

# PMMLD LINK

**The Bulletin of News and Information for Everyone Working  
with People with Profound and Multiple Learning Disabilities**

**Spring 2009**

**The Joy of the Arts**

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The Bulletin of News and Information for Everyone Working with People with Profound  
and Multiple Learning Disabilities

## The Joy of the Arts

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# GUEST EDITORIAL

## Spring 2009

### The Joy of the Arts

The other day I walked past a young man sporting an impressive pair of trainers, one with a luminous yellow lace, the other a luminous pink – the latest fashion statement, my companion informed me. Which set me thinking about creativity, self expression and this issue of PMLD-Link.

We engage with all forms of the arts in so many different ways – something that marks out music, drama, painting, sculpture, storytelling - and all other art forms – as *special* – different in many ways from other aspects of life. The arts offer people with profound and multiple learning disabilities, no less than the rest of us, the opportunity to be creators, partners, initiators and much more – as the articles in this issue of PMLD-Link illustrate.

The partnership, total involvement and power of sharing stories creatively, as described by Nicola Grove, does indeed 'offer us precious and unrivalled insights into the absolute fundamentals.' And what could be more important? Chris Fuller offers us yet more insights into the joys of story sharing – for both partners – and its potential in helping us move towards what we all want: real inclusion for people with profound and multiple learning disabilities. Inclusion is also a strong theme running throughout Peppy Hills' article, where children and young people with profound and multiple disabilities and children from mainstream schools experience the joy of knowing, understanding and sharing with one another.

Martin Goodwin and Cath Edwards highlight the importance of being truly person centred and the potential of combined arts for creative communication, illustrating this with both examples and photographs which paint the picture well. Susan McLaren develops this theme of communication through engagement with a wide range of creative and self-affirming arts experiences for all partners.

And I'm sure that, like me, you'll be fascinated and excited by the music gym when you read what Susan Heath writes. What comes across strongly is the sheer fun and exuberance of the experience, along with the other benefits she so ably describes.

Fundamental to the principles of PMLD-Link is our commitment to sharing practice, sparking off new ideas and making the most of our networks for the benefits of everyone with profound and multiple learning disabilities. I hope you'll agree that this issue helps us do this admirably. We'll be delighted to hear of your ideas and experiences of the arts so that we can develop the themes in this issue in the future.

Alice Bradley

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**Summer 2009**  
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## Telling and sharing stories

Nicola Grove

Storytelling is one of our oldest art forms. When we speak of storytelling we are encompassing a vast heritage of lore, myths, epic tales, folk tales, travellers tales; tales of the creation of the world, tales of its destruction; sagas of Gods and men; all the great traditional legends from around the world. These stories are not learned by rote or read from books but retold by the tellers, making each interpretation unique. Storytelling is more than just performance or entertainment; it can also educate, heal, lead to better practice in business, inspire and change lives. ([www.sfs.org.uk](http://www.sfs.org.uk))

On the face of it, storytelling would seem to be the most inaccessible of all arts when we are thinking about children and adults with profound disabilities, where intellectual impairments are confounded and amplified by complex sensory difficulties such as hearing loss, visual impairments, and physical restrictions. If you cannot hear the story properly; if your attention is fleeting, inconsistent or affected by pain, hunger and the drugs you are taking; if you do not have any experience of having stories read or told to you, and you are excluded from the anecdotal narrative conversations that feature so prominently in our everyday interactions – if all of this, how could storytelling possibly be a relevant or meaningful activity for you?

And yet and yet.

As so often in this field, we have to examine the art form in order to explore its potential for engaging this group of people. When we do this, they offer us precious and unrivalled insights into the absolute fundamentals.

I find that incidental conversations offer precious insights into theory and practice. In this case, when I was in discussion around a proposal for some storysharing work, with parents and professionals. One of the parents had said that his daughter really enjoyed listening to traditional stories. The conversation moved on to the practicalities of how and where the project might happen. One of the professionals expressed scepticism. "The main problem is that so many of the staff don't speak English well, and the service users can't understand them. So what on earth would be the point of them trying to do storytelling?"

I turned to the parent, and asked him what he thought his daughter was responding to when she heard something like "The Gingerbread Man"<sup>1</sup>. He answered immediately "It's the rhythm, and the

intonation in the story". Then he added "It could probably be in German as far as she is concerned".

This parent was not being facetious. On the contrary, he had grasped the essentials of storytelling for people functioning at an early developmental level. We are accustomed to defining story as something like:-

*A sequence of two or more events that are causally connected, narrated in a monologue*

Is that what you think of when you think of the word *story*? Or does the word conjure up feelings, imagination and enjoyment?

Unfortunately, twenty years of an educational system which puts story firmly into a box marked "literacy" means that people tend to think of story as a) a book b) for children.

But all through history, since time began, people have told each other stories, directly, not through the written medium. The great epic stories such as Mahabharata, Odyssey, Monkey, were told long before they were written. And we still tell each other stories compulsively, sometimes as monologues, but often collaboratively as the following conversation illustrates:-

N and her husband B and her friend S have just met an acquaintance at a public lecture and N launches into a riff about what happened as they walked to the restaurant where they were having lunch.

N So you won't believe how embarrassing it was  
S. We were so embarrassed

N. In this loud voice

B. Two hundred and ninety-nine pounds! For a bit of plastic. I thought it was a misprint....

N. The most beautiful fabric

S. It would really have suited you

<sup>1</sup>This traditional European folktale involves many repeated refrains and is highly rhythmic and repetitive

B. ....for twenty nine ninety nine. And even at that price it was barefaced theft  
 N. I mean in this loud voice, everyone could hear, it was SO embarrassing  
 S. I'm surprised we weren't kicked out.

This is not the way in which stories are generally written down, but it does illustrate perfectly the very highly choreographed, socially situated nature of personal anecdotes, which are not told primarily for exchanging information, but as an expression of social relationships, to entertain, and to make sense of experience. Note the number of repetitions and the way in which N takes the lead, but depends on one co-narrator, S as reinforcement, whilst B functions as a counterpoint. The roles here are gendered and predictable, because essentially what N, S and B are doing is to launch into a well known song with its own internal logic and structure. We are working with two fundamental emotions – outrage and embarrassment, overlaid strongly with irony, since B, N and S know perfectly well the game they are playing.

In our work developing shared stories with people who have profound and multiple disabilities, we have found that with the right preparation and support, this type of story is very accessible, because there is so much meaning carried through intonation and rhythm. Through supportive collaboration and with the judicious use of props and simple voice output devices, people start to recall their experiences and engage in social retelling.

For example, Mary starts telling the story of taking the cat to the vet. Her support worker helps her if she gets stuck. The conversation goes something like this.

Mary: Nicola!– cat – injection. Bad leg. Injection  
 Jane (support worker) Yes, we had to take her to...  
 Mary: vet. Bad leg.

At this point, Tommy, who is another resident, chimes in

"Fluffy!" where are you?

Jane: we looked everywhere  
 Mary: injection. Bad leg  
 Tommy: oh dear.

Tommy's *oh dear* marks a real advance because what he is doing is listening to Mary and responding to what she says. It is quite unusual to see these real conversations carried on between people with more severe learning disabilities, as opposed to with staff.

Personal stories like this have the power to help people develop a stronger sense of identity and to

build social relationships. What about traditional legends?

We have to understand that even the most farfetched and elaborate tale has its roots in the everyday. Those stories of gods and goddesses were not handed down on tablets of stone – they grew out of the everyday stories that people told each other. So of course they are grounded in real feelings and real interactions. These stories of course use all sorts of strategies to gain and hold our attention, which can be used effectively with listeners of all abilities. These include

#### *Call and response*

Kwasukha sukhele? Xhosi  
 (do you want to hear a story – sure; Xhosa)  
 Anansi/Story (Jamaica)

#### *Traditional phrases that can be used on communication aids*

Far, far, farther than far  
 The wine dark sea  
 On and on and on

#### *Rhymes and songs*

Fee Fi, Foh Fum  
 I smell the blood of an Englishman

But more importantly than this, they help us to engage with the deep structure of our lives, teaching us about how to face danger, solve problems, find happiness and love – feelings and experiences which are just as important to people with profound disabilities as the rest of us, even if at what seems like a very microcosmic level.

I was once told that it was tokenistic to try to tell hero stories with very autistic children, because "they don't know the meaning of the word brave".. and I thought – but these children have to be brave all the time, even if it is just putting their face in the water, or getting in a different taxi from the one they had expected. It's a matter of how you tell these stories, which need to be carefully mediated, as the work of several practitioners such as Keith Park, Louise Coigley ([www.lisntell.com](http://www.lisntell.com)) and Michael Jones amongst many others, can demonstrate.

In conclusion, our fundamental need for stories was illustrated for me by a commentator about the recent Davos symposium on global issues. "They are totally confused" he said" no-one knows how to make sense of what is happening with the financial meltdown. We need a new narrative".

Precisely. When your world is a chaotic jumble of sensation and confusion, what you need is a narrative to help you make sense: a narrative

which works to help you select experience, shape it and share it with others. That's what stories and storytelling are about.

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- Bag Books: [www.bagbooks.org.uk](http://www.bagbooks.org.uk)
- Lis'n Tell: Live Inclusive storytelling [www.lisntell.com](http://www.lisntell.com)
- Real lives, real stories: personal stories using a bag books approach [www.dundee.ac.uk/pamis/projects/sensory.htm](http://www.dundee.ac.uk/pamis/projects/sensory.htm)
- Society for Storytelling PO Box 2344, Reading, RG6 7FG [www.sfs.org.uk](http://www.sfs.org.uk)
- [www.talk4meaning.co.uk](http://www.talk4meaning.co.uk)
- [www.teachingexpertise.com/articles/storytelling-to-facilitate-inclusion-3275](http://www.teachingexpertise.com/articles/storytelling-to-facilitate-inclusion-3275)

The Unlimited Company of Storytellers with Learning Disabilities have transformed themselves into a charity called Openstorytellers at [www.openstorytellers.org.uk](http://www.openstorytellers.org.uk),

Nicola is writing *The Big Book of Storysharing for Children*, a resource book on how to tell personal stories with children who have complex needs. This will be published later in the year by SENJIT at the Institute of Education.

Courses in Storysharing and storytelling are run by Openstorytellers. Contact [info@openstorytellers.org.uk](mailto:info@openstorytellers.org.uk).

