE provision and ultimately better outcomes for the young people using MOVE.

Going forwards

2020 has been a steep learning curve but has ensured that MOVE Europe continues to meet the needs of MOVE Member schools and ensures that disabled young people continue accessing opportunities to reach their full potential. We are proud of the way we have adapted every single one of our services and, while we are looking forward to the day when we can start visiting schools again, online delivery will remain a key method for us to continue our mission: to enable disabled people to gain independent mobility through the use of the MOVE Programme.

This mission has never felt timelier than it does now. COVID-19 has had a significant negative impact on young people with complex needs, and they now need support to regain skills and continue making progress going forwards. MOVE will be a vital tool to support this recovery, which is why we've launched our 'Recover with MOVE campaign'. Add your voice to our campaign and help us spread the word – just visit our social media or website and share our content with the hashtag #RecoverWithMOVE!

If you want to know more about MOVE and how it is used to support the development of independent mobility, please contact us to join an upcoming free 'Introduction to MOVE' webinar. We'd love to hear from you!

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Training in the new world: when hands on suddenly became hands off!

Sarah Clayton

The past 12 months have been somewhat rocky, both personally and professionally. As we begin to see light at the end of the tunnel, in the shape of vaccine wielding nurses and pharmacists, I wanted to reflect on the changes we have seen as an equipment supplier and CPD accredited training provider, which of the changes will stay and how we might look to support people in the future.

As an organisation we specialise in the development and delivery of postural care training. We help people to understand why a person might be vulnerable to gravity if they find it difficult to change position themselves. We also provide night time positioning equipment. Prior to Covid we had a team of people on the road taking equipment from house to house, school to school, care home to care home. The perfect virus vectors, it would seem.

As a parent of a clinically vulnerable young person I was very aware of the potential for harm in the way we and other providers were working. The risks posed travelling from place to place seemed too much. Not only were our customers depending on us to find an alternative way of providing our support, our team of fantastic people risked their livelihoods if we couldn't find a way forward. Above all we needed to keep everyone safe – customers and staff alike.

Before the Coronavirus pandemic we had been successfully using a secure, GDPR compliant telehealth system to support our overseas clients in assessment, set up and review of their equipment. It became apparent as Coronavirus took hold that this system would be ideal for supporting our customers in the UK. Due to the vulnerable nature of our customers, and to protect our staff, we made a decision long before lockdown to stop our face to face visits and use the telehealth system. We work in partnership with talented, dedicated therapists who can be present with the person being assessed if needed and who have access to their own assessment kits. The feedback we have had has been astonishing: the whole experience is less intrusive for families; the assessment takes a shorter amount of time; it's more convenient; the appointments can be arranged in a more timely manner; and the person is more relaxed with fewer unfamiliar people around them.

The telehealth system has resulted in a significant reduction in the number of equipment returns we see. This is due to us being able to support people before a molehill becomes a mountain – within minutes people can access specialist support. We have also calculated that we have reduced our carbon footprint by an incredible 4 tonnes a year! This method of assessment will be a permanent feature for us as an equipment provider and we hope to increase the number of assessors available in the near future in order to make the process even more accessible. Mortality rates of people with disability speak for themselves in terms of the vulnerability of this group. 6 out of every 10 people dying with Covid have a disability with death rates for people with learning disabilities 30 times higher in the 18 -34 age group (Public Health England, 2020). We intend to do all we can to minimise any unnecessary risk.

Whilst the equipment side of our organisation underwent seismic change it was also very important to us that we ensured our customers had access to our CPD accredited training. We quickly honed our webinar creating skills and signed our fellow lockdown bubble members (our children) up for starring roles. We now have an online suite of videos tackling 'Complex Care in Lockdown' which will remain online for people to access whenever they need to. They were created with families in mind and we hope they provide access to information to build confidence and language to advocate well for their loved one's postural care.

Over the years we have developed some fantastic relationships with leading experts in our industry – it was time to start calling in some favours! We were able to host webinars with leading seating experts such as Gail Russell and Sharon Sutherland which proved to be extremely popular as well as webinars on how to stay active with Special Olympics' physiotherapist Alistair Beverley. It has been fantastic to see the uptake of these webinars and to see organisations such as WellChild and the Disabled Children's Partnership engaging with them.

We have been contacted by schools who have used the videos as part of staff training, even one who has been running family workshops and discussions based on specific videos. In addition to pre-recorded content we have been able to offer live one to one sessions with families and schools – the time we save in our cars has enabled us to reach more people more often and is something we are going to continue to work to provide.

As a training provider and equipment supplier we recognise that not everything can be done remotely. The question we have been asking ourselves is WHO needs to provide the hands on assessment or training directly with people and their families. The answer we came to? It needs to be the clinicians closest to the person, who know them well, with our efficient and effective support every step of the way.

Contact Details

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References

Public Health England (2020) *Covid 19 Deaths of people identified as having learning disabilities.* London: Public Health England. Available at https://www.gov.uk/government/publications/covid-19-deaths-of-people-with-learning-disabilities. Accessed on 1st April 2021.

Further Information

Simple Stuff Works Associates, an award-winning organisation providing therapeutic positioning equipment for children and adults as well as CPD accredited training across the UK and internationally.

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Not Keeping Our Distance

Sandra Archibald, Becky Downey and Esme Brown

Professional distance was hailed as one of the key attributes of people management when I worked in a local authority. A certain amount of ‘professional distance’ between managers and the people they manage is necessary to ensure relationships do not stray into the personal, as this makes managing expectations and performance difficult. I applaud this idea as I make my way pyjama-clad to the door, making sure not to look in the mirror. Opening it I stare steadily at the young man dripping in the rain. “Where’s your coat?” I scold. In our house the boundaries easily blur when the work in question is caring for our vulnerable son and the worker in question is walking in on a family barely awake.

Our family has been managing a team of workers for twelve years. Isaac, my 24-year-old son, will always need very high levels of support. He lives with his parents, an assortment of animals (he takes little notice of) and his 17-year-old sister with whom he shares a love of musicals.

The workers care for Isaac most days, but also support me with my additional responsibilities; managing resources, Human Resources & policy development, recruitment, mentoring, communication development, research, and protocol for instance. Our family cannot do that on our own; we are already busy trying to earn money and caring for our offspring. It is not a choice that we would have wanted to make manging a team around our son, but the other options were more insupportable.

The COVID crisis has, of course, complicated all our lives. We have suspended recruitment to minimise risk and relied on our small team more than ever. They have rallied to ensure we were supported. They have stopped using public transport, become cyclists and walkers and have sacrificed indoor socialising with friends and family outside our little bubble for almost a year.

There was the terrible moment when in spite of all our precautions, the alert came: ‘I’ve tested positive for Covid, I’m sorry’. My stomach plummeted and the next four days I existed in a haze. Just days past we (the whole team) had huddled together, overheated by the wood stove, laughing at my clumsy attempt at gaming. We closed our door and sent the workers home to wait. From the outside a worker took hold of the reigns, enacted our recently formed Covid policy and maintained daily contact with us all. The relief was visceral as first one then a second worker tested negative; and the glimmer of hope turned to fireworks as some 4 days later, the family were also in the clear. Managing over-worked and stressed staff as an over-worked and stressed parent of a vulnerable person during a crisis is almost undoable; we managed because of those pre-existing relationships created in the absence of professional distance.

The people we recruit are essential to our functioning as a family and we do look for people with particular attributes. Workers are supporting not only Isaac, but doing so as part of the family, adapting to its style, its rhythms. It's critical the people we employ have a value base similar to ours in which Isaac's experiences, wellbeing and feelings are as important as their own - without which all else will fail. Practical skills such as personal care, moving and handling or medication are easily taught, skills such as empathy, responsibility, curious and flexible minds, are not.

Finding people who fit this description is difficult and can't be ascertained through interviews alone. It is not always, nor most often about experience. So long as applicants demonstrate an ability to reflect, develop and engage enthusiastically with Isaac there is potential. However, we do apply process to this; job descriptions, person specifications, interview questions, probation periods and 'the hunch' are crucial in finding these people. Sometimes though a decision makes itself and is even a little comic. One young applicant (claiming experience), on being introduced to Isaac, pressed him into the wall and looked on terrified. Isaac acknowledged his presence with a brief sideward flick of his eye and paused not at all in his deep drone as he clapped excitedly at something on the TV.

We invest a lot in team development because the difference that a trained and engaged team make to Isaac's wellbeing is substantial. This includes practical training but also training in intensive interaction and sensory activities. Our current team have all achieved a Level 3 qualification in PMLD and are involved in consultations with professionals. It is important that while the team is with us, they are supported to develop their skills and feel passionate and inspired by the work. This is where the energy to care deeply, comes from.

The team would not be able to appropriately support Isaac without such training. It takes a lot of effort to keep consistent quality in a care team with continuous turnover. It is exhausting. Some flexibility in the type of support we buy in might go some way to reducing some of the load, especially in managing a team. When it works, we all feel we are part of something purposeful, progressive and rewarding but it is all so precarious.

Having a trained team invested in finding creative ways to support Isaac's development has made a huge impact on him. Resurrecting Isaac's ability to sign, has excited us. As a two-year-old Isaac, signed drink to me in a dark sensory room, having been reluctant to use it generally. I assume he thought I needed a little more help in the dark. Over the years in school he stopped signing, most likely due to lack of consistency. In the past few years, having finally left formal education, he has been living with his family who employ workers to deliver care and a bespoke programme. He has regained these skills and built upon them. This is only possible through consistent hard work and consulting talented professionals such as Sarah Hall (Willows Sensory Service) and Rosie Rushton (Big Top Musical Adventures and Melody), to whom we are grateful. Turnover of workers is high, three years on average, though some last much longer, a drop in quality and burn out are unwelcome realities of such close working. Progress can unravel all too quickly, so even as we enjoy the time when a team is good, it is tinged with apprehension of having to start all over again.

The strength of the relationships Isaac has with his workers is something strangers pick up on, often assuming we are all related "Is he your brother?" people ask as they travel on the bus or sit down in a café (pre Covid!), never mind the varied ethnicities. In a way this is about the type of people we employ and how we have trained them, but it is also because Isaac draws people to him. During introductions to potential new workers, Isaac will do his own assessment (the negativity of the fearful applicant above is rare). Isaac reacts very positively to people who want to communicate with him. As the applicant greeted him smiling and sat eagerly in the chair beside him, she needed no prompt from us to take the hand he offered. He turned to face her so he could better take her in, they locked eyes smiling broadly and we knew we were looking at our new team member.

Workers and Isaac's family bounce off each other, celebrate our birthdays together, help each other out when need arises, in work or outside of it. We feed off each other's energy to keep pushing forward, in Isaac's development and in our own.

The insufficient career structure, lack of professional recognition and intensity of the job all contribute to high turnover of staff. The departure of a good worker is a painful event for everyone and there aren't currently any training or discourse for either party, on how to manage this.

Workers do leave Isaac with not only brilliant professional development opportunities but a particular perspective on care and how a family and their vulnerable person really should be supported and respected.

We are interested in building a community with other families in which we can share experiences and resources such as workers and training. Please email us on acollectivecare@gmail.com if you are interested in discussing this (or anything really) with us.

Contact Details

Sandra is a behaviour expert who worked in youth services specialising in play, equality, and disabilities. Sandra is Isaac's mother and she set up a care team to help care for Isaac in the family home.

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For blogs go to: https://acollectivecare.wordpress.com/

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HOP Part 3: The untraining approach?

Sheridan Forster

HOP stands for Hanging Out Program. It stands for making a decision to give a person 10 minutes of your total attention and making short notes of what happened in that time.

On hearing that the theme of this edition's PMLD-LINK was to be training, I had to really stop and think. You see, HOP, for me, was a decision to not train people. It was a paradigm shift: the core problem was not the skills or ability of disability support workers (or others) to engage but was the culture that discouraged sitting down and engaging with people.

"Do you still spend that nice time together?" I asked the research participant support worker. "When the work is finished", she casually replied. Everything from that research project (Forster and Iacono, 2008) was telling me these support workers knew how to interact, they knew what worked and what the person responded to; but they felt that they were not allowed to do what worked and couldn't celebrate meaningful interaction. The support workers told me about "just mucking around," the lady with a disability inquisitively scratching the surface of handbags, playing on the floor together, and sharing quiz show theme tunes. But they also told me of "having to pull their socks up if managers came in" (i.e. stop playing), having pressure to be 'age-appropriate,' being discouraged from any attachment because they were "just staff". Essentially, they said that engaging with the person was full of dilemmas, some written into policy, but most, etched into the culture of service through the precedence of previous workers or the agenda of current management.

Many of these dilemmas for support workers of adults with PMLD have been described by the researchers Antaki, Finlay, and Walton (Antaki, Crompton, Walton, and Finlay, 2016; Finlay, Antaki and Walton, 2008; Finlay, Antaki, Walton and Stribling, 2008; Walton, Antaki and Finlay, 2020). What is ultimately empowering for the person with PMLD, and how do you reconcile what is needed in interactions when this can be very different from the typical rules of engagement?

Reading many other research studies about interactions with people with PMLD, I read reports of low rates of engagement or overly high level of speech complexity of support workers. The resultant assumption was that staff lacked the knowledge to do the right thing, and subsequently the solution suggested by researchers was to train them. The small number of intervention studies of staff training demonstrated small, positive changes in staff behaviour, but these studies were short term, placing questions whether sustained change had occurred, and the degree to which the staff changes resulted in change for the people with PMLD.

But what if the issue was not knowledge (first and foremost) but culture? And there, HOP was born. HOP was an attempt to change the culture to say, "spending time with the person with a disability is not an optional extra – it must happen" and "we will attune and celebrate the small things that the person does in these interactions," because this is what quality of life is about.

Since developing and seeing HOP work in 2007 through a little booklet that most anyone can read and understand (Forster, 2008), I have developed a 90-minute workshop to enhance HOP. Colleagues in Finland also run HOP workshops. But the aim of these workshops is not to teach theory or what to do. In the workshop, through HOP role plays with participants being the person with a disability and the support worker, participants share and explore what feels like it works in each role. They share what felt comforting and uncomfortable, and unpack the issues that may arise relating to engage. They safely explore the barriers, the ethical dilemmas, instead of avoiding the issues. Avoiding the issues of engagement, too often, results in avoiding interaction with the person with a disability for fear of being perceived to be doing the wrong thing or self-consciousness.

HOP workshops are as much about what each participant shares about their experience and issues, than being about what the workshop facilitator can bring in terms of best practice and theory to contextualise the lived experience.

HOP can be done with or without the workshop. No expertise is needed to commit to spending 10 minutes paying attention to a person with PMLD and write down reflections. These cumulative 10 minutes may however contribute to a developing expertise in being that person's partner; to being a skilful disability support worker.

I am sure there will be many great training ideas shared in this edition of PMLD Link. Some issues are well-addressed by education. I also know that HOP may be equally critiqued in lacking research to support its efficacy for long-term change. But sometimes issues require a flip of the coin, a re-examination of where the breakdowns are occurring, and a repositioning of solution.

HOP, a commitment to engagement and reflection, is perhaps the un-training approach to communication. It asks interaction partners to reflect on what works for an individual, what is right when two people are present with each other, and how a community of engagement can surround each person with PMLD regardless of the person's interaction skills.

Contact Details

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References

Antaki, C., Crompton, R. J., Walton, C., and Finlay, M. (2016). How adults with profound intellectual disability engage others in interaction. *Sociology of Health and Illness*, 1-18. https://doi.org/10.1111/1467-9566.12500

Finlay, W. M. L., Antaki, C., and Walton, C. (2008). A manifesto for the use of video in service improvement and staff development in residential services for people with learning disabilities. *British Journal of Dearning disabilities*, *36*(4), 227-231. https://doi.org/10.1111/j.1468-3156.2008.00511.x

Finlay, W. M. L., Antaki, C., Walton, C., and Stribling, P. (2008). The dilemma for staff in "playing a game" with a person with profound intellectual disabilities: Empowerment, inclusion and competence in interactional practice. *Sociology of Health & Illness*, *30*(4), 531-549. https://doi.org/10.1111/j.1467-9566.2007.01080.x

Forster, S. (2008). *HOP: Hanging Out Program: Interaction for people at risk of isolation*. Author. https://sheridanforster.com.au/passions/hanging-out-program-hop/

Forster, S. L., and Iacono, T. (2008). Disability support workers' experience of interaction with a person with profound intellectual disability. *Journal of Intellectual & Developmental Disability*, *33*(2), 137-147. https://doi.org/10.1080/13668250802094216

Walton, C., Antaki, C., and Finlay, W. M. L. (2020). Orienting to affect in services for people with severe or profound intellectual disabilities: A UK-based investigation. *Journal of Applied Research in Intellectual Disabilities*, *33*(5), 876-886. https://doi.org/10.1111/jar.12707

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What About Teaching Assistants?

Nancy Beesley

First things first, a disclosure: until recently I worked as a teaching assistant (TA) myself. I am now a teacher in the same setting. I am female, I am in my 40s, I am a mother and I have just completed the University of Birmingham's M Ed. S/PMLD. The reasons for me telling you all this will become apparent. For my dissertation I looked at how classroom support staff felt about their role. The aim of the study was to offer an insight into the working lives of classroom support staff at a large special school for students with severe and profound multiple learning disabilities (S/PMLD) in London.

Research that exists tends to focus on teaching assistants working with pupils with special educational needs (SEN) in mainstream settings. TAs that work in special schools are almost completely missing from education literature and policy. My research looked at several key issues for classroom-based support staff, but for the purpose of this article the focus will be on training.

Before we get down to the nitty gritty a brief explanation of terminology and a little bit of history is necessary. The 'International Administrative Review of the Use of Non-Teaching Adult Support Staff in Schools for Students with Additional Care Needs' (NCSE, 2018) found over 70 titles used worldwide, although some of those included therapists and other visiting professionals. In my own setting, as well as the TAs, LSAs (learning support assistants) and apprentices, I have come across 1:1 carer, classroom support assistant, special educational assistant, para-educator and paraprofessional. In one academy chain support staff are known as 'teaching partners'. From the late 90s successive governments have opted for TA as a generic term of reference for all those employed in support of teachers in primary, special and secondary classrooms (DfEE, 2000) and the Workload Agreement document (DfES, 2003a.) fixed the generic title 'support staff' to cover all non-teachers working in schools but settled on 'teaching assistants' to demarcate those working directly with pupils in classrooms. I will use TA in line with common practice. You may think 'what's in a name' but as Kerry (2005) states neither the employment nor the training, of support staff can be effective until the role itself is described in ways that help both employee and employer to understand what precisely each job covers—and what it does not.

