

PMLD LINK

sharing ideas and information

Technology

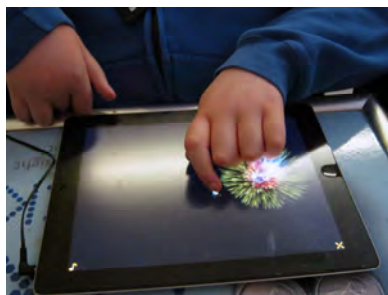
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PMLD Link is a journal for everyone supporting people with Profound and Multiple Learning Difficulties

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GUEST EDITORIAL

Technology

It's been exciting putting this winter issue of PMLD Link together. Thank you all writers for your inspiring contributions. Several themes emerged as we read through your articles, the overarching one enthusiasm for what has been achieved through technology for people with profound and multiple learning disabilities and what we've yet to discover.

Our first group of articles, from Gail Paterson, Flo Longhorn, Karen Sells and Fiona Fraser, is about tablet computers, mainly iPads – in particular their potential to open up 'a new world of engagement, excitement and opportunity' (Flo), to enhance communication and promote choice, inclusion, person centred learning and closer ties between home and school.

We move on to music and articles by Tim Swingler and Carrie Lennard. Even if you've never experienced a soundbeam or been part of an iband, you can't fail to appreciate the creativity and excitement and won't be surprised to find words like 'fantastic', 'unique' and 'empowering'.

Technology, like all developments, is only as good as the people behind it. Its effective use requires collaboration across boundaries and disciplines, school, home and community.

Ken Holland and Annie Lawton (UK) and Naomi Rezzani (Australia) highlight teamwork when they describe their use of multimedia and its capacity to enable people to have more control over their lives, improve communication and promote advocacy and empowerment. Nina Martinez tells how technology has strengthened the partnership between a Day Centre and the local library and opened up new opportunities for the people involved. And we are reminded by Penny Lacey that 'low' technology also has an important role in life and learning.

Medical technology sustains life and optimises health for increasing numbers of people with pmlD, as Jeanne Carlin points out, sharing with us her personal experience and knowledge of this vital area. Wendy Newby shows how integrating medical technology into everyday classroom life results in a more personalised and holistic approach. On a related theme, though not strictly about technology, Lauren Allen writes about assessing pain in children with pmlD.

Finally, we have a piece by Harsharn Singh Khatar and Deborah Gittins about multi-disciplinary teamwork in the combined use of sensory stimulation and intensive interaction.

Running throughout all of these articles is the crucial importance of *people* – not only the learners, but those doing the loving, the caring, the teaching, the support. Gail Paterson cautions against using technological devices to replace spending time with someone. Fortunately, as relatives, friends and professionals we are in no danger of being replaced by technology – but we can use it creatively and supportively to make life and learning more fulfilling.

Alice Bradley and Wendy Newby

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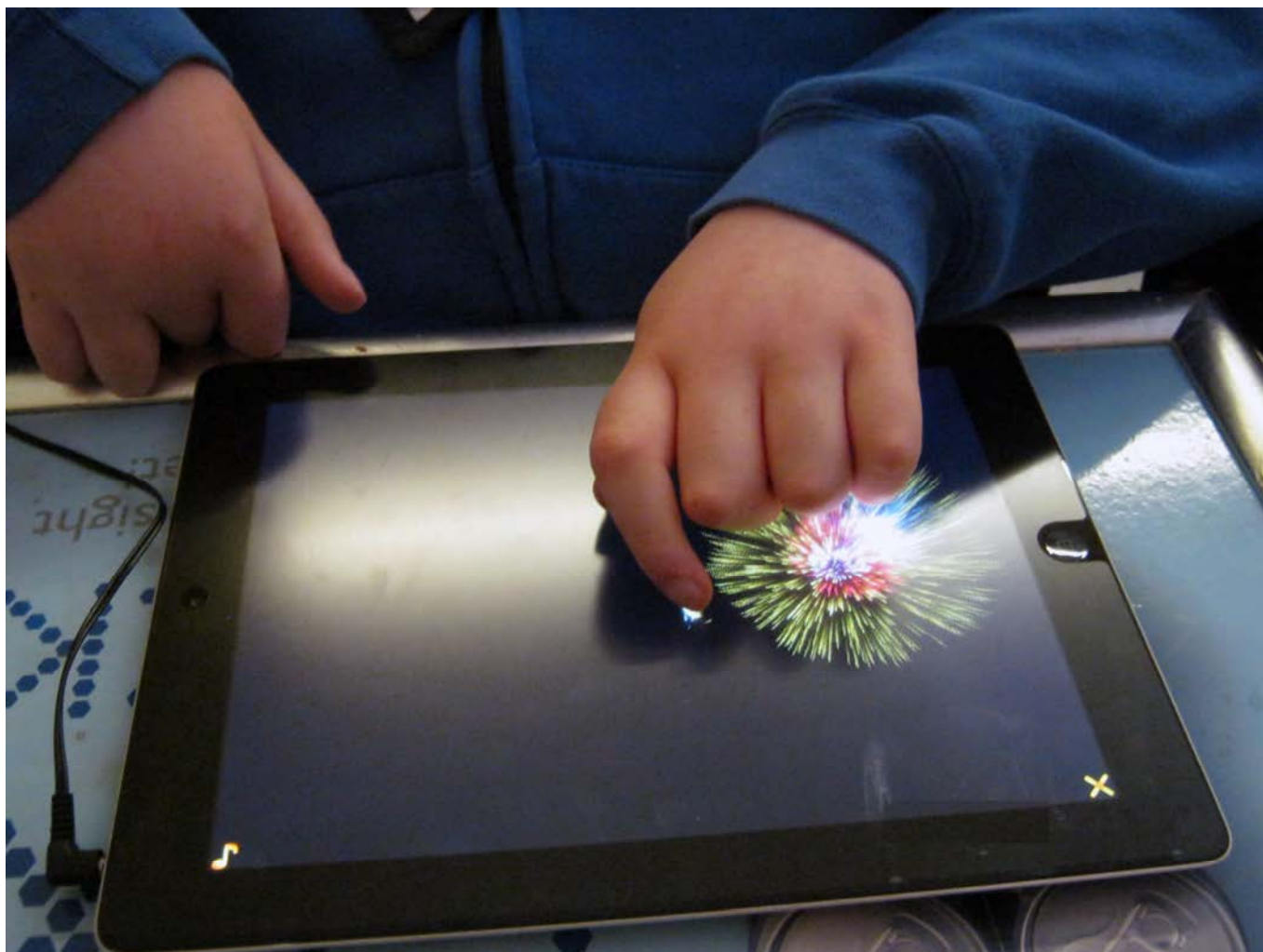
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Don't forget your tablet!

Gail Paterson

I heard this phrase a lot growing up as my brother had chronic asthma and tablets were a part of his keeping-well regime. Thankfully he no longer needs to take his daily tablets because his asthma improved as he grew older. This is not to say the phrase has gone out of his life, it's just now he's more likely to say it to his wife as she heads out to work. In their household the word tablet now refers to her tablet computer which is used as much for work as it is for pleasure. That tablet is a window on the world with the latest news and views, facts and figures at the touch of a screen.

It is also a means of communication with each other, friends, family (I know because the bottom of his email likes to brag he's been using it), colleagues and the wider world. It's a source of entertainment and occupation (if playing angry birds can be called that) but probably most importantly it's a way of interacting. Now it might not be interaction in the way we immediately think, of like sitting in a cafe over a cup of coffee or playing a game of

flying wet bunnies in the bath (for those of you not aware of this game it involves the bath sponge and water and my Dad getting in a lot of trouble for the state the bathroom got in at bath time). However, if we think of interaction as having an effect on one another, another person or thing, we can see how a tablet supports a whole range of interactions.

You will have guessed by now that I don't have my own tablet but I do have use of a tablet, more specifically an iPad, at work. Seeing how my brother and his wife use their tablet has directly influenced how I use that tablet with the people I work with. I am a speech and language therapist and work with people with learning disabilities, including those with profound and multiple learning disabilities. I definitely don't fall into the technophobe bracket but I am not so wowed by technology that I can't see its limitations. When I first became aware of tablet computers that cost anywhere from £125 (if you opt for an android tablet, more if you go for an iPad) my mind immediately went into overdrive with the possibilities for the people I work with.

For a start the touch screen immediately allows people with a range of physical disabilities to access the device. There is always the option to connect a switch if this makes access easier for an individual and to control what they can access if there is potential for them to accidentally select apps. Any tablet computer is light and portable. This comes at the cost of not being especially robust but a readily available plastic film can protect the screen and a range of soft and hard cases are on the market to provide protection from dropping and throwing. There is even a waterproof case available that means you can still use the tablet in the bath and swimming pool! It shouldn't matter but these tablets look cool and stylish and they are increasingly becoming a part of normal life (I am sure they will be at the top of a lot of people's Christmas lists). Their versatility means that not only can paid and unpaid carers use the tablet for interacting with others and the world around them but the people they support with PMLD can too. My exploration of the potential uses of our iPad with people with PMLD has involved talking to carers and colleagues, online research and from showing our tablet to people with PMLD. I have set out below a number of ways we can see/have seen the iPad being used. This is by no means exhaustive and apologies for any glaring omissions.

Communication Passports and Life Stories

The tablet can be used to create and share a communication passport or life story. The built-in camera and video camera means that it will be easy to compile and keep up-to-date. If a picture can replace a thousand words then a video can explain in seconds what we can't put across in words. The videos can also provide opportunities for individuals to engage in meaningful interactions with people around important aspects of their life and care. I have experience with using an app called Scene and Heard (available for the iPad from Therapy Box for approximately £35) to link together pictures, videos, spoken labels and symbols and can see

how it would allow you to produce the ultimate interactive communication passport or life story.

Story Telling and Choice Making

The tablet also provides the opportunity for an individual to not only pass on information but to engage in and enjoy the telling of a story, whether that be fact or fiction. By using apps to add in sound effects, such as the whoopee cushion app, or visual effects, such as the pocket pond app, (both free) an individual is able to contribute to the telling of a story. By engaging in the process in this way the individual has the opportunity to experience that their actions have immediate and enjoyable consequences. Learning this is fundamental to communicating and interacting with others. The beauty of the tablet is that you have a whole host of apps at your finger tips that provide a means for developing these skills further. Without the need for a box full of switches (and functioning batteries) and appropriate photos, you can with a few taps create a choice board for an individual at a level that is meaningful for them. I have used the Choiceboard Maker app (free) on our iPad and created a choice of 2 activities using photos taken with the iPad within minutes.

Exploring Sensory Experiences

Clearly a tablet is limited to only offering individuals the opportunity to explore different visual and auditory experiences but there is such a range of apps to explore it's easy to forget this. Individuals I have worked with have enjoyed controlling how Fluidity (free) looks, watching the fireworks they have caused to go off (Fireworks Arcade, free) and examining how the Photo Booth (free) alters their appearance. Others have enjoyed listening to the noise the Drum Kit (free) can make (their carers less so), hearing Talking Tom (free) replaying their vocalisations at a high pitch, or simply listening to their favourite song on the music player. I would like to end with a few words of caution. As with the tablets my brother took as a child, a tablet computer can only be of benefit if you use it and use it with caution. To be of benefit to a person with PMLD a tablet should never be used to replace spending time with that person. It can, however, be used by a carer with the necessary skills and knowledge and realistic expectations to enhance the time they spend with the individual they support.

I would be really interested to hear of your experiences of using tablets with people with PMLD and any apps you have come across that have had a positive reception.

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Shut up! Phew! Phew!

iPads, apps and special learners

Flo Longhorn

Modern technology has had a tremendous impact on very special learners lives in the last couple of years. The arrival of portable touch screens (such as iPads), with millions of applications (apps), has opened a new world of engagement, excitement and opportunity. The most significant fact has to be, that there is really no longer a need for a 'special needs' category of person. Everyone is in there with a powerful tool of learning and pure pleasure based on personal choice, not on disability. The touch tablet itself, can be tweaked to accommodate anyone, cradle to grave.

Ipads are proving powerful, user-friendly tablets to use. The sensory elements of touch, sound and vision are really good, with the proviso that the apps are wrapped around with sensory events and materials. The main problem I had in using iPads ceased when I bought an indestructible protective cover (designed for use by the SAS). The second problem remains of how to leave without injury, whilst wrestling my iPad away from a keen user!

With the careful selection and provision of apps, personalised learning can take place in any setting, anywhere, anytime for any learner. They are mainstreaming without effort. This will become most significant when the very special learner leaves full time education. They will take with them their senses and a very powerful piece of technology, their iPad, to continue with lifelong learning.

So, here is a range of apps to encourage the happiness and chuckle element in very special learners' lives. Hopefully these simple but effective jokey apps will provoke curiosity, anticipation and sheer horror with a bit of wickedness thrown in for good measure!

Censorship of these apps by those in power? Mmmmm, there's a moot point.....freedom of apps....

Communication

This is the only area that really needs to make provision for learners who require access to a wide range of methods of communication. However, here are some non-specialist apps that are effective fun for the first levels of communication.

'Hey, I am here!'

Buzzer
there is a screen with rows of buzzers to press. Loud clear buzzing noises to attract attention in a swipe.

Siren
A choice of a piercing fire engine, police car, ambulance or SWAT vehicle is sure to catch attention and annoy!

Air horn
three horns to choose from BLAST to hurt adult ear drums.

Party popper
a party popper appears on the screen, swipe the string and POP! A great explosion party!
fake-a-bell
There is a selection of bells to ring and attract quick attention.

'Shut up! Go away'

Shut up!
Press the button and 'shut up' blasts out. Take it a step further, tweak the setting so the speaker can say it in other languages. German is best 'DEN MUND HALTEN!'

'Call and response'

Talking Fred
Fred is a whacky pig complete with piercings, leather gear and attitude!

Dork
He is a talking monster who tells jokes as well!
Jam Dance Jay D
A hoodie, moody guy with a sneer, great to talk with teenagers.

Wicked story books

Horrid Henry horrid app
Beware, this app includes 'flick the bogie' and a water balloon battle.....
Alpha belch
An ABC with a difference, rude farts and belches from animals.
The Grunts: a beard of bees
Build a beard of bees in the funny story.

'Up your nose'

clean my screen
Touch the blank screen and a slurpy animal tongue washes the screen to reveal themselves. Disinfect the screen afterwards.....
light switch
Switch on and off, on and off, on and off.....a great calmer for upset obsessives.....

Anti-social

Spit on you
This game is what it says. Spits come from the top of a roof so nobody sees the guilty party.
'Graffiti art free' and 'spray paint neomad interactive' for underground Banksy art.

Santa smash
Little Santas pop up and down , see how many can be smashed!

'farts and belches finale!'

Feed the monster
A 3D animation. Create a monster of sneezes, zits, burps, then a feeding frenzy!
Atomic fart Burp and fart piano Fart fart fart Fart cushion

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Renew your Subscription for 2013

Now that all subscriptions run from January each year it is time for everyone to renew for 2013 - apart from those of you who are very recent new subscribers, and those early birds who have already renewed. As usual, a separate subscription form is included with this issue and we are pleased to be able to keep the cost at the 2012 level.

Passwords will remain active until the end of March to give you time to send your renewal, but please do this as soon as possible so that it doesn't get forgotten. If you have forgotten your password let me know, and I will send it to you.

Happy Christmas to all and happy reading in 2013!



Marlborough School

Karen Sells

Marlborough School is a secondary special needs school for students aged 11-19 based in Sidcup, Kent and we work with some of the borough's most profoundly disabled young people. As the ICT Co-ordinator I faced a dilemma.

