

PMLD LINK

sharing ideas and information

Penny Lacey:
A Celebration

Summer 2015

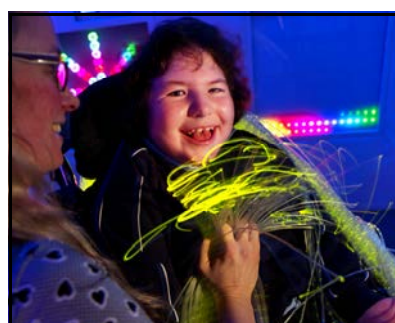


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Cover picture: photograph taken by Alan Wylie

PMLD Link is a journal for everyone supporting people with Profound and Multiple Learning Disabilities

www.pmlmlink.org.uk

GUEST EDITORIAL

Penny Lacey: A Celebration

This issue is dedicated to our friend and colleague Penny Lacey who died after a sudden and short illness in January of this year. Penny was a remarkable woman who is greatly missed. The articles and comments that appear in this celebratory issue of PMLD LINK are testament to her inspiration to others and her impact on improving practice. So too is the fact that so many people gave willingly of their time to make contributions in her memory.

Penny actively worked as a consultant to schools and organisations around the UK and she had an enormous influence on curriculum development as evidenced by the articles from Liz Gerschel and Yvonne McCall about developments at the Swiss Cottage and Castle Wood schools and the outcomes of a recent conference. Liz, Christopher Robertson, Jill Porter and Christine Tilstone also recall that Penny was an exceptional lecturer both at the former Westhill College in Birmingham and since 1991 at the School of Education at the University of Birmingham. Some of the quotes here make plain that she has had a huge and lasting influence on many of her students and, indeed, some may never have moved into this field of education at all but for her encouragement. Many of them have been inspired to do research themselves; there are examples here in the articles by Jennifer Quibell, Mel Bullivant and Martin Goodwin.

Penny was absolutely dedicated to improving the lives of children and adults with PMLD and their families. This is recognised by Peter Imray and Dave Hewett and Julia Barnes in their memories of Penny and their two interesting articles both of which reflect the content of chapters they willingly produced for Penny's new textbook, *The Routledge Companion to Severe, Profound and Multiple Learning Difficulties*, published this April.

Penny would have approved heartily of the articles by Matthew Umpleby on inclusion and its benefits and on Alan Wylie's article on Soundbath showing what good, quality experiences should be like. My own offering is intended to complement other articles here that show the breadth and quality of her published work and its implications for people working with children and adults with PMLD and their families. Penny was a modest person and might well have felt uncomfortable about being the subject of a celebratory issue but her inspirational ideas (who else could have conceived of SCRUFFY targets?) and her prolific output have left us a lasting legacy that has greatly helped, and will continue to help, to improve practices and deserves to be widely appreciated.

We conclude with reprints of three articles written by Penny for PMLD LINK which are illustrative of just some of her abiding interests (music [from 1998], integrated services [2006] and teaching thinking skills [2009]).

Rob Ashdown



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A Tribute to Penny Lacey

Liz Gerschel

I was lucky enough to work with Penny Lacey for nearly two decades, as a distance learning tutor on the Learning Difficulties (SLD/PMLD) course at the University of Birmingham School of Education. She was passionate, inspiring, truly collaborative and fun to work with and I learned an enormous amount from her about high expectations and how to open up possibilities for pupils with PMLD. Penny was as good a teacher as she was because she truly loved what she was doing, supporting learners with PMLD and those who supported them.

The group of Learning Difficulties tutors met, first under the wonderful Christina (Tina) Tilstone and then led by Penny, for two residential weekends and some extra days each year. We were a diverse and lively collection of headteachers, advisers and lecturers and, as the university changed conditions and terms, Penny had her work cut out sometimes. Dealing with bureaucracy and admin were not her natural areas of strength, but there was a feeling of intense loyalty to Penny that kept us in her team. Penny, elegant and calm as she appeared, was never overly solemn: she had a great sense of humour and a rebellious streak and we tutors spent many hours sharing stories and laughter. I miss her giggle and seeing her flash the long earrings that were so much a part of her personal style.

I learned so much from Penny. She had academic rigour, a vast breadth of knowledge and experience of working with pupils with PMLD, coupled with a huge generosity of spirit towards the students, whom she guided and encouraged, in the process modelling how to give support that pupils truly learned from. That is what had the greatest impact on me: Penny's ability to empower students who, in turn, were learning how to empower and give voice to their pupils, often the most socially devalued in society. I co-marked with her for some years and honed my own tutoring expertise on the supportive wheel that she provided! Her kindness, gentle (but firm!) manner and the high expectations she had of all those with whom she worked, ensured that her team of tutors and the students were able to extend their own understandings: she empowered us implicitly and explicitly and we wanted to do the best we could. Students and tutors deeply appreciated her generosity with time, advice and material.

Penny was a practitioner turned researcher: she kept scrupulous and detailed records and many of her tutor team marveled at her astute analysis of what those records revealed, as she continuously developed her knowledge of how to give the greatest learning opportunities to those with PMLD. She wrote clearly and powerfully, capturing her practical experience and research and sharing it in language that was accessible

and engaging, while underpinned by the highest academic standards.

She was an excellent and lively speaker, and I often went to what was apparently the same lecture (according to the title) at different residentials. It never was the same and I always learned something: a different perspective, a new idea to mull over, a question to consider. The students (and many tutors) on the course did not miss Penny's sessions, whatever else was on.

Penny was very much a hands-on person and was happiest working directly with teachers and pupils to extend learning and change lives. She gave invaluable advice, support and weekly demonstrations in 2011-2012 to Swiss Cottage School in Camden, NW London, where I am a governor. The new extended school was to absorb the SLD/PMLD students from neighbouring Jack Taylor School but the staff had, largely, not experienced the challenges that the most complex learners could bring. Penny changed all that. She inspired the staff with her passion for PMLD learning, created and built on their enthusiasm, shared her knowledge of appropriate curriculum and assessment for those with SLD and PMLD and revolutionised thinking. Students from the Birmingham course came to work in the school and Swiss Cottage staff, inspired by Penny and led by Tracy Edwards, Leader of Curriculum and Assessment, developed distinctive progressive and creative curricula, personalised to meet the needs of individuals, and are spreading this way of learning through training others in Penny's memory.

Penny changed the world of PMLD and her legacy will live on in her books and in the minds, work and lives of all those who learned so much from her and because of her. She shaped the future and truly made a difference.

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Glad That I Live Am I

Penny Lacey with Liz Gerschel and Debbie Wilson

The following was extracted from a tribute by Liz Gerschel to Penny Lacey on the Swiss Cottage website (<http://www.swisscottagedrc.org/the-world-of-pmld-will-mourn-penny-lacey>). The final line here was contributed by Debbie Wilson, another tutor on Penny's SLD/PMLD course in Birmingham.

In Penny's last posting (3rd January) to SLD Forum, she responded warmly and thoughtfully, combining erudition with common sense as usual, to a query about collective worship for EYFS pupils with SLD/PMLD.....Penny wrote:

"A bit of awe and wonder seems appropriate for pupils with PMLD, such as sharing something from our beautiful world - starting and finishing with quiet and a candle (real or battery driven depending on the nature of the children). 5 minutes at the end of the day seems about right?? Try feathers, fir cones, leaves, flowers, pebbles, insects, berries, seeds, bark - anything portable from the natural world. Do you know the lovely little hymn 'Glad that I live am I'? It would go well with the theme.

Glad that I live am I;
That the sky is blue;
Glad for the country lanes,
And the fall of dew.

After the sun, the rain,
After the rain the sun;
This is the way of life,
Till the work be done.

All that we need to do,
Be we low or high,
Is to see that we grow,
Nearer the sky.

There is a reasonable rendition using the tune Water End on You Tube

<https://www.youtube.com/watch?v=MB4paKLbP4s>
It only needs 3 chords to accompany it on a guitar/ Q Chord/ chime bars/ keyboard

Relax and enjoy a little quiet time before getting on the buses.

NB - do have enough resources so all the children can enjoy them at the same time and they don't have to wait their turn."

It sums her up beautifully, and seems particularly appropriate now.

Sue Thurman writes:

As a speech and language therapist, I learnt so much from Penny's teaching experience and knowledge and, above all, her passion for the children she worked with; a passion I share. It was a privilege to work alongside her on the editorial board of PMLD Link where her insight, love for life and sense of humour was in much evidence. She will be greatly missed.

SCRUFFY is the New SMART



Tracy Edwards says:

"We ran a conference (in May), which was dedicated to Penny. One of the sessions explored Penny's significant contribution to the field of special education and was facilitated by both myself and Yvonne McCall, Head Teacher of Castlewood School in Coventry where Penny worked one day a week. An artist, Michelle Ku, captured the

dialogues through "live scribing". This led to the attached piece of artwork being produced, which Yvonne plans to display in the reception of Castlewood. A second piece of artwork from Michelle will also be displayed here at Swiss Cottage. This will mark the impact which Penny had on both Castlewood and Swiss Cottage, and emphasise the partnership between our schools that we will continue to grow and build, in Penny's memory."

Tracy also wrote a tribute which is on the Swiss Cottage website including quotes from two of Penny's students who now work there. The link is <http://www.swisscottagedrc.org/the-world-of-pmld-will-mourn-penny-lacey/>

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Dawn Male writes:

I have an equally lovely (but alternative?) memory of Penny when - about 15 years ago - she and I co-presented a paper at a conference in Helsinki. On our return, we were required to write a report to our respective universities to whoever was responsible for 'accountability' and, for some reason, we wrote in the personas of 'Tracey and Sharon from Essex'. On reflection, I don't know what possessed us to do so (!), but Penny reminded me of it when I met with her last October in my (serious) role as External Examiner to her excellent PMLD course. I won't share the details of our 'Sharon & Tracey' Helsinki experience, but it certainly made both of us laugh last October - and caused us to wonder what our 'accountability' people in our respective universities made of our report!

Helen Daly writes:

Penny will be missed. My son has profound multiple learning disabilities. Penny's passion and contribution to the understanding and rights of people with PMLD was tremendous. Thank you Penny.

Penny Lacey's Influence on Castle Wood School

Yvonne McCall

The sudden loss of Penny has made us aware of the great person she was, an academic and educator who placed those learners with PMLD at the centre of her work. Penny always strove to connect research with practice, to share knowledge for the benefit of all. She demonstrated this when she asked to join us and became a member of staff for a day a week at Castle Wood School, a primary broad spectrum school in Coventry.

Penny's approach was multi-faceted, teacher, coach and mentor; she informed our thinking about the curriculum for learners with PMLD. Our last area for development focused on learning environments which appears in her final co-edited publication, *'The Routledge Companion to Severe, Profound and Multiple Learning Difficulties'* (see Chapter 37). She made a real difference to the way staff taught learners with PMLD, encouraging all to become reflective practitioners.

The following information is about our ethos and practice for learners with PMLD, borne from many discussions with Penny:

An inclusive school

Learners with PMLD are educated at Castle Wood School alongside their more able peers. Sometimes they work in mixed ability groups and sometimes they work on activities that are different and special to them. All learners are encouraged to participate in lessons at a level that is meaningful to them and learners with profound difficulties may be engaged in simplified or alternative activities alongside their peers or even in another part of the school, if that enables them to participate meaningfully.

Personalised learning

The curriculum is personalised for each child based on assessments of individual needs. A range of assessments are used both by classroom staff and representatives of our partner agencies. Personal targets are identified in consultation with families, classroom staff and representatives from partner agencies. These targets focus on learning fundamental skills and gaining basic understanding of the world (Communication, Cognition, Physical and Self Help and Independence). These are likely to be 'door-openers' for the child: they will open doors to wide learning opportunities. As learners cannot directly express their views on personal targets, observations of learners are made regularly to ensure targets are based on current strengths and needs. These targets are reviewed at least half-termly.

The Curriculum

The curriculum for learners with profound learning difficulties is driven by the identification of individual personal targets. However, elements of the national curriculum, the wider curriculum and relevant therapies provide a rich context within which to develop these fundamental skills and understanding. Some learners may be at a very early stage of development and it may be appropriate for them to draw on a very focused curriculum: focused on developing object and social interaction skills. Others, who have mastered the basic skills of social interaction and engaging with the world, may be able to benefit from a full and varied curriculum. However, some learners who can benefit from a varied curriculum may need that to be carefully controlled because of their medical, physical or sensory difficulties.

Multi-agency Approach

Most learners with profound learning difficulties also have other difficulties, for example medical, physical and sensory difficulties. It is not possible for Castle Wood School to meet the diverse needs of this group without the help and support of partner agencies such as therapy allied to health, nursing, arts therapies, sensory support services and psychology. The mode of working adopted by the school is interdisciplinary, where all services involved with individual learners meet to discuss how to meet learners' needs. They may work alongside each other and they may work individually but they keep each other informed through agreed lines of communication.

Working with Families

Learners with the complex needs, experienced by learners with PMLD, require particularly close contact between school and home. Parents or carers are involved in planning and meeting needs and help to identify priority targets. School and partner agencies keep in close contact and try to meet whole family needs wherever possible.

Quality of life and the 'voice' of the child

The complexity of needs experienced by the learners means that sometimes they are uncomfortable and need to endure difficult procedures. They are often unable to control their own environments and they need to wait for the world to come to them. We try to minimise these unsatisfactory moments and engage them in activities they enjoy to increase their quality of life. Staff keep the learners' needs always in mind, using observation to help them keep the 'voice of the child' at the centre of everything they do.

The day I shared the tragic news about Penny with the staff was the same day we received the "Phone call" from Ofsted (six months before we were due) informing us that they would start their inspection the next day. However, the school team were galvanised by Penny's

spirit and we received an 'Outstanding' judgement across all areas; this is a testament of Penny's influence on us.

Penny's work will be her legacy; it will inspire future professionals and parents. Our lives were all the richer for having known such a wonderful, selfless and humorous person who made it her life's work to enrich the lives of children and adults with PMLD.

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Wendy Newby writes:

I was just a teacher trying my hardest to teach pupils with PMLD and then I went to Birmingham University to study for my Masters. I met Penny, who inspired me and changed my practice. She gave me the passion to enquire and strive for improvement, the opportunity and hope for the future. She has had a lasting effect on my life. Her contribution through research, writing, lecturing, PMLD LINK, and as a friend is her legacy. A great loss of a dedicated and inspirational woman.

Barry Carpenter writes:

Penny was just a calm, wise force; passionate and caring; loyal and courteous. Her deep commitment and passion for children and young people with SLD/PMLD was unequivocal. She was a loyal, sincere and trustworthy friend, as well as a hardworking, dedicated colleague.

What does Care have to do with Education?

Peter Imray

All learners with PMLD and many with SLD will face a life in which care plays a considerable part. Given the complexity of their social and health needs, care features heavily among activities at school.

This article, containing previously published material from a chapter (Imray and Bond, 2015) in *The Routledge Companion to Severe, Profound and Multiple Learning Difficulties*, seeks to discuss the nature of care in educational environments, the pedagogical opportunities provided by care activities and strategies for promoting all learners' independence in care situations.

The Need for Care

The need for this care is apparent 24 hours a day, seven days a week and can be an onerous burden for the caregiver. The implications of having to wake up every two hours throughout the night in order to turn their child with PMLD, who is physically unable to turn independently, will be known in detail by all parents in this position, and, whilst the demands are not so high for schools and school staff, they are still considerable. The tasks of changing clothes, dressing and undressing, toileting, padding, washing, regular positional changes, massage, stretching, and assistance with eating and drinking will probably apply for the vast majority of those with PMLD. In addition, school staff will need: some expertise in tube feeds (nasogastric or via gastrostomy) feeds and equipment such as pumps and giving sets; training regarding epilepsy and the administration of emergency medication such as rectal valium; tracheotomy training, especially around cleaning; setting up and administering daily medication; and training in issues relating to degenerative conditions. Whilst historically such clinical responsibilities have been carried out by a nurse or health care assistant, it is increasingly the case that education staff will be trained to carry out these activities instead of, or in conjunction with, the medical staff. This enables education staff to have a holistic view of the learner and encourages a greater understanding of their world. It gives confidence to be able to work with the learner and know it is possible to keep them safe at all times. Such expertise also enables a class to go on trips, day or residential, and be prepared for all possible situations, for example a learner having a seizure or a feed pump breaking. Even in relation to general classroom activities, if a feed pump 'beeps' to indicate it has finished, being able to check, stop and turn the pump off is helpful. The alternative of waiting for the nurse to come and turn it off might be both time consuming and disruptive.

Care as an Educational Imperative

What are we therefore to make of this care and the need for care? Is this something that happens outside of the 'normal' curriculum? What status does it have compared to the 'normal' curriculum? The 'M' of PMLD, emphasising multiple difficulties and first suggested by Evans and Ware (1987), is missing in other descriptive 'labels' of this group of learners such as 'low incidence disabilities' in the USA or MSID (Most Severe Intellectual Disabilities) in Australia (Lyons and Cassebohm 2012). Yet, there is a general assumption that the more intellectually impaired the learners, the more likely they are to have attendant and multiple physical disabilities (Ware 2003). Such additional physical disabilities may further deleteriously affect the learner's ability to learn. Goldbart and Caton (2010), for example, point out that a person's health, their sensory skills, and sensory difficulties, will critically affect their communication and their ability to communicate effectively. Imray and Hinchcliffe (2012, 2014) go further in suggesting that this combination of profound intellectual and physical difficulties has a direct effect on relevant pedagogy and curriculum and thus both should be fundamentally different from that normally on offer to learners who are developing typically.

Andrew Colley notes that:

....during our lives, we all, more or less, create our own narrative. The story of our lives. It's an unfinished story, but a story nevertheless, with many unpredictable twists and turns. Many joys and sorrows. Many successes and failures. Young people with PMLD don't often get the chance to do that. For practical reasons, they tend to be 'done to'. They are defined, analysed, restricted, contained, prescribed, followed and led.

(Colley 2013: 30-31)

And it is this 'doing to' rather than 'doing with' which can lead to many lost learning opportunities. Promoting the argument that care should not be treated as a curriculum by-product but as a crucial element of the curriculum, Imray and Hinchcliffe (2014) suggest that teachers should stop treating care as a necessary but time-wasting affair, something to be got over as quickly as possible, and

recognise the pedagogical opportunities that care activities offer. Moreover, a sophisticated approach is necessary to address the social and health care needs of learners with PMLD. Carnaby and Pawlyn (2009) have posited using a rigorous and continuous assessment cycle to ensure a holistic, person-centred approach and to decrease the likelihood of symptomatic changes in behaviour going unnoticed. To address the concern that poor care practices can also lead to the development of learned helplessness relatively easily, Imray and Bond (2015) have extended Carnaby and Pawlyn's (2009) model for complex care. Figure 1 attempts to show this more integrated approach to meeting learners' complex needs through a cycle.