Support staff working alongside teachers in classrooms are not a new millennial phenomenon. Extra adults were gradually drafted into classrooms from the mid-1940s onwards and discussed at length in the 1967 Plowden Report and Duthie's 'A Study of the Teacher's Day' (1970). Both reports saw the development of highly trained auxiliary roles as a positive step but, depressingly, Plowden and Duthie both highlighted issues of training, status and role that are still being argued about over 50 years later. If asked to think of a teaching assistant (TA), the image that comes to mind will almost certainly be of a woman, possibly an older woman, probably a mother looking for part time work and perhaps not well-educated. This persistent stereotype has allowed the TA role to be largely overlooked by serious academic study and policymakers who, for decades, largely dismissed TAs as a 'mums army' (Coe and Dew-Hughes, 2002). Worries about an ever-increasing reliance on classroom support staff reached their zenith with the publication of the Deployment and Impact of Support Staff report (Blatchford et al., 2009), DISS for short, which claimed that teaching assistants had a negative impact on the academic progress of the pupils receiving most support from them. However, those with SLD or PMLD who are working below national curriculum levels are not mentioned. It was acknowledged that there was a group within the SEN umbrella who have needs to be met which are not directly related to learning: physical or sensory impairments, social, emotional and mental health issues, speech and communication difficulties, for example. However, because the authors did not consider these issues to be within the remit of teaching no further comment about how support may affect the learning experience for these children was made.

The 'mums army' epithet was always unjust and is increasingly so (Coe and Dew-Hughes, 2002). The TA population is predominantly, but by no means exclusively female (HMI, 2002; Skipp and Hopwood, 2019). Of the TAs surveyed by Coe and Dew-Hughes, 12% were graduates, 10% were already qualified teachers, and nearly 40% would like to be qualified teachers. Almost all had a recognised qualification in nursery nursing, childcare or learning support. 88% had English GCSE and 64% had maths. Even Blatchford and his colleagues (2009) found that 15% of the TAs they surveyed had a degree. Skipp and Hopwood (2019) also found that schools in urban areas were more likely to have applicants for classroom support staff jobs who were highly qualified and looking at the TA role as a route into teaching. Some schools viewed the recruitment of TAs as a good way of 'growing their own teachers.' In fact, in the current job market and with the push at the turn of the century for 50% of young people to go to university younger applicants are increasingly likely to be graduates. These findings were borne out in my own study.

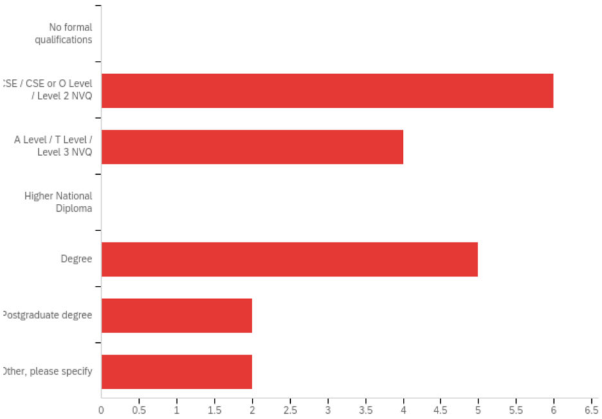

Fig. 1. Highest level of qualification achieved

While it is true that almost a third of respondents have GCSE or equivalent qualifications almost half hold degrees and higher qualifications. Of those that stated 'other', one has a master's equivalent qualification degree and the other holds an NVQ level 4 which is equivalent to the first year of an undergraduate degree. Therefore, the figures can be slightly amended so that 6 people have a degree or level 4 qualification and 3 people have a postgraduate degree. There is a heavy implication in the literature about support staff that they are poorly qualified. The further inference is made that they are unlikely to aspire to teach or to any other 'professional' role as these would not be open to them, but this appears not to be true.

So, are all TAs 'wannabe' teachers? Under nationally agreed pay deals teachers in special schools receive a SEN allowance in recognition of the more challenging nature of their role. A similar allowance for support staff in special schools was scrapped under the single status agreement that aimed to standardise pay and conditions for all local authority employees (Keter, 2009). There is a strong feeling amongst support staff that they are the ones who bear the brunt of the extra challenge for no reward. That said only 3 people in my study were sure they wanted to be teachers, although several more were undecided.

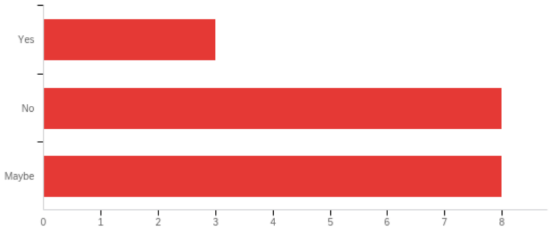

Fig. 2. Aspirations to be a teacher

While some support staff may not aspire to teach, almost everyone saw a need for their continued personal and professional development. It is not expected that many nurses will become doctors and both professions have clear and distinct career paths. It is not unreasonable therefore for support staff to want some form of career development without the goal of teacher.

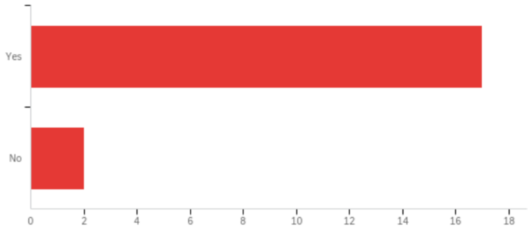

Fig. 3. Need for more specialist TA roles

The substantial level of agreement about a need for more specialist roles in my setting could reflect the fact that a specialist role is the only way to ensure further financial progression for TAs at my school. Equally, however, there could be a real desire to be able to develop skills and expertise. 13 people wanted more training opportunities within school with several key areas highlighted. 5 people wanted training on strategies for dealing with challenging behaviour, 2 people requested in depth instruction in PMLD and sensory learning techniques. 3 people wanted more training in speech and language and communication techniques and 3 wanted to know more about occupational therapy strategies. Other areas specified were medical procedure, mental health, and visual impairment. This suggests a real desire for specialist knowledge pertinent to the setting.

The NVQ qualifications that are endorsed by my school are generic SEN TA courses that are designed with a mainstream focus on supporting children with mild to moderate learning disabilities. A more specialised course is not available. All apprentices are expected to complete the courses and periodically they are opened to LSAs who need the level 3 qualification to be eligible for a TA position. Over the years there have been ongoing issues with course providers and the awarding institution has changed several times. Despite these apparent drawbacks most people who had undertaken one of the courses found it relevant.

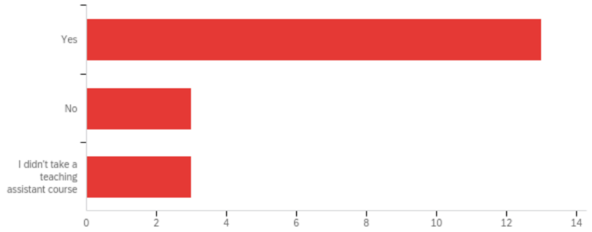

Fig. 4. Relevance of NVQ Teaching Assistant Course

However, when asked if there should be a course specifically designed for support staff working in special schools all but one person agreed. This further suggests that support staff recognise the need for specialist knowledge.

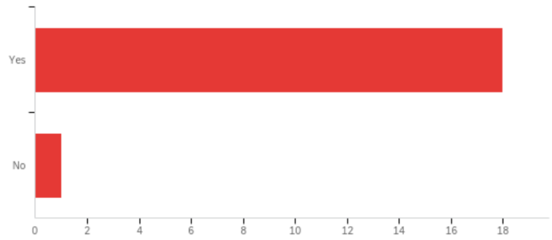

Fig. 5. Need for specialist training course specifically designed for support staff working in special schools

Imray and Hinchcliffe (2014) note that the training needs of support staff are frequently overlooked. Carpenter et al. (2015) highlighted the need for high quality training for implementation of their own engagement profile, an updated version of which is currently being rolled out across special schools as a statutory method of assessment. Carpenter et al. further recognised the marked difference between the role of support staff in special schools and their mainstream colleagues. They recommended the training needs of all teaching assistants working with children with Complex Learning Difficulties and Disabilities should be thoroughly considered. Aird (2000), Grove (2000), Carnaby and Cambridge (2006), Abbott et al. (2011), Lacey and Ouvry (2012), Ware (2012), Colley (2013) and Imray and Hinchcliffe (2014) all agree that TAs in special schools often know their students better than anyone else in the setting. This expertise needs to be recognised both by TAs themselves and their managers. Support staff deserve recognition for the difficult job they do. As Abbott et al. (2011) point out the range of duties, skills and responsibilities expected of them can be vast, and span pedagogical, health and complex medical needs.

High quality training is key to instilling professionalism and imbuing value to the support staff role. I agree with Carnaby and Cambridge (2006) that it is important support staff have some 'theoretical background' to the tasks they perform and many of my respondents felt the same. Often, they are told what to do, but not why it is being done. However, support staff need training materials that are accessible to hard-working people with busy lives, not dense academic works. With high staff turnover in schools all training should include an explicit restatement of basic principles. Possibly that would be dull for 'old hands' who think they have 'heard it all before' but it is counterproductive to assume knowledge and leave people to fill in their own blanks. This can lead to misconceptions and bad practice. Any INSET programme should be designed with clear intent and not a tick box exercise to ensure staff 'do their hours'. Training for support staff should be responsive and reflective, along similar lines to the teachers' continuing professional development (CPD) within the school.

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References

Abbott , L., McConkey, R. and Dobbins, M. (2011) 'Key players in inclusion: are we meeting the professional needs of learning support assistants for pupils with complex needs?', *European Journal of Special Needs Education*, 26:2, 215-231, DOI: 10.1080/08856257.2011.563608

Aird, R. (2000) 'The case for specialist training for learning support assistants employed in schools for children with severe, profound and multiple learning difficulties'. *Support for Learning* 15, no. 3: 106–10.

Blatchford, P., Bassett, P, Brown, P., Martin, C., Russell, A. and Webster, R. (2009) *Deployment and Impact of Support Staff Project*. www.dcsf.gov.uk/research/

Carnaby, S. and Cambridge, P., (eds.) (2006) *Intimate and Personal Care with People with Learning Disabilities.* London: Jessica Kingsley Publishers.

Carpenter B., Egerton J., Cockbill B., Bloom T., Fotheringham J., Rawson H. and Thistlethwaite J. (2015) *Engaging Learners with Complex Learning Difficulties and Disabilities: A resource book for teachers and teaching assistants*. Abingdon: Routledge.

Coe, J. and Dew-Hughes, D. (2002) *Routes in teaching for teaching assistants: a report to the DfES* (Oxford, Oxford Brookes University).

Colley, A. (2013) *Personalised Learning for Young People with Profound and Multiple Learning Difficulties.* London: Jessica Kingsley Publishers.

DfEE (Department for Education and Employment) (2000) *Working with teaching assistants: A good practice guide*. London: DfEE Publications.

DfES (Department for Education and Skills) (2003a.) *Raising standards and tackling workload: A national agreement.* London: DfES.

Duthie, J. (1970) *Primary school survey: A study of the teacher's day*. Edinburgh: HMSO.

Grove, N. (2000) *See What I Mean*. Kidderminster: bild.

HMI (Her Majesty's Inspectorate) (2002) *Teaching assistants in primary schools: an evaluation of the quality and impact of their work*, Report by HMI no. 434 (London, DfES).

Imray, P. and Hinchcliffe, V. (2014) *Curricula for Teaching Children and Young People with Severe or Profound and Multiple Learning Difficulties: practical strategies for educational professionals.* Abingdon: Routledge.

Kerry, T. (2005) 'Towards a typology for conceptualising the roles of teaching assistants', *Educational Review*, 57(3), 373–384.

Keter, V. (2009) 'Pay in Local Authorities'. Standard Note: SN/BT/4992 Last updated: 4 March 2009. House of Commons Library file:///E:/Green%20book.pdf

Lacey, P. and Ouvry, C. (eds.) (2012) *People with Profound and Multiple Learning Disabilities: A Collaborative Approach to Meeting Complex Needs*. Abingdon: Routledge. pp. 39-48.

NCSE (National Council for Special Education) (2018) *International Administrative Review of the Use of Non-Teaching Adult Support Staff in Schools for Students with Additional Care* Needs. file:///E:/TAs/International-Administrative-Review.pdf

Plowden Report (1967) *Children and their primary schools* London, HMSO.

Skipp, A. and Hopwood, V. (2019) *Deployment of Teaching Assistants in Schools*. www.gov.uk/government/publications

Ware, J. (2012) *Creating a Responsive Environment for People with Profound and Multiple Learning Difficulties*. 2nd edn. London: David Fulton Publishers

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Initial Teacher Training

Rob Ashdown and Iain Chatwin

The aim here is to review the initial teacher training (ITT) opportunities that have been available over several decades to enable teachers to work with children and young people with severe, profound and multiple learning difficulties (SLD and PMLD). Changes in the way this training has been funded and organised over the years have had a number of ramifications and have led both directly and indirectly to shortfalls in the supply of appropriately experienced staff for teaching these pupils.

1971 to 1985

This year marks the fiftieth anniversary of a step change in the development of the education of children and young people with SLD and PMLD. The Education (Handicapped Children Act) of 1970 mandated the transfer of responsibility for their education to the local education authorities (LEAs) from the local health authorities. From 1st April 1971 all children were entitled to an education at school but change did not occur overnight. There was not a sudden flood of qualified teachers into the new special schools and existing instructors, who were not certified as teachers, needed to be given opportunities and time to do courses to become accredited as teachers.

As Porter (1996) points out one practical response was the development of initial teacher training courses which gave a practical grounding in the teaching of these children. These courses recruited committed and well-motivated students of good ability and with experience but there were concerns that this specialised ITT could result in a ‘narrowness’ of course content and hamper moves by teachers to and from mainstream education (DES, 1978).

In-service diploma courses became available for teachers in special schools or seeking to move for the first time into special education but concerns were expressed that teachers did not generalise or maintain the new skills, knowledge and understanding that they acquired on these courses. Of course, as noted by Porter (1996) it might be that LEAs and schools simply did not capitalize sufficiently on returning teachers’ new abilities. Courses might provide teachers with a catalyst to change schools but they could be faced with trying to implement change in an unsupportive environment. Whatever the reasons, the cost of this form of training was consequently viewed as high relative to any gains for the schools and LEAs.

Mid 1980s to 1990

Increasingly, with the push for inclusion and systematic identification of special educational needs and disabilities (SEND) in mainstream provision, there were demands that all training courses should equip all teachers to identify special educational needs and to adapt their teaching to make it inclusive. Following an unfavourable review, a decision, regretted by many (e.g. Imray and Hinchcliffe, 2014), was taken in the mid-1980s to wind down the specialist courses and all available resources were switched to the development of in-service courses to provide additional training for those with recognised positions of responsibility. The expansion of in-service courses was expected to offset the loss of specialist ITT. In the case of children with SLD and PMLD, it was calculated that this required some 200 teachers to be trained annually through in-service provision but for various reasons this target was never achieved (Porter 1996, 2001). A number of factors mitigated against the fulfilment of this target, including the fact that teams of ITT specialists were broken up when funding ceased and were not available to deliver the in-service training (Imray and Hinchcliffe, 2014; Tilstone, 1991).

Porter (1996, 2001) describes how in the late 1980s and 1990s, in-service education and training (INSET) came to be planned and systematically managed by LEAs at the behest of UK governments. There were several changes in the way INSET was funded and it became focused on national priority areas, with central funding accessed by LEAs through an annual system of bidding.

1990 to 2010

Secondments for teachers for one-year full-time courses in relation to pupils with SLD and PMLD were virtually impossible to access. Instead, a range of part-time modular courses delivered through ‘distance learning’, day release and/or twilight sessions became the norm but only for those teachers who were motivated to fund themselves or whose schools or LEAs were willing to pay (Porter, 1996, 2001). Real concerns remained about shortages in the supply of appropriately trained teachers for a rapidly changing pupil population (e.g. Carpenter, 2007).

The Salt Review (DCSF, 2010) reported the outcome of an independent investigation into teacher supply issues relating to teachers of children with SLD and PMLD. The report noted rapid developments in the pupil population and increasing complexities of needs. It expressed concerns that the teaching population with expertise in this area was ageing and that there was a pressing needs for attractive and accessible opportunities to develop a new cadre of expert teachers.

> “The evidence presented to the review leaves no room for doubt that there is currently not enough focus on supplying a highly skilled workforce trained to meet the needs of learners with SLD/PMLD. We need to act now and put in place structured training and support over the next five to seven years, or risk losing the expertise we currently have when specialist practitioners and academics retire. The profession does not have the high status it deserves and consequently, does not attract the best new graduates or other candidates into the profession. ”
>
> (DCSF, 2010, p.41)

The report did not recommend reintroducing specialist ITT. Instead, it recognised a range of initiatives undertaken by the Government in relation to teaching of children with SEND and suggested how these could be augmented to address the needs of teachers of children with SLD and PMLD. Therefore, it included recommendations about developing exemplars to describe how the Qualified Teacher Status (QTS) standards can be met at a special school or specialist setting and increasing special school/setting placements so that they are available to all who request them. It also recommended developing ‘tasters’ of SLD/PMLD teaching, with SLD/PMLD modules to be made available during ITT.

2010 to 2020

Specialist professional development modules commissioned by the DfE have become available through an open-access, free, on-line developmental training resource on severe and complex learning difficulties (DfE, 2012). These modules do not lead to qualifications although they can be used flexibly: within teacher training modules; to support school placements; by educators seeking self-help and self-directed study; and for staff development (Peter, 2015).

Another development of note is that across the whole special schools sector the number of ‘unqualified teachers’ has steadily increased and by November 2019 there were 3,729 which is 14 % of the workforce (Howson, 2020). Schools could employ unqualified teachers when they could not find a teacher with QTS and from 2012 academies and free schools were allowed to employ unqualified teachers. This raises questions: Why are they being employed? Do the schools that employ them offer clear progression opportunities and mentoring to achieve QTS? It is quite likely that these unqualified teachers have considerable experience and special skills that benefit the education of these children and, therefore, their employment and work is not to be decried. Nevertheless, schools' budgets have been squeezed and it is a concern that there may be limited resources available to encourage and support people who want to gain their QTS.