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## Mark Gray Associates

" for all your specialist communication training & sensory function assessment in PMLD" for details contact Mark Gray on 0115 9732540 web site [www.markgrayassociates.com](http://www.markgrayassociates.com)



## pARTnerships

### Peppy Hills

Making friends and developing working relationships is something we do throughout our lives at different times and in different contexts. The skills of communicating and establishing partnerships are crucial life skills. At Sunfield (a residential school and care facility for students with severe and complex learning needs, with specialist provision for profound autism), we run a number of projects that link our students with local schools in the area and further afield. As Sunfield is a residential experience for the vast majority of our students, it is particularly important for them to have the opportunity to work with other people and visit different places.

Utilising the arts is a wonderful way for our students to work alongside mainstream students. For many of our students, words are not a natural or preferred way of communicating. Therefore the potential 'languages' and expressive elements of visual art, dance, drama, music and other media are rich tools for us to use as the basis of exploring partnerships with others. For many mainstream students, the arts may be a less familiar mode of communication. The potential of learning, for everyone involved in an inclusive creative arts project, is vast – and it is exciting.

The arts are not always creative. There is nothing creative about repeating set ballet exercises or learning your piano scales. It is how the arts are used and applied as a vehicle of creativity that is key. For example, it is the choreography and composing that are the creative acts. At Sunfield, the Creative Arts Team are committed to exploring ways of working that are creatively challenging for all involved and we have explored a number of project models that require different ways of working.

#### Joint projects

We have recently devised three projects that involved joint sessions with local schools.

##### 1. Drama project

Over 4 weeks, Sunfield students visited a Year 6 class at Clent Primary School and worked on a drama based project. Joint sessions in their main hall consisted of drama games and the development of a mystery story. Hot seating and improvisation tasks resulted in students developing the characters and ultimately the story line of the mystery. This was led by Sunfield's Creative Arts Team.

##### 2. Getting to Know You – creative communication

A Y6 class from Hagley RC Primary School and a class of students from Sunfield were 'pen pals' over a period of 4 weeks. Instead of writing letters to each other (writing is not

possible for many of our students), they swapped creative pieces of work. These varied from visual art (decorated hand shapes, flags, a creative jigsaw puzzle of body parts) to music based poems and a rap. The final session involved all students meeting at last and working together on pieces of visual art that were included in our Winter Open Day.

##### 3. Shared Beat

A drumming group visited groups of students at Hagley RC High School and Sunfield separately over a period of 4 weeks. These sessions introduced drumming and percussion skills to the students. The final 5<sup>th</sup> session involved the two groups coming together to perform at Sunfield to the whole school. All sessions were led by local drumming experts, Drumlove.



*Benefits of this approach include:*

- The local primary schools receiving drama/ drumming/creative thinking/arts input they otherwise would not have had
- Sunfield and Hagley/Clent students developing ways of working alongside each other
- Mainstream students gaining experience of



students who have different learning needs from themselves

- Sunfield students visiting schools outside Sunfield.

### **‘At a Distance’ – contributing to projects**

Two projects that have a more distanced but clear involvement from Sunfield students are:

1. **Moving Postcards – an arty correspondence**  
A class of Sunfield students swapped Digiblu films (short video movies) with students from Abbey Special School in Rotherham. Though the students never met (the distance being considered just too much for students to cope with for a day visit), they introduced themselves and their school through visual art, paintings and digital media – Digiblu and Photostory films with student commentary.
2. **Jazz project – a local cluster project**  
Hagley RC High School has invited Sunfield to take part in this arts project as one of 8 local schools involved. Sunfield will host a live performance from a jazz band. Students will then work with a visual artist and respond to the jazz music by painting and mark making using various media. The artist will collate elements of the students’ work into a hanging of some kind. This will then be Sunfield’s contribution to the Celebration Day at the end of the project.

#### *Benefits of this approach include:*

- This is a fairly ‘light touch’ way of being involved in a joint arts project. There is no pressure on students to work in new spaces with new people in close proximity. This approach can involve students who would not cope with the transitioning to a new place and new people. All students involved can meet new people, and be aware of life beyond their own school setting, without having to leave their familiar setting.
- There is less of a need for an immediate response and contribution from students (as compared to a joint drama session, for example). They can work at a relaxed, non-pressured pace.
- There are fewer logistical arrangements to make (minibuses, booking rooms or halls to work in etc).

### **Hosting visits**

As part of a project, ‘*Sounds in the Grounds*’, Y9



students from Hagley RC High School came to Sunfield to work with land artist, Mike Fletcher. The brief was for those students to devise some sound sculptures that would be hung in the grounds for Sunfield students to interact with. A small number of Sunfield students from the FE department documented the visit using cameras.

#### *Benefits of this approach include:*

- Sunfield students were responsible for hosting and documenting the session
- Mainstream students had to explore and consider the needs and desires of Sunfield students and the grounds when designing their sound sculpture. It widened their awareness.

### **Accessing arts opportunities in the community**

A small number of Sunfield students attend the local pyramid orchestra on a weekly basis. This is held at a local high school and involves students from three other high and primary schools in the area. Sunfield staff accompany and support our students. Sunfield students are now the percussion section of the orchestra. Our staff suggested ways for the orchestra conductor and other music staff from the school to ‘include’ our students more fully. Strategies such as:

- The use of Widgit Software symbols – symbols such as ‘start’ and ‘stop’ are used by the conductor to cue our students. Sunfield staff sign ‘listen’ and ‘look’, at appropriate times, to guide our students’ focus.



- An acceptance that Sunfield students might need to leave the room at unscheduled times has been negotiated and is fully accepted.
- We identify students on an annual basis to attend the orchestra, and they attend for an academic year. Different students will be invited to attend for the following year and so on.

*Benefits of this approach include:*

- Sunfield students visiting an external venue on a weekly basis
- Sunfield students and mainstream students working with each other over an academic year
- Sunfield students developing working relationships with other adults over an academic year
- Sunfield students touring with the orchestra



and performing in concerts at other local schools

- The conductor and music staff adapting their delivery to enable multiple access points (informal professional development).

All of the above projects have a key focus of linking

with others and the art forms are used as a creative way of doing this. One of the other essential elements of a successful partnership project is the preparation. This means preparation of all staff involved, of our students and also of mainstream students. We often run a small number of introductory sessions with only mainstream students to explore the notion of 'special needs' and 'difference' and what this actually means. We consider the apprehension, excitement and/or indifference that they may be feeling about meeting people with disabilities, particularly if they have no previous experience of this.

Below are some of the responses from an evaluation questionnaire from a recent pARTnership project. Mainstream students were asked the following questions:

**What were the 3 best bits of the project for you?:**

'Meeting the children and recognising differences but similarities too – we can all have fun.'

'Being able to have contact with different people and learning how they feel.'

'Being able to make friends so easily.'

**Has the project made you think any differently about anything?**

'I will respect differences more.'

'I'm not scared of differences any more.'

'I understand more about how special some children are.'

The Creative Arts Team at Sunfield will continue to experiment with ways of working together and building partnerships with creative arts at the heart of projects. We are also very open to any school who would like to devise a project with us. Any ideas anyone!?

**Contact details**

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## On the road with stories: Story-Go-Round UK

Chris Fuller

Sitting in the Bag Books office one morning, the director and a member of the management team decided to look at how the work of the organisation could be brought to life, be more 'sparkly!' Bag Books, a company with charitable status, had been publishing - creating and producing - multi-sensory stories for thirteen and a half years. The stories consist of separate pages of card to which are attached objects and materials which the listener can feel, smell, hear or look at, while a simple tale unfolds. They are designed for children and adults with profound and multiple learning disabilities.

Between 800 and a thousand stories are distributed each year, mainly to Special Schools, Schools Library Services, Sure Start and other Early Years services. A small number have gone to public libraries and an even smaller number to residential and family homes.

The concept of multi-sensory storytelling has been shared by providing INSET in special schools and Sure Start, through training and storytelling in adult Day Centres and residential homes, with parent groups and in a handful of public libraries, but we felt sure that we could offer a more enriching service for children and older people with severe and profound and multiple learning difficulties.

From that brainstorming session in the summer of 2006, the Story-Go Round project took shape. The organisation would aim to tell stories in each region across the UK and they would be told where mainstream children would go if they wanted a good read, in libraries! The difference from all our other approaches would be that we would try to leave a legacy of storytelling so that children with severe and complex needs would not just have one great day of stories, but would be able to start using their library on a regular basis.

**Story-Go-Round project therefore had two main aims:**

1. To demonstrate multi-sensory storytelling, showing how it can provide both a leisure session of fun and/or a learning activity, for children with profound and multiple or severe special needs in their local community libraries; and
2. To enable library staff to continue providing regular multi-sensory storytelling to local children and their families, by training them to use the story-packs effectively.

**To achieve these aims would require the following objectives:**

### **Aim 1. – demonstrate effective storytelling**

- a. Recruiting professional storytellers which would mean that CRB checks were likely to be in place
- b. Training the storytellers in how to deliver multi-sensory stories and, if necessary, how to work with children with additional needs appropriately
- c. Providing on-going support and monitoring for the storytellers during the tours
- d. Contacting Borough Library Services in the target boroughs offering the service to them centrally before approaching individual libraries
- e. Offering the tours to their local libraries free of charge
- f. Gathering feedback from the storytellers and participants
- g. Demonstrating accessible stories and storytelling to librarians

### **Aim 2. – enabling library staff to continue to provide sessions**

- a. Providing training in conjunction with the storytelling demonstrations
- b. Suggesting librarians invite other services such as early years' services, children's centres, parents or carers to join the training sessions. (The training was not for school staff, unless they asked to attend, as they would already have the educational knowledge and awareness which underpins multi-sensory stories and storytelling.)

East Anglia was chosen for the pilot project and we were very fortunate that emails sent to the main Borough Libraries in Cambridgeshire, Norfolk and Suffolk, received an immediate and enthusiastic response. We were also greatly assisted by the director of The Persula Foundation, a charitable

organisation using professional storytellers, who recommended a storyteller she thought might be interested.

We met Bernard in July 06 and he was definitely interested! He had a free month in January 07 and agreed to do the pilot tour. Being a professional storyteller, he only needed to observe the stories in action, to practise handling the page cards and familiarise himself with the story lines. All was good, fundraising began in earnest, the Bag Books workshop began to make a set of thirteen story-packs for Bernard to use, the local libraries in each borough were offered a selection of dates and we waited to get firm bookings.

One borough approached their local schools and had secured bookings for their week by the end of October. The other boroughs were not so fortunate; Christmas term and the teachers were busy, schools did not respond or commit to specific dates or, for other reasons, library staff having a very heavy work load and not having time to pursue schools, some library staff undergoing dramatic role changes within their service etc. By the end of November, two weeks of the tour diary remained very sparsely booked. This was going to be an expensive non-event!

