

PMLD LINK

sharing ideas and information

Ethics and Values

Summer 2019



Vol 31 No 2. Issue 93

ISSN 2042-5619

Summer 2019 contents



05 Engineers of the Imagination



44 Colours impact on vision



47 Creating to connect

Cover picture: provided by Saima Kaur. The image is from a piece called 'The fairies came flying in'. The title is a fragment from an old Punjabi folk song.

Page		
1	Guest Editorial: Values and Ethics	Martin Goodwin, Rachel Parry Hughes, Rob Ashdown
2	What is Community?	Andrew Colley
5	Steve and Trev – Engineers of the Imagination	Trevor Boddington and Jane Thakoordin
7	Variations in interaction: examining how social engagement is contingent upon context	Ben Simmons
10	The ethics of belonging	Melanie Nind and Iva Strnadová
12	Respect, human dignity, and children with PMLD	John Vorhaus
15	Should International Evening be cancelled this year?	Tracey Edwards
19	Why is research important? Reflections for professionals and parents	Lila Kossyvaki
21	Is it a good thing to identify people as having profound and multiple learning disabilities?	Peter Imray
24	How do we create and sustain 'ethical organisations' to support people with PMLD (including schools, care providers, social services and health services)?	Nancy Keeley
27	Are cleaners more valuable than support workers?	Dreenagh Lyle
30	The power of parent voice	Rebecca Pender
33	What has bedtime to do with me?	Sarah Clayton
36	Theoretical context for ethical practice: a creative and therapeutic arts graduate perspective	Carrie-Ann Sutton
39	There's no place like home – the ethics of home ownership for people with disabilities	David Abbey
41	Sound and silence	Eleanor Gibson
44	How do colours impact on vision?	Isabel Beck
47	Creating to connect	Saima Kaur
50	Nursery Rhymes and Dream Boys	Emily Woolman
53	In The Next Issue	Jeanne Carlin, Annie Fergusson, Michael Fullerton, Bella Travis and Maureen Phillip

GUEST EDITORIAL

Ethics and Values

Do we care enough? Since people with PMLD are subject to the impact of the ethics and values of those who support them, how we should care is not always clear cut and requires ongoing reflection.

This edition of PMLD Link features the theme of 'Rights, Values and Ethics'. Values and ethics are deeply situated and are complex, yet they permeate the daily life and experiences of people with PMLD. This edition of PMLD link highlights some of the complex issues and dilemmas that arise through the day to day experiences of living a life with PMLD; not only because the needs that arise due to having multiple impairments but also because societal barriers and attitudes interfere with the rights, freedoms and quality of life that we would expect. Communities and services do not always take the vulnerable position of people with PMLD seriously and care is not always taken to afford them their rights. People with PMLD rely on people who sensitively listen and contingently respond and need support to be provided both ethically and reflectively. This edition highlights some of the challenges to supporting ethical practice and celebrates practice that affirms human rights of people with PMLD.

We were overwhelmed with articles for this issue and would like to thank all contributors. Some are being put into the next issue since we just did not have enough space in this one. In this bumper edition a range of articles have been included, both from an academic, practitioner and family perspective. There is not space here to describe each piece, but we would like to highlight some of the cross cutting themes which we regard as important.

Community, friendship and belonging feature in articles by Andrew Colley, John Vorhaus, Ben Simmons, and Melanie Nind and Iva Strnadová. Following the same theme is an article by Trevor Boddington and Jane Thakoordin which has been reworked in part as a tribute to Trevor's close friend Steve who died recently.

Lila Kossyvakis reflects upon the importance of practitioners doing research that is ethically based and involves as true participants people with PMLD and their families.

The importance of equal relationships between practitioners and people with PMLD and their families is brought out in different ways in articles by Rebecca Pender and Emily Woolman and Nancy Keeley explores the same theme with ideas about how one charity has sought to create and sustain an ethical organization.

Valuing people for who they are and developing practice that truly meets their individual needs, enthusiasms and situations are explored in articles by Peter Imray, Tracey Edwards, Sarah Clayton and Dreenagh Lyle.

Dreenagh's article and one by David Abbey on home ownership also examine the economic rights of people with PMLD and the failures of our society's systems and agents to recognise these properly.

Creativity and the value of beautiful things to all are explored in contrasting articles by Saima Kaur, Eleanor Gibson, Isabel Beck and, from an ethics perspective, creative and therapeutic arts by Carrie-Ann Sutton.

As usual, we also include details about a range of news, resources and training courses and conferences. In particular, we would like to draw your attention to the adverts herein for the third Raising the Bar conference in Birmingham on 25th October. If you are a family carer or education, health or social care professional, there is so much to be gained from this wonderful event. The fantastic speakers, exhibitors and participants do so much to exemplify the PMLD Core and Essential Standards, available on the PMLD Link website, as indeed do the articles in this issue.

Rachel Parry Hughes, Martin Goodwin and Rob Ashdown

Contact Us

Subscriptions

Rob Ashdown
15 Cliff Gardens,
Scunthorpe,
North Lincolnshire, DN15 7PH
info@pmlmlink.org.uk

rob.ashdown@ntlworld.com
Tel: 01724 852818

Production

Paul Bramble
The University of Northampton
Email: info@pmlmlink.org.uk

Website: www.pmlmlink.org.uk
Twitter: @PMLDlink

ISSN 2042-5619

What Is Community?

Andrew Colley

This is an article about the word 'community', but more specifically about what 'community' means or might mean for the 70,000 or so people of all ages with profound and multiple learning difficulties (PMLD) in the UK.

First though, I want to try to make a link between the word 'community' and another word we all talk about seemingly endlessly and some of us teach, read and write about equally endlessly: 'inclusion'. To try to make that link, I am going to go back to a period of my life more than 30 years ago where without even realising it I was involved in issues of 'inclusion' and 'community' from the perspective of a 'service user', a term which certainly wasn't in use in the mid 1980s. I was in fact referred to then as a 'patient'.

For several months in the spring and summer of 1985 I was a 'voluntary in-patient' at a state-run psychiatric hospital on the outskirts of London. Built on top of a hill in 1905 it was very much in the mould of the typical large Victorian asylum. This is the kind of institution which in a sense has been at the forefront of debates around 'inclusion' and 'community' in this country for the last 50 years at least. After the end of the Second World War, asylums of this type almost universally came to be seen as something we didn't want in an 'inclusive' caring society. They segregated people on the basis of their mental health or learning difficulty, and they were subsequently almost all swept away: knocked down, or – in the case of the hospital where I had been a patient – turned into executive housing estates with green spaces, play areas, gyms and pools. 'Communities' perfectly situated – if you could afford it - for the commute into London. Why were they swept away? Because 'care in the community' was – and still is - the way forward.

My experience as a patient in this hospital however was a very positive one. I was well treated and respected; I was given the medical and therapeutic support I needed; I was encouraged to take part in hospital events and activities; I made friends of sorts amongst the other patients, and once I was feeling well enough I was given a job in one of the hospital's psychogeriatric wards as a kind of nursing auxiliary. For this job I was even paid, queueing up every Friday to receive my pay-packet which I would spend on little treats – often cigarettes I am afraid - in the hospital shop. I was part of a community, and quite an effective and supportive one as well.

Despite the success of my time in this 'community', there was no danger at any point of me becoming institutionalised. Once I had learnt to function effectively

again within the community of the hospital I was actively encouraged to venture more and more into the wider local community until eventually I was able to move gradually from one professional community of care, to another domestic community of care: that of my family and friends.

However, the reputation of these large residential institutions for being toxic and undesirable persists. Like everyone in our SEN community, I was sickened by the truly appalling abuse exposed by the recent BBC Panorama documentary at Whorlton Hall in County Durham – a 'hospital' for people with learning difficulties. There was no denying that – in the words of the reporter - it really was 'a bleak place', and Dr Paul Lelliott, Deputy Chief Inspector of Hospitals at the Care Quality Commission commented: 'These hospitals should shut because they are no longer needed', with Sir Stephen Bubb, the author of 'Winterbourne View: a time for change' (Bubb, 2012), adding: 'There will continue to be such scandals while we have these institutions'.

Sir Stephen also made this comment however: 'money needs to be spent on good community facilities. Not on abusive institutions', and of course he is right. It is not the existence of institutions such as Whorlton Hall which is wrong, it is what goes on within them and, in the case of Whorlton Hall, the shocking failings of management and staff, which make them so toxic. As Professor Glynis Murphy, Professor of Clinical Psychology and Disability at the University of Kent, commented when faced with evidence of the level of abuse meted out by the staff: 'This lot should definitely not be working in care homes. They are the absolute antithesis of what care workers should be'.

With appropriately recruited and trained staff, adequate funding, and an emphasis on ethos and values, Whorlton Hall could have been a community: a community of care for all who stayed there and all who worked there, in the same way that the hospital I was in more than 30 years ago was a good community of care, albeit one fast running out of time and money and soon to be closed.

It is my contention then that in the same way that we have debated the meaning of 'inclusion' for the last 30 years or more, so we need to debate and possibly

reframe the meaning of the word 'community' with respect to people with PMLD. If we don't, we risk making the same mistakes which were made in the 1990s when hospitals were closed in favour of Care in the Community: people were and still are left behind: excluded in the rush for inclusion, uncared for in the rush for cheaper care. We must now think about the word 'community' in the same broad, pragmatic and realistic way we have come to think about the word 'inclusion'.

In the SEND Code of Practice (SENCoP) (DfE, 2015), there is a clear emphasis on concepts such as 'community participation' (p124), and in fact one of the only mentions of learners with profound needs in the SENCoP is an acknowledgement of the importance for young people with more complex needs 'to participate actively in their local community' (p. 47). Similarly, the SENCoP specifies that outcomes should include those within wider areas of 'personal and social development' (p. 25), as well as 'positive social relationships and emotional resilience and stability' (p. 163). In the same way, one of the four key aims of the Preparing for Adulthood programme (www.preparingforadulthood.org.uk) is to promote friends, relationships and community inclusion so that young people can access their community and feel safe and confident.

So, the acknowledgement that 'community' is an essential ingredient of a decent human life is there in policy, but without any real attempt being made to examine what 'community' means in reality for people with PMLD, and as a result there is perhaps a real possibility that the rights of people with PMLD to take a full part in a community or communities will be unfulfilled or at best compromised in the same way that their rights to 'inclusion' have been compromised by a lack of clarity about what 'inclusion' actually looks like. We have tended to look at 'inclusion' in a simplistic way, and we must not do the same for community. To make 'community' work takes time, money and effort.

The dangers of not fully addressing this issue were highlighted for me in November 2018 when I carried out a short and informal survey of practitioners in the field of PMLD at a conference at Swiss Cottage School in London. I found that there is real concern that, as one Head Teacher put it, although the SENCoP appears to 'cover' learners with PMLD, it may not at the same time 'cater' for them. When I asked the participants at the conference to write down what they thought the burning issues are currently in the education of young people with PMLD, 'community participation' came across as one of the most commonly cited concerns, with the following specific questions being selected as particularly important:

- To what extent can we be sure that pupils with

PMLD access the community at the same rate as those with less severe learning difficulties?

- Is the local community encouraged to engage with pupils with PMLD?
- To what extent do pupils with PMLD engage with their 'mainstream' peers or with the wider community of the school?
- How do schools overcome barriers to Community Participation?

One of the practitioners expressed a particular concern:

- 'I worry that my PMLD pupils are not able to access the community'.

So these are questions we as a community of professionals must address and try to answer, but first perhaps we need to have a wider discussion about what 'community' actually means or could mean for people with PMLD. My sense is that perhaps all too often we simply mean a short trip to somewhere 'in the community' – a shop, or café for example - and certainly as a former PMLD teacher I confess that this was all too often the sum of the community engagement of my class. These sorts of activities are of course all part of building an active and meaningful community life for people with complex needs, and they are things that we and policy makers must ensure are as accessible and meaningful as possible. But are they enough?

My own life is made up of many different communities, large and small: my family, my friends, the schools I attended, the places I have worked, the people I sit next to on the train, my neighbours, my memories, the view from my window.... All this and much much more makes up what the French sociologist Pierre Bourdieu called my 'social capital' (Field, 2008) and I am lucky: it is a rich and colourful one and it gives me a sense of dignity and self. It also means that I am never likely again to fall into the very depths of despair and anxiety which led me to spend those months in hospital I referred to at the beginning of this article.

But my right to a social and community life, a meaningful and dignified life, my ability to build up a rich social capital is no more or less than the right of someone with profound and multiple learning difficulties to do the same. This is our challenge, and if we don't rise to it we may find that the people we care about, the people we talk and debate about, the people we teach, will still not be achieving 'a life compatible with human dignity' (Nussbaum, 2006. p. 79), will not be 'active in the world' (p. 73) have diverse 'opportunities for activity' (p. 74), enjoy nature, and experience 'life, health and bodily integrity as well as emotional attachments and the removal of overwhelming fear and anxiety' (p. 168). These are just some of the elements of what the word

'community' should mean for people with PMLD, because they are the same elements which define the meaning of 'community' for all of us.

I have another confession. This is not an entirely disinterested article. With a fair wind, a little bit of money, and a calm mind, I hope in early 2020 to carry out a survey of the approximately 400 state-funded and non-maintained special schools approved for PMLD provision in England (DfE, 2018). The research will be supported by the University of Cambridge Faculty of Education and will consist of an online questionnaire which will aim to find out if Educational Health and Care (EHC) plans for young people with PMLD reflect statutory guidance with respect not only to community participation but also to other more holistic outcomes such as independent living, health and well-being. I will also ask what barriers schools are facing in supporting their pupils to achieve these life outcomes.

So, if and when a questionnaire like that pops into your inbox in early 2020, it won't be a spam email from someone offering PPI refunds, it will be from me, so please if you can take the time to fill it in or pass it on to someone who will.

Thanks!

Contact Details

Andrew Colley is senior lecturer in special education at the University of East London, Cass School of Education and Communities and a p/t PhD student at Wolfson College Cambridge.
e-mail: awcolley@outlook.com

References

Bubb, S. (2014) *Winterbourne View – time for change. Transforming the commissioning of services for people with learning disabilities and/or autism*. A report by the Transforming Care and Commissioning Steering Group, chaired by Sir Stephen Bubb – 2014 <https://www.england.nhs.uk/wp-content/uploads/2014/11/transforming-commissioning-services.pdf>

DfE (Department for Education) (2018). *SEN Statistics*: <https://www.gov.uk/government/collections/statistics-special-educational-needs-sen> [accessed January 8th 2019]

DfE (Department for Education) (2015) *Special Educational Needs and Disability Code of Practice: 0 – 25 years*. London: Department for Education. Available online at: <https://www.gov.uk/government/publications/send-code-of-practice-0-to-25>

Field, J (2008) *Social Capital* (2nd edition) London: Routledge

Nussbaum, M.C. (2007) *Frontiers of Justice – Disability, Nationality and Species Membership*. Cambridge MA: Harvard University Press

Panorama (2019) *Undercover Hospital Abuse Scandal*. TV, BBC1, 28 May 2019. A written account is also on the BBC website at : <https://www.bbc.co.uk/news/health-48367071>

Preparing for Adulthood (2019) [online] Available from: www.preparingforadulthood.org.uk [accessed June 10th 2019]

Raising the Bar III Conference

Raising the Bar III will take place on 25th October. PMLD Link organises Raising the Bar, the only national conference with a focus on the support of people with profound and multiple learning disabilities.

Raising the Bar III focuses on a review of the Core & Essential Service Standards for the support of people with profound and multiple learning disabilities. Building on the previous Raising the Bar National Conferences, we aim to bring together speakers, delegates and exhibitors from the UK, Ireland and beyond to share positive stories and practice to inspire and promote the very best support.

If you are a family carer, education/health or social care professional there is so much to be gained from this wonderful event. In addition to fantastic speakers and exhibitors, we attract the most amazing delegates!

You can register to attend here:

<https://www.eventbrite.co.uk/e/raising-the-bar-iii-national-pml-d-conference-tickets-59938834668>

We look forward to seeing you on 25th October!



Steve and Trev – Engineers of the Imagination

Trevor Boddington and Jane Thakoordin

“Even on bad days we found ways to have a laugh, and I miss all that, I really do.”

It's with sadness for a life ended, but equally with joy for a life filled with great adventure, that we learned that Steve Woodhouse passed away earlier this year. Steve along with Trevor Boddington, his personal assistant were guest presenters at Raising the Bar 2 conference in 2018.

Steve and Trev had known each other for over twenty years and shared many creative adventures, both at home and aboard. Their friendship was based on complete trust, respect and mutual admiration. Trev first began supporting Steve to go to a day centre, but it didn't take long for them to both realise they could have a much more ordinary, fun filled, life out and about and they soon escaped, claiming their place in the world!

With a shared love of toys from the 1970s and 1980s, Steve and Trev began to experiment with creative ideas that expressed their own dynamic and fantastical imaginations and attracted attention from others, keen to share in the experience of making together.

Trev explained that the pair had focussed more on film making in recent years. The films were a wonderful way of including people and creating a network around the two artists. People say that Steve and Trev made a space for everyone. As Trev says, *“whoever you are, whatever your interest or skill, there is a role for you here. That can be acting, writing, costume making, set building, marketing, tea making and an endless list of jobs.”* Steve and Trev worked with people's strengths, getting to know people and what they had an interest in and finding them a role.

Many of the people who were part of Steve and Trev's film-making family live with a mental health difficulty,

and as Mauvette says, "People can label you, and once that happens they look at you differently. They tend to label you as not able to do things. Labels are for boxes, not people. Learning scripts, building a character and sharing ideas about the film really helps me to focus on positive things in my life. Their flexibility is fantastic if things don't work out, it doesn't matter, we just try it another way."

Gary explains, "I hadn't played music for such a long time due to the affect my bi-polar was having on me. When I came along here, they gently encouraged me. It took a while, but I got swept up on the wave of friendship and enthusiasm that the two of them radiate."

People that knew and respected the two guys say that the best thing about Steve and Trev was the friendship they extended to others. They opened up their sculpture and film studio for people to use in a relaxed and uncomplicated way.

The ordinariness of the friendship between Steve and Trev, and between them and their large creative

friendship circle, was wonderful. A shared creative passion, a meeting of minds, coupled with a wicked sense of humour meant that, as Tony says, "being with Steve and Trev lifted you up! It was such a happy, welcoming and positive place to come".

We wish Steve's family all the best for the future and hope that Trevor carries on the creative work in Steve's name.

Contact details

Jane Thakoordin is a development officer at Changing Our Lives (<https://www.changingourlives.org>)

e-mail: Jane.thakoordin@changingourlives.org

Trevor Boddington and Steven Woodhouse, more commonly known as 2arttoyguys, were among Guest Speakers at Raising the Bar 2018 Conference

Click on the link below to see some of their sculptures and films:

www.youtube.com/user/2arttoyguys



Variations in interaction: examining how social engagement is contingent upon context

Ben Simmons

This article reports the findings of a study that explored how a mainstream school and a special school provided social interaction opportunities for two primary-aged children with PMLD (Emma and Harry). Both children attended a special school four days a week and a mainstream school one day a week, with a special school teaching assistant (SSTA) providing support in the mainstream. The findings suggest that the SSTA interacted differently with Emma/Harry depending on which school she was in, and heavily shaped early interactions between Emma/Harry and mainstream children. The findings also suggest that mainstream children quickly developed confidence, evidenced by the emergence of novel (playful and physical) styles of interaction.

Despite on-going international calls for ‘inclusive education’ by United Nations agencies children with PMLD are typically educated in special schools. This is not only the case in the UK but also appears to be a global trend, as Lyons and Arthur-Kelly (2014) note: ‘From an international perspective most students with [PMLD], if they have access to any school education, are educated in “special” schools or classes by “special” educators’ (p. 446).

Given that mainstream opportunities for children with PMLD are relatively rare, it is perhaps not surprising that there has been very little empirical research published on the topic. Existing research tends to focus on two areas: (i) parents and teachers’ attitudes towards the inclusion of children with PMLD, and (ii) descriptions of practice (i.e. what happens in the mainstream). Researchers who have examined the former have suggested that the more severe a child’s learning difficulties the less enthusiastic teachers and parents are towards inclusive education (e.g. Coutsocostas and Alborz, 2010; de Boer and Munde, 2015). However, it is important to note that these studies have taken place outside the UK with countries that have different education systems (e.g. in Greece and the Netherlands).

Whilst some researchers have expressed reservations about inclusion, studies that describe the participation of children with PMLD in the mainstream have reached positive conclusions. For example, researchers in Australia compared levels of alertness between children with PMLD in a mainstream class and children with PMLD in a special school class. The researchers reported that the children in the mainstream school spent longer awake, active and alert compared to children in the special school (Foreman et al., 2004). The present author (Simmons and Watson, 2014, 2015) conducted research in England which examined the engagement of a child with PMLD who attended both a special school and a

mainstream school, and found that the child appeared happier (e.g. less self-harming) and more socially active in the mainstream school compared to the special school. The purpose of this paper is to contribute to the small but growing empirical literature that describes how children with PMLD are supported across mainstream and specialist settings.

Research focus and methodology

This article presents the emerging findings of a three-year project funded by the British Academy that examined how different types of school provide different social interaction opportunities. The paper focuses on two students – Emma and Harry. Both students attended the same class for pupils with PMLD in a special school four days a week, and an age-equivalent class in their local mainstream school one day a week. At the time of data collection Emma was five years of age and attended a Reception class, whilst Harry was eight and attended a Year 4 class. A special school teaching assistant (SSTA) transported and supported Emma and Harry during their mainstream placements.

The methodology resembled an ethnographic approach. Ethnography involves direct experience and exploration of a particular social setting, through participation and observation (Atkinson et al., 2001). The project reported in this article combined participant observation with the writing of observational fieldnotes. The researcher’s interpretation of the meaning of Emma and Harry actions was further developed through formal interviews with parents and teaching staff, as well as on-going informal dialogue with school staff who could be consulted during observation. Each child was observed one day a week in a mainstream school and one day a week in a special school for a ten-week period (twenty observations per child). The findings are reported below.

Findings

The bulk of the data described Emma/Harry's interactions with special school staff and/or mainstream peers. Analysis of this data suggests that the nature of the interaction was contingent upon the location of the interaction and the communication partner.

- **Special school staff in the special school**

The theme '*social invariance through environmental change*' refers to the ways in which special school staff were consistent and predictable in their interactions with Harry and Emma despite variation in location within the special school (e.g. classroom, school hall or multisensory room). For example, on a daily basis Harry and Emma were encouraged to express a preference for an object, person or event. Children were asked to smile or look at an object such as a toy to express 'like', or turn away from an object to express 'dislike'. If the children did not respond to choices offered by staff then a range of prompts would be issued including verbal prompts (the question would be reiterated, reworded, and/or spoken in a more dramatic tone), gestural and visual prompts (pointing at an object or showing a symbolic representation of the object), followed by a physical prompt (e.g. rubbing a vibrating snake on one arm and rolling a spikey ball on another arm whilst observing the child's reactions). These interactions were typically dyadic in nature (staff worked with children one-to-one), symbolically normative (the interactions were deemed to be developmentally appropriate), and functional or pedagogically-framed (the interactions were timetabled and aimed to foster children's emerging symbolic communication). Staff were jovial (cheerful and friendly) and respectful (e.g. recognising when Emma/Harry were not interested in engaging and returning when they were more alert).

- **Special school staff in the mainstream school**

When supporting Emma and Harry in the mainstream school, the special school staff typically embodied a different style of interaction dubbed '*narrated bodily appropriation*'. These interactions had a chronologically normative dimension meaning that special school staff encouraged Harry and Emma to behave like other mainstream children of the same age. During the interaction Harry and Emma's bodies were re-positioned or moved according to the contextual demands of the situation. The interactions were invariably accompanied by narration or a description of what was about to happen to Emma/Harry and why. The

main interactive partner during these events was typically the SSTA, but there were also occasions when the mainstream teaching assistant would engage in a similar manner. For example, during numeracy the SSTA repositioned Harry so he sat upright rather than slouched, turned his head so he faced the teacher, opened his palm and placed a pencil in his hand, closed his fingers around the pencil and move his hand across a page to make marks. The physical event would be narrated, meaning that Harry would be given an explanation as to why he was being moved.