Our ICT provision was historically centred around an ICT suite with 10 computers and interactive white boards in each classroom with adaptations where possible. Students were used to sitting at traditional often impractical workstations to undertake their ICT learning. The changing needs of our students meant that going forward a revolution was required in order to help them meet their potential.

The leader of that revolution was Apple and with the support of the Head during December 2011, students were given the opportunity to trial for two weeks the use of iPads during their ICT lessons with a view to expanding

our reliance on the conventional PC based model. We were seeking a solution to meet the ever growing complex needs of our students and embed ICT more easily across the curriculum. Minimal instruction was given in the operation of the iPads and students were encouraged to explore using their prior knowledge of ICT and their natural instinct to touch things.

A large majority of our students find it difficult to manipulate a mouse or access a keyboard successfully and this results in them requiring a large amount of adult intervention to allow them to navigate through and engage with programs. The iPads enabled our students



to access a wide variety of apps with a greater degree of independence. The overwhelming success of the trial resulted in the school initially purchasing ten iPad 2s in February 2012 and a further ten in April.

The iPad has made it possible for our educators to embark on a collaborative journey with their students, to explore the device and get used to a distinctly different way of learning through the use of free and paid for apps across all aspects of the school day.

Seven months on we have seen a significant impact on our students' gross and fine motor skills, communication skills, cognitive skills and self-help skills. But, most importantly the iPad has enabled us as a school to start to embed a strong element of flexible personalised learning with a curriculum offering that places our learners firmly at the centre. But the journey doesn't end there, as our learners continue to drive and challenge our ICT provision and we look for new and innovative ways to use the iPad to support their learning needs.

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The emerging role of the tablet computer in specialist education: How prepared are families and carers to make best use of new technologies?

Fiona Fraser

I left a career in IT design and manufacture to care for my husband, disabled in a road traffic accident. During his recovery I worked as an integration assistant in a mainstream school, a key worker in a play centre, a regional manager for a parent led social enterprise supporting families with disabled children and am now a personal assistant for 3 young people with PMLDs. This article is based on work I'm undertaking for a master's degree in special educational needs (SLD, PMLD and complex needs) at The University of Birmingham.

Over the past year I have observed the introduction of tablet computers (iPads and similar) into special schools. Two of the young people I support have their own tablet PC sent home with them from school and yet they aren't being used at home. Having studied alternative and augmentative communication (AAC) systems in my postgraduate course, I was curious why such versatile and portable equipment was not helping to bridge the gap between home and school, to stimulate communication or simply entertain. To find out more, I conducted interviews with two parents regarding their experiences. New media such as practitioner blogs and internet news sites (Hirstwood, 2012) gave useful insight as to how this new technology was being used in specialist settings.

In mainstream settings, having a "special needs" device can re-enforce difference and mark a child as an outsider. These well established devices have done much to serve the needs of disabled children and adults alike and will continue to do so. However, contrary to the potentially stigmatising aspects of specialist IT, the flexibility of an "off the shelf" tablet computer permits all users at all ability levels to benefit, and brands such as the Apple iPad carry a desirable label. When everyone uses the same equipment the stigma is removed. As the use of hand held computing devices in schools grows, to deny them to children with SLD and PMLD would further exclude them.

Murray & Aspinall (2006) have documented the importance of IT training for parents, teachers and educational support workers. It has long been known

that lack of competence in the circle of supporting adults is a major reason for the failure of IT tools to work for the child. This highlights the need for a close dialogue between parents and schools when planning the delivery of personal tablet devices. Flexibility is the key to delivering the most accessible training for this group of learners, with the onus on schools to provide a range of options to choose from. This has implications for school budgets and project timescales and needs to be accounted for from the earliest phase of a school's project planning

Providing an opportunity for the child to communicate choices is very important. With its portability, the tablet can cross the home school divide and enable a common language across both settings. It is hard to ignore links between poor communication and behaviour that challenges both teachers and parents of children with SLD and PMLDs (Enable Scotland, 2012), or to imagine the frustration felt by a young person when those around them at home or school can't communicate in their language. If the tablet can promote a unified communication channel, it is possible that behaviours triggered by such frustrations might diminish. Little is known about mental ill health in people with SLD and PMLD (Hatton and Taylor, 2005), but it is possible that with decreased stress levels, fewer harmful behaviours and an easy to use communication tool, the tablet might also play a part here.

Listening to Parents

The parent interviews conducted were semi structured and open ended with common themes

emerging. The primary finding was that training is important and needs to encompass a wide circle of individuals including parents, siblings, grandparents and carers using varied and flexible formats and delivery mechanisms. Hopes that tablets might support the child in communicating choices were balanced with fears of damaging the equipment and neither parent envisioned using them for school work or communicating with the school. These themes are not new and the challenges faced in implementing IT solutions for children with learning difficulties remain constant.

However, it may be that in some circumstances the tablet provides less of a challenge to the adults and siblings involved than these results indicate: many families already have access to tablet technology and the interface is almost identical to that found on many modern smart phones. Also, the use of icon (picture) driven, touch screens has been designed to provide a more intuitive user experience.

Unsurprisingly, both parents interviewed expressed concerns about the risk of damage to the school equipment. While tablets are substantially more robust than PCs or laptops, they are still susceptible to high impact knocks and bumps. Questions surrounding insurance and liability need to be answered before a tablet device is sent home with a child. Protective cases can help, e.g., the TabToob, a shock proof protective sleeve designed by a parent of a child with severe learning difficulties who describes her product testing: *"They have been bounced downstairs, outside, on slate, on wooden floors, thrown from head height and off tables. They have been bitten, bashed and dribbled on.* (TabToob, 2012)

Providing a protective cover adds to costs but can reassure parents, save money through fewer breakages and help ensure that the device is used.

Both parents saw a role for the tablet as a multimedia platform and entertainment hub, along familiar lines, naming the types of recreational activity generally available on most family computers. While insightful, these views fail to engage with the new possibilities generated by the nature of tablet technology and how it differs from traditional equipment. Training could help parents to understand and unlock the potential of these new devices.

Only one parent mentioned the tablet's role in controlling a sensory environment and yet this is where tablet devices have proved to be low cost replacements for expensive custom built systems. Hirstwood (2012) has demonstrated this, opening the way for children and young people to enjoy multi sensory stimulation and relaxation in their own homes or other shared spaces at greatly reduced cost and without the need for technical expertise.

The uptake of tablet computing in schools is helped by the ready availability of free or relatively inexpensive learning software. For children in the earliest stages of learning (P1-4) this often takes the form of games using touch or switch devices. As the parents in this study already relate to the tablet as a recreational device it is not a huge leap to position educational game playing under the same banner. If training is available to the wider circle of carers, the child's opportunities for informal learning broaden significantly.

The opportunity for personalization brought about by the child's "ownership" of their tablet holds huge potential for enhanced home-school communication. Each child with a tablet has their own personal learning device, with content tailored to meet their learning needs and available to them at all times, containing a record of their activities available to parents and teachers alike. Another area of potential benefit is the use of tablets as an electronic communication passport (Call Scotland, 2012), a live and accessible document detailing likes and dislikes, preferred methods of communicating, eating, drinking and other important information such as health status or medication needs. Where a child uses body language or idiosyncratic behaviours to communicate, a parent or carer can record video clips to enable others to support the child more effectively.

Conclusion

My small study can in no way be considered as representative of the wider population as a whole. However, what became clear is that barriers exist to the home use of school supplied tablet computers. Broadening the use of tablet devices through training to include extended family, care workers and other professionals is important and could reduce stress levels in both adults and children and help to defuse behaviours that challenge us. There may also be benefits for mental health particularly for the child and those living closely with them.

The tablet computer has the potential to bridge gaps in communication between home and school as well as provide additional opportunities for the child. This presents us with a rich area for further research.

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Beam Me Up!

Tim Swingler

A small girl is standing in the middle of a large hall. The other members of the class are watching her intently – two of the boys have already tried out this strange new instrument, playing drums and loud guitar with an enthusiasm which threatened to eject them from their wheelchairs. I ask her what instrument she would like to play and she replies immediately: “I want it VERY romantic, and YOU LOT...”turning to face her classmates “are NOT allowed to laugh”. I select a ‘string orchestra’ setting and turn up the volume. She throws her head back and her arms out and begins a dance with all the high drama of flamenco-meets-tango-meets Isadora Duncan, totally immersed in sound and movement. After five minutes she stops and says “I’ve finished”. After a brief, stunned silence, the audience applauds. NOBODY laughs.

Joey lies on his side on a trolley. Oxygen streams through the humidifier and tracheal tube to his neck and the nurse who is with him uses suction to clear fluid from his mouth and throat. He has grown longer and thinner and his skeletal arms and legs very rarely show any movement. His eyes, though, are alert and in motion, as though searching for the bass line that weaves around the bubbling accompaniment of the humidifier. If you look more closely a different picture emerges. That roll of the eyeball is always accompanied by that particular musical phrase, that slow blink of the eyelid by another, different, set of notes. Sometimes he makes the same movement several times in succession, rapt in concentration. He is playing the bass with his eyes. (1)

Emma is a 13-year old on the Oncology ward at the end of her chemotherapy treatment. She “never wants to take part” in any activity, preferring to be left alone, according to the hospital staff. Ignoring this comment, I went over to her and asked her to tell me her name – from the look she gave me it was as if I’d asked her to climb Mount Everest. Names abandoned, I gave her a sensor and some switches and showed her how to play – she seemed intrigued. I watched with increasing delight as she became more adventurous with the sensors. She soon discovered that with the sensor in her hand she could use her legs, her elbows, and her beautifully bald head to activate the music with the beam. A real sense of cheeky fun came through, and her written comment at the end of the session was “Enjoyed all of it. Lightened my day.” (2)

Most of us consider ourselves to be ‘non-musicians’. We may have tried to learn an instrument in the past, but been defeated by the complexities of notation, or the

skill and dedication required to attain even a basic level of mastery of the instrument.

So – imagine an instrument which does two radical and unexpected things. Firstly, it can sound like anything you want it to (an electric guitar, a harp, a waterfall) and, secondly, you can play it straight away. Imagine how motivating and empowering that might be for you. Now imagine how much more profound that experience could be for an individual with PMLD.

Soundbeam – commonly described as ‘the invisible keyboard in the air’ – is just such an instrument. It utilises special movement sensors to detect body movements, however small, translating these movements into music and sound. The technology has a respectable pedigree, being produced by Electronic Music Studios in England, the people who helped contribute a lot of the electronic magic to the albums of musicians such as Stevie Wonder and bands like Pink Floyd, Led Zeppelin and Roxy Music in the 1970’s. The device has undergone extensive development and improvement since it first appeared in 1990 and the new Soundbeam 5 offers an all-in-one unit with minimal setting up, wireless switches, recording functions, an extensive instrument and sound-effects library, as well as many other features.

Ironically, Soundbeam was originally conceived as a performance tool for dancers and other artists, giving them a new relationship with music and sound by making it possible for them to control and shape the aural dimension of their performance with expressive gesture and movement, rather than being purely responsive to this aspect of the performance.

However, those professionals working with special needs individuals were not slow to recognise the potential of the technology for the recreation, therapy and education of the individuals with whom they worked. It has become increasingly clear that combining purposeful, intentional, self-motivated movement with the powerful stimulus of music can have profound implications for youngsters and adults across a broad spectrum of age and disability.

An individual's movements in the beam – anything from the blink of an eye to a daring leap across the room – will do more than simply generate random 'noise'. The programmability of the system means that coherent and meaningful musical material is generated regardless of the degree or quality of the movement performed: there are no mistakes (4), and consequently the pressure to generate right/wrong responses is removed. At the same time, varying levels of complexity can be loaded into the 'sonic space', making the Soundbeam a 'serious' educational tool which can be used in a progressive way. The developers have tried hard to create something which squares the circle of being *both* instantly rewarding and highly physically and cognitively accessible, *and* continually challenging and exciting over time, leading to enhancements in playing skill (as would be expected with any 'normal' instrument) and a continuing sense of achievement and internal motivation.

In traditional music therapy, the less the 'client' is able to say something with sound because of a physical or cognitive disability, the heavier becomes the therapist's responsibility for empathy and interpretation. The main focus and engine for the mood and meaning of the music which is happening is on the therapist, and this creative

and interpretative role is increasingly shifted away from the client with more profound levels of disability. This allocation of creative 'power' may have no clinical or therapeutic rationale, it may simply result from what is physically possible. New evidence suggests that interactive technology like Soundbeam can provide answers to this problem.

The experience of *initiation* is central to the success of Soundbeam, especially for individuals with profound disabilities. If one's overall experience of life is essentially passive, it may be difficult to develop any concept of 'selfhood', any idea of oneself as a separate individual. What Soundbeam offers, perhaps for the first time and regardless of the individual's degree of immobility (or what some teachers describe as 'unreachability'), is the power to *make something happen*. This is the vital experience of "that was me!", a 'Eureka!' moment which can function as the foundation stone for further learning and interaction.

Work by Dr.Phil Ellis (5) at the Institute of Education at the University of Warwick and latterly at the University of Sunderland in England, has provided us with the first systematic long-term evaluation of Soundbeam's potential for PMLD-labelled children. The beam is positioned so that as soon as the child begins to move an interesting sound is triggered, motivating further movement and, eventually, radically enhanced posture, balance and trunk control. All of this is accomplished in parallel with a strong sense of fun and achievement

From systematic analysis of videotape session records, Dr. Ellis has identified several criteria of progression and development:

Dependent	Responsive	Independent
Isolated	aware	contributing
Indifferent	reactive	expressive
Frowning	smiling	laughing
Crying	laughing	expressing
Silent	content	receptive
Withdrawn	thoughtful	communicative
Inward	poised	interactive

He notes that children with PMLD respond to Sound Therapy by:

- performing, listening, verbalising, 'composing' with sound;
- often showing 'aesthetic resonance' through telling facial expressions;
- being actively involved for extended periods of time;
- revealing an ability for concentration not apparent elsewhere;
- beginning to discover, explore, give expression to and communicate their own feelings;
- making significant physical responses - movements and gestures which hitherto have not been seen, or have not previously been made independently.

"...in addition, a change has been seen in behaviour patterns beyond the immediate environment of Sound Therapy. Some children are now more self-aware and are interacting...Other children show more tolerance and a growing awareness of other people, moving towards interpersonal skills."

We are taught that 'serious' musicianship demands years of dedication. So what are we to make of devices which allow musical expression to happen almost immediately? How can we assess the musical validity of what we hear? With conventional instruments, designed for those with average or above-average physical, mental and sensory functioning, the time gap between musical imagination and musical realisation takes years to develop. Good technology radically shortens this gap. It extends the limits of selected-scale or percussion-based work, and it asks the player to learn not the technical skills of the traditional instrumentalist but the freedoms and disciplines of improvisation. This kind of music is difficult to evaluate because there are no right or wrong ways of

playing it - a performance of a piece of music played with Soundbeam will rarely sound the same twice; but it is possible to assess the extent to which the player enjoys it and gets a feeling of achievement from it, and some of the research reviewed here indicates strongly that the attainment of significant milestones in the physical, cognitive and social development of individuals with a range of disabilities can be radically assisted by the use of such technology.

(Names have been changed).