The Carter review of ITT (DfE, 2015) again reported concerns that ITT inadequately prepares new teachers to address the needs of children with SEND. The review acknowledged the challenges of addressing SEND within ITT programmes, particularly those that are just one-year long, but opined that there was too much variability across the system in what is covered in SEND.

The Carter review showed the different ways that prospective teachers can train as undergraduate or post-graduate students. Undergraduate programmes are offered by universities for trainees who do not already have a degree. New teachers may also train through post-graduate programmes and can do so via various routes. Accredited ITT providers can either be universities or School-Centred ITT providers (SCITTs). Where the provider is a university, the course will normally lead to a Postgraduate Certificate in Education (PGCE) as well QTS. SCITTs may also partner with a university to offer an academic award (most often a PGCE) as well as QTS. ‘School Direct’ courses are led by a group of schools. The school partnership chooses an accredited provider – a SCITT or university – to work with them and to be accountable for the provision. The school partnership will normally play a greater role in recruiting and selecting applicants as well as delivering part or all of the course. Most School Direct programmes do not offer salaries but some are salaried so that trainees can earn while they train.

The Gov.UK website provides descriptions of courses from SCITTs with a SEND specialism (https://www.find-postgraduate-teacher-training.service.gov.uk/). However, only a minority of these courses offer placements in special schools for children with SLD/PMLD. It seems that a good number of special schools for children with SLD/PMLD do offer placement blocks alongside mainstream placements. Some of these schools are the lead teaching school for a group of schools. As ever, opportunities seem to be determined by luck or locality.

Chadsgrove Teaching School is a good example of a special school which offers an opportunity through its School Direct programme to qualify as a primary school teacher, but with additional enhanced skills to effectively teach pupils with SEND in both mainstream and specialist settings. Iain Chatwin is the Teaching School Manager and explains (in a personal communication) that the programme was set-up in 2014 specifically to address the significant difficulties local special schools were experiencing in relation to recruiting teachers with relevant experience of teaching children with SLD/PMLD. Iain believes that much of the broader ITT provision does not offer sufficient experience, even for those with an interest in moving into this field. Generally, recently qualified teachers would need to undertake additional post-qualifying training.

The Chadsgrove Teaching School ITT programme is solely for trainees undertaking placements in special schools, and has averaged 7 trainees per year up until the past 2 years and 10 trainees for the most recent 2 years. Early cohorts on the programme had a high proportion of experienced teaching assistants and unqualified teachers (c. 80%), but in more recent years this proportion has fallen to about 30%. The training programme has the advantage of being presented by experienced special school teachers, senior leaders and nationally recognised individuals in the SEND field, and is focused on teaching children with SLD/PMLD.

The trainees do an 8-week placement in a mainstream primary school during the autumn term, but the remainder of the training year is spent in a special school. Iain asserts that trainees can fully demonstrate meeting the requirements for QTS within a special school setting, but the school is obliged by its university partner to include a mainstream placement during the year.

The school has worked closely with university partners to promote special school placements and training within all ITT programmes. Iain argues that ITT providers need to be a lead on promoting special school placements as having an equal status to any other setting. He also argues that the impetus for this also needs to come through the DfE, but unfortunately it does not seem to recognise the nature of SEND provision fully. Iain says that the school has worked with several other special school ITT providers to lobby for greater recognition of SEND in ITT, but the feeling is that special education is always an afterthought in any policy decisions.

Concluding Remarks

So, how is the country faring as regards the recruitment, training and retention of suitably qualified teachers of pupils with SLD/PMLD? Well, this rather hard to judge due to insufficient data collection and analysis by Government agencies but we constantly hear that there is a shortage of teachers for all schools and teachers of pupils with SEND in mainstream and specialist settings and that this situation has been steadily getting worse (e.g. Mulholland, 2020). Fifty years after children with SLD and PMLD first became entitled to an education at school, it seems that there still is a real need for a renewed and revitalised national strategic effort to recruit and prepare teachers for working with them.

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For more information about Chadsgrove Teaching School and ITT go to: http://www.chadsgroveschool.org.uk/web/welcome_to_chadsgrove_teaching_school/192882

References

Carpenter, B. (2007) Changing Children – Changing Schools? Concerns for the future of teacher training in special education. *PMLD Link*, 19 (2), 2-5

Department for Children, Schools and Families (DCSF) (2010) *The Salt Review: independent review of teacher supply for pupils with SLD and PMLD.* Nottingham: DCSF Publications. Available at: https://webarchive.nationalarchives.gov.uk/tna/+/http:/www.dcsf.gov.uk/saltreview/downloads/SaltReportRevisedFinal.pdf. Accessed on 3rd April 2021.

Department for Education (DfE) (2012) *Training materials for learners with severe, profound and complex learning difficulties*. Online. Available at: http://www.complexneeds.org.uk. Accessed on 3rd April 2021.

Department for Education (DfE) (2015) *Carter review of initial teacher training*. Online. Available at: https://www.gov.uk/government/publications/carter-review-of-initial-teacher-training. Accessed on 3rd April 2021.

Department of Education and Science (DES) (1978) *Special Educational Needs: Report of the Committee of Enquiry into the Education of Handicapped Children and Young People*. (The Warnock Report) London: HMSO.

Howson, J. (2020) *How many unqualified teachers are there?* Blog, 4 September, 2020. https://johnohowson.wordpress.com/2020/09/04/how-many-unqualified-teachers-are-there/. Accessed on 3rd April 2021.

Imray, P. and Hinchcliffe, V. (2014) *Curricula for Teaching Children and Young People with Severe or Profound and Multiple Learning Difficulties: practical strategies for education professionals* London: Routledge.

Mulholland, M. (2020) Training to make a difference *SEN Magazine*, March 4, 2020 (Accessed online: https://senmagazine.co.uk/content/care/training/7939/training-to-make-a-difference/)

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Initial teacher training for people who want to work in special schools: a personal viewpoint

Jackie Saha

Jackie is a teacher at Humberston Park School, Grimsby who did her one-year training course through the School Direct route in 2013/2014, having previously worked as an unqualified teacher and a teaching assistant. In this article Jackie offers a personal perspective on how well initial teaching training programmes from 2013 to the present day address the teaching of children with severe, profound and multiple learning difficulties (SLD/PMLD).

Jackie writes:

In this piece I would like to highlight what, to my mind, is a lack of opportunities to attract suitable candidates to teaching children with SLD/PMLD and the poor quality of teacher training in this area. The SALT Review (DCSF, 2010) was full of hope and high expectations that there might be improvements in the opportunities for candidates wanting to become teachers in special schools but it seems to me that, unfortunately, little has changed.

I was a qualified nurse (SEN) and had done an HND in 1998. But, to progress as a teacher, from 2006 I worked to gain GCSE mathematics, an honours degree (2-1) in social and behavioural studies, AS level human biology and, of course, the mathematics and English key skills tests (which nearly pushed me over the edge because they were so stressful).

I had attended many useful courses through my employer, Humberston Park School, but these did not seem to help when applying for teacher training. I felt that my fourteen years initially as a teaching assistant and then as an unqualified teacher at Humberston Park School weren't considered as enough evidence of teaching experience. I had to prove that I had some mainstream school experience to qualify for a place on the course. I had to complete 2 weeks experience in a mainstream setting as well as supporting 2 pupils attending the local primary school from Humberston Park School for several times a week as part of their transition into a mainstream school. I also had to observe phonics teaching.

It was fortunate for me that Humberston Park School was my specialist training provider as training in special educational needs and disability (SEND) seemed to be very limited, unless a trainee requested a placement in a special school setting. From my cohort of 20 trainees, no other trainee requested a placement in a special school. If they requested a placement in a special school, they could do a 12-week placement. However, it was my impression that this wouldn't have been easy to arrange. I had a placement for 8 weeks in a mainstream school during my teacher training. When being observed by the university's trainers in my placement at Humberston Park School, it seemed to me that they lacked understanding of what is involved in teaching children with SLD and PMLD and relied heavily on my school-based mentor's knowledge for help in evaluating my work.

I also think that at that time a teaching role in a special school was not regarded as being of equal standing with that of a teaching role in a mainstream school. During the university-based training, I felt that my contributions derived from my special school experiences were often seen as not being valuable or not having any relevance.

Two years after completing my training, I became involved in the process of training another unqualified teacher at Humberston Park School through the Schools Direct process. I found that things did not seem to have changed much from when I undertook the training. The trainee was required to complete a minimum of 12 weeks' mainstream practice to gain QTS because the training provider said it would be difficult to meet all the QTS standards while training solely in a special school setting. It is worth noting here that a teacher trainee could do all their practice in a mainstream setting, achieve QTS and be qualified to teach in a special school but would, in my view, be totally unequipped for this role.

From my conversations with other colleagues at school who have more recently achieved QTS, I know that their SEND training was limited to lectures on topics like Autism and Dyslexia. They said that the skills and training that they had received at Humberston Park School when they were teaching assistants helped enormously in their teaching placements in mainstream settings. They reported that during their mainstream placements their school-based mentors frequently sought advice from them about the pupils with SEND in their classes. They agree with me that teaching in a special school setting just wasn't seen as equal to that of teaching in mainstream. Yet the Salt Review argued that teachers in special schools should be viewed and valued as equal to teachers in mainstream. In my experience this is still very far from the case.

As the numbers of children with SLD/PMLD rise, there is likely to be a huge demand for teachers in this area. In my view, the present organisation of initial teacher training is failing to attract enough suitable candidates. It seems to me that initial teacher training, as it is today, is failing children with SEND in all educational settings and newly qualified mainstream teachers are not prepared sufficiently to teach children with additional needs from the outset.

Recruiting, training and retaining suitably qualified teachers is going to continue to be a challenge for special schools until teaching children with SEND and teaching in special schools is no longer seen as a 'poor relation' and is valued as much as a career in mainstream teaching.

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References

Department for Children, Schools and Families (DCSF) (2010) *The Salt Review: independent review of teacher supply for pupils with SLD and PMLD.* Nottingham: DCSF Publications.

Editors' Note

We would be very interested in publishing future articles from anyone with recent experience of applying for, undertaking or providing initial teaching training who might be able to offer further perspectives on the issues Jackie raises.

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Get it?

Joanna Grace

In 2019 I completed an independent research study into the use of multisensory rooms in the UK. The study identified the aspects of multisensory rooms that users of the rooms felt made them effective and barriers that prevented the potential of the rooms being realised. Readers interested in the findings can find them written up in full in the book Multiple Multisensory Rooms: Myth Busting the Magic (Grace, 2020a) and published in the Tizard Learning Disability Review (Grace, 2020b). In this article I want to focus on the findings of a follow up study which sprang out of something commonly said by the people I interviewed for the first study.

The research into the effectiveness of multisensory rooms was conducted using a semi structured interview model which led participants through a reflective process of considering their experiences in multisensory rooms and identifying what was essential to their efficacy and what got in the way of them realising the potential of the rooms. Invariably, as we spoke, my interviewees would pause in their explanations (perhaps they would be describing a particular piece of equipment that they had seen great reactions to or they would be explaining an issue around logistics – timetabling often cropped up) and reflect that “The trouble is they just don’t get it” or “But if they get it, then that doesn’t matter.”

Time and again the people I interviewed used this phrase “get it” about other people facilitating in multisensory rooms. It happened so often that I decided to embark on a second phase to my research. The original study was conducted on a relatively randomly selected group of people. For the second phase I hand-picked people I have enormous respect for or people I knew had done amazing things with people with profound and multiple learning disabilities. I am in a very privileged position in that my adventures around the country bring me into contact with all sorts of amazing people and so I was able to ask over fifty extraordinary individuals one very simple question: “With regards to people with profound and multiple learning disabilities, do you find some people get it and some people don’t?”

I never defined what I meant by “get it” but everyone understood and immediately leapt to give me an example of someone they had encountered who either did or did not get it. I would then ask them what it was that made the difference between getting it, and not getting it. Everyone’s first answer was that it was innate, just a basic fact that some people do and some people do not. But I would push them to describe the difference. It led to some fascinating and challenging conversations, and often people I had asked that question would get in contact with me weeks later to report that they had been pondering it and had a new insight to share.

I took notes on all the interviews and once they were all done I cleared some space on the floor and set to the printed transcripts with scissors. I cut what people had said up into chunks of meaning and then spread them out on the floor placing similar sentiments alongside each other. Out of a sea of insight twelve key themes emerged: four characteristics of people who do “get it”, four characteristics of people who do not “get it” and four suggestions for ways to encourage someone who does not “get it” to “get it.” I think the outcomes represent a start of a conversation.

The participants from my original study and the people I interviewed for the second phase were all very clear that the “get it” quality was critical to the effectiveness of their practice across the board, not solely within multisensory rooms. Everyone struggled to reflect on something they knew instinctually and to articulate their feelings. I expect the notion of someone “getting it” will resonate with many readers. I’m keen to hear your insights. I think that, however tricky this conversation is, it is important we turn our attention to something which can otherwise be an elephant in the room standing in the way of effective provision for people with profound and multiple learning disabilities.

Four characteristics of people who “Get it” – as identified by the participants in my study.

- Reflective – People who ‘got it’ were described as being constantly reflective, asking why they saw particular responses, but also reflecting on their own actions and how if they had been different outcomes might have been different.
- Seeing Identity As Separate From Functionality – Interviewees distinguished people who didn’t get it from people who did in terms of their understanding of identity and functionality. Some people who did not get it held their own identity as a facet of their functionality; they were the person who did, the person who was busy, the person

juggling fifty balls at a time. Because their identity was so tied up in their function where they saw no function they saw no identity.
- Empathetic – People spoke of the genuine empathy of those who 'Got it' sometimes contrasting this with people who didn't 'get it' yet loudly declared themselves as empathetic.
- Confident – Interviewees often described those who did not 'get it' as lacking in confidence, but then in their descriptions of people who did 'get it' they did not describe overly confident people, rather people who were secure in their own skin, self-assured, etc.

Four characteristics of people who do not "Get it" – as identified by the participants in my study.
- Toughened – In response to life's difficult experiences they had made the choice to toughen up rather than ride the emotional roller coaster. This had made them insensitive to the ebb and flow of other people's emotions.
- In need of power – People who in their own life experience very little power and control can be drawn to settings where they know they will be more powerful than others: cleverer, stronger, able to dominate. This in turn can lead to bullying.
- Ended up here – People often identified people who didn't "get it" as people who felt they had ended up in their roles, not chosen or selected to be there. They quoted people saying "Well there was nothing else I could do" or pointed out that other roles would have required training that this person was not motivated or able to complete. The lack of pride in their jobs and the lack of prestige in their roles, both internally within the setting and externally in the wider world, made them feel the roles were valueless and this was reflected in their interactions with the people they supported.
- Short thinking – Interviewees identified that people who did not "get it" tended to have very short chains of thought, stopping at the most obvious answer and not questioning or reflecting further. In particular stopping at 'like me' answers, e.g. "If I made that noise it wouldn't mean anything, therefore when they make that noise it is meaningless."

Four suggestions for supporting someone who does not "Get it" to transition into someone who does "Get it" – as identified by the participants in my study.
- Feedback – Interviewees spoke about the importance of detailed meaningful feedback given in an accessible manner as a tool for shifting people's perspectives. They often spoke about the person who did not "get it" as being unable to read the feedback given by the person with profound and multiple learning disabilities with whom they were interacting.
- Teach in different ways – Interviewees commented on the one size fits all approach to training, acknowledging that they would never expect those they care for to learn in the same way. Yet those that care for them are expected to learn in the same way.
- Generate awareness – Interviewees remarked that people who do not 'get it' are often unaware of certain aspects of the people they supports lives or unaware of information relevant to the lives of the people they support. They also commented on the impact of wider public awareness on their practice.
- Stunned or Stagnant – Interviewees described two groups of people who they viewed as in the not 'get it' category. What united these two groups was an inertia. (i) Stunned – These were people who were so daunted by the apparent complexity of the challenge of engaging with someone with complex disabilities they simply froze. One interviewee described a supply teacher with a look of panic in their eyes who just sang nursery rhymes for a week. (ii) Stagnant – These were people who had done it all before and did things the way they had always been done because that was the way they were done.

For a more detailed discussion of what my interviewees said please explore *Multiple Multisensory Rooms: Myth Busting the Magic*. To share your experiences and insights please come and connect with me online. I am very interested to learn more.

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References

Grace, J. (2020a) *Multiple Multisensory Rooms: Myth Busting The Magic*. Abingdon: Routledge.

Grace, J. (2020b), Multisensory rooms: essential characteristics and barriers to effective practice, *Tizard Learning Disability Review*, Vol. 25 No. 2, pp. 67-75. https://doi.org/10.1108/TLDR-10-2019-0029

Soundabout Inclusive Choirs

Eleanor Gibson

For someone with PMLD, joining a choir may not seem a natural fit. The word ‘choir’ conjures up images of big groups singing in harmony, all dressed alike, performing for an audience. However, the growing awareness of singing as an activity which positively supports wellbeing and the fact that when we sing with others those benefits are amplified, has stimulated the growth of many choirs of different kinds and descriptions, expanding the very definition of the word ‘choir’.

Back in 2001 there was a ‘laughter choir’ in Berlin (https://www.theguardian.com/world/2001/apr/14/johnhooper). More recently I’ve heard about the ‘tuneless choirs’ which are growing rapidly in the UK (https://www.tunelesschoir.com/). Whilst I firmly believe that everyone can sing, doing so in time and in tune can be a challenge, and the tuneless choirs cater for those who want to meet that challenge with joy. There is so much more to being in a choir than singing!

Singing is our first language, containing the seeds of self expression, of creativity, of growth. Even before birth we are tuning in to the music of our mother’s speech and song and the world around us, as hearing is fully functioning at 6 months gestation. The spontaneous sounds of babies and infants are their wonderfully authentic way of engaging with the world. For those with PMLD, whose ability to engage with the world might be limited in all sorts of ways, the mouth, the lips, the teeth, the tongue can become a fantastic playground: a means of expression, but also a rich source of sensory satisfaction and a primary way to communicate with the world around them. They may not need words to communicate and most of us find that words themselves cannot contain or convey the depth of our feelings; that is where music comes in. Through music, through singing, we have the opportunity to connect with others without, above and beyond words.