The Problem of 'Learned Helplessness'

Education for learners with PMLD is not simply an intellectual or cognitive process, since their multiple and often extremely complex physical disabilities combined with a profound intellectual impairment makes for a very different learning map. Part of this learning map is the notion that educators must teach learners to respond to the world as independently as possible, since (i) it is not a given that all learners will automatically strive for independence and (ii) it is extremely easy to dominate those with PMLD even if that is not the educator's intention. The learner must be actively engaged in the process of care in the same way that they must be actively engaged in the process of art,

or music, or literature or pressing a switch to communicate. Care must become something the individual learns to take responsibility for so that they become initiators and controllers rather than the merely receivers. We must be very careful that the current obsession with measuring progress does not force us into only teaching what can easily be measured and does not blind us to the fact that education for those with PMLD is a holistic process. Measurement of progress for those with PMLD may well become a case of hitting the target but missing the point.

In 1975, the American psychologist Martin Seligman coined the phrase 'learned helplessness' to describe the condition where people actually learned to adopt helplessness when they were denied control over their lives, even when they did actually have the power and it was in their best interests to change things (Seligman, 1975). This was especially evident in long stay mental institutions where staff, for a number of reasons, took control of even quite mundane things, such as making a cup of coffee, away from their patients. The same patients lost the will and even the ability to do these simple tasks for themselves and thereby lost the ability to take control over their own lives. This in turn, Seligman noted, led to further, often quite deep, depression.

It is not difficult to imagine that such a state of affairs could be evident in very many 'care' situations where so much has to be done for learners with PMLD who tend to be passive and numerous writers (such as Barber 1994; Wilkinson 1994; Smith 1994; Collis and Lacey 1996; Hewett and Nind 1998; Ware, 2003; Imray 2008) have argued strongly that addressing the issues of control inherent in caregiver/learner interactions are difficult for the teacher, but vital for the learner. Imray and Bond (2015) have suggested a number of pedagogical strategies which might be used to counteract such a potentially highly damaging state of affairs.

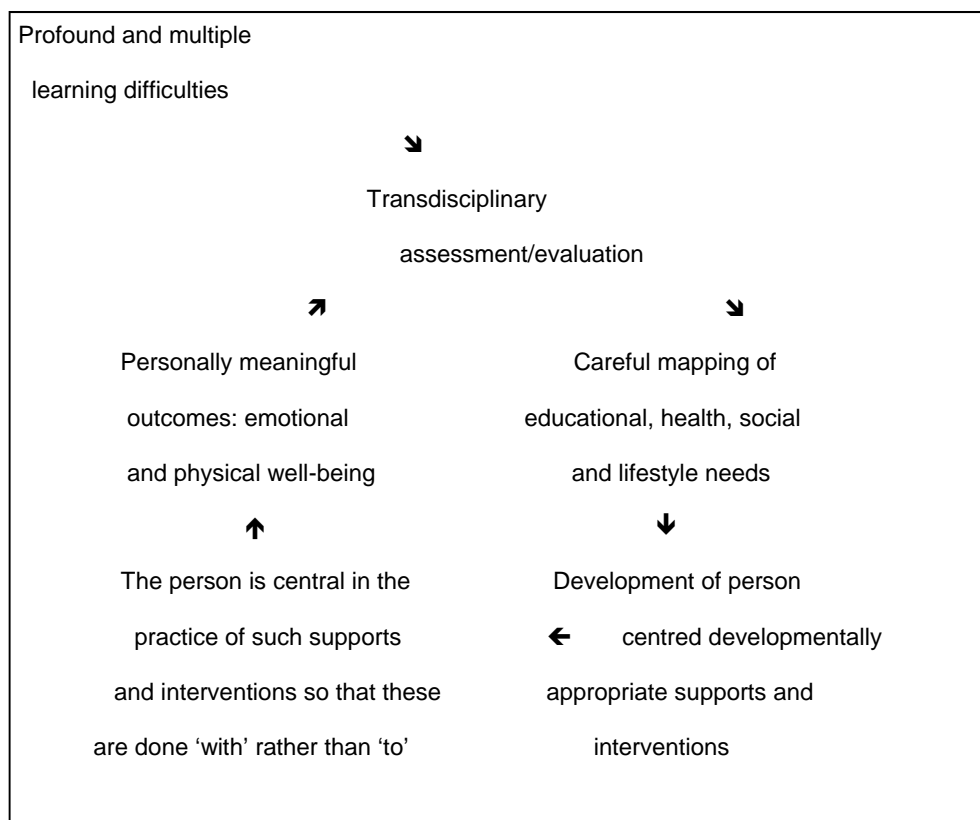


Fig 1. Complex Educational Care Cycle (from Imray and Bond, 2015, p165).

Conclusions

It may be that care has a very low status in education, because it is perceived that this is not what education is for and it is not what teachers do. This, however, represents a very considerable danger for the learner with PMLD because it assumes that there are more educationally important things to do than take control of one's own life. Care must not be rushed so that the more important business of 'education' can be got on with!

Ensuring the right approach to care and the increasing opportunities to work towards independence in care situations must be a priority if learners are to avoid becoming 'helpless'. It can indeed be argued that there is no greater educational priority; there may be equal educational priorities, but no greater one.

Care is an area that learners can most definitely succeed in, though this may not be measurable in any quantifiable sense. The tiny advance from touching the hoist switch, to holding the hoist switch, then to pressing the hoist switch may take a number of years to teach. Not teaching this process assumes that learners with PMLD cannot succeed. Not teaching this process, and innumerable others like it, condemns the learner to a life of being done to.

And finally.... two questions to ask of your own practice:

Am I thinking about how learners in my setting can maximise the control they exercise in relation to care?
Am I turning those thoughts to action?

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Physical contact, 'age-appropriateness', the SLD curriculum and the courage and conviction of Penny Lacey

Dave Hewett and Julia Barnes

People with PMLD are naturally tactile and physical and still mostly at a sensory exploration stage of development. Yet, at school or in other settings, they are unlikely to receive anything like the quantity of normal touch experience enjoyed by their peers in their natural interactions with adults and others. This theme is treated in detail (Barnes and Hewett, 2015) in 'The Routledge Companion to Severe, Profound and Multiple Learning Difficulties' which provides information on what constitutes good, safe and nurturing touching and makes plain the importance of physical contact for the wellbeing learners with PMLD. The article here summarises some of that original material and offers additional comments for consideration.

Dave Hewett writes about Penny

It was about twenty years ago. Penny was on stage for the hour before me. I was already anxious about showing this audience videos of Intensive Interaction activities. It was a big conference, 300 or so people. There were quite a few bold, brash, managerial-type men in suits. I had been briefed that this was likely to be a group where many had based their careers around 'age-appropriateness', and various notions of 'properness' and 'normalcy'. This was something of a bastion of Wolfensberger's, putting it kindly, inappropriate vision of 'Social Role Valorisation' (Wolfensberger, 1983).

Penny (oh Penny, thank you) quickly showed a video of a lovely play and romping activity by a member of staff and a person with complex needs. She took the audience by its metaphorical lapels and addressed them very directly with those honest, penetrating eyes, something like:

I expect many of you are having difficulty with this video where you have just seen an adult person playing and romping, exchanging meaningful physical contact. You perhaps have misgivings on grounds of 'age-appropriateness'. Well I have to tell you that this widespread notion of age-appropriateness and the way it is often operated is just plain daft.

Penny went on carefully to unpack for the audience the technicalities of the importance of addressing all the various aspects of a person's developmental state. This means for instance, balancing their chronological age needs with provision of crucial, developmentally pertinent experiences. She also surveyed the lack of technical/academic underpinning to the vague notions and practices of 'age-appropriateness'. These improperly articulated ideas she said, too frequently prevented access to formative, developmental input for the person.

Julia Barnes write some reflections on Human Touch and the Curriculum

This week I was attempting to photograph students to create a portfolio of images that can be used in the school's digital website or prospectus. While photographing anyone isn't easy, photographing people with complex needs is especially challenging. I endeavour to reflect them accurately without being unflattering - we ensure clothes are clean, hair is combed and chins are wiped free of saliva. We endeavour to make sure that they are looking engaged and, more importantly, happy or having fun, looking fulfilled. Taking photographs in the sensory room requires a photographer with specialist equipment to take a sharp image at low light levels. So as I brought in Alex, her expression changed from her normal smiley appearance to a 'concentrating' or confused expression of her with her tongue extended out of her mouth and her brow furrowed. I encouraged her to look at the fibre optic tail, a resource with which she is familiar. The photographs that were taken showed her looking, but

with her tongue extended, giving the impression of someone with very special needs - not as I knew her and hoped to depict her, but I accepted we'd tried. At this point I gave her a 'well done' hug and she lit up and we got the shot. Presumably she had needed the physical reassurance from me that this unfamiliar set-up in front of unfamiliar people was okay. Within our day-to-day interactions she experiences a range of physical contacts from us, ranging across on-the-body signing (Goold and Hummel, 1993) to hand under-hand-support (Miles 2003), massage, and yes, hugs. In the posing situation, that is what Alex needed to reassure her and obtain the beautiful photo that captured her essence.

The photographer commented something along the lines of; "I didn't think you'd be allowed to do that" and I reflected that when I started working at Ravenscliffe High School in 2003, it would have been prohibited. At the time we had a strong ethos of 'age appropriateness' which effectively prohibited social touch but allowed functional touch - those necessary to meet their needs or support them to access switches, hold a spoon etc. I remember we even encouraged the students with very complex needs to offer their right hand to shake hands when greeting people - even though it was a contact that many students instinctively pulled away from. Nurturing touches - if at all - came from massage and aromatherapy which support staff were trained in and was overseen by the school's professional. A dozen years later and our ethos has changed and developed to, I believe, a much more human focus on the individual and encouraging well-being by considering emotional needs. This is physically manifested through nurturing physical contacts.

We acknowledge the role and value of social touch for people who are early learners and make it available. We also endeavour to ensure that each touch a student experiences is of a nurturing nature. This effect is experienced across all curriculum areas and all the other, what can seem, more mundane aspects of the day such as when limbs are manipulated as part of a physiotherapy exercise regime or when they are wiped during their personal care. Staff make themselves available for students to reach out and initiate physical contact, are responsive to these communications and allow touch experiences to linger as led by the student and be a common, natural aspect of communication experience. This supports students and staff to share what Hart (2010) describes as a common 'touchpoint' within the perceptual experiences of both.

Touch, 'age-appropriateness' and the landscape of our work

The practice transformation at Ravenscliffe School has not happened accidentally or incidentally. There has been careful, ongoing consideration of the developing thinking on behalf of people who are at the earliest levels of development and a gradual contribution by this school to the literature on the issues. A key influence has been

Intensive Interaction. The approach, of course, has a focus on communication and emotional development priorities. From the beginning, Intensive Interaction literature has iterated a technical challenge to vaguely thought-out notions of 'age-appropriateness' which may have the effect of preventing beneficial experiences rather more than promoting them (Nind and Hewett 1994, 1996, 2001, 2005). Collis and Lacey (1996) shared this unease. Intensive Interaction also asserts the positive sense of developmental pertinence in the act of making available touch experiences to people (of whatever age) who are still in a stage of development where sensory input is normal and crucial. This perspective has been further expanded in its both developmental and sociological aspects by Hewett (2007), by Penny Lacey in a national press interview (Gold, 2005) and by Rhodes and Hewett (2010). Barnes (nee Rhodes) (2012) conducted observations on the touch experiences of pupils with complex needs within Ravenscliffe School and surveyed the likely effects on quality of daily life for those pupils. Policy and safeguarding issues have not been neglected in the Intensive Interaction viewpoint (see Hewett and Firth, 2012).

This brief literature resume resolves to a point made by Hewett (2007). A great part of all of the literature on physical contact experiences for people with SLD/PMLD within the UK has just been listed in the sections above. It is surely not enough. Penny Lacey shared the concerns of

these authors that this huge human issue tended to be neglected or worse still, purposely avoided, due to its human complexity, its awkwardness or delicacy, or simply through a failure to recognise its critical nature. This failure to address this issue, for whatever understandable reason, is nonetheless a failure. Another, related failure in our field, has been the historical tolerance for the widespread application of what were in effect, restrictive practices in the name of 'age-appropriateness', when the idea had little technical or academic support.

Most recently Penny Lacey and co-editors (Lacey *et al* 2015) have determinedly ensured that the issues have a rightful place within what will be a milestone work on curriculum and lifestyle for people with SLD/PMLD.

Dedicated to the memory of Penny Lacey

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Penny Lacey's Lasting Influence on In-Service Training

Jill Porter and Christina Tilstone

Penny provided exciting and innovative approaches to in-service training for teachers and other professionals in order to develop and expand their knowledge and understanding of the teaching, management and welfare of children and young people with severe difficulties in learning (particularly those with PMLD). In this article we identify the ways through her writing, in which she encouraged practitioners to review and reconsider their practice alongside changes in legislation that occurred during her career from the late 1980's until her untimely death earlier this year.

Penny taught first in mainstream schools but soon became deeply involved in special education. She was never happier than teaching in the classroom and was able to develop a rich store of well tested knowledgeable and innovative ideas which she willingly shared with others. Her role as a deputy head teacher of a Coventry special school, then as a lecturer in special education at Westhill College, Birmingham and finally, as a senior lecturer in education at the University of Birmingham widened her range of influence. Penny joined the staff of Westhill College of Higher Education in 1989 to teach on the four year B.Ed course for teachers of children with severe learning difficulties and later on a newly formed B.Phil. Ed degree in special education.

The effect of changes in teacher development

In 1972 the James Report (DES, 1972) stated that initial teacher education and professional development should be part of the same life long process, and by offering both pre and post graduate courses Penny, and the other staff working in special education at Westhill College, attempted to reinforce the findings of this report. Courses were created that allowed qualified teachers working, or intending to work, with children with difficulties in learning to embark on a programme of professional development at various points in their careers. The ideas embedded in the James Report were taken further in the Warnock Report (DES, 1978) which emphasised the need for specialist in-service training for teachers of children with special needs. One of Penny's responses to such initiatives in the early 1990's was to write *Managing the Classroom Environment* (Lacey, 1991) for both pre-service students and those with more experience.

The Warnock Report also stressed that all teachers should become teachers of children with special educational needs and consequently the Advisory Committee for the Supply and Education of Teachers

(ACSET, 1984) proposed that specialised initial teacher training courses designed to develop the skills necessary for teaching pupils with severe learning difficulties should close. Consequently the four year Westhill BEd course, with others like it, finally ended in the late '80s. At this time there was an increasing emphasis on providing school-based programmes of study in addition to the one year post experience courses already established. This school-based school focussed approach was one in which Penny flourished. She and other members of the Westhill SLD team moved to the University of Birmingham in 1991 and it was there that she and a colleague wrote *Support Services and the Curriculum* (Lacey and Lomas, 1993) which successfully fulfilled another of the Warnock Committee's major recommendations: that of encouraging close working relationships between professionals employed in different services for children with special educational needs. Penny's emphasis was on collaborative problem solving which was almost unheard of in 1993.

She took the need to encourage work across disciplines further in her publication *Interactive Approaches to Teaching: A Framework for Inset*, which she wrote with Mark Collis in 1996 (Collis and Lacey, 1996). Collaboration had become central to her work and was fully explored two years later in the seminal book, *People with Profound and Multiple Learning Difficulties: A Collaborative Approach to Meeting Complex Needs*, which she and Carol Ouvry co-edited (Lacey and Ouvry 1987).

Penny's research had now extended to include working with adults as well as children (particularly those with PMLD) and, in exploring different aspects of their lives, she embraced multidisciplinary team work to the full. Her work became 'fully inclusive' and her books (*Support Partnerships: Collaboration in Action*, (Lacey, 2001) for example) were designed to extend the knowledge base of those working in health, education, social care and the

voluntary sector. Such an initiative was in line with the Government policies of the early 90s in which a range of agencies were encouraged to work together (DES, 1991). This emphasis continued as was evident in the DfES legislation of 2004 (Every Child Matters) and working in a multi-agency context was also very much in line with Penny's thinking and she inspired groups of professionals in both mainstream and special schools to engage in collaborative teamwork; see for example, *Pupils with Learning Difficulties in Mainstream Schools* (Tilstone, C., Lacey, P., Porter, J. and Robertson, C. (2000), and her chapter in *Promoting Inclusive Practice* (Lacey, 2008).

The National Curriculum and other reforms

The introduction of the National Curriculum (DES, 1988) provided one of the greatest challenges to special educators. At one level it reduced the opportunities available in initial education courses for other elements to be explored including developing ways of meeting the requirements of children with special educational needs. At another, its introduction demanded that teachers and other professionals should ensure that the rights of pupils with difficulties in learning to a statutory curriculum were honoured and that such children and young people were not marginalised.

Penny, together with other teacher educators and practitioners in the field, was able to influence the National Curriculum Development teams in keeping the needs of pupils with learning difficulties centre stage (NCC, 1992). The production of the guidance on planning, teaching and assessment (QCA 2001 and 2009) are testaments to this work. Over time, staff in schools became more confident in using these documents as starting points to curriculum development and delivery and Penny was a prime mover in encouraging them to develop their own curriculum for their pupils by emphasising developmental perspectives. Her article in *SLD Experience* (Lacey, 2010) which deals with 'Smart and Scruffy Targets' is an example of her innovative approach.

Penny had a passion for music. Her office was often filled with wonderful sounds- including her singing. She "applauded" when music was included as one of the 11 subjects of the National Curriculum and the impact this would have on both special and mainstream schools. Unfortunately, by the time she wrote again about the 2000 revision of the National Curriculum it had once again become a Cinderella subject (Lacey, 2001), but this did not curb her enthusiasm. Instead it gave her an opportunity to emphasize the very particular place of music in the education of children with profound and multiple learning difficulties. She wrote:

"both children and adults have music surrounding them constantly (from 'muzak' in the shopping centre and advertising on the TV...) and to omit the study of this phenomenon would be nothing short of criminal!" (Lacey, 2001, p121).

She devised ways in which pupils could be involved in composing or improvising by relating this to the programmes of study and by inspiring teachers to look beyond core subjects and devote time to the arts. Music chimed (!) well with her interest in the inner life of pupils with PMLD through helping to understand their thoughts and feelings (see Lacey, 1996).

Penny argued that music was a language, an idea that supported her interest in literacy for pupils with PMID, and she was particularly concerned about how children made sense of, and used, other signs and symbols in their environment. She was centrally involved in a series of projects, the first with Carol Miller and Lyn Layton at the University of Birmingham surveying how staff of mainstream and special schools made the literacy hour inclusive for all pupils (Miller et al., 2003). This study revealed that not all children had access to literacy learning and drew attention to the need to support schools in developing activities, which Penny duly set about doing. In 2007 she published further research carried out with two other universities and thirty five schools (Lacey et al., 2007), asking the fundamental question: "What is literacy for students who do not learn to read and write?" The project looked at the adaptations teachers could use in the literacy hour. In true collaborative fashion she also worked with libraries, supporting them in their capacity to provide for people with severe and profound learning difficulties. The British Institute of Learning Disabilities was also involved in disseminating this work through a short film on their website and a booklet to assist libraries.