Bag Books leapt into action! The director telephoned the special schools in the immediate vicinity of the chosen libraries, managed to reach the literacy co-ordinators and convince them that yes, it really was for children with the most profound needs, the stories would be appropriate, their pupils would have a fun time out in the community library, and it was free! We made it, with only one day left not booked which Bernard kindly agreed to take back. We had learnt our first major lesson. We must give the libraries much more help and book the schools ourselves.

The tour was a success. Forty two sessions were held in seventeen libraries, two hundred and sixty five children had fun with the stories and fifty eight library staff attended workshops. On this first tour the director undertook all the training sessions. The event was covered by East Anglia Television and Suffolk Radio and heralded in library newsletters as an exciting experience. Each participating library ordered their two free story-packs and we know that they are being used.

After that first tour it was clear that the training should be handed over to the storytellers, not only to be more cost effective but also to ensure an expanding service. Now it was time to roll out the project; originally with the help of two temps from an agency but finally and very much appreciated, with Kate our Story-Go Round co-ordinator. Multi-

sensory stories have now been on the road for over two years from the sunny tip of Cornwall to the snows of Cumbria!

In Wales, Bernard once did storytelling in three



libraries and the training in a fourth, all in one day, and in Cumbria when all the schools had to cancel because of the weather, he transferred the event to the schools and the librarians joined him there.

The storytellers' flexibility, professionalism and good natured dispositions have been invaluable to the success of the project.

As Janet, our Inner London storyteller said, "London is a challenging place to work in when you have eight crates of Bag Books in the back of your car and the library has no parking whatsoever!"

And an email from Bernard is typical of their positive attitude:

"End of the first week of this Northern leg of SGR tour coming up....all going very well indeed...well done Kate! Lots of people turning up to observe and/or participate in the training sessions, and a sense of some real networking and planning going on between schools and libraries."

Three tours per year have taken place, East Anglia, Wales and Inner London, as previously mentioned, the South West, South East, the North and North West, and the West and East Midlands are currently being booked. Nina, the SEN co-ordinator for Bexley Libraries has joined the team as another storyteller/trainer, and by instigating networking with her own library, has inspired several libraries on the way.

Since the pilot tour, over 2000 children with severe to profound learning difficulties, have taken part

and just under 900 library staff. (More children took part but one can never be sure who is actually going to turn up! Some had mild learning difficulties, some only expressive language delay or physical disabilities, one group included two adults and a one year old! And when schools cancelled at the last minute, mainstream nurseries kindly trolled along to fill the gap.)

Has the project fulfilled its aims? In part, yes, the storytelling sessions were a great success, but just as importantly, it highlighted a number of useful things. One of the key aspects to come out of the monitoring feedback from both the host libraries and the storytellers, was that having the opportunity to observe the sessions made all the difference. Library staff could see how the children were spoken to, how they responded to the stories and what made that happen. It was pointed out that the horseshoe shape of the group with school staff sitting behind or on the ends, allowed the children to be aware of the page cards moving around their peers without interruption and they could see how the storyteller took the children's hands and helped them to access the page cards.

The physical interaction was an issue for librarians, as one would expect, but as one Head of Children's Library Services said, the staff are always there, the storyteller/librarian would never be alone. Many of the children who attended were on the autistic spectrum and library staff could see how useful it was to have everyone on a chair so that at least one behaviour option was limited and if they left the session for a while and then re-joined, they returned to the same place! In other words, helpful tips on the actual "nitty gritty" of hosting a session for children with diverse needs.

In the feedback forms, a number of libraries commented on how their tour had helped them to build relationships with their local school and to date 85% of participating special schools would like to bring their pupils to the library for regular sessions.

"So often when we come to special events for our SEN children, we are a little disappointed, despite people's best intentions....but this was wonderful!"  
*Denise Kell, Springwood School, Harlepool*

Interestingly only 65% wanted the library to be open to the general public, which was a surprise as we imagined that school staff would consider "inclusion" to be about interacting with the local community.

However the aim only partly achieved, was that of leaving a legacy of storytelling. Only 23% of library staff expressed confidence in continuing multi-

sensory storytelling as things stand now, but given the option of additional mentored support, this figure rose to 72%!

"Such simple stories with brilliantly simple props, but I can see the training is essential to give librarians confidence to use them."

*Diane Lonsdale, Brotton Library, Redcar and Cleveland*

To enable more library staff to gain that confidence - and when funding has been secured - the next three-year project, "Telling Tales," will see a trained mentor in each of the nine regions for six months. She or he will support a minimum of two library staff in libraries keen to participate and together they will establish on-going partnerships with schools. This will give library staff time to get to know the children really well, starting with visits to the school, and gradually building confidence until the sessions in the library are established and running easily without support.

In conclusion, not all library staff in children's libraries are storytellers, not all libraries still have children's librarians, but in virtually all the libraries visited there have been at least two members of staff who are really interested in developing their service for children with special needs.

What has been really good, is to see children with complex needs, some with oxygen tanks and tube feeds, all of them great characters, being welcomed into their community libraries and enjoying stories. Together with the new research focussing on libraries, (*Lacey P. "Retro" PMLD Link. Winter 2008. Volume 20*) there should be greater scope in the future for sharing good practice and good ideas, and for introducing a range of literacy activities and resources which will include everyone in being able to use their local library.

*Chris Fuller  
Consultant*

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## I'm Creative Too

Martin Goodwin and Cath Edwards

In this article, we describe the process of working with a group of children and young people with Profound and Multiple Learning Disabilities (PMLD), aged between 6 and 18 years old and their paid carers within a creative arts and play project. The young people live at a local authority care home and much of the project was carried out within the home. We visited on a weekly basis, spending half a day with the staff and youngsters each time. There was one initial staff training day, twelve play sessions and two other sessions to begin developing communication passports.

Our intentions, in planning, initiating and carrying out this project, were to:

- enjoy the company of the young people
- create opportunities for shared experiences
- focus on supporting the young people to communicate their choices and to develop meaningful interactions
- offer a variety of adult-initiated and participant-led activities
- listen and respond to the participants by developing experiences that are led by them and lead to organic play opportunities
- train staff, in formal and informal ways, in good practice and effective approaches to youngsters with PMLD.
- begin to introduce relevant concepts and approaches such as schemas and intensive interaction
- model good practice
- lead or facilitate a variety of creative and play opportunities with the intention of having fun at the time and of giving staff ideas for creative play sessions that they could offer in the future
- develop a listening and responding cycle that will enable person centred and participant led opportunities and encourage the individual's 'voice' to be heard
- collaborate in the creation of permanent or semi-permanent communication aids
- Exploration of materials which may or may not lead on to something else, e.g. choosing fabrics for den building, investigating play-dough, messy play etc.
- Considering options and making choices and communicating those choices in their own style e.g. eye-pointing, reaching, vocalisation etc.
- Interacting with the person involved by entering into their world by joining and mirroring (Nind and Hewitt 2001)
- Differentiation of approach to enable the participation of youngsters and play to be meaningful and at a developmentally and age appropriate level
- Gross and/or fine motor movements or stillness in response to stimuli
- Enjoyment of group activities, e.g. singing, bowling
- Experiencing and responding to a performance, e.g. a dramatic sensory story
- Spontaneous shared experiences with a partner, e.g. peek-a-boo, other simple games and shared stimuli
- Encounters with peers, e.g. when lying on the floor, discovering the other person, perhaps making eye contact or vocalising

### Play and young people with profound and multiple learning disabilities

For the purposes of this project we defined play in the following ways:

- Supporting experiences and interactions to be person centred and as participant led as possible in order to enable open ended, intrinsically motivated play
- Participation, supported or otherwise, in structured games

We realise that this is different from Bob Hughes play taxonomies (2002), but we feel that in the case of PMLD youngsters, it is important to be aware of those behaviours which are precursors to, or the building blocks of, play.

### Staff Training

The project started with a full day's training for staff in approaches to play with people with PMLD. Some of the topics covered were intensive interaction, how to offer choices, techniques to aid communication and how to apply a child-led approach with this group. We also touched on the topic of staff's own childhood memories of play; we have often observed that an adult's ability to



provide play opportunities for children is dependent on her experiences of play and interaction as a child.

The staff who attended this day found it enjoyable as well as informative; there were comments,

'I never expected to have so much fun while learning',

and

'I hadn't thought play was relevant for these kids before'.

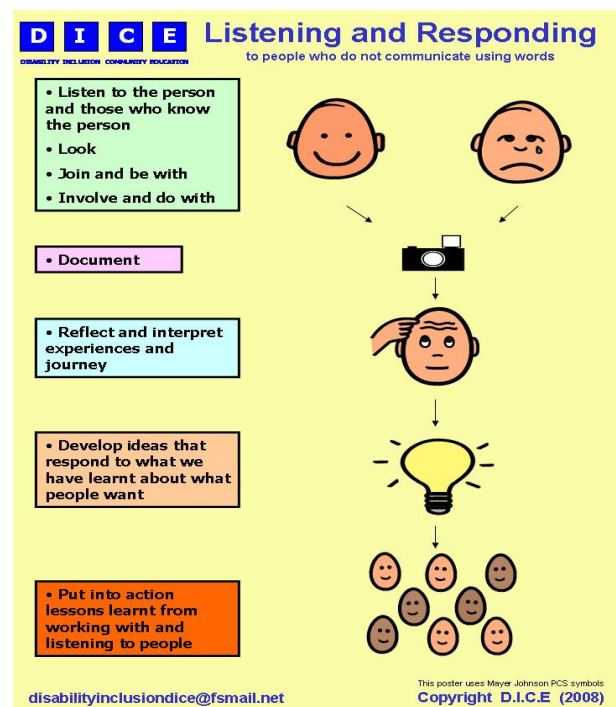
However, although the training day was successful, we felt that it was too brief to cover the topics in sufficient depth, and also, due to the large number of staff involved with the youngsters and the constraints of patterns of shift working, not all staff were able to attend the initial training. Therefore, significant amounts of staff training were done 'in the moment' as we worked with the youngsters; this took the form of brief explanations to all staff at the start of a new activity, modelling of good practice by the facilitators and prompts and suggestions to individual staff throughout the session. We stressed the importance of the process and the young person's 'learning journey' (Edwards et al, 1998) rather than the tangible end product that is all too often viewed as paramount. In addition we highlighted the importance of sharing the activity with the person and importantly sharing control with the person to avoid 'highly controlled activities' which as suggested by Cavett '... leave little chance for people with PMLD to make choices and decisions' (Cavett et al 1998; pg 209).