Our new world of Covid restrictions has, of course, prevented most choirs from meeting in person, but the plethora of singing opportunities online is a testament to the importance of singing for many people as a way to connect with others. Singing online is imperfect, we are all muted, we are missing that essential ‘surround sound’ experience, hearing and feeling the vibrations of others’ voices, being one among many, but now we are no longer limited by geography our potential singing landscape has expanded to encompass, through the digital, the whole world. I had been imagining the possibility of a truly inclusive choir in my local community for a long time, but was always thwarted by the logistics involved in getting people together. However, when I heard that Soundabout had taken their Inclusive Choir online, and on the basis of that success were looking to roll out the format across the country, I was excited! I was invited to attend a rehearsal of the Oxford inclusive choir on Zoom, and found it an occasion of pure joy – the smiling faces, the enthusiasm, the levels of engagement and participation, the welcome offered to all participants and their every contribution was wonderful to see, hear and feel.

Since then, Soundabout has partnered with local music hubs and other local arts organizations to create, so far, 6 inclusive choirs across England in the last 6 months. There are now choirs based in Oxford, Bristol, Wiltshire, Peterborough, Leicester and the West Midlands. They are all firmly based in the core values of Soundabout practice, using music to empower and unlock the potential of people with severe and profound learning disabilities. Multi-sensory music-making techniques help to stimulate communication, learning and self-expression, enabling people who may be unable to hold an instrument or speak to make their own unique contribution.

The aim is for each choir to have its own individual flavour, whilst being rooted in shared core practices and repertoire. At the time of writing, all choir rehearsals are on Zoom, although the intention and the plan for the long term is to offer a blend of in person and online practices. Under the inspired leadership of Emma Hughes, Soundabout practitioner, the choirs have developed their aims, core principles and strategies through practice, feedback and reflection.

The choirs aim to:

- Foster connection and community
- Develop musical skills
- Promote wellbeing
- Develop self confidence and social skills
- Be fun
- Offer new opportunities and experiences

This is achieved through

- Always looking for the ‘can dos’ in planning and practice
- A firm structure with Hello and Goodbye songs which acknowledge every participant, giving them their ‘moment’
- Bespoke arrangements of songs which include space for individual and instrumental contributions
- Participant led – we welcome suggestions for songs and will always try to adapt songs to enable participation in a variety of ways, adaptations for multisensory input
- Creating a balance between entertainment and interaction
- Looking out for signs of engagement and interaction, recognizing and praising these, offering opportunities to be heard by the group, building on developing skills
- Providing options and choices within key learning
- Makaton signing, actions and gestures to accompany songs
- Invitations to share individual sounds, or what we have just learned
- Opportunities for individuals to share something of their own with the group, to ‘perform’ in a supportive environment

Every choir is facilitated by two leaders who plan and structure the sessions, but volunteers are an incredibly important element in the format. They are there because they want to be, because the sessions bring them joy, and they offer unbounded enthusiasm and support. Volunteers bring their own skills, energy and interests, and may offer to lead part of a session. One of our volunteers brought us the gift of scat singing, something she had been doing with another group she sings with. The enthusiastic participation of the Soundabout Inclusive Choirs has led to the aim of producing our own scat song, as well as expanding the notion of ‘singing’ and enabling us to embrace a broader definition of vocal expression through a variety of warm up activities, and by creating choices and opportunities within songs, using idiosyncratic sounds and vocables as well as more conventional sung sounds. This is just one small example of what our volunteers add to the choir. They also function as extra pairs of eyes and ears, so that they can draw attention to signs of engagement that leaders might miss, and act as cheerleaders for less vocal or confident choir members. Some volunteers go on to become Soundabout interns, and from there to become Soundabout practitioners. Soundabout's vision is to enable and empower participants at every level, and have created an 'emerging leaders' program which offers choir members the opportunity to become leaders in their own right, developing leadership skills and having a lot of fun in the process. Volunteers, interns and emerging leaders tend to 'pop up' in more than their local choir, some attending all six choirs, made possible by Zoom, and demonstrating the level of pleasure and connection that the choirs inspire.

Most of the children and young people in the choirs, participating from their homes, will need a parent or carer to support them both in using the technology and participation through the session. These very necessary and welcome people are also considered to be members of the choir, and many have reported increased musical confidence in themselves and their child, and a growing tendency to sing around the house. Engaging in music and singing can allow participants to blossom in surprising ways, and witnessing this, being part of it as a parent or carer, can foster connection, fun and pleasure. Parents and carers report that their children are happier, more confident, less stressed, a demonstration of Adam Ockelford's recommendation that music becomes 'a strand in the fabric of everyday life, continuously supporting communication, understanding, interaction and wellbeing'.

The children and young people themselves show their enjoyment by turning up every fortnight, by their smiles and enthusiastic engagement, and by telling us that the choir makes them feel 'happy', 'excited', more confident and friendly, and offers a sense of belonging.

What does the future hold for the choirs?

One of the very exciting opportunities afforded by the choirs has been collaborating with the Kings Singers: at the start of 2020 the Kings Singers launched their 'Finding Harmony' campaign – their mission was to use singing as a tool to find unity in a divided world. They approached Soundabout, choosing the Oxford based Soundabout Inclusive Choir as ambassadors in their campaign. Sadly, the in person workshops with the Soundabout choir were not able to take place as lockdown intervened, but both choirs took on the challenge of working together through lockdown, firstly on an arrangement of Amazing Grace. The innovative arrangement was inspired by and built around the singing of one of the Oxford choir, and created by Steve Dunachie, the father of one of the Kings Singers, a composer and music therapist. The resulting video became part of an edition of 'Songs of Praise' and never fails to move those who watch and listen (https://www.youtube.com/watch?v=2AdcUbjPr2A). The next collaboration under the 'Finding Harmony' banner involves the Sing for Freedom choir and the Mixed up Chorus alongside the Soundabout choirs and the Kings Singers. It promises to be very exciting, and we look forward to more exciting collaborations. One of the Kings Singers reports: 'We met many members of the Soundabout Inclusive Choir at their zoom rehearsal a few weeks ago; it was one of the highlights of my time in the Kings Singers so far'.

For the choirs themselves we are very much looking forward to a time when we will be able to meet in person in our local groups, to really hear and feel each other's voices. And we hold the hope of one big 'superchoir', a celebration of truly inclusive and enabling music making.

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Further Information

Join a Soundabout inclusive choir, or enquire about starting one in your area at choir@soundabout.org.uk

https://www.soundabout.org.uk/soundabout-inclusive-choir/

PMLD LINK
sharing ideas and information

Supporting MB to reduce his swallowing risk

Gerard Wainwright

The annual report from the Learning Disabilities Mortality Review (LeDeR) team indicate pneumonia as one of the biggest causes of death amongst people with learning disabilities (LeDeR, 2020). This increases dramatically for people with profound and multiple learning disabilities and often results from the aspiration (inhalation) of food, liquid, or vomit into the lungs.

Case Study

This case study demonstrates the importance of considering and addressing the complexity of problems which may lead to a high risk of aspiration. Complex problems require careful planning and monitoring of interventions by different people working in close harmony and keeping in mind the holistic needs of the individual. Some medical terms are explained in notes at the end of this piece.

MB was referred to the service I manage in August 2018 following a near fatal sepsis infection. He had previously lived with his parents. He has profound and multiple learning disabilities and is unsafe to eat or drink orally. He takes all his fluid, nutrition and medication via a balloon gastrostomy. Despite this, he remains at high aspiration risk and has had several aspiration pneumonia infections which have led to hospital admissions. To those who know and care for MB, he's also full of life, charismatic, enthusiastic, amusing and loves musical.

Aspiration pneumonia is caused by breathing in food items or fluid which then bypass the digestive tract and enter the lungs leading to infection. In MB's case this can also include saliva and other secretions, as well as vomit that can re-enter the airway in the form of acid reflux.

The service where MB lives, which supports eight adults, has had twelve deaths in the last four years and ten of these have been the result of aspiration pneumonia. That is ten people who were individuals, not just a diagnosis; sons and daughters, friends, people who brought happiness into the lives of others, whose life was of equal value to anyone else's. As a service we are determined to do all we can to provide the best possible outcomes for our clients and reduce health inequalities where possible.

When he was initially referred to the service at Heatherstones, MB was severely malnourished and due to acid reflux would regularly regurgitate feed even though given via his PEG (Percutaneous Endoscopic Gastrostomy). In addition, he had difficulties with oral secretions which he would often swallow increasing the risk of aspiration. He also produced mucus which he would attempt to clear by coughing. Although, as he recovered, his cough was relatively strong, he was often unable to clear this from his mouth. In the past, suction had been tried unsuccessfully to clear secretions from his mouth. The suctioning tube would increase the risk of him gagging and potentially vomiting, and he would also be uncooperative with the procedure, closing his mouth which had led to trauma of the soft tissue to his gums, tongue and the inside of his mouth.

There appeared to be three issues which initially were assumed to be connected. These were vomiting stomach contents, regurgitating phlegm and secretions including saliva, and coughing which if prolonged sometimes led to vomiting. The service worked very closely with the dietician and PEG nurse and steps were immediately taken to ensure he sat at the correct angle in his wheelchair when having his enteral feed via his PEG, with a minimum 45 minute break when feed, fluid or medication were discontinued prior to him being moved out of his wheelchair, for example onto his bed or into the bath. The feed was administered at the recommended speed and separated into two lots of 500mls one given in the morning and one in the afternoon with a break between.

MB has a hyoscine patch to reduce saliva production. Other combined medication he takes to help reduce risks related to reflux and aspiration include antacids for reflux, an antihistamine for a suspected stomach ulcer and an anti-emetic to help reduce vomiting.

This had the effect of stabilising things for him and he was able to gain weight and consistently receive the right level of nutrition; he had previously been prescribed appropriate levels of nutrition but persistent vomiting had prevented absorption. Since his referral he has gained over ten kilograms and gone from underweight to a healthy weight for him. At the age of 29 this had the effect of a late onset puberty and he developed both physically and socially, having previously presented as withdrawn and disengaged with his surroundings. As MB does not communicate linguistically a sensory approach to promoting communication was used. He began to interact with staff and his environment, developing an understanding of cause and effect, reaching out for chosen objects, and playing percussion instruments. Despite having a highly sensitised sense of touch, he enjoys head massage and some physical interaction with staff and his peers. This was a marked contrast to his previous passive presentation.

But, despite him flourishing in most other aspects of his life (progressing physically, cognitively, developing relationships, a sense of agency and a recognition of his ability to intact and relate to both his environments and other people), the issue with vomiting, regurgitation and phlegm remained significant.

His weight gain also had a subsequent impact on his postural care. Due to his cerebral palsy MB has a pronounced curvature of his spine. In addition, he tends to draw his limbs in which over time appeared to lead to a deterioration in his body's alignment. With advice from a physiotherapist, postural care techniques were introduced. Unfortunately, the recommended sleep system was not effective and in certain respects represented a further risk as it required him to lay on his back at night in order to encourage the alignment of his legs. But due to vomiting risk this was not an ideal position and appeared to increase the risk of aspiration - if he was to regurgitate or vomit, he would need to be quickly moved onto his side in order to allow him to clear his mouth, but the sleep system actively hindered this. As a result, a postural care support plan was put in place using gravity and working in opposition to his curved spine. Each day he spent up to 45 minutes supported with a v pillow to lay on his right-hand side on his bed. Initially he objected to this, so the sessions had to be built up slowly to enable him to gradually tolerate longer. Then he began to feel comfortable enough to sometimes fall asleep during these sessions which were usually around midday. They were then introduced when he first went to bed at night and after a short time he was sleeping longer and less fretfully than he previously had – often remaining on his right-side throughout the night.

An unseen advantage of this technique was it enabled postural drainage. When laying on his right-side he was able to clear his mouth of any secretions and there was a significant reduction in incidents of coughing, regurgitation and vomiting. It appears that, as secretions weren't gathering and pooling in his upper respiratory tract, he was not producing mucus so didn't experience the discomfort and difficulty of expectorating this by coughing. The secretions which he did produce were able to naturally drain from his mouth. In a period of two months he went from vomiting, regurgitating and coughing up mucus several times per night to a couple of times per month. A bonus was he has enjoyed a much more restful night's sleep which has meant he has appeared less agitated during the day.

Conclusions and Follow-up

MB's case illustrates the complexity of specific risks which can affect people with profound and multiple learning disabilities - aspects of people's health we often wrongly accept as inevitable and a part of their condition which we can do nothing about. As professionals we are also sometimes guilty of viewing people as separate components – the person is epileptic, they have swallowing difficulties, they have an altered body shape, they have problems with acid reflux – and their case is overseen by different specialists who may view these issues as totally separate to one another. Consequently, there is a danger of focussing on specific problems and losing sight of the individual. The PMLD Core & Essential Standards document (Doukas et al., 2017) demonstrates the need to for a person-centred and holistic approach. We are all first and foremost people. If we don't put the person at the centre of any approach, we are failing that person and ourselves. Viewing MB's unsafe swallow and regurgitation in this way was ultimately the key to significantly reducing the risk and consequently improving his quality of life and life experience.

In terms of specific staff training, I am currently leading a project funded by the Queen's Nursing Institute which is looking at how we can support our organisation's non-nursing services to identify adults with learning disabilities they support who are at swallowing risk, to be aware of what signs to look out for and how to reduce any risks related to an unsafe swallow. A video on YouTube provides an overview of the project – (https://www.youtube.com/watch?v=q_efMcAdRLY). We know that, in many cases, unsafe swallowing can lead to the person aspirating and result in hospital admissions and discomfort, distress, and reduced life expectancy. We know that to treat an aspiration related infection costs the NHS between £10,000 and £20,000. This underscores the value of staff training.

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Notes

A balloon gastrostomy is a feeding tube that is placed directly through the abdomen into the stomach and held in place by an inflatable balloon.

Aspiration pneumonia is a lung infection that develops after you aspirate (inhale) food, liquid, or vomit into your lungs. You can also aspirate food or liquid from your stomach that backs up into your esophagus. If you are not able to cough up the aspirated material, bacteria can grow in your lungs and cause an infection.

A PEG (Percutaneous Endoscopic Gastrostomy) tube is the technique for putting a gastrostomy feeding tube in place. Percutaneous means ‘through the skin’.

In this context, the term enteral feed refers to the nutrition delivered via tube feeding.

Hyoscine hydrobromide can be used to reduce excess saliva and may be delivered via adhesive patches that are placed on the thin skin behind the ear. The medicine is absorbed through the skin and into the bloodstream. Hyoscine hydrobromide patches are regularly replaced and are available on prescription only.

References

LeDeR (2020) *Annual Report 2019*. Learning Disabilities Mortality Review Programme: University of Bristol. Available online at: http://www.bristol.ac.uk/sps/leder/

References continued from page 24

Peter, M, (2015) Training and developing the inclusive teacher for learners with SLD and PMLD. In Lacey, P., Ashdown, R., Jones, P., Lawson, H. and Pipe, M. (eds) *The Routledge Companion to Severe, Profound and Multiple Learning Difficulties.* Abingdon, Oxon: Routledge

Porter, J. (1996) Issues in teacher training. In Carpenter, B., Ashdown, R. and Bovair, K. (eds) *Enabling Access: Effective teaching and learning for pupils with learning difficulties*, 1st Edition. London: David Fulton.

Porter, J. (2001) Issues in teacher training and development. In Carpenter, B., Ashdown, R. and Bovair, K. (eds) *Enabling Access: Effective teaching and learning for pupils with learning difficulties*, 2nd Edition. London: David Fulton.

Tilstone, C. (1991) Teacher Education: The Changing Focus. In Ashdown, R, Carpenter, B. and Bovair, K. (eds) *The Curriculum Challenge: Access to the National Curriculum for Pupils with Learning Difficulties* London: Falmer Press

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Working for an inclusive future

Claire Graham

Inclusion Un.Limited is an organisation based in Buckinghamshire hosting inclusive and accessible activity sessions for children and adults of all needs, with a particular focus on the needs of those with profound and multiple learning difficulties (PMLD). It aims to create a safe environment to allow individuals to be valued and seen for who they are, as well as encourage empowerment, trust and friendships through meaningful activities. We are working towards a truly respectful and inclusive community.

Starting out originally as an activity coordinator at the Epilepsy Society in Buckinghamshire kick-started my passion for supporting adults with profound and multiple learning difficulties. Now, working as the Hydrotherapy Pool Manager at the outstanding Jack Tizard SEN school has made me realise how limited the funding and opportunities for adults with disabilities really were in Buckinghamshire, compared to individuals of school age. After all, why should the availability of accessible and meaningful activities reduce just because someone has become an adult?

I began development on Inclusion Un.Limited in 2019; originally just at the weekends and in any spare half term days whilst I continued to work at Jack Tizard School (who have been incredibly supportive of my future goal). I wanted to design positive and safe social sessions to support individuals with additional and complex needs to access their community as well as build a social network for those families who still cared for their sons, daughters, siblings or other family members at home.

It was a really positive start and one that cemented my enthusiasm to turn this vision into a reality. I was designing the community sessions specifically around those people who were actually attending them, allowing me to keep focused on what activities my community wanted.

I believe activities should always be person-centred, but this was really difficult to do when I first began as I didn't know who would turn up for the community sessions. To counter this challenge, I set up activities that were accessed at different levels, for people to explore at their own pace and with no expectation of final results or products. This allowed me a chance to get to know each individual and making my activity programme more and more appropriate and meaningful.

Our inclusive community began to grow and it was truly diverse, with people of all ages and abilities attending, friends and families, aunties and nieces. Our community sessions offered a varied programme, included sensory play sessions, inclusive discos, accessible live music gigs, exploring clay workshops and sensory art sessions to list a few. When venues can reopen safely, I am looking forward to us hosting new sensory storytelling sessions as well as Inclusion Un.Limited offering more meaningful activities for those with complex needs.

Hydrotherapy

Drawing on my passion for hydrotherapy and experience of managing pool-based activities, I also began supporting individuals with PMLD to access 1 to 1 swimming activities on my available weekends. Finding truly accessible pools locally for adults with PMLD has been the biggest hurdle, but the benefits of being in a hydrotherapy pool make that search worthwhile. Hydrotherapy can allow individuals with PMLD to stretch and exercise in ways that aren't possible on land as well as being the perfect environment to develop and enjoy many other skills.