One of the unforeseen consequences of the demise of initial teacher training, and the diminution of award bearing courses was that the body of people engaged in building and disseminating the knowledge base for teaching expertise also changed. Penny was a firm believer in the 'reflexive practitioner', in enabling professionals to develop skills of action research particularly through small scale, locally based research. In *Researching Learning Difficulties* (Porter and Lacey, 2005) her chapter on "small-scale research" specifically illustrated the variety of methodological approaches available through the use of assignments and dissertations as well as PhD studies to show: "how research can be carried out by anyone, not just by professional researchers" (Porter and Lacey, 2005, p 127).

Perhaps her most widely read methodological contribution however came from her work on action research. Its origins appeared in an article published in 1996 entitled *Improving Practice through Reflective Enquiry: confessions of a first-time action researcher*, in which she describes her approach through the action research process.

"What am I trying to do? My intention is to lead participants to reflect on the strengths and weaknesses of their present practice and from that to plan ways in which they can develop more effective ways of working. I tell them about what I have found in my research in other organisations and make suggestions about what I consider to be good practice, but I only offer this when I judge that they are ready to consider it. I could produce transparencies and handouts and work my way through the aspects of teamwork I think they are going to need, but my belief is that this would not be as effective as commenting on what they tell me about their work." (Lacey, 1996, p357)

In many ways this style was also characteristic of how Penny responded to children by starting with their own interaction with the environment and building on their strengths. It also illustrates the integral nature of her research and her practice, with both practitioners and with pupils. Her writing also demonstrates her commitment to moving the field forward through the type of research she carried out:

"I hope that I have demonstrated how I moved from merely locating the problems and possibilities of teamwork to taking action and attempting to improve it. My own development has been substantial and in sharing this, I hope that others will be encouraged to engage in major projects which lead to improvements in their own teaching" (Lacey, 1996, p 360).

She produced a useful guide to action research (Lacey, undated) that is still available on the Teamwork Around the Child website to enable practitioners to build knowledge and expertise. (A shortened version appeared in the Spring 2015 issue of PMLD LINK.)

In 2010 The Salt Review, set up to consider the teacher supply issues relating to children with both severe learning difficulties and those with PMLD, stressed the need to find attractive and accessible opportunities to encourage new teachers and those already in the profession to consider working with such children. In this article, by highlighting some of Penny's publications, we hope we have shown that throughout her career Penny has done just that. She has, however, not only inspired teachers, but a wide range of professionals involved in

the lives of children and adults with complex needs.

Her legacy will live on through her outstanding work. In addition to her new book *The Routledge Companion to Severe, Profound and Multiple Learning Difficulties* published this year, the Department of Disability, Inclusion and Special Needs at The University of Birmingham has set up two annual awards in her honour. The first (with Gary Thomas) will be for the best undergraduate dissertation (The Penny Lacey Memorial Award) the second for the best dissertation at Masters level (The Penny Lacey Masters Dissertation Prize). A fitting tribute to a dedicated teacher.

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Lana Bond writes:

I first met Penny when she was my tutor at University. I spoke about her work and wisdom so frequently that when I graduated and Penny came to congratulate me my parents thought I was friends with a celebrity. I know Penny would not agree to being a celebrity but her inspirational ideas and personality made her well known and well loved.

Creating a Fairer World: Better Education for Children and Young People with PMLD

Christopher Robertson

Recently I was privileged to be able to write a short appreciation for Penny having worked with her at the University of Birmingham's School of Education for over fifteen years (Robertson, 2015a). In this brief celebratory reflection I commented on some of our co-teaching experiences when we worked together, lecturing and running seminars with a wide range of undergraduate and postgraduate students from the UK and a wide range of international contexts. These students were taking courses with a focus on special and inclusive education, and very frequently these considered the educational needs of children and young people with profound and complex learning difficulties (PMLD).

In this article I want to say a little more about the discussion and debate that Penny and I, together with our students, engaged in on many occasions. This centred on the concept of inclusive education and where children and young people with PMLD should be taught. In doing this, rather than looking backwards, I want to suggest that we continue to talk about developing educational provision for students with PMLD, and that to do so will provide the most positive and sustaining legacy for Penny's pioneering contribution to the field of education.

In our discussions, both Penny and I recognised, as Male (2015) notes too, that special school provision for students with PMLD will continue to exist for the foreseeable future in England. We also agreed with each other that teaching in specialist settings for this group of learners is often excellent and innovative. However, I took the view, and still do, that we – politicians, policymakers, education professionals, parents/carers and young people with direct experience of learning disabilities – have not moved forward with regard to ensuring that all students can attend, as of right, mainstream schools in their local community (Robertson, 2015b). The newly introduced Special Educational Needs Code of Practice (Department for Education, 2015), for example, takes a pragmatic and status quo position with regard to the future of specialist provision for a wide range of students experiencing difficulties in learning while adopting a rhetoric of inclusive education that seeks to remove barriers to learning (Robertson, 2014). There is also some evidence that the special school placements are increasing for the first time in many years (Department for Education, 2014). Although this data needs cautious interpretation, the possibility that it signals a reverse in our efforts to introduce mainstream

schools for all students, including those with PMLD, concerns me. Furthermore, if we are not increasing the capacity of mainstream schools to include all students then the UK government's commitment to implementing education provisions in the United Convention on the Rights of Persons with Disabilities seems to me, to be both partial and weak (United Nations, 2006).

Article 24, 2 and b states that countries shall ensure that: 'Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability; Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live'.

To summarise my argument, notwithstanding the many remarkable developments in education for students with PMLD (see for example, comprehensive accounts of these in Lacey et al., 2015), I think we continue to tinker with system change, introducing various types of unit/resource base and co-located special and mainstream schools without grasping the radical nature of reform that an inclusive philosophy requires.

Penny, gently but assertively, drawing on years of experience took a different view to me. In doing this, she argued as a pragmatist with vision, and always utilised the knowledge she had gained from the families and countless education professionals that she worked directly with. Most notably, she would reflect on examples of special school based inclusive practice. Whilst I spoke about the importance of changing policy and provision from the top down Penny reflected on

class and school/setting level practice and identified the ways in which great special school staff facilitated community participation, especially through the creative arts. In doing this, she always highlighted the work of others without mentioning her own influence as a catalyst for bridging school based activities with wider social engagement (for example in libraries or churches). This influence was, of course, significant, creative and imaginative (Park, 2015).

Penny also wanted to see the development of more inclusive mainstream schools and argued that they might best operate – for students with PMLD – as schools within schools. These would be managed and run by staff with enhanced knowledge and skills pertaining to PMLD, but connections between the academic and social activities of all learners in a school would be essential and not optional. In advocating the development of more inclusive mainstream schools, Penny was well aware of the strengths and weaknesses of specialist units, resources bases and co-located schools. She was also, quite rightly, insistent on acknowledging the strengths of such settings and discrete specialist provision.

In sharing our views with students we were frequently surprised and delighted with the experiences shared and subtlety of views expressed. More often than not, our seminars on inclusion almost ended in agreement and we continued conversations over a cup of tea or via email. Of course, debate about the nature of provision for students with PMLD is perennial, and may never have a conclusion. In writing this article, I want to encourage readers of PMLD LINK to continue to reflect on provision for the children and young people they work with on a daily basis, with the aim of continuing to try and make it better. This is what Penny always sought to do, and with great success. Let's take her legacy into the future!

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Inclusion at Frank Wise School

Matthew Umpleby

I would start by asking that you imagine a mainstream classroom - any classroom. It could belong to any type of mainstream school, for any age group. The population of the classroom could be homogenous, or as varied as they come. The teacher could be leading any sort of lesson, Art, Science, D&T, whatever. It might not be a classroom at all, but a P.E. lesson held outside or in a school hall. Now imagine that there is a small group of pupils, including some with Profound and Multiple Learning Difficulties (PMLD), who are mixed up within this class. Some are directly supported by adults, some are not. What sort of interactions would you expect to see?

Would you expect to see pupils with PMLD working alongside their peers on the same activities? Do you imagine some pupils being left isolated? Is it possible to expect pupils with PMLD to participate and contribute within a group of mainstream pupils? Is it possible that a child with PMLD could be valued and feel valued by their classmates in this setting? Is it possible for both groups of children to value their individual distinctiveness, and the commonalities they share with others? Do you even believe that a person with PMLD can be valued for their uniqueness, whilst still belonging to their group and sharing common values and experiences? And why should this be important? We believe that they can, and that this it is vitally important for all the pupils at our school to have this opportunity in order to go on to experience fulfilling and satisfying lives.

I have worked at the Frank Wise school for 10 years. Inclusion is central to our set of values, and directly informs how we arrange the school. Our pupils have a wide spectrum of special needs, with classes organised by age rather than ability or diagnosis. At the moment I teach in the 6th Family Group, a class of eight 10 - 11 year olds. They have a range of physical, behavioural, medical and learning needs. It might sound odd to have such a diverse group of children altogether, but we believe that we can deliver highly structured, differentiated learning to all children (including those with PMLD) within a community of their peers. We do this not because it is easy, or more efficient on staffing or resources. The fact is that it is neither. We do this because of a firmly held belief that it is not simply what our pupils learn, but the manner in which they learn it that determines how successful they are once they leave school. Pupils learn that it is normal to participate in their community with others, regardless of how different they make look or behave. We consider inclusion to be the process by which all pupils have equal access to an appropriate level of learning alongside their peers. All pupils have equal value, and all pupils can learn to appreciate the value of others. This includes pupils with

PMLD. We believe that children with PMLD can have meaningful, authentic, mutually beneficial friendships with children who do not have PMLD. Pupils with PMLD can learn alongside children of their own age who themselves have a wide range of learning needs. We plan and deliver lessons that fulfil the rights that pupils have to a broad and balanced curriculum, while simultaneously differentiating learning objectives, activities, timings and resources for each individual within the lesson. Pupils with PMLD share core experiences with their peers, while focusing on learning objectives specific to themselves. Simultaneously their classmates use and build upon the same core experience in order to meet their own learning objectives. These shared experiences form the basis of their relationships with each other. Pupils learn to view each other as contributors to their individual lives. Rather than mixing together like oil and water, in proximity but never combining, instead they become one 'Family Group'. They learn to appreciate how interacting with a diverse group of people can add value to their lives, irrespective of their level of ability. This is the first step towards becoming effective participators in the wider community, which will contribute towards their independence and self-confidence when they eventually leave school.

We all develop and grow as individuals through our life experiences. Our social circle, family, friends, school teachers, hobbies, trips, daily routines and interactions, all affect who we turn out to be. We develop self-knowledge through a variety of situations, good and bad, finding out our likes and dislikes, our goals and priorities. Experiences shape our attitudes and personality, and determines what we consider personal success. We believe that people with PMLD are no different, except that factors such as nonconventional communication, limited mobility and complex medical needs can limit their access and exposure to life experiences that we may take for granted. Unless we give them these opportunities, and enable them to access them fully, there is a danger that people with PMLD become passive

recipients rather than active participators in their own lives. Supporting people to physically and communicatively access opportunities is very different to enabling them to emotionally grow through the experience. And we believe that people with PMLD are capable of growing and developing as individuals, even if we have to explicitly teach them to do so at school by having mixed ability groups. We take the same approach to shared experiences at a whole school level, through curriculum days, assemblies and Christmas productions. All pupils learn to participate equally in whatever is going on, and by doing so learn to relate and grow as individuals.

For many years the school has fostered understanding and positive attitudes towards our students across the community, linking with local shops, services, businesses and schools. Pupils regularly learn to learn from and within the community, whether it be generalising Number skills at the shops or visiting the local pet shop in PSHE. 'Inclusion' is also the name given to the dedicated, protected timetable space when all classes join together with a mainstream partner school. This is for at least one morning or one afternoon per week. Activities are carefully planned and are National Curriculum-based, with mixed groups of pupils working together with staff and helpers from both schools. There is a genuine commitment on the part of the staff most directly involved and on the part of the management of the mainstream school to making it work. The philosophy must be right - it is an educational opportunity, not a patronising act of charity. Inclusion allows mainstream pupils and those with PMLD to see value in each other, to see each other not just as 'different' but as an individual that can be learned from in their own right. They might not articulate it in this way, but by sharing a moment, an activity, or a series of activities over the course of the year, all children learn to be better participators and contributors to society. While this is important for their mainstream peers, it could be argued as being more important to pupils with PMLD. The world does not easily revolve around them, so they need specific opportunities to adapt, accept change and connect with unfamiliar people and places. Most children learn this incidentally through long term exposure in a range of social contexts. It is much harder for children with PMLD to get these opportunities, unless someone else goes out of their way to make it happen. We hope that the lives they go on to lead are full of opportunities that require them to have had these experiences - full of meaningful occupation, relationships, self-advocacy and life satisfaction. My class participate in 'Inclusion' on a Tuesday afternoon, with the year 6 pupils at a local primary school. Some schools have 'done Inclusion' with us for decades, but this particular Inclusion link was only established last year. The response from the children (and their parents) has been fantastic. The children work together in groups on different projects, learning to

include and be included. This year we have learnt songs using Makaton and British Sign Language, made plasticine animations, filmed videos and enjoyed P.E. together. The activity is less important than the connections and insights that the children get from the experience - that differences in ability are a normal part of life. This is important because the greater knowledge children have of different ways in which people live, the better prepared they are for participating alongside them in life. It teaches them that in the real world everyone has to be able to adapt, and that being able to can enrich their lives in ways they didn't anticipate.

Helen was 4 years old when she met Katie at Greatworth Primary School. Katie was doing Inclusion with the year 6 class, but they would come out at break time to play. Helen remembers sitting in the corner in a particular place under trees and sharing her Doritos with Katie. For some reason, Katie would always have the corners of the Doritos, and Helen would have the middles. Helen remembers going home and talking about Katie all the time to her family. As a result, Helen's mum got in contact with Greatworth School and found out that Katie was from the Frank Wise School. Helen was obviously very happy and motivated to be with Katie, and so her mum requested that the school pass on their details to Katie's parents. From then on Helen and Katie grew up having day trips together, playing as equal partners, with Helen's sister and the girl across the road. They would go to the park together regularly, and Katie's mum increasingly looked after Helen and her sister in the holidays. Katie's severe learning difficulties, poor mobility and unconventional communication did not prevent her from learning to value Helen as a friend. It did not prevent Katie from feeling valued by Helen. It certainly did not prevent Helen liking Katie and sharing her company.

It is our understanding that inclusion is when you value the interaction, relationship and connection with others, for what they bring to your life or to 'the table'. People are all different, some more obviously than others, but to be inclusive is to appreciate others regardless (or even because) of these differences. This holds true for anybody, including people with PMLD. There are social barriers, but they can be overcome. This is our ultimate aim with Inclusion. It starts in our classrooms and expands out into the wider community, beginning at an early age and producing lasting effects right into adulthood. Twenty years on, Katie and Helen continue to be good friends. Helen now works at the Frank Wise School as a classroom assistant, and begins her initial teacher training in September 2015.

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Julia Barnes writes:

I came to know Penny when I enrolled on the Masters course (Severe, Profound and Complex Learning Difficulties) at Birmingham University. I had previously been unaware of her research and understanding of the world of SLD/PMLD.

Penny was an engaging and knowledgeable lecturer. Her softly spoken voice and entertaining anecdotes live on in my memory. Penny made us feel that anything was possible from writing an entirely new curriculum to developing a method of assessing pre-reading skills. Penny was interested in my work, supportive of my research and encouraged us all to take the steps necessary to have our work published and to aspire to changing practice for the better. It was not until I started reading and researching that I saw how often Penny was credited in a range of documents from the developments of SCRUFFY targets, to teaching thinking skills and multi-agency working. Her name often featured on replies to people's queries on the SLD forum. Just where did she find the time? I can only think it was her commitment and drive that made it all possible.

Having finished my Master's course I was invited to contribute to her latest book. I first attended a meeting with around 30 of the writers and marvelled how Penny chaired the meeting. She was welcoming and approachable and made sure everyone had the opportunity to speak.

However, my favourite memory of Penny was watching her walk up the central aisle during our graduation ceremony. Wearing her hat and gown, her well-worn trainers could be seen peeking out from beneath the hem! It made me smile at the time and it continues to make me smile each time I think of her.

Self-injurious Behaviour in Cornelia de Lange Syndrome

Mel Bullivant

Alex is an 18 year old young man in my Post-16 class of individuals experiencing PMLD. He enjoys swimming, spending time in the Multi Sensory Room and, most of all, he absolutely loves any activity involving food! He has a range of non-verbal vocalisations including laughing, giggling, humming, deep, throaty sounds and crying. He can indicate preferences by eye pointing and gesture, he anticipates some routines and is beginning to engage in interaction activities with an adult.

Alex has the condition Cornelia de Lange Syndrome (CdLS). This is a rare genetic disorder which is characterised by a number of physical features including a low birth weight, small build and head size, arched eyebrows and severe gastroesophageal reflux, as well as developmental delay and behaviours ranging from compulsive or repetitive behaviours to self-injurious behaviour (Rojahn et al., 2012). Studies have found that between half and two thirds of individuals with CdLS have some form of self-injurious behaviour, the most common of which is hand-biting (Basile et al., 2007). When I began teaching Alex, his hand-biting occurred daily and was severe in its intensity.

Functional Analysis Of Self Injurious Behaviours In CdLS

In order to attempt to help Alex overcome his self-injurious behaviour, I conducted some research in Functional Analysis (observing what happens before and after a behaviour in order to find out why it occurs). In their presentation of the history of Functional Analysis and Applied Behaviour Analysis, Dixon et al. (2012) note that an understanding of the function of behaviour when planning ways in which to treat it is now considered to be essential practice, although this was not always the case. Three areas of Functional Analysis (Carr, 1977) have been useful in determining some possible reasons for Alex's hand-biting.

Positive Reinforcement

This hypothesis suggests that self-injurious behaviour is developed because of the positive attention resulting from it. Several studies of individuals with CdLS have found that giving positive attention at other times had the effect of reducing the level of self-injurious behaviours (Johnson et al., 1976; Menolascino et al., 1982; Berney et al., 1999; Sloneem et al., 2009). After working with Alex for a number of months, it became clear that he has a range of meaningful vocalisations which he uses to communicate his feelings and needs. He



uses a particular vocalisation to request attention after he has been alone for a period of time. Before I began putting interventions in place, I noticed that if these vocalisations were ignored, other compulsive behaviours increased, such as flapping his arms and slapping his leg. If he continued to be ignored, this often led to hand-biting. At the point when hand-biting occurred, he would then receive attention from staff, who would attempt to stop him by talking to him and bandaging his hands to prevent further injury. I soon learned that, if this particular vocalisation was responded to by giving him some attention, he would quieten and hand-biting would not occur. Oliver et al. (2003) state that this process has led to self-injurious behaviour being described by many

as a form of communication because it affects the behaviour of others in the same way as communication can.