It was also helpful, in terms of staff training, to work in the residential home and therefore encounter first hand the constraints that staff are working under: the care needs of the young people; shift working and the necessary hand-over time; and very little funding being available for day-to-day purchases of basic play materials. We tried to partially overcome this last concern by offering some activities which were either cost-free or very cheap.

Finally, by working within the home we had a clearer picture of the daily environment and we could therefore tailor informal training to the realities of the situation, for example, when we discovered that it was the norm to have a radio or television on in many of the rooms, we could explain the concept of single-channel communication, and how, if the auditory or visual channel is receiving constant distracting input, the youngster's ability to communicate may effectively shut down.

## The Listening and Responding Cycle

We engaged in a process of observation, reflection and interpretation as proposed by Rice (1996), who describes a process of observing the schema cluster, supporting the schema cluster and extending the schema cluster (but see our observations on schemas in the section below). A process of enabling organic child centred experiences was additionally supported by a model developed by Goodwin (2008) who describes a process of 'Listening and responding to people who do not use words to communicate'.



This process was supported by staff who gave their observations of the youngster's responses to a particular session, but who were also able to add comments based on their knowledge of the young person: their likes and dislikes and their usual ways of expressing their feelings. We were thus able to suggest further opportunities for subsequent sessions based on the youngsters' preferred areas for exploration, so the project as a whole was as participant-led as possible.

## Choice-Making and Schemas

During the project we constantly modelled the process of offering choices to the young people. Sometimes, we would simply offer two items and then use the one on which the youngster settled his gaze. An example of this was choosing between two wrapping papers for an art project. At other times, or with other youngsters, it was more appropriate to offer the items one at a time for the person to feel, taste, listen to and in other ways

explore, and to interpret his responses so as to make a decision on his preference. Examples might be choosing a musical instrument or choosing fragranced play-dough. This approach was also more appropriate for youngsters who may be at an early level of functioning and who therefore could be unable to retain a clear memory of a previously presented item, thus being unable to make a choice. We did feel, though, that offering choices or assessing preferences was an essential part of the process for two reasons: it is the start of a continuum that leads ultimately to being able to initiate communication, though many youngsters may never achieve this level; and it is also an important part of treating young people in a respectful and inclusive way.

It was sometimes difficult to explore and develop participants' schemas. Some of the young people appeared to have very early schemas that were not significantly developed; most of the schemas that we were able to identify seemed to be operating at a basic sensori-motor level, rather than the other levels described by Athey (cited by Bruce 2005) of symbolic, cause and effect and abstract thought. It was also clear that some youngsters encountered difficulty in expressing their schemas due to physical limitations. When it was difficult to identify the schema, we looked at the preferences that the youngster may show, and gave them continued experiences that allowed for exploration and further development of the preference.

### The Activities, Opportunities and Experiences Offered

For each session, we prepared a range of opportunities and experiences, with some more structured activities. All were based on the interests and preferences of the youngsters developed through using the listening and responding and observation cycle. The following is a selection.

**Resonance board:** A plywood board large enough to lie on, slightly raised from the floor by means of battens fixed around the edge on the underside. As the name suggests, it resonates in response to small movements that the person might make with their own bodies or with play items and therefore gives amplified feedback.

**Chandelier:** A large hoop with objects chosen by the young people hanging from it, suspended above the floor at a convenient height for a youngster to lie underneath.

**Music activities:** 'Kitchen percussion': we provided a large box of kitchen utensils (e.g. metal bowls, wooden spoons) for the youngsters to explore

freely and also to use or be helped to use in more structured song sessions, when we also used objects of reference to represent the songs and more conventional percussion instruments.



**Ball run:** A game in which the youngsters chose a ball which they were helped to roll down a length of plastic guttering into a goal which they had previously made from a small wine box (given away free in supermarkets) covered with shiny paper. The balls were chosen to appeal to the senses, e.g. a 'koosh' ball, a ball with bells inside, a knobbly ball that rolled erratically.



**Spin the bottle game:** Ostensibly a dressing up game, a bottle filled with water and glitter was spun and the person it pointed to could choose a hat or scarf to adorn themselves, thus allowing an exploration of their sense of self when they were offered a mirror to look at themselves 'before and after'. There was also a degree of cheating with the bottle spinning to ensure that everyone had a turn.

**Sensory pocket ball game:** This used a large piece of fabric which had pockets sewn onto it, which contained sensory items, e.g. bubbles, a space blanket, a plastic slinky. Youngsters took turns to roll or throw a ball onto the fabric; they would be



given the item in the pocket nearest to where the ball landed, or if it was something like bubbles or a nice smell, everyone would share it.



**Hallo game:** We started each session with everyone sitting in a circle holding or being helped to hold the edge of a large piece of stretchy fabric. A person (youngster or adult) would be named and we would all collaborate to roll a ball across the fabric to land in that person's lap. It would then be their turn to choose (perhaps with some interpretation) the next recipient of the ball.



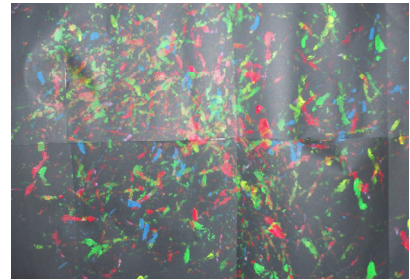
**Sensory dough:** Several batches of playdough were made, all with a different distinctive smell, some with food colouring added, some with glitter. This gave an opportunity for demonstrating preferences as well as free exploration.

**Sand, water, clay:** These were all available as free play items. Some youngsters were able to access them by lying on the floor; others had them placed on their laps or on a wheelchair tray.

**Cornflour:** Some youngsters liked to help to mix water into the cornflour to make a gloopy

consistency; again this was available for free play.

**Paint-ball rolling:** Youngsters chose textured balls and paint colours and were helped to roll the ball in paint and then over a large shared sheet of card, giving opportunities for motor skills, visual tracking and awareness of others.



**Messy bags:** An A4 laminate or larger (converted into a pouch by ironing three of the sides) filled with crunchy, messy materials (paint, shaving, foam, cereals, hair gel, shaving foam etc) and then sealed up to provide a play toy.

**Sensory dramatic story-telling:** A story-telling performance with instantly-constructed scenery, freely or cheaply available sensory props for the youngsters to handle and recorded music made a scene come alive.

**Den-building:** Earlier in the project, we made small dens with the youngsters by taping bamboo canes to a spongy mat and attaching fabric and dangling items to the canes with pegs, making a haphazard tent-like structure which the youngsters could crawl into and around and lie inside. Later, when we had more space, we constructed a more robust and larger structure, a pentagon with open triangular bamboo sides and a conical bamboo roof. The initial construction of the skeleton frame required the concerted efforts of six adults; it was also necessary to shout conflicting instructions at each other and trip over a lot. If anyone has seen the barn-raising scene in the Harrison Ford film 'Witness', it was like that but without the competence. Once it was assembled, though, the youngsters got to work in choosing fabrics to fill in the sides and roof; some were able to indicate where they wanted us to place the fabrics, too. We suspended a white mosquito net from the centre of the roof and projected coloured lights onto it and the youngsters chose eye-catching objects to hang inside. The finished den was large enough for an adult to stand up in and for two or three wheelchair users to be inside at a time. As well as being used as an alternative (more fun and

participative) multi-sensory room, the den was ideal for sensory storytelling and drama, exploration, investigation, discovery and as a space to just be.



Through the creative play opportunities above we encouraged staff co-actively to engage with youngsters by closely playing and interacting with them in line with our definition of play for youngsters with pml. Close attention was given to the process of meaningful interaction, creating a fun shared experience, experimentation and the exploration of creative play hooks that engage and inspire the youngsters in order to enable as much participant initiated play as possible based on emerging schema and preferences that youngsters have.

### Case Studies

There follow three brief case studies which give a flavour of the youngsters' responses; the third also illustrates the listening and responding cycle.

#### Isobel

Isobel uses a wheelchair. She is able to use a few words and is communicative with her facial expressions and posture. During the den-building, Isobel was offered fabrics to choose. Reaching for a gold net fabric, she lifted it as though trying to put it on her head. The adult helped her drape it over her head and then took her to a large wall mirror so she could see the effect. Isobel kept making eye contact through the net, so the adult joined her underneath it and together they improvised and sustained a game of peep-boo.

#### Lisa

Lisa also uses a wheelchair. She has very little control over her movements, if any, and her communication is pre-intentional. She tires very

easily. Included in a group singing session, she appeared to be dozing and we were unsure whether to offer her a musical instrument. Her adult companion, who knew her well, wanted to 'give her a chance', and gently placed two different percussion instruments in her hands, one at a time, and helped her to shake them. The adult interpreted Lisa responses and picked the instrument that she felt Lisa had preferred. Lisa became more alert and seemed to show some awareness of the song and of her own part in it. She continued to participate in the session with sensitive support, being helped to choose several different instruments and also being given a turn to choose a song using objects of reference.

#### Matt

Matt is a young man with very limited mobility. He makes eye contact and varies his vocalisation to reflect his feelings and responses. Most of his communication is not yet understood. In common with all the youngsters, Matt was observed and his responses recorded, as a collaborative effort of all staff, over several sessions, to build up a picture of his preferences and responses and to decide which experiences he would be likely to enjoy and benefit from.

The recording was in the following categories:

#### What do we see the person do?

- Repeatedly shake rattle by grasping it and bringing it backwards and forwards
- Appears to be more aware of people when they are close to him
- Chews and mouths objects
- Makes sounds, apparently to himself
- Touches soft toys
- Sustains his gaze on lights
- Lying on the floor, partially covered himself with fabric

#### What does the person appear to enjoy?

- Massage, especially around his ankles and the soles of his feet
- Music – he moves his upper body from side to side
- Sounds – he responds to many sounds by sitting up straighter and appearing alert
- Taste – he seemed to enjoy mayonnaise, tea and mini cheddars
- Attention from staff – he makes eye contact and seems to be absorbed

### How does the person respond?

- Vocalisation
- Facial expression
- Gives focussed eye contact
- Becomes very still
- Squeaks loudly
- Looks more intently at the adult when being touched during massage
- We then reviewed the information and considered the final category:

### What opportunities or experiences could we provide?

- Massage
- Light choices – torches, projector, acetate sheets, being taken outside on sunny days, fairy lights when appropriate as props for story telling
- Sound CDs and music CDs to signal routine activities or for his listening pleasure
- Freely available choice of textured items and malleable materials
- Sensory dome
- Fragranced bags and play-dough
- A variety of tastes

We found that this process (referred to as the creative play opportunities map) as a whole helped staff to consider the youngsters' needs and preferences and to see that many of these needs could be met by making small changes to the person's environment and by offering cheap and easily available opportunities.