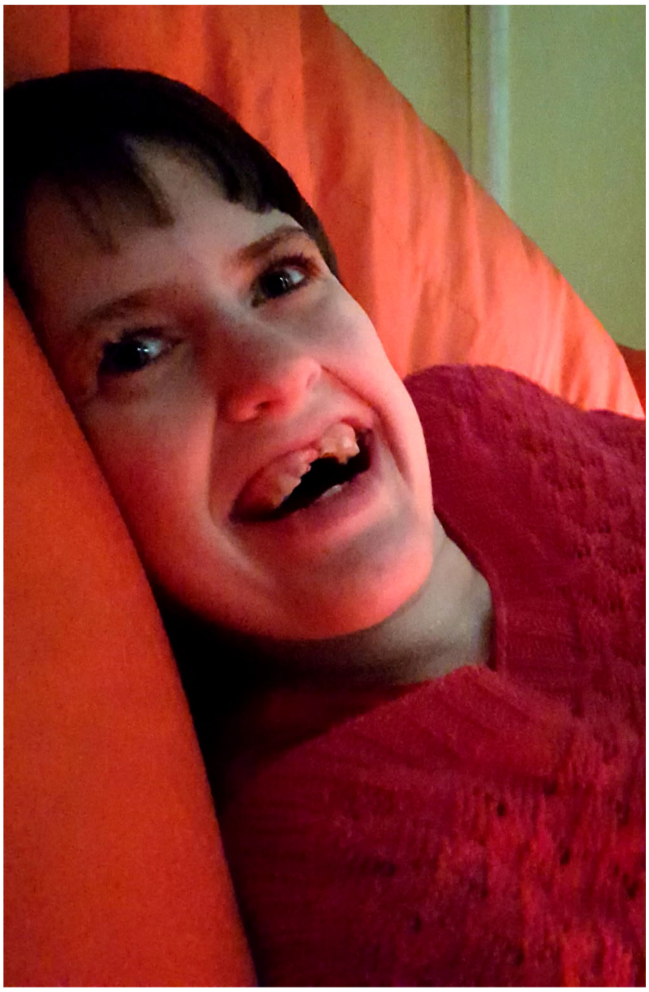
Using combinations of the Halliwick Method and exercises designed by AquaEpp Paediatric Aquatic therapists, hydrotherapy can promote balance, core stability and sensory integration through exploration of the different senses. 1 to 1 hydrotherapy sessions can also have mental health benefits for the individual you are supporting, allowing for the person to feel seen and heard for the entirety of the session, building trust, communication through intensive interaction as well as encouraging independent choices through cause and effect.

Hydrotherapy can be used for relaxation however it is also a great place to get creative - Oily Cart and Anne Newell Theatre Adventures show just how imaginative water sessions can be. It can allow for a fully immersive experience, encouraging curiosity and beneficial stimulation within the session, being cautious to do so without a risk of sensory overload or distress to the individual.

Some ways that hydrotherapy can support the Sensory system:

Visual Stimulation: Eye movements and eye tracking skills can be strengthened throughout water play sessions with the use of toys, objects, contrasting colours and movement. Pools with sensory lighting can also help to support or develop coping strategies for an individual's hyper or hypo sensitivities when they are used in a person centred manner.

Auditory Stimulation: Music or a soundtrack can aid the mood you are working towards in a session for example relaxation or high energy. Planned movement to music, used consistently, could aid understanding and anticipation of what is going to happen in the session as well as understanding of when the session will be ending. However sometimes just the sound of the water flowing, splashing or swirling in the room's acoustics can be enough auditory stimulation for an individual. The different acoustics can also encourage an individual to explore their own voice and vocalisations which can be a great opportunity for intensive interaction to take place.



Tactile Stimulation: The changes in temperatures and humidity in the environment of a swimming pool and changing area, felt through the tactile receptors can support the individual to build an image of the world around them. The water itself can be used to explore different tactile stimulation through sprinkling, pouring, bubble blowing, turbulence; as well as using different textured objects in the session such as spongy, hard, soft, prickly, smooth or vibrating objects.

Olfactory Stimulation: Smells can evoke memory which can produce an emotional response surrounding the activity. The smell of the swimming pool, changing area and warmth in the air can support an individual's

understanding. It can also support them to explore a variety of new smells such as new shower gels or shampoos.

Vestibular Input: Water can support individuals to explore their own movements and sense of balance safely and more independently, sometimes achieving movements that could be extremely difficult or painful to practice on land. For individuals who show repetitive behaviours such as rocking; being able to explore this movement and change position in the water can stimulate their vestibular sensory system. In the water there can be a reduced fear of falling making individuals more confident to explore mobility, coordination, directions and speeds of movement.

Proprioception Input: As an individual receives this input through their joints and muscles, the water can enhance the individual's body awareness whilst also improving their tolerance to touch. The resistance from the water can allow an individual to explore moving different body parts and feel the effects of their actions without having the visual of actually seeing their body moving.

Hydrostatic Pressure: Being in a swimming pool can offer deep pressure as the water surrounds the individual's entire body. Individuals can find this extremely soothing and calming. There can also be a reduction in pain and swelling; as the deeper their joints and body parts are in the water; the more pressure can be felt. Hydrostatic pressure can also support an increase in blood circulation which can improve organ and bowel function. This can help to engage an individual's interoceptive system as it can affect their awareness of pain, heart rate or internal messages such as needing the toilet.

Psychological Well-Being: it's fun! Having the ability to be independent in water, to achieve skills that may be difficult or impossible on land can have lasting psychological effects which boost confidence, morale and trusting relationships that can be carried over on to land.

As we know 2020 was a difficult year for everybody, and no more so than for those living with disabilities and their family members, who push heaven and earth to keep them safe. I missed running our community sessions in 2020, but I was fortunate that I could use my time to continue my development and learn from many incredible practitioners (many who have featured in this magazine). Makaton, becoming a Sensory Spectacle's Sensory Detective, completing the Story Massage Instructor certificate as well as attending the fantastic Hirstwood Training Sensory Festival are just some of the courses that have all helped to get me through the last year. They have inspired me to design new sessions that I hope will allow those with PMLD to flourish.

What made me smile in 2020 was discovering the immense community that PMLD Link has built. From families sharing their experiences and support, to practitioners providing a wealth of knowledge, online sessions and training; I cannot wait to develop Inclusion Un.Limited to become part of this community, 'raising our sights' for those with complex needs.

Watch this space!

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Anne Newell Theatre Adventures: https://www.annanewell.co.uk/
AquaEpp Paediatric Aquatic Therapy: https://aquaepps.co.uk/aquatic-therapyhydrotherapy
Halliwick Method: https://halliwick.org.uk/
Oily Cart: https://oilycart.org.uk/
Jack Tizard School – Hydrotherapy: https://www.jacktizard.lbhf.sch.uk/hydrotherapy-pool/what-is-hydrotherapy

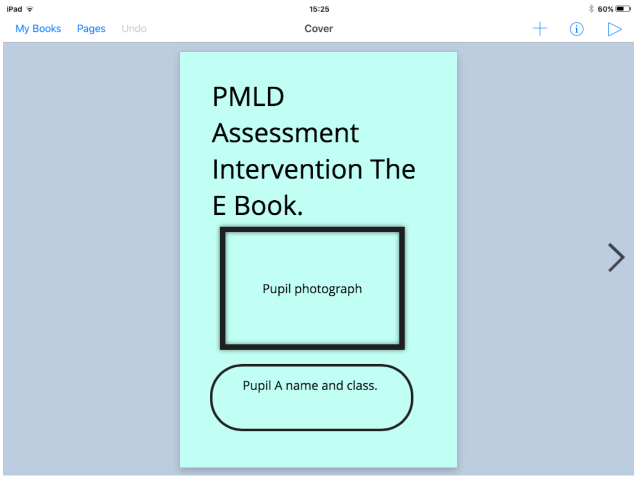
Using an e-book to assess learners' progress

Neil Mullen

As part of my Thesis for my MA (Education), specialising in Special Educational Needs, I performed some action research within the school where I worked on a specific ICT e-book assessment for learners with PMLD. An electronic book, also known as an e-book, is a book made available in digital form, readable on the display of computers or other electronic device.

I was inspired to use the Book Creator e-book as the school where I was working at the time had begun to use this for Rebound Therapy plans. The e-book app is available on App stores and is available for a small fee. Book Creator allows for text, images, audio and video to be added to a page, all from one simple menu. What's more, you can add shapes, comic templates, stickers and emojis. It has been used before in the school where I was at and across other schools within the North East of England.

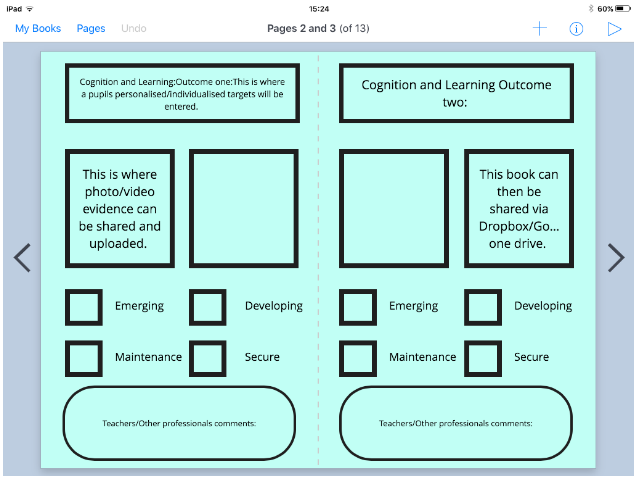
My research took the form of working across two classes with identified learners and implementing the use of the e-book assessment of their learning and progress. Teachers were provided with a template e-book to input photo/video evidence of learner progress, changes in need, and change in Physiotherapy (PT), Occupational Therapy (OT), and Speech and Language Therapy (SALT) interventions, as well as allowing verbal audio feedback from teacher and support staff. In addition, to this written annotations of teacher/support staff feedback could be inputted. This linked into the learners Education and Health Care Plan (EHCP) and individual learning plan (ILP) targets and allowed teaching and support staff and agencies working with the learner (PT/OT/SALT) to input feedback on progress in relation to each target. In addition, it also allowed for more collaborative, cross agency work to identify changes in need as well as thoughts/input from parents and carers.



PMLD
Assessment
Intervention The
E Book.

Pupil photograph

Pupil A name and class.



Cognition and Learning:Outcome one:This is where a pupils personalised/individualised targets will be entered.

This is where photo/video evidence can be shared and uploaded.

☐ Emerging ☐ Developing
☐ Maintenance ☐ Secure

Teachers/Other professionals comments:

Cognition and Learning Outcome two:

This book can then be shared via Dropbox/Go... one drive.

☐ Emerging ☐ Developing
☐ Maintenance ☐ Secure

Teachers/Other professionals comments:

The e-book format was familiar to both teachers involved as they were currently using a similar template with Rebound Therapy books. A brief 30 minute overview of how to input and navigate the app was given to teachers prior to starting. The e-book was implemented over a half-term timescale and teachers used this method instead of their usual method of assessment (learning record paperwork printed into a file). They inputted all outcomes into the document and assessed progress of each learner with PMLD within their class. The feedback from teachers using this method was that they had seen an increased personalised approach to recording progress of learners and changes in need as well as allowing other colleagues to put their input into a single document that provided an holistic overview of each learner and their progress in relation to their outcomes. Sharing of the e-book was done between professionals via the school's password protected drop box account. Parents could access this via downloaded format on their own devices or via a printed PDF (which doesn't include video or voice feedback options)

Further benefits of using the e-book were found when sharing findings with learners (where applicable) and their parents/carers who noted that the e-book format allowed all their child's progress, changes in need and therapeutic requirements to be kept together in one place. Teachers working alongside support staff (who could directly input progress into the app alongside teachers) also reported that there was a more collaborative approach to recording assessment and more focus for teams working around learners when recording progress in relation to an outcome.

Once the action research had been concluded, the findings of this study were shared across the school with a particular focus for teachers who had learners with PMLD in their classroom. This informal professional development was part of the school's ongoing development of the curriculum and assessment offer for these learners. The e-book was talked through and ideas shared on how to input photo/video of progress into the document alongside how to input audio feedback. Further support, in the form of increased training on how to best use e-book features, creating templates and how to upload to drop box secure account, was offered to these teachers, some of whom have begun to implement further trials in the use of the e-book as a more personalised assessment tool for learners. In their trials, teachers reported that assessing progress and need within their class teams had been improved and they felt this method was more appropriate than previous paper-based ones used. The previous systems included printing off typed moderating/evidence sheets that went into a paper based file.

Building on my findings for my MA thesis, there is a possibility of further study leading to a PhD looking at teachers' practice (specifically assessing outcomes) in relation to working with PMLD learners, the appropriateness of e-book/ICT assessment and incorporating parents/carers as well as agencies around the learner. I am hoping to find that by allowing multiple professionals and parents/carers to be fully involved in the process of assessment/change in outcome that teachers will have a greater understanding of capturing learners' progress in a more streamlined way. This would allow further analysis of the impact e-book assessments have on teaching practice, understanding of learners with PMLD, how best to observe progress and how to collaborate with agencies and parents for better sharing of progress.

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Further Information

For more about Book Creator, its development and examples of its use go to https://bookcreator.com/

For a case study on its use by parents of disabled children go to: https://bookcreator.com/2016/01/book-creator-helps-transform-experience-families-affected-disability

Supporting the emotional wellbeing of people with severe and profound learning disabilities

Julie Calveley

Since the last edition of PMLD Link (Winter 2020; Issue 97), in which the launch of the NAC (Non-verbal Affective Care) website was announced, we have been overwhelmed by the response and delighted that carers and others are finding the site useful in supporting the emotional wellbeing of people with severe and profound learning disabilities.

Over 130 accounts have been created on our website, enabling users to save collections of wellbeing experiences, and on the 30th January 2021 NAC we held our first webinar which was attended by 50 family members, carers, supporters, therapists and teachers. The webinar is available to view on YouTube at https://www.youtube.com/watch?v=qfgJY3ANi9I and has, at the time of writing been viewed over 800 times, giving some indication of the level of need and interest in this important area of care and support.

The webinar looked at:

- What some of the latest neuroscience tells us about how everyone can take care of their emotional and mental wellbeing using natural, non-invasive approaches.
- Considerations that need to be made to make these approaches suitable, accessible and safe for people with severe and profound learning disabilities.
- Practical techniques for promoting emotional and mental wellbeing.

We have also been busy conducting focus groups and gathering feedback to inform the development of our training offerings and website services and functions. Consequently, two workshops, free for family members to attend, were held in March focusing on the impact of the pandemic, trauma and emotional wellbeing. We are also trialling the an 'Emotional Wellbeing Journal' for tracking changes in mental health and wellbeing and developing a membership package including additional resources, documentation templates and access to discussion forums.

We are keen to hear from anyone who would like to get involved in our work, and particularly in the development of training programmes to support and equip carers and professionals in this very important aspect of their role.

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The NAC website: https://www.nacwellbeing.org/

NAC are offering workshops, training and consultancy. For more information go to: https://www.nacwellbeing.org/training-consultancy-page/

You can sign up for a free e-newsletter to keep up to date with the latest news and events. https://www.nacwellbeing.org/newsletter/

PMLD LINK
sharing ideas and information

Spring 2021, Vol. 33 No. 1 Issue 98

The Seldom Heard project

Jill Bradshaw and Siobhan Humphreys

Everyone has the right to have a say about their own life and about wider issues that impact on them. This includes children, young people and adults with severe learning disabilities and profound and multiple learning disabilities. In reality, we know that these peoples' perspectives are seldom heard. This can be because people think it is impossible, but this is not true, it just requires more skilled and creative approaches.

Introduction

In 2017 the Challenging Behaviour Foundation published a report called 'Valuing the views of children with a learning disability' showing how a range of people were using different methods to understand the views of children with learning disabilities. In 2021 a report was published called 'Stop Look and Listen to Me'. This report details methods developed by the Challenging Behaviour Foundation and the Tizard centre to understand the views and perspectives of young people with severe learning disabilities. We did this as a pilot for the 'Seldom Heard' project.

In recognition of the need to get better at seeking the views of children and adults with learning disabilities and more complex communication challenges, NHS England has funded the Seldom Heard project. The Seldom Heard project builds on existing good practice around listening to and involving people with severe and profound learning disabilities. We all need to be more creative to make sure we listen properly to everyone, especially about decisions that make a difference to peoples' lives. This includes people who might not have their views and preferences considered, for example:

- Children and adults with severe learning disabilities;
- Children and adults with profound and multiple learning disabilities;
- People with learning disabilities who are also autistic.

The Challenging Behaviour Foundation and the Tizard Centre have been working on new and creative ways to improve how we listen to these individuals. We have been supported by an advisory group which includes family carers, providers, Mencap and PMLD Link.

The Seldom Heard project will use these methods to find out about the views and preferences from nine people. We will try to find out how to deliver better support to people with learning disabilities. Children and adults who take part will benefit by:

- Having their views heard by NHS England. We will write a report;
- Getting a personalised tool with ideas about how best to gain their views and how to support better communication, choice and control. This can be used by families and caregivers to make sure their views and preferences are always taken into account in the future;
- Helping to show how everyone's views and preferences can be heard;
- Helping influence how the NHS delivers support to people with learning disabilities and autistic people;
- Influencing better support and ensuring services are designed that truly meet the person's needs and preferences.

The Seldom Heard Website is now live at: https://www.challengingbehaviour.org.uk/driving-change/seldom-heard.html

This article reflects on our learning to date, with a particular focus on identifying families, consideration of whether or not individuals would like to take part and the impact of the pandemic.

Identifying communication partnerships and explaining the project

We had help from our advisory group to understand the definitions and to clarify the individuals we were looking for in this project. Our advisory group had highlighted that they felt that many projects had not included people with the most complex communication challenges. In order to do this, we advertised through our existing networks.

We had an initial phone call with interested people. This was to:

- talk through the project;
- check shared understandings about this group
- explain that this was an exploratory project and needed an individualised process.

We were aware that individuals (paid supporters and family carers) had limited time available and so this initial meeting was brief. Those interested were then contacted to go through consent processes. As expected, this group of people are those with the most complex communication needs which therefore means that people were unable to comprehend the abstract nature of the project and therefore unable to consent. Therefore best interest processes were followed as needed. Independent checks were carried out on best interest decisions.

For the best interest process, we needed quite a sophisticated understanding of each person's communication and interaction skills, particularly around indicators of pleasure/distress. At the same time, people expressed interest in this project because they wanted to develop their shared understandings of such issues and so some information was less clear at this point.

Participants were varied in terms of age, communication partner (e.g. family member or paid supporter), age (children and adults), where they lived (e.g. at home with families, in residential adult services or residential schools) and whether they attended any day provision. Some communication partners had daily contact with the individual and some had less frequent contact.