- **Special school staff and mainstream peers in the mainstream**

One of the aims of the research was to compare and contrast how different groups (e.g. peers or school staff) interacted with Emma/Harry. However, what became apparent during analysis of the mainstream school data was that interactions often involved both peers *and* staff interacting with Emma/Harry. The special school teaching assistant initiated and sustained interactions between Emma/Harry and mainstream children. For example, the SSTA would unintentionally attract other children to Harry during care-based activities such as tube-feeding. At first children observed from afar. However, over time children would approach the SSTA and ask questions about Harry (e.g. 'What's that going into his tummy?'). The SSTA would answer questions, invite children to address Harry directly, and ask them to hold or shake his hand. The SSTA would sit Harry next to a group of children and ask them to say 'hello', show Harry their work, and suggest ways of interacting with Harry (e.g. help him draw through hand-on-hand support, read with dramatic intonation, and take turns when talking to him). The SSTA modelled how to interact, helped children interpret Harry's behaviour (e.g. 'He's tilting his head to listen to you'), praised children who initiated interaction, and took a step back if the children appeared confident when interacting with Harry. The SSTA made use of similar strategies to support interaction between Emma and her mainstream peers.

- **Mainstream peers**

As the project progressed the mainstream children began to initiate interactions themselves without invitations by staff. Children chose to sit next to Emma and Harry (e.g. drinking milk beside Emma during snack time, or sitting beside Harry during art). Children also enjoyed performing for Emma and Harry (e.g. dancing, singing, acting, and making

Emma/Harry laugh). The children interacted with Emma/Harry by showing off objects (e.g. Lego cars and paintings), giving Emma/Harry objects to play with (e.g. balls and hula-hoops), and demonstrating how to use objects (e.g. spinning tops and whoopie cushions). They invited Emma and Harry to play games with them in the playground. Sometimes the interactions resembled those that took place between Emma/Harry and the SSTA (e.g. the children would assume the role of the SSTA and, unprompted, put an apron on Harry during painting, help him move a brush around the paper, and wash his hands afterwards). However, interactions between the mainstream children and Emma/Harry sometimes embodied a more informal style of interaction (dubbed ‘*interaction-for-interaction’s-sake*’) and involved playful engagement such as tickling or giving objects of affection (e.g. daisy chains, cards, and friendship bracelets). These interactions were often physical in nature and involved on-going or sustained, intimate exchanges such as reciprocated hand squeezing and ‘tug-of-war’ with interlocked fingers. These physical exchanges could also be subversive. For example, during carpet time children were required to sit down, face the front of the class, listen to the teacher and stay silent. However, whilst the children were verbally quiet, they held Emma’s and Harry’s hands, rubbed their legs, touched their wheelchairs, and leaned against them.

Conclusion

This paper presented the emerging findings of a project that explored how different school environments afford children with PMLD opportunities to interact. The findings illuminate how interaction can be context-specific (e.g. the SSTA’s style of interaction was contingent on the context of interaction). Furthermore, the research shed a light on more plural forms of interaction – particularly in the mainstream. The SSTA and mainstream peers collectively shaped the social milieu for Emma/Harry, initially with the SSTA heavily influencing the interaction before the mainstream peers developed the confidence and skills to interact in their own unique (playful and physical) ways. Further research is needed to develop understandings of how different contexts shape social opportunities for children with PMLD, and the impact this can have on participation in school.

Contact details

Ben Simmons is Senior Lecturer in Education Studies, Bath Spa University
 b.simmons@bathspa.ac.uk
 Twitter: @BenSimmons_PhD
 Postal address: Bath Spa University, Twiverton (TN.G05), Newton Park, Newton St Loe, Bath: BA2 9BN

References

- Atkinson, P., Coffey, A., Delamont, S., Lofland, J., and Lofland, L. (2001) *Handbook of Ethnography*. London: Sage.
- Coutsocostas, G., and Alborz, A. (2010) Greek Mainstream Secondary School Teachers’ Perceptions of Inclusive Education and of Having Pupils with Complex Learning Disabilities in the Classroom/School. *European Journal of Special Needs Education* 25 (2): 149–164.
- de Boer, A., and Munde, V. (2015) Parental Attitudes Toward the Inclusion of Children with Profound Intellectual and Multiple Disabilities in General Primary Education in the Netherlands. *The Journal of Special Education* 49 (3): 179–187.
- Foreman, P., Arthur-Kelly, M., Pascoe, S. and King, B. (2004) Evaluating the Educational Experiences of Students with Profound and Multiple Disabilities in Inclusive and Segregated Classroom Settings: An Australian Perspective. *Research & Practice for Persons with Severe Disabilities* 29 (3): 183–193.
- Lyons, G., and Arthur-Kelly, M. (2014) UNESCO Inclusion Policy and the Education of School Students with Profound Intellectual and Multiple Disabilities: Where to Now? *Creative Education* 5: 445–456.
- Simmons, B., and Watson, D. (2014) *The PMLD Ambiguity: Articulating the Life-Worlds of Children with Profound and Multiple Learning Disabilities*. London: Routledge.
- Simmons, B., and Watson, D. (2015) From Individualism to Co-Construction and Back Again: Rethinking Research Methodology for Children with Profound and Multiple Learning Disabilities. *Childcare in Practice* 21 (1): 50–66.

The ethics of belonging

Melanie Nind and Iva Strnadová

This article is a preview of some of the ideas we are working on for our new edited book to be published by Routledge in the Spring of 2020: *Belonging for Individuals with Profound and Multiple Learning Difficulties: Pushing the Boundaries of Inclusion*. We discuss how attention to people with PMLD can help us ensure that belonging is inclusive of everyone.

In our professional careers in special and inclusive education and as academics we have witnessed the culture around the rights of people with learning difficulties change. We have celebrated people with learning difficulties being properly valued in examples of teaching inclusively and doing research inclusively. And we have been part of trying to push the boundaries of inclusion (Nind, 2007; Nind, 2011; Strnadová, I. and Walmsley, 2018). Yet we know that the sense of inclusion in community has not always reached people with PMLD. Working on our new book we knew that lamenting this fact would not make a great read or a constructive addition to the literature. However, inspired by examining doctoral studies in which boundaries were well and truly being pushed (Forster, 2011; McCormack, 2017; Warwick, 2017), we set out to create a collection that would help to show and understand how people with PMLD can be part of things: included in education, research and community. This project is about ethics, values and rights.

In exploring the landscape of rights and inclusion for people with PMLD, Mansell's picture looms large - with them and their families 'written off, as not worth bothering with, as too difficult to support well and as people for whom the poor standards of the past are all that can be achieved' (Mansell, 2010, p.7). But more is being achieved with positive steps that show ethics in action in fostering belonging and we need to consolidate and amplify these. In our forthcoming book, examples include Ben Simmons illustrating children in inclusive classrooms reaching out to and appreciating of the value of a peer with PMLD, and Debby Watson, Noelle McCormack and Melaneia Warwick explaining how they involved people with PMLD in research. Sheridan Forster argues for attuning to people with PMLD as part of valuing spending time with them, and Catherine de Haas shows how this was part of how her daughter formed reciprocal relationships with people in her local community. The chapters and accounts from family members communicate how belonging is made possible.

In this special issue of PMLD Link we want to dedicate to belonging as an ethical project. In some senses belonging is the logical counterpoint to the exclusion that people with PMLD have experienced. The philosophers, Eva Feder Kittay and John Vorhaus have powerfully argued that profoundly disabled lives matter and with this that those with PMLD belong and contribute (Feder Kittay, 2019; Vorhaus, 2006, 2014). The idea that both a sense of belonging and actually being actively involved in communities matters for people's quality of life is entrenched in the UK PMLD Core and Essential Standards. But what does it mean to belong? The concept of inclusion has been somewhat sullied by government rhetoric and fighting about special versus integrated, mainstream or inclusive education. The concept of community may be less sullied and more helpful when we think about ethics, values and rights: community involves meaningful relationships and social ties. The concept of belonging remains both fresh and about everyone – for now.

Belonging has been debated among philosophers, practitioners, researchers and disability activists. The Australian Early Years Learning Framework (DEEWE, 2009) positions it as 'integral to human existence' and Antonsich (2010) argues it is central to well-being. Belonging is also about place – safe spaces; memory – feeling connected over time; and relationships – being at ease with people. People with learning disabilities, when asked by researchers (Robinson et al., 2014; Strnadová et al., 2018; Renwick et al., 2019) about their experience of belonging, have focused on having friends with similar experiences, places where they feel comfortable and opportunities to be valued and make a contribution, as well as their continuous quest for finding a good fit and negotiating their independence/interdependence. Research to date has not considered how people with PMLD experience belonging but the ethics of belonging means that the concept must include them. It must involve being regarded as 'worthy of moral parity' (Feder Kittay 2019, p.3). The implications of this are about having a place in education, research, and communities and a right to be on the inside of progress rather than left behind as others take up their rightful places in the heart of things.

Contact Details

Melanie Nind is Professor of Education at the University of Southampton. She is also Director of the Centre for Research in Inclusion in the Southampton Education School.

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

Iva Strnadová is Professor in Special Education and Disability Studies at the University of New South Wales in Sydney, Australia.

e-mail: i.strnadova@unsw.edu.au

SUBSCRIPTIONS

New Subscription Rates

UK Individual £25.00
UK Organisation £35.00

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

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

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

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

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

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

References

Antonsich, M. (2010) Searching for belonging – an analytical framework, *Geography Compass*, 4(6), 644–659.

DEEWE (2009) *Belonging, Being and Becoming: The Early Years Learning Framework*. https://docs.education.gov.au/system/files/doc/other/belonging_being_and_becoming_the_early_years_learning_framework_for_australia_0.pdf

Feder Kittay, E. (2019). *Learning from my daughter: The value and care of disabled minds*. USA: Oxford University Press.

Forster, S. (2011) *Affect attunement in communicative interactions between adults with profound intellectual and multiple disabilities and support workers*, Monash University

Mansell, J. (2010) *Raising our sights: Services for adults with profound intellectual and multiple disabilities*. DoH.

McCormack, N. (2017) *Making memory sites: Extending opportunities for people with profound and multiple learning disabilities to participate in life story work*, University of East London

Nind, M. (2007) Supporting lifelong learning for people with profound and multiple learning difficulties, *Support for Learning*, 22(3), 111-15.

Nind, M. (2011) Participatory data analysis: A step too far? *Qualitative Research*, 11(4), 349-63.

Renwick, R., DuBois, D., Cowen, J., Cameron, D., Schormans, A. F. and Rose, N. (2019) Voices of youths on engagement in community life: a theoretical framework of belonging. *Disability & Society*, DOI: 10.1080/09687599.2019.1583551.

Robinson, S., Hill, M., Fisher, K., Graham, M., & Valentine, K. (2014) *In the picture: Understanding belonging and connection for young people with cognitive disability in regional communities through photo-rich research, final report*. Centre for Children and Young People, Lismore.

Strnadová, I., Johnson, K., & Walmsley, J. (2018). "... but if you're afraid of things, how are you meant to belong?" What belonging means to people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 31, 1091-1102.

Strnadová, I. and Walmsley, J. (2018). Peer-reviewed articles on inclusive research: Do co-researchers with intellectual disabilities have a voice? *Journal of Applied Research in Intellectual Disabilities*, 31(1), 132-141.

Vorhaus, J. (2006) Respecting Profoundly Disabled Learners, *Journal of Philosophy of Education*, 40(3), 313–328.

Vorhaus, J.S. (2014) Philosophy and profound disability: learning from experience, *Disability & Society*, 29(4), 611-623.

Warwick, M. (2017) *Meaningful engagement: The participatory arts practices of adults with profound and multiple learning difficulties*, University of Brighton.

Respect, human dignity, and children with PMLD

John Vorhaus

It is a widely held belief that all people have human dignity, and that all of us are absolutely bound to respect the dignity inherent in every human being. Words to this effect can be found in international human rights instruments around the world. The opening statement from the Universal Declaration of Human Rights is typical, referring to the 'inherent dignity' and 'equal and inalienable rights of all members of the human family'. In this article I look at ideas of respect and human dignity, and at how they apply to some of those children and young people with PMLD who may not develop awareness of their dignity, or the respect owed to them. I do not mean to imply, what is certainly not true, that all people with PMLD are unaware of their dignity.

I start with some words from teachers of profoundly disabled children, and later move on to some philosophical reflections.

'You show a child with PMLD the same dignity and respect as you would any other child'

Leonda Ratcliffe is a 54 year-old Jamaican mother of two children, and a support assistant at St. Peter's School. It is especially important to Leonda that the children with PMLD she works with are human beings, however much they may differ in their capabilities from other people: 'they can't help the way they are, but still, they're the same as anyone else. You mustn't treat them any differently from anyone else – they're still human beings, they're still children. If it was me, I'd want to be treated like I treat them. I'd want the same respect as I give to others. And it doesn't cost anything to be nice to people.'

One way of failing to respect people is to patronize them, something that Leonda seeks to avoid: 'I just talk to the children with PMLD the same as I talk to you. I don't see why I should talk to them any differently. Some people "baby them" too much. You don't need to do that.'

Sian Peterson is a senior support assistant at Alfred Marks School. For Sian, as with Leonda, showing respect for children with PMLD is to see them, fundamentally, as just like any other children. Sian talks to them in the same way too, including those who are very sick: 'I believe that you show a child with PMLD the same dignity and respect as you would any other child. If a child is very weak, someone might say, "Oh God, they've been sick again!", rather than saying something more kindly, more understanding. One child I had been working with – aged 3 - was sick almost every day. But that didn't matter to me; that was the way he was. I'm very accepting. I take someone as they are'.

When toileting a child, Sian takes care to communicate using body signs, so that there are no surprises - the child knows what is about to happen and is not simply 'thrust into a toilet':

'You have to treat them with the dignity and respect you would show to any child, no matter if they are disabled or able bodied. Say if I'm taking a child to the toilet I'll do body signs on them. As you speak, "Are you ready to go to the toilet?" you have a different touch for every word – like the Makaton signing but this is on the body. So I take them into the bathroom and make sure that the door is closed and then hoist them on to the toilet, using a touch cue. Then you toilet the child, put them back in the hoist, using the touch cue. And with an able bodied child you wouldn't just thrust them into the toilet without telling them what you are doing. And you wouldn't leave the bathroom door wide open.'

Respect

Dignity should always command respect, but respect is sometimes lacking, or withheld, as when: some important fact about the person is not properly attended to or is not taken appropriately into account . . . the person is dealt with as though he is not what he actually is . . . Pertinent aspects of how things are with him are treated as though they had no reality (Frankfurt 1999: 152-3).

Usama is the profoundly disabled 6 year-old son of Rameen Gurmani. Not everyone in the family was able to accept that Usama had learning difficulties. Rameen reports that: 'they just found it difficult to accept, though I think they knew in their hearts. Perhaps they were ashamed. They couldn't get used to Usama being different. My mother in law was always looking for a

reason why Usama might stay at home rather than join us all at a family gathering'. Usama is 'different' – 'flawed' – and is neither recognised nor accepted as 'one of us'. He is stigmatised and rejected.

One manifestation of looking on someone as different and worth less is to (feel free to) stare at them. Since staring at someone is generally felt to be intrusive and insulting, those who stare suggest by their behaviour that they do not regard the person as deserving of respectful attention, but see him, rather, as a creature to be gawped at rather as we might an animal at a zoo. Rameen knows better:

'Usama has made me more accepting of people who are different. It brings home to me that I wouldn't want to be stared at. We still get a lot of that – sometimes people stop and talk to each other and then they both turn to stare. We wouldn't mind if people asked – just asked us about Usama – but what we really don't want is people making us feel that there is something wrong with him'.

Human Dignity

Dignity, or human dignity, should always command respect; but what is this 'dignity' or 'human dignity'? It is very difficult to come up with a good answer. Consider how Veronica describes an incident with her daughter Harriet:

'I need to hold her dignity for her. I wanted only women handling her. I didn't want a male carer cleaning her nappy pads. Once Harriet ripped her clothes off and began to rip her nappy pads in a public space. Her carers formed a circle round her, and what they were doing was respecting her dignity. Of course, Harriet wouldn't understand these concepts, and couldn't protect her dignity herself. "Respect for dignity" is trying to understand the world from Harriet's perspective'.

It is important that we try to understand the world from Harriet's perspective, but this perspective may not help us determine what we should do in order to respect her dignity, since her perspective may not include any idea of respect, or dignity, and may not include any experience of behavior that she understands in anything like these terms.

Head teachers of schools for children with PMLD demand of their staff that they should never pull a child in a wheelchair backwards; never talk over the head of a child to a colleague as if the child was not there; never bring a child into a public space without being sure that she is dressed. Readers will surely agree that these behaviours would be unacceptable; but is the reason why they are unacceptable that they are incompatible with human

dignity? Suppose a child is perfectly happy to walk about on a public street without any clothes on, or to be toileted in a place that is open to strangers, or to be talked about as if she is not there; suppose that she is wholly unaware of anything amiss with her dignity – blissfully unaware even. How, then, is her dignity compromised, if she herself has no sense of anything amiss?

Several questions present themselves. What does the term 'human dignity' refer to: a property or a quality inherent in each human being? What could that possibly be? Where should we look to find it? When did we first acquire it? (In the womb? When we were born?) Alternatively, is dignity something we as groups or societies confer on each other? By what process can we confer this special property on someone – just by our collectively saying or believing that she has dignity, or behaving as if she does? What would happen if we did not believe that she has dignity, and treated her with contempt, and as not deserving of our care and protection? Some people are treated as if they are animals or sub-human; is someone to be deprived of dignity just because dominant groups in their society refuse to confer it upon them?

There are more questions still: is dignity the name of something subjective, in the sense that it requires that we have some awareness of when our dignity is upheld or violated? Harriet has no such awareness: is she therefore someone who does not possess dignity? We would not want to say that. To avoid this conclusion should we say, instead, that dignity does not demand any awareness on our part – that we have dignity regardless of whether we know that we have it – as Harriet would have had her dignity violated if she had not been protected by her carers, even though she had no idea of what was being protected when a protective circle formed around her.

If we want to say that human dignity is something that all human beings possess, without exception, we must come up with an account of dignity that does not require that we are always aware of it, or that we are necessarily even capable of any such awareness. It is possible that there is no such account. It may turn out that dignity is, after all, a fiction, a myth. Some people believe – Andrea Sangiovanni (2017) is one of them – that we can say everything we want to say about how to treat people with humanity without any mention of dignity whatsoever; that we do not need to go looking for a chimerical magical property in order to explain what is wrong with treatment that dehumanizes and degrades; that we can explain why we should abhor and prohibit cruelty and inhumanity without having to discover this thing we call dignity which it has proved so difficult to define and pin down.

On the other hand, I shall finish with these thoughts. No one reading this article would think it acceptable to let Harriet be seen naked in a public place. You would never think of countenancing anything like this; you would think it appalling. Perhaps one reason for thinking it appalling is this: that any such treatment amounts to a gross violation of a dignity that Harriet possesses in full; that respect for dignity rules this out, irrespective of whether Harriet would have any sense of her dignity being injured or violated. I am guessing that you believe that Harriet, like any other human being, and irrespective of any disability, has full and equal human dignity – and not one jot less than anyone else. This is what I too would like to believe, but lack the ingenuity to explain.

Notes

Some paragraphs in this article are based on material in Vorhaus (2016; 2017). All names and places are anonymised.

Contact details

John Vorhaus is Professor of Moral and Educational Philosophy at University College London, Institute of Education

Email: j.vorhaus@ioe.ac.uk

References

Frankfurt, Harry. 1999, 'Equality and Respect', in Frankfurt, H., *Necessity, Volition and Love*, Cambridge: Cambridge University Press, 146-154.

Sangiovanni, Andrea. 2017. *Humanity without Dignity*. Harvard: Harvard University Press.

Vorhaus, John. 2016. *Giving Voice to Profound Disability*. Abingdon: Routledge.

Vorhaus, John. 2017. *Valuing Profoundly Disabled People*. Abingdon: Routledge.

Get Involved

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

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

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

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

Should International Evening be cancelled this year?

Tracy Edwards

How can we think through strategic decisions that impact on individuals with PMLD? This article reflects on what will be a familiar dilemma for those working with pupils with PMLD in education settings.

Yew Tree Wood is a small generic secondary special school in a deprived coastal town. A diverse range of needs are represented in its population. The only two other special schools in the local authority specialise in autism provision, making it the default education setting for large numbers of pupils with Education Health and Care Plan and without an ASC diagnosis. At Yew Tree Wood, therefore, young people with PMLDs learn alongside pupils who may go on to sit GCSEs.

For the past five years, International Evenings at Yew Tree Wood have been one of the most successful events on the school calendar. Many pupils participate in dance performances and enjoy tasting food from different parts of the world. Other pupils like to create artwork based on different national flags, and to dress in clothes associated with a particular country. Families who do not otherwise attend meetings at the school come to international evening, and a number of pupils access valuable opportunities to develop their literacy and numeracy through preparing stalls and creating posters and menus.

14-year old Brian did not attend International Evening last year. Attending either means a long wait with his teaching assistant for it to start (or making the difficult journey back into school in the evening, after going home on the school bus). Brian's adult sister is also unsure of the benefits for Brian, who is tube-fed and often tired in the evenings due to his epilepsy. Brian's sister is also very critical of his class teacher to whom she sends emails several times a day which include intimidating language. This has been a great cause of distress amongst the class team who feel that they cannot do anything right and have, at times, been tearful.

A group of teaching assistants, however, are making every effort to ensure that those with PMLD can participate in the international dance performances and enjoy the occasion at some level.

So, from an ethical perspective, should whole school events still take place if pupils with PMLD cannot easily or meaningfully engage in them? Does holding events that are accessible to some students but not others represent a form of exclusion? Would it be right to cancel

International Evening and potentially deny other learners in the school with a highly valuable learning experience in the process? Should we therefore not just accept that different individuals need different things and think less about the "whole school" when planning extra-curricular and enrichment activities?

Is it not our professional and moral duty however, to establish the conditions through which everyone can come together and be together, as a community? Is planning something separate and bespoke for pupils with PMLD merely "othering" them to those who do not have PMLD? Surely, as members of the human species, young people have much more in common with each other, rather than things which set them apart). Is the need to belong greater than the need to be "met" at your individual point of learning? How can educators appropriately meet individual needs in an activity whilst simultaneously establishing a basis upon which to build a positive and inclusive society?

Questions around access and entitlement

The above questions are linked to the principles of "access" and "entitlement". These principles are based on the notion that each individual has the right to particular opportunities or experiences, and that it is the collective responsibility of a community to remove barriers to reaching them. The United Nations' Convention on the Rights of the Child (United Nations, 1989) outlines 45 "articles", each detailing an entitlement, to which all children, regardless of ability of need, should have access. This includes the right to an education (article 28) and the right to play and leisure activities (article 31).

The principles of "access" and "entitlement" underpinned the rationale for teaching the National Curriculum to all pupils in schools, including those with PMLD. In more recent years, however, these exact same principles have been used to argue that those with complex learning needs and low prior attainment should be offered an alternative to the National Curriculum. "Entitlement", surely, is not about having the right to the same offer as everybody else. It is about the right for an individual to be met, at their particular point of learning. If a National

Curriculum subject such as Geography can only be “accessed” at a superficial level (so the argument goes) then why study Geography? Surely “entitlement” is instead about having access to curriculum areas which instead enable deep learning. For an individual with a PMLD this is likely to be in areas such as ‘Communication’, ‘Cognition’ and ‘Physical Development’.

The contemporary American philosopher Martha Nussbaum (2011, pp 30-31) lists a set of ten Central Capabilities which respond to the question “What are people able to do and be?” Within this list is “affiliation” (being able to live and coexist with others) “bodily health” and “play”. With this, it is noteworthy that the ten Central Capabilities in Nussbaum’s list are not outlined in any hierarchy and all have equal value; “practical reason” for example, is not presented as a higher capability than “bodily integrity”. It is also noteworthy that Nussbaum emphasised that the purpose of the “Capability Approach” is not for all citizens of the world to access each of the 10 capabilities equally; human diversity means that some individuals will reach some capabilities to a higher degree than others would. The point, however, is for all people to reach a threshold of acceptability for each of the 10 Central Capabilities and also to ultimately realise each one to the maximum degree possible.

The ideas of Martha Nussbaum raise some important considerations for the development of provision for pupils with PMLD. They provide a helpful framework for example, for the design and evaluation of a needs-based

curriculum. They can also support us to plan and make decisions around whole school events such as International Evening. Are they supporting learners with PMLD to reach their central capabilities or are they undermining them? With this, it is noteworthy that there are no easy answers. Different rights and articles within the United Nations Convention on the Rights of the Child can simultaneously support and clash with one another; one child’s behaviours, for example, can arguably impact on another’s right to learn. With pupils with PMLD, rights and capabilities need to be viewed in context. What does “the right to play” look like for a pupil who is not demonstrating curiosity or initiation? In our planning are we aiming therefore to emulate “play” (for example through staged photographs of Brian “playing” an international board game) or do we need to start to define “play” differently?