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Welcome to the iBand Taking down the barriers to musicmaking for children with PMLD

Carrie Lennard

"Music bypasses the cognitive processes" (Pat Lennard 1980) Just about everyone, everywhere, regardless of who they are, is affected by music. The appreciation of music does not require cognitive ability even though it is a language in itself. This means that, through the enjoyment of music and music making, it can be employed for its own musical goals as well as being a motivation to move, feel, learn about all sorts of events and to use our voices. This comes about through the structure of music itself. By being able to connect the children musically, i.e. same keys, complimentary scales/modes, syncing of rhythmic sounds across iPads using wi-fi, underscoring with the guitar as the children are playing, hearing the notes that the children sing and being able to enhance the awareness of their skills by repeating them back and including this into the whole experience, we are able to provide the unique experience of connectivity to each other.

The initial idea came to me from meeting a dance teacher with cerebral palsy called Alan. I met him last year when he came into our school to run dance workshops. Alan communicated to us through a woman who facilitated his communication and a computerised speech board. He told us that it took until he was thirty years old before people realised that he did not have severe learning difficulties. Even though this kind of revelation should shock me, I was not surprised at all; and it got me seriously thinking about what I could do in my music lessons to make a change. The iPad is an excellent tool and it is easy to see how effective it could be for children with profound and multiple learning difficulties. The problem was getting hold of them and in sufficient numbers to make this idea a workable project that could then be developed. I put together a proposal to raise funds for 8 iPads. The Breakaway Committee came forward and agreed to fund them so long as 4 of the iPads were utilised throughout the school and that the remaining 4 could then be used just for the music project. Paul Mcmanus from Music for All, kindly donated four small guitar amps so that each child could hear what they were playing/singing.

Drake Music (the charity provides instruction to establishments on the use of music technology, thus breaking down barriers for people with learning

difficulties) had previously been booked and they started working with us, one session a week, over ten weeks. It was fantastic to have Gary Day and Gawain Hewitt and their expertise. We realised, pretty quickly, that this project was unique and we have continued to be excited about what we're doing and where we are going. The possibilities are opening up to us.

When the children come into class on Friday mornings and see all the equipment set up ready, they smile big smiles. And as soon as they are placed in front of their iPad instrument or Soundbeam (movement activated sound maker using a sensor connected to a sound module/ iPad/ keyboard) and are connected up with their wireless microphones, they start to move their hands and arms to reach out and play, to vocalise and to look across at each other as they engage in the exciting shared experience. The parents are very happy about what they see their children doing. We video lots of the sessions so that they can see how their child is progressing and enjoying themselves. We gave our first big performance in front of the whole school at the end of the summer term. It was a gas!

I am now investigating the feasibility of using a Kinect sensor with the appropriate software with a view to the children creating music with their movements - like the

Soundbeam but more so. I am meeting with Simon Holland of the Open University to look at such possibilities. In my mind, the ramifications of this is that, sometime in the not too distant future, we might be looking at a way for children with very restricted movement to "speak" using their individual style of movements with some kind of modified Kinect/software setup. Why not?

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PS Carrie Lennard has been the music teacher at Mandeville School in the London Borough Ealing for seven years. She has worked as a class teacher as well as being the music coordinator in other London special schools over the last thirty years. Back in the days of Inner London Education Authority, she was a project coordinator at the Resources for Learning Difficulties Team for nine years where Carrie produced and co-produced a variety of music learning materials (Body and Voice LDA; Caterpillar; Galaxies - multi-sensory music-drama for children with PMLD; Seaside) as well as running courses and project working parties.

Seeing Beyond and Tell me a Tale

present

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Tunnels mixes live music, sign and sensory experiences to create a unique and original piece of theatre specifically for teenagers with Profound and Multiple Learning Disabilities. Every young person must be accompanied by a parent or carer.

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Performance times: 11am, 1pm, 5pm

Performance length: 60 minutes

Tickets: £8.00 per young person (accompanying adult free)

Box office: 01603 63 00 00

Maximum 6 young people per show

When i means much more than I

Ken Holland and Annie Lawton

Using digital technology to involve and include people with complex needs and multiple learning disabilities.

Many organisations now use a wide range of technology to enable people with complex needs to communicate, and be involved in telling their stories, planning their lives and sharing their passions, interests and skills.

The emergence of I-Pads, Apps and recognition software can open up a new world for people with learning disabilities, people with complex needs and people who use non-verbal communication. I remember when Facetime first came out and thought *'with a little adjustment, this would be perfect for people with learning disabilities to keep in contact with friends and family'*. Technology moves at a fast pace and it wasn't too long before Apps like 'Facetime' were being adapted and used by young people and adults who had previously been excluded from the world of technology, social media and digital media.

But many front-line staff in particular feel they lack the confidence or resources to open up this world to the people they support and cannot see that it is often just a simple adaptation of the things they use every day.

In this article, I want to share the experiences and impact of using video, audio and photos as part of VOX 'Living My Life' reviews.

VOX (UK) Community Interest Company was established in 2011 and supports individuals and organisations to think about outcomes and how they might enable people to have a better quality of experience. We call this 'Living My Life' reviews.

Living My Life reviews find out what support or services are like by looking at outcomes for people who use them. The key to the reviews is to move away from 'the way that services are provided, to the way they are received' and suggest what might need to change or get better

A Living My Life review is simple yet very effective and works particularly well for people with non-verbal communication, complex needs and people with multiple learning disabilities. This is because it primarily uses observation on a 1:1 basis and in a variety of settings – for example, home, school, day activity, community, hobby etc.

Reviews are carried out by a team made up of staff, families and people from outside the service. Each team member is paired with one person who uses the service and visits and observes them over a 6 week period to find out what happens in their life and get a feel for which outcomes are working well and those which are not working so well.

Following this period of observation, the team come back together to share what they have found out and learnt. VOX recognises that A4 reports, wordy presentations and reams of flip chart bullet points can exclude some people and de-personalise the people who are the focus of the review. Instead, we ask the team to use posters to share what they have found out. These are a mix of pictures, drawings and photos that tell others what life is like for the person they have spent time with. Posters work really well and ensure that people who use other forms of communication and who are part of the review team are fully integrated in the process and included in the work. They are also a very powerful way to get others to see life through the person's eyes and 'put themselves in their shoes'

More recently, we have seen the use of video and other forms of digital technology to capture what life is like for the person and this has proved to be very successful. Some team members have shown a short video, which can include photos, music, film clips and words to powerfully convey the person's experiences.

There have been other times where the use of technology has helped identify what the person may or may not like by looking at their responses to different You Tube clips, photographs projected onto a wall or sounds on a mobile phone. For example, finding out that one man likes surprises, unexpected loud noises and has a real sense of 'cause and effect' made the staff team think about how they could really broaden his range of experience.

Using technology to find out about and include someone with complex needs can offer a number of benefits. For example:

- Videos enable the person to have more control over what they want to share about their lives – through the use of facial expressions, sounds and gestures or using a large switch to stop and start the clip.
- Easy to use video cameras such as a 'Flip Video' are really simple products that, with minimal support, the person can use and instantly see what they have taken. This works really well if the camera is plugged into an interactive whiteboard, TV or laptop so they can view the images larger.
- Playing music, watching a person's responses to different pieces and involving them in indicating which music they want to share moves away from making assumptions and can provide some real surprises
- Showing digital photos on a screen (laptop, computer, TV) allows the person to indicate which ones they like and want to share and by adding sound and music, you can bring their story to life. Again large switches or Big Macks can give the person real control over what is shown and for how long

None of this is new but such technology is still not as widely used as it could be and a number of organisations have tried to address this. The Mencap - 'Involve Me' project has online resources and guidance to support staff. Acting Up 'Multi-Media Profiling' and The Rix Centre's 'Big Tree' project both show how you can use a range of multi-media technology (software and hardware) to support people to communicate and share their stories.

The power of technology as part of a Living My Life review is that it often highlights aspects of a person's life that are sometimes overlooked, mis-understood and or simply not recognised. For example, at a recent review the use of video and technology was clearly enjoyed by the person who was being visited, so much so that they now regularly use a video camera (with support) and music as a diary to tell others about their life and experiences. Before the review, support staff were not aware of this interest and had made an assumption that he would not be interested in or able to use technology. This has changed the way his person centred planning meetings are run and they now start with a film show.

Another example, where a person has embraced technology as a result of being part of the review, is the regular use of Skype to see family and friends on a regular basis, listen to their news and share what they have been doing in their life, again using video clips, photos and playing, music. For this person, her skype has

become an important part of her life and preparing for this regular event has introduced a new activity, one that she is very much in control of.

The ethical issues of using video and photos as part of looking at outcomes is important and we only advocate their use with the agreement of the person concerned, their family, circle of friends and other significant people in their life who are able to contribute to this important decision making process.

Even if team members do not use technology during the visits, we encourage them to think about creative ways for people to tell their stories to others in the final session which takes place about twelve months after the start of the review. This is a celebration event, where everyone who has been involved – people visited, their families, friends, the review team, local community members, other external organisations and individuals - get together. They celebrate what has changed for the people, what difference the review has made, what is now working well and the future plans in place to further improve the quality of experiences for everyone the service supports.

An example of this is where young people with complex needs were going through transition from school to adult services and wanted to share their fears and worries at the celebration event. They made a short film entitled 'On the Edge' which highlighted how they were feeling by filming a journey along Hadrian's Wall and choosing the music to capture the mood. No words were used in this video, but its message was extremely powerful.

The final celebration event is fun and has in the past included music, drama, role-plays, workshops, presentations and posters. Increasingly, these events include digital technology, particularly videos, film and music. This is a very powerful way to put people who use the service at the centre of the process and ensure we are talking *with* them, not talking *about* them. The pride and sense of achievement at seeing your work on the big screen and valued by others sends out a strong signal about partnership working and giving people a voice in the services they use.

Contact details

If you want to find out more about VOX Living My Life reviews visit our website:
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Ken Holland and Annie Lawton
Directors
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Multimedia Profiling Project - Report Summary

Naomi Rezzani

Scope's Communication Resource Centre

Scope is a not-for-profit organisation providing disability services throughout Victoria, Australia, to thousands of children and adults with physical and multiple disabilities

In 2010, Scope's Communication Resource Centre was awarded grants from the Telematics Trust and the Jack Brockhoff Foundation to work on an innovative and important project. This Multimedia Profiling Project aimed to resource and co-ordinate an approach to multimedia communication profiling / multimedia advocacy for people with severe to profound intellectual disabilities.

The approach used to create multimedia communication profiles in this project differed from existing approaches in Australia and the UK. The profiles are designed to be stand-alone as they contain videos, photos and brief written descriptions that clearly convey the individuals' perspectives. They do not rely on another person's voice-over or additional commentary. For people who do not use speech or other formal systems to communicate, a multimedia profile can assist them to have a 'voice'. A multimedia profile can provide a range of communication partners with much needed information such as; how a person communicates, how a person likes to be treated, their strengths, their health needs, their relationships, their support needs and their likes and dislikes. An individual can show their multimedia profile in many ways, such as in planning meetings, when transitioning between services or with a new service provider/support worker.

Each individual with a disability was required to have two to three people who knew their communication well enough to support them to participate in the project. These people formed a Circle of Support for the project. People in the Circles of Support included parents, disability support workers and speech pathologists.

Scope's Communication Resource Centre assisted eight individuals and their Circles of Support to develop multimedia profiles. The approach was an effective way to capture quality information about each participant's

communication, which included their routines, likes/dislikes, expressions and the interaction with communication partners. The multimedia profiles enabled effective transfer of information between project members and was a more efficient method in comparison to reading written information.

The pilot also compared the experiences of creating the DVD/USB format vs the website format (www.multime.com) and there were positive and negative features with both formats.

To make the DVD profile multimedia such as videos and photos were collected, edited and then developed into a movie that was saved onto a DVD. Each movie was approximately 25-30 minutes long and had 4-6 chapters.

Each participant who chose to use Multi Me - www.multime.com to create their profile were provided with a 12 month subscription, which at the time cost approximately \$140 per person. Each individual received a username and password for their own page on the website. During the project, staff from the Communication Resource Centre and members of the Circle of Support administered the participant's site. Multimedia was collected, edited and then uploaded into the 'stories' section of the website.

On reflection, more time was needed at the beginning of the project to understand each participant's

communication and to provide support to the Circles of Support with their understanding of each participant's routines, communication attempts, expressive communication and how to communicate effectively with participants.

The project aimed to assist the Circles of Support to complete the different stages of developing each multimedia profile including: planning, filming, downloading, reviewing, editing, uploading, creating profiles using basic video editing software. In reality, 75% of the Circles of Support contributed to the planning, filming and downloading, but had limited time and required a great deal of support. Scope's Communication Resource Centre committed nearly 1000 hours to the project, equating to an average of 80-125 hours per participant. A large proportion of the work was completed by technology assistants to complete the editing, uploading to Multi Me and production of the DVD/USB profiles, where applicable.

The Communication Resource Centre purchased separate storage for video footage in the form of portable hard drives, as the size of the video files would have had a significant impact on the Scope servers. The Information Communication Technology in some workplaces limited the participation by staff due to the limited software available and restrictions on using USBs or playing DVDs on computers. Internet bandwidth was also a factor when delivering support to regional areas via web conferencing.

A set of six Tip Sheets was developed covering areas such as filming tips, downloading footage and using Windows Movie Maker. Some of the relevant Tip Sheets can be downloaded from the Scope website.

www.scopevic.org.au (Resources). Training sessions on Multi Me and Windows Movie Maker were delivered both face-to-face and online to members of the Circles of Support.

Feedback and project evaluation

Feedback was collected from the Circles of Support throughout the project and a formal evaluation was also completed.

The feedback from the Circles of Support revealed that families and staff became more aware of participants' non-verbal communication and staff were more willing to spend time with participants throughout the project.

It was found that a special/dedicated video camera was useful to capture predetermined events or extended periods of time. However, to capture footage spontaneously, flip cameras, digital cameras or mobile phones were preferred.

In the formal evaluation one-third of respondents reported that time was a significant barrier to working with a new approach such as multimedia profiling. Further barriers were skills and confidence with the technology. However, respondents also reported the support materials (Tip Sheets) were very helpful.

Evaluation results also showed that the multimedia profiling approach was an effective way to share information, particularly when compared to reading written information. There were mixed responses regarding the satisfaction with the consistency of sharing information. This may have been due to the limited time that staff, families and therapists had for using and sharing the multimedia profiles with others.

Respondents reported that they had a better understanding of participants' communication and their verbal and written descriptions of participants' communication was much more detailed and informative. This was a result of the time Circles of Support had spent focused on the individual through filming, viewing video footage and talking together at meetings. Respondents also suggested that the multimedia profile conveyed so much more because it is visual.

It was found that multimedia profiling can be used by a person with profound intellectual disabilities to self-advocate, in a way that they traditionally have been unable to, as they usually rely on others to convey information for them. Respondents also reported that the aspirations, hopes and dreams of project participants could be understood more easily through the participants' multimedia profiles.

A Multimedia Profiling Project Presentation has been created. This presentation includes excerpts from some of the participants' profiles. Thank you to those individuals, families and support staff for giving us permission to share these with you. Scope's Communication Resource Centre can provide a copy of this presentation on request.

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Making Communication Accessible

Ken Holland

WebEnable share their experiences of supporting people to use multi-media to enhance their communication

WebEnable is a social enterprise, providing websites, films, sounds and images for accessible communication.

WebEnable was founded in the last century to bridge the digital divide opening in front of people with learning disabilities. We pioneered easy to use websites with, crucially, navigation that kept people feeling safe in the environment of the internet. The method has been adopted by 28 partnership boards, local authorities, Mencap groups and many other voluntary sector organisations, in total about 200.