Negative Reinforcement

Self-injurious behaviour may occur because an individual wants to avoid an aversive task and has learned that such a task will be withdrawn when the behaviour occurs. A study by Steege et al. (1990) found that hand or arm biting in two children, occurred during grooming tasks and was decreased upon withdrawal of tasks. Oliver et al. (2003) cite an example of a young man with CdLS who most often self-injured when demands were made of him, such as to take part in certain activities or to move to a different place. Alex's parents have told me about occasions where he has self-injured during times when he has needed to have a hair cut or trim his nails. Knowing this has helped me to ensure that I listen to Alex's vocalisations or interpret his use of body language to communicate his willingness to participate in tasks in the classroom situation. When he indicates a preference in this way, I adapt the task to something which he is comfortable participating in. It is very important to ensure that individuals experiencing PMLD are given as much control as is possible: when there is a lack of learner control then self-injurious behaviours are likely to develop as a response.

Self stimulation

An individual may display self-injurious behaviour and/or other 'stereotyped behaviours' to seek sensory stimulation which is lacking in his or her environment. In the case of individuals with CdLS, Oliver et al. (2003) refer to both the 'pleasant sensations' which may result from self-injury and to the alleviation of pain which it may bring. Regarding sensory reinforcement, in their 1980 study, Horner et al. concluded that 'maladaptive behaviour' was lower when toys and other objects were present in the environment, sometimes in conjunction with reinforcement of appropriate use of these by adults. In his 1993 open letter to doctors treating patients with CdLS, Dr. Gualtieri wrote that many of the compulsive or self-injurious behaviours seen in young children with the syndrome are forms of self stimulation which will disappear once they find other means of 'amusement'. Gualtieri also referred to the possibility of self-injury to alleviate pain or discomfort, as a type of 'auto-acupuncture'. Moss et al. (2005) note the association between challenging behaviour and gastrointestinal reflux which has been found in a number of studies, indeed one of the participants in their study stopped his self-injurious behaviour immediately following an operation to correct his reflux. As noted above, gastrointestinal problems are common in individuals with CdLS so the relief of the pain associated with these may be seen as a possible cause of self-injury.

With regard to Alex, in order to test the self stimulation hypothesis, I conducted an observation of him for two five minute periods, one in which he was alone with no interaction and the other in which he was interacting with a staff member. When alone, Alex engaged in some form of self-stimulatory behaviour (including hand posturing, chewing his hands, tapping his leg, turning his head, flapping his arms and blowing raspberries) for a total of four minutes 34 seconds, or 91% of the time. In the second observation, during which he was interacted with for the entire period, Alex engaged in self-stimulatory behaviours for only a total of 1 minute 47 seconds or 36% of the time. Due to the close link between self-stimulating and self-injurious behaviour (Hyman et al, 2002), this may seem to suggest that self stimulation may be a factor in his self-injurious behaviour. When learners are cognitively engaged, self-stimulatory behaviours are much less likely to develop. When learners are given control over their experiences, they are likely to be more engaged, hence reducing even further the likelihood that self-stimulation will be necessary.

Summary

My research helped me to discover some of the reasons for Alex's self-injurious behaviour, including a need for attention, a form of communication, to escape from task demands and as a form of self stimulation, sometimes because of pain or discomfort. Interventions I have introduced to support Alex include the use of Intensive Interaction to develop his communication skills, giving him positive attention when he is not self-harming, interpreting and responding to his different vocalisations and ensuring he is engaged as much as possible during activities. I have seen a dramatic decrease in Alex's self-injurious behaviour during recent months, which now occurs very infrequently. I strongly feel that learners with PMLDs should experience a responsive environment because 'it is by interaction with other persons that we become persons... (experiencing an) interactive environment teaches us that we are valued and respected' (Ware, 1996). When pupils are responded to appropriately, this may lead to a reduction in self harming behaviours. I am also very interested in the possibility that reducing the amount of time that pupils spend 'waiting', without interaction, in my classroom will also lead to a reduction in other self stimulatory behaviours (which are prevalent in over 70% of my pupils). I intend to investigate this further in the future.

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Annie Fergusson writes:

Her legacy will now be with all of us, to continue to be inspired and enthused, to be innovative and reflective of what we think and do - but ultimately, to make a real difference to individuals with severe and profound learning disabilities. Thank you Penny x



Soundbath An Innovative Approach to Music with Children

Alan Wylie

Special schools are uniquely musical places. Each day is punctuated by music. Music welcomes the children – a different piece each day to help them to make sense of and to sequence their week. The ubiquitous welcome song before lessons start – ‘Let’s get ready to work’. Music indicates the end of a session and the start of break. ‘It’s dinner time I’m hungry now!’. ‘It’s time to stop now. It’s time to go’. ‘Sing Goodbye to’

Researchers have found that the more accomplished the musician is, the greater the positive responses and engagement of the children with PMLD. Most classroom staff are non-musicians and those who have a little music experience are in awe of therapists and qualified staff. In light of the findings where does this leave us mortals?

We mostly sing to our pupils and play recorded music. The special schools who are lucky enough to be able to employ a music teacher or music therapist will find that they introduce different and other dimensions to the musical experiences of the children.

I was looking for ways in which to make my music teaching more exciting and relevant to my youngsters who have complex needs but also make the most of my limited skills as a musician. I scanned the internet, shopping for suitable courses. Eventually I found something I thought had real potential but worried about using the technique in the form it was usually presented to adults.

Music Therapy appeared at the top of the searches. I am very familiar with Music Therapy and have had the privilege to work alongside some outstanding practitioners but I’d need another lifetime to play at the



required standard. I play piano like I type, with two fingers. I stumbled across Sound Therapy a little further into the search.

I liked the thought of an holistic approach to sound and enrolled on a 'Sound in the Community' course from the British Association for Sound Therapy (BAST). This would qualify me to use sound as a therapy with groups of people – groups of children perhaps? I had little idea what I was letting myself in for. Like most people I am aware of the ability of music to relax, invigorate, its effect on the emotions and its capacity to bring memories to the front of the consciousness. However I was not prepared for the power of sound. On the first evening we were treated to a 'soundbath' – an immersive experience of sound which was intensely relaxing but equally an invigorating and profound experience. Lying comfortably we were treated to an hour of exotic sounds carefully chosen for their ability to relax and create a deep sense of security and comfort. Himalayan bowls played like bells then made to sing using felt wands. Huge, sonorous gongs and bowls made of pure quartz crystal that produce a haunting but reassuring sound. Finally we were brought back to the real world by percussion played rhythmically and with increasing volume. I was genuinely sceptical at first. I remember lying there



wondering what on earth I'd let myself in for and wishing I could see the instruments that were being played. I could also hear snoring and remember thinking 'Oh dear, someone's fallen asleep' - it was me! Over the next 12 months we were shown how to use other instruments, all in a therapeutic way following the basic principles of sound therapy developed by the BAST. I loved the experience but knew this was not suitable for our youngsters with complex needs because they have no way of giving their consent to such 'treatments'. If adults find they don't like the sounds or the feelings that are created during the soundbath, they can simply refuse to take part or get up and leave the room.

However, the course had introduced me to a range of new instruments that produce amazing sounds and beautiful effects when played together AND no musical skill was needed to play them. I set about putting together a set of 'sound tools', starting with Himalayan bowls, wind chimes, dream chimes, wah-wah tubes and an old zither. For contrast I used thunder shakers and a small but powerful gong. Rain makers and percussion provided the grounding part of the soundbath at the end. I put together a sequence of sounds that followed loosely the suggested format of the soundbath for adults but avoided using the specialist techniques that would establish deep relaxation. I briefed the staff and then led a session.

I tried to make sure we had a clear uninterrupted 45 minutes. All personal care and medical intervention was out of the way. A sign on the door warned visitors not to interrupt!

We started with a moment of calm. A single Himalayan bowl was struck, taken around the room and then placed with a Teaching Assistant (TA) who continued to play. Gradually more bowls were introduced. The TAs played for the individual pupils, moving between them, allowing them time to respond and all the time contributing to produce an overall beautiful sound. The striking of the bowls was gradually replaced by the sonorous singing of the bowls being 'wanded'. The soundbath then continued with the introduction of the challenging sounds of the thunder shakers and the gongs which in turn were replaced with the melodic sounds of the chimes in combination with the zither. The rain makers began the last part of the session, shakers and percussion joined in and a rhythm was established. The speed and volume of the rhythm increased and then suddenly stopped, plunging the room into silence.

After a few seconds the staff started to applaud. There were quite a few tears too!

The reactions of the pupils had been amazing. The staff said they had not seen engagement like it and we then



knew we had stumbled on something very special.

The challenge was now to refine, formalise the approach and test it out with other groups. We established a general format for the soundbath, a recording sheet on which to score the intensity of response and also record 'sparkly moments' at the end of each session. Each assessment sheet included details of the pupil's individual target taken from their Personal Learning Plan (PLP). The soundbath continued to motivate and engage both pupils and staff.

The session was repeated with different classes and a similar intensity of response was recorded. I had the opportunity to introduce Soundbath at Saxon Hill School in Lichfield and Ivy House School in Derby. It quickly became a favourite activity and is now included in the repertoire of activities that are presented to their pmlD groups each week.

"It has been a wonderful addition to our new sensory curriculum. It fills a gap, focussing on the emotional wellbeing of our pupils."



"Soundbath and its 'structure' allows for pause and burst within the session with contrasting elements that include periods of calmness and reflection. Soundbath is also a 'pause' in the curriculum with other activities offering the 'burst'."

"Soundbath is one of the best things we have ever implemented in school. The staff all look forward to it each week. It has brought us closer together as we have had to listen to each other carefully. Staff are calmer and more relaxed too."

Comments about individual pupils have consistently included reference to them responding to the calming nature of the sound. One parent reported that her daughter slept through the night following a soundbath. Some very interesting observations have been made about the engagement of pupils who have sensory impairments. The teacher for the hearing impaired said she had never seen one pupil engaged in any activity for such an extended time. This boy had no hearing in the conventional sense due to fusion of the bones in the middle ear.

The challenge now is to try and understand why the soundbath approach is proving to be such a successful technique. Staff have noticed that the children are more content, relaxed and less stressed during and following a session. We are well on the way to being able to suggest soundbath positively promotes well-being.

The approach introduces the powerful motivator of sound into intensive interaction sessions. This could mirror some of the successes music therapists achieve through the use of their advanced music skills when trying to promote interaction.

The instruments are attractive and the sounds they produce are unusual and stimulating. It could be that the activity is new and the novelty value sustains the interest of the pupils, although our initial data shows responses remain with the pupils beginning to anticipate the changes and begin to still within seconds of the start of the activity.

During a soundbath staff work closely with one pupil and then move onto the next. In the pause between this intensive interaction the pupil continues to experience the beautiful sounds created as they await their turn. The sound could be helping to hold the attention of the pupil during the 'down time' before the TA returns to work with them intensively.

I have a feeling that some of the success is due to the effect the sound has on the staff. Some recent research has shown that during music therapy sessions similar physiological changes occur with both the client and the

therapist. The same seems to be happening here. The staff have a complex task, they have to interact with the pupil while listening to the overall sound. They have to work together to create the music. They are listening, responding and anticipating what should come next. The responses and comments of the staff are very similar to those of adults who have undergone conventional sound therapy sessions – and they are creating and playing music together!

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Sana Rizvi writes:

I am truly and deeply saddened that I have lost my most dear mentor. To me, she was a teacher, a friend, a mentor, a constant source of support, a font of ideas, a shoulder to cry on, a brilliant academic and a great human being. She always gave a lot more to others without any expectations and was always modest and humble. Penny has been an inspiration for me personally but she has never appreciated the huge influence she has had on my career, which is typical of her - always modest.

Nicola Grove and Openstorytellers write:

“In 2009, just as the charity was becoming established, a small group of us (Brian, Fiona, Vicki and me) were fortunate enough to be invited to Birmingham to work with the library service. We were welcomed and hosted by Penny, and spent a wonderful evening in her home as guests of herself and David. I know I speak for us all in saying that we remember her warmth and hospitality and how great it was for us all to be accepted as friends and colleagues. It was a beautiful summer evening, and the garden was full of flowers. Penny's smile, her gentle, musical voice, her passionate commitment to helping children with learning disabilities to be real participants in society rather than sitting on the sidelines, will never be forgotten.”

Implementation of Routes for Learning and SCRUFFY Target setting

Jennifer Quibell

This article describes a study which investigated whether the implementation of Routes for Learning (Welsh Assembly Government, 2006) and SCRUFFY targets (Student-led, Creative, Relevant, Unspecified Fun For Youngsters), or those developmentally young, (Lacey, 2010) had an impact on the learning of students with S/PMLD. The research was done as part of my Masters in Severe, Profound and Multiple Learning Difficulties (S/PMLD) and therefore I was limited to doing all the research and writing it up in the space of one term.

I work in a mainstream college, which has a learning support department which provides courses for students with S/PMLD, and we currently have about 35 students with S/PMLD aged between 16 and 25. In the past it has been a challenge to successfully assess students with the most complex needs and write SMART (Specific, Measurable, Achievable, Realistic, Time-bound) targets for them, so the research offered an opportunity to try something different that might suit these students more adequately. The students who were identified for the research needed to use the skills they are learning far more generally so that they are functional rather than merely being able to demonstrate a specific skill in a specific environment. Their needs seemed to be better supported by having SCRUFFY targets. Some students also tended not to be very motivated to work on their targets and therefore it might be suggested that they make less progress because of this.

At the beginning of January 2014 a small group of students was assessed using 'Routes for Learning'. I then wrote SCRUFFY targets for seven students. Previously the students had been assessed using the assessment method we use with the rest of the students with S/PMLD and had a set of SMART targets. I also asked staff who were involved in this work with the students to complete a questionnaire about SCRUFFY targets. I asked a range of staff to complete these: from the Learning Support Assistants (LSAs), who have implemented many of the plans during 'keyworker sessions', to the manager of the department. (Students work on targets each day in keyworker sessions with an LSA who works closely with them). I decided to do this so as to give me an indication of how successful different members of staff believed that the SCRUFFY targets were and how much progress the students seemed to be making.

There is likely to be a number of inaccuracies within the research for a number of reasons. The sample group of

seven is too small to draw any definitive conclusions as to whether SCRUFFY targets allow for greater progress and development than those students on SMART targets. The results can only give an indication as to whether this might be so. There was also the considerable time constraint. This has meant that there has not really been enough time for definitive results to become clear, especially so, when you consider the level at which the students are working and how long it takes them to make progress. Another possible inaccuracy may have arisen from the fact that staff carrying out the 'Routes for Learning' assessment were not very experienced in doing this and, if we started using 'Routes for Learning' on a more regular basis, they would need further training and practice. Similarly, staff had only limited training about SCRUFFY targets before I expected them to be implemented. For them, it was a totally different way of working towards targets as it is much less prescriptive and meant that the staff had to be far more imaginative as to what the students could do, instead of working on very similar things all the time.

I discovered that 'Routes for Learning' was very useful for some of these students; but less so for the more able students within this group and it might be argued that we are in need of something which bridges that gap in between the 'Routes for Learning' and the current initial assessment method we use. It did suit our most impaired students better than the method we employ currently. 'Routes for Learning' has definitely identified some "activities" which the students can't do and which they could be working on. For example, one student seemingly has no idea of object permanence, so bringing in some activities surrounding this may be useful.

I used a questionnaire with the staff that helped me complete the 'Routes for Learning' assessment. The general consensus seemed to be that they found it easier to do, once they totally understood what they were

meant to be looking out for at each stage. However, those who completed the questionnaires agreed that it would only be useful for those learners with the most complex needs and was not relevant for more able learners.

SCRUFFY targets largely seemed to have some success. Generally, having observed students undertaking their “target work”, they seem to be more engaged in work identified from SCRUFFY targets. This might be because they aren’t necessarily doing the same thing over and over again. 80% of the staff who completed the questionnaire agreed that students seemed to be more engaged when working on SCRUFFY targets. The students are getting more choice as to what they want to do and more opportunities arise to “practice” their targets as this can take place at various times throughout the day. This may be in lessons, in the canteen at lunchtime, in “target time” or even whilst they are doing physiotherapy. It also may be surmised that some of the LSAs are more enthusiastic about working towards these targets with the students as they aren’t getting the student to do the same thing over and over again.

Extremely early indications show that SCRUFFY targets are having a positive effect on progress. There seems to be lots of “firsts” occurring: for example, one student (who we shall name Emily) was looking through a pile of photos and then came out with “there are only 3 of me here”. Emily is very motivated by pictures of herself. This is something that she would not have done a month ago. She was very skilled at counting from 1 to 10 by rote, but her SCRUFFY target was to actually use these numbers functionally and she has been practicing this a great deal.

Of those staff who responded to the questionnaire, 90% thought that SCRUFFY targets allowed students with PMLD to make more progress than SMART targets do and over 50% of respondents thought that it would probably allow students with SLD to make more progress. Staff believed that both SMART and SCRUFFY targets are fairly “administratively burdensome” (Male, 2000). It is probably true that the amounts of record keeping surrounding both sorts of targets are probably about the same, but records do need to be kept so progress can be tracked and students can have new targets when they have achieved. Having now written targets in both forms, I think it is fair to say that both have their challenges. SCRUFFY targets do take a fair amount of time to write as you need to give some idea of the student’s difficulties and needs and then come up with plenty of activities which can be done with the student to meet his/her target. I can imagine that once you have written a number of targets you can start to reuse the targets and ideas with different students whose needs suggest similar goals. Staff didn’t really come to a consensus as to whether the SCRUFFY targets were easier to write or not. Probably because they had

not been given the chance to try and write them themselves but have only seen what I have done. It also became clear that most staff thought that SCRUFFY targets were “easier to do” with the students; 75% believed that this was so. On the surface they probably are easier to set if you are fairly creative and can think of activities which will develop a target. However, there is the possibility that some members of staff may struggle to come up with suitable ideas.

Having now carried out this preliminary research I would like to do some more in-depth action research in the future. I would endeavour to pilot and collect data for a full year so that the students’ progress could be tracked for longer to give a clearer indication of their achievements. I would also have another group of students of similar ability and needs working on SMART targets at the same time, so that some comparison could be made between the two groups.

The introduction of SCRUFFY targets into the department seems to have had a positive effect on the students’ progress, although a definitive conclusion is very difficult to draw. In some cases it might be appropriate for some students to have some SMART and some SCRUFFY targets. I hope that we will continue to use SCRUFFY targets with those students within the department who may benefit from them. ‘Routes for Learning’, as an initial assessment tool, has also seemed to have been useful in the assessment of some students with the most complex needs. ‘Routes for Learning’ has given us a better picture of what some of our learners with the most profound learning difficulties can and cannot do. Therefore, this tool has given us ideas on what we could try with them next and therefore will continue to play a part in planning their individualised timetables.