Questions around agency/voice

Key to making decisions related to International Evening in a special school, are questions around pupil agency and voice. How do we know that Brian and his classmates are consenting to their participation in the Xhosa dance performance? If they are unable to give consent, what strategies do we have for eliciting their “voice”? Who is carefully observing Brian’s responses to the situation, for example, and establishing whether or not he seems to be experiencing pleasure and enjoyment?

In considering the role of pupils with PMLD in school performances, we also need to ask ourselves whose “voice” is coming through. In the above scenario,



Figure 1: Martha Nussbaum’s List of ‘10 Central Capabilities’. How can this support ethical and strategic decision making involving individuals with PMLD?

The Ladder of Participation

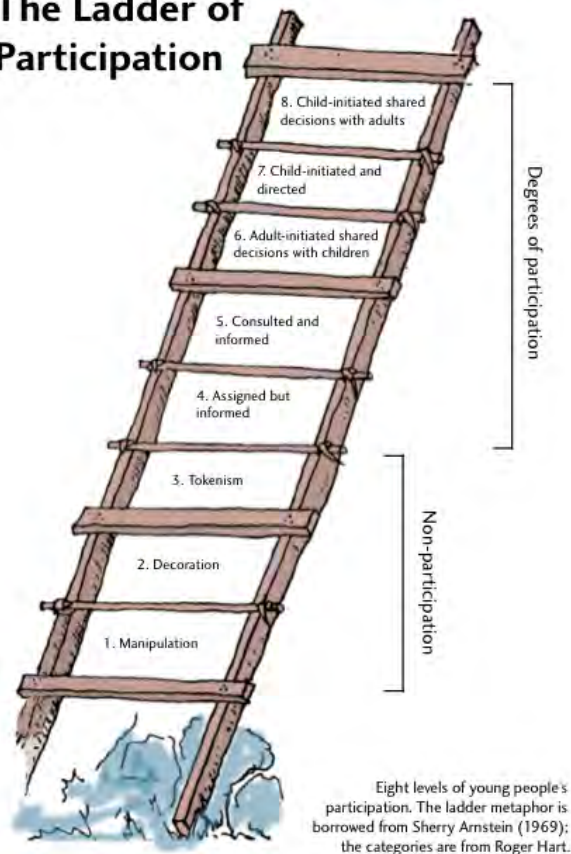


Figure 2: Hart's Ladder of Participation

featuring Yew Tree Wood School, for example, is it the voice of Brian's teaching assistant, his teacher, his sister, or of Brian himself? Who is the performance truly for? Over the years, I have seen some incredible participatory performances within school concerts, involving pupils sat amongst the audience, operating switches which bring interactive displays and sound recordings to life. This tends to offer greater agency than performances involving elaborate costumes and decorated wheelchairs (although it depends, of course, on the pupil).

Hart's Ladder of Participation (Hart, 1992) has been around now for many years. It offers practitioners working with pupils with PMLD the opportunity to evaluate the degree of agency and voice which the individual has throughout an activity. The use of engagement-based assessment, as outlined in the Complex Learning Difficulties and Disabilities Research Project (Carpenter et al., 2015) and subsequent Rochford Review (Standards and Testing Agency, 2016) into the assessment of lower attaining pupils, also provides opportunities to evaluate and plan for enhanced agency and voice amongst pupils.

Questions around fairness and justice (the teacher and Brian's sister)

The above scenario about International Evening also touches on issues related to fairness and justice. If Brian's sister has been so difficult with the class teacher, then should this be allowed to continue beyond the school day? Or should everyone be expected to draw upon their reserves of professional resilience and focus on Brian?

Questions around representation

With a whole school international evening, issues around representation and voice are also key. How are pupils with PMLD being represented to the rest of the school community? Are they visible? Are all their very many positive characteristics being made apparent to all and able to shine through?

For me personally, questions around representation provide the strongest arguments for not cancelling international evening and for pulling out all the stops to ensure that those with PMLD can attend. Ethically, we need to make every effort to prevent the "othering" of those with PMLD and normalise their inclusion in all activities. This should not however come at the expense of comfort levels, safety and wellbeing (which makes planning for an international evening a logistical juggle).

Interestingly, questions of representation also apply to the "international" dimension to the event, which I have so far overlooked. With all the costumes and "ethnic traditions", are negative stereotypes of particular cultures and countries being perpetuated? How "educational" is it for the pupils at Yew Tree School to associate 'Africa' with grass skirts or French men with berets? Sometimes, in making these events accessible, are we simultaneously compromising the same international ideals which we were aiming to promote in the first place? With this, what I have personally found to be helpful, is a focus on bringing people together to learn about each other and using events such as International Evening to enable real encounters between real people from different parts of the world, rather than imagined ones. Who could be invited into the school to meet with pupils? Are there any staff members and families for example with stories to share? This principle of "bringing people together" also applies to young people with special educational needs and disabilities; bring pupils with PMLD and without PMLD together so that they can really learn to "know" each other. It also applies to relationships between families and professionals (including Brian's teacher and sister) who will inevitably feel less estranged face-to-face than over email.

Another contemporary philosopher, Gayatri Spivak (2012) writes about "the ethical engagement with the other". If the international evening at Yew Tree School can enable this, then it will be truly beneficial.

Contact Details

Tracy is a PhD Elphinstone Scholar at the University of Aberdeen School of Education. She is currently collecting/creating 'Stories of Exclusion and Inclusion' with teachers, about dilemmas relating to meeting individual needs in diverse classrooms.

e-mail: r01te16@abdn.ac.uk

References

Arnstein, S. R. (1969) 'A Ladder Of Citizen Participation', *Journal of the American Planning Association*, 35: 4, 216 — 224 Available online at: <http://dx.doi.org/10.1080/01944366908977225>

Carpenter, B., Egerton, J., Cockbill, B., Bloom, T., Fotheringham, J. and Rawson, H. (2015) *Engaging Learners with Complex Learning Difficulties and Disabilities*. Abingdon: Routledge

Hart, R (1992) *Children's Participation: From Tokenism to Citizenship*. United Nations Children Fund (UNICEF): Florence, Italy. Available online at: <https://www.unicef-irc.org/publications/100-childrens-participation-from-tokenism-to-citizenship.html>

Nussbaum, M. (2011). *Creating Capabilities: The Human Development Approach*. Belknap Press.

Spivak, G. (2012). *An aesthetic education in the era of globalization*. Cambridge, MA: Harvard University Press.

Standards and Testing Agency (2016) *The Rochford Review: final report. Review of assessment for pupils working below the standard of national curriculum tests*. Crown copyright. Available online at: <https://www.gov.uk/government/groups/the-rochford-review>

United Nations (1989) *Convention on the Rights of the Child*. Available online at: https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-11&chapter=4&lang=en

IN THE NEXT ISSUE

Summer Vol. 31 No. 3 Issue 94

Looking Ahead

Do you have any stories to share?

If so, contact the Guest Editors:

Jeanne Carlin, Annie Fergusson, Michael Fullerton, Bella Travis and Maureen Phillip

jeanne@jcarlin.karoo.co.uk Or annie.fergusson@outlook.com

Copy date

1st November 2019

More information on page 53

Why is research important? Reflections for professionals and parents

Lila Kossovaki

I decided to write this article in order to present in brief my line of argument on why research is important. This is a question I often get from professionals and parents of learners with complex needs. In a nutshell, my answer is that research is a concise and efficient way to improve the life of the people we work or live with and care about. Given that the focus of this edition is on communication, the PMLD Link readership should be aware that effective interventions in the field such as Intensive Interaction (Nind and Hewett, 2012) and Responsive Environment (Ware, 2003) are based on extensive research.

Research has always played a significant role in how I approach teaching; now as a university lecturer and in the past as a schoolteacher. I feel more confident to either teach communication skills to learners with PMLD or innovative interventions for learners with PMLD to university students if I am aware of the current research on the topic. Why not to benefit from work that other people have done before and learn from their successes and mistakes? Am I a minority? Maybe, but I am not definitely the only one thinking and acting this way. I am extremely passionate about this topic, as I often see people underestimate the academic background of teachers and the science behind education, let alone special education. I will use the term teachers in this article to refer to all professionals working with learners with PMLD as my arguments are more relevant to school-based staff but they also have applicability to other relevant professions. Many of the points I will raise might also be pertinent to parents and carers. For this article, I will focus on the importance of intervention research, as I believe the benefits of this type of research are very explicit.

The main benefit of research for teachers is that they can use it to improve their practice. Teachers have very limited time to try out interventions which have no evidence that they can be effective. Usually these interventions come with expensive training packages and in some cases with the added cost of equipment. Schools buy them and by trialing them they soon find out that they cannot be used in their setting due to staffing and time limitations or inappropriateness for their learners. Is this good use of a school's budget? To take this a step further, is it ethical to waste money as well as staff and learners' time experimenting with something we have no data showing that it can be beneficial for learners with PMLD? Sometimes when data are finally collected, they show that the learners did not develop any new skill while they could have spent this precious time on interventions which have some research evidence behind them. For the above reasons, teachers should read

research and also be critical consumers of it. For example, a study conducted by an independent body (e.g. university, charity) carries far more weight than studies which are conducted by people who are going to benefit financially from the use of an intervention. Scholars have listed quality indicators in order to conduct good quality studies or judge the quality of existing ones (e.g. the characteristics of participants should be provided in detail, more than one researcher should collect a certain amount of data and check whether they agree on what they see, reliable outcome measures should be used before and after the introduction of an intervention, etc).

Another equally important benefit of research is that it can be used to show the wider public what works. Teachers might have come up with some amazing interventions which sadly stay within the limits of their school or even class because they do not feel confident enough to collect data on their effectiveness and disseminate the findings broadly. The same question comes to mind again. Is it ethical to keep knowledge for us when, by sharing it, the lives of other people can improve? This is why teachers need to be trained in basic research skills and where the universities should step in. I have often witnessed teachers struggling to collect data using a number of sources while a single but well developed data collection tool can do the job. In research, it is about quality not quantity and sometimes novice researchers should do less but do it properly. For example, asking the right interview questions to support staff is likely to provide more useful data than combining long unstructured observations and a reflective diary completed by a single person. An argument which should be addressed here is that research with people with complex needs cannot develop further as they are a very heterogeneous population. So are the people who have autism ranging from individuals who gain PhDs to learners with autism and PMLD but they are the most widely researched group within special needs in the last decades.

I can go on for many pages listing arguments in favour of research and elaborating on them. This is what I do for a living; I train professionals (i.e. teachers, teaching assistants, therapists, key workers) and parents/carers in Severe, Profound and Multiple Learning Disabilities (SPMLD) at the University of Birmingham, sadly currently the only university programme of this kind in the UK. One of the learning outcomes of the programme is to facilitate students in developing rigorous evidence-based practice. The SPMLD programme consists of a mixture of undergraduate and postgraduate students who have to conduct small research projects for their assignments. These are based on theory, professional practice and also very importantly, research. Many of the students' assignments can be found as articles in the PMLD link and elsewhere, building on the limited existing research in the field of PMLD. These students can confirm that I live and breathe research; in other words, I am biased. This is what in research we call 'positionality', a researcher's stance in relation to the wider context, and should be disclosed in good quality studies. In sum, research can help teachers do their job better and disseminate their good practice widely. It might seem hard in the beginning but there are some ground rules to follow in order to expand the certainly limited research in the field of PMLD.

Contact details

Dr Lila Kossovaki is Lecturer in Severe Profound and Multiple Learning Disabilities in the Department of Disability Inclusion and Special Needs (DISN) of the University of Birmingham
e-mail: a.kossovaki@bham.ac.uk

References

Nind, M. and Hewett, D. (2012) *Access to communication: Developing the basics of communication with people with severe learning difficulties through intensive interaction*. London: David Fulton Publishers.

Ware, J. (2003) *Creating a Responsive Environment for People with Profound and Multiple Learning Difficulties*. London: David Fulton Publishers.

Gift Aid

Are you a tax payer?

Is your subscription to PMLD LINK for yourself and do you pay tax? If this is so and if you sign a gift aid form, then PMLD LINK can get an extra 25p for every £1 you pay to us for your subscription, in a tax refund from the government. This will help PMLD LINK significantly.

If you pay online via the website, you will be given the opportunity to fill out a gift aid form. If you have forgotten to do so or if you are paying by cheque or by setting up a bank mandate, please fill out the subscription form available on the last page of this journal or downloadable from the subscribe page of the PMLD LINK website (www.pmlmlink.org.uk). Send it to the PMLD LINK Treasurer at the address shown on the form.

You can cancel this Declaration at any time by notifying PMLD LINK. If you pay tax at the higher rate, you can claim further tax relief in your Self Assessment tax return.

If you are unsure whether your donations qualify for Gift Aid tax relief, refer to help sheet IR65 on the HMRC web site (www.hmrc.gov.uk)

Many thanks for your support.

Is it a good thing to identify people as having profound and multiple learning disabilities?

Peter Imray

Refusing to accept that someone with PMLD (profound and multiple learning difficulties) actually has PMLD, and that this is a condition for life, will help no-one. The careful labelling of a learner being within the PMLD spectrum must lead to the establishment of an appropriate pedagogy.

In 2007, Lauchlan and Boyle conducted a literature review on whether the use of labels in special education was helpful or not. As strong inclusionists it is hardly surprising that they were sceptical about the positive elements of labelling, and echoing Gillman et al (2000), came to the conclusion that

‘Those working in special education need to adopt an ethical framework to the application of labelling, one which can be considered valuable, not in terms of whether the labels are accurately applied, but in terms of whether it opens [and not closes] doors and creates opportunities for the person concerned’
 (Lauchlan and Boyle, 2007, 41, original emphasis)

On the whole this seems a reasonable demand, since all things related to education, including labelling, have to be in the learners’ long-term interests. That is, the label of a learner being within the PMLD spectrum has to lead to the educational establishment of an appropriate pedagogy, teachers pursuing a curriculum and class staff applying specific skills and expertise, that will allow learners to educationally do the best that they can do and be the best that they can be. However, the problems associated with the inaccurate and vague application of labels, especially by those who intrinsically distrust and reject the whole issue of labelling can mean that learners are pushed through the wrong doors in the first place. Labelling, and even more importantly, precise labelling, therefore carries significance when attempting to ascertain the nature of a curriculum that is fit for purpose.

In other arguments against labelling, much is made of the personalisation imperative, so that for example a *‘favourite recollection is when a teacher said in a meeting that his pupil was more David than Down’s’* meaning of course that *‘the child’s character, individual experiences and support network were of far more importance than the medical diagnosis’* (Briggs, 2016, p11). This does of course assume that David’s learning style, his character, personality and individual experience have not been shaped by his learning difficulty, though it is impossible to know if this is so and if it is so, by how much.

Lorna Wing’s often quoted observation of *‘show me one child with autism and I will show you one child with autism’* is equally applicable to both severe and profound learning difficulties. That is, whilst each learner with autism is bound to be different (as all children are different from each other), a deep and meaningful understanding of autism is essential if we are to be successful teachers of children, young people and adults with autism, as Wing would have been the first to acknowledge. As it is with autism, so it is with both SLD (severe learning difficulties) and PMLD. Knowledge that a child has profound learning difficulties is extraordinarily useful if one knows about PMLD (but not very useful if one doesn’t). Even more helpful is the knowledge about roughly where the learner is within the PMLD or SLD spectrums, which an in-depth and working knowledge of the P scales can provide. The P scales will not give an absolutely accurate assessment of the nature of the individual’s learning difficulty since they were not designed to do this; what they will do is give clues, provide a common language, point professionals in the right direction. Both the curriculum and the teaching of that curriculum may well be very different at one end of the PMLD spectrum (P1) to that applied at the other end of the SLD spectrum (P8). Equally, the way children learn and what they are likely to be able to learn will be very different from one end of the spectrums to the other. Teachers are, however, highly unlikely to have an in-depth knowledge of the P scales if they do not already have an in-depth knowledge of PMLD and SLD.

I have argued elsewhere (Imray and Hinchcliffe, 2014, Imray and Colley, 2017) that knowledge of SLD and PMLD is at least as complicated and necessary to effective teaching as knowledge of subject is to those teaching at higher school (in UK terms ‘A’ level) and possibly even undergraduate level. Teaching children, young people and adults with SLD and PMLD is very different from other categories of disability and very, very different from teaching neuro-typical conventionally developing learners (Imray and Hinchcliffe, 2014). If the teaching is very different, teachers need to know very different things.

It seems to be the case that the opposition to labelling arises from the tendency (certainly in the past but also today) towards stigmatisation and denigration of the individual(s) so labelled. This may be so, but the answer does not lie in pretending that differences don't exist in any generic form, as in the labels PMLD and SLD for example, but only as individual differences to be celebrated (Florian, 2010) within a truly inclusive 'personalisation agenda' (Ekins, 2015, p97) since this denies our basic instinct and common sense approach to having 30 'different' children in front of us waiting to be taught. Teachers cannot, and I would suggest, should not teach 30 individual lessons, but will rely on generic information and broad ability groupings; it is our natural tendency as rational beings (Kauffman, 2002; Imray and Hinchcliffe, 2014). If there are pupils in the class with SLD or PMLD, teachers will want to know this and indeed can only teach effectively if (i) they do know this and (ii) they have a deep and meaningful understanding of the learning difficulty which applies.

The reality is that

'children with SEND attract labels from other children and teachers even when they are not formally identified as having SEND. So being stigmatised is not necessarily a result of the identification or labelling but is related to the fact that having a special educational need/disability marks them out as different from other children in some way.'

(Hornby, 2015, 240)

Avoiding identifying and labelling children with SEND (special educational needs and disability) will not prevent them from being stigmatised, but it may prevent them from getting the education that they need (Ayres et al, 2011; Kauffman and Badar, 2014,) since it might well present limits in teachers' understanding of children's difficulties (Terzi, 2010).

One of the key difficulties in any discussion about 'SEN'.....is the embedded assumption that there is a need to identify 'SEN' as different from what is 'normal' or 'normally accepted'. Whether we do this in well intentioned ways or not, what is implied in such an approach is an outdated, hierarchical notion that there is a 'normal', that 'we' are part of that 'norm', and that others outside of that are therefore different.

(Ekins, 2015; 94).

The problem with this comment and similar statements (Runswick-Cole, 2011; Hart and Drummond, 2014; Goodley et al, 2016 for example) is not only the implicit political incorrectness of alternative views, but also the fact that they don't really make sense. Of course special

educational needs is different, because the very nature of special is different. Recognition of difference from the norm is not outdated (in the sense that racism or sexism might be) because there will always be differences from the norm. There is no such thing as a group, community or society where everybody is the same, and there never will be. Refusal to accept words like norm and normal (by for example placing them inside inverted commas) don't make them go away and don't alter the fact that people with PMLD are very different. Holding this view does not make one hierarchical or elitist and does not indicate a belief that some people are superior to others, or that 'we' are superior to 'them'. There are undoubtedly some who axiomatically regard those outside of the norm as being inferior to themselves. They are called ignorant, but in the immortal words of Dilbert 'since when did ignorance become a point of view?' (Adams, 2001).

Words like norm and normal are relative and contextual. What is normal in one situation or society or setting may not be in another. Words that are relational clearly suffer from clarity at certain points, and words like normal are open to misuse and abuse; they must be used and treated with care. But the word normal still exists and has real meaning, unlike that other more infamous 'n' word. We must think very carefully about stopping using words simply because they have been mistreated in the past and we certainly can't base a whole pedagogy around the notion that there are certain words that are unpalatable to our modern, western, liberal sensibilities. We must be mindful of Terzi's (2010) warning; if we deny any reference to the norm, that is, typical human functioning, how can we evaluate impairment and disability, and thereby distribute resources accordingly?

Let us be very honest about this, learners with PMLD do not learn in normal ways; their learning is abnormal in the sense that they learn very, very differently from the vast majority of learners and that this can be very worrying and perplexing for very many stakeholders, not least the person themselves. This is however neither undesirable nor distasteful nor deviant nor freakish; it is what it is. Not putting a label on it does not make it go away.

Surely the way to overcome negative and stigmatising labels is to prove that individuals who suffer from impairments can be successful in both education and society, but they will not be able to be successful in education until an appropriate pedagogy and curriculum is arrived at and specialists in PMLD are given time to develop both ideas and practice. Success in society and the quality of an individual's life is dependent on a number of supporting attitudes and agencies, but individuals with PMLD are likely to be disabled if they meet with failure in education. Education and success are inextricably linked. Curricula development must at least

in part, be driven by how we envisage those with PMLD maximising their quality of life chances; what a person can do and what a person can be (Nussbaum, 2011). Curricula development takes time; it cannot and will not happen overnight. The starting point for those with SLD has only just begun, having been effectively stifled in the UK at least, and probably in many other countries as well by the insistence upon a common (national) academic curriculum framework. Curriculum development for those with PMLD is, at least in the UK, slightly further along the road, but there is still a long way to go before conclusions as to its efficacy can be drawn. In the UK there are numerous pockets of good and outstanding practice in teaching children, young people and adults with PMLD, but this has been done despite the system not because of it and there is as yet, no cohesive understanding of where the journey might take us. Nor will there be until the journey has had a chance to get considerably further down the road.

Refusing to accept that someone with PMLD actually has PMLD, and that this (like autism) is a condition for life, will help no-one. It will not help parents and families, it will not help teachers and teaching assistants, it will not help supporting professionals, because all will need to know about the interventions and supports that can make a real difference. It will not help society, it will not help governments because both will need guidance on the level and depth of support needed. Most importantly, it will not help the person with PMLD because no-one will know what to do if they don't understand the problems and therefore the potential solutions. We can have a real and lasting effect on the quality of life of all people with PMLD, but we have to be grown up about this. Pretending that differences don't exist, pretending that we're all the same, does not make differences go away.

Contact details

Peter Imray has been a teacher of children, young people and adults with special educational needs. He provides consultancy and training in both special school and mainstream settings.
 e-mail: peter.imray@hotmail.co.uk
 website: <http://www.peterimray.co.uk/>

References

- Ayres, K. M., Lowery, K. A., Douglas, K. H. and Sievers, C. (2011) I can identify Saturn but I can't brush my teeth: What happens when the curricular focus for students with severe disabilities shifts. *Education and Training in Autism and Developmental Disabilities*, 46: 11–21.
- Adams, S. (2001) *When Did Ignorance Become a Point of View?* Kansas City: Boxtree.
- Briggs, S. (2016) *Meeting Special Educational Needs in Primary Classrooms*. Abingdon: Routledge.
- Ekins, A. (2015) *The Changing Face of Special Educational Needs*. London: Routledge.
- Florian, L. (2010) The concept of inclusive pedagogy. In F. Hallett and G. Hallett (eds) *Transforming the Role of the SENCO: Achieving the National Award for SEN Coordination*. Maidenhead: Open University Press.
- Gillman, M., Heyman, B. and Swain, J. (2000) What's in a name? The implications of diagnosis for people with learning difficulties and their family carers. *Disability and Society*, 15 (3): 389–409.
- Goodley, D., Runswick-Cole, K. and Liddiard, K. (2015) The dishuman child. *Discourse: Studies in the Cultural Politics of Education*. <http://dx.doi.org/10.1080/01596306.2015.1075731>.
- Hart, S. and Drummond, M. (2014) Learning without limits: Constructing a pedagogy free from determinist beliefs about ability. In L. Florian (ed) *The Sage Handbook of Special Education (2nd ed.)*. London: Sage.
- Hornby, G. (2015) Inclusive special education: Development of a new theory for the education of children with special educational needs and disabilities. *British Journal of Special Education*, 42 (3): 234–256.
- Imray, P. and Colley, A. (2017) *Inclusion is Dead: Long Live Inclusion*. London: Routledge.
- Imray, P. and Hinchcliffe, V. (2014) *Curricula for Teaching Children and Young People With Severe or Profound Learning Difficulties*. London: Routledge.
- Kauffman, J. M. (2002) *Education Deform: Bright People Sometimes Say Stupid Things About Education*. Laham, MD: Scarecrow Press.
- Kauffman, J. M. and Badar, J. (2014) Better thinking and clearer communication will help special education. *Exceptionality: A Special Education Journal*, 22 (1):17–32.
- Lauchlan, F. and Boyle, C. (2007) Is the use of labels in special education helpful? *Support for Learning*, 22 (1): 36–42.
- Nussbaum, M. C. (2011) *Creating Capabilities: The Human Development Approach*. Cambridge, MA: Belknap Press.
- Runswick-Cole, K. (2011) Time to end the bias towards inclusion. *British Journal of Special Education*, 38 (3): 112–119.
- Terzi, L. (2010) *Justice and Equality in Education: A Capability Perspective on Disability and Special Educational Needs*. London: Continuum.