### **Communication Passports**

The final activity of this project was to compile communication passports with the youngsters involved; these were documents that were individual to each person and were designed to accompany the person much of the time (perhaps by being attached to the wheelchair) so that all adults who come into contact with the youngster can quickly understand their preferences.

The passports were illustrated with photos of the youngster engaged in some of their favourite activities and showed likes, dislikes and how the person expresses feelings such as happiness or sadness. We tried to show how these feelings might be specific to situations, for example, 'Lisa is happy when someone she knows holds her hand'.

### **Conclusion**

We were happy that the project fulfilled our original objectives of using creative approaches to build communication, interaction and to support us to listen and respond to children and young people with pml, but we felt that much more could be done and needed to be done in terms of staff training and support. To continue the success and to maintain the momentum, we felt, staff would require ongoing support and leadership.

Creative opportunities and a process of listening and responding have resulted in the development of communication passports that will enable us to respond to the messages of the children and young people and further develop person centred provision. We hope that communication passports will be used in conjunction with a process of listening and responding to the youngster.

The project supported youngsters with pml to access and engage in meaningful and developmentally responsive creative play and combined arts opportunities. This has supported staff to further develop their interaction and communication with children and young people who are considered 'hard to reach' and is an ongoing process and meaningful opportunity that staff and children wish to continue.

*Martin Goodwin is a freelance trainer and development worker trading as D.I.C.E who specialises in working with children and young people with severe, profound and complex learning disabilities. Martin's professional interest is in advocacy, inclusion, participation and engagement, play and creative arts. He has a first degree in Learning Disability Studies and is currently pursuing a MA in Youth and Community Development.*

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Note: To protect identity of children and young people involved in the project pseudonyms' were given

**Free Resources**

Listening and Responding to People who Communicate Using Words Poster (available from: [www.disabilitydice.co.uk](http://www.disabilitydice.co.uk))

Creative Play Opportunities Map (available from [www.disabilitydice.co.uk](http://www.disabilitydice.co.uk))

The Listening and Responding Cycle - exploring the process of observation documentation, interpretation and reflection in supporting children with profound and multiple learning disabilities (available from [www.disabilitydice.co.uk](http://www.disabilitydice.co.uk) - released September 2009)





## **Invasive Procedures: Breaking barriers and achieving control for people with profound & complex disabilities**

**This conference is essential for family and paid carers/professionals working in the learning disability field. Including professionals from:**

- **National Health Service**
- **Local Authority Services**
- **Education Providers**
- **Trade Union Representatives**
- **Residential Service Providers- voluntary and private sector**
- **Respite Services**
- **Advocacy Services**

**Discussion at the conference will contribute to the development of planned expert consensus guidelines on invasive procedures.**

Individuals with profound intellectual and multiple disabilities (PIMD) have complex and significant healthcare needs. For many, a wide range of invasive medical procedures are required including the management of epilepsy through the administration of rectal anticonvulsants; severe spasticity requiring Baclofen implants; the management of respiratory problems through the use of ventilators and deep suctioning; and procedures requiring non-oral feeding (gastric and nasogastric). Execution of these procedures by social care staff remains a contested area, with some staff refusing or not being allowed to carry out one or more procedures, leading to people with PIMD being denied services. There is a recognised need for change in the way this vulnerable group receive care and access services and in particular health services. This is supported by Mencap's *Death by Indifference* enquiry report and a number of other reports from across the UK.

The research project "*Practice and Policy in the Administration of Invasive Procedures for People with PIMD*", supported by the Scottish Government, is at present being undertaken by PAMIS' *Invasive Procedures Working Group*. This work will be reported as background to the conference. Speakers at the conference will include: Professor Chris Cullen, Professor Barry Carpenter, Dr Douglas Paterson, Dr Michael Brown, Loretto Lambe and a family carer. They will address the changing needs of people with PMLD and the ethical issues underpinning invasive procedures, family experiences will be addressed as will the training needs of parents and care staff. Workshops will be conducted in order to develop a consensus on good practice in this area.

Conference fees £90 with a limited number of sponsored places for parents on request.

If you would like further details or a booking form please contact:

Brenda Garrard, PAMIS, Springfield House, University of Dundee, Dundee. DD1 4JE  
Tel: 01382 385 154 Email: [b.garrard@dundee.ac.uk](mailto:b.garrard@dundee.ac.uk)

## The Music Gym

Susan Heath

Looking down from the café balcony you might think you've stumbled upon a village fete. There's lots of colour in the bouncy castles, the huge inflatable maze, the two-metre high balls, and the gazebo with its bright seats and its dangling fish. Bubbles float up into the nets hanging in the roof of the sports hall.

On one castle people are jumping energetically, making music play. On the other they are sitting, swaying, or resting on the edge enjoying the gentle movement. In the far corner of the hall someone in a wheelchair is using a switch table to alter images on the wall. Two people in wheelchairs are being helped to play a game with the giant inflatable ball. People sitting in the gazebo are creating sound and vibration by their movements while looking out at coloured patterns projected onto the far wall. Someone carrying a ball wanders from one end of the hall to the other, seemingly avoiding everyone but happy to be here. In the maze excited shrieking suggests a game of hide and seek.

This is the Music Gym and since 2005 it's been happening each Friday in Hastings, East Sussex. At Decoda we'd been running music workshops for several years and we were increasingly aware that although very successful for people with milder learning disabilities they weren't really including those with PMLD. We'd incorporated Soundbeam and worked one-to-one with that but we felt more was needed especially for those whose behaviour was challenging. "What if", we thought, "people could be in a huge space, where they could choose what to do and where they could make things happen?"

Eventually we secured funding via the Learning Disability Development Fund and 40 people tried it in the first year, at subsidised rates. It was a struggle when we had to introduce a realistic fee and numbers fell to 15. Now we have over 65 members, some of them making round trips of over 50 miles to be there each week. Increased membership has meant the Gym is sustainable and no longer relies on grant funding, although we still apply for grants for new equipment. Currently we're waiting for the local Round Table to install a hoist and changing table in the toilets to enable people to attend who need to be changed regularly.

Although we don't ask questions about the nature of members' disabilities we're aware they cover a wide range including autistic spectrum disorders and Prader Willi Syndrome. About a third are wheelchair users and very few have speech. Some have visual impairments and there's a "dark time"

in the middle of the day when we dim all the lights so that the projections show up more vividly.

### Benefits of the Music Gym

Why travel so far? What are the benefits? We believe that we offer a place where the member and their staff can enjoy time together. There *are* facilitators and volunteers in the Music Gym but they're there to show carers how to use the equipment, to join in where appropriate and to keep an overall eye on what's happening. The main interaction is between the member and their carers, it's a place where they can have fun together and communication can develop. A lot of those who come to the Music Gym experience difficulties in making their choices clear to those who support them. Because at the Gym they make the choice to have fun their staff now have a way to reinforce their learning and aid further choices by reinforcing the fun.

The main finding of the independent evaluation at the end of the first year was that where support staff believed in their clients' capacity to make their own choices and in their potential to develop then the members were actively encouraged and clearly improved. 97% were said to have benefited from attending: the sense of benefit increased however with the level of staff involvement. Other benefits noted in the evaluation were sustained interest, trying new things, improved mobility and generally being calmer and more relaxed. In addition to the activities, members benefited from the space that the sports hall provides and the opportunity to participate in the wider community.

Since then we've recognised other advantages including the exercise the members are getting: for example someone who *can* walk finds an incentive to do so in walking through the maze. One young woman walked with her frame but unaided by staff for the first time as the space allowed for this. With her new confidence she was then able to do this at home. Students who attend have used the space to learn how to operate their new wheelchair. There's an opportunity for both staff and members to meet people from other homes and some relationships have been formed this way.

The Music Gym is a tool box which has something in there somewhere to grab the person's attention and we trust that it will happen eventually whilst knowing that it *can* take time. Even those who profess to show no interest on their first visit will eventually become engaged, if they're allowed time. What's a few weeks or even a few months in this valuable process?

### Developments

At Decoda we've always been client-led, developing and adapting technology to help and engage the people we work with. It was through feedback at the Music Gym that we developed the idea of the Decodamaze. A support worker from a local school suggested an obstacle course that could give teenage wheelchair users more excitement and fun. The course evolved into an inflatable maze which we set about making interactive so that images and sounds would be triggered and changed by movement. This follows the methodology of the Music Gym, where nothing happens without the participant making the decision to move. In the new design we've split the maze into two parts to make handling and moving easier for two people. This now means that the

maze is modular, starting at 8metres by 4metres, a size that allows it to be used in a community, or school, hall.

Following its evaluation in a local special needs school the Decodamaze will be available for use with both adults and children. Alongside the maze we have been developing our Dancing Squares, a fun piece of equipment where dancing triggers different loops so that four people become a band. We demonstrated this in the Arts Zone at Learning Disability Today in November – it was great to see how the staff at the neighbouring coffee stall kept stopping to watch the dancing on display.

Finally, for organisations who appreciate the ethos of the Music Gym and want to install the whole outfit we can offer this on a franchise-type basis. Our aim is simple – for the enjoyment we've seen here in Hastings to be happening in as many areas and with as many people as possible.

### Contact details for Decoda

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Email: [enquiries@decoda.org](mailto:enquiries@decoda.org)

Website: [www.decoda.org](http://www.decoda.org)

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## The use of the Arts in different settings with people with profound and multiple learning disabilities

Susan McLaren

Support & Key Worker, Capability Scotland and Assistant Co-ordinator, PAMIS, in Tayside

### Experience and Overview

I have been employed by Capability Scotland for the past 18yrs. Capability Scotland provides services to people with disabilities in Scotland in areas including education, employment, accommodation, respite and independent living. It is a very large charitable organisation and has been in existence for over 60yrs. My role as a support worker at Upper Springland Capability Scotland Adult Day Services in Perth, was principally as group leader/facilitator in music, drama and photography and also as keyworker for seven people who used this day service.

In September 2007 I began a secondment with PAMIS based at their head office at Dundee University. PAMIS is a registered charity working in partnership with people with PMLD, their families and professionals and has offices in Fife, Glasgow, Grampian, South Lanarkshire and Tayside. PAMIS is also a unit within the School of Education & Social Work, University of Dundee.