But our websites were not just for the consumer – the content management system we developed meant that, for the first time, people with learning disabilities could create their own websites. These websites were easy to manage, used pictures, symbols and photos to get important information across and more importantly, allowed the individual to build their own website of their choice. Examples have ranged from on-line CVs, video diaries, passions (football, music, sport) and important things in a person’s life that they want others to know about. So far, around 300 people have been supported to have their own website.

In this present century, WebEnable has become a provider of all things multimedia – websites, films for disadvantaged groups and excluded people and photography. Our progress mirrors that of the internet itself – from static words ‘n pictures to the full multimedia experience.

As the internet has become multimedia, people with learning disabilities can be well served by it. One of the uses is person centred planning. Person centred plans created on secure websites, to which the circle of support can contribute and engage with the person, have opened up a new world and one that is interactive, ever changing and live.

A secure login leads to a simple page with the elements of the plan laid out as symbols and words. Click on one of the symbols and the person goes to the page or pages where that element of the plan is laid out in multimedia format. Progress recorded and family, staff and friends

can evidence their commitment, be updated to show progress and, in the case of support staff and other professionals, be held to account.

No longer are the person’s records concealed from those who need to know – or from those who ought to know what has and what hasn’t happened. This private website brings transparency and the opportunity for two-way communication among those journeying through life with the person. The biannual review meeting becomes a thing of the past: the person now lives in a world connected with the people who matter most, with regular communication at times that suit the person and the people around them. This doesn’t replace the review meeting and with more and more people demanding a person centred review, the use of multi-media becomes a valuable tool for the person to be in and remain in control.

We have seen it work very successfully for people with different degrees of ability. For example, a young man in Cumbria whose abilities enabled him to run his own online plan, including linking to images on estate agents’ websites to show the kind of house he wanted to live in. This became particularly useful at his review, when he could clearly show the professionals in the room his personal choice about his preferred home, location and style. This was further enhanced by the young man showing his favourite colours, the friends he wanted to live with and/or spend time with and his interests that he wanted to continue doing.

Being interactive brings a person’s story to life and allows people to have more control over the important decisions in their life as well as the small ones that make someone’s day be a happy one. Another example is of a profoundly disabled man who had limited ability, non-verbal communication, but *could* just touch the large navigation icons on the screen. And, as he was using a touch screen computer – everywhere these days, like iPads, he was in charge. Having control of this simple act meant a huge amount to him – not just in terms of achievement, but to be in control of the route through his plan.

In both examples, the individuals have gone on to develop their skills at using multi-media technology and it is now a regular part of their lives, the way they are supported and the way they communicate with others. WebEnable continues to promote multi-media technology with people who have previously been excluded and are now supporting people to use, edit and upload their videos on-line for the world to see.

Contact details

If you want to find out more about the work of WebEnable please visit our website:
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Renew your Subscription for 2013

Now that all subscriptions run from January each year it is time for everyone to renew for 2013 - apart from those of you who are very recent new subscribers, and those early birds who have already renewed. As usual, a separate subscription form is included with this issue and we are pleased to be able to keep the cost at the 2012 level.

Passwords will remain active until the end of March to give you time to send your renewal, but please do this as soon as possible so that it doesn't get forgotten. If you have forgotten your password let me know, and I will send it to you.

Happy Christmas to all and happy reading in 2013!

"Wii" always have a great time...

Nina Martinez

Bexley Library Service started working with Carlton Road Day Centre five years ago. The Centre, one of three of its kind in Bexley, helps adults of all ages with physical disabilities, medical needs and profound and multiple learning difficulties, to access different activities during the day. Initially their photographic club came to Sidcup Library to use the computers to produce calendars, consisting of their own photographs taken during their weekly outings. Simple instructions and encouragement in managing a mouse, brought with it joy and pride from the service users as they could see the screen change in front of them. The Library Service was conscious of their needs and accommodated them with the correct equipment. In time they were able to upload their own photographs and produce some fantastic end products.

This led to an extremely successful exhibition of their framed work in Sidcup Library. During that time the local press and Councillors viewed their work and many items were bought by the general public. To date they have successfully held another three displays and are currently creating new work to exhibit in Central Library, Bexleyheath.

A group from the Centre now join me and a colleague for Nintendo Wii sessions. This group are of very mixed ability and age. They all have a severe learning disability and a combination of physical or medical conditions, some profound. Initially some members of the group found the whole concept of using the Wii controller an impossible and daunting task, but with regular weekly visits, laughter and fun, the group has now doubled in size and many need very little support to enjoy playing the game.

Through successful funding bids the library service has bought new games and two additional Nintendo Wiis for use across the borough. But I do sometimes ask myself "Why new games?" The service users adore the 100 pin bowling and get quite put out if I suggest another game! I was recently informed by a member of staff that, on a Tuesday morning, one young man arrives at the Centre reception and refuses to move until it is time for his library visit. I think that speaks volumes. Each service user has, with assistance, developed their own character on the Wii, which I have to say looks remarkably like them. The healthy competitiveness gets stronger week by week but a session is never without laughter - particularly when it is my turn.

In December 2011 Bexley Library Service held their third Inter-Centre Wii competition in a Library. The three day centres in Bexley were invited to enter a team and we all enjoyed lunch together halfway through. Carlton Road won the competition with much pride but all participants left with a medal. Let us see if they can hold the title again this year!

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Low Tech Ideas

Penny Lacey

There are many occasions when high tech is not necessary when working with people with PMLD. Low tech has a lot to offer but might need you to spend a bit of time designing and making things if you can't find a ready-made item.

Have you heard of TOBIs?

T rue Object Based Icons (TOBIs) can be used with individuals who have difficulty understanding two-dimensional visual symbols (i.e. photographs, line drawings). TOBIs can be any line drawing or picture that are cut out in the actual shape or outline of the object they represent. The individual can see the symbol and outline of the shape, which helps him/her to more readily understand two-dimensional symbols. TOBIs are usually larger than typical two-dimensional symbols.

Source: presentation from Barbara Bloomfield, MA CCC-SLP, ICON to I Can: Visually Based Strategies

Najma uses TOBIs to exchange for a biscuit and her drink. The two TOBIs are the same size as the real objects so she can begin to make connections between a real object and an image. She is enthusiastic about the TOBIs as she gets an immediate reward for handing over the picture. We hope to extend this to TOBIs of objects that she likes to play with. Incidentally, we laminate the pictures so they last longer.

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Medical Technology – A parent's perspective

Jeanne Carlin

Erica, who is now 30 years of age has profound and multiple learning disabilities as well as some rather complex health issues. During her life we have been asked to make a number of decisions which have led to her becoming increasingly dependent on medical interventions as part of her daily routine. Each time we have been asked to consider an intervention we have needed to weigh up the benefits for Erica, not only in terms of her health but also in terms of the quality of her life. As a person who does not easily understand science and technology, I remain in awe of what medicine can do to support and sustain life, whilst at the same time I have struggled to come to terms with how routine these procedures have become in our lives.

When Erica was very young, she was extremely underweight. Her eating and drinking was poor, due to a lack of oral muscle control. She was also often

constipated. Each time she was ill she was admitted to hospital as her low weight made her so vulnerable. When she was about 5 we were asked to consider having a gastrostomy fitted so she could be tube-fed. Whilst it made sense from a medical point of view, we were conscious of how few children there were 25 years ago who were routinely fed via a gastrostomy and there appeared to be a lot of confusion and argument between services as to who would be responsible for feeding at school, summer play schemes and so on. Our feeling at the time was that if we went down this road, it would severely limit her quality of life, as at the time it would have restricted the services she would be able to access.

We eventually resolved the problem by putting our energies into finding a specialist dietician (outside our area) who advised us on diet and also by working with a speech therapist to improve her eating and drinking

ability. Slowly she gained weight, and although as an adult she still weighs under 6 stone, she is physically more robust.

The second decision we were asked to make came a lot later, when she was an adult. Constipation had remained a health issue for Erica and we tried everything – enemas, medication, alternative remedies, diet etc – I am sure a familiar story to most parents of sons and daughters with PMLD. In early adulthood the problem became so severe, it was causing Erica not to sleep, to have severe stomach cramps often during the day, and her skin colour permanently looked ‘yellow’. We were referred to a consultant and then to a stoma nurse, who discussed various surgical options. The one we felt was least intrusive, although it involved major surgery was the A.C.E procedure. This procedure would mean that her bowel could be ‘irrigated’ by passing either water or an enema solution through it every day.

In this instance the health issues won the day as Erica’s health was so severely affected by the toxins that were in her body; and although the operation did not all go smoothly, once the ACE was in place and working, it had a major positive impact on improving Erica’s health. However, I soon learnt that it placed other restrictions on both Erica’s life and our lives – these were not obvious prior to the operation. We have always employed support workers in our home and not everyone is comfortable with carrying out the bowel procedure. Because this intervention is not a widely used procedure, I always feel Erica needs to be within a 2 hours drive from our hospital in case the ‘button’ falls out (this has only happened once). Going on holiday, for example, involves taking a lot of specialist equipment, and on one occasion her irrigation pump broke down and we needed to find an alternative way of ensuring her bowel remained irrigated – so we go to the same Center Parcs – an hour and a half from our hospital – each year. The residential short breaks/respite unit Erica attends will not agree to their staff being trained to carry out the procedure, which means a specialist nurse needs to visit daily whilst she is there to irrigate her bowel. But on balance it was the right decision for Erica.

The next area we journeyed through was with regard to her epilepsy. Erica has rarely had a 24 hour period in which she has been seizure free. When she was a child I still clung to the belief that we would find ‘the drug’ that would control her seizures. By the time she was an adult I realised that was extremely unlikely. The consultant raised the issue of Erica having a VNS (Vagus Nerve Stimulator). Once again it meant surgery, and this time in a specialist centre as our local hospital did not carry out the procedure, and it was yet more ‘technology’ to learn about. Having read whatever literature I could find, I felt this decision was not a difficult one. It seemed less

intrusive than the ACE or a gastrostomy, although perhaps that is my lack of understanding of all things technological. The VNS has reduced Erica’s seizures from an average of 7 per night to 2 or 3, and I am still in awe of how it works. But I do feel I have been given something that I can use to attempt to stop a seizure – as a parent that ticks many of my emotional boxes.

We are now faced with having to revisit the possibility of a gastrostomy. This will mainly be used to ensure that Erica takes her anti-epilepsy medication and that she is having enough liquid in her diet, both of which have become issues for her. This time round gastrostomy feeding is more common place in services so it won’t restrict access to services, yet it will mean more equipment to become familiar with and to carry around when away from home. Many other parents have said ‘it starts with only using the tube for medication, but soon progresses to becoming the main option for feeding’. This is not something I want, as Erica enjoys her food and meal times are an opportunity for social interaction. The medical issues seem less clear cut, which makes it a more difficult decision and one that we have not yet resolved.

Recently we attended a Continuing Health Care Funding meeting for Erica and I certainly came away from that feeling that we never spoke about Erica as a person; we spoke about Erica as a series of medical issues. I do think as a parent the more that medical interventions become part of our everyday life the more strongly I need to advocate for my daughter to ensure that her rights to a life in her local community are not eroded. Because of the immense health problems people with PMLD often face they so easily risk having their other needs overlooked, and we lose sight of the whole person.

Medical technology - Children and adults with Profound and Multiple Learning Disabilities and complex health needs

Jeanne Carlin

Although we do not have specific figures on the numbers of children and adults with PMLD who also have complex health needs, it is evident to commissioners of services, managers and staff working in schools and other services that the population of disabled individuals with PMLD is growing and their needs are changing. Far greater numbers are now using a medical device or health intervention – such as a gastrostomy or ventilator to sustain their life and ensure that they maintain optimal health. Advances in medical technology have meant that larger numbers of children with very complex needs are surviving and a growing number are now entering adulthood. This increase is evident in any service if one compares the number of adults with PMLD who require nasogastric, gastrostomy or jejunostomy feeding with the figures 5 or 10 years ago.

Children and adults with PMLD and complex health needs will need long term and continuing support, often including clinical procedures, in order to sustain life and to ensure that they maintain optimal health whilst attending school and accessing services and activities. 'Clinical procedures' is a term that is used to describe certain interventions or procedures which an individual with complex health needs may require, either as part of their routine every day care, or in a potential emergency situation in order to maintain their optimal health or sustain their life. These procedures are sometimes referred to as 'invasive clinical procedures'.

Routine and regular clinical procedures may include:

- nasogastric, gastrostomy and jejunostomy feeding
- oxygen administration
- catheterisation
- suctioning of airways
- nebuliser administration
- tracheotomy care
- stoma care

Procedures required in an emergency include:

- the administration of rectal diazepam
- the administration of buccal Midazolam
- the administration of adrenalin
- the reinsertion of a tracheostomy tube

As stated earlier we do not have specific figures for this group, however the research data we do have supports the experience of those working on the ground that this group of individuals with PMLD is increasing in size and complexity. The most comprehensive study of children who are 'technology dependent' (not necessarily children with PMLD) was carried out in the late 1990s (Glendinning et al. 2001). This study estimated that there were 6,000 'technology dependent' children in the UK. This group of children included those who were receiving treatments such as 'mechanical ventilation, tracheotomy and oxygen therapy, enteral and parenteral nutrition, intravenous drug therapies, and peritoneal and haemodialysis' (p. 323). Although this data is now significantly out of date and there is no later comprehensive review of this group of children, the significant rise in numbers can be illustrated by the

increase in the number of children on long-term ventilation.

In 1999 a study identified 141 children on long-term ventilation (Jardine et al. 1999). Ten years later this figure had increased significantly and a study conducted in 2008 identified 933 children in the UK who were below the age of 17 years, medically stable and requiring a mechanical aid for breathing, either invasively by tracheostomy or by non-invasive mask for all or part of the 24 hour day (Wallis et al. 2011).

Raising our Sights (Department of Health, 2010) recognised that services for disabled children have developed well established policies and procedures to ensure their inclusion. However, the situation in adult services is often very different and this report identified that many adults with PMLD and complex health needs were being denied services or access to certain opportunities and activities because some agencies were preventing their staff from undertaking clinical procedures or using medical devices to sustain or support life – for example, administering rectal diazepam or Buccal Midazolam, tube feeding, suctioning or administering oxygen. This situation arose for a number of reasons, including a lack of agreed local and national guidelines, organisational policies and procedures, fear of litigation, lack of adequate insurance cover for clinical tasks and a lack of clarity about training and support for staff and carers. As more disabled children with PMLD and complex health needs survive and enter adult

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services, commissioners and managers will need to meet the challenge that medical technology has faced us with.

Technology in the class for pupils with PMLD

Technology plays a vital role in my classroom. Jeanne kindly shared with us, in the previous article, the medical technologies and subsequent issues that her daughter Erica has encountered. Within my classroom medical technology is a major factor to the well-being of the majority of my class. This could be a serious issue. However, as a school we have overcome this through careful staff training. This training has resulted in technologies such as vagal nerve stimulators, oxygen, gastrostomy feeding and suction being a part of my everyday classroom life. It allows for a responsive environment where all the classroom staff can react to the needs of the children there and then. We do not have

to rely on the nurse coming to set up Wilf's gastric feed, or administer oxygen to Mary, who goes cyanosed during seizure. When Alice has a seizure we can use her vagal nerve stimulator to help reduce the duration. I think this means that there is a more holistic approach to their learning and school life and a greater understanding by the staff of the 'bigger' picture. It is possible and just requires a careful program of training.