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Martin Goodwin says:

As a student I wanted to know more about working with people with PMLD and as part of my university module a book of Penny's was recommended reading. I had worked briefly with people with PMLD at that time, and her book brought new ideas to my attention. Many years later, and after many interactions with people with PMLD and SLD, I now appreciate even more the depth and breadth of knowledge, insight and skill that Penny had. The catalogue of books that she authored, co-authored and edited, including her most recent, is a testimony to her insight, skill and passion. I am sure that her latest book, *The Routledge Companion to Severe, Profound and Multiple Learning Difficulties*, will be as well thumbed!

Having been in awe of Penny's knowledge and approach, I was somewhat surprised when she asked Cath Edwards and me to write an article for PMLD Link, 'I'm Creative Too!' about utilising creativity and a listening and responding approach (Spring 2009, Issue 62, 11-19) and to facilitate a seminar at the University of Birmingham. Penny was very kind and freely supported a national pathfinder project in conjunction with Solihull Council that supported the development of provision for children and young people with PMLD.

Penny very kindly spent time commenting on my book 'Communicate with Me' (co-authored with Jennie Miller and Cath Edwards soon to be published by Speechmark [<http://www.speechmark.net/search/Goodwin>]) and provided encouragement and critique that greatly aided the direction and message of the book. Penny was committed to enabling people who work directly with this group to articulate their views and experiences, breaking down barriers to research and leading bottom-up research by valuing practitioner insight.

In getting to know Penny my admiration for her grew. When faced with an issue concerning people with PMLD/SLD, I would find myself asking 'What would Penny say or think'? Penny's legacy will continue to inspire.

Penny Lacey's Contributions to Improving Teaching and Learning for People with PMLD

Rob Ashdown

As made plain in the articles by Jill Porter and Christina Tilstone, Christopher Robertson and others in this issue of PMLD LINK, Penny Lacey conducted rigorous research and wrote extensively on many aspects of the education of children and adults with PMLD. She had an ability to set down in writing her experience and others' experiences in a way that was accessible to all. This article is intended to remind readers of her articles for this journal and use them to illustrate the innovation and breadth of her work.

Working Together

One of Penny's enthusiasms was promoting working together by people from different agencies with parents of learners in an organised manner. She viewed this as crucial, especially for learners who have complex disabilities and needs which require many people to be involved in their education and care. However, she was acutely aware that effective joint working is difficult to achieve and in various writings she discussed why that is so and explored what kind of strategies can be used by practitioners. In one article (Lacey 2006a), she described a familiar scenario in a school setting where more than 20 people were involved in contributing to the well-being of one young pupil with PMLD. She identified effective ways of working together from this particular example. She was plain that 'Unfortunately little can be done to improve the integration of programmes without time being set aside for teachers and therapists to talk and work together', but still upbeat saying that 'Change can be painful but oh so rewarding!' (Lacey 2006a, p.9) Recently, she noted that joint working has been discussed and researched since the 1960s but the research evidence for the effectiveness of joint working is still small and mainly related to health and care services working together. Nevertheless, Penny rightly concluded that joint working should be 'the Holy Grail' for agencies and practitioners even though policy, funding and regulation structures often set up unintended barriers to the collaborative work required (Lacey et al., 2015a).

Inclusive Literacy and Inclusive Libraries

The term 'inclusive literacy' was used by Penny (Lacey 2006b, 2006c) to denote literacy in its widest sense. Penny was concerned that schools were adopting uncritically a mainstream approach to the teaching of literacy which was not suitable for learners with SLD or PMLD. Drawing on research into literacy practices within

special schools by herself and colleagues, Penny discussed the implications for learners with PMLD and their teachers in particular (Lacey 2006b). Literacy activities should include sensory stories and multimedia stories, photo albums and scrap books, reading icons and symbols, simple conventional and picture books, television and films, visiting interactive websites, and using digital media. Ways of sharing stories should not just focus on a book, although the story may originally have come from a book. The multi-sensory experience of storytelling should involve objects to touch, look at, listen to, smell and even to taste. Stories may only be a few sentences long, with each sentence being repeated several times to help the learners to become familiar with them and learn to anticipate what is coming next.

During childhood, schools are usually the main place for inclusive literacy activities and, in some areas, colleges for young adults. For most adults, however, Penny realised that there is often nowhere other than the public library to access books and computers. This is due to the demise of day centres and attempts to improve the daytime opportunities in the community. Penny and colleagues worked with librarians in an action research project to enable them to meet the needs of people with SLD and PMLD (Lacey and Smith, 2011). They were conscious that inclusive literacy requires much more than a good stock of picture books or specialist resources such as 'Story Sacks' or 'Bag Books'. Therefore, they trained library staff to support these people in a range of inclusive activities.

Music Activities

In an article on composing for learners with PMLD (Lacey, 1998), Penny insisted that she was no music specialist, just an enthusiastic amateur whose love of music was enormous. She believed that good music activities could be delivered by non-specialists without

any special musical ability. She argued that learners with PMLD, if given the right support, resources and sufficient time, can compose simple improvisations or short pieces and that these can be recorded in a variety of ways. Elsewhere she voiced her concerns that music might become a Cinderella subject in the school curriculum but set down a rationale for teaching music, detailing the cultural, social and learning opportunities, and provided examples of how even youngsters with profound learning difficulties can learn through music (Lacey, 2001b). She stressed that the arts should not just be viewed as an opportunity for learners to relax and enjoy themselves. Too often, she felt, music might be just a sing-song with drums and tambourines used to fill in moments between 'real work' and that many people in special schools did not take music very seriously as a subject in its own right. In contrast, she was plain about the need for careful planning and organisation of music activities. She stressed that it is always better to have a smaller number of good quality instruments than lots of poor quality. Although Penny was clear that music therapy should not be confused with classroom music activities, she claimed with some justification that music could be taught in schools in a therapeutic manner.

Interactive Approaches

Penny was not a proponent of the narrow, prescriptive, teacher-led activities derived from behaviour modification approaches that featured in special schools until the mid-1980s. Instead, she was very much in favour of interactive approaches that took place in stimulating learning environments and involved activities which were flexible enough to allow for learners to initiate and even change the direction of activities and for their responses to have an influence on future planning. For example, very recently she wrote about the importance of a well organised, stimulating and responsive learning environment (Lacey et al., 2015b); with Mark Collis she produced the book 'Interactive Approaches to Teaching' (Collis and Lacey 1996); and she called for a long-overdue return to the teaching of learning and thinking skills and appropriate assessment practices (Lacey, 2009a, 2009b).

Famously, Penny asserted that learners with PMLD are poor 'consumers' of the SMART targets (Specific, Measurable, Achievable, Realistic and Timed) associated with more prescriptive, teacher-led approaches (Lacey, 2010). She instead proposed SCRUFFY (Student-led, Creative, Relevant, Unspecified, Fun, For Youngsters) targets. She did not shirk rigorous planning of activities but stressed the importance of 'Strengths and Needs' analyses based on careful observation and evidence involving those who know the learner well. It is a measure of the importance of this 2010 paper that it has been reproduced in the Spring 2015 issue of The SLD Experience journal.

Provision for Adults

Penny was also interested in the provision for adults. With Sally Miller she wrote an article about a young man (actually a member of Penny's family) to demonstrate that, with determination, personalised supported living is possible, even for people who have very severe or profound learning disabilities (Miller and Lacey 2007).

Penny was asked to write one of a series of guide booklets for Mencap's 'Raising our Sights' campaign. Her comprehensive guide for planners and providers is called 'What People do in the Day'. (To read about 'Raising our Sights' and to download all the guides, go to: www.mencap.org.uk/raisingoursights). In an explanatory article for PMLD LINK (Lacey 2010), Penny focused just on the communication and interaction opportunities described in the guide as these skills are so fundamental. She articulated both principles and specific ideas for interactive activities that are likely to engage people with PMLD, covering such topics as Intensive Interaction, ways of sharing stories and the value of theatre experiences that are lively, noisy and engaging.

Academic Teaching and Research

Penny was a hardworking and valued lecturer for a lively professional development programme for people interested in the education of learners with SLD and PMLD. She was passionate about doing research that would make a difference to the lives of people with PMLD. Christopher Robertson, Jill Porter and Christina Tilstone, and others in this issue show how Penny did much to encourage her students and others as researchers and to publish their findings. She maintained that all practitioners have it in them to do useful research as shown in her article for TAC Interconnection which was abridged for the most recent issue of PMLD LINK (Lacey, 2015). She promoted the view that action research is so much more than the 'reflective practice' which might reasonably be expected of all practitioners; crucially, she argued, what transforms reflective practice into action research is collecting and analysing data systematically and then sharing the process and results publicly. This typified her own research practice.

Penny's concern about the lack of an appropriate UK textbook and source of ideas for practitioners meant that she became the prime mover, inspiration and lead editor for the recently produced textbook, 'The Routledge Companion to Severe, Profound and Multiple Learning Difficulties' (Lacey et al., 2015c). From her own contributions to this book and other writings referenced elsewhere in this issue it is clear that she believed that there is much that is positive to trumpet about what is going in schools and other settings. However, Penny was concerned about inequalities in provision and services for learners. For instance, she did research for the UK charity

Mencap to inform its vision for an effective education for children and young people with learning disabilities for the next 10–20 years (Lacey, 2011). She found considerable variation in the educational provision and resources (physical and human) for learners with SLD and PMLD across the country.

Conclusions

For all of her professional life, Penny campaigned for some basic entitlements for all learners with SLD/PMLD:

- appropriately trained professionals (teachers, support staff, therapists and others) who are willing and enabled to work together with the learners and their families to achieve the best possible outcomes for them;
- curricula and teaching approaches that are tailored to learners' specific individual needs;
- offering learners opportunities to participate in meaningful and engaging learning experiences;
- ensuring that learners have full inclusion in their learning and social communities, whether those be specialist or mainstream settings.

Penny's life was cruelly cut short at a time when she was pursuing further projects directed towards these goals and still had so much more to give. Nevertheless, her major achievements should not be forgotten and they provide us all with the direction and methods to pursue these basic entitlements for learners and their families.

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Dave Hewett writes:

Penny had greatness in every gentle, considered thing she did, professionally or personally. We have lost a great thinker and a guiding light. The world is lessened today

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**Articles by Penny Lacey
in PMLD LINK**

**Winter 1998/9 No. 32 Vol. 11.1 Theme Music,
Movement and Dance**

Composing with pupils with PMLD

Spring 2006 No. 53 Vol. 18.1 - Working Together

Integrated Programmes in Schools

**Winter 2006 No. 55 Vol. 18.3 - Changing
Perspectives**

Inclusive Literacy

Spring 2007 No. 56 Vol. 19.1 - Adult Years

Personalised Supported Living for Peter by Sally
Miller, Penny Lacey

**Summer 2008, Vol 20 (2) Issue 60 – Community
Partnerships**

Inclusive Libraries Research Project

**Summer 2009, Vol 21 (2) Issue 63 – Sharing
Perspectives**

Developing the thinking of learners with PMLD

Winter 2010, Vol 22(3) Issue 67 - Lifelong Learning

Inclusive libraries in practice by Penny Lacey and
Penny Smith

Vol. 24 (1) Issue 71 – Life is for Living

What people do in the day

Winter 2012, Vol. 24 (3) Issue 73 – Technology

Low tech ideas

Spring 2015, Vol.27 (1) Issue 80

Action research: when the practitioner becomes the
researcher

We Welcome any Contributions to PMLD Link

We are very flexible in our requirements for contributions to the PMLD LINK journal.

Articles are usually between 1 and 4 pages of A4 single-spaced, regular font size. This usually equates to between 350-1500 words. However we are happy to accept shorter or longer pieces. Ideally, we want you to have the opportunity to discuss what you want, rather than tie you to a fixed number of words.

Our readers are family members, carers and a range of professionals working across child and adult services, so any specialist terms used should be clarified. Articles vary from those with a research/academic focus to those that are very practical in nature. It is useful to include references and contact details to enable readers to follow up information – and they do!

As this is the only journal dedicated to people with PMLD, it is important that your article is specifically related to them. If appropriate, give examples of the work in practice and how it could be applied elsewhere. We can include images, photographs or samples of materials, which will appear in black and white only, if this is appropriate and where relevant permissions are given. Please send a completed consent form with your article (downloadable from the PMLD Link website).

We also welcome short informative pieces about new resources, books, websites, events, courses and news in general.

Email: pmlmlink@gmail.com

This article by Penny Lacey originally appeared in PMLD LINK, Issue No 32 (Winter 1998/9), pages 25-27

Composing with Pupils with PMLD

Penny Lacey

When I work with teachers on music workshops and in schools, they are often at a loss when thinking of ways to involve pupils with PMLD in composing. The National Curriculum Orders for Music refer to improvising and organising sounds in ever more complicated structures which, at first sight, seem out of the reach of pupils who have complex disabilities, one of which is profound intellectual impairment. There appear to be lots of decisions for a composer to make as well as physical manipulation of instruments to make the music come to life. I certainly do not underestimate the difficulties that teachers and pupils face, but I would like to share some of the ideas I have which are based on experience which spans nearly thirty years in special education. I would just like to add that I am no music specialist, just an enthusiastic amateur whose love of music is enormous. All the ideas I come up with in this short article should be accessible to non-specialists and I do not assume any prior musical ability, though perhaps basic knowledge based on current practice in schools.

Firstly, it would be helpful just to consider what might be the essence of composing in music. This can be helpful when trying to figure out how pupils with PMLD can be involved. Music is about sounds and patterns of sound and composing is about putting these sounds together into patterns which may (or may not) be different from the way in which other people have put them together. Composers usually have some way in which to record their music, either onto paper of computer or directly onto a tape recorder. Usually the composed piece can be played again and again but sometimes, as in improvisation, music is composed on the spot and is gone, never to be played in quite the same way again. According to the National Curriculum improvisation is an important aspect of composing and this might be a good way into composing for pupils with PMLD. Strictly improvisation is a skill which uses previous musical knowledge to enable the performer/composer to experiment freely with notes and rhythms within a piece but the element of freedom with sounds can be useful in the context of pupils with PMLD.

Example

Choose a set of notes on a tuned instrument such as a xylophone or chime bars which are pleasing to the traditional ear. Try the pentatonic scale (CDEGA) or notes of a chord such as CEG or DFA or if you are feeling more adventurous (and have the notes) try the whole tone scale (CDEF*G*Bb). Encourage experimentation with the sounds in an improvisation. If possible always use two beaters but that may be impossible for some pupils with PMLD. Record the piece on a tape recorder and play it back to 'the composer'. Talk about using the sounds

made and encourage more improvisation.

You could try to encourage experimentation if this becomes a partnership enterprise either with you or with a more able peer. Practice copying each other and having a conversation on the instrument. Remember that improvisation is usually not repeated so compositions can be as wild as the pupil/s like.

Improvisation does not have to be with tuned instruments. Setting up a small bank of unpitched percussion in front of the composer can encourage experimentation with a variety of sounds. There are many very interesting instruments around at the moment.

Example

Choose three or four instruments which have very different timbre (quality of sound), such as a drum, a woodblock and a gong. These all require hitting but yet produce very different sounds. Set these up with the composer with two beaters) so each can be reached easily. Encourage improvisation as in the previous example.

It is important that instruments offered to young composers are of very good quality. It is a false economy to penny-pinch on instruments. It is better to buy a few very good and interesting instruments than lots of inferior ones 'so that everyone can have something'. Pupils will be drawn to the sounds if they are exciting to listen to. Choose one orchestral sized cymbal on a strap rather than several small pairs and large drum with real

skin (or very good plastic) with a variety of beaters (from soft to hard) and a big bass xylophone (also with a variety of beaters rather than lots of little toy ones. Go for the expensive Latin-American and African percussion so that the sound is actually worth listening to. Test out whether you can actually 'feel' the sound as well as hear it. Some pupils with PMLD are not very good at using their ears and need help to appreciate the sounds they are composing.

So far I have talked about improvisation for pupils who can use their hands (even if they need help) to use beaters and I have only talked about school percussion. Electronic music is very useful for those who find conventional instruments difficult or impossible to handle. Soundbeam, for example, can capitalise on any movement that a pupil can make, however tiny. This is a beam of light which when broken will activate a sound (or visual effect) which can be an electronic keyboard or synthesiser with an amazing number of different kinds of sounds.

Example

Set up the Soundbeam with a variety of different sounds in different places to encourage as much movement as possible. If the pupil needs social encouragement to compose, then turn-taking with a more able person can help the artistic mood. Again if the improvisation is tape recorded, it can be commented on, thereby helping the composer to recognise what s/he has been doing.

Switches attached to samplers or a communication aid that can accept recorded messages can also be effective for composing.

Example

Record three or four different sounds or phrases onto a communication aid and encourage selection to 'compose' an original piece. It is also possible for a profoundly physically disabled pupil to compose vicariously, by which I mean, a physically able person can make the sounds that have been chosen by the pupil with PMLD. This is, perhaps, less spontaneous than improvisation is usually, but can be helpful with some pupils.

Example

Set out a variety of instruments, known to be liked by the composer. Encourage choice of a small number for the improvisation (probably two or three). Then follow any indications for order of playing. Rehearse first and then announce the performance, remembering that this is an improvisation and does not have to be the same each time. Tape record the result and play back, perhaps pointing to the instruments as they are played on the recording.

Some pupils with PMLD may be able to manage the intellectual challenge of composing slightly more formal pieces. Any of the examples so far could be moved a step further by composing short phrases that can be repeated and even handed over to others to perform. Often it is helpful to put this kind of composing into a story or game that provides plenty of opportunities for repeats and developing routines.

Example

Use the story of 'Rosie's Walk' by Pat Hutchins and compose music to represent Rosie and the fox walking through the farmyard. Each time the characters appear, their music can be played. This can be improvised each time, using the same instrument or can be more formally a repeatable phrase. Any instruments can be used as long as they are contrasting in timbre or volume, one set for Rosie and the other for the fox. A third piece of music can be written for the disaster that befalls the fox every time he tries to catch Rosie. This might be a crash on the cymbal or the vibraslap. The composer can choose the sound s/he wants. The piece can be first rehearsed until the performers are happy and then, after a suitable hush to create the right atmosphere, the work can be performed.

It is good to get musicians into the habit of rehearsing first and then performing, even if the audience is only members of their class. This can give even the least accomplished player a sense of performance and enhance the drama of 'making music'

Drama games can be good starting points for composing a piece of music. These can be very simple.

Example

This game is based around greeting a friend. Instead of saying 'hello' or shaking hands, each pupil plays their own piece of music when they are greeted. In a class of mixed ability (including PMLD), each pupil can spend some time composing their own phrase of music. This can be improvised on the same instrument each time or can be a phrase which is repeated each time they are greeted. When the separate pieces are ready, one pupil (or an adult) chooses to greet each of the others. S/he approaches each person and says 'Hello, name' and that person replies through his or her composition. The 'hello' part can be sung if that is appropriate.