My role as Tayside Assistant Co-ordinator with PAMIS has given me the opportunity to learn more about their work, particularly their Family Support Service and Futures Project (Transition), the relationship between statutory and voluntary services and the examples of partnership working that PAMIS is involved in with other agencies to assist the Scottish Government when consultation issues come up for public debate.

### The Arts and Capability Scotland

I began working with people with disabilities in arts subjects in 1991 as part of a caring and educative social environment with the underpinning theme of 'promoting independence' at its root. The people I have worked with have been adults with varying degrees of care needs and from a range of backgrounds. I employed a range of arts subjects which included music, drama and photography/film. Many of the people I've worked with have been non-verbal, either using Touch Talker Boards in English or Bliss Symbolics, or simply using eye contact and body language. Others are deaf or hearing impaired and communicate using British Sign Language (BSL) or Makaton. Many have conditions affecting their visual spectrum. A high percentage of group members are wheelchair users and several have profound and multiple learning disabilities (PMLD).

The approach I used for this work is an

environment of two-way learning; learning of the group member; learning of the group facilitator(s); learning between group members and the possibility of an accumulative learning process as a group. This works especially well with music, drama and photography/ film as these subjects can be created separately but can come together as a whole:

- drama being enhanced by music
- music being enlivened by dramatic movement
- photo and film techniques being used to partner music or create visual props for drama
- photo and film also being used to document the total project and, in many cases, allowing the participants to gain confidence in their own abilities by watching themselves on screen.

These are also activities in which rules do not have to be applied in a strict manner. Any outcomes are flexible.

When working with a group of people of mixed abilities it is important to try to spend time with each person, to recognise each other and try to begin to build trust. Everyone is an individual with their own preferences; their own areas of sensitivity; their own expressive abilities. We all need nurture to grow and to realise our own potential. We also need reassurances from others to build confidence in ourselves, as recognised by Carl Rogers in Client Centred Therapy (1951) '... the need for positive regard determines the self-concept'.

The same applies when working with a person or group of people who have profound and multiple

learning disabilities. It may seem like a slow process to the facilitator, the person who has been geared to 'reach targets' and 'produce outcomes' but it is the regularity of sessions combined with a person-centred approach, changing slowly over weeks and months and years that can achieve progressive results in the response, expressiveness and creativity of a person with PMLD. The following example illustrates these points.

### **Louie, Musical Instruments / Behaviour**

Since the mid 1990s when all things relating to light and sound became more versatile through the advances of technology, I have tried to utilise them in my work. When 'Sound Beam' devices were first on the market for music we acquired a basic starter kit at Upper Springland to enable group members who were unable to handle or play instruments to make music.

A new person had moved into one of the flats. His family were from Glasgow and as he had reached adulthood, decided that it was time for him, like most young people who have left school, to move on from the family. He had PMLD and was, in the early stages following his move, very subdued and slept in his wheelchair. I'll call him Louie.

After a short period in his new home Louie began to respond to the residents of the other flats and staff members and was no longer subdued. He emerged as a very joyous and energetic person who needed one to one care and attention at all times. When Louie began coming to our music session, in which we used 'Sound Beam' devices, I noticed at break time that when a drink was within his reach he would grasp the cup handle and then throw it and the contents away. He thought this was great fun – other group members who were in the firing line of wet tea or juice did not! We identified this as something that he might be able to overcome.

Selecting the sound producing instrument, which consisted of two hand-held sticks of wood which, when passed across the invisible area of the sound beam, would make music but when thrown away the music would stop.

We introduced this to Louie, one stick at a time, gradually over weeks and months.

He liked the group attention and enjoyed being able to create noise. He began to visually search out what he now saw as 'his music sticks' and steadily built up the ability to hold one in each hand and make music. Over a period of eighteen months, attending the group once a week and also, when staff requested it, taking the sound beam

equipment to his flat at weekends, Louie began to realise that when he held something in his hand it might lead to a more fulfilling experience if he held on to it. He has for many years now been able to take his own drinks unassisted and continue to make and enjoy music.

This is but one example of using music as a tool for development and self-actualisation and of promoting independence as Maslow notes: 'I did it; I can do it' (Maslow;1954)

### **Secondment with PAMIS.**

My secondment with PAMIS over the past eighteen months has involved working with the PAMIS Family Support Service, Futures Project (Transition) and the Healthy Lifestyles Project. This has given me the opportunity to meet families in their own homes or at venues where training or leisure events are being held and to assist in SOMA (Sporting Opportunities for Motor Activities) workshops at schools or sports centres. (see Ramsay, 2006)

During this time I have, with the consent of all people involved and families taking part, made photographic documentation for use on photo boards, Power Point presentations and for PAMIS leaflets. In these photos I have tried to capture and promote a positive view of disability. For instance:

- In people's living spaces we can capture the essence of unconditional love between families – the bond between brothers and sisters - the trusting relationships with family carers;
- In workshops we can capture people working together for training, sports or drama with determination of purpose and much laughter!

In summer 2008, for the Healthy Lifestyles Project (HLP) in the Tayside area, I worked together with the HLP Development Officer, to create an interactive drama with a group of adults with PMLD, their carers and some family members. We arranged two evening sessions on consecutive weeks.

It was appropriate in such a short timescale to use a story from a film that many of the group members could relate to. We used the story of The Wizard of Oz and made costumes for all the characters and sourced the music.

These events were well attended with over twenty people at each. In late August we used this 'interactive drama' as part of the Healthy Lifestyles Fun Day at Baxter Park, Dundee. Many of the people who had taken part in the two sessions

earlier in the summer were also at the fun day and they were all keen to re-enact the story and to lead the drama, drawing people from the surrounding audience to join in and reinforcing their feelings of belonging to and being able to share an experience with others.

In November 2008 I was asked to go to Gleneagles Road Day Centre in Perth to work with seven adults with PMLD. This would be each Friday for 6 weeks, ending just before the Christmas break. On the first day I met the people with whom I would be working, spent time with them, learned how to best communicate with each person and found out from staff members if anyone taking part did not like music or lights or wearing hats.

As there was a staff shortage due to winter colds and flu and I was warned that there may be no one available to help for the following five weeks so decided to work with two service users at a time. The allocated space was limited and quite busy so I decided to use the multi-sensory area. The seven day attenders with PMLD have high level care needs and to enable two persons to take part in the session each week the staff agreed to attend to their personal care first, which allowed them to spend time in the multi-sensory room.

Once again I decided to use a story and music that might be familiar to the people taking part. In a local shop I spotted 'Snowman' hats with faces (as in *The Snowman* by Raymond Briggs) and a CD with narrative and music and we were well on our way to a snowy multi-sensory Christmas. The following weeks went well. The lighting effect that, with a little adjustment, seemed to create snowflakes around the room, the snowman hats and faces which we all wore, the voice of James Nesbitt telling the story and the music to which we moved as if we too were gliding through a snowy sky, seemed to be relaxing and enjoyable for all involved. A digitally enhanced space had been created. The story and music lasts forty-five minutes and throughout the five weeks only one person wanted to leave the multisensory room before the end of the story.

The promotion of the arts within social care settings for people with profound and multiple learning disabilities, and the availability of access to a range of materials, does not have to cost a lot of money. Even in the case of digital sound, light or photographic equipment – which has been available for so long and is upgraded at such a rate by manufacturers that last year's (or even last month's!) model – can be bought at a fraction of the original price. The benefits of involvement of people in creative arts is well documented as noted by Hogg 1998: "The involvement of people with profound and multiple learning disabilities in the

creative arts has heightened our expectations of them, confirming a growing body of international research that shows a far higher potential among them than, in the past, has been thought possible". Ensuring that whatever arts medium you use is both physically and intellectually accessible is paramount to ensuring that the person with PMLD is given every opportunity to both take part and to enjoy the activity.

Sometimes in the daily rush and running of a service the arts resources available do not get used to their best advantage. Sharing working knowledge and offering training to support workers in adult day services enables them to use these resources more effectively. Working together in this way is a positive step forward.

When funding is 'tight' the arts are always first in line for cuts. In the current financial climate we all know that this situation is becoming a reality. Let's be proactive and use our imagination together with available staff and resources, to make the arts work for people with PMLD.

### Changing Places - Public Art and Museums

Access to public buildings has been improved since the implementation of the Disability Discrimination Act (1995) and has made it easier for people with disabilities to get into Museums and Art Galleries. However as we all know, to enjoy a day out, view an exhibition, go to a museum, visit a castle or an ancient monument, have lunch at the café, there is one common denominator – we all need to use the toilet!

PAMIS is a member of The Changing Places Consortium which consists of a group of organisations working to support the rights of people who need Changing Places toilets to enable them to access life outside their home environment. A changing places toilet consists of a changing bench, a hoist and more space than a standard accessible toilet. Currently we are actively campaigning to promote the inclusion of changing places in public arts buildings in Scotland which are being refurbished or newly built. (For more information about Changing Places visit: [www.changing-places.org](http://www.changing-places.org) For all enquiries in Scotland contact [PamisChangingPlaces@dundee.ac.uk](mailto:PamisChangingPlaces@dundee.ac.uk))

In conclusion, I can say that my secondment to PAMIS has been a rewarding and stimulating experience.

### Contact details

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## **PMLD Link: Future Focus**

### **General Issue**

Carol Ouvry

In PMLD-Link we cover a wide range of themes in the hope that whatever situation our readers are living or working in there will be issues discussed and information shared which is relevant, interesting and helpful to everyone. However, every so often we have a general issue where those topics that have not been touched upon in recent issues, or even at all, can be raised and discussed.

The summer issue is one of these. So, if there is anything you would like to share with others whether it is something that has worked particularly well, or perhaps a problem you have not yet been able to solve; a new approach you have come across, or would like to find out more about; a response to one of the articles you have read, or a follow up of ideas contained in a past issue; any resources you have found that are particularly useful – or even any that are not; if you have a burning issues that you want to air, now is your chance.

Articles can be any length up to 2000 words. Short or long, they are all equally welcome. This issue should be really interesting, covering a wide variety of topics.

Please send articles or any other information to [carol.ouvry@talktalk.net](mailto:carol.ouvry@talktalk.net) by 5<sup>th</sup> June 2009. I'm looking forward to receiving them.

Carol Ouvry

## Mencap response to the Health Ombudsman's investigations into the deaths of six people with a learning disability



### A damning indictment of the NHS

Following the publication of *'Death by indifference'* (Mencap 2007) the government asked the Parliamentary and Health Service Ombudsman to investigate the deaths of the six people with a learning disability described in the report. The Ombudsman conducted detailed investigations into the events that led up to the deaths of Martin, Mark, Ted, Tom, Warren and Emma.