How do we create and sustain 'ethical organisations' to support people with PMLD (including schools, care providers, social services and health services)?

Nancy Keeley

The shocking Panorama expose on Whorlton Hall in May (<https://www.bbc.co.uk/iplayer/episode/m00059qb/panorama-undercover-hospital-abuse-scandal>) showed unethical treatment of people who rely on our support to lead safe, and fulfilling lives. Undoubtedly, government backed investigations and reports will need to be initiated, re-visited and reviewed to provide clear policies and procedures to prevent this from happening in the future. However, in light of this programme, I have been thinking about ethics, and have some thoughts on practical ways we can work towards creating and sustaining ethical organisations for people with PMLD.

I find that the more I think about what we consider to be 'morally good or correct' (definition of 'ethical' in the Oxford dictionary) for people with PMLD, the more diverse and complex this question becomes. Most of us are, thankfully, opposed to what is clearly unethical. However, we are all individually governed by our personal values, ethics, and codes of conduct. Some of these are subjective, but all are affected by social influences and conditioning, assumptions, our culture, upbringing, past experiences, our genetic predisposition, and our 'in the moment' energy levels and mood. Balancing the expectations of society, an efficient and effective organisation, and the individual needs of the person with PMLD, is complex. Add to this the limited resources available for people with PMLD (funding, consistent staff, time etc...) and the question becomes even more multifaceted.

It is, of course, ethical for people with PMLD to be supported to lead a fulfilling, productive and social life, to be heard, understood and responded to, treated with dignity and respect, and to be safe. Recruiting the right person for the supportive role is, obviously, an ideal starting point. Posing well thought out questions should give an employer a 'feel' for someone's suitability. Detailed, ethical policies and procedures are also obvious requirements, as are robust induction and training packages. In addition, and in my experience, staff who are educated about the physical, sensory and communicative differences of the people they support are usually more empathic and sensitive to their diverse needs. Intensive Interaction training is one way in which employees can gain an insight into the people they support, and foster positive relationships with them.

Intensive Interaction channels our empathic instincts, and is based on the way all people learn to engage, connect, communicate and become social beings. From the day we are born, our parents and/or caregivers instinctively 'tune-in' to us, spending relaxed, undemanding, time observing our expressions so that they can understand our personality, idiosyncrasies and needs. They encourage our communication and sociability by mirroring our expressions, and echoing our vocalisations, instinctively embellishing them in a conversational way to enhance our skills. This in-turn builds upon fundamental communication skills that develop before language such as, attention and concentration, shared engagement and turn-taking, understanding expression, gestures, body language, eye contact, vocalisation, and leaning to have fun and play. Many people with PMLD and/or autism may have found it difficult to understand the self-affirming attention given to them at the early stages of development. They also, very probably, were unable to fully access and learn our typical communication techniques. Intensive Interaction encourages staff to re-explore these initial stages of social exploration and communication with people with PMLD and autism. Engaging in a recognisable and meaningful ways (i.e. 'tuning-in', copying, echoing, sharing interests) opens up the possibilities of connection, understanding and development in communication skills and sociability. This in turn, should also lead to enhanced feelings of self-worth and empowerment for the people we are supporting.

Sustaining an ethical organisation can, I feel, often be more of a challenge. Despite good intentions, staff turn around, heavy workloads, necessary administration tasks, fatigue etc. can impact on best practice. The basic needs

of the person being supported (as shown in Maslow's hierarchy of needs below) understandably take priority, and staff may naturally revert to their habitual and personal ethics and codes of conduct, as opposed to those stipulated by the company. This can then impact on the emotional, communicational and social well-being of the people being supported. Ironically, this can then cause 'basic needs' tasks to become more challenging and time costly for staff and the person being support.

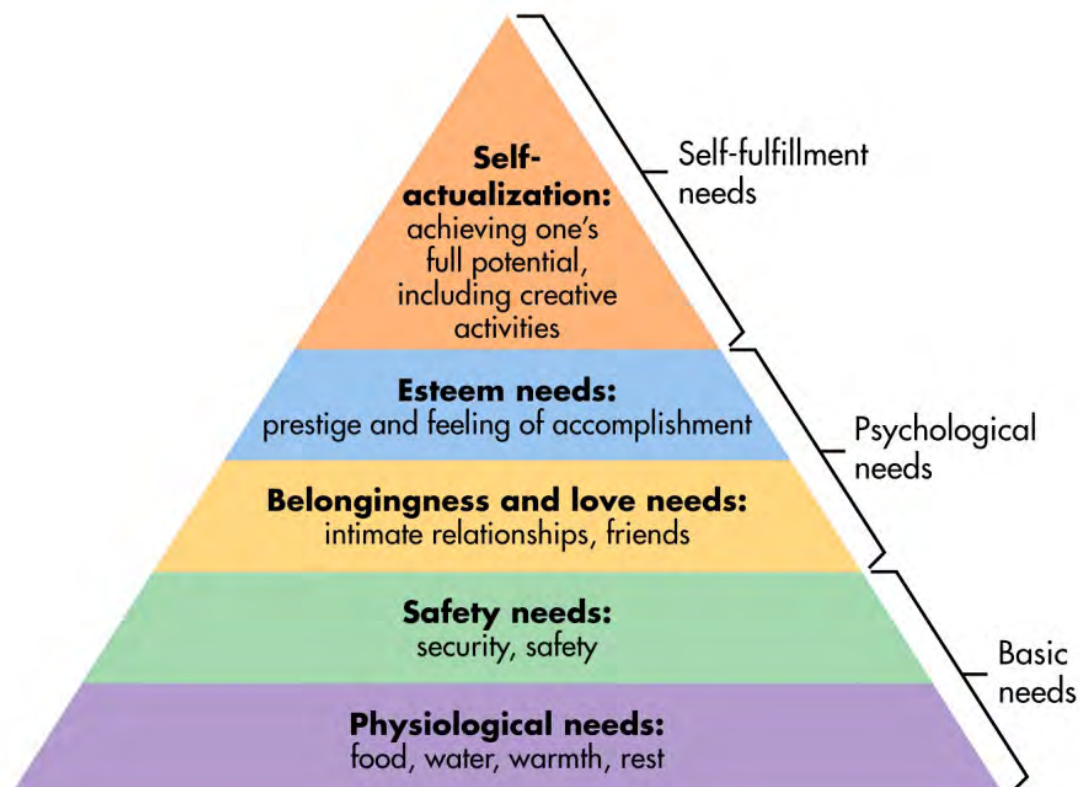
Comparable to the people that we care for, employees need to feel supported and listened to. Also, policies, procedures, and training outcomes need to be re-visited and revised regularly to become firmly established. Structured supervisions, 'in the moment' conversations, appraisal systems, staff meeting, and training re-fresher courses are invaluable. In addition, 'day to day', ongoing expectation of ethical standards need to be embedded.

I work for 'Us in a Bus', an organisation that supports people with PMLD, complex needs and/or autism. We visit people in their homes or in a community space and, using creative, client-led and Intensive Interaction based methods, provide opportunities for people to express themselves and build relationships with others. We also offer training and consultancy, and coaching and mentoring. We have an 'Ethics & Conduct' policy, the purpose of which is to engage with others in a way that embodies and reflects the principles of dignity and respect. Our four core conditions (simplified for the purpose of this article) are:-

- **Congruence** – Between what is expected of the people we visit and what we expect of ourselves. Much is expected of them, including being observed, reviewed, reported about, encouraged to stretch their comfort zones. We should not expect less from ourselves.
- **Acceptance** – Unconditional positive regard. We can separate our judgement of the behaviour from our value of the person. Acceptance is fostered by working relationships based on mutual support, active encouragement, trust and respect.
- **Realness** - Being real and genuine in all our interactions. It is then easier for others to recognise us, relate to us and be themselves. In this way, we can be truly equal with our service users and each other.
- **Empathy** - Aiming to try to understand the person from their point of view. Hasty decisions do no one any favours.

The policy goes on to describe expected conduct from Us in a Bus Staff:

- **Communication** – To keep all channels of connection and communication open.
- **Confidentiality** – We have a duty of confidentiality to the people with whom we work and each other.



ETHICAL EMPLOYERS				
<u>CREATE</u>				
Recruitment	Induction	Policies and Procedures		
Training (Inc. Intensive Interaction)				
<u>SUSTAIN</u>				
Supervision	Appraisals	Code of Ethics	Ongoing Training	Staff
Meetings		Feedback	Discussions	Support
<u>BENEFITS</u>				
Ethical Practice Better Relationships				
Happier, More Empowered, More Fulfilled Staff and People with PMLD				

Causes for concern should be reported through the right channels.

- **Awareness and sensitivity** - With our service users. We should not make assumptions. When it is necessary to have specific information about a person, we get this from that person, from our observations and in co-operation with their support staff.
- **Working relationships** – We work towards creating working relationships based on mutual support, active encouragement, trust and respect.
- **Reputation** - We are all responsible for the good reputation of Us in a Bus.

The principles of our Code of Ethics are emblazoned on the wall of our office, and are referred to regularly! The four core conditions apply to our working relationships as well as those with the people that we visit. We also have a robust ‘feedback’ system whereby we are required to give both positive and, if necessary, negative feedback to each other. These discussions are not always easy, but are an unconditional part of our contract and, with practice and repetition, foster better practice and open, trusting relationships between colleagues.

So, as mentioned, creating and sustaining ‘ethical organisations’ to support people with PMLD is complex. However, I feel that, giving employees and the people they support continuous opportunities to learn, to revise their learning, to be heard, understood and supported, will result in improved relationships and more ethical organisations.

Contact Details

Nancy Keeley is an Interaction Practitioner for Us in a Bus

e-mail: keeleynancy24@gmail.com
website: usinabus.org.uk

Further Reading

If you want to read more about how Us in a Bus evolved its ethical stance read the chapter written by Janet Gurney, the charity’s Director of Training, in *Delivering Intensive Interaction Across Settings: Practice, Community and Leadership*, edited by Mark Barber and Graham Firth.

This book is available from Amazon both as a Kindle e-Book and, now, in paperback at very reasonable prices.

Are cleaners more valuable than support workers?

Dreenagh Lyle

Two events prompted this paper. My need for a cleaner and the arrival of my daughter's thirty-page Capability For Work questionnaire, which I was invited to complete on her behalf. I was dismayed to discover a cleaner might even charge more than the London Living Wage which is more than my local authority budget pays for support for my daughter, Odyssey. I am not opposed to paying cleaners a decent wage. I simply balked at the idea of there being some equivalence between the job of cleaning and that of supporting a vulnerable adult with highly complex support needs. Do we really value cleaners above support workers? It seems that, if wages are our gauge, yes we do.

In any discussion of the values and ethics we employ either supporting or advocating for an individual with PMLD, we need to ask ourselves a number of questions. We need to be honest, especially if our views are being used to inform government policy. I constantly query if we are doing our daughters and sons a disservice by not acknowledging the dependent nature of their being? Whenever I raise this subject in academic circles I am told, 'no man is an island' or 'we are all interdependent'. Or even 'as the individual grows older the dynamic changes, so now the person with learning disabilities supports their elderly parent'. The first two of these statements recognise that we are indeed social beings. The third applies very well to some people with learning disabilities who I interviewed for a research project. However they do not convey the lived experience of someone like Odyssey. I am concerned that in the push to accommodate people with PMLD in social theoretical accounts, we have lost sight of the nature of their unique position in the world of disability, and indeed the world at large.

Assumption

We can only ever make assumptions about how these people feel or what they may want. I struggle to think of another group who cannot self-advocate in the typical sense. To be blunt, many literally have no voice and others like Odyssey use idiosyncratic vocalisations or echolalic bursts of song. I have lost count of the times I have been asked what she means. I always answer truthfully, 'I have no idea. I can make a guess, based on having lived with her for over forty years, but it is still only a guess.'

We constantly hear about our ageing population these days and their need for social care. Many older people experience loss of cognitive capabilities to the point they need someone to advocate on their behalf. However,

rather like people who experience extreme mental health distresses, such as psychosis, they have arrived at their current status from a position of cognitive ability. This is not the same as lifelong cognitive impairment.

If I use the example of my daughter's congenital total blindness, it may better illustrate my point. Odyssey has been totally, neurologically blind since birth. She has a rare condition called Leber's amaurosis. Put simply her optic nerves never developed. We need the optic nerve to convert light signals to images in our brain and hence to see. Odyssey sees nothing. No light and shade, no response whatsoever. This is vastly different to people who experience sight loss or visual impairment. All her experience is abstract. She does not have the cognitive capacity to understand what certain things are. We all make sense of the world by assigning mental representations to various objects. Hence we can instantly conjure a mental image of a swimming pool for example. But what is a 'pool' to Odyssey? A meaningless word. For over five years we would take her to the local swimming pool and try to encourage her to 'get in the pool'. She always refused. It was a children's training pool and a little warmer than the main pool. One week, I was trying to encourage her in and for some reason said, 'it's like the bath, get in the bath darls'. To our surprise she stepped in straightaway. 'Bath' had meaning to her.

Adult life

For most families life with a child with PMLD is a constant round of hospital stays, specialist appointments, assessments and eventually diagnoses. Then there is the flurry of school and statementing as having a child with PMLD often means they will attend a Special Needs school. Some pupils are lucky enough to be offered college placements until they are twenty-five. Eventually though education options run out. After that, what? How do people spend the rest of their lives?

There used to be the offer of attending a Day Centre. In fact the most appropriate centre for an adult with PMLD would have been an ISU, an Intensive Support Unit. The original idea for these centres was that they would encompass all the additional therapeutic needs of someone like Odyssey. Speech and language, occupational, psychological and physio-therapy all under one roof. And there would be no reason why the day service could not include art and music therapy. Our last standing local day centre was originally purpose-built as an ISU. But family carers point out it was never professionally staffed or adequately funded to provide the intensive support such a centre ought to. The relatively low numbers of people with a need for such a service seems to work against them. Combined with the local authority's cost-cutting response to the government's austerity agenda we have seen a reduction of services locally from three day centres and a respite centre, to one day-centre and no residential respite centre. If this article is discussing 'value' then we have to acknowledge that the needs of our PMLD population are not highly valued.

I often wonder when it was decided that a therapeutic approach was no longer necessary or desirable for services supporting people with PMLD? It was certainly prior to the publication of Valuing People (DoH, 2001, 2009), the current government policy for meeting the needs of people with learning disabilities. However I do believe that original policy paper missed a trick by not acknowledging the continuum of learning disability. Perhaps it was easier to view all people with learning disabilities as having the potential to gain employment. Especially as the policy was nested within the then Prime Minister Tony Blair's Welfare to Work strategy, which he called his Third Way (Powell, 2000).

It was during this period that the Department for Social Security was changed to the Department for Work and Pensions (DWP). I sincerely wish there had been acknowledgement of people with PMLD then and an agreement to set up a Disabled Persons pension, for example. That is, an agreed sum of money to be paid to those people whom it was understood would never work.

Potential

If there was a resistance to describing the fundamentally dependent nature of people with PMLD, sadly it has now become essential, not least with regards to their benefits payments. The changeover in benefits is deeply problematical for people with more severe and profound intellectual impairments. The move from Severe Disablement Allowance (SDA) to Employment Support Allowance (ESA) ought to have been challenged. After all the original term was clear enough. An allowance paid to support the extra cost of

living with severe disability. The new term is merely a reflection of the original welfare-to-work agenda.

When Odyssey was first moved to the new benefit, I was advised that it was fully recognised she would never work. I was told there were in fact two strands to the ESA, the work group and the support group. She was assigned to the support group and I thought, okay at least they acknowledge she is profoundly impaired. There are bigger issues to be concerned about than designated benefit names.

Two years later the Capability For Work questionnaire arrived. I rang to point out they had sent the form in error. I was told emphatically that, 'most people only have a limited capability for work FOR A SHORT TIME.' To this end she will now have to be assessed at least every two years, 'because some illnesses, health conditions and disabilities can change over time.'

I trust readers have noted the words, 'most' and 'some'. Most people who break a leg do in fact recover. Indeed. But I wonder which of Odyssey's nine or ten significant diagnoses is likely to change so radically that she will develop capacity to seek and gain employment? I know, realistically she will never develop that capacity. Does this mean I value her less than my older daughter, who has been gainfully employed for many years? Is the DWP affording my daughter more value because they allude to some hypothetical potential she is highly unlikely to develop?

I used to work as an National Autistic Society Early Bird practitioner, delivering intervention programmes to families with a child newly diagnosed with autism. My colleague and I always discussed the non-autistic potential all people with an autism spectrum disorder have. I believe there is much more worth in discussing this potential than that described by the DWP. Unfortunately, in order to keep receiving her benefit, I have to itemise all her diagnoses and the impact of these on her daily life. Having to state and reiterate over 40 pages the nature of her impairments was not a comfortable experience. I may describe Odyssey as being dependent on support in all aspects of her life. However I could never be accused of lacking ambition for her. Although, my ambitions are more realistic than, 'getting a job'. For example I am still ambitious for her to be continent. Someone once asked me how long I would be trying. I explained it was clearly a lifelong task. She may not be fully continent, but she tolerates toileting now. What a major achievement.

Conclusion

John Vorhaus (2016) has recently written about the practice and theory of valuing people with profound

disability. He describes notions of relations and relationships, belonging to the human species and intrinsic characteristics. He refers to the philosopher and parent Eva Kittay and her ideas about the value of her daughter Sessa. Eva describes this as her daughter's capacity 'to love and to be loved' (Kittay, p74). Her latest book 'Learning From My Daughter. The Value and Care of Disabled Minds', has just been published. I am looking forward to reading this as she challenges the prominence given to ideas around 'reason' when discussing profound intellectual impairment. And like me she takes issue with the foisting of normative assumptions on to people with PMLD.

Finally it would be remiss of me not to point out the glaring example of how we value people with PMLD. I must return to the cost of a cleaner and the fact that skilled support work is paid AS IF it were unskilled. If we return to my idea of learning disability being viewed as a continuum, it would make sense to describe support work as graded in some way. Hence we could have a three-tier system, which recognised the support people need as basic, intermediate or complex. This would demonstrate we value support workers at least as well as our cleaners.

Contact Details

Dreenagh Lyle is self employed as an independent researcher, visiting lecturer and consultant. Her daughter, Odyssey, lives at home with her and she has taken over full management of her care.

Her book 'Understanding Profound Intellectual and Multiple Disabilities in Adults' has just been published by Routledge. <https://www.routledge.com/Understanding-Profound-Intellectual-and-Multiple-Disabilities-in-Adults/Lyle/p/book/9780367029623>

e-mail: lyle_dr@yahoo.co.uk

References

DoH (Department of Health) (2001, 2009) 'Valuing People, Valuing People Now.' HMSO, London.

Kittay, E. (2019) 'Learning From My Daughter. The Value and Care of Disabled Minds.' Oxford University Press: Oxford New York.

Powell, M. (2000) New Labour and the third way in the British welfare state: a new and distinctive approach? *Critical Social Policy*, Volume 20, pp39-60 .

Vorhaus, John (2016) *Giving Voice to Profound Disability Dignity, dependence and human capabilities*. Routledge London and New York

SUBSCRIPTIONS

New Subscription Rates

UK Individual £25.00
 UK Organisation £35.00

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

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

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

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

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

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

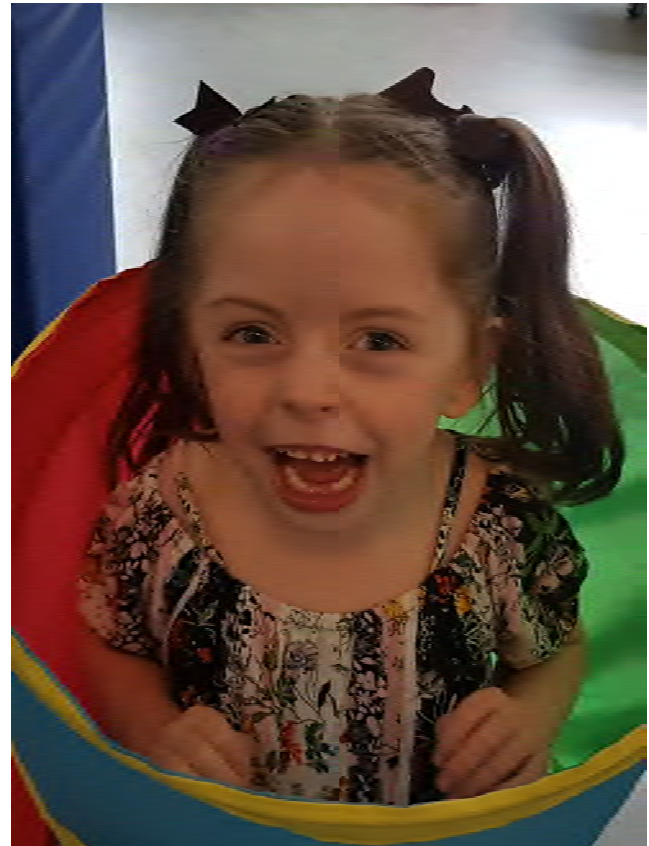
The power of parent voice

Rebecca Pender

I wear many, many hats in my day to day life. I work full time as well as writing, advocating, raising awareness for rare genetic conditions, with a side of inclusion activism thrown in for good measure. I'm also a bit of a social media addict. My favourite and most treasured hat I wear is being Mum to my three beautiful daughters, Hannah five, Molly, three, and Daisy, one.

The reason I do what I do, the person who gives me the drive and determination to change the narrative, is my eldest daughter Hannah who is almost 6 years old. She is a daughter, a sister, a granddaughter and Nana's Hannah. She is a cousin, a friend, a student and a teacher. She is a bringer of light in what sometimes seems like quite a dark world. She was conceived in our hearts for five long years before she was actually conceived. She is an actress, a musician and singer, a selfie queen, a snuggle monster and a wind-up merchant. She loves music and Curious George, school and friends and dancing, handbags and dressing up, and her favourite pastime is seeing how far she can wind up her little sister. She loves people and being included. She knows when she has been left out. She loves food but especially chocolate and gravy. She teaches unconditional love, patience, gratitude, resilience and strength. She also happens to have PMLD. Hannah's primary diagnosis is 'Inv Dup Del 8p', a rare genetic condition with only eighty known affected worldwide. She also lives with a severe learning disability, epilepsy and pineal gland cysts. She is non-verbal although EXTREMELY vocal, doubly incontinent, hypermobile and hypotonic. She has seizures which go in to Status Epilepticus and become life threatening in the blink of an eye. But first and foremost, she is Hannah.

We no longer start conversations in a deficit-led way unless it is necessary, like a medical emergency or the dreaded DLA renewal. I talk publicly about The Power of The Parent Voice and how important it is in the context of Person Centred and Collaborative Health and Social Care, and Co-production. Specifically, under the banner of co-production when dealing with rare conditions and diseases. In Hannah's case I am her voice as she doesn't have one. It's a difficult thing, to admit to yourself that you think there is something wrong with your child. It's harder again to say that statement out loud to your loved ones or health professionals. It becomes a battlefield when those professionals repeatedly dismiss your concerns. It took strength I didn't know I possessed to persevere for eighteen months in the face of accusations of 'Munchausen's by Proxy' and statements such as "I can assure you Mrs Pender, there is categorically nothing wrong your child, she is just lazy" and "You're a paranoid, sleep deprived first time mum."



I started to question my own sanity, whether I was crazy and whether my daughter inability to crawl, walk or babble by 18 months was simply down to bad parenting or was something else really amiss. We wiped the slate and changed our medical practice and our health visitor. I invited the new health visitor to our house to see my daughter and I let it all out. Then came those words I will never forget - "I believe you." I finally had an ally. Genetic testing was ordered - and so, we waited.

On a November evening, when the phone rang, it was her new paediatrician. She mentioned the blood tests findings were significant. I stood there and let the tears fall. A bizarre moment where I felt vindicated, but also heartbroken to be right. I wasn't crazy, paranoid, delusional, though I was sleep deprived and I still am. I wasn't projecting and most importantly I had advocated so strongly on her behalf and it had paid off.



I am not here to vilify our healthcare system. It is world class and has saved my daughter's life on countless occasions. She is kept alive and healthy because she has access to daily meds, oxygen and emergency care at point of need. We are very lucky. But that doesn't mean there are not improvements that can be made in practice and the attitudinal culture of hierarchy which sometimes exists.