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Vagus Nerve Stimulation (VNS)

A number of individuals with PMLD and epilepsy may have a small device implanted (during an operation) under the skin, just below their collar bone. The device has a lead or wire which is then wrapped around the vagus nerve at the side of the neck. This device sends electrical impulses via the vagus nerve to the brain in order to decrease the frequency and severity of seizures.

The frequency and strength of the impulses can be set and adjusted by trained health staff at the time of the implant and at subsequent monitoring appointments. In addition, the individual is given a 'magnet' which is moved over the area of the device to send extra impulses to the brain. This is usually done at the start of a seizure or if the person indicates that a seizure is about to start.

There are some common side effects which have been reported. These include temporary hoarseness or change in voice tone, sore or tickling throat, shortness of breath, coughing and a prickling feeling in the skin. In addition, the battery in the device does need to be replaced – on average a battery lasts for between 6 and 11 years. However, if the frequency and strength of the impulse is high, the battery will not last as long. The replacement of a battery does require a small operation. However, on the plus side many VNS users report a general decrease in seizures once the VNS is in place.

For more information:
<http://www.epilepsy.org.uk/info/treatment/vns-vagus-nerve-stimulation#introduction>

A.C.E / M.A.C.E procedure – Malone / Antigrade Continence Enema Procedure

The A.C.E procedure is carried out on a relatively small number of children and adults with PMLD who have severe constipation/faecal elimination problems. The procedure means that water or an enema solution can be flushed through the bowel on a regular basis to assist the individual to have regular bowel movements.

An operation is carried out that constructs a small tube (using the appendix) starting with an opening in the skin of the lower abdomen and leading to the bowel. A plastic tube is fed through this with a 'balloon' on the inside to

keep it all in place and an access 'button' on the outside to maintain the opening. Having an ACE procedure is a major operation and is therefore only carried out after all other avenues of treatment for constipation have been explored. Each day fluid – either water or an enema solution - is introduced into the bowel via this tube.

For more information:
<http://www.hirschsprungs.info/Information/literature/ACE.pdf>

Assessing Pain in Children with Profound and Multiple Learning Difficulties (PMLD): A Student Nurse Perspective

Lauren Allan

Most people are familiar with the experience of pain; how it feels, how it can be treated and how to express it. In healthcare the 'gold standard' of pain assessment is self report (the Royal College of Nursing, 2009), so assessing pain in children who have communication difficulties presents a unique challenge. Training as a paediatric nurse often involves a variety of placements in hospital, schools and the community, which provides an insight into different practices. In my experience, the nursing knowledge around pain assessment for children with profound and multiple learning difficulties (PMLD) is variable and although many excellent pain tools for children with a 'cognitive impairment' are recommended by the Royal College of Nursing (2009), I have worked in care settings that do not use them at all.

A pain tool is a resource that assesses the level of pain a child is experiencing and measures the effectiveness of pain-relieving interventions. The National Service Framework for Children and Young People (Department of Health, 2004) says it is a child's right to have pain well assessed and children who cannot indicate pain as effectively must be considered. Children with severe learning disabilities are often at more risk from pain due to complex health needs and frequent medical interventions (Dowling, 2004). If some care settings do not have resources available to assess pain in children with PMLD, are they doing the best for them? I decided to explore this issue further, to raise awareness of the type of pain tools available for children with PMLD amongst my fellow students and understand why they are not always being used routinely.

The Royal College of Nursing (2009) recommends three pain tools for children with a cognitive impairment. These are the 'Non-communicating Children's Pain Checklist' (NCCPC), the revised 'Faces, Legs, Activity, Cry and Consolability' scale (FLACC) and the 'Paediatric Pain Profile' (PPP). They are based upon behavioural observations and do not rely on verbal response.

The NCCPC was first developed in the 1990's. It is a chart of thirty pain indicating behaviours that are each scored

from 0-3, where a higher score means a greater presence of the action described. The behaviours used on the scale were compiled from interviews with caregivers of children with severe learning disabilities and include vocal noises, facial movements and disruption to normal eating and sleeping habits. Breau *et al.* (2000) suggested it could be used regularly by caregivers to build a 'profile' of knowledge about a child's reaction to pain.

The FLACC scale was originally developed for use in neonates and infants, but later revised for children with severe learning disabilities. It has five behaviour categories (faces, legs, activity, cry and consolability) each describing three types of action scored from 0-2. A higher score represents the presence of a pain indication, such as arching of the back or jerking limbs. It is designed for use in a hospital environment but allows the addition of a child's unique pain behaviours to the scale by the parents or carers to help professionals better recognise pain (Malviya and Voepel-Lewis 2006).

The PPP is designed as a parent held document that can be given to different professionals caring for their child, promoting consistency of pain assessment and management (Hunt *et al.* 2007). The PPP includes a 20 item behavioural pain assessment scale scored from 0-4, with the score increasing with greater presence of pain

behaviour. It also allows the parent or carer to record significant pain history, baseline assessments of a relaxed state, which treatment methods effectively relieved pain and relevant conversations with professionals.

Evidently, there are pain tools available for children with PMLD and I am aware of more in the literature and under development. Breau *et al.* (2000) says that pain tools for non-verbal children with severe learning disabilities are available in practice but not always used. The implementation of a new tool takes time, training and money (Voepel-Lewis *et al.* 2008), but for me the most surprising issue related to the healthcare professional's attitude to the pain experienced by children with severe learning disabilities. The RCN (2009) discusses an existing belief amongst some professionals that children in this population are not as sensitive to pain and their behaviours are too individual to be assessed effectively using a pain tool. As a student nurse we are taught about the 'expert parent' and I believe by learning about the child's behaviour from the family that knows them best, pain assessment can be facilitated. I have had the opportunity to train in some truly proactive and positive environments during my three year degree, but I hope in future to see more pain tools available for children with PMLD to improve their experience in hospitals and other care settings.

For more information on the pain tools discussed in this article please visit:

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SMILE PROJECT: a pilot project for people with PMLD

Harsharn Singh Khatkar & Deborah Gittins

The Profound and Multiple Learning Disability (PMLD) team at Ridge Hill Centre consists of a multi-disciplinary team of clinical psychology, speech and language therapy, occupational therapy, physiotherapy and nursing staff. Our aim is to work closely together to provide assessment, treatment and advice to help the person with PMLD reach their maximum potential.

In 2008 the team visited Redlands Centre at North Cherwell Day Services in Banbury, Oxfordshire (<http://www.oxtc.co.uk/SMILE.shtml>) where a number of Sensory Musical Interactive Learning Experience (SMILE) projects had been developed and running for a number of years for clients with PMLD and or severe challenging behaviour.

SMILE Model

SMILE was introduced at Redlands Centre, Oxfordshire in 2003. The aim of the SMILE approach is to:

“Provide a venue that is responsive and consistent where interaction/communication occur through the use of sensory stimulation, using smell, touch, taste, sound and sight. In addition to use Intensive Interaction to encourage turn-taking, sharing, waiting, listening, and making choices to be a forum where communication and active two-way learning is a priority.”
Redlands (2008) (www.oxtc.co.uk).

Inspired by the difference that the Oxfordshire service makes to individuals' lives, the team planned to bring this approach to Dudley. The Oxfordshire service recommended staff should complete some Intensive Interaction training before piloting the SMILE approach. A one-day introductory training course in Intensive Interaction was conducted by Dave Hewitt at Ridge Hill Centre. (www.intensiveinteraction.co.uk).

Partnerships

Staff from the Ridge Hill Centre, Social Services and the private sector who work with people with PMLD and had attended Intensive Interaction training, were invited to develop the SMILE Project with us. Following expressions of interest it was decided to pilot a SMILE project at Ridge Hill Centre in partnership with three organisations consisting of a local authority day service, voluntary sector residential service and a private day

service. One service user from each of the partnership organisations and their link worker, alongside staff from the occupational therapy and clinical psychology team attended the SMILE project. Table 1 displays group members' demographic information.

Table 1: Demographic Information (see on page 31)

Session Content

The group met weekly for 24 weeks at Ridge Hill Centre between April 2010 and November 2010, with a break for the summer holidays. A session was divided into 5 distinct activities which were repeated each week. Each group member was given individual goals for each of the 5 structured group activities; greetings, interactive games, music activity, story and goodbyes. Table 2 shows an example of a group members individual goals. Two facilitators were present in each of the sessions with the group members and their link workers. Each of the sessions began with a 'Good morning' greeting to each individual and the whole group. The interactive game used a parachute activity linked to the song "somewhere over the rainbow". The music activity was based on "soundabout" which involved each member choosing an instrument and following the rhythm led by the facilitator. This activity continued for approximately 15 minutes followed by a period of silence. Following a break we then had a story - age appropriate multisensory fiction - using objects and tactile boards. The objects and boards were passed around the group members while the story was read aloud to encourage anticipation, and exploration. This was followed by a goodbye song to signal the end of the session.

Link workers engaged members in each of the interactive elements on a one-to-one basis. If clients were seen to avoid interaction through the use of avoidant behaviours then the facilitator would follow this lead and disengage,

Table 1: Demographic Information

Age	Sex	Day Service	Type of Accommodation	Health Needs
40	M	Local authority	Residential	Physical disability
50	M	Voluntary sector	Residential	Physical disability, Dysphagia, Epilepsy
25	M	Residential	Family home	Down's Syndrome, Epilepsy, Physical disability, Hearing impairment
56	M	Private sector	Family home	Physical disability, Epilepsy

Table 2: Individual goals for structured group activities

1 Greeting	2 Game	3 Music	4 Story	5 Goodbye
a) Holds out hand	Holds edge of parachute	Chooses instrument from box	Takes items to hold/touch	a) Gives eye contact
b) Gives eye contact			(aim for 4 items)	b) Waves goodbye

usually attempting to interact at a later stage or in a different way.

Table 2: Individual goals for structured group activities (see above)

Group Evaluations

Formal assessments were completed with either family members or link workers using Vineland's Adaptive Behaviour Scale (VABS) and Pre-Verbal Communication Schedule (PVCS) assessments. These assessments were completed before and at the end of the group with either family or carers.

Each group member was videotaped for 90 minutes in week one or two of the SMILE project to provide a baseline measure. Group members were videotaped in SMILE sessions at two further intervals; at mid-point in

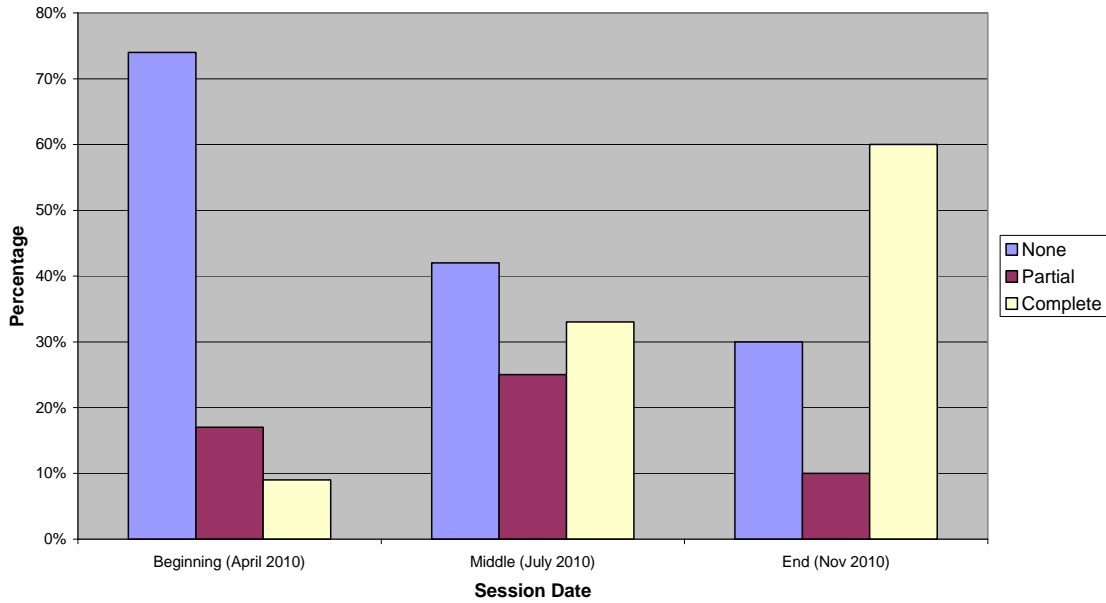
July 2010 and in the penultimate session in November 2010. Video data was analysed for each group member's individual goal behaviours. In addition to the video data, staff evaluated each session using session record sheets.

Time sampling techniques were used to count the presence of each group member's target goal behaviours. All video ratings and analysis were conducted "blind" by a researcher who was not involved in the running of the group. Inter-rater reliability checks were incorporated within the analysis.

Overall Group Results

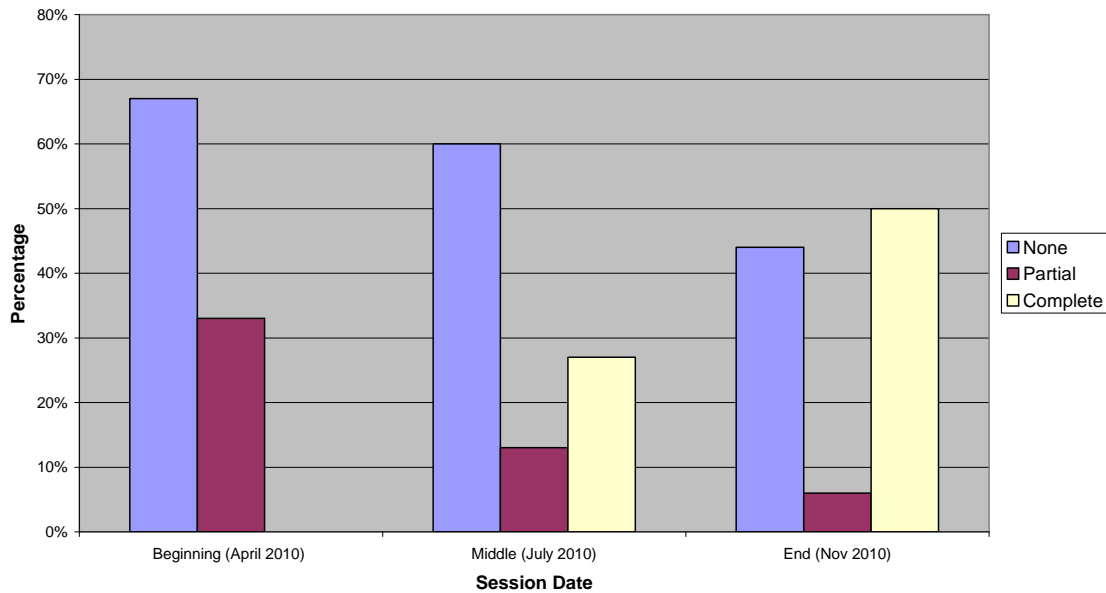
The following graphs represent an average of each group member's individual goal behaviours for each activity.