We wanted our processes to be complete so that individuals had all the information that they needed. However, providing detailed information was not always consistent with our commitment to making the process as easy as possible for those who had expressed an interest in the project as it took time to go through all the information.

Impact of the pandemic

This project started in early 2020. As the reality of the pandemic became clearer, the project paused until November. We then (hopeful of a more normal life) started to identify possible families with the hope of being able to do at least some direct engagement work in early 2021. It became apparent as we moved back in to lockdown that the project needed to take place online, particularly as people with severe or profound learning disabilities had been identified in the group of people who were clinically extremely vulnerable.

Whilst we were confident about our ability to work through communication partners, we were also aware that:

- Everyone was tired and all experiencing challenging circumstances;
- Unpaid carers for this group always have very many challenges on their time and these have been amplified by loss of services;
- People with PMLD have also lost so much and the need for this project has become even greater.

Moving forward

Our online engagements are about to start and we aim to report our findings in Summer 2021. We will co-produce this process with communication partners, identifying what the focus of gaining views should be and any opportunities to find out views directly from the individual. This might include asking communication partners to observe the individual in different situations and think about the evidence there is that the individual might have preferences for what has happened in each situation.

We plan to disseminate our project widely and the Seldom Heard website will be able to sign up for updates.

Families told us that it was important that information about the project was circulated from trusted networks. We have had a huge response which is a good indication that this issue is something that is very important. However, we are of course aware that this might mean we have contacted families/individuals who are already known to us. On balance, we felt that at this stage, we needed to demonstrate that we can do this work. Our plan moving forward (subject to funding) is that that we can then disseminate and plan for wider engagement. In doing this, we want to be able to demonstrate to other organisations what is possible and to support them to consult much more widely with this group.

The Seldom Heard project builds on existing good practice around listening to and involving people with severe and profound learning disabilities, including:

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The Seldom Heard Website is now live: https://www.challengingbehaviour.org.uk/driving-change/seldom-heard.html

We also have a link to the Stop look and listen to me report: Stop, Look and Listen to me https://www.challengingbehaviour.org.uk/learning-disability-assets/stoplookandlistentome.pdf

References

Doukas, T. et al (2017) *Supporting people with profound and multiple learning disabilities: core and essential service standards* (www.pmldlink.org.uk/wp-content/uploads/2017/11/Standards-PMLD-h-web.pdf)

Mencap and BILD '*Involve me' project* – see the practical guide, evaluation and top tips summary (https://www.mencap.org.uk/advice-and-support/profound-and-multiple-learning-disabilities-pmld/pmld-involve-me)

Mencap and the PMLD Network (2013) Raising our sights: communication how-to guide (https://www.pmldlink.org.uk/wp-content/uploads/2017/10/2012.340-Raising-our-sights_Guide-to-communication_FINAL-1.pdf)

Goldbart, J. and Caton, S. (2010) *Communicating with people with the most complex needs: what works and why this is essential* (https://e-space.mmu.ac.uk/198309/1/Mencap%20Comms_guide_dec_10.pdf)

Thurman, S. (2011), Communication as a human right, *PMLD Link*, Vol 23 (1), Spring 2011 (Issue 68), 10-14, (https://www.pmldlink.org.uk/issue/speaking-up-being-heard/)

The Challenging Behaviour Foundation (2017) *Valuing the Views of Children with a Learning Disability (https://www.challengingbehaviour.org.uk/learning-disability-assets/valuingtheviewsofchildrenwithalearningdisability.pdf*)

The Seldom Heard Project Group (2021) *Stop Look and Listen to Me* Available online at: https://www.challengingbehaviour.org.uk/learning-disability-assets/stoplookandlistentome.pdf

The Oliver McGowan Mandatory Training in Learning Disability and Autism

The Oliver McGowan mandatory training in learning disability and autism aims to ensure staff working in health and social care receive learning disability and autism training, at the right level for their role. They will have a better understanding of people's needs, resulting in better services and improved health and wellbeing outcomes.

The training is named after Oliver McGowan, whose death shone a light on the need for health and social care staff to have better training. Find out more: https://www.hee.nhs.uk/our-work/learning-disability/oliver-mcgowan-mandatory-training-learning-disability-autism

Take part in an online event: Oliver McGowan mandatory training in learning disability & autism: stakeholder forum #3 on Tuesday 6 July 2021 - 10:00 - 12:00 via Zoom

The purpose of this event is for anyone working to support people with learning disabilities and autistic people to hear about the progress to date on the work currently taking place with partners to design, develop, trial and develop the mandatory training. It is an opportunity to convey updates, obtain feedback and answer questions raised.

Please note registrations for this event will close on Friday 25 June 2021.

To book: https://www.eventsforce.net/skillsforcare/1159/home

I don’t want to go the dentist

Sarah Hall

The PMLD Standards asks that organisations “Recognise and respond to the holistic vulnerability of people with profound and multiple learning disabilities and ensure the quality of their physical and mental health status.” (Doukas et al, 2017, page 20). I was asked to help a man who experiences great sensory sensitivities, prepare to visit the dentist. Here are some of the ideas we tried. (I do appreciate the irony here … I had dental treatment yesterday and I was absolutely terrified!)

Firstly for reference, I watched a short video from Sensory Spectacle’s YouTube channel, Why Brushing Our Teeth can be Difficult (https://www.youtube.com/watch?v=WCOTtDLgjkI). Becky offers great advice – clear information, insight and practical ideas.

Visit the dentist beforehand (if allowed) and just sit in the waiting room – with a bit more preparation, even sit in the dentist’s chair if possible! Due to Covid we avoid possible mounting tension in the waiting room by waiting outside the building or in the car. If things change, maybe keep this system in place.

Preparation is key. We need repetition; everything - over and over again. Familiarity not only to remove fear of unpredictability but also to enable learning and understanding to occur. We used our weekly sensory sessions to get familiar with everything about teeth and the dentist’s routine.

“’Sensory stimulation’ is the offering of sensory stimuli in order to cause sensory neurons to fire, cross synapses, connect together and create a neural sensory pathway to the brain, via the nervous system. This requires the constant repetition of many varied sensory experiences for the strengthening of these sensory pathways to the brain.”

Flo Longhorn (2007, p.6)

Flo Longhorn’s ‘Sensology Workout’ recommends a warming up of our senses, akin to athletes warming up. This man has reflexology as part of his regular sessions with me. I decided to do this after his “hello” song. (Happy to meet you by Celine Dion). Partly to wake up his senses but also to help him feel nice and relaxed.

This was easy for us to emulate at the dentist surgery, using a lavender roll-on, but sprays, or oil on a hanky or a tie work just as well. I made this roll-on for him but you can buy these, or an Aromastick, ready-made. Lavender is great for relaxation. (I now use oils on aromatherapy jewellery too). I massaged the man’s hands and played his personal reflexology music playlist. For him I use Silver Stars by Jessica Curry which is a track from the ‘Connections’ CD collection of music for autistic children and young adults (Curry and Curry, 2005). It is very calming and repetitive.

In the sessions to this music, we also incorporated some de-sensitisation work around his head, face and mouth. Touching his face with soft make-up brushes, pastry brushes, face massagers, any soft material, fingers and massage oil, head massagers, saying “aah” and making circles around the mouth.

Sensology activities help with preparation for an experience but also provide positive touch. Another example of using a positive touch approach is a story massage. This could be done before, at the visit and then afterwards to remember what happened. For this man I particularly used palm presses or shoulder squeezes because they are calming moves.

If appropriate, you can additionally use any visual aids (photos, pictures, symbols), timers, create social or sensory stories, sets of rules or rehearse set-conversations, traffic light systems or concrete props, to suit your client.

There is also a story called ‘The Dentist’ on the Rhyming Multisensory Stories website (https://www.rhymingmultisensorystories.com).

The song “5 White Teeth” was our introduction to ‘teeth’ (for example see: https://www.youtube.com/watch?v=p-LKar3EtFY). He likes lights so I used a light up Mohican headband for teeth and removed one ‘tooth’ after each verse. He liked the intonation and I added an ‘ow’ sound too. Humour is a great tool in helping alleviate stress and calming down. It can also be a distraction.

At the dentist it might be worth having a worry bag/box or similar such as an ‘all about me’ or fidget or busy bag/box. Favourite familiar books, items, songs, activities, smells may provide comfort and reassurance. Calming resources e.g. stress ball or weighted blanket or calming music may help. Being relaxed yourself helps. This is not easy if someone dislikes an activity, especially when you care for them.

Cleaning teeth can be functional, so slow it right down. Cue the person in with set terms of reference- a song, smell, words, object, as appropriate. The toothpaste or toothbrush or both make an obvious object of reference for brushing teeth. A latex glove or some mouthwash in a travel spray bottle could be used for the dentist smell. This is used to give a clue, to cue someone in as to what is going to happen. The same object/smell/touch cue needs to be used by all staff/ people involved for consistency- and to create predictability.

If I told you to clean your teeth repeatedly, it feels like nagging. However by singing instructions it allows you to repeat instructions over and over again, in a way that removes nagging and make it fun. Making up songs to familiar tunes also allows personalisation and singing the person's name repeatedly adds clarity and self-awareness. Sutherland House School use this technique for a musical interactional approach for example,

- It's time to clean our teeth now (to the tune "everybody conga")
- We're going to the dentist (to the tune "seaside")
- This is the way we clean our teeth (to the tune "mulberry bush").
- Open, open, open your mouth today (to the tune "Daisy Daisy")

Songs used in the sessions were used with a slowly, slowly approach - a song for toothbrush, a song for toothpaste, a song for both together, a song to relax with instruments, dentist songs with tools.

For our "Brush Your Teeth Each Morning" song we explored a light-up toothbrush, held a vibrating toothbrush and maybe put in mouth. If able to understand the light acts as visual timer too.

Consider trying

- toothpastes with flavour or no flavour and low-foam pastes (good for those who cannot rinse and spit!)
- brushes - chewy ones, fingertip dog toothbrushes (you can now get human versions of these!), service station brushes in a ball,
- smells -try different hand-gels or mouthwash in a spray
- sounds – look for Ipad apps – there are always new weird and wacky ones appearing on social media,

Our final routine had a song for each element which included

- Clean Your Teeth - we tasted different toothpastes and tried unusual, fun and no flavour pastes
- Brush Your Teeth in the Morning - I used the finger toothbrush gently near and in his mouth, using whichever toothpaste he had favoured that day.
- Brush Brush Bree (https://www.youtube.com/watch?v=SDrFdHM_wMg) - this is a fun song which we played instruments to. Gave him a bit of a break too! Autonomy is important -having some control and being able to do some parts of the routine by themselves. This aids emotional wellbeing.
- The Dentist and Open Wide songs - we used a set sequence to pretend to be at the dentist. We had dentist smell, we practised lying down in my massage chair, moved lamps, practised with latex glove on in his mouth and poking a dentist mirror and poky stick in his mouth, saying "aaah" and pretend conversations.

We concluded his session with his goodbye song. Another one by Jessica Curry but he is not keen on the word goodbye so we play an instrumental version and I just say it once or twice.

Try to develop a positive association with the dentist visit too e.g. stickers, or maybe a treat – sweets (?!?), McDonalds or coffee afterwards.

To conclude, familiarisation through preparation and rehearsal using the approaches of sensology, de-sensitisation, musical interaction fun and distraction, together with sensory resources and favourite items, may all help allay anxieties.

Please bear in mind - I am also a bit of a hypocrite. As I said, I went to the dentist yesterday. I did not get a sticker - I did not deserve a sticker. As well as shouting out loud at one point, when he said "Open your mouth", very quietly and sullenly I replied, "I don't want to!"

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References

Curry, C. and Curry, J. (2005) *Connections: a double cd collection of original music, songs, stories and games for children and young adults across the autistic spectrum*. CDs and paperback. Onnections Music Company.

Doukas, T., Fergusson, A., Fullerton, M. and Grace, J. (2017) *Supporting People with Profound and Multiple Learning Disabilities: Core and Essential Service Standards*. (downloadable pdf document available at: http://www.pmldlink.org.uk/resources/#pmld-standards)

Longhorn, F. (2010) *The Sensology Workout - Waking Up the Senses*. Available online: https://drive.google.com/file/d/12MB24Utcyi_UnRPG5RN6h3vIPrIJMEvL/view?usp=sharing

Listening and responding through Non-Instructed Advocacy

Martin Goodwin

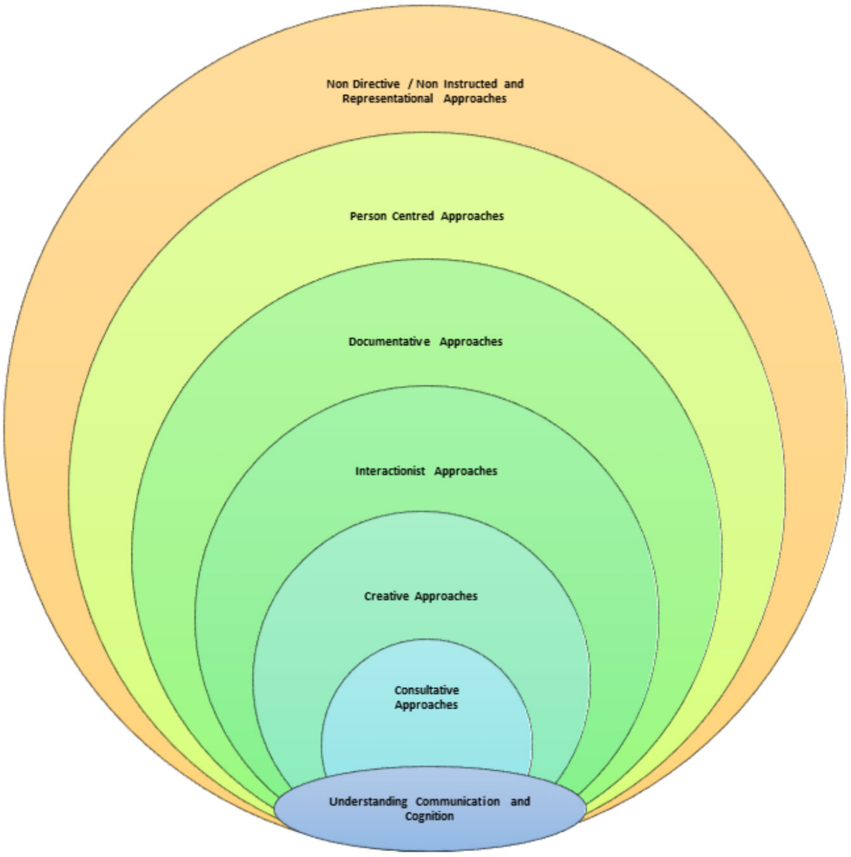
Advocacy is based on notions of human rights, citizenship and inclusion, however, people with PMLD can be regularly denied advocacy support due to the challenges faced in supporting their voice to be heard. This article explores the concept of 'non-instructed advocacy' and how it can be used to articulate the rights of people with PMLD.

Non-instructed approaches support practitioners or advocates to help decisions to be made that reflect the person's perceived interests, wishes, lifestyle and personality. Non-instructed approaches challenging service to secure the perceived interests, views and needs of the person. Henderson defines the approach of non-instructed advocacy as:

> '..taking affirmative action with or on behalf of a person who is unable to give a clear direction of their views or wishes in a specific situation. The non-instructed advocate seeks to uphold the person's rights; ensure fair and equal treatment and access to services and make certain that decisions are taken with due consideration for their unique preferences and perspectives' (Henderson 2007).

People with PMLD are vulnerable to acute discrimination in all sectors of their lives. Non-instructed advocacy can usefully support with a myriad of issues; advocating on behalf, supporting with complaints and challenging access, ensuring equality of opportunity and outcome and strengthening human rights. Non-instructed advocacy can be facilitated through a model of blended approaches that support the process of listening and responding (Fig 1).

The right to advocacy is enshrined through the ethos of UN convention on the rights of the child and recognised in law, in example through the Children's Act 1989, 2004, Children's and families Act 2014, Health and Social Care Act 2012 and learning disability related policy such as Valuing People (2002) and Valuing People Now (2007).



Advocacy provision has been variable in availability, accessibility and quality (Children's Society, 2011). Non-instructed approaches have been utilised within the advocacy movement but are viewed contentiously. Purist advocacy schemes were initially cautious of the approach as its stance and methods are incongruent with traditional advocacy models. Due to increasing recognition of the need for people who are considered not to have the capacity to direct advocacy in a specified circumstance the application of non-instructed advocacy has been increasingly used. However, the practice, outcomes and efficacy of non-instructed advocacy have received limited empirical research. Non-instructed approaches are primarily used when a decision needs to be made. The following approaches may be useful in combination with each other, and as shown in the model above (fig 1).

Best Interest Approaches

Some people with PMLD may rely on 'best interest' approaches. Within the advocacy movement the issue of best interest is contentious, however, (for people aged 16 and over) the Mental Capacity Act stipulates that in cases where people may not have the capacity to make a specific decision that the best interest decision can be made. It is morally important that before pursuing the best interest decision, all other possible attempts to involve the person should be made. Frameworks such as the ones described below can support in making decisions on behalf of people.

Shadowing and Witness Observer Approach

A 'getting to know you' approach, as described by Brost and Johnson (1982), is essential in working with people with PMLD. Both the 'shadowing' and 'witness observer' approaches are forms of observation that can be utilised to represent the person's perceived wishes or comment on issues that a person may face. The approaches help to gain a sense of what is important to a person or challenge issues on behalf of people.

Money and Collins (1999) describe a shadowing approach where the lived experience of people we are supporting is understood.

As a children's rights advocate, I utilised the witness observer approach by regularly visiting children's homes to observe potential issues. This approach is necessary as many children would not be able to refer themselves to services. So as an advocate I supported the improvement of issues through working with staff (albeit cautiously to ensure that I remained as impartial as possible). This approach increased awareness of rights issues and staff became confident in referring issues on children's behalf. Examples of specific issues supported through pursuing an witness observer approach included advocating increased meaningful access to communities, play and leisure activities, negating institutionalised practices and ensuring provision of education.

General and specific issues were also championed at a service level with heads and local commissioners of services so that rights-based issues were resolved without having unnecessary burden. It would be highly beneficial in safeguarding the rights of people with PMLD if all services that provide support to people with PMLD have regular visits where the witness observer approach is carried out on a regular basis such as through an independent visiting scheme.