The government also set up an independent inquiry into the health care of people with learning disabilities. Sir Jonathan Michael, chair of the inquiry, published his findings in July 2008 in a report called 'Healthcare for all'.

This briefing is about the Overview report 'Six Lives: the provision of public services to people with learning disabilities' which was published on March 24<sup>th</sup> 2009 and the six detailed investigation reports.

### Summary

*'The investigation reports illustrate some significant and distressing failures in service across both health and social care.....They show the devastating impact of organisational behaviour which does not and apparently cannot adapt to individual needs, or even consistently follow procedures designed to maintain a basic quality of service for everyone.'*

This powerful report reinforces the urgent need for systemic change within the NHS for people with learning disabilities. It supports Sir Jonathan Michael's inquiry report 'Healthcare for all', bolstering what has been said about the failure to understand the law in relation to disability

discrimination and human rights. It supports Mencap's view, and the findings of the independent inquiry, that the six tragic deaths described in *'Death by indifference'* were not isolated and likely to be part of a wider problem.

The report makes three recommendations aimed at *'changing underlying attitudes on a lasting basis'*. These include actions for the NHS and social care organisations in England, actions for those responsible for the regulation and inspection of health and care services and actions for the Department of Health in their role of promoting and supporting the implementation of the recommendations. Each are given between 12 and 18 months to report progress.

### The Parliamentary and Health Service Ombudsman said

*'We have not upheld all the complaints, but the very nature of our thorough and impartial investigations serves only to heighten the sense of outrage at the treatment received by most of the people involved.'*

*'We believe these outcomes are a shocking indictment of services which profess to value individuals and to personalise services according to individual need'*

*'No one took a proactive approach in owning and resolving problems by making reasonable adjustments and seeking urgent solutions. It is this aspect of the quality of the service they experienced that Mencap described as "indifference" and it is unacceptable'*

*'Nevertheless, the recurrent nature of the complaints across different agencies leads us to the view that the understanding of the issues and the focus on the quality of care is at best patchy'*

*and at worst an indictment of our society'*

### **Mencap's view**

Mencap welcomes this hard hitting report. It confirms what we said in 'Death by *indifference*' and should be a wake up call to the NHS.

The overarching report and detailed investigation reports identify a catalogue of serious failures which led up to the unnecessary deaths of the six people described in our report and subjected them to the most appalling pain and suffering. It confirms that they were discriminated against and that their human rights were violated.

Shockingly, the investigations also revealed actions and omissions by health professionals that we were previously unaware of. For example, Emma's mother did not know that when her daughter was given the prognosis of 10% survival with treatment, this wasn't actually based on the staging of the cancer but on a flawed view of the difficulty of treating someone with a learning disability. Tom's family found that during his final stay in the acute hospital he had twice been overdosed with morphine.

Whilst Mencap believes that the Ombudsman's reports are a significant contribution towards the systemic change we have been campaigning for, we also think that she has not gone far enough to reinforce the fact that NHS staff must act within disability and human rights legislation. In particular we are concerned that she has not fully understood the requirements to make reasonable adjustments and has not properly interpreted the guidance on best interest decision making.

The report also shows how the families of the six people who died were totally let down by the complaints process, both at the local and Healthcare Commission stages. The complaints

process did not provide them with the answers they had a right to. This condemned the families to a battle for justice that has spanned up to five years and has had a profound emotional and physical impact on all their lives.

Mencap are very disappointed that the Ombudsman has not brought an end to this fight for all the families. We will continue to support those families until they do achieve justice. Mencap hope that they will all take comfort in knowing that the lessons that can be learned from the powerful combination of their stories, the subsequent inquiry and detailed investigations will result in changing practice in the NHS for the better for many thousands of people with a learning disability and their families.

**We want every person working in the NHS, from the nurses on wards to the chief executives of strategic health authorities, to treat this issue as a priority. This means ensuring that all of the recommendations from the Health Ombudsman's reports and from Sir Jonathan Michael's independent inquiry are fully implemented to make sure that people with a learning disability receive the care and treatment they have a human right to.**

[www.mencap.org.uk](http://www.mencap.org.uk)

Registered charity number 222377

Find out more about the Health and Local Government Ombudsman's report at <http://www.mencap.org.uk/page.asp?id=9603>

Read Mencap's response to the reports on each of the six cases at <http://www.mencap.org.uk/document.asp?id=9607>



## Useful Websites for the arts

Here are some useful websites and a bit about what people say on their site about their work with people with profound and multiple learning disabilities.

### **Bamboozle Theatre Company**

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

'Our "Multi-Sensory Magic" residencies are designed for children with complex needs, sometimes described as having profound and multiple learning difficulties, and their parents and carers. These residencies are typically a week or fortnight in length with 5 children and their parents attending for 2 or 3 days. The small groups along with the number of artists [we have 4 artists for a group of 5 children] allow us to tailor the workshops to the specific needs of the children and their parents.

We create multi-sensory spaces, provide lots of time and gently draw people in at a pace that is comfortable for them. We seek to allow the direction of the activities to be led by the participants' needs and likings. We see it as an integral part of the way we work that the participants are given all the time they need to engage with any of the experiences / activities.'

### **Oily Cart**

<http://www.oilycart.org.uk/index.php>

'Oily Cart creates theatre for young people with complex disabilities (Profound and Multiple Learning Disabilities or an Autistic Spectrum Disorder). This highly acclaimed work often utilises unusual settings such as hydro-therapy pools and trampolines and incorporates a vast array of multi-sensory techniques including water and bubbles, paper fans, perfume sprays and ultra-violet lighting.'

### **Soundabout**

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

'Soundabout exists to help people who have severe and complex learning difficulties. Through sound and music we help them develop their ability to communicate and interact with the world around them.'

### **Open Storytellers**

(formerly the Unlimited Company of Storytellers)

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

Amongst other things, uses StorySharing:

'In StorySharing we teach people how to make space for a partner to join in, how to use multisensory techniques in storytelling, and how to identify roles for narrators with severe communication difficulties.'

'In Storysharing™, we look for what the child can put into the story and we scaffold the story with the child. We use a multisensory approach, with props, music, and basic communication aids.

### **Project Artworks**

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

'Project Art Works is an artist led, visual arts organization that creates opportunities with and for young people and adults who have complex needs to communicate and express themselves through making art. Project Art Works is inspired by the young people and adults we work with.'

### **Art Spider**

<http://www.artspider.org.uk/gallery>

Mencap's Arts website with information, news, resources and much more. Information about 'In the Moment' '... a Mencap DVD about the arts and people with profound and multiple learning disabilities (or PMLD). It shows the work of 4 arts companies who specialise in this area. Find out about theatre from Oily Cart, visual arts from Project Art Works, music and sound from Soundabout, and story-telling from The Unlimited Company.'

### **Mencap Guide: The arts and people with profound and multiple learning disabilities (PMLD)**

<http://www.mencap.org.uk/guides.asp?id=322>

'This guide has been written for professionals to outline the importance of engaging people with PMLD in the arts, and to explain the steps you can



take to make the experience as enjoyable and productive as possible. It also contains useful information about additional resources and support that are available. '

'The information in this guide has been taken from a booklet which accompanies the DVD 'In the Moment', which demonstrates the use and power of many of the techniques described here. It also shows people with PMLD taking part in the arts and showcases some of the most exciting work in this area.

## DICE

[http://www.disabilitydice.co.uk/about\\_us.php](http://www.disabilitydice.co.uk/about_us.php)

'Provision of Creative Arts workshops using visual arts, multi media arts and music with disabled children and young people on behalf of PLAYTRAIN, Dens of Equality, ATHAC'

'D.I.C.E uses multi sensory methods that promote active choice and decision making and participation. Observation, documentation and reflection aid consultation participation and engagement approaches with hard to reach groups including children and young people with severe profound and complex disabilities.'

## The Touch Trust

<http://www.touch-trust.org/touch-trust-charity-wales.asp>

'Providing creative, touch-based art of movement and dance programmes for individuals affected by Autistic Spectrum Disorders, behaviour that challenges and profound and multiple disabilities.

Music, dance, movement and touch as an aid to Life Development'

## Storytracks

<http://www.storytracks.net/>

This website offers information and ideas on access to story telling and literature including some downloadable sample materials.

# RESOURCES

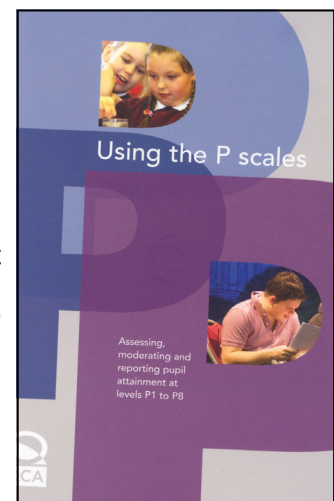
## March 2009 update—now includes case studies of learners at P1—3

### Using the P scales (DVD and booklet)

This pack is for teachers in mainstream and special schools, special educational needs coordinators, assessment coordinators and headteachers. It offers guidance on assessing pupils who work below level 1 of the national curriculum and on moderating judgements made. The pack contains a DVD and a guidance booklet.

To order a copy please visit

<http://orderline.qca.org.uk/bookstore.asp?>



## PMLD Network Email Forum A Digest of Discussions January – March 09



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:

### 1. Mats that detect nocturnal seizures

Someone wanted advice about how to get mats that detect nocturnal seizures. Responses included:

- Someone said they thought their community nurses get them via continuing healthcare funding.
- Someone said this style of mat is available via Telecare equipment. Each county has a different way of accessing this equipment but asking a social services OT would be the best place to start.
- Suggestions of other people who might be able to advise or put an order through included: consultant neurologists, specialist epilepsy nurses, district nurses or health visitors.
- Someone suggested contacting the Maxwell Muir Trust who fund mats for seizures <http://www.muirmaxwelltrust.com/>
- Someone else added that they use Epipads, audio monitoring and full physical checks each night with people who have a vulnerability to SUDEP (Epilepsy and Sudden Unexpected Death). They pointed out that any alarm system does require someone to hear, see and respond to it.

### 2. Defining intellectual disability as opposed to learning disability?

Someone asked for a definition of 'intellectual disability' as opposed to 'learning disability'. Responses included:

- 'Easy as far as I'm concerned I think they mean the same.'
- Someone said that 'Intellectual disability' has been adopted by many international organisations and they suspect that this term or something like it will take over as the recognised international term. The World Health Organisation has begun to use it, and it (or something similar) will become their official term in the next few years.
- The same person said they thought it would be helpful in terms of communication with others overseas to adopt it in this country. But that they weren't sure it would help in terms of communication here in the UK (especially with carers and self-advocates – who prefer 'learning

difficulty' anyway), it could just confuse things.