In November 2014, I took Hannah to see six GP's over the course of ten days and was repeatedly turned away with "it's just viral, treat with Calpol, return if she gets worse." So, I did return, repeatedly. Some were my own GP practice, and some were out of hours services. It wasn't until day 10 and GP#6, that I demanded immediate action, I explained that I am sure it was viral, but it was not going away and she was worsening. The doctor said that although Hannah was clinically fine she would write a letter for her to be seen at A&E if it would make ME feel better.

They checked her temperature and it had gone up to 39.3 so we were immediately taken through. We were explaining to the doctor what had been going on when I noticed her hands had gone blue. She went limp and started to have a seizure in my arms. Two minutes went by, then three, four, six. By the time we hit seven minutes they had administered the drug midazolam - but it didn't work. She was choking, and I had to run, carrying her in my arms while twenty weeks pregnant, into the resuscitation area. I watched as a team of twenty doctors and nurses cut her clothes off and fought and fought to save my baby girl.

Hannah had seizures for over forty minutes and aspirated her stomach contents. It didn't stop until she was ventilated. She spent five days on life support and we were unsure if she would pull through or not.

I am forever grateful for that resus team. Their quick action saved her life. However, they were only able to act so quickly because we were already at the hospital after I had demanded we be seen. It was a team effort. We all saved her life that day. But I shouldn't have had to push so hard for it to be taken seriously. She had respiratory syncytial virus and a chest infection which should have been picked up on examination before it ever got to the life and death scenario we had just endured. Had she been prescribed antibiotics for her chest infection then it could have all been avoided.

As a contrary experience, a few months later Hannah had a bad seizure requiring blue lighting to A+E at 4.20pm. They wanted to discharge her almost immediately but I held firm, telling them that her pattern was to have two large seizures twelve hours apart. They were reluctant but I stood my ground so they agreed. Sure enough at 4.15 am Hannah had her second seizure within twelve hours and we were in completely the right place. The nurse who I had told and had helped me argue our case with the admitting doctor, took me aside and praised my foresight. I am not psychic but I know my daughter, I know her patterns and therefore my voice as her advocate should be heeded.

I cannot change our story or our experience. Instead, I hope to use it to show how things can be done differently and that by working together we can prevent scenarios like that happening. Something needs to fundamentally change within our system. There needs to be more awareness surrounding rare diseases and conditions and what they mean for people. I would say patients but all too often the person is lost behind the diagnosis. I've lost count the amount of times I have given her medical history, got to her genetic diagnosis and been met with a blank look. A doctor once asked me if she would grow out of it. What we must start doing is making it better known that these conditions exist, that they are largely unstudied, and that the parents of these children are the experts. We are the ones searching frantically for more information, forming bonds and connections with other families with a similar diagnosis and swapping stories about their children's development and about best practice.

We must raise the bar in terms of how families and professionals work together. We need to leave ego and hierarchy at the door and work together and listen to each other to ensure that carers and those with disabilities are not let down. We need to invest time in carers, helping them find their confidence to effectively advocate for their children and teaching them not only to

find their voices but to harness them to advocate effectively for change and inclusion. It's not 'parents vs professionals'. It's figuring out how we can work together to achieve better outcomes for everyone. It's about highlighting the benefits of coproduction to ensure all needs are met. It's also about health professionals using one of the most useful tools in their arsenal for treating patients: the patients and their families.

We can't continue the way we are currently. Health professionals are overworked and overstretched, stressed, tired and at risk of burnout. So are parents and carers of those with PMLD. We are all in the same boat. If we work together we can raise the bar beyond what ever seemed conceivable. We are on the precipice of change and the future of person-centred care is still able to be re-written, by listening and having an even playing field with those polished by their profession and those who are experts by daily experience. The possibilities are limitless.

Let's learn to listen to parents – to listen to the experts in their own children and their children's bodies. Listen to people describing their symptoms and asking for help. Let's think outside the box rather than take a wait and see approach. Let's stop allowing parents to question their ability to parent and allow them instead to advocate on their child's behalf and be truly heard. Let's take a step back and look at the bigger picture and truly place the best interests of these people at the heart of their care. Let's not keep making the same mistakes and let's avoid the unnecessary rollercoaster of misdiagnosis or refusal to diagnose which prevents access to the medical and emotional support required to allow our children to flourish.

If you are a professional, I want you to consider the way you deliver news to families, whether that be diagnosis or otherwise - especially if the patient is in the room. Our choice of language is so important and can have a profound impact on families' acceptance and journey with rare conditions. I would love if you could subtly change the conversations you have with families and truly listen to what they are telling you – especially if they have had a hard time being listened to in the past. You could be the one person to change their lives for the better and believe them.

If you are a family or patient, I would love if you could become the expert on your condition not only in general terms but what it means for you or your loved one. Remember most conditions have a spectrum so they manifest differently in everyone. Get involved in your care, make decisions in collaboration with your healthcare providers, join studies. It may not make a drastic change to your own loved one but it will pave the way for those who walk the path behind us. Have pride in

your condition. It can be hard when it causes symptoms but our genetics make up who we are. And most importantly, remember who you are aside from your condition. Our genetic conditions DO NOT define who we are. They are but are a small piece of the incredible puzzles that make us each individual and lovely.

Contact Details

Rebecca Pender is a writer, blogger, trainer and mother of three young girls, the eldest of whom has PMLD.

e-mail: rebeccapender@btinternet.com

<https://twitter.com/HannahMeIDD8P>

What has bedtime to do with me?

Sarah Clayton

If you are interested in inclusion, in promoting the rights of people with complex physical disability, in participation and genuine coproduction then you are interested in the way people lie down and sleep. Why? Because...

The way we lie
Is the way we sit
And the way we sit
Often dictates what we can do
How we feel
What we can enjoy
The extent to which we can participate

Rachel Wright (www.bornattherighttime.com) describes a lack of postural care as the carbon monoxide of complex disability. A silent killer that affects so many but because of its diffuse nature is easy to think about another day.

Positioning people well day in, day out, is not sexy. At no point on Casualty will you see a good looking medic rush into a room, flick her hair from her face and declare that she is going to reposition the person she is caring for. There are no blue lights when we position people at night-time, no heroic stories of how so and so simply took control when everyone else was panicking and popped a cushion in exactly the right place.

There is no accountability when things go wrong, when children experience hip dislocation or scoliosis and ultimately lives are cut short.

Postural Care is the tortoise of hare racing fame - gently, slowly and steadily working towards a goal. Small, seemingly unimportant actions accumulate day after day, night after night to account for thousands of hours. Thousands of hours that can be supported or destructive, beneficial or harmful. Yet many self-advocates, parents, teachers, social workers and health practitioners do not have a full understanding of 'good' positioning and so are unarmed in the face of the devious, wicked, silent killer that is gravity.

Coupled with this lack of recognition and understanding the people who are in the most danger often face monumental challenges in expressing their needs effectively. A toxic combination of ignorance and an inability to let people know that you are uncomfortable leads to children, young people and adults being left to endure hours in limited positions. Just try to imagine that long haul flight in Economy every single day...

I have supported people who are at risk of being left in limited positions for twenty years now. I used to say that I support people at risk of developing changes in body shape but I've come to realise that in doing so I place the responsibility with those individuals. I am ashamed to say it has taken a long time for me to realise this (I support people who are at risk of being left for many hours in limited positions); the responsibility lies firmly with us.

In those twenty years I have seen some fantastic advances in our knowledge and in recognition for the need to protect people but I have also come to recognise deeply entrenched values, beliefs and systemic issues that are hampering our progress. Issues that put people at risk despite our knowledge and the predictable impact of gravity over time.

Here I would like to outline just a few and to ask you to reflect on whether you have the ability to play your part in overcoming them.

Low expectations

The vast majority of children start life with a symmetrical body. Our skeleton is nothing more than a bag of bones that is held up and supported against gravity by our soft tissues, our muscles, ligaments and so on. If we are unable to get up and move about to develop these soft tissues, our skeleton is at risk of being damaged. If we are left in a limited number of positions, then gravity will start to mould our skeleton. This moulding is highly predictable and is related primarily to the position we spend the most time in – the position we sleep in. By taking action to encourage independent movement but also to offer a wide range of positions during the day and neutral, supported positions at night we minimise the risk to our skeletons.

Until we genuinely believe that changes in body shape are a symptom of inadequate care we will not make a difference to people's lives or their life expectancy.

A lack of outcome and responsibility

Validated and objective outcomes used to measure children's body symmetry as they grow have been available since 1992. The Goldsmith Indices of Body Symmetry (Goldsmith and Goldsmith, 2013) are not used as a standard measure across the UK and so many parents and practitioners are completely in the dark as to how effective their positioning strategies are. We cannot compare the success of different services and commissioners are blind to the impact of the services they are paying for. Imagine an obesity strategy without weighing anyone. We have to ask why we don't insist on objective outcomes in this area, are the children and young people we are supporting not worth it?

Knowledge

You can't know what you don't know. If no one has explained, in detail, the dangers that face your child when they are seemingly safely tucked up in bed you are unable to protect them. You are also at a significant disadvantage when it comes to huge decisions around surgical intervention and medication. Children grow at night – growth hormone is released while they sleep. The position and shape they adopt at night is the one that they will grow into. But if you don't know this, if you don't know what to look for, you can be forgiven for leaving your child without support in bed. After all he is trussed up in a chair all day he deserves his freedom through the night... right? We cannot blame people for taking such views if they are not in possession of all the facts.

Communication

The great Alan Alda talks about knowledge being a curse (Alda, 2017). He does not mean that knowledge is a bad thing but that, when you have a great deal of knowledge and are immersed in it, you forget what it is like not to have that knowledge. This makes communication difficult. We use jargon and terms that are not necessarily fully understood by the person we are communicating with. We need to find common language and to ensure we have the time and energy to communicate effectively. If we don't have time for effective communication, to listen well, we are on a hiding to nothing.

A failure to recognise assets

When we work together we are truly powerful. However there exists such a power imbalance between families and those providing services that examples of genuinely co-productive postural care services are rare. The commonly used term 'non-compliance' is in and of itself a symptom of a desperately

unbalanced situation. One solution is to ban the term from your service, from your classroom and from your thoughts. Instead ask 'why?' a few more times before declaring that the blame for a lack of progress or implementation of a positioning plan sits with the family. Monitor the answers to the additional whys... you may well be surprised by the pointers they will give you to improving outcomes for everyone.

Equipment

The British Healthcare Trades Association (2016) report, "Failing Disabled Children Across the UK", estimated that 60% of assessed equipment needs are currently unmet by statutory services. The gap is being filled by charities for children but when we look at charitable provision for adults we find there simply is none. Whilst charitable provision solves an immediate problem for families it masks the failure of statutory services to meet their obligations to provide. Arbitrary rules and a postcode lottery conspire to leave everyone confused as to what is available and what should or could be provided.

These difficulties lead us to a rather thorny place. We need to consider a lack of postural care provision as a safeguarding issue for any person at risk of being left in limited positions for long periods of time.

Safeguarding is a relatively new term, which is broader than 'child protection' or 'adult protection' as it also includes prevention. It is defined as:

"All agencies working together with children, young people, vulnerable adults and their families taking all reasonable measures to ensure the risks of harm to their welfare is minimised.

There is a duty to protect children and vulnerable adults from abuse. Abuse can be defined as any behaviour which knowingly or unknowingly causes harm, endangers life or violates rights."

HMG (2018)

In many settings responsibility for Postural Care provision lies with an Occupational Therapist or a Physiotherapist. But protecting people from predictable harm is everyone's responsibility, poor positioning, knowingly or unknowingly, causes harm, endangers life and violates rights.

One bright shining light in the world of postural care is the recent publication of reasonable adjustment guidance (Public Health England, 2018).

And so we find ourselves back at the beginning. If you are interested in inclusion, in promoting the rights of people with complex physical disability, in participation and genuine co-production then you are interested in the way people lie down and sleep.

Contact Details

Sarah Clayton is CEO at Simple Stuff Works, an education provider and equipment manufacturer (www.simplestuffworks.com). She has worked with families of children living with complex disability since the late 1990s. Sarah's daughter, Abigail, was diagnosed with a malignant brain tumour aged 6. Abi is doing well at a mainstream college with additional support. Sarah has three other children.

e-mail: training@simplestuffworks.co.uk

References:

Alda, A. (2017) *If I Understood You, Would I Have This Look on My Face?: My Adventures in the Art and Science of Relating and Communicating*. Mayflower Publications:

Goldsmith, J. and Goldsmith, L. (2013) *Goldsmith Indices ® of Body Symmetry Procedure: 3rd Edition* Available online at: <https://www.simplestuffworks.com/wp-content/uploads/2016/10/Goldsmith-Indices-of-Body-Symmetry-.pdf>

British Healthcare Trades Association (2016) *Failing Disabled Children Across the UK: making the right decisions*. Report available online at: <http://bhta.com/wp-content/uploads/2018/04/BHTA-Equipment-Provision-Paper-2016-Update-Version-2-COMPRESSED-1.pdf>

HMG (Her Majesty's Government) (2018) *Working Together to Safeguard Children: a guide to inter-agency working to safeguard and promote the welfare of children*. Available online at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/779401/Working-Together-to-Safeguard-Children.pdf

Public Health England (2018) *Postural care and people with learning disabilities: guidance*. Available online at: <https://www.gov.uk/government/publications/postural-care-services-making-reasonable-adjustments/postural-care-and-people-with-learning-disabilities>

Raising the Bar III Conference

Raising the Bar III will take place on 25th October. PMLD Link organises Raising the Bar, the only national conference with a focus on the support of people with profound and multiple learning disabilities.

Raising the Bar III focuses on a review of the Core & Essential Service Standards for the support of people with profound and multiple learning disabilities. Building on the previous Raising the Bar National Conferences, we aim to bring together speakers, delegates and exhibitors from the UK, Ireland and beyond to share positive stories and practice to inspire and promote the very best support.

If you are a family carer, education/health or social care professional there is so much to be gained from this wonderful event. In addition to fantastic speakers and exhibitors, we attract the most amazing delegates!

You can register to attend here:

<https://www.eventbrite.co.uk/e/raising-the-bar-iii-national-pmld-conference-tickets-59938834668>

We look forward to seeing you on 25th October!

Theoretical context for ethical practice: a creative and therapeutic arts graduate perspective

Carrie-Ann Sutton

This article will discuss my learning about ethical considerations and frameworks from my Creative and Therapeutic Arts Degree which has helped me become the practitioner I am in working creatively with children and young people with PMLD today. I will discuss the evidence base underpinning ethical practice in this field, the importance of ethical considerations to this role and how learning about the theoretical context has helped prepare me for my future practice.

The role of a Creative Arts Practitioner

Being a Creative Arts Practitioner is more than being an artist who delivers an arts experience. It is having the wider skills and understanding to be able to take your art practice and work with others to improve their health and well-being (Swindells et al., 2016). Through my three-year degree I have been introduced to a variety of theoretical frameworks that have enabled me to develop my own art practice and professional practice. Not only have I developed as an artist, but I have learned to become inclusive, ethical and provide a person-centred approach when delivering my arts sessions.

The triangle below represents three areas of development that I have been introduced to as a Creative and Therapeutic Arts student.

The Role of a Creative Arts Practitioner

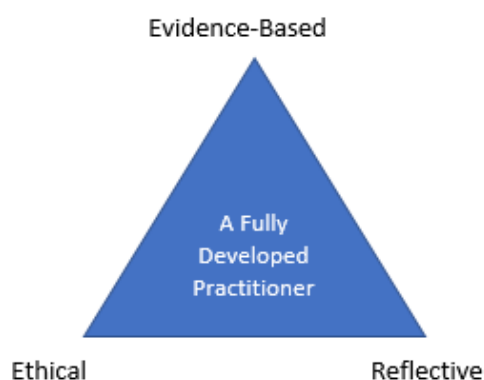


Figure 1: Creative and Therapeutic Arts (2018) "A Fully Developed Practitioner" Unpublished Course Materials

1. Evidence-based - Using theory to inform your practice.

2. Ethical – Your professional moral compass; observing professional standards; prioritizing the safety, well-being and growth of your participants and being accountable at all times.
3. Reflective – Developing skills to monitor self; develop self-awareness; awareness of the participant experience and the creative process within which s/he engages.

The course has offered me a range of theoretical contexts which have all had an influence on my role as a Creative Arts Practitioner. Eudaimonic theory is about self-actualising and realisation of core values and beliefs which in turn impact our well-being and happiness (Ryan and Deci, 2000). Carl Rogers' (1951) core conditions allow us as practitioners to understand how to have a therapeutic relationship and aid person-centred facilitation which benefits the individual. ArtWorks Cymru (2015) provide quality principles for artist and practitioners working in community environments maintaining quality from the start of a project right through to the planning of the next one. It enables the practitioner to assess and evaluate the success of their facilitation. From this range of theories, my own way of working has evolved.

My Learning as a Creative Arts Practitioner

To become a Creative Arts Practitioner I have come to understand that ethical considerations are important when working closely with any child, no matter the role of the practitioner. I have been introduced to values and ethics (Farrant, Pavlicevic and Tsisir, 2014) and the fundamental principles, standards and guidelines for professional practice (ArtWorks Cymru, 2015) and worked on applying these in my role on placement.

There are many elements of ethical practice I have encountered as a Creative Arts Practitioner. Simply put, ethics is a system of moral principles which influence how people make decisions and lead their lives. Ethics is

concerned with what is good for the individuals and society and is also described as moral philosophy (Skånfors, 2009).

There are five often-cited key ethical values:

- Beneficence – aim to do no harm
- Autonomy and Choice – issues of capacity, consent, appropriate information, non-coercion
- Justice – issues of fairness, equality, equity of resources
- Respect – Issues of dignity, confidentiality, anonymity
- Truthfulness and honesty – issues of what to say, when?, how? To whom?

(British Psychological Society, 2018)

When working creatively with young people with PMLD, each of these ethical values are at play. The health, safety and well-being of my participants is foremost in my mind. Being aware of ethical principles such as autonomy, beneficence and non-maleficence is key when making decisions along with a sense of moral awareness. This echoes three of Beauchamp and Childress's (2009) four main principles, the fourth being justice: a concept that emphasizes fairness and equality among individuals. When I facilitate my creative arts sessions I always aim to be the best practitioner I can. This means being non-judgemental (Rogers, 1951) and striving to ensure the participants are provided with an environment which allows them to become their best-self. As a Creative Arts Practitioner I have been taught to ensure my practice is fair, non-judgemental, respectful and non-prejudicial (Rogers, 1951). I always consider differentiation techniques and ways that I can diversify instructions and activities to celebrate children's differences and meet all individual's needs. Doing this ensures that I put the child's best interests ahead of other considerations. I interpret these person-centred values to be a part of ethical practice.

Why are Ethical Considerations Important?

As a Creative Arts Practitioner, like other professionals, I have been introduced to ethical standards and guidelines. I have a responsibility to those with whom I work with, not only my participants but also my fellow work colleagues. Developing a relationship with a participant can sometimes mean incorporating the immediate family into a session. I found that getting to know the parents of my participants helpful, but at the same time it made it quite difficult for me to detach myself from what these families have to go through. It is a natural characteristic of mine to be compassionate, but as a Creative Arts Practitioner it's important to channel this compassion professionally. I found that through

reflecting on situations within my work placement in a seminar group, combined with experiences my peers had shared, I was able to develop a professional boundary that was safe for participants but also effective for good ethical practice that allowed me to show this compassion. This reinforces the application of the three areas of a fully developing Creative Arts Practitioner referenced above.

It is important to draw from other areas of ethical practice such as Nursing. Nurses follow "The six C's" which are care, compassion, competence, communication, courage and commitment (Cummings, 2013). Creative Arts Practitioners can easily adopt these elements in their pursuit to establish relationships in a safe and secure environment. Creative Arts Practitioners possess similar qualities to Nurses. For instance, if a disability or impairment renders a participant vulnerable, they may require extra time to develop relationships. The skill set of a Creative Arts Practitioner should accommodate this, facilitating the participant's safe embarking on a therapeutic journey. This provides evidence of moral and ethical conduct that is relevant to multiple professions. As a Creative Arts Practitioner, it is important to remember these are embedded within the individual, and how my profession can enhance this to meet the needs of the individual participants at each stage of the therapeutic process.

The ethical way in which I work with my participants calls into question what the correct or incorrect way is in dealing with a situation that is of a sensitive nature. How I deal with these issues reflects personally on myself as a Creative Arts Practitioner. The need for confidentiality is important but, in some situations, I may find the need to ask for guidance on a child or issue and therefore would it be ethical to pass on any information to a mentor or colleague? As most of my participants are young children with PMLD, consent is vital. Consent is an important part of the participation therefore we come up with differentiated ways of gathering consent through accessible and inclusive creative mediums as well as asking a guardian so that the individual is at the forefront of their choice and engagement

As a Creative Arts Practitioner, I strive to make no judgements and I believe that no child should be disregarded for their capability to understand. Through facilitation it is key to be equal with participants and their confidentiality is vital, but they must have the understanding of others involvement if it is required as this situation may effect a child's well-being. As a Creative Arts Practitioner I aim to create safe environments which are moral and ethical, however a safe space often becomes a space for people to open up and this can be challenging not to get emotionally attached. Boundaries and professionalism are important,

while maintaining compassion and empathy.

Conclusion

It is clear that ethical practice is first and foremost putting the well-being of my participants at the heart of my practice. Using my own morals combined with techniques learned from reflecting on experiences alongside research I have developed ethically within my practice pushing me to become a better facilitator, enabling me to promote the well-being of participants. I have learned that each participant is a unique individual and their experiences, and their therapeutic journey will differ as will my facilitation, to tailor my approach maintaining professionalism and ethical boundaries.

Contact Details

Carrie-Ann Sutton is a Creative and Therapeutic Arts Practitioner

Email – carriesutton@btinternet.co
Twitter – [CarrieSut96](https://twitter.com/CarrieSut96)

For details about the BA (Hons) Creative and Therapeutic Arts:

Email – beth.pickard@southwales.ac.uk
Twitter - [@USW_CTA](https://twitter.com/@USW_CTA)

References

- ArtWorks Cymru (2015) *Quality Principles* [Online] Available at: <https://artworks.cymru/quality-principles> Accessed on: 15/05/2019
- Beauchamp, T.L. and Childress, J.F. (2009) *Principles of Biomedical Ethics*. Sixth Edition. Oxford University Press, New York.
- British Psychological Society (2018) *Code of Ethics and Conduct* [Online] Available at: <https://www.bps.org.uk/news-and-policy/bps-code-ethics-and-conduct> Accessed on: 17/05/2019
- Cummings, J. (2013) *CNO on the six C's* [Online] Available at: <https://www.nursinginpractice.com/article/cno-six-cs> Accessed on: 23/05/2019
- Farrant, C. Pavlicevic, M. and Tsiris, G. (2014), *A Guide to Research Ethics for Arts Therapists and Arts and Health Practitioners*, London: Jessica Kingsley
- Rogers, C. (1951). *Client-Centered Therapy*. Boston: Houghton Mifflin
- Ryan and Deci (2000) *Self-Determination Theory and the facilitation of intrinsic Motivation, Social Development, and Wellbeing* [Online] Available at: https://selfdeterminationtheory.org/SDT/documents/2000_RyanDeci_SDT.pdf Accessed on: 25/05/2019
- Skånfors, L. (2009) *Ethics in child research: children's agency and researchers' 'ethical radar'* (PDF). *Childhoods Today*, 3(1): 1-22
- Swindells, R., Lawthom, R., Parkinson, C., Clennon, O., Kagan, C. and de Bezenac, C. (2016) 'I'm not a therapist you know...I'm an artist': facilitating wellbeing and basic psychological needs satisfaction through community arts participation. *Journal of Applied Arts & Health*, Vol. 7, No. 3, pp. 347–67.

There's no place like home – the ethics of home ownership for people with disabilities

David Abbey

As the media keep telling us it's taking a lot longer for people to buy their first home these days but imagine if, through no fault of your own, this option was simply never available to you. Sadly that was the situation that almost every single person with a disability (who was also unable to viably work in paid employment) found themselves in until the launch of a unique Government backed housing model known as HOLD (Home Ownership for people with Long-term Disabilities) back in 1997.

Despite the fact that HOLD exists, and it's been used by many hundreds of people with disabilities and can completely transform the lives of the individuals concerned, it's not always offered as a housing option by Local Authorities or Clinical Commissioning Groups and many individuals who could benefit from it are still unaware of its existence. This article seeks to help remedy this situation and to demonstrate why supporting HOLD really is the ethical thing to do.