Graph 1: Overall Group Greeting



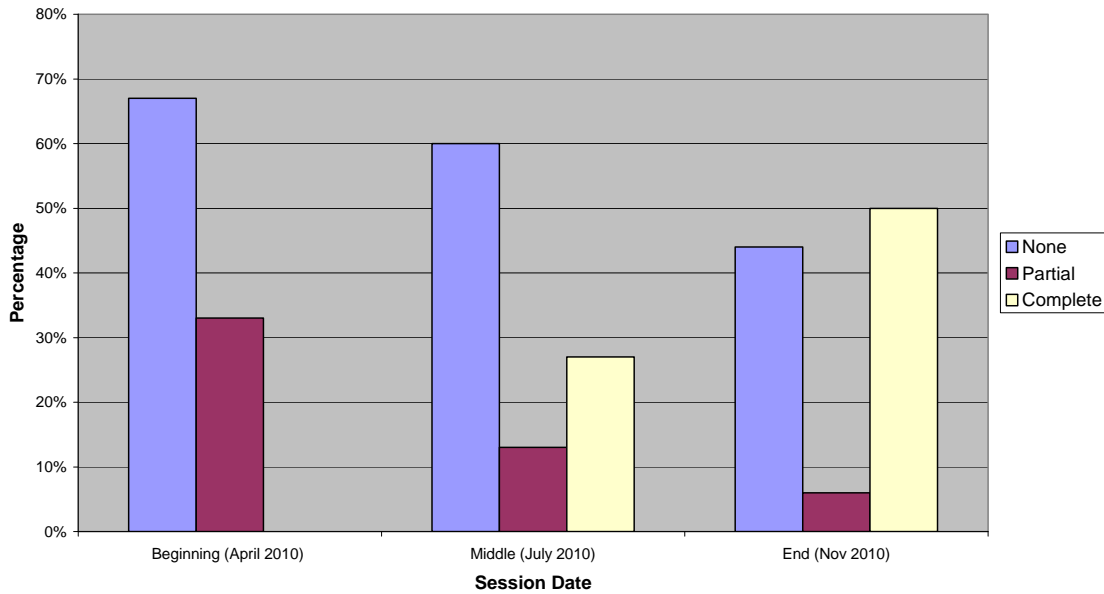
At the beginning of the SMILE project 9% of overall group greeting goals were successfully achieved; this rose to 32% mid-way through the project and increased to 60% at the end of the group.

Graph 2: Overall Group Music



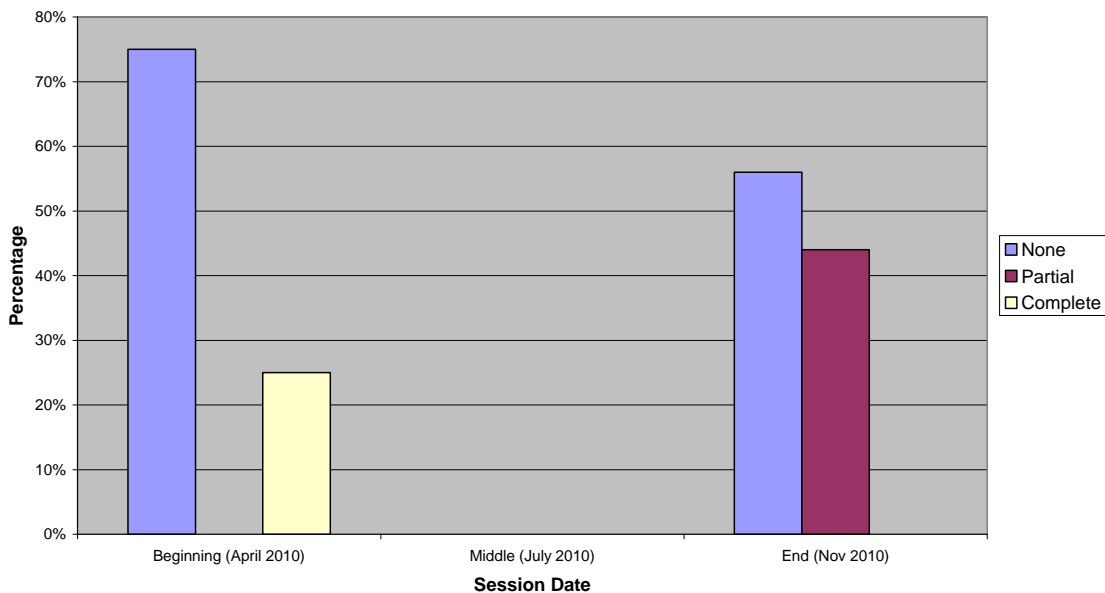
From the beginning to the end of group, the percentage of music goals successfully achieved increased from 0% at the beginning of the group, to 26% at mid-point and 50% at the end of the group.

Graph 3: Overall Group Story



The percentage of successfully achieved group story goals increased from 0% at the beginning of the group, to 26% at mid-point and 50% at the end of the group.

Graph 4: Overall Group Goodbye



Data from the overall group goodbye activity was not conclusive. Mid-point group goodbye data was not collated due to video camcorder difficulties at this time interval. At the beginning of the group 25% of group goodbye goals were successfully achieved but at the end of the group this dropped to 0%. However, partially completed goodbye goals increased from 0% to 44% at the end of the group.

Discussion

Following completion of the group, detailed individual feedback was given to group members family and carers on progress made. Overall, we felt the VABS assessment was not sensitive enough to reflect any changes in improved individual goal achievement, as scores for each individual remained at a similar level.

The PVCS assessment highlighted that a number of new skills had been gained at post-group assessment. Examples of areas in which individual skills had been reported to having been gained included the following areas:

- Development of sounds, e.g. babble with sounds close to normal speech.
- Consistent use of sounds, e.g. making sounds.
- Communication through looking, e.g. looks at something and then at staff.
- Social interaction, e.g. initiates eye contact with person nearby.
- Giving, e.g. giving objects to another person.
- Communication through whole body, e.g. offering feet for shoes.

The results for overall goodbye data were not conclusive. We could speculate that group members may have been showing fatigue towards the end of the session and that the degree of prompting and levels of concentration from link workers had decreased towards the end of the group.

Overall the results of the SMILE project are encouraging and reflect that the SMILE approach can improve people's skills, particularly in the areas of communication, turn-taking and engagement.

Reflections

Staff were interviewed following completion of the group for their views and reflections on the SMILE project; the following themes were highlighted:

- Intensive Interaction training enabled staff to learn more about "age appropriateness" and meaningful occupation.
- These skills were put into practice for the SMILE project with staff members working at the individual's developmental level and gaining more understanding of being person-centered, i.e. working with individuals at their pace for their goals.
- The project helped staff learn how to engage better with individual clients and gain a better understanding of optimum conditions to improve engagement, for example, with seating group members and staff appropriately to communicate.
- Staff developed confidence in discussing principles of SMILE with other colleagues.

- All staff had a feeling of "joint ownership" of the project. Staff recognised how clients are able to work better in different conditions, e.g. distraction free space.
- The level of support and organisation that was required to enable PMLD clients to experience SMILE was highlighted. Examples of difficulties experienced included: attending sessions if health had fluctuated, organising transport, making staff available and meeting group member support needs within sessions.
- Link workers felt that it was a worthwhile project and much of what had been learned could be applied to their own workplace.

Taking things forward

- Promote the SMILE model within Dudley.
- Offer training and support to staff in the SMILE approach.
- Offer support for organisations should they wish to set up their own SMILE project.
- To look at feasibility of offering another SMILE project in partnership with different organisations.

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“Thanks to you, I’m able to do anything I want to.” - Joe

I was very interested to read a thread of the PMLD Network about Technology for people with PMLD. This charity was recommended by a parent of a young person with PMLD.

Sometimes it’s the small things in life that make all the difference. For Joe, it’s the flick of an eye. His muscular dystrophy has left him unable to speak or move his body, but his life has been transformed through the loan of a special computer that can be controlled simply through eye movement. All he needs to do is move his eyes to be able to put the fun and independence back into his life through being able to do the one thing he’s always wanted to do – play computer games.

Joe is just one of the hundreds of lives that SpecialEffect has touched in its short four-year history. This dynamic Oxfordshire charity do whatever it takes to enhance the quality of life of people with disabilities by using technology, and they’re making a name for themselves as *the* organisation that can help everyone play and enjoy computer games.

They’re changing the lives of people with all kinds of needs, including stroke and road traffic accident patients, individuals with life-limiting conditions and injured soldiers returning from overseas.

“Computer games have a tendency to get a bad press,” said Mark Saville, the charity’s Communications Officer. “But if you strip away the headlines of violence and console addiction, there’s a whole community buzzing with enthusiasm, sociability and inclusion. What we’re doing is levelling the playing field for people who have to sit and watch their peers having fun playing computer games.

“It’s not about encouraging people to kill each other onscreen, it’s about putting enjoyment back into life. We’ve used technology to enable people to play popular computer games like FIFA12, but we’ve also helped people to play Scrabble, to fill in a Sudoku grid, and even to throw balls for their dogs.”

“Sometimes it’s a simple modification like moving a joystick underneath a games controller so that it can be used with the knee. In more complex cases we’ll go back again and again until we get the right combination of adapted controls to suit an individual.”

The charity have also found that the benefits of enjoyment go way beyond computer games. “Arm or body motion games like the Kinect can contribute to physical rehabilitation,” said Mark, “and the motivation is doubled when the people we help realise that they cannot only take on their peers but they can beat them as well.”

The demand for the charity’s services have rocketed in recent months, but Mark remains undaunted. “There’s already a huge amount of off-the-shelf adapted equipment out there. In many cases we can help by simply directing people to where to buy the right piece of kit.

We also help by running games roadshows, where we cram our van full of specialists and adapted gaming equipment, and spend an afternoon or an evening at a hospital, school or disability group, showing people how they can have fun and be included.”

With computer games set to continue to grow in popularity, there’s always going to be a need for specialist access, and for people like Joe, getting back in the game makes a huge difference.

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Top 10 websites for Technology

Some useful websites for families and friends

<http://www.epilepsysociety.org.uk>

A charity that provides information and support about epilepsy including information about technologies such as Vagus Nerve Stimulators.

<http://www.sense.org.uk/>

National charity that supports and campaigns for children and adults who are deafblind and who can advise on suitable technology, e.g., sensory toys

<http://www.gosh.nhs.uk/medical-conditions/procedures-and-treatments/living-with-a-gastrostomy/>

Information from Great Ormond Street about living with a gastrostomy

<http://www.inclusive.co.uk/>

Company which provides software and hardware for learners with a physical disability, sensory impairment or learning difficulty. They also run training courses and provide consultancy services, as well as information days, focus days and web based seminars.

<http://voxcommunityinterest.org.uk/>

Vox is a community interest company (CIC) which works in partnership with individuals and organisations to help people shape the lives they lead and the services they use.

www.webenable.org

WebEnable is a social enterprise, providing websites, films, sounds and images for accessible communication, as well as training.

<http://www.multime.com/>

Multi Me is an online networking tool based on the idea of people telling their story through the use of multimedia.

<http://www.ianbean.co.uk/>

A website specialising in the use of ICT and assistive technology to support learners of all ages with severe and complex additional needs and offering training and consultancy.

<http://www.multi-sensory-room.co.uk/>

Provide training in a range of areas including multisensory approaches, communication, iPads and goal setting, as well as digital products.

<http://www.drakemusic.org/>

Drake Music breaks down disabling barriers to music through innovative approaches to learning, teaching and making music

<http://www.cenmac.com/helpsheets/switches/single-switch-cause-effect-software/>

A useful list of single switch cause and effect software.

http://www.donjohnston.com/products/low_incidence/c_e_software/index.html

Company providing a wide range of cause and effect software that can be used with a single switch

and don't forget...PMLD Link **www.pmlmlink.org.uk**

FUTURE FOCUS: Celebrating 25 Years of PMLD Link

Next year will be the 25th anniversary of PMLD Link – a remarkable achievement for a grassroots publication which relies entirely on its readers and writers who are commissioned by the editorial board for the articles, and does not rely on any funding from advertising. The original purposes of PMLD Link – to enable people who work with, or care for people with profound learning disabilities to have contact with each other, and to disseminate ideas, good practice, and research as widely as possible - are still the core values 25 years later.

Quite something to celebrate!

Much has changed, particularly the look of PMLD Link itself which started as a cyclostyled newsletter of only a few pages long and has evolved into the glossy version we have today. It is, of course, much more substantial now, thanks to the editorial board whose wide experience and contacts mean that we can tap into a much larger body of people to write for us and find information about what is new in the field. Ideas have developed, but there are still many which have stood the test of time and, with little change would read as well today as when they were first written sometimes many years in the past.

As always, we really welcome contributions from you, our readers – whatever your ‘role’ in this area. We see our 25 year landmark as an opportunity to ‘take stock’ of where we are now, what developments or ideas [large or small] have made a real difference to the lives of people with profound learning disabilities or those in their supporting or caring for them. And, very importantly, what should we do in future to move forward, positively into our next 25 years...and beyond?

With this in mind the next issue, Spring 2013, is going to look back and look forward. We are going to tap in to the articles over the last 25 years and bring to you both the changes and the ideas that have endured. We hope that you will find them interesting, and useful as well, and that it will encourage you to continue to support PMLD Link for another 25 years – now that would be an achievement!

Please send contributions or requests for information to Carol Ouvry carol.ouvry@talktalk.net or Annie Fergusson ann.fergusson@northampton.ac.uk who are Editors of this celebratory issue.

**Date for articles is 15
February 2013**

GIFT AID

Is your subscription your own personal one and do you pay tax?

If so, by signing the gift aid form we can get an extra 25p in every £1 you pay to us in tax refund from the government. This makes a significant contribution to our finances at no cost to you.

If you can't remember if you have already signed the Gift Aid form, just sign it again – I can check whether you are on the gift aid record.

Thank you to all personal subscribers who have already done this.

PMLD Network Forum A Digest of Discussions July 2012 to November 2012



The PMLD Network forum is an open email discussion group which focuses on issues relating to PMLD. Here is a summary of the key themes that have come up on the forum over the last few months.

Technology with people with PMLD

Someone from PMLD Link asked forum members for their views on technology for people with PMLD. They asked if people feel technology is essential to the quality of the lives of people with PMLD or whether they feel it is irrelevant. They asked if people had any technological innovations to share. They asked if anyone wanted to contribute to the Winter issue of PMLD Link (this issue) which focuses on technology.

Responses included:

- 'Probably not the kind of technology you're looking for, but the SATs monitor, O2 concentrator and CPAP machine keep my daughter alive overnight. The thermometer helps us ensure her autonomic dysfunction doesn't cause her to overheat or freeze. The vitamix enables us to blend her food, including meats and nuts and seeds, to a fine paste we can push through her gastrostomy tube. All of those are fairly essential to her life. The kaleidoscope light thingy she has confuses her seizures into letting her sleep. The iPod plays music all night so she doesn't feel alone. The switch operated bubble machine puts her in charge of the fun when we go to parties, and her foot switch enables her to shout for attention. The people at www.specialeffect.org.uk/index.htm have found some beautiful high tech ways for my daughter to enjoy making music too. Essential? Not compared to her life support. But adding richness to the tapestry of her life, definitely.'
- I have found 'Soundbeam' (we have Soundbeam 2) invaluable in my work as a music therapist with people with PMLD. It has opened up opportunities that were impossible before. People who found it a struggle to sound a traditional percussion instrument, or who need to move beyond the limited choices open to them, suddenly have a world of sound opened up. The movement sensor can pick up even tiny movements, feed them into the synthesizer and the next thing you know, a cascade of flute / electric guitar / saxophone notes is produced. And people can control the sounds by the movements they make. It can be a bit unpredictable at times - such as picking

up people's breathing - but with practice, the benefits outweigh the challenges in my view. It is wonderful to see someone who has hardly any voice or hand use able to make themselves heard, or to give a teenage boy the chance to make the same sounds his contemporaries are making. People can become really motivated and focused when using it.