This sort of game can be repeated many times so that pupils with PMLD can begin to recognise the musical phrases and perhaps even anticipate what is to come from each person, especially if the compositions are very different from each other.

Improvised or simple repeatable phrases can be put into almost any story, however complex (e.g. 'The Billy Goats

Gruff' for young children or a story such as 'The Scarlet Pimpernel' for teenagers - mainly about chasing, hiding, surprising people and fighting. Alternatively, parts of longer stories can be used as inspiration for musical composition. Even if the pupils with PMLD cannot really understand a story such as 'The Snow Queen' or 'Gulliver's Travels', there are ways in which they can be involved in their telling.

Example

While working on the story of the Snow Queen, a small part could be taken for setting to music. This story is full of cold episodes with snow and ice and reflections which could suggest working on metal instruments. The last part of the story lends itself well to musical composition. Young Gretchen has been searching for her friend Kay who has been kidnapped by the Snow Queen and she finds him in her ice palace playing with ice and snow. His heart has been frozen and it is only when Gretchen cries with joy at finding him that her tears melt the ice in his heart and they escape to live happily ever after. Use metal instruments such as cymbals, triangles, bells, metalophones and glockenspiels to represent the icy beginnings and then contrasting sounds such as drums, maraccas and tambourines to end the piece to represent the warmth of the tears and living happily ever after.

Time can be spent on composing the two contrasting sections (either essentially improvised or more formal patterns) which can then be played one following the

other to complete the piece. Performance can be accompanied by visual effects from shiny materials and narration which will give a multi-sensory experience.

There is really no end to the possibilities for inspiration for short compositions for young musicians with PMLD. What the pupils actually do is much the same each time, that is, they choose instruments and improvise on them in whatever way they can. If they are able they can begin to develop some control over what they are playing and perhaps can write phrases that they can repeat or are repeatable by others. These compositions can be tape recorded or an amanuensis can write them down in some way. (Remember that the famous blind composer, Delius, had an amanuensis to write his music down for him). Profound intellectual impairment and complex disabilities should not be a bar to the experience of composing even though individuals will need much support. Remember also that it is better to 'lead from behind' (so that you give enough time, control and autonomy to individuals as possible) than from in front, when it is tempting to take over and play instruments hand over hand or decide that three beats on the drum is what is called for. Given time and opportunity, who knows what young composers with PMLD can achieve?

NOTES

For details about Soundbeam, visit the website at <http://www.soundbeam.co.uk>

Melanie Peter wrote this and it was included in the eulogy to Penny at her funeral:

I've been thinking about something fitting to say as a tribute to dear Penny... and I keep coming back to this quote from Nelson Mandela: 'If we let our own light shine, we unconsciously give other people permission to do the same'. Penny naturally radiated enthusiasm and humanity with a mischievous twinkle and zest for life... she enabled all to flourish as a consequence. As a professional, she had it right all those years ago, and I think we have all been trying to do it like Penny ever since.

Peter Imray

Penny's life was a life lived, and in as much as it briefly touched mine, suffused with kindness, common sense, humour, clarity of thought, compassion and a deep generosity of spirit. A number of years ago I attended a day's training that Penny ran on problem solving and thinking for those with SLD, and was inspired by her real ability to communicate even quite complicated messages in the simplest of ways. She had effectively, resurrected ideas that were just emerging in the 1980's but had got lost amongst the angst of the National Curriculum, and was single-handedly promoting them as both entirely relevant and essential for today and tomorrow.

I was however frustrated by the fact that so few schools seem to have heard of problem solving and thinking as a subject to be taught and the amount of time and planning that was needed in order to promote it effectively in classrooms. I wanted to run a course on it and spread the word, but my problem was that the words were Penny's and not mine. I didn't want to steal her power points (which was what I was effectively doing!) or be accused of plagiarism, but I did want to run the course. After a number of guilt ridden weeks, I eventually wrote to Penny and explained my predicament, and Penny's response was so typical. 'No-one owns ideas' she wrote back 'run the course'.

I am indebted to Penny in so many other ways and probably always will be. She was a beacon!

This article by Penny Lacey appeared in PMLD LINK, Issue 53 (Spring 2006), pages 8-9

Integrated Programmes in Schools

Penny Lacey

With the encouragement from the Early Support programme, many pre-school services are addressing how to integrate the work of teachers, therapists, nurses, Portage workers and medics who work together with a particular family and profoundly disabled child. It is by no means universal across the country but the most effective services are working closely together, closely enough to combine their individual programmes into one document which belongs to the family. Sometimes there is a very large group of people who provide services for families and children with PMLD and the integration between them is only partial. So, for example, the speech and language therapist, physiotherapist and occupational therapist work closely together; combining their assessments and jointly writing therapy programmes. In addition there may be other programmes relating to cognition and sensory development.

Integrating programmes is just as important in school settings, and it is to that context that we now turn. Once a child with PMLD starts school, the focus for intervention shifts from the home to the classroom (although of course both are important). Most of the visiting professionals such as therapists and specialist teachers work in the school, certainly during the term time, and often the teacher becomes a co-ordinator of the different aspects of the intervention. Sometimes the teacher takes on a formal co-ordinating role but at others co-ordination seems to occur by default. Visiting professionals each provide a separate programme to be carried out in the classroom and the teacher needs to bring these together somehow or the targets and activities will be unwieldy. In classrooms where co-ordination is not well-planned, the teacher can find it very difficult to integrate advice which at worst can be contradictory and at best disparate.

Let us spend a few moments on a familiar scenario in the school setting. Edward is 8 years old and has complex needs. He has spastic cerebral palsy involving all 4 limbs and is a wheelchair user. He has had a gastrostomy and takes medication for epilepsy which is mainly well controlled. He has a visual impairment but the extent of his useful sight is not fully known. Edward's communication is mainly unintentional, although he can quite clearly show his likes and dislikes.

Edward attends a mainstream school where the teachers are very keen to meet his needs. Various peripatetic professionals come to the school to work with him but that means that sometimes in the course of a week, he will have been seen by:

- his teacher
- his teaching assistant

- 3 specialist teachers for Science, Music and ICT
- speech and language therapist
- physiotherapist or her assistant
- community nurse
- specialist teacher for the visually impaired

In addition, there are intermittent visits to various clinics at the hospital for checks on his physical condition, his epilepsy, his gastrostomy, his boots and his wheelchair. Edwards also goes to a local children's home for respite care once a month. Altogether there are more than 20 people involved, all of whom contribute to his well-being.

So what would be an effective way for all the people to work with Edward and his family? At the moment the community nurse has a keyworker function in that she liaises as best she can between most of the different people involved and the family. She helps to organise the many appointments and provides a listening ear. The teacher co-ordinates what happens in the classroom, often through the classroom assistant, who is assigned to Edward full-time. The speech and language programme was written by the therapist and checked with the teacher and it informs Edward's classroom work as far as possible. The same is so with the work on his vision.

There seem to be some effective ways of working at the moment. For example, the keyworker role taken on by the community nurse makes all the hospital appointments much more manageable. Edward's mother usually takes Edward to appointments and as she works part-time, she likes to see more than one specialist each time she goes to the hospital, to minimize the number of days she has to get time off work. The co-ordination in the classroom seems to be working well on one level. The teacher and the teaching assistant meet together frequently and work together on suitable activities for

him in subject lessons. Where more could be done is in integrating the intervention programmes from the therapists and visiting teacher of the visually impaired (VI).

Unfortunately little can be done to improve the integration of programmes without time being set aside for teachers and therapists to talk and work together. It is rarely satisfactory for therapists or visiting teachers either to withdraw the child and work with him separately or to write programmes and expect classroom staff to carry them out. The first scenario means that whatever happens in therapy does not influence Edward's daily life and the second scenario means having to find extra time for therapy programmes on top of an already full curriculum. Neither is effective.

Integrating the different programmes seems to be the most effective way of working. Not only does it mean Edward is treated as a whole person and not a sum of limbs, mind, eyes and mouth but it also means that the most important things happen constantly. Everyone communicates with Edward in the same way, everyone can use the same range of positions, everyone knows how to help him use his vision effectively and everyone can help him practice stretching out his arms and learn about simple cause and effect. When the speech and language therapist is able to work with Edward she can work in the classroom alongside everyone else, supporting Edward to contribute to lessons, enjoy lunchtimes or play with his peers. She would know exactly what his physiotherapy targets are, how to encourage him to use his vision and how to enable him to progress cognitively.

Integrating programmes means that schools and visiting services need to work in different ways from those that are traditional. Therapists and visiting teachers should not only be seen as working directly with individual children, but also with classroom staff. This will mean arranging to meet outside lesson times, using preparation time or time after school. It could mean paying teaching assistants for an extra hour each week so they are available at a time when teachers are. Therapists may need to vary their times so they can see children in class and talk to staff when they are free. It could mean therapists and visiting teachers clustering their time for a particular school, so they can spend a whole day or several days in one place whilst they are conducting assessments with classroom staff, writing programmes together and talking about the holistic needs of individual children. Visiting professional would need to co-ordinate their school visits so they could all meet together as a team. My motto is 'You can't be a team if you haven't got time to talk' and if the needs of children like Edward are going to be met holistically on a daily basis then time needs to be managed in a way that enables people to talk together and work together. Many special schools have achieved integrated working but it is undeniably harder in mainstream schools because fewer members of the team are on site. It is relatively easy to talk to people you pass in the corridor (although not always achieved) but more difficult when team members have to travel halfway across the county to meet. It is not impossible though, especially if schools and visiting services are prepared to change their working practices. Change can be painful but oh so rewarding!

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Developing The Thinking of Learners With PMLD

Penny Lacey

In the Winter (2008) edition of PMLD Link, I wrote briefly about a literature review I was undertaking on developing a curriculum for teaching learners with SLD and PMLD to think more effectively. Now I am in a position to share with you what I found. Most of the literature that I reviewed relates to typical children or to children and adults with mild, moderate and severe learning difficulties. There is very little that is specifically about people with PMLD learning to think. However, I think it is possible to understand the kinds of difficulties faced by learners with PMLD from the body of literature consulted, extrapolating the essence and applying that to learners who have the most difficulties in thinking.

Difficulties in Thinking

Learners with PMLD by definition have enormous difficulties in the area of cognition (thinking and learning). They struggle with even the most rudimentary logical thinking, understanding cause and effect, solving simple problems and using what they have learned in one context in another. Even those who have acquired basic understanding of cause and effect, appear to be very limited in how they can apply this understanding. For example, Susie could search for and find pens, her favourite objects, but did not use the same strategy to find other things. She could spot an open door and was through it immediately running down the corridor clearly watching for someone following her but yet did not anticipate other events. Why could she do a few seemingly thoughtful things but not others? It seems that many people with profound learning disabilities have learned certain behaviours that are very successful in their effect but because of their limited understanding of the world, these learned behaviours do not lead to real comprehension.

Sometimes the presence of learned behaviour, such as using individual words, manipulating objects or laughing appropriately can persuade us that the person has more understanding of the world than s/he really has. If we observe carefully, the behaviour can only be used in certain circumstances and is a product of constant repetition rather than really thoughtful behaviour. The most striking example of this is when John opens his mouth in anticipation of a spoonful of food and yet cannot anticipate anything else that happens to him, even when it is an activity that has been used with him many times. Just think about how many times John will have experienced the spoon held to his mouth even if he is only 5 years old (maybe 100,000!). Gradually after so much repetition, John can anticipate one event but still cannot transfer that learning to enable him to anticipate

other events.

Developing Thinking

So what do we know about the development of thinking in typical children and how it can be applied to people with PMLD? Firstly, the theory that all children go through the same development sequence is reasonably well established in relation to children with learning difficulties, although not to those with multiple impairments or particular syndromes and conditions. For example, children on the autistic spectrum do seem to develop differently, especially in the areas of communication and language (Jordan, 2001). Many learners with PMLD do not progress very far along the developmental route set out by the biologist, Jean Piaget. Piaget describes the first stage of development in young infants as 'the sensory-motor stage' (0- 2 years) within which typical babies learn to use their senses and connect those with moving their bodies to start the journey of understanding the world around them (Goswami, 2008). Most people with PMLD remain within this stage throughout their lives, depending highly on personal sensory-motor experiences which they find hard to generalise. Some people with PMLD seem to get stuck on a particular developmental step, for example, mouthing objects. Perhaps this is an example of a learned behaviour getting in the way of developing new behaviours that enable more effective exploration of objects?

Glenn (1987) suggests that typically developing babies have been shown to be more able than Piaget thought but because they cannot show easily what they understand, it is assumed they do not understand. She cites the research that shows that typical infants can recognise their mother's voice at only 3 days old and newborns can imitate their mother's facial gestures and then wonders if this is also true for babies and older

people with PMLD. She reports on her own experiments where children with PMLD functioning at a six month level showed preferences for the same stimuli as typical infants at the same developmental age. Given a tone and voice, they preferred the voice; given a nursery rhyme sung or played on instruments they preferred the sung version and given an adult speaking 'motherese' (baby talk) to them than two adults talking together they preferred the motherese. She used switch access to obtain these results.

From her work, Glenn (1987) suggests that if learners with PMLD are not given opportunities to act on their environment, because of their multiple difficulties, they will be severely restricted in their cognitive development. She cites other work that shows learners with multiple disabilities functioning at a three-month level who could learn to break a beam to set a go-cart in motion. Motivation and opportunity are both important and technology can help with accessing the opportunities, though generalisation of such skills is likely to be a challenge.

Problem Solving

Generalisation and problem solving are known to be difficult for all learners with learning difficulties. There is research evidence to suggest that people with Down syndrome and Fragile X syndrome have specific difficulties in this area (Fidler et al, 2005; Mazzocco et al 2005) even if they have a good grasp of cause and effect. Few people with PMLD will reach the developmental stage where they can solve problems, except at a very rudimentary level where they might repeat an action where the first attempt is unsuccessful. They might be able to modify their actions when repeating it does not work or trying a new strategy when the old one fails (Welsh Assembly, 2006). Of course there are always exceptions, like Samuel who can solve problems with more than one step. He can open boxes and lift covers for favoured objects; find the right doors and remember routes to find these objects and persist until he is successful. However there are predictable limits to his problem solving. His highly developed search strategies are only related to what he wants, and remain strictly within that context. He will not search for something in which he has no interest.

Neuroscience

If we turn to a different set of theories on cognitive development, we can apply what is known about what is happening in the brains of typical infants to help explain the difficulties faced by those who have brain damage or a different brain structure. Neuro-imaging has shown that typical infants have most of their brain cells (neurons) at birth and the connections between them (synapses) are rapidly developed in response to use. Neural pathways are made and lost throughout our lives,

depending upon our experiences but the greatest number are made in the first few years of life (Ward, 2006).

The effect of brain damage or lack of parts of the brain, by definition, will restrict the number of neurons present from the outset and, of course, also restrict the numbers of synapses that can develop. However, if we remember that synapses are formed throughout our lives (brain plasticity) there are always possibilities that people with PMLD can make new connections and learn new things just like typically developing people. Sensory stimulation, experiences with objects and new activities are just as important whatever the age of the learner.

Memory

The development of memory is vital for all learning and in typically developing infants, this seems to be present from birth. Experiments have shown that babies as young as 3 weeks can remember simple objects because they look longer at new objects than those they have seen many times (Bushnell et al, 1984). There have been a number of experiments on memory, particularly with people with Down syndrome showing their difficulties with memory when it is reliant on verbal input. Their memory for visual-spatial information is better and this points to the importance of providing plenty of visual aids such as objects, pictures and symbols during learning (Wishart, 1998). The work of Hulme and Mckenzie (1992) suggests that difficulties with memory are experienced, not just by people with Down syndrome but by others with severe learning difficulties and this can help explain why people with PMLD seem to have huge difficulties in remembering even much repeated activities. Maybe some people with PMLD constantly experience, even much repeated, activities as if for the first time? Maybe even people they meet on a daily basis are strangers to them every time?

So if people with PMLD have such difficulties with memory, how can they learn? As was suggested earlier in this article, sheer repetition is likely to be the answer. If John can learn to open his mouth to anticipate food on the spoon, then he can learn to anticipate other things, but not without a tremendous amount of repetition. In my experience we do not repeat activities sufficiently. We want to give learners with PMLD an interesting life with lots of different sensory experiences, where perhaps we should be concentrating on a few that are repeated many times. If we are going to be driven by repetition, then understanding the exact level of each person's learning is vitally important. It would be of little use to be offering experiences that are either below or above the level of cognition. The first is boring and the second impossible.

Routes for Learning

The development of a simple assessment tool, 'Routes for Learning' (Welsh Assembly, 2006) has made the task of pinpointing the cognitive level of people with PMLD much easier. The assessment covers both communication and cognition that are usually developed in the first year of life. This first year is divided into 43 different behaviours and learners with PMLD could take many different routes through those behaviours. It is very important to see the Routemap as a guide and not as steps to be completed from 1-43.

About halfway down the Routemap is 'contingency awareness' which refers to 'cause and effect'. If the person is able to connect what s/he is doing with the effect this has, then we can say s/he has grasped basic cause and effect. This skill is of vital importance in developing, for example, the capacity to communicate 'more' and 'no more' and to go onto making choices between objects and activities. Before that time, it is very unlikely that people will be able to make choices. They may be able to show that they like or dislike activities/objects as they occur but they are not yet able to make a specific choice even between two. In my experience, many people offer choices to learners who are not yet at that developmental stage and declare that the object the person has looked at is their 'choice'. This assumption can be very misleading and can encourage teachers and supporters to attribute greater understanding than individuals actually have.

So how do we make use of the results of assessment using Routes for Learning? If we have discovered the learner with PMLD is beginning to learn about 'contingency awareness' then that should become central to all their learning. School children may be working on a range of curriculum activities and adult learners are likely to be involved in a range of community activities but what is required for all at this stage is for teachers and supporters to provide as many opportunities as possible to practice contingency awareness. This should be done throughout the day, preferably with a range of different resources so the person can learn to generalise his/her understanding in many different situations. Technology is particularly good for practising contingency awareness (e.g. pressing a switch to hear music) but reactions from people can sometimes be even better, especially as people can make decisions about how to respond in relation to the input from the person with PMLD.

Intensive Interaction (Nind and Hewett, 2005) can be extremely useful in teaching contingency awareness as a central intention is to react to the actions and sounds by echoing these back to the person. The learner claps her/his hands and the interaction partner joins in or maybe offers a slightly different action known to be within the

repertoire of that person. The cause is the learner's actions or sounds and the effect is the reply from the partner. Many people with PMLD understand they can control the 'conversation' and much enjoy the effects.