Person-centred approach

A 'person-centred' approach is about focusing on what is important to the person and emphasises what the person wants or what is important to the person. This can be determined by getting to know a person through building a relationship with them overtime, building a picture of the person with the people who know them well. Practitioners can also use existing documents to develop a picture of a persons' life, observe their preferences and personality and discuss with others how a person communicates. It is important that much time is afforded to this process and that the practitioner checks interpretations and does not make assumptions (Goodwin, Miller and Edwards, 2015; Voices through Advocacy, 2008). The frame of being person-centred allows decisions and observed support to be questioned. Whilst being a children's rights advocate I utilised a person-centred approach.by me Specific examples include institutional regimes of enforcing bed at a very early time without consideration of individual needs or wishes, choice and control over basic decisions such as observation of preferences for particular ways of being supported, preference of communication methods and transition arrangements.

Rights-Based approach

A 'rights-based' approach is about ensuring that the person's rights are met. Within this approach, a practitioner would ask questions utilising legislation, such as the Human's Rights Act and the Equalities Act, so that the person's rights are not contravened. Rights-based issues should always be challenged and where needed complaints should be made. There is sometimes a hesitation to take issues to the level of a formal complaint, sometimes due to not being sure if it is what the person wants. Complaints systems also entail representation on behalf of people, which means that many issues can be pursued from a rights-based agenda and enable valuable insights and experiences to be acted upon. Whilst being a children's rights advocate, I frequently used a rights-based approach by challenging service responses that contravened among others the Human Rights Act, the Children's Act and the Equalities Act. Specific examples include challenging inaction from social workers in accordance with legislation; for example, in relation to visitation rights from parents, safeguarding, specialist equipment and not making reasonable adjustments.

Questioning: Watching Brief

The 'watching brief', which was developed by Assist (an advocacy project in Staffordshire, UK in 1994), provides a structured framework for questioning propositions for decisions that are being made. The framework utilises eight domains that are based on factors of a quality of life and supports practitioners to structure questions that could help make a decision. Assist (no date; pg. 3) provides the following definitions:

- Competence – developing and using skills to be as independent as possible
- Community presence – using, being involved with and contributing to the local community
- Continuity – having a past, present and future with critical people and events in your life
- Choice and Influence – influencing and making choices about your own life
- Status and Respect – being held in esteem and valued for who you are
- Individuality – being a unique and distinctive person in your right
- Partnerships and Relationships – having meaningful contact with other people
- Well-being – feeling physically and psychologically well

There are many contexts in which the watching brief could be used. For example, the impact of moving a residential home placement was a major decision that was often made without fully considering the needs and potential wishes of the child. In such a scenario questions asked on behalf of a person supports the service to consider the impact of decisions or suggest alternative proposals to how they could support a person. For example, such as how the proposed move might impact on their wellbeing and if the proposed move enables the person to sustain consistent relationships with people who know them. As a children's rights advocate, I found that the watching brief effectively supported questioning the rationale of decisions and ensuring that they focused on person centred and rights- based outcomes.

Challenges with Non-Instructed Approaches

In practicing non-instructed approaches there is always a level of uncertainty and active reflection is needed to ensure that we are supporting decisions to be made within the frame of the potential view or perspective of the person we are supporting. As a children's rights advocate, I found that representations on behalf of the child were rightly questioned. However, this led to a deeper understanding of who the child is, what is important to them and elicitation of their potential view. The above frameworks support person-centred decisions or observations to be made, however, reflexivity, as Ware (2004) suggests, is needed so that the potential intentions of people with PMLD are not misused or misapplied. Equally, when using non instructed advocacy it is important that advocates do not feel pressured to represent an issue or decision proposal or presume a role of automatically knowing a person's potential view. In all advocacy partnerships getting to know a person and finding ways of involving that person in their lives as much as possible is essential.

It is important that staff working with people are supported to be part of advocacy partnerships, especially where independent support may not be available. Staff can support people they work with by when decisions are to be made by utilising the above approaches. However, conflicts of interest may invariably arise. Within services any member of staff can raise issues on behalf of a person using a service and policies promote a listening culture. Whilst whistleblowing and a duty of candour is stipulated, in practice staff may not feel confident to advocate on behalf of people who they support for fear of reprisal or reprimand; rendering the rights and protection of people with PMLD precariously vulnerable.

Ongoing relationships that prioritise listening and responding are needed to circumvent rights-based issues. Staff should be supported to understand non-instructive advocacy approaches as part of their commitment and responsibility to involving people and within the co-production of services/support. Training in rights-based approaches supported by strong arrangements for ongoing practice-based leadership would support staff to develop effective responsive partnerships where people are listened to.

The human rights and liberties of people with PMLD are frequently overlooked. Non instructed advocacy provides a central role in safeguarding the rights of people with PMLD and ensuring that services, access to goods and services and equality issues are challenged. The Core and Essential Service Standards (Doukas et al, 2017) promote the central role of all supporters being advocates for people with PMLD; let's give families, staff and advocates the tools to champion their rights and support their voice.

Contact Details

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References

Assist (no date) *Watching Brief.* Available from: http://www.asist.co.uk/assets/uploads/PDF/Watching_Brief_leaflet_for_care_givers_and_professionals_web_version.pdf (Accessed 16/8/17)

Brost, M.M. and Johnson, T.Z. (1982) *Getting to Know You: One approach to service assessment and planning for individuals with disabilities.* Wisconsin: Wisconsin Coalition for Advocacy.

Children's Society (2011). *Someone on our side: Advocacy for Disabled Children and Young People*. Accessed from: https://councilfordisabledchildren.org.uk/sites/default/files/field/attachemnt/advocacy_report_2011_final.pdf (Accessed 09/02/2020).

Doukas, T., Fergusson, A., Fullerton, M. and Grace, J. (2017) *Supporting People with Profound and Multiple Learning Disabilities: Core and Essential Service Standards*. (downloadable pdf document available at: http://www.pmldlink.org.uk/resources/#pmld-standards)

Goodwin, M., Miller, J. and Edwards, C. (2015) *Communicate with Me – A Resource for Effective Communication and Involvement of People with a Learning Disability*. Abingdon: Routledge

Henderson (2006). *Non-instructed advocacy in focus*. London: Action for Advocacy.

Money, D. and Collins, G. (1999) Satisfaction for all: a framework for assessing life satisfaction for all people with learning disabilities. *British Journal of Learning Disabilities***.** 27, 52–57

Voices Through Advocacy (VTA) (2008) *When Communication Gets Tough*, Scope, London.

Ware, J. (2004) 'Ascertaining the views of people with profound and multiple learning disabilities', *British Journal of Learning Disabilities*, 32, pp175–9.

Access recent issues online

Subscribers can log on as a members of PMLD LINK on its website (http://www.pmldlink.org.uk/login) and access downloadable pdfs of the most recent ten issues from the last three years. Only 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@pmldlink.org.uk

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

Coronavirus and people with learning disabilities: Wave One survey results

Jill Bradshaw, Samantha Flynn, Tom Bailey and the Coronavirus and people with learning disabilities study team

In the Winter edition of PMLD link, we wrote about our UK-wide project, looking at the impact of coronavirus on the lives of adults with learning disabilities. We have two surveys which we will ask people with learning disabilities or family carers/paid support staff to complete three times over the next year. We have now completed Wave One. This article reports the results of our initial findings from the survey with family carers/paid support staff about the impact of the coronavirus.

Who completed the survey?

We had completed surveys from 378 family carers/paid support staff, 166 of whom were supporting/caring for people with PMLD. Most surveys were completed by family carers (80%). They told us about roughly equal numbers of men and women with PMLD. Most people with PMLD were under 45 (76%) and white (92%). They told us about people living in towns (43%) cities (34%) and villages (24%). Some people with PMLD were living with their family (59%). It varied whether or not people who lived with their families had support from staff, with more people who lived with their family not having support from staff than having support from staff.

We were very pleased to have recruited so many family carers/paid support staff of people with PMLD in this study. Members of our advisory groups had previously told us they felt that people with PMLD were often invisible within research. We are very grateful for all the help with recruitment that we have had from our partners.

Health

Most people with PMLD (60%) were reported as being in good health on the day the survey was completed but one third of people were described as having physical health that had changed for the worse since lockdown began.

Almost three quarters (72%) of family carers/paid support staff of people with PMLD reported that the person they supported/cared for had a health condition that was likely to increase vulnerability should they be exposed to COVID-19. The most common health conditions reported as being issues for people with PMLD were asthma and epilepsy.

COVID-19

Around 43% of people with PMLD had had a test for COVID-19. Most of these (78%) produced a negative result. Twenty three people with PMLD had a confirmed or suspected case of COVID-19 and 4 of these people were admitted to hospital due to their symptoms.

Around 8% of people with PMLD were reported as having experienced a death, from COVID-19, of someone close to them. This was a similar number to those people who had a learning disability but not PMLD.

Most people (83%) with PMLD were reported as being likely to accept the COVID-19 vaccine if it was offered to them.

Shielding and Social Contact

Sixty three percent of people with PMLD had been shielded at some time since March 2020. Some people had been shielded since the start of lockdown. This meant that neither they nor their family members who were shielding them had left the house or garden at all during that time. Around 90% of people with PMLD had access to a private or shared garden where they lived.

As with everyone, face to face contacts reduced during lockdown. Although a relatively small number of people with PMLD used video or telephone calls to stay in touch with people before lockdown, use of these methods of remote contact increased during lockdown.

Table 1: How people with learning disabilities stay in contact with friends, family and other people

Around one fifth of people with PMLD had not been allowed ANY visits from family and friends since the start

Face to face	Do this now	19%
	Did prior to lockdown	70%
	Never did this nor do they now	14%
Meet outside	Do this now	19%
	Did prior to lockdown	74%
	Never did this nor do they now	10%
Meet in others' house	Do this now	4%
	Did prior to lockdown	67%
	Never did this nor do they now	25%
Meet in own house	Do this now	7%
	Did prior to lockdown	76%
	Never did this nor do they now	14%
Meet in other indoor places	Do this now	8%
	Did prior to lockdown	82%
	Never did this nor do they now	11%
Talk on telephone	Do this now	30%
	Did prior to lockdown	15%
	Never did this nor do they now	60%
Through video calls	Do this now	58%
	Did prior to lockdown	11%
	Never did this nor do they now	36%

of the first lockdown. The majority of people with PMLD (74%) were reported to have experienced a negative impact as a result of visitor restrictions.

More than 50% of people with PMLD were reported to get on well with the people with whom they lived, with the remaining people reported to have relationships that were 'up and down'. Some people with PMLD who lived with other people with learning disabilities were reported to be not particularly interested in the people with whom they lived.

Personal Protective Equipment (PPE) and Essential Equipment

Most family carers/paid support staff (59%) of people with PMLD told us that they were wearing PPE. They were twice as likely to wear PPE than family carers/paid support staff of people with learning disabilities who did not have PMLD. Nearly 40% had had or were continuing to have difficulties in being able to access the protective equipment they needed. Most people (75%) did not say that they thought wearing PPE had had a negative impact on their relationship with the person with PMLD they were supporting/caring for.

Family carers/paid support staff of people with PMLD were 2.5 times more likely to have experienced some difficulty in accessing equipment and resources, compared to those who support/care for people without PMLD. Over half of these people were still having difficulties at the time of completing the survey.

Face Masks/Coverings

People with PMLD were over five times less likely to wear a face mask covering when compared to people with learning disabilities who did not have PMLD. They were nearly 4 times more likely to be exempt from wearing a face mask/covering. Just over 40% of people with PMLD were reported as not wearing a face mask/covering because they did not understand the reason why one was needed.

Health and Wellbeing

Over 70% of people with learning disabilities with and without PMLD who saw their healthcare professionals regularly before the first lockdown in March 2020 reported seeing them less since the first lockdown. Over 40% of people with PMLD had had a planned hospital appointment cancelled since the start of the first lockdown. Around two thirds of people with PMLD had not had an annual health check since lockdown began.

Most family carers/paid support staff of people with PMLD reported that the wellbeing of the person they supported/cared for had changed for the worse since lockdown began.

The majority of people with PMLD (72%) had had their Winter flu vaccine in Winter 2020/2021.

Sources of Support

Prior to lockdown, people with PMLD were reported as experiencing a variety of supports including day services (68%), community activities (79%) going out with support workers (72%) respite or short breaks away from home (45%), support workers helping them at home (72%) and professional contact by telephone or video contact (23%).

Support for people with PMLD was reported to have substantially reduced since the March 2020 lockdown. This was particularly the case for day services, with 97% of family carers/paid support staff of people with PMLD commenting that services had reduced or stopped completely by the time of the surveys (Dec 2020 – Feb 2021). Almost all people with PMLD (98%) were reported to have had their community activities stopped or reduced and 96% of people with PMLD had experienced a reduction or stopping of their short breaks or respite since the start of the first national lockdown in March 2020. People with PMLD were reported to be nearly twice as likely to have NOT been to day services and nearly two and a half times more likely to have NOT attended community activities, compared to people without PMLD.

People with PMLD were almost always reported to have been getting the food and medications they needed, with much of the support for this coming from family.

Work and Finances

Twelve people (7%) with PMLD were reported to have had a paid job before the start of lockdown and 8 of these people were reported to be still working or furloughed. A similar number of people were reported to have had a volunteer job before the start of lockdown. Seven of these people had lost this role. The majority of people with PMLD were reported to have had the same amount of money to spend now as they had had before the first lockdown.

What next?

We are about to start wave two of our data collection. We hope to get information from all those who completed the survey in Wave one. This will help us to see what is happening to people with PMLD over time. We have been working with our advisory groups and we are particularly pleased to have an advisory group for this group that is across all four nations. As the group of people with PMLD is small, we hope that this group will help us to focus on asking the right questions and to understand the implications of the results so far.

If you want to know more about the results, please visit the project website for more details: www.covid19learningdisabilities.co.uk

Contact Details

This report was coauthored by Dr Jill Bradshaw, Dr Samantha Flynn, Dr Tom Bailey and the Coronavirus and people with learning disabilities study team. The advisory team includes members of PMLD Link and Learning Disability England.

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In the Next Issue

Our Summer issue of the journal is a general issue without any specific theme and we would welcome articles on any topics for this issue. However, we are conscious that during the past twelve months of the Coronavirus pandemic people with profound and multiple learning difficulties and their families and carers have suffered a great deal. We know of cases that have been particularly distressing and we have also heard remarkable stories of many people who have behaved selflessly and even heroically. So, we would like to share these kinds of stories more widely.

We welcome submissions from anybody. We do realise that many of our readers have a story to tell but do not consider themselves as writers. However. PMLD Link’s editors are very happy to help you shape your contributions. Your insights are valuable and by sharing your knowledge, understanding and ideas you can have a positive impact on other people's lives as well as your own. We want to hear from you!

Of course, your article need not be about the pandemic at all. Do you have anything you wish to share that relates to the lives of people with profound and multiple learning disabilities? It could be something you alone have experience, 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. And we are always keen to share relevant news, events, new resources or publications so please let us know about these too.

All contributions by 31st June please.

The Summer issue editors are Wendy Newby, Martin Goodwin and Rob Ashdown.

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

REPORT BACK

Emotional wellbeing for people with severe and profound intellectual disabilities presented by NAC Wellbeing

I’ve just watched the webinar and thought it was a really excellent source of information and very much enjoyed it. I was very pleased that in the webinar NAC recognise that people with PMLD are affected by emotional and mental wellbeing in the same way as everyone else. I found the information provided about the scientific background really interesting. It seems likely that during the pandemic they will have been even more affected because of their inability to understand why their lives have changed so much and because so many of the activities and relationships that are meaningful to them have disappeared. It was very helpful that NAC provided strategies to help to manage the detrimental effects of the pandemic on the lives of people with PMLD.

I also took the opportunity to have a closer look at the NAC website and was incredibly impressed by the range and depth of the information, advice and ideas provided. I shared a link to this website with both of my daughter's care providers as I thought that the information would be invaluable for their staff and the people they support, and in particular would be an excellent training resource for staff who are new to people with severe and profound learning disabilities.

Pat Graham, Family Carer

The 50 minute webinar is available to view on YouTube at https://www.youtube.com/watch?v=qfgJY3ANi9I

For more about NAC: https://www.nacwellbeing.org/

IN THE NEWS

Consistency in uncertain times

The Scottish Commission for Learning Disability has teamed up with the Challenging Behaviour Foundation on a joint newsletter to provide practical advice and resources for family carers and supporters of children and adults with profound learning disabilities.

You can access the newsletter online: https://bit.ly/31eYSP4

A limited number of printed copies are available to order in Scotland. To order a copy, please email admin@scld.co.uk or phone 0141 248 3733.

Ellie Griffiths of Oily Cart receives international award

Ellie Griffiths, of Oily Cart and an active supporter and contributor to PMLD Link, has become the first UK artist to receive the ASSITEJ International Award for Artistic Excellence. ASSITEJ is an international association of theatre for children and young people. The award is given to celebrate outstanding achievements and contributions to theatre for young audiences.

The award is shared with Dalija Acin Thelander, a Serbian choreographer working in Sweden, who makes sensory theatre work mainly for babies.

Speaking about her award, Ellie Griffiths said. “I am particularly excited that this year, the award for Artistic Excellence has been given to two artists working in a sensory way. It is about time that sensory theatre was recognised as a way of making ambitious, high-quality theatre that doesn't exclude anyone, rather than being seen as a specialism on the fringes. By thinking beyond words, we can shift the power dynamics and level the playing field in cultural spaces. Far from being specialist, sensory work connects us to the source of our humanity. Most of our most treasured, emotive moments are sensory ones”.

Launch new centre for improving adult care

March saw the launch of a new UK Centre for implementing evidence in adult social care. The new Centre is called IMPACT (Improving Adult Care Together.) It is funded by the Economic and Social Research Council (ESRC) and the Health Foundation. The Centre will receive phased funding until 2027 and builds on previous ESRC investments in social care development.

IMPACT will be an ‘implementation centre’, drawing on knowledge gained from different types of research, but with an emphasis on the lived experience of people using services and their carers and social care staff. It will work across the UK and is promised to be sensitive to the very different policy contexts in each of the four nations as well as being able to share learning across the UK as a whole.

Jon Glasby, University of Birmingham professor of health and social care, has been appointed director of IMPACT and will be working with a range of partners from across the UK to lead the co-development, establishment and delivery of the centre.

The fragmented nature of the adult social care sector poses real challenges for ensuring the consistent provision of evidence-based, high quality care and support. The Centre stated aims include bringing together people with lived experience of social care, those providing unpaid care, people working in adult social care, experts in the mobilisation and implementation of evidence, social care providers, commissioners and policy experts, and academic teams from across the UK. Key objectives are to enable practical improvements on the ground, and make a crucial contribution to longer term cultural change.