Home truths

So why does being able to buy a home of your own matter so much? If you don't have a disability, ask yourself that question and the chances are that exactly the same reasons will apply...independence, freedom, privacy, security, the chance to personalise your environment and to become a valued member of a community...but for people with disabilities there are other unique factors. For example many of the buyers we support have lived in the family home for their whole lives; as parents age and perhaps become unable to look after their son or daughter they're desperate to see them settled and secure whilst they're still able to help with this journey.

Is it right that people with a disability who don't have an 'earned' income should be helped to buy a home of their own though? That's a question we've been asked many times over the years and as you might expect we firmly believe that it is the right thing to do. Why? Well first and foremost disability isn't a choice and, whilst we rightly celebrate the amazing achievements of our home owners, the reality is that often their physical, learning disabilities or mental health issues simply make traditional paid employment unviable. We wish this wasn't the case but by then removing the right to choose where and how someone lives their lives, forcing them and their family to put their future in the hands of a private landlord or care provider, simply cannot be right or acceptable. As Tina Cooper, mother of James, one of our many home owners puts it, "Home ownership is the

dream of many so it's only right that all sections of society have the right opportunity and support to own their own home".

Inpatient's not a virtue

Of course a significant number of people with profound and multiple learning disabilities or behaviour that challenges are still sadly being 'locked up' in inpatient units (also known as Assessment and Treatment Units (ATU) or hospitals). At a time when we should be focussing on breaking down barriers between all members of our society, isolating people with disabilities in these facilities, some of which are no better than prisons, is quite frankly as unethical as you can get. Way back in 2011 BBC's Panorama uncovered horrific abuse at Winterbourne View. As a result the Government promised to take swift action to close down such units and, wherever possible, move people (many of whom are detained against their will under the Mental Health Act) back into their local community. Some progress has been made and bed numbers have been reduced - from 3,400 to below 2,300 since 2012 in England - but that falls significantly short of the government's target of below 1,700 by March 2019. More worryingly eight years later Panorama went undercover once again and found similar levels of abuse taking place in another 'hospital', Whorlton Hall (BBC, 2019).

But even if an inpatient unit is being run properly with the right level of care and support, this kind of accommodation is still far from ideal. Chris Hatton, academic at the Centre for Disability Research, Lancaster University, reported that that 19% of people in an inpatient unit were at least 50 kilometres away from the family home and 21% more than 100kilometres away (Hatton, 2019). Imagine facing a four or five hour return trip every time you wanted to see your loved one. Needless to say this distance from family and friends can also create the conditions under which abuse takes place. Furthermore people are still on average spending a shocking five and a half years in some form of inpatient

unit, often being moved from one to another without seeing the outside world (Hatton, 2019). The impact that such separation and incarceration (and in many cases there really is no other word for it) has on an individual and their family can be devastating. Of course it then takes many months to undo the damage when the person with a disability is finally released and the scars, both mental and physical, may never heal.

Money, money, money

Although it's not the main factor there's also the issue of value for money. Would it surprise you to learn that the cost of keeping someone in an ATU can be in excess of £150,000 per person per year (CCHR, 2017)? Whilst moving someone from an ATU can potentially save the NHS millions over their lifetime some of the cost is then transferred to the individual's Local Authority who, already facing huge cuts in their budgets, perhaps understandably fight such moves every step of the way. At the end of the day though this is all still 'public' money and as it stands millions of pounds are being needlessly wasted every single year.

Rights and wrongs

Finally, if all of the above isn't compelling enough, Article 19 of the 'United Nations Convention on the Rights of Disabled People' clearly states that those who adhere to it should ensure that 'Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement'. This really couldn't be a clearer

References

BBC (2019) Whorlton Hall: Minister 'deeply sorry' for hospital abuse. Available online at: <https://www.bbc.co.uk/news/health-48381270>

CCHR (Citizen's Commission on Human Rights UK) (2017) How much does it cost to be detained on a psychiatric ward and 'treated'? Available online at: <http://www.cchr.org.uk/latest-news/cost-detained-psychiatric-ward-treated/>

Hatton, C. (2019) Transforming Care report card 2: How far are people from home, for how long? Available online at: <https://chrishatton.blogspot.com/2019/03/transforming-care-report-card-2-how-far.html>

endorsement for giving people with disabilities the chance to buy a home of their own, righting the wrongs of the past and creating a much fairer future. Better for the individual, the public 'purse' and society as a whole as well as honouring a person's human rights...surely these are values we should all HOLD dear?

Contact Details

David Abbey is Managing Director, MySafeHome Limited
e-mail: davidabbey@mysafefhome.info
website: www.mysafefhome.info

Connect with us on social media



@PMLDlink on twitter

Facebook pages:
PMLD Link

Raising the bar - COP for the PMLD care standards

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

See you online

Sound and silence

Eleanor Gibson

Somewhere in a town near you, in a yoga studio, an arts centre or a community hall, a strange phenomenon is taking place. There will be people lying down, wrapped up in sleeping bags and duvets, small pillows over their eyes, waiting to receive an improvised symphony of sounds. They will have approached this experience with a variety of feelings: curiosity, eagerness, trepidation, a wish for relaxation, rest, wellbeing, sleep, healing. The sound bath or gong bath is growing in popularity, with celebrity endorsement and articles in mainstream media. But what is it? Where does it come from? What can it do for us? Is it good for everybody?

My first experience of a gong bath coincided with a request in school for some singing bowls which a colleague had thought would be 'good for' our pupils who have severe learning disabilities, profound and complex disabilities, autism and challenging behaviours. I discovered that there were sound practitioners close enough to invite into school, and as a one off experience for learners, the effects were very impressive: for some children, breathing slowed and there were obvious signs of physical relaxation, a loosening of chronic tension, sometimes smiles and vocalisations. For one young man on the autistic spectrum, his habitual challenging behaviour completely dropped away as he spontaneously laid down and completely stilled. An observer [who knew him well] commented that it was as if he had 'put his burden down'. Other youngsters, who were often unresponsive during the school day, were coaxed into alertness by the sounds, opening their eyes, showing signs of pleasure, sometimes moving limbs and vocalising.

One lottery funding application and some months later, a group of six staff awaited our own training in this mysterious art. We spent ten days over a period of months learning about the instruments and their effects, learning to play them and to put the sounds together to create opportunities for relaxation [mostly] and for stimulation [sometimes]. This involved quite a lot of lying down to receive the sounds ourselves, but also opening up to new experiences and new worlds. Sound can be said to occupy a space which is neither inside nor outside, but moves between them – sounds [except when we speak or sing] happen outside the body, but they are heard inside. The sounds used are rich with resonance and vibration, so they are often felt as well as heard. The instruments: gongs, drums, singing bowls - draw on traditions which are thousands of years old, which, while they may have their origins in religious, spiritual or healing practices, don't necessarily carry those associations for most of us in the UK, where we are more likely to associate the sound of a Church organ or

choir with religion. So the sounds have an ancient quality but also an ambiguity: the improvised soundscapes are not what we generally think of as music; they don't have melody or, usually, a consistent pulse. They are, rather, an opening to a sound world, which we enter with ears and bodies, hearts and minds.

Everybody's experience in a soundbath is different. Some people just have a nice, relaxing experience, they may drop off to sleep, or become very deeply relaxed. Others may have a kind of waking dream or see colours. Memories and emotions may be evoked, some are visited by people dear to them or by spiritual guides. Perhaps what we experience depends partly on our belief system, what our minds are 'set up' for – but I also know people who have been very surprised by what, or who, came to them in the course of a soundbath.

So, how were we to transfer these experiences into a practice that would benefit the children and young people we work with?

I felt a need to look into the theory behind these practices, so that I could have some confidence in expounding the potential benefits. Whilst they may have been practiced in a variety of cultures for thousands of years, there is now a renewed interest in sound in the world of self development and healing and therefore an increase in research around sound and related subjects. Claims which at first appear fantastic, e.g. 'sound affects us at a cellular level', later began to make sense – we can see the effect of vibration on water, and we are, in different estimates, somewhere between 60-80% water. The experiments of Masaru Emoto show the difference positive and negative vibrations can have on water (see notes below). Jumping to Quantum physics, we are all vibrating, everything is vibrating, so anything that 'tunes' those vibrations, creating coherence, is going to make us feel better. A lot of research has been done into the effect of sounds on brainwaves: particular sounds, such as binaural beats [when we hear a slightly different pitch in each ear, producing a clashing effect] which have

spawned a whole wave of relaxation and sleep systems. There is entrainment, where rhythms begin to coincide and cohere, meaning that a heartbeat might slow to the pulse of a drumbeat, and breathing might slow to match the undulating pulse of a rainstick. And, of course, there was our own experience of the benefits, more relaxation, better sleep, more resilience to stress.

The slow wash of sound built by the gong creates a wall of frequencies that emulate 'coloured noise': variations on white noise that emphasise different parts of the sound spectrum. We were all subject to white noise and its variations inside the womb: the brain is well used to processing these kinds of sounds and perhaps for this reason most people find them very calming. The next sound that we hear in the womb is our mother's insistent heartbeat: we may hear this in the beat of the drum, or in the pulsing of the singing bowls as they set up waves of binaural beats. An ocean drum or rainstick, another kind of 'coloured noise' that we associate with the natural world, adds to the creation of calm. The voice, gently adding open vowel sounds or perhaps a poem, prayer, chant or mantra, gentles us back into the world.

We very quickly found that soundbaths were appreciated by staff as much as by the children and young people in school. 'Best staff meeting ever' was posted on facebook after a 'wellbeing' soundbath for staff. But we have found consistently that soundbaths create relaxation, that they are enjoyed almost universally, that they promote wellbeing and readiness for learning. Just as the experience of receiving a soundbath is different for everybody, each person develops their own style of giving a soundbath, favouring different instruments, some using voice in addition. I was taught that in a soundbath we are taken into another world, and that we need to be brought back from that world very gently: so coming out of a soundbath needs to be as gentle as a mother's lullaby. Our voices are very potent soundgivers, and that's a subject for another time!

Soundbaths also began to happen in a variety of contexts – for individuals and small groups, for larger groups, at the end of PE sessions, as a learning activity, as part of religious education, worship and other spiritual, moral, social and cultural activities. Many staff wanted to learn how to give soundbaths, and it is still a very popular training!



Figure 1 - A Sound Bath is an immersion in beautiful sounds and vibrations that are healing for your body, mind and spirit and can be a deeply relaxing experience. Everything in the Universe, including our body, is composed of vibrations. Every organ and every cell in our body vibrates at a particular frequency. Sound and vibration travels up to five times more effectively through water. As the human body is made up of over 70% water, sound vibrations can affect us at a cellular level.

Why use soundbaths in a special school? What is the particular relevance? What are the benefits?

The children and young people we work with, for many reasons, may find it hard to relax. The reasons are numberless: for those with restricted mobility, there is little opportunity for gross motor movement, for the exercise which many of us rely on to discharge physical energy but also to discharge the effects of stress from our bodies. There is a much larger incidence of mental health issues in people with learning disabilities, and this will often be reflected in mental and emotional tension. The youngsters we work with will have fewer resources for expressing and processing emotion, yet will have likely faced many challenges, whether physical, mental, emotional or social, and continue to do so, day after day after day. Many may be in a chronic stress state, with their nervous systems permanently on alert. So relaxation is an incredibly relevant skill, and one that needs to be learned and practiced, carving out new neural pathways to reverse the ravages of being in constant fight or flight – with little or no ability to do either.

It's particularly important to support those with learning disabilities during and after a soundbath – the 'normal' range of experience can range from pure bliss to somewhat strange and unsettling: as with any experience, the young people we work with may experience it very differently because of differences in hearing or sensory processing: most people experience relaxation, but there are no guarantees. When a soundbath ends, there is usually a period of silence – this is very important, it is when the mind and body can absorb and integrate whatever changes have taken place; it is a time for the mind and emotions to settle, a time of transition back to the everyday. We all need time to make this transition but I have found that many of our young people need longer, they need a very gentle lullaby back into the world: it is a bit like waking from sleep, but you are not waking in your usual environment, or from your usual sleep. Sometimes people feel 'spacey' after a soundbath, and it is important to make sure everyone is grounded before everyday life continues – perhaps through touch, although traditionally this would be done through awareness of breath and the body's contact with the floor, mat or chair.

Above all, many of our young people will not be able to tell us how they are feeling or what they have experienced, so we need to stay sensitive to the signals that tell us what that particular young person is feeling. We need to pay attention and make sure that the experience is safe, that they feel held in the sound and not split apart by it. Although I don't like the term 'sound therapy' in this context, as the goals are fuzzy and non-specific, the soundbath needs to be approached with

care and preparation - with love.

Greater relaxation will benefit every aspect of life: if we can take the system off full alert, the brain gets ready to learn, the heart gets ready to love, we can begin to fulfil our potential, to be the best and the brightest and the shiniest that we can be.

Human beings in the fullness of health are like the gong.... fully resonant.

The more resonant we are, the more alive we are, resulting in happy and abundant lives.....

[Roz Crampton, Sound practitioner, Sacred Hoop magazine, Issue 52]

Contact Details

Eleanor Gibson teaches at the Phoenix School, Peterborough

e-mail:
eleanor.gibson@phoenix.peterborough.sch.uk

Recommended reading

Joshua Leeds (2010) *The Power of Sound: how to manage your personal soundscape for a vital, productive and healthy life*. 2nd edition. Healing Arts Press

Joanna Grace (2017) *Sensory-Being for Sensory Beings: Creating Entrancing Sensory Experiences* Abingdon: Routledge [particularly chapter on auditory stimuli]

Alan Wylie (2015) Soundbath An Innovative Approach to Music with Children. *PMLD LINK*, Vol. 27 (2) Issue 81, pp26-31

Youtube presentations

Dr, Masuro Emoto's explorations of water, consciousness and intent: <https://www.youtube.com/watch?v=tAvzsjcBtx8>

Shea Trahan's TEDxVermilionStreet talk about the interactive nature between architecture and sound: <https://www.youtube.com/watch?v=R-BMF4e-1bg>

How do colours impact on vision?

Isabel Beck

I am a qualified intervener from Chailey Heritage School and this article is based on research I did to try to discover how colours may impact on vision. Dutton (2013) says people with CVI (Cerebral Visual Impairment) usually retain full awareness of colour. This is because colour processing is difficult to damage neurologically.

I concentrated my research on a 4 year old child, Theo, who was severely sight impaired with a divergent squint. He was diagnosed with a CVI and limited eye movement in the vertical plane. He had quadriplegic athetoid cerebral palsy, severe dystonia, low tone in the lower quadrant and epilepsy. He could hear and was able to give a positive response.

Theo's curriculum included visual stimulation to improve vision (e.g. presenting bright colourful objects against black backgrounds) which was met with differing reactions. Sometimes, Theo was engaged and vocal when presented with images such as orange stars; other times, the response was less enthusiastic or non-existent. This might be because Theo's vision was likely to change when tired and could alter from minute to minute due to CVI or epilepsy. It might also have been because Theo could see some colours more clearly and I hoped to clarify this.

Dutton (2003) suggests children with CVI often find red and yellow easier to see. My aim was to build up an understanding of colour boundaries to distinguish what could and could not be seen. In future, colours that were not greeted with enthusiasm could be avoided and concentration could be given to colours that gave positive visual stimulation.

Longhorn (1988) suggests that a visual preference programme can motivate vision by using bold stimuli to grab visual interest. If opportunities to promote vision using stimuli are presented frequently the child may start to show preferences for certain visual activities.

The assessment and observations

I believed that familiarity of the assessment equipment would be beneficial. In the days before the assessment, Theo was introduced to the apparatus several times to make the process recognisable. Reassurances were continually given during these trials and in the assessment.

For the assessment, Theo needed to be comfortable. Athetoid dystonia made it difficult for him to control his head, therefore a lying support was provided with neck

reinforcement and a wedge to lift his head as suggested by Blaikie (2003). The assessment took place in the morning when Theo was generally more alert and before there were a series of interruptions for lunch, hygiene and medications. The location needed to be quiet to avoid distractions of the usual classroom noises. The assessment was done when the other students were out of the room.



Image 16.1 Theo under the A frame

Theo was placed in a lying support and a small sturdy wooden A-frame was put in front of his head, which acted as a scaffold. Long single lengths of bright mono coloured paper were then draped over the frame to flood the centre and peripheral fields of vision in one colour. This was a basic set up as the TSBVI (Texas School for the Blind and Visually Impaired) (1998) advises that, when showing visual images to children with CVI, the simpler the visual information that is presented the easier it is for the child to manage (see websites below). The CVI Society (2015) suggests the Kiss Principle – Keep It Slow & Simple.

Care was taken over the sequence of colours presented. Dutton (2003) states that the more diverse one colour is from another, the more likely a differentiation can be made. A colour sequence was decided upon: yellow, blue, pink, orange, purple, green and red. On the day of the assessment, a video was taken of Theo's reactions for reference ensuring that nothing was missed. I knelt down next to Theo's head and filmed from the side.

The CVI Society website explains that having CVI does not mean you cannot see, but you will need more time to make sense of what you do see. Theo was given time to process the new colour after each colour change. Each colour sheet remained in place for 2 minutes. He was warned when a new colour was being introduced.

The first colour to be presented was yellow. Theo's feet moved within seconds. A sigh followed. He reached out an arm towards the paper directly in front of him. He was asked if he wanted to touch the colour and he gave a positive vocalisation to affirm. The vocalisation continued as did the arm reaching and he touched the yellow paper. He was asked if he liked the yellow colour – again, a positive affirmation. Theo moved his head backwards so that he could look directly above. His eyes were wide and he remained relaxed. He moved his head and eyes upwards again and then to the left, away from me. He moved his head back to me with a smile on his face and continually vocalised. I took this reaction to mean that he could attend, distinguish and liked yellow.

Blue was next. Theo blinked and lay calmly not moving but looking straight ahead. His head turned slowly to the left and his eyes scanned the paper directly in front of them. His arms remained in the same position throughout, and although he moved his legs momentarily his body was otherwise still and his whole demeanour was more passive. He made no vocalisation. The colour was introduced as 'blue like the sky' but no reaction was given to this. This appeared to be a neutral response.

The third colour was pink. There was no pink paper sheet available so a pink length of material was used instead. Theo vocalised almost immediately and smiled. He turned his head to the left, looked upwards and reached out his left arm in an attempt to touch the material. When asked if he liked the pink colour, he made a positive vocalisation. This positive reaction might have been because he was already familiar with the material.

When orange was presented, Theo was immediately positive. He smiled and moved his head to see the colour from all angles, whilst making positive vocalisations. Theo scanned the colour with wide eyes, opened his mouth and moved both his arms to the side and upwards. He was asked if he liked orange and he responded positively. He then became more still, breathing more softly as he continued to scan the sheet.

When purple was introduced, Theo lay still and looked straight ahead. He then looked a little to the left but came back to the midline. He was passive and silent and remained calm. He appeared to be neutral about purple.

The next colour was green but Theo began to look tired and the green paper was removed.



Image 16.2 Theo under the A frame with orange paper

On a later occasion when red was introduced, Theo turned his head to the left and opened his mouth. He raised his left arm up towards the paper, gave a big sigh and looked straight ahead again. His body remained still and calm but his eyes were looking all around. When asked if he liked the red colour, he gave a positive response and continued to scan the paper attentively in front and above.

Conclusions

Interestingly, when the equipment was set up in the days before the assessment, orange and yellow received a positive response and this was reflected again during the assessment. The findings suggest that bright colours grabbed Theo's attention more than darker colours.

Had more time been available, it would have been interesting to see how his reactions changed with longer exposure to the colours.

To try to build on these results, Theo was positioned by the colour wash wall in the school's sensory studio. He was not keen on the brightness of the light reflected on the white wall despite fading it. He gave one positive reaction (smile and vocalisation) to pink, the first colour introduced, which could have reflected excitement towards the new stimuli or a liking for pink.

Theo was then shown other colours but gave a reflex reaction to all; immediately shutting his eyes tight and grimacing. This exercise was then abandoned. It should be noted that Theo had a similar reaction to sunlight and this could be suggestive of photophobia. The TSBVI website states it is estimated that a third of children with CVI are photophobic.

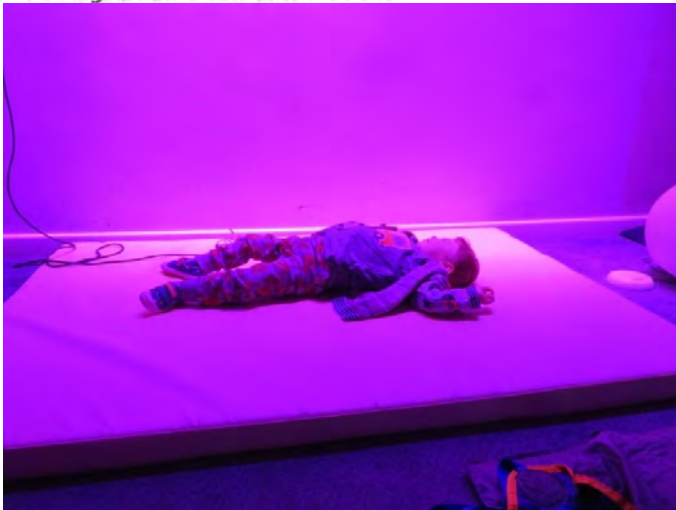


Image 16.3 Theo by the colourwash wall

I was able to make recommendations that bright coloured lights were not to be used with Theo, and instead staff should use yellow, orange, red and pink coloured paper and materials when helping him with his visual motivation exercises.

Note - This article was submitted with the kind permission of Theo Crunden's parents. Theo sadly died in October 2017.

Contact Details

Isabel Beck is a qualified intervener at Chailey Heritage School which is a non-maintained special school for children and young people, aged 3 to 19, with complex physical disabilities, high health needs, sensory impairments and associated learning difficulties.

e-mail - ibeck@chf.org.uk

References

References

Blaikie, A (2003) Introduction to cerebral palsy and visual impairment. In: Buultjens M and McLean H. (eds) (2003) *Cerebral Palsy and Visual Impairment in Children: Experience of Collaborative Practice in Scotland*. CPVI Working Group. Scottish Sensory Centre pp. 8-14

CVI (The Cerebral Visual Impairment Society) (2015) *CVI and Profound and Multiple Learning Disabilities* Available online from https://cvisociety.org.uk/mem_portal.php?article=105&k=KISS

Dutton, G (2003) A more detailed look at the visual system. In: Buultjens M and McLean H. (eds) (2003) *Cerebral Palsy and Visual Impairment in Children: Experience of Collaborative Practice in Scotland*. CPVI Working Group. Scottish Sensory Centre pp. 38-59

Dutton, G. (2013) *Cerebral Visual Impairment in Children: Designing Strategies to Help*. Brighton Racecourse, 7th June. Unpublished Lecture Handout.

Longhorn, F. (1988) *A Sensory Curriculum for Very Special People*. London. Souvenir Press

TSBVI (Texas School for the Blind and Visually Impaired) (1998) Cortical Visual Impairment Pediatric Visual Diagnosis Fact Sheet. In *See Hear*, Autumn (1998), Texas. Reprinted from Blind Babies Foundation. Available from www.tsbvi.edu/seehear/fall98/cortical.htm

Websites

Cerebral Visual Impairment Society - <https://cvisociety.org.uk>

Sense - <https://www.sense.org.uk>

Royal National Institute for the Blind - <https://www.rnib.org.uk/>

Texas School for the Blind and Visually Impaired - <https://www.tsbvi.edu>



Creating to connect

Saima Kaur

'Autism/This is Me' is an exhibition I created to explore the experience of being the mother of a severely autistic daughter. This article charts how my understanding of disability was shaped by cultural and social factors and my aims for creating a highly personal exhibition about the lived experience of severe autism.

I studied Contemporary Arts at University and then went onto work in museums' outreach. I worked with diverse people from marginalised groups, but always found a way to bypass working with people with complex disabilities. I feared I wouldn't know what to 'do' or how to 'be' and would somehow get it horribly wrong. My exposure to people with disabilities in my working life was minimal, as it had been throughout my upbringing in India and later the UK.

Years later, my first daughter was diagnosed with autism and profound learning disabilities at the age of five. As in so many cases, the diagnosis was painfully late and the experience woefully inadequate. The years leading up to

the diagnosis were also full of confusion. Perhaps one of the most shocking things was the realisation that neither Hindi nor Punjabi had terms to describe developmental disability or autism. The words used either described physical disabilities or translated as 'simple', 'not right' or 'mad'. I didn't have the vocabulary to explain her way of being to my family or those in my community. My only lifeline was a recent Hindi blockbuster in which a female superstar played the character of a severely autistic woman. Thankfully, most people had seen the movie, but imagine my difficulty when they hadn't!