'Routes for Learning' is not just an assessment tool but it also contains teaching strategies to move learners to the numbered behaviours. An example relates to an earliest behaviour on the Routemap, 'notices stimuli' where there is advice to try a range of actions and sensory experiences in a pattern of 'on-off' so the learner has a greater opportunity to notice something happening and then not happening. There are suggestions about making the stimuli very obvious and looking for any changes in behaviour to indicate the stimuli are being noticed, such as stilling, turning or a change in breathing. As the learner becomes more skilled at noticing stimuli then supporters can start to look for stronger reactions e.g. vocalising, open mouth or finger movement and later responding differently to different stimuli e.g. smiling, eye contact or touching each as appropriate. Once the reactions are secure, during the on-off sequence it might be possible to see the learner anticipating a repeated stimulus. 'Notices stimuli' is the first step and 'anticipates repetitively presented stimulus' is number 14, which indicates the tiny steps of learning at this stage. Typical infants can anticipate which visual image will appear next in a sequence by the age of 3 months (Wentworth, Marshall and Karrer, 2001) but it can take learners with PMLD many years to reach this point, and there are some who may never learn to anticipate. Learners who are so restricted in their understanding of the world are likely to need a small repertoire of stimuli that are repeated very often if they are going to have a chance of moving on in their thinking.

Multiple Disabilities

It is important not just to consider the development of typical infants when considering how to teach thinking to people with PMLD but we must also recognise the limitations placed on those with multiple disabilities. Lack of vision, hearing, and the ability to move are just three of many possible impairments that severely limit the path of cognitive development. Typical infants learn from being able to see, hear and act upon their environment in the sensory-motor stage and if any or all of these are difficult or even impossible, it is very hard for that learning to take place. Cognitive development for those who have a sensory or physical impairments but no learning difficulties is usually delayed but the combination of impairments often seen in learners with PMLD has devastating effects.

Whatever the combination of difficulties, it seems to be most important to build on strengths rather than weaknesses. Hodnapp and Dykens' (2004) research shows that different syndromes and conditions have

different strengths and weaknesses in cognitive functioning but that generally areas of strength develop well over the years but areas of weakness develop slowly or not at all. That seems to be important when considering how to teach children with SLD/PMLD to think and learn more effectively. Building on strengths maybe much more fruitful than trying to remediate weaknesses.

Sometimes it is hard to find strengths, especially if the learner is at the very early stages of cognitive development. It can be very helpful to conduct an Affective Communication Assessment (Coupe et al, 1985) as from this it is possible to find a range of stimuli to which the person reacts. The purpose of the assessment is to gather information about precisely how the person reacts to these stimuli. For example, Michael smiles and moves his legs and arms when he likes a stimulus and gives a 'pained look' when he doesn't. If he really does not like something, he will cry; and if he really likes something, then he will smile broadly. From these small beginnings it will be important to build on these reactions, gradually increasing the different kinds of stimuli that provoke the strongest reactions to form a repertoire of motivating activities. Once motivating activities have been established, opportunities are given for Michael to learn to anticipate the favoured events (and the unfavoured) and from that learn to indicate when he wants 'more' of an activity. This course of events is much more likely to occur if the following is true:

- activities are motivating and build on the smallest of strengths
- they occur in the same order each time (until anticipation is established)
- they are repeated many times every day
- supporters are responsive to even the smallest of reactions
- expectations are realistically related to the level of cognitive development reached by the learner with PMLD

When I'm working with people with PMLD, I always remind myself of the adage:

'start where the learners are and not where you think they should be.....but you can't leave them there'.

I know I must expect people with PMLD to learn how to think but I must also be realistic and build on what I can see is happening. I can't just give sensory experiences and hope that learning will take place. I need to know how many times to repeat the stimulus, what the likely reaction will be, how long it takes for that reaction to occur, where the best reactions take place, who gets the best reactions. It has to be very precise or I may not be 'where the learner is'. Typical learners can learn as long as the input/activity is roughly in the right cognitive area.

Learners with PMLD need more precision or they may sink into helplessness or resort to learned rather than thinking behaviour.

Conclusions

From the literature, it can be seen:

1. Learners with PMLD have enormous difficulties in learning to think.
2. They are likely to develop thinking in broadly the same way as typical infants, with allowances for their multiple disabilities which may mask their abilities.
3. Cognitive development may be prevented not only because people with PMLD do not have sufficient opportunities to learn to connect cause with effects but also because successful learned behaviour might prevent new learning.
4. Learning to think is possible throughout childhood and adulthood through creating new neural pathways (brain plasticity).
5. Learners with PMLD are likely to have great difficulty with memory, with perhaps some having virtually no memory at all, meaning every person and activity they experience is as if for the first time, every time.
6. Thus learners with PMLD require an enormous amount of repetition to learn.
7. Routes for Learning' and the Affective Communication Assessment' are very valuable tools in understanding the level of cognitive development of individuals with PMLD
8. Once the level is established and motivating activities are found then new learning can be encouraged through building on the person's strengths

So, despite the profound difficulties faced by learners with PMLD, it is possible to teach them how to think more effectively. Even if the tiniest progress is made, it can be celebrated, though perhaps not always through the officially recognised tools for recording. Recording of progress is another topic and I won't get into that now!

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FUTURE FOCUS

The Arts and Culture

The theme for the coming Winter 2015 issue is Arts and Culture. While we are all familiar with what we mean by the arts, the term 'culture' requires some explanation. A culture is the set of ways in which a society expresses itself, its customs, traditions, values and institutions.

A culture may be the expression on an entire nation, e.g. the UK which is made up of four countries, England, Scotland, Wales and Northern Ireland will have both common cultural areas and those specific to the respective countries, or of a particular religious or ethnic group within these and other societies. While the arts form an important part of cultural expression, in this edition we do not wish to limit contributions just to the arts. We welcome, for example, papers on the cultural celebration of important events in society or an individual's life and the rituals that may accompany these.

There is also our popular culture - our pop groups, our videogames, our TV programmes, cookery, pubs, parks, street art and other activities which we value and enjoy – all of cultural relevance?

An important part of our cultural heritage is our great literature and storytelling traditions. Many innovative ways have been developed over the years to ensure that people with PMLD have access to this important area. Please share your own stories and experiences with us.

We are often challenged when thinking of ways to involve people with PMLD in cultural activities which, at

first sight, seem out of their reach because of their complex intellectual and other disabilities. Yet we know that many people have found creative and innovative ways of giving them time and opportunity to participate meaningfully and genuinely achieve in different spheres.

People with PMLD can, and should, experience pleasure and fulfilment as to others in their community. So, we would like to know your own experiences both as an individual and as someone who supports people with PMLD to have access to artistic and cultural activities. Please let us have your thoughts, ideas, tips and accounts – we will welcome snippets, longer news items and articles up to 1500 words. We would especially welcome photos or artwork illustrating activities (but would need written permissions to publish!). Finally, we would like to hear about any books, DVDs, CDs, other resources, websites or organisations you have found particularly useful.

Though we have mentioned above the countries that make up the UK, we would very much welcome contributions from other countries on the theme of the arts, culture and PMLD.

Please send your contribution directly to us by 26th October. Thank you very much. We look forward to reading them.

Loretto Lambe and Rob Ashdown

E: mail addresses: loretto.j.lambe@gmail.com / rob.ashdown@ntlworld.com



We have launched our first steps into the world of social media with our very own twitter account. We plan to keep followers up to date with news and development regarding the journal, and also share relevant news and information. We have had a positive start with lots of engagement and a good number of followers.

REPORT BACK

Art of the Cart

An Oily Cart exhibition to view by appointment from May 16 - August 31:

Email: oilies@oilycart.org.uk Tel: 020 8672 6329

As part of the Wandsworth Arts Festival in South West London, the Oily Cart theatre company which creates multi-sensory, highly interactive and totally age appropriate productions for young people with PMLD and on the Autistic Spectrum, opened its doors to display the array of wonderful costumes, puppets, custom made musical instruments and set pieces, amassed over its 34-year history. With its light, white-painted airy position on the upper floor of Smallwood School annex, it creates its magic from the moment you enter the gate, for the first thing you see is a two floor high, golden and jewel studded lift for wheelchair users!

Once inside we were free to touch and explore all the different costumes and pieces of equipment. Here was the swinging hammock-like chair for children with PMLD to move independently, the huge green pipes – originally plastic drainpipes! – which respond to any strike with a variety of different sounds, the giant blue egg which can be tuned to make sounds that are appropriate for whoever is rocking it, bowls with lighted bases, so inviting to peer into and explore the contents. Photographs and

videos took the visitor through the wonderlands that are the essence of the company's work; a

wheelchair user suspended high above the ground so that the young person is in space with the actors, a floating 'audience' in a hydrotherapy pool transformed with lights for the BIG SPLASH and the joy on participants faces in THE BOUNCE as they experience that special freedom of supported exaggerated movement on vast twin trampolines, to name just a few.

Claire de Loon, head of design, Max Reinhardt, who makes the music, and Tim Webb, who writes and directs most of the productions, established the company originally for very young children but in 1996 pioneered a radical new form of performance and, with their imaginative and focussed approach for their specific audience, they have opened up the magic of theatre for young people with profound and complex needs. It is a fascinating exhibition.

Oily Cart:
Web: www.oilycart.org.uk



Top websites for this issue

About Penny Lacey

<http://www.swisscottagedrc.org/the-world-of-pmldwill-mourn-penny-lacey>

<http://www.telegraph.co.uk/news/obituaries/11392897/Penny-Lacey-educationist-obituary.html>

http://www.taylorandfrancis.com/education/articles/a_tribute_to_dr._penny_lacey

<http://www.ucet.ac.uk/6331>

Some articles by/with Penny Lacey

A curriculum for Learners with PMLD - <https://www.senmagazine.co.uk/articles/396-designing-a-curriculum-for-pmld-a-profound-challenge.html>

'Raising our Sights' – For information and to download all the Mencap guides (including the one authored by Penny) - www.mencap.org.uk/raisingoursights

Article in TES: When Touch is One Way to Talk - <https://www.tes.co.uk/article.aspx?storycode=2156867>

Open Story Tellers – A charity based in the Somerset town of Frome that works with adults with learning and communication difficulties - <http://www.openstorytellers.org.uk>

Oily Cart – A group that creates theatre for young people with complex disabilities – <http://www.oilycart.org.uk>

Frozen Light - multi-sensory theatre for audiences with profound and multiple learning disabilities - <http://frozenlighttheatre.com>

The Schools Network for details about the 'Engagement for Learning Framework' assessment and inquiry tools - <http://complexld.ssatrust.org.uk>

Routes for Learning assessment - <http://wales.gov.uk/topics/educationandskills/schoolshome/curriculuminwales/additionaleducationalneeds/routeslearning/?lang=en>

Quest for Learning Assessment - http://www.nicurriculum.org.uk/inclusion_and_sen/assessment/pmld.asp

TAC Interconnections - Monthly electronic TAC Bulletin and the TAC Journal and consultancy/training for developing the TAC System (Team Around the Child) <http://www.teamaroundthechild.com/themes/work.html>

REVIEWS

Title: The Routledge Companion to Severe, Profound and Multiple Learning Difficulties

Editors: Penny Lacey, Rob Ashdown, Phyllis Jones, Hazel Lawson and Michele Pipe

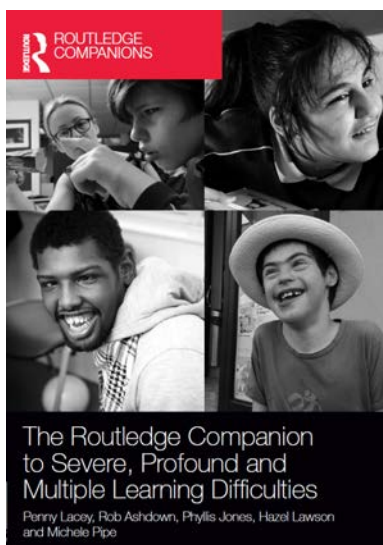
Publishers: Routledge

Published Date: April 2015

Pages: 435

ISBN: 978-0-415-70998-9

This is a long-awaited resource for students and practitioners in education supporting children and young adults with SLD/PMLD. It is an up-to-date, rich resource that incorporates both academic and practitioners' perspectives. There are over 70 contributors to this book all specialists in their field and with a wide range of practice and research.



This book acknowledges the complexity of the educational provision needed for children and young people with SLD and PMLD. As the editors suggest, it is not a book to read from cover to cover, but more one to dip into depending on the needs of the children you are working with or the area of study you are concentrating on. There is a wealth of knowledge and expertise covering a wide range of issues within its 39 chapters. The advantage to students and practitioners is that it is all in one book. The book, therefore, reflects the heterogeneity of children and young people with severe and profound multiple learning difficulties.

The chapters are organised in six sections;

- Provision for learners with SLD/PMLD
- Involving stakeholders
- Priorities for meeting personal and social needs of the learners
- Developing the Curriculum
- Strategies for supporting teaching and learning
- Towards a new understanding of education for learners with SLD/PMLD

Within these sections there is a myriad of topics, from historical development of provision to curriculum models, from working with families to communication strategies, from sex, relationship education to learning to play, from recognising progress to care in an education setting. The list goes on. The underlying principle of this book is that the emphasis is on meeting the individual needs of the child and that permeates throughout all the chapters.

The chapters in each section are discrete and easy to access. They have a similar structure in that they start with questions that are addressed within the chapter. They each conclude with questions for the reader and a reference list. It challenges the reader to reflect on the content of the chapter and aims to challenge them to consider the context of their own work, the continual professional development and indeed the wider context of local and national provision. The conclusion acknowledges eleven general themes throughout the book. These themes reflect a holistic approach to the educational provision of children and young people with SLD and PMLD.

This is an important and very useful contribution to literature available for students and practitioners in education settings for children and young people with SLD/PMLD and a must have for any postgraduate student embarking on educational studies within the SLD and PMLD field.

This book is dedicated to Dr Penny Lacey, one of the editors. As the prime mover for this book, it is an accolade to her passion and dedication to children and young people she worked with and the students she enthused. It is a small, yet significant part of the legacy of her contribution to this field.

Wendy Newby

PMLD LINK Editor and Deputy Head at The Shrubberies School, Stonehouse, Gloucestershire

Title: Engaging Learners with Complex Learning Difficulties and Disabilities: A resource book for teachers and teaching assistants

Authors: Barry Carpenter, Jo Egerton, Beverley Cockbill, Tamara Bloom, Jodie Fotheringham, Hollie Rawson, and Jane Thistlethwaite.

Publication: February 2015 - Routledge
ISBN: 978-0-416-81274-0 (paperback)

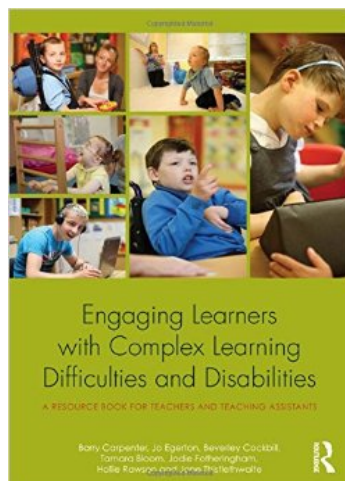
Pages: 194 + xxii

Price: £26.99

This book provides details about the 'Engagement for Learning Framework' which has been developed and trialled over several years in a range of educational settings. The Framework offers a means of assessing, recording and developing personalised learning pathways and demonstrating progression for learners with 'Complex Learning Difficulties and Disabilities' (CLDD). This DfE/DCSF funded project resulted in useful materials still available on the SSAT (The Schools Network) website (<http://complexld.ssatrust.org.uk>) and key materials have been explained, with case studies, for this book. The book is not merely a rehash of the online materials but genuinely offers further insights and descriptions of innovations.

The book briefly explains the CLDD project and then sets out the argument that there now exist 'new generation children', children with CLDD, who 'are presenting with new profiles of learning that the teaching profession struggle to meet through existing teaching styles or curriculum frameworks' (p.6). CLDD is defined in terms of co-existing and overlapping conditions which can manifest in complex learning patterns, extreme behaviours, a range of socio-medical needs and 'disengagement from learning'. Clearly, learners with PMLD may be regarded as a small but important minority within this diverse and large group.

'Engagement' is defined and its importance to learning is identified. The book sets out an approach to measuring seven indicators of engagement via the 'Engagement Profile and Scale' which are the core tools. The proposed approach to Intervention will be quite familiar: it entails identification of SMART targets using information gathered during the initial assessments, establishing baselines, making regular observations to evaluate progress and making considered decisions about any changes in approach on the basis of this ongoing information gathering. What is new here is the use of the



'Engagement for Learning' tools to gather, record and evaluate the information before and during intervention. Several case studies from schools show the benefits to individuals of using the tools to develop personalised teaching and learning strategies. The authors are clear that '.....it was the educators and families who held the key to engaging the complex learner through recalling and sharing things that they collectively knew about the child.'(p79). Crucially, the profile and scale provided a framework for observation, recording and assessment and, importantly, a common vocabulary to facilitate sharing of information and ideas.

The book goes on to explore the experiences of families and identifies best practice in establishing genuine partnership with families, providing a thorough review of the available literature and reporting the findings from working with families of learners with CLDD during the project illustrated with case studies. A similar approach is maintained for the chapter on teachers in schools collaborating effectively with different professionals. Chapter 8 reinforces the need for this joint working with families and professionals in dealing with mental health issues. It alerts us to the fact that serious mental health problems are often 'masked' by children's learning disabilities, particularly when the focus may be on communication and other disabilities.

The authors argue that teachers will need to find new ways of working to meet the needs of learners and pushes strongly for a more scientific approach to inquiry utilising the 'Inquiry Framework for Learning' (also to be found on the SSAT website). The final chapter, 'Visioning the Future' provides a number of interesting case studies showing how schools are developing their practice using the 'Engagement for Learning Framework' and systematic 'practitioner inquiry'. Finally, there are various Appendices with supporting templates for forms and additional guidance.

People working with learners with PMLD will find here interesting cases studies explicitly related to children and young people with PMLD, their families and their schools. There have been questions about the reliability of the profile and scale as quantitative measures of progress (Chalaye and Male, 2014) but this book does give schools the details and inspiration that they need to do their own action research and explore systematically and objectively whether these tools will work for them. This book is highly recommended.

Reference

Chalaye, C. and Male, D. (2014) 'An evaluation of the Complex Learning Difficulties and Disabilities Engagement Profile and Scale as a measure of engagement for children and young people with profound and multiple learning difficulties', *The SLD Experience*, Volume 69, (Summer 2014), 3-9

Rob Ashdown

IN THE NEWS

Frozen Light Announces 'The Forest' tour dates

The Norwich-based Frozen Light Theatre has a good reputation for creating exciting and original multi-sensory theatre for audiences with profound and multiple learning disabilities.

Frozen Light theatre has announced 'The Forest' tour dates for Autumn 2015. The company will be heading to 26 venues throughout the country starting on 29th August in Canterbury and finishing on 5th December in Brighton.

'The Forest' tells the story of Thea and Robin who both want to escape from their everyday routines. One day they are drawn into the dark and mysterious forest and find themselves on an unexpected journey of self-discovery filled with surprising encounters and experiences that change their lives forever.