IMPACT will start its initial engagement work from 1st June 2021, and will spend the rest of 2021 consulting with stakeholders across adult social care, and across the four nations of the UK.

It has to remembered that adults with PMLD are a minority group receiving adult social care and it is important that to articulate their experiences and needs. If you want to find out more as IMPACT starts its work, please email impactcentre@contacts.bham.ac.uk with your name, role and location. You might also like to see a video on You Tube of Jon Glasby talking about the project at: https://www.youtube.com/watch?v=6xRi_my0G7I

Launch of a new 'Connecting with Intensive Interaction' website

18th March saw the official launch of the new 'Connecting with Intensive Interaction' website. On this website, you will find a lot of useful information about the social communication approach called Intensive Interaction. This website should help users to understand what Intensive Interaction is, who it is for, how best to use it and what benefits it can bring.

On the website, you can also read about research reports and Graham Firth's 'Connecting with Intensive Interaction' blog series and you can sign up to be notified of all new posts by email.

If you are a parent, a carer, a teacher, a health professional, or anyone else who is interested in Intensive Interaction, then you may find something useful here. Have a look at:
www.connectingwithIntensiveInteraction.com

Oily Cart's 'Space To Be' On Tour Now

During this first year of the pandemic Oily Cart has been performing personalised songs on doorsteps and online, creating packages for individual family members. Now Oily Cart is sending their new show 'Space to Be' direct into homes. Families open up a series of packages over the course of a week to experience the show. The story unfolds through specially designed objects in each box, inspiring sensory experiences in sound, light and touch. The sensory show has been created for and with disabled young people (aged 0-18).

Space to Be explores each family's unique story: our individual differences and how we are all connected like a constellation in the universe. Space to Be is touring from March until August 2021. It is free to all families. For more details go to: https://oilycart.org.uk/shows/space-to-be-2/

If you're interested, email alison@oilycart.org.uk
Call, text or Whatsapp Oily Cart on 07943 438 336
Or you can fill in a short form: https://forms.gle/KqwCc8qZoRZ9t3xc8

SPLASH Study

Hydrotherapy is the use of water for therapy and rehabilitation and is widely used but there is a lack of hydrotherapy evidence regarding adults with SLD/PMLD.

Carrie Tbaily, a Postgraduate Researcher, Bournemouth University, reports on a new SPLASH Study. SPLASH Study aims to explore caregiver experience of hydrotherapy, and any perceived biopsychosocial impacts on adults with SLD/PMLD.

January saw the start of recruitment of caregivers (paid carers, health/social care professionals and family members) of adults with SLD/PMLD to participate in the study. Participants will be asked to attend a virtual semi-structured interview (1 hour) and complete an online questionnaire (10 minutes). The questionnaire asks participants about their caring role, the needs of the adult they support and the type of hydrotherapy they receive. This information will add depth to understanding of each individual's lived experience.

If you would like to take part in SPLASH Study, the online consent form and study questionnaire is available at: https://bournemouth.onlinesurveys.ac.uk/splashstudy

Or contact Carrie Tbaily
email: ctbaily@bournemouth.ac.uk
phone: 01202 961150

https://www.facebook.com/SPLASHstudy

The Building Back Better Report

The Royal College of Speech and Language Therapists (RCSLT) is the professional body for speech and language therapists in the UK. It aims to promote the art and science of speech and language therapy – the care for individuals with communication, swallowing, eating and drinking difficulties.

Between November 2020 and February 2021 the RCSLT conducted a survey of people's experiences of accessing speech and language therapy during the first UK-wide lockdown (March–June 2020).

The report – Speech and language therapy during and beyond COVID-19: building back better with people who have communication and swallowing needs – was published in March. It tells the stories of the five hundred people who filled out the survey.

The survey revealed that some people continued to receive speech and language therapy during lockdown. Sadly, however, the survey has revealed that lockdown had a negative impact on people's communication and swallowing. It also had a negative impact on their access to speech and language therapy. This was especially the case in the most deprived areas of England. People also reported how their lives and the lives of their families and carers were made worse because they had less therapy.

The report details the impact on them and their families and carers of not having speech and language therapy, or having less therapy than they had before lockdown.

It also sets out what needs to happen to ensure that people with communication and swallowing needs can access the speech and language therapy that they need.

https://www.rcslt.org/wp-content/uploads/2021/03/Building-back-better-March2021.pdf

On 17th March the RCSLT wrote to the Prime Minister urge him to build back better with people who have communication and swallowing needs. The letter gives the headline news from the report as well as requesting urgent action to not only address the huge backlog facing services, but also ensure that building back better secures a real, sustained improvement in the lives of the people and their families and carers. The open letter can be viewed at: https://www.rcslt.org/wp-content/uploads/2021/03/Prime-Minister-letter-FINAL.pdf

The Longest Lockdown

The Disabled Children's Partnership (DCP) is a coalition of organisations campaigning for improved health and social care for disabled children, young people and their families. In January, the DCP asked its 'Parent Panel' of 1200 families about the impact of the latest lockdown – and the cumulative impact of the pandemic – on them and their families.

635 parents of children with a range of disabilities and needs responded to the survey. Inevitably, they reported that the lockdowns were having a devastating impact. Many said that their children were not receiving support for the disability or medical condition via health services or school. This has had detrimental impacts on their children's disabilities during a time of reduced levels of support at home during the pandemic.

The stark reality is that disabled children and their families are continuing to be left in lockdown despite promises from Government to prioritise vulnerable children. The DCP has called on the government to create an ambitious and funded Covid recovery and catch up plan for disabled children, covering not just education, but also health and wellbeing, and support for all the family.

The DCP has produced a report called 'The Longest Lockdown' that details what the parents reported and what action the DCP says is needed. The report is available at: https://disabledchildrenspartnership.org.uk/the-longest-lockdown/

New NHS policy on learning from the lives and deaths of people with a learning disability

LeDeR is a service improvement programme which aims to improve care, reduce health inequalities and prevent premature mortality of people with a learning disability and autistic people by reviewing information about the health and social care support people received.

This NHS policy sets out for the first time for the NHS the core aims and values of the LeDeR programme and the expectations of different parts of the health and social care system in delivering the programme. Responsibility for ensuring the delivery of LeDeR reviews currently lies with clinical commissioning groups (CCGs). There is a move into new arrangements in the NHS through 2021 and into 2022 and local integrated care systems (ICSs) will become responsible for ensuring that LeDeR reviews are completed for their local area and also, and very importantly, that actions are implemented to improve the quality of services for people with a learning disability and autistic people to reduce health inequalities and premature mortality.

In developing this policy, NHS England has engaged with over 400 including people with a learning disability and their carers, bereaved families, commissioners, health and care providers, members of the LeDeR workforce, social care providers and voluntary sector organisations, academics and policy experts.

There policy details roles and responsibilities and expectations of how to learn from the lives and deaths of people with a learning disability and autistic people (LeDeR)- and how to act to stop people dying too young.

Link to the easy read policy https://tinyurl.com/LeDeRPolicyEasy
Link to the full policy https://tinyurl.com/LeDeRPolicy
#LeDeR #EasyRead #Autistic #LearningDisability

Updated EasyHealth website launched

In April, Easy Health launched their refreshed and updated website (https://www.easyhealth.org.uk/).

This website provides an excellent source of information about many common health issues, treatment and medical procedures. The site is being constantly reviewed to ensure it is up to date and relevant to the current pandemic. Currently they have over 370 health resources about 120 health conditions or topics.

The website has a 'Common Health Conditions Section'. Each page contains an introduction to the topic and links to further resources about the condition and how it is treated. They plan to provide pdf downloads for each condition. These pages are open to anyone.

There is also an Easy Read Health Resources Section. This information is accessible to anyone who finds written information hard to understand, including people with learning disabilities. The formats include pictures, simple text and video clips. All of the videos and leaflets are tagged with relevant health conditions and these appear on the left-hand side of the page. Simply click on the name of the condition to see all the resources in one place. You will need to sign up as a member (free) of Easy Health to see these resources.

Vital health training for family carers - Identifying early signs of worsening health in a person with a learning disability

NHS England and NHS Improvement hosted free online training sessions for family carers throughout the month of March 2021. The 90-minute online workshop was for carers of individuals over the age of 16. The training was designed to help carers easily identify the often, very subtle signs that someone may be unwell and to let them know what they should do next. The training used SBARD and Restore2mini™, which are two resources that help guide the carer to have a clearer picture of a person's overall health condition, especially the early indications of deteriorating health. They help identify the signs and symptoms needed for medical professionals to more accurately assess and triage a person's health situation and more speedily take appropriate action. This version of the Restore tool has been specially adapted for people caring for people with a learning disability. Training in the use of these tools and approach are being promoted across all sectors as well as family carers - GPs, Primary Care professionals, social care providers and support workers, as part of a wider NHS strategic plan to address health inequalities in people with learning disabilities

Some responses to the training from PMLD LINK's Facebook page include:

My son is 21 and has presented as a toddler throughout childhood and beyond. I could have done with Restore 2 mini especially as he almost died of pneumonia - I simply had no idea of how-to lookout for signs, especially due to him having no spoken language and high pain threshold.

I am part of the Lancashire Health Inequalities Group and they are currently making plans to roll it out across the whole area. Similarly, several of the Greater Manchester areas have included it in plans to roll out widely

Self-advocacy for people with profound and multiple learning disabilities.

Jan Walmsley writes about her project funded by the RTR Foundation in a guest blog for Learning Disability England. She ran some Sharing Good Practice events about self-advocacy. At one event, Jan and some self-advocates spoke to members of Campaign 4 Change (a fully inclusive campaign group) and two parents to explore their insights and views on how to meaningfully include and encourage people with PMLD to be more involved in self-advocacy.

You can read Jan's guest blog on the Learning Disability England website using this link: https://www.learningdisabilityengland.org.uk/news/latest-news/self-advocacy-for-people-with-profound-and-multiple-learning-disabilities/

Find out about Campaign 4 Change : www.achievetogether.co.uk/about/campaign-for-change-c4c/ and watch their YouTube film "WE ARE PEOPLE" on the Campaign 4 Change channel

BOOKS AND RESOURCES

Flo Longhorn's latest edition of "Apps for Very Special Learners"

Flo Longhorn has recently made available her sixth Apps List for you to use with 'very special' children and adults. There will be one later in the year which Flo hopes will continue to be useful to people working with both children/teenagers and adults. This edition contains apps and information about fingers, especially the pointy one and thumb which access the magic world of tablets for everyone.
Download Edition Six of "Apps for Very Special Learners" at: https://sites.google.com/view/flolonghornsensorybooksfreedow/home

The previous Apps lists are still available. If you have any questions, Flo can be reached at flopmld@gmail.com

Four more books for free download from Flo Longhorn

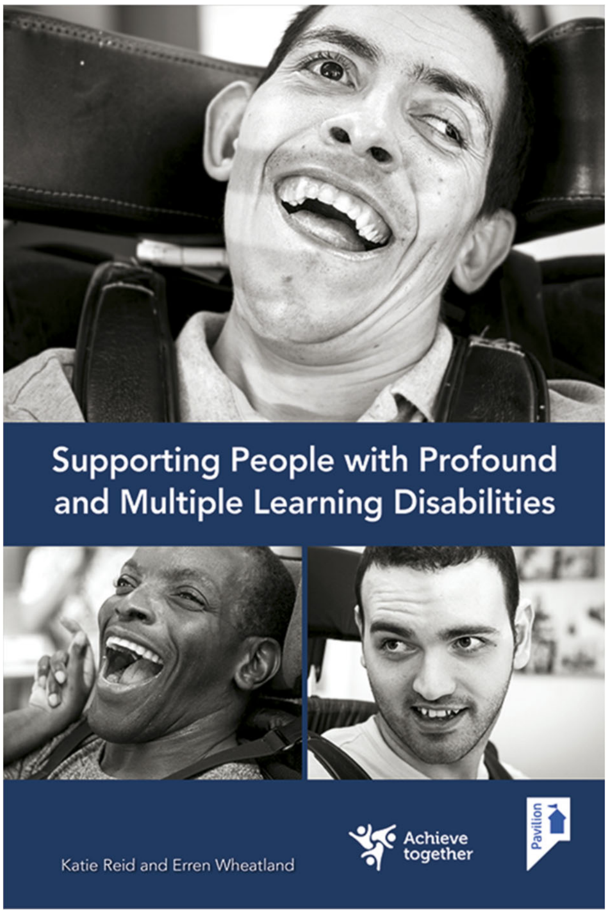
'Planning a Sensory Curriculum and Sensory Banks for the Very Special Child: A Practical Approach to Curriculum Planning' - Flo Longhorn (1984)

'A Feast of Music: Music and Drama for All' – Volume One - Diane Haylor and Sue Bradshaw with Flo Longhorn (2005)

'A Feast of Music: Music and Drama for All' – Volume Two - Diane Haylor and Sue Bradshaw with Flo Longhorn (2005)

'Making Friends with Johanna: Communicating with Very Special People' - Johanna de Haas and family, edited by Flo Longhorn, (2003)

For these and other great books made available for free by Flo Longhorn and other useful information go to: https://sites.google.com/view/flolonghornsensorybooksfreedow/home



Title: Supporting People with Profound and Multiple Learning Disabilities Self-study guide

Authors: Erren Wheatland, Katie Reid

Publisher: Pavilion (www.pavpub.com)

Publication date: November 2019

Price: £21.95 pbk

ISBN: 978-1-912755-61-5

This self-study guide will help support staff and others working in the adult health and social care sector to understand and respond to the complex and holistic needs of people with profound and multiple learning disabilities. Written by trainers and practitioners in the field, it will help to develop knowledge in how to support, communicate, engage and develop appropriate strategies to provide effective, meaningful support.

The guide includes key knowledge, case studies, reflective exercises, learning points and video clips to enable staff to study at their own pace as part of their continuing professional development or to support any qualifying training in the field. The self-study route guides the reader through the content and materials and when to watch particular videos and do the various exercises and activities, to encourage independent thinking and learning.

SHORT COURSES & CONFERENCES 2021

Training providers are mostly not publicising face-to-face or in-house training courses, but there are now some excellent online training opportunities available. In the Winter 2020 issue we published a list of regular and relevant providers together with their contact details. We suggest that you regularly visit their websites to see what may be on offer. The following events have been publicised at the time of writing.

June 2021	
Title:	Parenting a child with complex needs workshop
Date:	Tue, 22 Jun 2021 12:00 BST
Location:	Online
Provider:	Born at the Right Time
Contact:	Telephone: 01702 963019 Email: admin@bornattherighttime.com
Title:	Intensive Interaction Training
Speakers:	Janet Gurney
Date:	22 June, 9.30 to 3.30
Location:	Online
Provider:	Us In A Bus
Contact:	info@usinabus.org.uk or tel 01737 823310.
July 2021	
Title:	Parenting a child with complex needs workshop
Date:	Wed, 7 Jul 2021 19:30 BST
Location:	Online
Provider:	Born at the Right Time
Contact:	Telephone: 01702 963019 Email: admin@bornattherighttime.com
Title:	Growth after Bereavement Irene Tuffrey Wijne, Theresa and Richard
Date:	Tuesday 13th July 10 – 12
Location:	Online
Provider:	Open University Social History of Learning Disability Research Group
Contact:	email : Elizabeth.Tilley@open.ac.uk
August 2021	
Title:	Intensive Interaction Training Janet Gurney
Date:	20 August, 9.30 to 3.30
Location:	Online
Provider:	Us In A Bus
Contact:	info@usinabus.org.uk or tel 01737 823310.

September 2021	
Title:	Finding the gaps and closing the gaps: Dying, death, bereavement, COVID-19 and people with learning disabilities
Date:	16th September 2021 10.00-15.00
Location:	Online
Provider:	PCPLD Network
Contact:	
Title:	In Response: Making academic journals more inclusive
Speakers:	Melanie Nind
Date:	Tuesday 21st September 11-12.30
Location:	Online
Provider:	Open University Social History of Learning Disability Research Group
Contact:	email : Elizabeth.Tilley@open.ac.uk
October 2021	
Title:	Intensive Interaction Training
Speakers:	Janet Gurney
Date:	7 October, 9.30 to 3.30
Location:	Online
Provider:	Us In A Bus
Contact:	info@usinabus.org.uk or tel 01737 823310.

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About Us

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

Rob Ashdown	Former teacher of pupils with severe and profound and multiple learning difficulties and special school Headteacher.
Annie Fergusson	Annie has been the main advocate for her brother (with profound and multiple learning disabilities) for almost 20 years. Retired from a long career as a practitioner and university lecturer in the special education and learning disability field. She is a member of Advisory Groups for the national Learning Disabilities Mortality Review (LeDeR) programme and NHS England Seldom Heard Voices project and has a role as a family associate with Dimensions, a social care provider. Annie was one of the team who developed the PMLD Standards.
Michael Fullerton	Michael is Director of Health & Wellbeing with Achieve Together, a social care provider supporting adults with profound and multiple learning disabilities. Michael is a registered learning disability nurse and leads a health team focused on the quality of life of people with profound and multiple learning disabilities. Michael was one of the team who developed the PMLD Standards.
Martin Goodwin	Martin is a teacher of pupils with PMLD and a Regional Tutor/Visiting Lecturer for the Severe and Profound Multiple Learning Disabilities course at the University of Birmingham. Martin has specialised in approaches to improve interaction, communication and participation of people with severe and profound learning disabilities. He has experience of working in the fields of play and leisure, education, residential and advocacy.
Rachel Parry Hughes	Lecturer in Social Work, Goldsmiths, University of London and a Senior Social Worker at Buckinghamshire Council. Rachel has a long-standing interest in the support of people with profound and multiple learning disabilities.
Becky Loney	Becky has supported people with profound and multiple learning disabilities and their families for almost 30 years. She currently works an independent advocate, an involvement worker and a LeDeR Reviewer for the Learning Disability Mortality Review and uses creative communication approaches and sensory storytelling throughout her different roles. Becky is a member of the Advisory Group for the NHS England Seldom Heard Voices project.
Wendy Newby	Deputy Headteacher at The Shrubberies School, Stonehouse, Gloucestershire. This is a school for students with Severe and Profound Learning Difficulties .
Maureen Phillip	Maureen is the Senior Family Support and Development 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 is a journal for everyone supporting people with profound and multiple learning disabilities.
Visit www.pmldlink.org.uk

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