How do you begin to understand, explain or accept profound, complex or multiple disabilities with such a



limited set of symbolic reference points? This question stayed with me as my daughter grew and things got easier, conversations richer and connections with friends and family became less fraught. This question, along with the experience of being the primary carer of a non verbal child with severe autism, inspired me to create an exhibition that would increase awareness, empathy and understanding of this condition. I chose to use my skills in hand embroidery as a tool for visual storytelling. I titled the exhibition 'Autism/This is Me' because it refers to both 'me' the mother and carer and seeks to humanise my daughter; she is not just a person with autism – she is my funny, loving, clumsy little daughter. As an extension, I wanted us, and thousands like us, to feel visible and valued. We exist and we are here.

The process of creating the artworks involved hundreds of hours of stitching. The aim was always to convey the nuances of our experiences with complete emotional honesty. I explored themes such as how I imagined things to be, the confusion and isolation of the early years, ideas around language, sensory overload and anger against social structures that undervalue and exclude carers and people with disabilities. The whole process was documented on my Instagram page using the #autismthisme. This in itself became a source of meaningful engagement with people from all walks of life. It started many conversations and increased awareness around autism and disability. As part of the project, I also ran a number of art workshops at my daughter's school, Woodbank Special School. The Head, Richard Pawson, was very supportive and provided free marketing plus a room and

refreshments free of charge. I had a handful of staff and parents take part, each one producing an artwork that expressed their experience of being the parent of a child with autism. It also became an opportunity for me to become informed about other people's experiences. For me, the most striking aspect about the workshops was the carers' inability to talk about themselves without constantly referring to their child. Eventually, at one session I asked, 'has no one ever asked you what it's like to be a carer?' The answer was a straight 'no' plus some tears. I am happy to say that asking this question did open up new areas of conversation which they then added to their artworks. Their final works formed an important part of the exhibition. They brought diverse voices and experiences of autism into the mix and opened up the viewers understanding of the spectrum within the condition.

'Autism/This is Me' was exhibited for six weeks at Kala Sangam, Bradford with my daughter's handprints forming the centre piece. The final exhibition was well received and the feedback was powerful. During its run, I developed and delivered two art based workshops on the theme of personal storytelling. This used the exhibition as a starting point for others to create artworks that expressed their stories. These sessions were attended by a mix of people, including carers and people with or connections to autism.

I am currently developing outreach and educational resources around the exhibition and aim to tour it at the end of next year. It has been a surprisingly emotional





project that at times felt like grieving and confronting the social inequalities that continue to exist for carers and people with disabilities.

Perhaps the most important thing that I have learnt from this whole process, is that maybe it is these small acts of bravery and vulnerability that create moments of true compassion and connection. I cannot be certain, but my feedback would suggest otherwise!

Contact Details

Saima Kaur is a tutor and freelance artist specialising in hand embroidery, textiles and storytelling. Her work is primarily with people with English as a second language, women with mental health problems and people with learning disabilities.

Her artwork can be viewed on Instagram @sewsaima and works linked to the exhibition can also be viewed on instagram #autismthisisme

Email: saimakaur@outlook.com

UPCOMING INTENSIVE INTERACTION EVENTS

from the
Intensive Interaction Institute



Intensive Interaction General Introduction Day

07.02.19. The Niland Centre, Bushey, Herts. (provisional, see website)
08.11.19 The Cambridge Hotel, Huddersfield.

Intensive Interaction for People with Autism 1 day

18.10.19, QEII Jubilee School, London, W9.

Intensive interaction for People with PMLD 1 day

08.11.19, QEII Jubilee School, London, W9.
06.12.19, Touch Base Pears, Birmingham B29 6NA

Intensive Interaction for People who Speak 1 day

18.10.19, Touch Base Pears, Birmingham B29 6NA
04.10.19, QEII Jubilee School, London, W9.

Intensive interaction Good Practice Course 3 tutored days

04.10.19, 13.12.19, 06.03.20, Angel View Hotel, Gateshead.
17.10.19, 12.12.19 & 06.02.20, QEII Jubilee School, London, W9.
27.09.19, 15.11.19 & 14.02.20, Holiday Inn, Bromsgrove, Birmingham

Intensive Interaction Coordinator Course 21 days

12-14.11.19, (Block 1), Mount Pleasant Hotel, Great Malvern, Worcs.

See full information and application forms: www.intensiveinteraction.org

Nursery Rhymes and Dreamboys!

Emily Woolman

This article is about the rights and ethics of people who have PMLD, particularly in regard to leisure experiences for people who have PMLD. It is a personal article about my relative, Rose, who is 54 years old. She has PMLD and lives in a local authority home. Rose is the reason why I am passionate about rights, values and ethics for people who have PMLD and she is the reason why I have chosen to work within the field of SPMLD.

Rose loves nursery rhymes and is an early communicator. As described previously by me (Woolman, 2019), she has made amazing progress with her fundamentals of communication (FOC) in relation to Intensive Interaction (Barber and Firth, 2019; Hewett, 2018) which is one very important aspect of her life. The FOC are basic, non-symbolic communication skills and concepts that should be the first communication learning that a person should be expected to undertake. These skills are the important foundations of communication. However, it is so easy for carers, strangers, professionals and family members to forget that she is also fifty four and is an adult and the revelation that she can enjoy both activities.

Men

Rose loves male company, I think this is because she has a lot of female carers and support workers and men are in short supply! An article in the Guardian by Apostolides (2017) entitled 'How can we encourage more men to choose a career in social care?' stated that social care faces similar barriers to nursing in terms of gender and diversity. Interestingly, there is a lack of current literature about this topic and more research needs to be done in this field. This does not just affect the workers and the issue of gender employability. It also affects the service users because they are being deprived of the company of males, who interact in a way which is different to the way females interact with a service user even just in their tone of voice and appearance. Imagine what it would be like to not interact with men on a daily basis either in the workplace or in the community? Rose enjoys the attention from men and she literally lights up, especially when she sees my dad. I think this is because he is a man as well as the fact that she knows who he is. The reaction is so special, she smiles, flaps and bounces in her chair. Rose has a similar reaction to other male service users within her home, which is lovely to see.

Deputyship

Currently, there is a governmental agenda on parents becoming deputies for their children who do not have mental capacity to make decisions alone. There is a petition to the UK Government entitled 'Make it easier



for parents to act as deputy into adulthood', which currently has almost 4,000 signatures. This is asking for the process to be made easier. The petition was provoked by a breach of the human rights of the petitioner's daughter and because the parents did not have Deputyship the system ignored concerns they raised. The petitioner claims that there is evidence of

many other similar cases.

Even though Deputyship is important for raising concerns, it is also very important to be able to make positive and spontaneous decisions that enrich the lives of the family members we love. Furthermore, it enables family members, like us, to make important decisions about Rose's day to day life and leisure activities. These decisions are based on how Rose responds to people and activities; how she communicates what she enjoys doing and dislikes doing through her own way of communicating and through careful observation and reflection.

Moreover, I believe that family members are the best people to make decisions on behalf of their loved one together with the support of care home staff and professionals. However, I am basing this on my first-hand experience and my own family involvement about how we care for Rose and I know that this may not be the case for every family. I believe this because professionals and care staff have to consider wider implications of their decisions, including issues around staffing, money/budgets and time. However, due to the vulnerability of people who have PMLD they need people who can make person-centered decisions in their best interest.

The Dreamboy Decision

One important decision that Rose's Deputy made on her behalf was for her to go to the theatre and watch the Dreamboys perform. This was a night out with two carers and another female service user. This is something that most of us could take for granted, i.e. booking tickets to a show and having a night out. People who have PMLD should also have the right to do this in their local community and be in the audience with people enjoying the same male entertainment.

As discussed in the Raising our Sights guide to Communication (Mencap, 2013), it is very difficult to find meaningful leisure experiences and opportunities for people with PMLD in their local communities, even though it is identified as an important aspect to ensuring a good quality of life. There are a few suggestions including; sharing stories, ordinary visits to shops, music activities and drama and theatre. Moreover, it is discussed that, whilst some theatre experiences can be accessible to some people who have PMLD, it depends on how much they enjoy watching and how aware they are of their surroundings. This relates to a person-centered approach, every person is different. However, from observing how Rose behaves around male company, it was decided that a meaningful leisure activity for her would be a night out at the theatre to watch the Dreamboys perform.



One way of achieving meaningful leisure activities includes trying new things and thinking outside the box as it can 'reveal new and enriching experiences' (Mencap, 2010, p12). This is what we did for Rose; we thought outside of the box and enabled her to have an experience that most people have the choice to make. Rose absolutely loved her night out along with her carers and service user, who is her friend. The main thing to remember is that it is not the activity that makes it enriching, it is the company, the engagement and the interaction between the carer and the service user. Communication and interaction should be at the centre of everything people with PMLD do. Furthermore, we adhered to the PMLD Standards (Doukas, et al., 2017) relating to social and leisure activities because Rose was supported to participate in the Dreamboys and because the experience was personalised around her known and perceived choices in regard to enjoying male company and her interest in men. Moreover, Rose was an active participant in the activity that she engaged in and most importantly she had so much fun!

Final Thoughts

We all have preferences and different enjoyments in life either age appropriate or not. It is our right to enjoy these things and freedom to choose activities that we partake in. I love watching Disney films and I am quite partial to watching an episode of Hannah Montana, but I also like going concerts, watching live plays and

musicals and researching about special needs in my spare time. Just because I am 26, it does not mean that I am not allowed to still enjoy things not deemed to be socially acceptable or age appropriate. Therefore, people with PMLD should be able to equally enjoy nursery rhymes and a night out watching the Dreamboys because it is what is appropriate for that person at the time or indeed what would be chosen by the person themselves. The staff may even have sang a nursery rhyme to Rose whilst she was at the theatre waiting for the show and that is allowed too!

Contact Details

Emily Woolman is a special needs teacher and specialising in severe, profound and multiple learning difficulties.

e-mail: em_woolman1@hotmail.com

References

Apostolides, Z. (2017) 'How can we encourage more men to choose a career in social care?' *The Guardian* 2015 [online] Available at <https://www.theguardian.com/careers/2017/sep/13/encourage-more-men-social-care-gender-nursing-career> (Accessed on 11.06.2019)

Barber, M. and Firth, G. (2019) (eds) *Delivering Intensive Interaction Across Settings: Practice, Community and Leadership*. Amazon.

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.pmlmlink.org.uk/resources/#pmld-standards>)

Hewett, D. (2018) *The Intensive Interaction Handbook*. 2nd ed. London: SAGE

Mencap (2013) *How-to guide 3: Communication for people with profound and multiple learning disabilities* [online] Available on: https://www.mencap.org.uk/sites/default/files/2016-06/2012.340%20Raising%20our%20sights_Guide%20to%20communication_FINAL.pdf (Accessed on 11.06.2019)

PMLD Link (2017) *Supporting people with profound and multiple learning disabilities Core and Essential Service Standards*. Available on <http://www.pmlmlink.org.uk/wp-content/uploads/2017/11/Standards-PMLD-h-web.pdf> (Accessed on 11.06.2019)

UK Government and Parliament (2019) *Make it easier for parents to act as deputy into adulthood*. Petition. Available at <https://petition.parliament.uk/petitions/242372> (Accessed on 11.06.2019)

Woolman, E. (2019) A transformation from socially isolated into a social butterfly through using Intensive Interaction. *PMLD Link*, Vol 31, No 1, (Issue 92), 11-13

In the Next Issue

Looking Ahead

The theme for the Winter issue is Loss – looking ahead. Families and professionals alike put great effort into planning ‘a good life’ for people with PMLD. We focus great importance on supporting them to develop meaningful relationships with people around them, to enhance their quality of life. But perhaps we shy away from putting the same care and attention into preparing for the inevitable? How can we ensure a death (or any other ‘ending’) and the consequent ‘loss’ experienced, is addressed in the best possible way? Whether this is the end of life for an individual with PMLD or the loss or death of someone significant in their life, there is so much we can and should do, where possible to prepare and involve them.

As an editorial group we had difficulty in deciding both the scope and the title for this journal’s topic. It was really important that our focus dealt with the time period when people with PMLD come towards the end of their lives, but we also wanted a theme that was broader and addressed this issue of ‘loss’ from a range of perspectives. Supporting people with PMLD when they themselves experience loss, whether it be from bereavement or loss/change through other life events, is equally important albeit with some different challenges. The descriptions ‘palliative care’ or ‘end of life care’ both have quite specific meanings yet are often misunderstood and can carry such negative connotations. We felt this focus was too narrow to encompass all we hope to explore in a positive way – plus, we really want people to read our articles and be encouraged to look and think ahead!

We welcome your contributions about this sensitive aspect of life and recognise they may take a different form from the usual articles – perhaps personal reflections, stories, poems as well as more practical ideas or resources that can help and inspire others to tackle this delicate topic in a positive way.

We are looking for items on as wide a range of topics as possible – ideas might include:

- What does a ‘good death’ look like? Including the planning that both professionals and families undertake to ensure that the final stages of a person’s life is meaningful, respectful and dignified.
- What planning do we need to undertake? particularly as the person with PMLD may be unlikely to participate in the planning
- Who supports families and support staff through this stage ... and how?
- How do we celebrate a life in a meaningful way?
- What does life look like one year on?
- How can we help the person with PMLD to ‘remember’ in meaningful ways, their family member or friend who has died or has gone from their lives?
- When is it appropriate to put a DNACPR in place, have an Advanced Care Directive or create a Respect document.

Send your contributions by the 1st November 2019 to:

jeanne@jcarlin.karoo.co.uk
Or
annie.fergusson@outlook.com

We are always happy to help with writing articles – do get in touch

Looking forward to receiving your contribution

Jeanne Carlin, Annie Fergusson, Michael Fullerton, Bella Travis and Maureen Phillip

REPORT BACK

Thoughts and reflections on Frozen Light theatre

Paul Pargeter

What are the signs of a good show?. 5 star reviews? A recommendation from an old friend? Big production? Big Audience? Perhaps some of all of those things help us build a picture, but the real sign for me is one I felt (yes, not read or heard...felt) during and after 'The Isle of Brimsker' by Frozen Light Theatre. I felt connected, immersed, and somehow, full. Was this a 'show'? It felt (there's that word again) more like an experience; something that was more than just in-front of me but captured me and other audience members in a wonderful dream, enhanced by a realisation that this is a moment in time that my memory bank will cherish and keep safe. Five minutes after it had ended, I was sat in my car motionless with an invisible bubble over my head reading "what just happened?". I loved it! Truth is though, it wasn't for me. I mean the company and performers had made me feel like it was (they're very lovely and talented folk) but it wasn't. Six people lined up in the front (and only) row and were instantly immersed in this experience; an almost fairy-tale story of what comes of our thoughts when left alone and how the world changes when we experience things together. It was fitting as the six audience members were gently guided into the story and the space between stage and spectator disappeared and we all became one.

As a professional that works for an organisation that supports people with more profound, complex and multiple disabilities it gave me real hope and a vision for how people can experience their world (our world) and that the embracing of difference, and boldness to bring ourselves closer, is all important. Sounds, light, touch, vibrations, musicianship and just great performance combined to tell a story and define an ambience that brought people a mixture of emotions as the tale was told. The story was literally brought to people.

Supporters and carers scrambled to take photos and capture expression and delight on video. This, at first, threatened to overpower the performance but I quickly realised that the motivation to do this came from the right place: an excitement to see people take part and an urge to 'show' others what it was like. Perhaps the scramble will calm once we learn our lessons and apply more of this creativity in people's lives, not as a 'treat' every now and then but as seamless everyday way to value people's place, and contributions, in this (our)

world. I urge others to go and learn (and feel) too.

Contact details

Paul Pargeter is Best Practice Manager at Dimensions-UK
e-mail: Paul.Pargeter@dimensions-uk.org

Raising the bar for theatre for people with profound and multiple learning difficulties

Carrie Lennard and Katy Snell

One sunny Saturday in May this year, Katy and I made our way along the Central Line to Stratford Circus Theatre in London. We were off to see a new play called, "The Isle Of Brimsker", the latest production by the young theatre company, Frozen Light, who are specialising in creating public theatre productions for audiences with profound and multiple learning disabilities. Having, ourselves, been involved extensively in devising and creating school-based multisensory and immersive theatre events for many years, we were excited and apprehensive. Excited because we enjoy seeing what is happening in this area of theatre and the new ideas and developments but also apprehensive about making judgements on a young company when we've been working in this area for so many years. We've also worked a lot with a wide variety of artistic and creative companies within our schools, including Oily Cart who've raised the bar in special theatre to an exceptionally high standard.

On arriving at the theatre, full of anticipation, we were greeted by the musician (Al Watts), who created beautiful music to welcome us and to gently support each person's transition from the foyer into the theatre itself. Once inside, each audience member was escorted to a seat that was surrounded by a suspended glistening curtain, then individually serenaded with a song that included their name. It was, indeed, a warm welcome. It was person-centred, in the moment and an immersive experience. The use of repetition worked well here to give each person in the audience, the opportunity to understand what was coming next, i.e. "I hear a song being repeated so that when it's my turn, I have an idea about what to expect" and to therefore, engage more meaningfully and enjoyably.

The music started, the lights changed and we were "transported" to a darkened landscape, followed by fast-

paced and quite complex spoken narrative. For mainstream audiences, this would work. However, we felt the narrative needed to be much simpler and less abstract, to have flexibility so that the performers could include the PMLD audience responses and make them part of the shared play experience. This would have created “in the moment” and immersive opportunities, essential for all PMLD theatre. We saw the two audience members with PMLD offering sounds and movement in their individual responses and these were golden opportunities for the performers to look out for and interpret as intentional communication, i.e. the gentleman was vocalising and the lady was rocking to the music. We would have liked to have seen the performers pick up on these aspects and use these moments to get to know their audience, within the story framework and to incorporate their responses into shared dialogue and actions within the play.

A shared framework of understanding and an openness to new ideas

Good special schools are a really big resource for theatre companies like Frozen Light. They can provide a safe place to ‘workshop’ potential plays; they are a fountain of knowledge in the approaches like Intensive Interaction, the use of communication aids, etc. The leaders in Theatre for people with learning difficulties, Oily Cart (based in London) and Bamboozle (based in Leicester) have recognised this and have made strong communicative links with schools. It is part of the secret of their success. This link has enabled them to develop a clear framework that has each individual audience member at the centre of their creations/ theatre. This relationship can then become reciprocal, benefitting all involved. As Bamboozle state on their website, “We believe that sometimes the education system can inhibit the development of children who have special needs so we work in partnership with schools to create innovative learning programmes that are appropriate to each situation.”

Bamboozle and Oily Cart are now in a position to offer training, based on their approaches which are open to not only staff from schools, but also actors. Sharing the arts, in any shape or form, with people who experience massive barriers, requires the organisers to be skilled and open to new thinking.

Raising the bar for theatre

We think that Frozen Light’s Isle Of Brimsker could make an exceptional and important contribution to theatre for people with PMLD if the points raised above are included in the company’s future planning and vision.

Contact Details

Carrie Lennard is a special needs music teacher and consultant

Website: www.improviseapproach.com
Tel: 078156 42714
Email: carriennardmusic@hotmail.co.uk

Katy Snell is a special needs drama and movement teacher and consultant
Tel: 07982 887999
Email: katysnell24@gmail.com

Theatre Websites

Bamboozle - <https://www.bamboozletheatre.co.uk/>
Oily Cart - www.oilycart.org.uk
Frozen Light - <http://frozenlighttheatre.com/>

Microbes exhibition at the Ferens Art Gallery

Lorna Fillingham

As soon as I saw the advertisement for the Microbes exhibition at the Ferens Art Gallery in Hull it jumped out at me as something that both my kids would love. I have 2 children – my daughter, 9 years old and who has severe learning and physical disabilities; and my son, 5 years old, who has no disabilities. Trying to find things that engage them both for the same amount of time can be a little challenging!

So we found ourselves last weekend visiting this same exhibition. In a gallery, huge multicoloured shapes were hung from the ceiling, weird and wonderful shapes, some looked like they had tentacles, others had lumps and bumps sticking out from the surface. These shapes represented microbes, the small beings that are ever present in our lives but are so small that we do not usually even consider their existence. Microbes are all shapes and sizes, as were these enlarged replicas. Children were encouraged to touch, feel and see them in all their glory. Cushions were laid underneath some of the structures so that you could just literally chill out underneath and get a totally different perspective. Not only this but the structures inflated and deflated, giving them a completely different “feel” within a few moments.

My son ran round pushing at the structures. I lifted my daughter out of her wheelchair and laid her underneath a structure that she could then reach. After a few moments though, she signalled to me that she wanted to stand up, in doing this she is able to tentatively take a few steps (with support from adults), she “walked” herself to another of the structures, this was repeated on several occasions, she kept going back to the same one (one that I would not have considered as it was well out

of her reach), but something attracted her to this same one, perhaps it was the lighting, perhaps it was the colours, maybe, just maybe she will find other ways to communicate to one day be able to tell me. But in this time, and in this place, this fabulously sensory exhibition kept both my kids entertained, for the same amount of time, just by its appeal to the senses.

The exhibition runs for 18th May to 1st September (<http://search3.openobjects.com/kb5/hull/events/event.page?record=6U6O51CjHM8>)

REVIEW

Title: Adult Interactive Style Intervention and Participatory Research Designs in Autism: Bridging the Gap between Academic Research and Practice

Author: Lila Kossovaki

Publisher: Routledge

Paperback: ISBN 9780367232757

Pages: 218

Published: 31 January 2019
Price: £36.99

This book is based on Lila Kossovaki's doctoral thesis about how to foster social communication in young children with a diagnosis of autism who also have severe, profound and multiple learning difficulties (SLD/PMLD). Additionally, she uses her thesis as an example of how to conduct 'real world research' working with stakeholders, in this case in a special school with a sample of six children and three staff.

After an introductory chapter outlining her main motivations and beliefs, three chapters of her book provide a comprehensive review of relevant literature on developing spontaneous communication in children with autism and SLD/PMLD and present details about the Adult Interactive Style Intervention (AISI) principles and opportunities that she has derived from this review and developed alongside the school staff. Two chapters present details of her study and some of the findings. She uses these to explore a number of issues relating to research methodology and data analysis which will be of interest to people developing similar research studies. In two more chapters she offers reflections on lessons she learned both from this study and her wider professional career.

Dr Kossovaki states that she wanted this book to be relevant to people (e.g. academics, parents and practitioners) who live, work and do research with individuals with autism and SLD/PMLD. She also wanted the book to avoid jargon as much as possible, explaining terms for lay audiences, and provide solid evidence supporting the claims she makes and the decisions she made during the study. Finally, she wanted the book to be helpful to part-time students pursuing professional development courses who are tasked with conducting naturalistic research in their normal workplace and who have limited research knowledge. Producing a book that covers such a lot of ground and remains appealing to such a wide-ranging group of readers is very challenging but she has definitely succeeded.

For me, there are some key passages and recurrent themes of this book that stand out: (1) the systematic review of differing approaches to teaching social communication and her elaboration of the guidance that emerges about what practitioner's must do to develop spontaneous communication; (2) the resulting easy-to-follow framework that sets out AISI general principles regarding practitioners' body language, speech and timing in interactions and how to set up situations that likely to provoke spontaneous communication; (3) the empowering use of video recordings and focus group reviews both in Dr Kossovaki's study and other research to collect data and help parents and practitioners reflect on and develop best practice; (4) the care that was taken to design a rigorous study in a real world setting to achieve worthwhile and practical outcomes for the children and staff; (5) the ethical obligations on academic researchers and practitioners and parents to work together to conduct good quality research and disseminate the findings; and (6) the fact that Anglo-American research on autism should not be applied to other countries and cultures without careful adaptations and involvement of people from these different populations.

There is no doubting Dr Kossovaki's enthusiasm for communicating the need for good quality research and the clarity of her presentations. This is a book that works on several levels, not just about what practitioners must do to alter their own behaviour and develop opportunities for spontaneous communication to evolve. Therefore, this is a book that I heartily recommend for both practitioners and parents as well as researchers who are willing to get involved in 'real world research'.