'The Forest' is a multi-sensory tale which seeks to immerse audiences in a world full of sights, sounds, smells and sensations. It has been created specifically for teenage and adult audiences with PMLD to enjoy with their friends and family.

For more details about the tour go to the website (<http://frozenlighttheatre.com>) or e-mail info@frozenlighttheatre.com

Complex Needs Training Materials

This is not so much a news item as a reminder for colleagues who are working in or with educational settings. The 'complex needs training materials' were developed for use by any audience with an interest in teaching children and young people with:

- severe learning difficulties
- profound and multiple learning difficulties
- complex learning difficulties and disabilities

There are 16 modules spread across 4 study levels. The content and the levels were designed to cater for teachers with varying expertise – school leaders, experienced teachers, trainee teachers, teaching assistants and anyone with an interest.

The training materials are no longer available through the DfE website and are now available via the National Association for Special Educational Needs (nasen) website (<http://www.complexneeds.org.uk>). These resources have proved popular and are an excellent support for school-based training and training in other settings as well as the interested individual reading through them on their own. They have the potential to contribute to raising standards of teaching and learning for these pupils at a time when there are concerns about the knowledge and experience of new teachers. nasen will keep the resources available, via its website, and make the multimedia clips (video and audio) available separately on its YouTube channel, 'nasen online'.

NEXT ISSUE

Winter Vol. 28 No. 3 Issue 82

The Arts and Culture

Do you have any stories to share?

If so, contact the editors:

Loretto Lambe and Rob Ashdown

E: mail: loretto.j.lambe@gmail.com or rob.ashdown@ntlworld.com

SHORT COURSES & CONFERENCES

Providers Details

Concept Training

15 Beach Street,
Morecambe,
Lancashire LA4 6BT
Tel. 01524 832 828
E-mail: info@concept-training.co.uk
Website: www.concept-training.co.uk/

EQUALS

PO Box 107, North Shields,
Tyne & Wear, NE30 2YG
Tel. 0191 272 8600
Email: admin@equals.co.uk
Website: www.equals.co.uk

Hirstwood Training

Tel. 01524 42 63 95
Email: richardhirstwood@gmail.com
Website: www.multi-sensory-room.co.uk

Flo Longhorn training

Email: fplcourses@aol.com
Website: www.flolonghorn.com

July

Title: **Conference: Posture and Mobility Group**
Date: 13th -15th
Location: Leeds
Provider: PMG
Contact: Email: conference@pmguk.co.uk
www.pmguk.co.uk/pmg-conference-2015.html

Title: **Creating with the Cart – professional training Opportunity**
Date: 27th – 1st August
Location: London
Provider: Oily Cart Theatre Company
Contact: oilies@oilycart.org.uk

August

Title: **Sensory Story Creation Weekend**
Jo Grace
Date: 28th - 30th
Location: Birmingham
Provider: Woodbrooke Quaker Study Centre
Contact: gillian.pennington@woodbrooke.org.uk

Title: **IASSIDD 15th World Congress 2016**
Date: 15 – 19th
Location: Melbourne, Australia
Provider: International Association for the Scientific Study of Intellectual and Developmental Disabilities
Contact: www.iasidd.org/conference/index.php/HPC/IWC/index

September

Title: **Practical and Effective Ways of Using Multi Sensory Equipment**
Dates: September 7th Glasgow, October 5th Dublin 6th Belfast, 13th Middlesbrough, 22nd London, November 27th Glasgow, December 3rd London
Provider: Concept Training
Contact: See provider details

Title: **18th SSBP International Research Symposium**
Date: Education day 3rd
Research Symposium 4th – 5th
Location: London
Provider: The Society for the Study of Behavioural Phenotypes
Contact: www.ssbpcconference.org

Title: **Training to help you help sleep-deprived families**
Date: 9 – 10th
Location: Birmingham
Provider: Handsel Project
Contact: www.handselproject.org.uk/sleep1.html

Title: Dates: Location: Provider: Contact:	The BILD Positive Support Coaches Programme 14,15, and 16 th Birmingham BILD Events Team: Tel: 0121 4156970 Email: learning@bild.org.uk	October	
Title: Dates: Provider: Contact:	Learning Outside the Classroom - Taking the Curriculum Outside <u>September</u> 15 th Glasgow, <u>October</u> 5 th Chorley Concept Training See provider details	Title: Date: Location: Provider: Contact:	Intensive Interaction: Sensory Issues and Communication using Body Language 1 st Chorley Concept Training See provider details
Title: Date: Location: Provider: Contact:	Positive Ways of Changing Behaviour 23 rd Glasgow Concept Training See provider details	Title: Dates: Provider: Contact:	Intensive Interaction: Building relationships with people who have profound learning disabilities and complex needs 7th Dublin, 14th Taunton Concept Training See provider details
Title: Date: Location: Provider: Contact:	Rebound Therapy for SEN, Open College Network, Level 2 24 th and 25 th Newcastle upon Tyne EQUALS See provider details	Title: Dates: Provider: Contact:	Sensory Play for All <u>October</u> 12 th London, <u>November</u> 18 th London Concept Training See provider details
Title: Date: Location: Provider: Contact:	Autism, communication and sensory – Dr Wenn Lawson 24 th London National Autistic Society www.autism.org.uk/LawsonCommunication2015D	Title: Date: Location: Provider: Contact:	‘Accessibility, Diversity and Inclusivity: The Journey Continues’ 22 nd and 23 rd Toronto, Canada OAICD www.oaicd.ca
Title: Dates: Location: Provider: Contact:	Understanding and supporting children with PDA (Pathological demand Avoidance) <u>September</u> 29 th Glasgow, <u>November</u> 18 th London National Autistic Society www.autism.org.uk/PDAtraining2015D	Title: Date: Location: Provider: Contact:	Writing a Behaviour Support Plan 29 th Birmingham BILD Events Team: Tel: 0121 4156970 Email: learning@bild.org.uk

<p>Title: Using happiness as an intervention in Behaviour Support Plans</p> <p>Date: 30th</p> <p>Provider: BILD</p> <p>Contact: Events Team: Tel: 0121 4156970 Email: learning@bild.org.uk</p>	<p>Title: Positive Sensory Approaches for Autism</p> <p>Dates: 16th London, 17th Birmingham, 19th Manchester</p> <p>Provider: Hirstwood Training</p> <p>Contact: See provider details</p>
<p>November</p>	
<p>Title: Intensive Interaction (Dave Hewett)</p> <p>Date: 6th</p> <p>Location: Birmingham</p> <p>Provider: Intensive Interaction</p> <p>Contact: www.intensiveinteraction.co.uk</p>	<p>Title: Communicating with people with Learning Disabilities</p> <p>Date: 18th</p> <p>Location: Birmingham</p> <p>Provider: BILD</p> <p>Contact: Events Team: Tel: 0121 4156970 Email: learning@bild.org.uk</p>
<p>Title: Multi sensory ideas, recipes and resources</p> <p>Dates: 9th Manchester, 11th Birmingham, 13th London</p> <p>Provider: Hirstwood Training</p> <p>Contact: See provider details</p>	<p>Title: PMLD: Profound and Multiple Learning Disability – engaging children in learning</p> <p>Dates: 18th Glasgow, 23rd London</p> <p>Provider: Concept Training</p> <p>Contact: See provider details</p>
<p>Title: A New Approach to Teaching Maths and English in the SLD/ PMLD Classroom</p> <p>Date: 13th</p> <p>Location: Manchester</p> <p>Provider: EQUALS</p> <p>Contact: See provider details</p>	<p>Title: Sensory Communication</p> <p>Dates: 23rd Manchester, 24th Birmingham, 27th London</p> <p>Provider: Hirstwood Training</p> <p>Contact: See provider details</p>
<p>Title: Music in the Everyday Classroom: for players and non-players</p> <p>Date: 12th</p> <p>Location: Manchester</p> <p>Provider: EQUALS</p> <p>Contact: See provider details</p>	<p>Title: Progress for children with Down's Syndrome: Health and Education.</p> <p>Date: 20th</p> <p>Location: London Royal Society of Medicine</p> <p>Provider: RSM in association with Down's Syndrome Medical Interest Group</p> <p>Contact: Tel: 020 7290 3942 E: intellectual.disability@rsm.ac.uk</p>

LONGER COURSES (with Creditation)

MA Education

Pupils with Severe and Profound and Multiple Learning Difficulties (P1: Contexts & Understanding P2: Curriculum & Teaching)

The modules address the requirements of the Teacher Development Agency (TDA) National Special Educational Needs Standards

The course provides students with an opportunity to gain an understanding of those influences which impact upon the learning, development and management of pupils with severe and profound and multiple learning difficulties.

For further Details: The University of Northampton. Tel: 08003582232 Email: study@northampton.ac.uk

MA Education Physical Disabilities (P1: Contexts & Interventions P2: Curriculum Issues)

The first module (P1) provides opportunities for those with QTS and professional qualifications and experience in services for children, to engage in structured critical reflection, exploration of key substantive issues and overarching policy determinants in respect of children and young people with physical disabilities. The second module (P2) provides students with opportunities to investigate, critique and evaluate a range of curriculum approaches in the field of physical disabilities. It engages students in debates concerning the relevance and practical efficacy of recent guidance and legislation in physical disability-related issues, and offers an in-depth series of curriculum-focused activity which is intended to enhance both the understanding and the practice of those working with children and young people with physical disabilities.

For further Details: The University of Northampton. Tel: 0800 358 2232 Email: study@northampton.ac.uk

MA Education Understanding Multi-Sensory Impairment

This module addresses the requirements of the Teacher Development Agency (TDA) National Special Educational Needs Standards (Extension 2.i – 2.iv.). It is directly related to Pupils with Multi Sensory Impairment (MSI) The module provides students with an opportunity to gain an understanding of those influences which impact upon the learning, development and management of pupils with multi sensory impairment. It provides professional development for teachers and other professional colleagues working in an area of low incidence need and addresses priorities established by Local Authorities, individual teachers and others working with children and young people who experience MSI.

For further Details: The University of Northampton. Tel: 0800 358 2232 Email: study@northampton.ac.uk

Certificate in Higher Education (CHESL): Supporting Learners with SLD/PMLD

This course aimed at Teaching Assistants will look in detail at the needs of learners who are known to have severe or profound and multiple learning difficulties. These learners may also have other additional or associated disabilities, such as physical or sensory impairments. The course will examine topics of both a theoretical and practical nature to provide students with a greater understanding about this group of learners, together with a broad range of strategies and approaches that can be applied to practice. The sessions will include lectures, workshop activities, discussion and some visiting speakers.

For further Details: The University of Northampton. Tel: 0800 358 2232 Email: study@northampton.ac.uk

BPhil, PGDip and MEd Inclusion and SEN

Year 1 Learning Difficulties and Disabilities (Severe, Profound and Complex)

Year 2 Autism (Children) or Autism (Adults)

Distance Education

This two/ three year course contains 6 modules and students study the required number from this list for their chosen award plus a dissertation.

1. Understanding Learning Difficulties and Disabilities
 2. Interventions for People with Learning Difficulties and Disabilities
 3. Learning Difficulties and Disabilities: Communication and Behaviour
 4. Special Educational Needs of Children with Autism *or* Autism (Adults) Understanding and Working with the Continuum of Need
 5. Curriculum and Treatment for Children with Autism *or* Autism (Adults) Intervention, Care and Education
 6. PGDip includes a practical project based on your work
- MEd includes a research methods module and a dissertation

For further details: The University of Birmingham, email: isen@contacts.bham.ac.uk

BSc in Professional Practice

BSc in Professional Practice - includes forensic, mental health/learning disability, challenging behaviour, older person with LD and epilepsy modules. Students will be provided with an educational experience, tailored to their particular requirements, so as to gain professional experience. This will enable them to work collaboratively and flexibly within health and social care systems.

For further details: University of Chester Tel: 01244 511000 Email: enquiries@chester.ac.uk

MSc in Advanced Practice

The School of Health & Social Care, University of Chester, MSc in Advanced Practice (Learning Disabilities) - includes generic modules in research and inter-professional working plus 3 LD specialist modules (socio- political themes in LD; developmental perspectives on LD; profound & complex needs). This course is suitable for health and social care professionals who would like to develop higher levels of professional knowledge and expertise in their sphere of practice.

For further details: University of Chester Tel: 01244 511 000 Email: enquiries@chester.ac.uk

Postgraduate Courses in Profound and Complex Learning Disability

The course is studied by distance learning plus attendance at an Autumn Study School at the University of Manchester. The course accent is on moving towards increasing choice; developing community presence and participation; and increasing respect for individuals with complex needs. This approach underpins all aspects of course delivery. The course has three aims:

- To support the professional development of people working with children and adults with complex disabilities.
- To empower course participants to advocate for people with profound and complex learning disabilities.
- To enable course participants to develop knowledge and understanding of key issues in the field.

For further details: The University of Manchester, Lesley Jenkins Phone: 0161 275 33337 Email: pld.distance@manchester.ac.uk

AdCert, BPhil, PGCert, PGDip, MEd.

Severe, Profound and Multiple Learning Difficulties

Blended Learning (a combination of online and occasional weekend study on campus)

The Severe, Profound and Multiple Learning Difficulties blended learning programme has been developed for a range of professionals/practitioners who work with children and adults with learning difficulties in educational settings across the severe and profound range (SLD/ PMLD). The programme covers issues for staff who work in any education and learning services and has particular emphasis on working together to meet needs. The programme aims to help participants to study systematically, critically and in-depth, aspects of educating children and adults with severe, profound and multiple learning difficulties. Participants are encouraged to research and reflect on their own practice, carrying out small-scale research leading to developments and innovation.

For further details: University of Birmingham, email: severepronfoundandmultiplelearningdifficulties@contacts.bham.ac.uk

AdCert, BPhil, PGCert, PGDip, MEd.

Multisensory Impairment (Deafblindness) - *Distance Learning*

This programme enables teachers and others working in education related fields to work more effectively with learners who are deafblind (multisensory impaired). Some students are teachers working with children or adults, but others are from social services, medical, or residential work. A one-year programme can lead to the awards of Advanced Certificate or Postgraduate Certificate.

- A two-year programme can lead to the award of BPhil, or Postgraduate Diploma.
- A two-year programme with a dissertation can lead to the award of an MEd.

Students working on BPhil or Postgraduate Diploma programmes with some additional activities can, on successful completion, be recognised as meeting the requirements of the DfES for the mandatory qualification for teachers of children with multisensory impairments.

For further details: University of Birmingham Dr Liz Hodges on 0121-414 4873 or email: e.m.hodges@bham.ac.uk

Adults with learning disabilities who have significant and complex needs

The School of Psychology at the University of St Andrews offers a Post Graduate Certificate by open/distance learning: "Adults with learning disabilities who have significant and complex needs". This consists of four distance learning modules, chosen from six, and is available to staff with a professional qualification or a first degree.

- Challenging behaviour
- Mental health
- Offenders with learning disabilities
- Older people with learning disabilities
- Profound and multiple disabilities
- Vulnerability, victimisation and abuse

The programme leads to further qualifications at Diploma and Masters level.

For further details: University of St. Andrews <http://psy.st-andrews.ac.uk/people/personal/mc1/> Dr Martin Campbell email: mc1@st-andrews.ac.uk

SEN Foundation Degree at Whitefield Schools and Centre in partnership with Kingston University

The SEN Foundation Degree is a higher education qualification which combines academic study with work-based learning. It provides a training pathway for those who would like to remain in work whilst studying for a higher education award. The degree is specifically designed for professionals working with children and young people in educational settings who have additional learning needs. You will have an appropriate Level 3 qualification and at least two years' post-qualifying experience and must be working at least 16 hours per week in an educational setting with children from birth to nineteen years. Course start date: September 2014

For further details: Whitefield Schools and Centre, Louise Langsworthy l.langsworthy@whitefield.waltham.sch.uk

Postgraduate Studies at Whitefield Schools and Centre in partnership with Kingston University

The Postgraduate Certificate, Diploma and Masters programmes are delivered at Whitefield Schools and Centre in partnership with Kingston University, London. The Certificate course runs for one year and the Diploma runs for two years. Both years carry 60 "M" level credits, allowing access to the third year Masters Degree that takes the form of an educational action research project.

The *Diploma and Certificate* courses are practitioner based and there is a requirement that students are working, either as a paid member of staff, or in a voluntary capacity for at least two days a week with children or young people with special educational needs.

The *Masters programme* is also practitioner based but there is no requirement for work to be but students can be accepted straight on to this programme (subject to an official transfer request and University approval) if they already have the appropriate number of credits at "M" level.

Whitefield can also offer the mandatory qualification for teachers of pupils with [Multi-Sensory Impairment \(MSI\)](#). Teachers undertaking this course complete two years of study as above, addressing the mandatory standards for this course, followed by a four week assessed teaching placement working with MSI pupils in a recognised centre of excellence.

Course start date: September 2014

For further details: Whitefield Schools and Centre, Louise Langsworthy l.langsworthy@whitefield.waltham.sch.uk

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PMLD Link is an informal journal for practitioners and carers working with people with profound and multiple learning disabilities (PMLD), of all ages and in all situations. It covers a wide range of issues of interest and practical use in the day-to-day work of practitioners, parents and carers in schools, colleges, adult provision, in the home, and covers issues pertaining to all groups, including occasional articles by practitioners and parents from overseas. It enables readers to create networks, and provides a forum for contact with others involved in the field. The contributions may be:

- short papers
- information sharing
- news of individuals, families or other groups
- requests from readers for information

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	Disability Retired Disability Consultant and a parent of a young woman with PMLD.
Helen Daly	Mum to a young Adult with PMLD, previous career in Further Education for 20 years - including Curriculum Team Manager for Inclusive Learning and Developing an Improving Choice Programme for people with Complex Needs. Currently involved in carers groups in the Eastern Region, Learning Disability Partnership Board and associated projects.
Jill Davies	Research Programme Manager for the Foundation for People with Learning Disabilities. Jill recently completed a Dept. of Health project on Meeting the needs of children with complex health needs. She facilitates the UK Health and Learning Disability Network.
Beverley Dawkins	OBE Chief Executive of Generate
Ann Fergusson	Researcher and tutor for severe learning difficulties and PMLD courses at The University of Northampton. Trustee of National Family Carers Network. Ann also has a family member with a learning disability
Chris Fuller	Founder and former Director of Bag Books: multi-sensory stories for people with PMLD, and previously special education teacher
Rachel Parry Hughes	Lecturer in Social Work, Goldsmiths, University of London, researcher in the field of profound and multiple learning disabilities
Loretto Lambe	Founder and former Chief Executive of <i>PAMIS</i> an organisation in Scotland working with people with PMLD, their family carers and professionals who support them. Loretto has worked supporting people with PMLD for most of her adult life. Although recently retired she will continue to work and campaign for a better life for people with complex disabilities.
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



sharing ideas and information

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

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