- 'We also use the sound beam and find it extremely good. We have started using it in conjunction with Intensive Interaction and have had some very good feed back from the people we are working with particularly with those people with PMLD where autistic traits are involved.'
- 'I would also suggest looking at the Ipad. There are some great music and sound apps that with help from a worker can work with very little movement. The favourite we have at the moment is the 'rainfall' app, but we find different people like different apps. They take very little movement and give instant feed back.'
- Someone suggested looking at www.multime.com - which is designed to help anyone communicate and plan their lives. It involves on-line support networks.
- Someone else suggested looking at www.videoprofiling.co.uk - an online secure video sharing site for teams working around children, adolescents and adults. Therapists, education and care teams can upload videos onto the service user's profile and share videos of successes and challenges within the team securely. Parers/ carers do not have to pay to use the site, and professionals only a minimal fee.

In education people with PMLD are working below P4? Reference?

Someone working in education said they feel it is generally accepted that students with PMLD are working below P4 of the national curriculum levels. However, they asked if anyone knew of a reference for that statement, and indeed whether people agreed with it.

Responses included:

- ‘For reference to P levels read the introduction to ‘Routes for Learning’ downloadable from the Welsh Assembly site: <http://wales.gov.uk/topics/educationandskills/schoolshome/curriculumwales/additionaleducationalneeds/routeslearning/?lang=en>.’
- Someone suggested looking at Penny Lacey’s PMLD curriculum (more info at: www.senmagazine.co.uk/articles/396-designing-a-curriculum-for-pmlid-a-profound-challenge.html)
- Someone said that the TeacherNet website had a definition, although it has been archived by the current government. With reference to pupils with PMLD the website (as accessed at 2009) said ‘...They are likely to need sensory stimulation and a curriculum broken down into very small steps. Some pupils communicate by gesture, eye pointing or symbols, others by very simple language. Their attainments are likely to remain in the early P scale range (P1 – P4) throughout their school carers (that is below level 1 of the National Curriculum.’
- Someone said to look at the The Profound Education Curriculum from St Margaret’s school, Tadworth. That is planned with work up to P4. They also said that in Jean Ware’s 2005 book ‘special children pedagogies for inclusion’, edited by Lewis and Norwich, she mentions the realisation that PMLD students will be operating within P1-3.
- Someone from a special school in Bradford said they use a core vocab of touch cues for pupils with PMLD, which have been developed by a team of interested professionals working across Bradford special schools to offer some way of providing a standardised communication system. These signs are shared with parents as appropriate so that there is continuity between home and school. They said they have always considered these cues as a way to provide information to pupils to enable them to anticipate what will be happening next (receptive communication). They said they had recently visited a secondary school where many of the students have experienced these cues for several years to see a pupil signing ‘finished’ on herself to indicate she wanted to end an activity. They were delighted to see the proof that these signs can really have an impact on communication for PMLD pupils.
- ‘I would be interested to learn more about these and how much application they have for young people. You say these are designed as receptive communication tools and from what I can see that you are working towards what I understand to be initiated communication.
- Someone said ‘Are these cues based on any standardised signs eg. Makaton or very individualised to Bradford schools. Would you be willing to share your core vocab?’
- Someone said they are developing touch cues/ body signs with pre-schoolers and parents. They suggested that they could be of equal value to adults and their carers as part of the adult’s personal passport, subject to feedback.

Play help for parents of pre-school children with complex needs

A specialist teacher who runs a group for parents of 1-2 year olds with profound and complex needs, along with a physiotherapist, speech therapist and a teacher for children with visual impairments, said she was developing some play cards for parents based on senses. She said they were also developing body signs to use in the group. She wanted to know if people thought the play cards would be useful, if people knew of any other resources, and whether parents are familiar with body signs/ touch cues for using with children with profound learning and complex needs.

Responses included:

- ‘At our recent PMLD conference, one of our workshops was on a new touch signing system being developed called Tassels. For more info contact j.woodall@orchard.sandwell.sch.uk’
- ‘I would also love to know more about these signs. I work at a special school in Rochdale. We use a sign a long and it would be great to have a system for our children with PMLD.’
- ‘We use a selected few of the Canaan Barrie on-body signs with my daughter, who has PMLD and is registered blind, specifically linked to her daytime programme of activities – after 2 years, it is clear by her responses and anticipatory excitement, that she understands the signs used for starting and finishing an activity, and the sign for more! All her support workers use the same little repertoire, and we encourage them to say a specified phrase, with a particular intonation, for each sign – her responses are much greater when the sign is accompanied by human voice.’

Help needed to justify care package

The mother/ carer of a 30 year old woman with PMLD said that her daughter's care package was at risk of being severely reduced because of funding cuts. The mother works full time and her daughter receives self directed support and is assisted by PAs. She asked for help in justifying her daughter's package of care. She said she had an idea of what to say but needed to put 'more meat' on it.

Responses included:

- Contact the Disability Law Service www.dls.org.uk
- Someone said it would be really useful to have an advocate; someone who is independent and who will guide them through the process. They also suggested talking to a community care lawyer who can advise whether the cuts would be legal. They also suggested contacting carers' associations for information and support or the Mencap helpline
- Someone suggested keeping a diary of a day and night, logging all the support their daughter needs and how much time she spends on activities. They said 'it is easy to under-estimate the amount of work they do because it happens every day. They suggested getting evidence from those who support her, including OTs, physios, GP, consultants etc. They said they should not be cutting care if her assessed needs have not changed since her last assessment. They also said that her needs may have increased in some areas, so to log that. They also said that the Carers (Equal Opportunities) Act 2005 places a duty on councils to consider a carer's outside interests (work, study or leisure) when carrying out an assessment, and to make sure they assess your needs as a carer.
-
- Useful links:
 - Using the law to fight cuts to disabled people's services <http://www.choiceforum.org/docs/ul.pdf>
 - Cemented to the floor by law <http://www.ldhealthnetwork.org.uk/docs/claw.pdf>

Pre: Lone staff using toilet whilst out with client in the community

A parent said they were worried about when their son is out with his carer and the carer needed to use the toilet. Their son is in a wheelchair and is unable to communicate. They are worried about him being left alone in a public place. They asked if there are protocols around that they could talk through with his carers.

Responses included:

- Someone said there a lots of Changing Places toilets around, especially in bigger towns. They are large accessible toilets with a hoist and changing bed and toilet. There is a privacy screen by the toilet so that parents/carers can use the loo in moderate privacy. See www.changing-places.org
- Another parent said that their son is a wheelchair user and cannot communicate through speech. They said that they don't worry about a single carer leaving him alone for short periods of time to go to the toilet, as the risk is small. They said 'the danger of making a huge fuss with a care provider is that they will come up with some protocol that involves only going out in pairs which can be very restrictive and you may find your son not going out so much. I prefer to accept (on behalf of my son) a small level of risk for a more fulfilling life.'
- Someone else said 'Good to hear a bit of reason. With a practical understanding of what care providers face.'
- Someone said 'You need to speak to the organisation providing the care. I can't imagine that they are allowed to leave anyone alone. If they go out in groups then there should be enough other carers around to keep an eye on the disabled person but I don't know about going out individually. As a parent I use the disabled toilet taking my son inside in his wheelchair, but it is a tight squeeze usually.'
- 'I certainly would not be happy for my severely disabled son to be left while the carer went to the toilet. The Changing Places toilet are a good idea with the curtain being used for modesty.'
- 'I think it is important that the parent of Deputy (or both in my case) has a strong input into any policies laid down by the care provider.'

To take part in discussions please join the PMLD Network Forum at http://www.pmlidnetwork.org/about_us/join.htm

Visit the PMLD Network website at www.pmlidnetwork.org

REPORT BACK

A magical creative day for special practitioners at the Royal Academy, London

Last March the Royal Academy in London, hosted a creative multisensory arts day. This was for over a hundred practitioners working in special education settings or establishments throughout the UK. Flo Longhorn and 15 presenters offered magical workshops from black light theatre, colour yoga, chocolate art, junk art to 'call and response' operatics throughout the day. The grand finale was entrance to the David Hockney exhibition held in the main galleries. The event will be repeated at the Royal Academy next year, on Saturday 23 March 2013 including admission to the Edouard Manet exhibition, is being held at the same time. Here are a selection of photographs from the event!

Huge wall hangings made from recycled materials from Kingsley High pupils.



Flo Longhorn chatting with presenter Robert Orr~painted on an iPad using the the app 'Brushes' as used by David Hockney.Painted by delegate Elizabeth Mcauley.



Toast carving art, creating a Turner masterpiece using a simple grid and toast~ brought to life by Clare Hobson from Ysgol Crug Glas Swansea.



Chocolate art with Sarah Hall from Willows Sensory Services ,Solihull.



IN THE NEWS



Spooktacular Multi-sensory experience for children at The Children's Trust

Children with profound and multiple learning difficulties have been incorporating Halloween into their multi-sensory curriculum.

Attired in their scary costumes, the learners, who have profound and multiple learning difficulties, went around the site trick-or-treating, experiencing the feel of slimey gunge and jellied spaghetti and playing Halloween-themed party games.

All departments at The Children's Trust in Tadworth, where the school is based, got involved to make it a spooktacular multi-sensory experience as the learners went around site trick-or-treating.

Staff and children from the acquired brain injury service at the Trust also got in on the act, carving pumpkins and making mummies out of each other with tissue paper.

And play therapist, Jan Vance fooled everyone in her character as Tadworth the Witch.

Steve Snook, class 2 teacher at The School for Profound Education, who lead the event said: "staff, families, learners and children all got dressed up for the trick-or-treat around the site. Everyone made a tremendous effort and the sensory experiences that we were all engaged with were met with enthusiasm by all the learners. It was great to see so many people enjoying the day and it brought the whole site together."

Picture above: Jamie, one of the learners, feeling some slimey eyeballs and jelly

Training via new technology: New web-based training resource is Smartphone compatible

Making Sense of Mental Health – understanding the mental health of children and young people with complex needs

The National Association of Independent and Non-Maintained Special Schools (NASS) and The University of Northampton recently launched their new web-based training resource to raise awareness and increase knowledge and understanding about the mental health of children and young people with complex needs. This e-learning has been developed by the two organisations through a part-government funded Knowledge Transfer Partnership (KTP) initiative.

The two year project built directly on the findings and recommendations of earlier research commissioned by NASS and carried out by The University of Northampton in 2007 [NASS, 2007; Fergusson et al 2008; Rose et al,2009]. The training offers a flexible approach for groups of individual staff – accessed



via web or Smartphone. It focuses on the issues and staff needs identified in the 2007 research. There are four sections to the training which aim to support staff to - Understand the meaning of mental health, Develop skills to identify mental health concerns in children and young people with complex needs, Build confidence in recording mental health information and to Share concerns appropriately within the setting, and externally to other appropriate services. The development of this suite of downloadable training resources involved leading specialists from the field and has been widely trialled by leaders and practitioners in school and residential settings. Using a highly interactive approach the four part training offers activities, video, podcasts, case study examples and editable templates, which are relevant to specialist settings – including those for children and young people with PMLD.

“Working through this training really helped me to understand the pupils I support. I now feel more confident and able to respond to their mental health needs”. (Teacher)

Ann Fergusson, University of Northampton. Ann.fergusson@northampton.ac.uk

For more on the training resource or the NASS(2007) research report contact NASS via Karen Rippon at krippon@nassschools.org.uk or http://www.nassschools.org.uk/making_sense_of_mental_health.aspx

Picture: (Left to Right) Rachel Allan, Annie Fergusson & Marie Howley

References

- Fergusson, A, Howley, M and Rose, R (2008) **Responding to the Mental Health needs of young people with PMLD and ASD: Issues and challenges.** Mental Health and Learning Disabilities: Research and Practice Vol 2, No. 2, October pp240-251
- Rose, R, Howley, M, Fergusson, A and Jament, J (2007) **Making Sense of Mental Health: the emotional wellbeing of children and young people with complex needs in schools** (NASS Research Final Report). Northampton: University of Northampton.
- Rose, R, Howley, M, Fergusson, A and Jament, J (2009) **Mental Health and special educational needs: exploring a complex relationship**, British Journal of Special Education, Vol 36, No 1 March 2009 pp3-8

An end to abuse? Government publishes final report on Winterbourne View

On 10th December the Department of Health published its final report following the abuse of people with a learning disability at Winterbourne View assessment and treatment centre.

The report, 'Transforming care', commits the government to an 18-month programme of action, which will be led by a national team.

The programme aims to reduce the number of people with a learning disability who are being sent away to assessment and treatment units like Winterbourne View, and return as many people as possible to their communities.

Local health providers will have six months to prepare individual care plans for people currently in assessment and treatment units and a further 12 months to find ways for people to be cared for in their communities.

The report outlines 60 actions to transform services and the ways that people with a learning disability receive support and care. Among its actions, are:

- A commitment to move anyone inappropriately being cared for in a hospital to community-based support by June 2014.
- Bringing forward plans to hold the senior managers, directors and board members of care organisations accountable for the quality of care that their organisation provides by spring 2013.
- Introducing high-quality care and support services in all areas by April 2014, including joint plans that meet best practice guidance for those who have behaviour described as challenging.
- Issuing new guidance on the use of restraint.
- Involving people with a learning disability and their families in decisions about care and support.

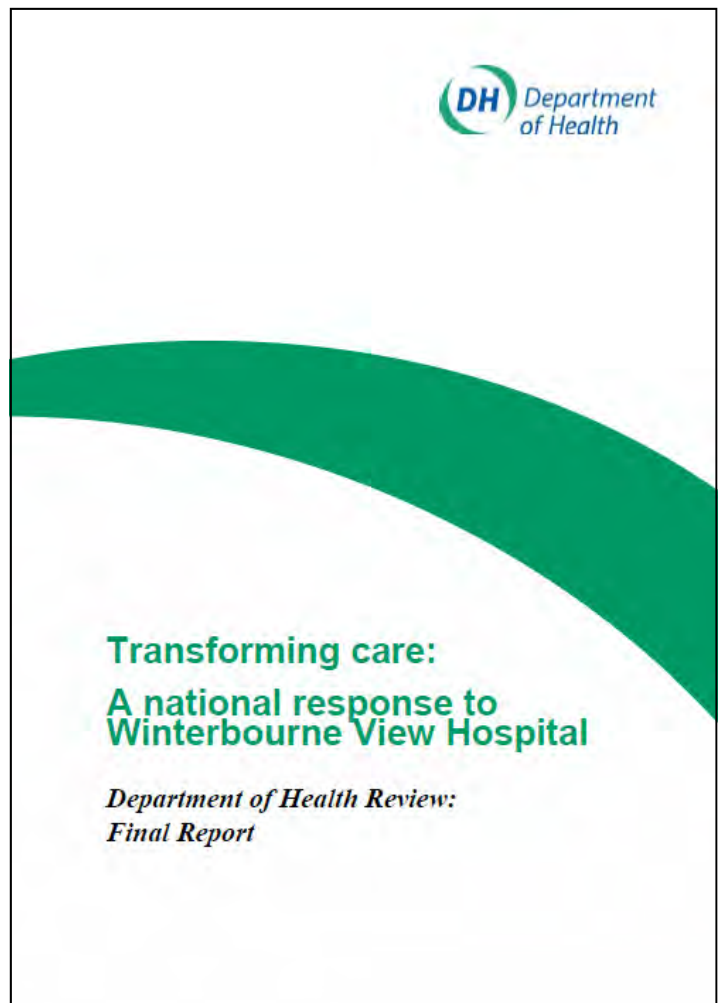
The Department of Health will report on the progress that has been made by December 2013.