Rob Ashdown

IN THE NEWS

The Learning Disabilities Mortality Review

The Learning Disabilities Mortality Review (LeDeR) Programme's 2018 annual report was released on 21st May. It indicates ongoing concerns about the premature deaths of people with learning disabilities. Between 1st July 2016 and 31st December 2018, 4,302 deaths were notified to the programme. These are some of the report's key findings:

- By 31st December 2018, 25% (1,081) of deaths notified had been reviewed by local areas in England.
- Adults with learning disabilities from Black, Asian and Minority Ethnic (BAME) groups appear to be under-represented in notifications of deaths.
- Just under half of the reviews completed in 2018 reported that the person had received care which met, or exceeded, good practice.
- One in ten (11%) of reviews completed in 2018 reported that concerns had been raised about the circumstances leading to a person's death.
- 71 adults (8%) were reported to have received care that fell so far below expected good practice that it either significantly impacted on their well-being, or directly contributed to their death.
- Women with learning disabilities died 27 years earlier; men 23 years, when compared to the general population.
- Pneumonia, or aspiration pneumonia, were identified as causes of death in 41% of reviews - conditions which are potentially treatable, if caught in time.
- There was evidence of bias in the care of people with learning disabilities, resulting in unequal treatment.

<http://www.bristol.ac.uk/sps/leder/news/leder-2018-annual-report.html>

Mental Capacity Amendment Act

The Mental Capacity Amendment Act was given Royal Assent on the 16th May. This means it has now passed into law. This Act introduces a new model for authorising deprivations of liberty, called the Liberty

Protection Safeguards. The Liberty Protection Safeguards will eventually replace the current Deprivation of Liberty Safeguards (DoLS), although the timescale for this happening has not yet been set out by the Government. Lawyer Tim Spencer-Lane, who worked on the Act, has written a useful guide:

<https://www.communitycare.co.uk/2019/04/26/law-authorising-deprivation-liberty-will-change/>

and the Council for Disabled Children also has helpful information:

<https://councilfordisabledchildren.org.uk/news-opinion/news/amendment-mental-capacity-act-becomes-law>

The World Congress

The World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities will take place in Glasgow from Tuesday 6 to Friday 9 August 2019. PMLD Link is an official 'Friend of the Congress'. IASSID has a PMLD Special Interest Group (PIMD SIRG) which will be hosting symposia and other events during the Congress. There will also be symposia focused on ethics. For more information on the Congress, please see <http://www.iassidd2019.com/>. For information on the ethics symposia, please contact Prof Jennifer Clegg (j.clegg@nottingham.ac.uk).

Death of Jean Vanier

Jean Vanier, Catholic theologian and philosopher of disability, died on 7th May. He wrote 30 books on spirituality and community, including *Community and Growth* (1979), *Becoming Human* (1998), *Befriending the Stranger* (2005) and *Life's Great Questions* (2015). He also founded the communities of L'Arche, where adults with learning disabilities live alongside others without learning disabilities. Along with other theologians and philosophers, Jean Vanier argued that the essence of being human is vulnerability and dependency. Through friendship with adults with learning disabilities, others can learn to value vulnerability and dependency, and to become more aware of their own vulnerability and dependency. In this way, we all become truly human.

Artwork produced by pupils using eyegaze technology

On Thursday 21st February the exhibition area of Garth Olwg lifelong learning centre in South Wales was turned into an interactive exhibition space featuring artwork that was produced by PMLD pupils of Ysgol Ty Coch in Tonteg using eyegaze equipment. The soundtrack to the event was kindly produced by Andy Pidcock who

created bespoke music to accompany the core pieces of artwork.

The opening event was attended by all the pupils who took part in the exhibition, family, local dignitaries and members of staff from Ysgol Ty Coch. The exhibition was in situ for two weeks and was enjoyed and praised by the local community.

Ysgol Ty Coch will be hosting another exhibition in February 2020. Ysgol Ty Coch is a 3-19 maintained special school in Rhondda Cynon Taf. (www.ysgoltycoch.co.uk ; [Twitter@Ysgoltycoch](https://twitter.com/ysgoltycoch)).

Andy Pidcock has led Creative Music Workshops working with large and small organisations, charities and schools with the aim of making the world of sound and music accessible to all (<http://www.andypidcock.com/> ; <https://twitter.com/andypidcock>). As shown on his website, he presented the first accessible BBC Relaxed Prom in the Royal Albert Hall in 2017 for the BBC Proms.

Profound Impact Day and new Health Resources

For Profound Impact Day, on 21st May, people with profound and multiple learning disabilities, their supporters and healthcare professionals were brought together to discuss how partnership can help improve the experiences of hospital care. Mencap, PAMIS, PMLD Link and Centre 404 focused on the issues facing people with PMLD in hospital, which tied in with the Treat Me.

Well campaign (<https://www.mencap.org.uk/get-involved/campaign-mencap/current-campaigns/treat-me-well>).

New materials were launched including:

- A brochure about supporting people with PMLD in hospital
- A multi-sensory storytelling resource about preparing for a hospital visit
- A checklist to help good partnerships in hospital

You can watch a video and access the downloadable resources from the Mencap website (<https://www.mencap.org.uk/get-involved/campaign-mencap/profound-impact-day-2019>).

The 'Open Book' project: Supporting children's social, emotional and mental health needs

Children with learning difficulties are four times more likely to have mental health problems than their mainstream peers (Emerson and Hatton, 2007). In response, Beyond Words (www.booksbeyondwords.co.uk) has embarked on the Open Book project – a two-year funded pilot scheme working with 22 special schools across the UK, training teachers in how the Beyond Words books and approach can empower, inform and support emotional development, safe relationships and confident decision-making for their pupils. For more information on the project, please email Jo: jegerton@booksbeyondwords.co.uk

About Books Beyond Words

Beyond Words is a not-for-profit organisation with over 25 years' experience publishing picture stories for people with learning disabilities and communication difficulties. The organisation was founded by Baroness Hollins, Emeritus Professor of the Psychiatry of Disability at St George's University of London, to help people who can't read or who don't like written words to explore and better understand their own emotions and relationships. Stories in the series cover a wide range of topics, from making friends and self-advocacy to health and employment.

Reference

Emerson, E. and Hatton, C. (2007) *The Mental Health of Children and Adolescents with Learning Disabilities in Britain*. London: Foundation for People with Learning Disabilities/ Lancaster University.

RESOURCES



PMLD Resources in Hertfordshire

PMULD Link readers may like to know that Watford Mencap has a number of resources for people with PMLD and their families and friends.

PMLD Network Hertfordshire

We host a network for parents, professionals and anyone involved in supporting people with PMLD.

Please visit our Facebook page: https://www.facebook.com/PMLD-Network-Hertfordshire-579168672531784/?modal=admin_todo_tour

PMLD Day Opportunities

This service has been running for nearly 3 years now starting in September 2016. We felt there was a need for this service due to families not wanting to send young people to a day centre setting where they could be with people of varying ages and potentially left with little to do. We devised this service to include 1:1 support where each service user is actively encouraged to choose and develop their own service. We have grown over the last nearly 3 years and have 5 young people who attend regularly during the week and enjoy doing things other young people of their age do. Activities have included going to the pub for lunch & a drink to celebrate

birthdays, been shopping for presents for family members for special occasions. We are off to the theatre in London next month to see Mamma Mia. Some days everyone enjoys a quiet time our sensory room or accessing the local community. We are really proud of the PMLD Day Ops service. It gives individualised support, promotes independence and inclusion and most of all is really fun!

Migloo changing facility

We take our Migloo, a portable changing facility, out and about to a number of local events over the summer so families with a person who has PMLD can join in the fun too! For more information on which events we'll be at this summer, or to request the Migloo for an event, please contact candyp@watfordmencap.org.uk.

Celebrating social care staff

For World Social Work Day on 19th March, Jeanne Carlin, one of our Editorial Group, made a video highlighting the outstanding care provided by the social care workers at her daughter Erica's residential care home. You can watch it here:

<https://www.hullccnews.co.uk/19/03/2019/why-hull-is-celebrating-its-adult-social-care-staff/>

“Let me show you my voice”- Making SENSE shares their creativity

Being in the moment is not a new concept, but one which can be easily overlooked, or taken for granted. Making SENSE Creative Services Limited has been working with young adults for the past five years, delivering creative, sensory sessions in residential care settings.

Art can be a wonderfully empowering platform for sensory conversations to blossom. It gives opportunities to make choices by offering a variety of resources; colours; textures and scents.

The sessions range in length and are bespoke to an individual artists interest, likes, strength, and preferences. In recent work there has been much exploration using acrylic paints but also pastels- oil and chalk; crayons; collage- using fabrics and paper; scented paint and fresh herbs and dried spices.

“Art is the means by which we communicate”- Antony Gormley.

Sensory art anchors and builds a scaffold between the artist and those needed, but also to create ample space for an artist’s freedom to develop. The finished pieces of artwork are visual and tactile conversations between the artist and the facilitator. It gives an opportunity for an artist to expose their feelings and voice. It provides supporting the artist. As a facilitator, it is vital to be regarded as a resource; on hand to offer physical and verbal support when es new means to explore their creativity and celebrate the process.

For further information please contact caroline at: caroline.hill1@outlook.com or find us on Facebook - Making SENse Creative Services Limited

Cherry Garden School Branch Maps

In 2015, at Cherry Garden School, we decided our assessment and reporting procedures were no longer fit for purpose. Although we had just received our third consecutive Outstanding judgement from Ofsted, we were aware that our assessment 'data' wasn't always meaningful, and that many of our children didn't make typical linear progress. We were also aware that talk of percentages and P Scales more often than not went over our parent's heads (and realistically a lot of our staff member’s heads too).

We had used Routes for Learning for many years for our children with PMLD, yet it felt as though this was an 'add on' and not necessarily at the heart of our assessment processes for those children. We liked the flexibility of the document and the fact that a child's progress didn't necessarily need to follow a designated path. We knew that we wanted the stepping stones from 'Routes' to form the foundations of whatever tool we came up with.

The concept we came up with for reporting progress to parents was that of a cherry tree that could grow with a child through their time at school. When a child secured understanding, a leaf would appear on their tree. This gave us a structure of branches through which to organise milestones that you may expect to find in a very young typically developing child. We were aware that the tree model still assumed a level of linear progress that didn't suit all of our children, so we decided that children working in the first four branches would have an alternative representation. This would be a cherry blossom, where petals grew with achievements and deepened in colour with generalisation. This meant that a parent would be able to see progress even for our

children with the most profound of needs. Over the following three years the teaching and leadership teams at Cherry Garden spent huge amounts of time compiling six main Branch Maps (linked to our curriculum areas). Four of these maps focus on our 'core' areas:

1. Communication, Language and Literacy
2. Cognition/Mathematical Development
3. Physical Development
4. Personal, Social and Emotional Development

These maps all start at a pre-formal level and link with our curriculum for this group of children.

Once written these maps were analysed and tweaked in teacher and whole school meetings to ensure that they were fit for purpose, and catered for the needs of all children at the school.

It was at this stage that we approached Tapestry to see if they could bring our graphical ideas to life. The 'Learning Journey' approach was an element that we wanted to incorporate so that parents could see photos and videos of achievements and Tapestry were the obvious team to approach as we knew from experience that they had an existing high quality product. They agreed and set to work on producing an attractive interface that parents and children could interact with to see evidence of learning and progress.

It was never our initial intention to share the Branch Maps with other settings, but, as the process was taking place, it became clear that many schools and nurseries in our local area were also on the lookout for something new. In particular, we found that many local Early Years settings were looking for a way of demonstrating progress for their children with additional needs. Regardless of whether other settings choose to go the Tapestry route or not, we are both in agreement that the Branch Maps should be freely available to anyone who may benefit from them. The graphical representations and evidence gathering aspects are very important to our school, but we are aware that this isn't necessarily the case for all settings. We hope that any setting deciding to make use of the maps will find them helpful in assessing children's learning as well as setting appropriate next steps.

For more information, and for free downloads please visit www.cherrygardenschool.co.uk/assessment

For support in implementing Branch Maps in your setting please contact stephen@eyfs.info

SHORT COURSES & CONFERENCES

April 2019		Title: Date: Location: Provider: Contact:	Norfolk Disability Pride 29th September The Forum – Norwich Equal Lives www.norfolkdisabilitypride.org.uk disabilitypride@equallives.org.uk
September 2019		October 2019	
Title: Date: Location: Provider: Contact:	Cassia Family Festival 30th August - 1st September Stithians Showground Cassia cassia@magicaleventscornwall.co.uk 01209820238	Title: Date: Location: Provider: Contact:	FEEL IT –introduction to Sensory Processing Difficulties 1 st October Leyland Sensory Spectacle hello@sensoryspectacle.co.uk or www.sensoryspectacle.co.uk
Title: Date: Location: Provider: Contact:	An Introduction to Intensive Interaction 6th September Redhill Us in a Bus Caroline - 01737 823310	Title: Date: Location: Provider: Contact:	FEEL IT – introduction to Sensory Processing Difficulties 3 rd October Manchester Sensory Spectacle hello@sensoryspectacle.co.uk or www.sensoryspectacle.co.uk
Title: Date: Location: Provider: Contact:	Be Not Afeard – a sensory telling of The Tempest 14th September, Eastrop Park, Basingstoke Collar and Cuffs Co - Part of All In The Mind Festival Tickets are FREE but need to be booked in advance via www.aitmfestival.com	Title: Date: Location: Provider: Contact:	Be Not Afeard – a sensory telling of The Tempest 6th October, Lincoln Performing Arts Centre - Roundabout pop-up Theatre Collar and Cuffs Co lpac.co.uk
Title: Date: Location: Provider: Contact:	FEEL IT –introduction to Sensory Processing Difficulties 24 th September Nottingham Sensory Spectacle hello@sensoryspectacle.co.uk or www.sensoryspectacle.co.uk	Title: Date: Location: Provider: Contact:	Story Massage 8 th October Manchester Story Massage (www.storymassage.co.uk) info@storymassage.co.uk
Title: Date: Location: Provider: Contact:	KNOW IT – focuses on 3 main internal sensations 25 th September Nottingham Sensory Spectacle hello@sensoryspectacle.co.uk or www.sensoryspectacle.co.uk	Title: Date: Location: Provider: Contact:	FEEL IT – introduction to Sensory Processing Difficulties 15 th October Doncaster Sensory Spectacle hello@sensoryspectacle.co.uk or www.sensoryspectacle.co.uk
Title: Date: Location: Provider: Contact:	Be Not Afeard – a sensory telling of The Tempest 28th September Angles Theatre, Wisbech, Cambridgeshire Collar and Cuffs Co www.anglestheatre.co.uk	Title: Date: Location: Provider: Contact:	Using Intensive Interaction with people who exhibit demand avoidance 18th - 20th October, Hill Top Farm Barn, Malham, Graham Firth Graham.firth@nhs.net 0113 8555162

Title:	Raising the Bar III: National Conference on the PMLD Core and Essential Service Standards	December 2019	
Date:	25 th October	Title:	An Introduction to Intensive Interaction
Location:	University of Birmingham	Date:	3rd December
Provider:	PMLD LINK	Location:	Redhill
Contact:	raisingthebarpmld@gmail.com	Provider:	Us in a Bus
		Contact:	Caroline - 01737 823310
Title:	FEEL IT – introduction to Sensory Processing Difficulties	Title:	FEEL IT – introduction to Sensory Processing Difficulties
Date:	29 th October	Date:	5 th December
Location:	Carlisle	Location:	Leicester
Provider:	Sensory Spectacle	Provider:	Sensory Spectacle
Contact:	hello@sensoryspectacle.co.uk or www.sensoryspectacle.co.uk	Contact:	hello@sensoryspectacle.co.uk or www.sensoryspectacle.co.uk
June 2019			
Title:	Story Massage	Title:	The Christmas Clock - a sensory exploration of waiting for Christmas
Date:	5 th November	Date:	7th and 8th December,
Location:	North London	Location:	Delapre Abbey, Northampton
Provider:	Story Massage	Provider:	Collar and Cuffs Co
Contact:	(www.storymassage.co.uk) info@storymassage.co.uk	Contact:	delapreabbey.org
Title:	FEEL IT – introduction to Sensory Processing Difficulties	Title:	The Christmas Clock – a sensory exploration of waiting for Christmas
Date:	8 th November	Date:	14th & 15th December,
Location:	Durham	Location:	Moggerhanger Park, Bedford
Provider:	Sensory Spectacle	Provider:	Collar and Cuffs Co
Contact:	hello@sensoryspectacle.co.uk or www.sensoryspectacle.co.uk	Contact:	www.moggerhangerpark.com
Title:	FEEL IT – introduction to Sensory Processing Difficulties	Title:	The Christmas Clock – a sensory exploration of waiting for Christmas
Date:	14 th November	Date:	20th - 22nd December,
Location:	Sheffield	Location:	Wales Millennium Centre, Cardiff
Provider:	Sensory Spectacle	Provider:	Collar and Cuffs Co
Contact:	hello@sensoryspectacle.co.uk or www.sensoryspectacle.co.uk	Contact:	www.wmc.org.uk
Title:	DO IT – follow on course from Feel IT	January 2020	
Date:	15 th November	Title:	FEEL IT – introduction to Sensory Processing Difficulties
Location:	Sheffield	Date:	15 th January
Provider:	Sensory Spectacle	Location:	Worcester
Contact:	hello@sensoryspectacle.co.uk or www.sensoryspectacle.co.uk	Provider:	Sensory Spectacle
Title:	Story Massage	Contact:	hello@sensoryspectacle.co.uk or www.sensoryspectacle.co.uk
Date:	21 st November	Title:	FEEL IT – introduction to Sensory Processing Difficulties
Location:	Glasgow	Date:	16 th January
Provider:	Story Massage	Location:	Cardiff
Contact:	(www.storymassage.co.uk) info@storymassage.co.uk	Provider:	Sensory Spectacle
Title:	Story Massage	Contact:	hello@sensoryspectacle.co.uk or www.sensoryspectacle.co.uk
Date:	22 nd November		
Location:	Glasgow		
Provider:	Story Massage		
Contact:	(www.storymassage.co.uk) info@storymassage.co.uk		

<p>Title: Date: Location: Provider: Contact:</p>	<p>KNOW IT – focuses on 3 main internal sensations 17th January Cardiff Sensory Spectacle hello@sensoryspectacle.co.uk or www.sensoryspectacle.co.uk</p>	February 2020	
<p>Title: Date: Location: Provider: Contact:</p>	<p>FEEL IT – introduction to Sensory Processing Difficulties 27th January Portsmouth Sensory Spectacle hello@sensoryspectacle.co.uk or www.sensoryspectacle.co.uk</p>	<p>Title: Date: Location: Provider: Contact:</p>	<p>FEEL IT – introduction to Sensory Processing Difficulties 13th February Plymouth Sensory Spectacle hello@sensoryspectacle.co.uk or www.sensoryspectacle.co.uk</p>
<p>Title: Date: Location: Provider: Contact:</p>	<p>FEEL IT – introduction to Sensory Processing Difficulties 28th January Hasting Sensory Spectacle hello@sensoryspectacle.co.uk or www.sensoryspectacle.co.uk</p>	<p>Title: Date: Location: Provider: Contact:</p>	<p>DO IT – follow on course from Feel IT 15th February Plymouth Sensory Spectacle hello@sensoryspectacle.co.uk or www.sensoryspectacle.co.uk</p>
<p>Title: Date: Location: Provider: Contact:</p>	<p>FEEL IT – introduction to Sensory Processing Difficulties 29th January Harlow Sensory Spectacle hello@sensoryspectacle.co.uk or www.sensoryspectacle.co.uk</p>	March 2020	
<p>Title: Date: Location: Provider: Contact:</p>	<p>Story Massage 29th January Birmingham Story Massage (www.storymassage.co.uk) info@storymassage.co.uk</p>	<p>Title: Date: Location: Provider: Contact:</p>	<p>FEEL IT – introduction to Sensory Processing Difficulties 19th March London Sensory Spectacle hello@sensoryspectacle.co.uk or www.sensoryspectacle.co.uk</p>
<p>Title: Date: Location: Provider: Contact:</p>	<p>FEEL IT – introduction to Sensory Processing Difficulties 30th January Luton Sensory Spectacle hello@sensoryspectacle.co.uk or www.sensoryspectacle.co.uk</p>	<p>Title: Date: Location: Provider: Contact:</p>	<p>DO IT – follow on course from Feel IT 20th March London Sensory Spectacle hello@sensoryspectacle.co.uk or www.sensoryspectacle.co.uk</p>
<p>Title: Date: Location: Provider: Contact:</p>	<p>KNOW IT – focuses on 3 main internal sensations 23rd March London Sensory Spectacle hello@sensoryspectacle.co.uk or www.sensoryspectacle.co.uk</p>	<p>Title: Date: Location: Provider: Contact:</p>	<p>KNOW IT – focuses on 3 main internal sensations 23rd March London Sensory Spectacle hello@sensoryspectacle.co.uk or www.sensoryspectacle.co.uk</p>

Subscription prices are: **UK:** Personal £25.00 Organisation:£35.00
Non UK: Personal £32.00 Organisation:£45.00

Name of Subscriber:

Address:

Telephone No. e-mail:

Place of work (if applicable).....

Contact name within organisation (if applicable)

This is a new subscription / renewal subscription

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

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

How did you hear of PMLD LINK?..... Date:

Please send this form with payment to: Rob Ashdown, 15 Cliff Gardens, Scunthorpe, North Lincolnshire, DN15 7PH
 If you require a receipt please enclose a stamped addressed envelope marked Receipt.

Gift Aid Declaration	
Name of Charity:	PMLD LINK
Details of donor:	
Title	Forename(s).....Surname.....
Home Address:.....	
.....	
.....Post Code:.....	
I want all subscriptions and donations that I make from the date of this declaration to be treated as Gift Aid until further notice	
You must pay an amount of Income Tax and/or Capital Gains Tax at least equal to the tax that the charity reclaims on your donations in the appropriate tax year (i.e 25p for each £1 you give on or after 6 April)	
Date/...../.....	

STANDING ORDER MANDATE (Send to your bank)

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

The sum of: £.....
 Commencing:
 Account to be debited:
 Account No.

Signature(s):
 Date:

About Us

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

- Rob Ashdown** Former teacher of pupils with severe and profound and multiple learning difficulties and special school Headteacher.
- Jeanne Carlin** Retired Disability Consultant and a parent of a young woman with PMLD.
- Helen Daly** Mum to a young Adult with PMLD, previous career in Further Education for 20 years - including Curriculum Team Manager for Inclusive Learning and Developing an Improving Choice Programme for people with Complex Needs. Currently involved in carers groups in the Eastern Region, Learning Disability Partnership Board and associated projects.
- Ann Fergusson** Annie is a senior lecturer in the SEN & Inclusion team at the University of Northampton, teaching on undergraduate and postgraduate courses relating to severe, profound and multiple learning disabilities. Her research interests relate to person-centred working, meaningful participation and the voice of the individual in promoting positive mental health and wellbeing. She works one day a week in a special school with a role for training and looking at impact. Annie has a brother with a learning disability. She is a family member of the Learning Disabilities Mortality Review Programme Advisory Group.
- Michael Fullerton** Michael the Director of Quality and Clinical Care with CMG, a social care provider supporting adults with profound and multiple learning disabilities. Michael is a registered learning disability nurse and leads a health team focused on the quality of life of people with PMLD.
- Martin Goodwin** Martin is a teacher of pupils with PMLD and a Regional Tutor/Visiting Lecturer for the Severe and Profound Multiple Learning Disabilities course at the University of Birmingham. Martin has specialised in approaches to improve interaction, communication and participation of people with severe and profound learning disabilities. Martin has experience of working in play and leisure, education, residential and advocacy.
- Joanna Grace** Joanna Grace is a sensory engagement and inclusion specialist. She is the founder of The Sensory Projects which are run on the principle that with the right knowledge and a little creativity inexpensive items can become effective sensory tools for inclusion. Joanna tweets for us on @PMLDlink follow for ideas and information.
- Rachel Parry Hughes** Lecturer in Social Work, Goldsmiths, University of London, researcher in the field of profound and multiple learning disabilities
- Becky Loney** Becky has a background in running creative services for adults with PMLD, and now works as a professional advocate and involvement worker for an advocacy charity. She uses creative and arts-based approaches including music, sensory storytelling, and intensive interaction. Becky is also passionate about raising awareness and expectations, to build high quality support that is truly person-centred.
- Wendy Newby** Deputy Headteacher at The Shrubberies School, Stonehouse, Gloucestershire. This is a school for students with Severe and Profound Learning Difficulties
- Sue Thurman** Former NHS Speech and Language Therapist for adults with learning disabilities with a particular interest in PMLD. Now writes and trains about communication and is a Registered Intermediary assisting vulnerable witnesses to communicate at police stations and courts.
- Bella Travis** Policy Lead, Mencap

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

PMLD LINK

sharing ideas and information

PMLD Link is a journal for everyone supporting people with profound and multiple learning disabilities.

Visit www.pmlmlink.org.uk

Vol 31 No 2. Issue 93

ISSN 2042-5619