In a joint statement, Mencap's chief executive, Mark Goldring, and Viv Cooper, founder of The Challenging Behaviour Foundation, said: "The horrific abuse uncovered at Winterbourne View shone a spotlight on a care system that has failed some of the most vulnerable people with a learning disability. In today's report, the government shows that it has listened to families and campaigners by committing to a national programme of change.

"But words are not enough. To achieve this, commissioners in local government and the health service must take urgent, joint action to develop local services, provide support to children and families from early on, and ensure that no one else is sent away. The many hundreds of people with a learning disability who are still far from home, in institutions like Winterbourne View, must now be able to quickly return to their communities, to be close to their loved ones."

Download the Department of Health's final report and programme of action concordat (including easy read versions):

www.dh.gov.uk/health/2012/12/final-winterbourne



Mencap's housing report reveals barriers to independent living

Councils are struggling to support people with a learning disability to live independently, according to Mencap's new report.

The 'Housing for people with a learning disability' report warns that local authorities are moving backwards from a long-established national policy to support people within their communities. It shows that aspirations towards providing independent living options for people with a learning disability are at risk of being derailed by government cuts and reforms to the welfare system.

Mencap conducted a freedom of information request of all local authorities in England and Wales and a survey of nearly 500 parent carers of people with a learning disability.

The results reveal the following findings:

- 8 in 10 councils recognise that there is a housing shortage for adults with a learning disability in their areas
- nearly 7 in 10 councils say that the housing shortage has worsened in the last 12 months
- just 1 in 3 people with a learning disability live independently in either supported accommodation, as a tenant or as a home owner
- nearly 1 in 4 people with a learning disability live in registered care homes.

The research highlights that around 22,000 people with a learning disability live out-of-area – an issue that Mencap is particularly critical of, given the recent scandal at the Winterbourne View assessment and treatment centre.

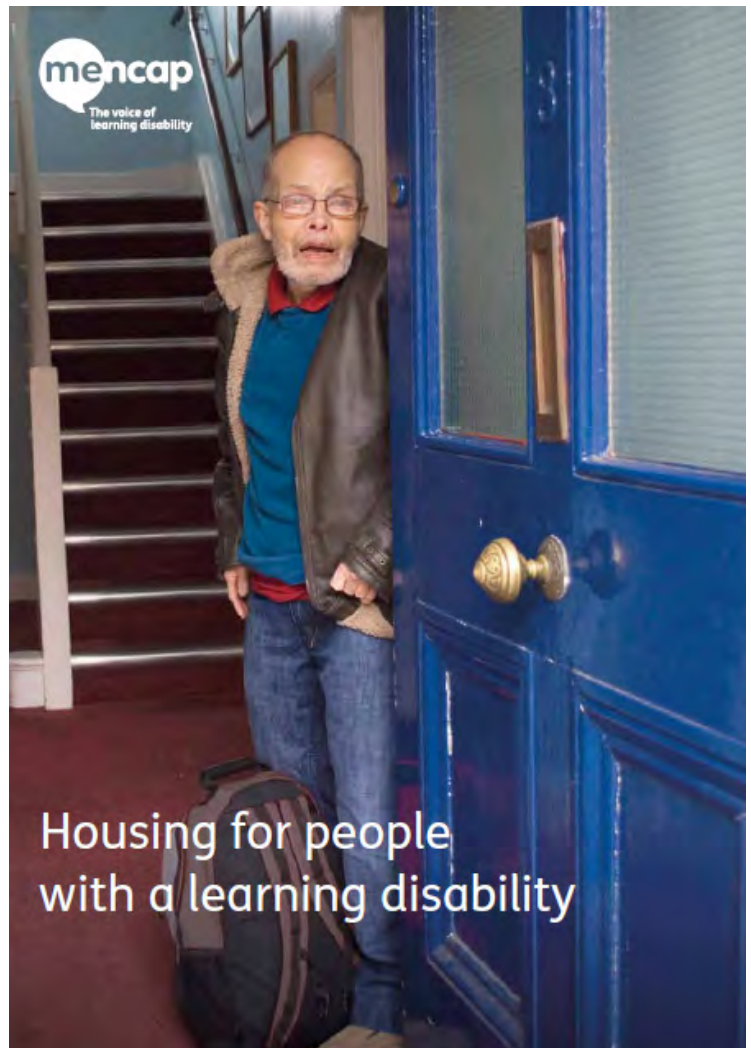
Financial pressures

The research highlights that 7 in 10 people with a learning disability want to live more independently. However pressures on council budgets are preventing many from doing so.

In the past year, a number of councils have taken the decision to only support people with a learning disability to live independently if the cost to support them is less than moving them into care. Mencap is concerned that councils are increasingly sending people into care because it is a cheaper option, rather than because it is the best decision for the individual.

"Less than half a century ago, people with a learning disability were locked away and kept a secret from the rest of society," said Mark Goldring, Mencap's chief executive. "Councils must not allow short term financial pressures to turn back the clock for people with a learning disability."

Read the report, <http://www.mencap.org.uk/housingreport>

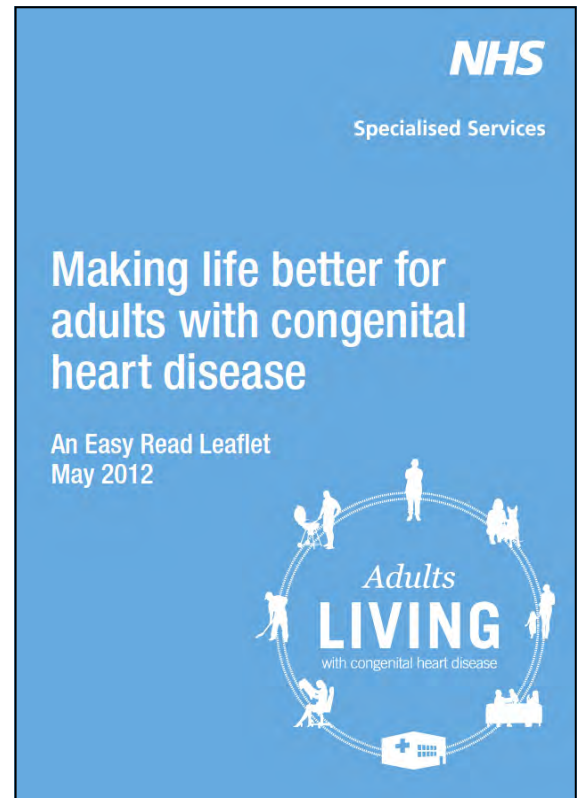


NHS calls for people's views on the future of adult congenital heart services

A document, *Adults living with congenital heart disease*, is published in May marked the start of a period of public engagement by the NHS on the future shape of services for adults with congenital heart disease (ACHD) in England. The review is led by NHS Specialised Services on behalf of specialised commissioners in England.

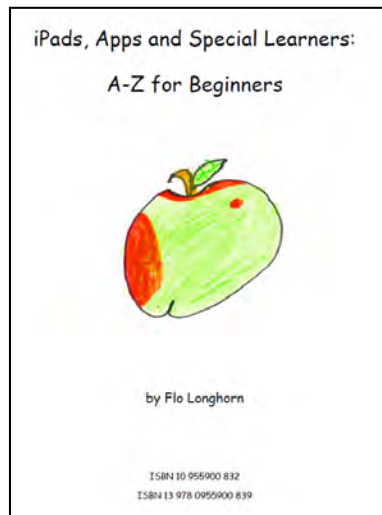
The review, which is in collaboration with the relevant medical, nursing and patients' associations, has been prompted by the increasing population of adults living with congenital heart disease. Those with the condition are living longer yet specialist services have developed in an unplanned way in some areas of the country. Evidence also shows that some hospitals are carrying out just a handful of surgical procedures on ACHD patients, resulting in some clinicians not carrying out enough procedures to be sure of developing their skills and delivering the best outcomes for patients.

<http://www.specialisedservices.nhs.uk/>



REVIEWS

Title: iPads, Apps and Special Learners A-Z for Beginners
Author: Flo Longhorn
Publisher: Flo Longhorn Publications
Year: 2012
ISBN: 0955900832



This is a fantastic book it is easy to read and split into chapters to make it easy to navigate when you want to recommend an app or find an app for a specific subject or requirement. The introduction is helpful and makes for light reading and inspires you to give an iPad a go. A recommendation for the introduction would be if it explained simply how to use the iPad without apps using features such as video, facetime and skype. Another handy hint would be examples of how schools which have got several iPads manage accounts and what

happens when you sync automatically and it wipes of previously bought apps more clarification on this would be helpful as it is a complex matter and there is only a short section on this.

The detailing and the amount of apps that Flo has reviewed and suggested are astonishing and it is very handy and helpful and it makes you want to buy them all. From a school perspective suggestions on how to use them in the classroom would be helpful but for other users of the book I appreciate it may seem to prescriptive. The back part of the book is also very helpful with boxes and adaptations from apple along with helpful websites.

All in all it has been an extremely helpful book that has resulted in many apps being downloaded on a school iPad for people to explore and now every class wants an iPad. A very helpful easy to read fantastic book. Thankyou Flo

Jessica Newcombe
ICT – Co-ordinator
Phoenix School
Peterborough

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 Sheilds,
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

January 2013	
Title: Date: Location: Provider: Contact:	Accredited Masters Level Unit of Study: Intensive Interaction: Theory to Practice Begins January 2013 Australia Deakin University, Burwood Campus. anne.savige@deakin.edu.au
	Tel:+61 3 924 46384
Title: Date and Location: Provider:	Make my Multisensory Room Fantastic <u>January</u> 18th Birmingham, <u>February</u> 4th Manchester Hirstwood Training Ltd

Title: Date: Location: Provider: Contact:	Meeting the mental health needs of children and young people with intellectual disability 24 th London Royal society of Medicine Chanel Roachford chanel.roachford@rsm.ac.uk
Title: Date: Provider:	Practical and Effective Ways of Using Multi Sensory Equipment <u>January</u> 28 th London, 29 th Birmingham, <u>February</u> 11 th Doncaster, 12 th Manchester, <u>March</u> 11 th Glasgow, 18 th London, 19 th Taunton, <u>April</u> 24 th Dublin, 25 th Belfast, 29 th Middlesbrough, <u>May</u> 9 th Birmingham, 10 th Liverpool Concept Training
Title: Date: Provider:	Profound and Multiple Learning Disability – engaging children in learning <u>January</u> 28 th London, <u>February</u> 7 th Chorley, <u>March</u> 15 th Birmingham, <u>April</u> 25 th Brighton, <u>May</u> 3 rd Glasgow, 16 th Doncaster Concept Training
Title: Date: Location: Provider: Contact:	Conference: Leading the way in Assistive Technology: Life enhancing technology to support people with learning disabilities 31 st Liverpool Pavilion working with Hft Pavilion customer services - 01273 434943 / info@pavpub.com
Title: Date: Location: Provider: Contact:	Conference: The learning and neurodevelopmental needs of children born pre-term 31 st London SSAT (The Schools Network) Natalie.Eccles@ssatuk.co.uk Fax: 0207802 2345

February	
Title:	Positive Ways of Changing Behaviour
Date:	<u>February</u> 6 th London, <u>March</u> 4 th Birmingham, 11 th Glasgow, 15 th Manchester
Provider:	Concept Training
Title:	Whole Person Communication
Date:	<u>February</u> 13 th Chorley, <u>May</u> 22 nd London
Provider:	Concept Training
Title:	Creating Exciting Low Tech Multi Sensory Sessions
Date:	<u>February</u> 6 th London, 27 th Birmingham, <u>March</u> 7 th Manchester, <u>April</u> 24 th Taunton, <u>May</u> 15 th London
Provider:	Concept Training
Title:	Autistic Spectrum – when things are not straightforward! (Children with a complex profile)
Date:	<u>February</u> 7 th London, <u>April</u> 30 th Birmingham
Provider:	Concept Training
Title:	Assessing Pupil Progress and Target Setting for Pupils and Students Working at or below Level 1
Date:	8 th
Location:	Manchester
Provider:	Equals
Title:	Intensive Interaction
Date:	<u>February</u> 12 th Chorley, 26 th Brighton, 28 th London, <u>March</u> 4 th Taunton, 14 th Birmingham, 21 st Glasgow, <u>April</u> 29 th Leeds/Bradford, <u>May</u> 9 th Antrim, 10 th Dublin
Provider:	Concept Training

March	
Title:	Inclusive Play
Date:	<u>March</u> 4 th London, <u>June</u> 6 th Birmingham
Provider:	Concept Training
Title:	Conference: Celebrating creativity and innovation
Date:	5-6 th
Location:	Harrogate
Provider:	The National Autistic Society
Contact:	www.autism.org.uk/conferences/professional2013
Title:	Moving and Handling
Date:	5 th
Location:	Newcastle upon Tyne
Provider:	Equals
Title:	North East SEN & Disabilities Conference: Achieving the best for everyone
Date:	13 th
Location:	Sedgefield, Co. Durham
Contact:	info@sentralconsultants.co.uk
Title:	Hands on emergent Literacy Workshop
Date:	15 th
Location:	London
Provider:	Ian Bean and Flo Longhorn
Contact:	flocatalyst@aol.com .
Title:	A PMLD Curriculum for the 21st Century
Date:	15 th
Location:	Glasgow
Provider:	Equals
Title:	Ipads, apps and special learners – with a sprinkle of sensory magic and switches!
Date:	19 th
Location:	London
Provider:	Ian Bean and Flo Longhorn
Contact:	flocatalyst@aol.com .

LONGER COURSES (with accreditation)

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, Penny Lacey p.j.lacey@bham.ac.uk or Helen Bradley h.bradley.2@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.

Learning Difficulties and Disabilities (Severe, Profound and Complex)
Distance Education

This distance education programme has been developed for the range of staff who work with people with severe, profound and complex learning difficulties, for example teachers and lecturers, nurses, therapists, psychologists and support staff. It is primarily about the learning and development of children and adults with severe, profound and complex learning difficulties, particularly in the areas of cognition and communication. Education, in its broadest sense, is seen as a key topic but other areas covered include health, therapy and social care. An important central theme is multi-agency collaboration and course participants will be expected to develop and reflect on their collaborative work as part of course. All the course assignments are grounded in reflective and evidence-based practice and are driven by the individual professional development needs of participants.

For further details: University of Birmingham Dr Penny Lacey, phone: 0121 414 4878 or email: p.j.lacey@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

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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	Headteacher of St. Luke's Primary School, North Lincolnshire, for children with complex learning difficulties
Alice Bradley	Has worked in schools, universities, health and social care settings in the UK, Canada, Thailand and various countries in Africa and Asia. Currently working in international development and as a volunteer with some UK charities.
Jeanne Carlin	Disability Consultant (freelance) 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.
Beverley Dawkins	Policy manager - profound and multiple learning disabilities, Mencap
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
Penny Lacey	Coordinator of the University of Birmingham course in severe, profound and multiple learning difficulties; freelance consultant; Penny has a family member with severe learning difficulties
Loretto Lambe	Director of PAMIS an organisation in Scotland working with people with PMLD, their family carers and professionals who support them
Wendy Newby	Teacher and curriculum coordinator St. Rose's School, Stroud, a school for children with physical disabilities and complex health needs
Carol Ouvry	Retired special education teacher, trainer and consultant in the field of PMLD.
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.

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sharing ideas and information

PMLD Link is a journal for everyone supporting people with profound and multiple learning disabilities. Visit www.pmdl.org.uk

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