- 'I've never liked the term 'learning disability' as it is often used in alternation with 'learning difficulty' neither of which seems to describe the issues for my daughter who is 'PMLD'. But they are preferable to what went before, and to explain to people my daughter is 'intellectual disabled' seems an impossible mouthful!'

### 3. How do you teach people with a learning disability?

A university student who is designing educational toys for people with learning disabilities said she had heard of teaching people with learning disabilities in a step by step approach, by breaking a task into a series of small steps. She asked if people had experience of this approach and if they had found it effective. Responses, which were not all specifically about people with PMLD, included:

- Small steps can be useful for daily living skills, such as teeth cleaning, and for some academic skills (like counting) but are not good for understanding concepts - like when to use counting.
- Someone suggested she visit her local SLD school or other specialist provision to get an overview of the range of intellectual, social, physical and sensory difficulties covered by the global term 'learning difficulties' and to see how they teach.
- 'We have found that people learn through regular opportunities through active support, in this way teaching is natural to the environment and learning is at the person's individual pace in ordinary surroundings.'
- 'I teach 10 adult students with PMLD and each are different in the way they receive, retain and let you know what they have learned. There isn't any one way for this group. It depends on where they are at in their cognitive development, what medication they are on and sometimes how they have been medicated and treated in the past. Lots of trial and error but it does work. Each of my students has progressed in their cognitive ability and each has developed their learning skills.'
- 'Pupils with profound and multiple learning

difficulties, in my experience, do not progress in a linear fashion so small steps is not always appropriate if it is hierarchical.'

- Someone said that if the tools she is designing are for pupils with PMLD then the Routes for learning material (from the Welsh government) and the accompanying booklet would be useful to look at: <http://accac.org.uk/eng/content.php?cid=3&pid=1309>

#### 4. Why do Valuing People refuse to use the term PMLD?

Someone asked for help on this. This prompted lots of discussion about the use of the term 'PMLD'. Responses included:

- In Valuing People Now I think they use the term 'complex' to describe the needs of people with PMLD but also people on the autistic spectrum and people with other 'complex' needs such as those living in secure/ forensic settings.
- Valuing people use a number of terms such as 'children with severe disabilities and complex needs', 'profound learning disabilities' and 'the most severely disabled'. If we can't agree a common term and definition then what hope is there of collecting any meaningful statistics?
- The PMLD Network said that Valuing People Now does actually refer to people with PMLD when defining who it means by people with complex needs. The Network also said whilst people with PMLD continue to be marginalised they think it is important to keep using the term 'PMLD' and explaining the specific needs of this group, so that appropriate actions can be taken to ensure they are properly included.'
- Some people said they recognised that terms such as 'complex needs' and 'high support needs' are overly inclusive. For information on why this can be problematic see the PMLD Network full definition of PMLD: [www.pmldnetwork.org/what\\_do\\_we\\_want/who\\_are\\_we\\_campaigning\\_for.htm](http://www.pmldnetwork.org/what_do_we_want/who_are_we_campaigning_for.htm)
- A number of people said they did not like the term 'PMLD': 'I believe it to be a very damaging label. It implies that the person is in a severe state of deficit'.
- Someone else said: 'As a mother, I like the fact that PMLD does describe the severe state of deficit that my daughter and I need to have recognised'.
- Someone voiced concerns at assessing people as being at a particular developmental level: '...there is no such thing as a person who is operating at a particular age level. Development is not that linear in any of us. It is even more complex in someone who has impairments...I worry about making hard and fast decisions about potential'. She suggested websites for people to look at, which included: [www.inclusive-solutions.com/](http://www.inclusive-solutions.com/) , [www.circlesnetwork.org.uk/](http://www.circlesnetwork.org.uk/)

[www.helensandersonassociates.co.uk/](http://www.helensandersonassociates.co.uk/)

- In Scotland the term PMLD is not used. We use the term 'additional support needs' instead of 'special educational needs'. We like this as it is not a deficit based term but highlights the duty of education services to support the kids rather than emphasising how 'different' the kids are.'
- 'How many times have you gone along to a training session or read a book and thought that the author had no understanding of the people you support, as all the techniques were based on having a symbolic understanding? I think the term PMLD is useful and supports a shared understanding.'
- Others were concerned that people can be wrongly 'labelled' as having PMLD: 'I personally have met many children whose support needs are undoubtedly extremely complex but who do not have profound learning difficulties. However having been labelled PMLD they are inappropriately supported and inadequately taught because the label has lowered expectations of their ability and has obscured the fact that they have particular types of support needs.'
- 'Coming from a country that does not consistently use any term to refer to people with PMLD, I am a supporter of the use of the term. In Australia this population is frequently invisible. There are no collective groups like PMLD Network operating for lobbying or sharing information.'

#### 5. Social and emotional experience of PMLD?

Someone has been tracking two young people with profound learning needs as part of their thesis. This has involved visiting the children once a week and attaching video cameras to their wheelchairs. She now has footage of both the children's average days and of one-to-one sessions she has had with them which will be looked at and analysed by different people (including parents and teachers) in terms of the child's social interactions and emotional experiences. The hope is that if there is a high degree of agreement amongst raters for certain indicators - such as facial expression, blink rate, trunk and limb movements - then she can comment on what appears to be a common interpretation of the person's social and emotional experience. However an expert in psychology research has told her she feels the research is not valid since there is no means of confirming the findings with the young people themselves. The researcher has asked for opinions/ advice from members of the forum:

- There was a lot of support for the research she is doing: 'I think it is vital that there is more research into the social and emotional experience of these very special people as they can lead very isolated lives where the only interaction is functional', 'Don't listen to the psychology expert! OK she may be strictly correct but that certainly does not

negate the research. We would never do this type of research with people with PMLD if we had to conform to what is expected. Go for it and you know there are lots of us out here wanting to learn from your study!

- 'It is not true to claim that the subject would need to personally confirm your findings to validate the research...just consider research into babies for example. What validation would be required to confirm that a baby was distressed? We all know how to tell but you can't ask the baby!'
- 'Unless you address the ontological, epistemological, and methodological questions (Guba 1990), you are in danger of producing an incoherent piece of research.'
- 'What do you mean by social and emotional experiences? If your psychologist means that the thoughts, feelings and other inner mental states of people with profound intellectual disabilities cannot be studied empirically, I tend to agree with that view point. That poses whether these concepts can be investigated more objectively.'
- 'Provided the claims you make are clearly situated in the data, with the context clearly outlined, then the data you gather is important. You are not claiming that you know what these people are thinking, but you are making observations based on interpretation of people outside of the person.'
- 'If I became highly disabled in my lifetime, I hope someone would be trying to ascertain my thoughts and opinions.'
- Someone said they had done some small-scale research at their school, describing how to quantify what makes their pupils with PMLD 'shine' – 'when you can just feel that they are engaged, even though their signs of being so are absolutely minute.'
- 'Seeing patterns which give some validation is better, far better than forgetting about people's emotional life because we don't know for sure.'
- Someone said if it does nothing but increase empathy, awareness and greater attention to communication then that will be good
- There were many suggestions of useful resources and research to look at including: Research from Katja Petry and Gordon Lyon who both have used proxies to gain an idea of quality of life of someone with PMLD who can not self-report; research going on at Trinity College Dublin which uses similar approaches and where data is being analysed using Grounded Theory, 'See What I Mean' by Nicola Grove, a 'listening and responding cycle' poster which clarifies procedures in attempting to ascertain views and experiences of people with PMLD from [www.disabilitydice.co.uk](http://www.disabilitydice.co.uk), 'The Wellbeing Workshop' resource which aims to help people identify and react to changes in the emotional and mental well-being of people with PMLD [www.learningdisabilities.org.uk/publications/](http://www.learningdisabilities.org.uk/publications/)

[EntryId5=22385&q=0%acprofound%ac](http://www.learningdisabilities.org.uk/publications/EntryId5=22385&q=0%acprofound%ac)

- Someone asked about consent and the researcher said that she has developed a 'circle of consent' around the children. Those who know them well watch as she works alongside the child and if at any stage they appear uncomfortable or unhappy she is completely ready to cease the work.
- Someone asked if the children may experience a bereavement when the project stops. Someone else said 'I would far rather my son had a relationship with someone who was making an effort to understand him, even if it was for a limited amount of time, rather than a long-term relationship with someone going through the motions. This is especially the case if the work results in other people knowing more about how to interact with people with PMLD.' However, the researcher said the comment has made her think seriously about putting in place some preparation for closure, perhaps in a sensory format for the child.

To take part in discussions please join the PMLD Network Forum at [www.pmldnetwork.org/about\\_us/join.htm](http://www.pmldnetwork.org/about_us/join.htm)

Visit the PMLD Network website at [www.pmldnetwork.org](http://www.pmldnetwork.org)

**To take part in discussions please join the PMLD Network Forum at**  
[www.pmldnetwork.org](http://www.pmldnetwork.org)

**Please note: The new PMLD Network website is launching in mid-April. The website address will be** [www.pmldnetwork.org](http://www.pmldnetwork.org)

**The PMLD network discussion forum, ([www.pmldnetwork.org](http://www.pmldnetwork.org)), is run and maintained by:**

**Foundation for people with Learning Disabilities**  
7<sup>th</sup> Floor, 83 Victoria Street,  
London SW1H 0HW.  
Tel: +44(0)20 78020301  
Email: [nmorris@fpd.org.uk](mailto:nmorris@fpd.org.uk)  
Website: [www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk)  
Registered Charity No: 801130 Company  
Registration Number: 235 0846



## NEWS

### Valuing People Now published!

The government has published 'Valuing People Now: A New Three-Year Strategy for People with Learning Disabilities'. It sets out the government's plans for learning disability services in England until 2011.



'Valuing People Now' brings the 2001 'Valuing People' white paper up to date.

The PMLD Network welcomes the publication of Valuing People Now and the renewed focus this will bring to improving the lives of all people with a learning disability, their families and carers.

In particular the PMLD Network welcomes that:

- Valuing People Now pays greater attention to ensuring that people with complex needs benefit from all the proposals and 'Including Everyone' is the first chapter.
- Valuing People Now defines who it means by 'people with complex needs' and explicitly states that this group includes people with profound and multiple learning disabilities.
- Valuing People Now identifies the need to take specific actions to include people with complex needs.
- A National programme lead will be appointed to champion issues for people with complex needs and the Department of Health will take forward a programme of work around complex needs.

Anne Williams, National Director for Learning disabilities has one of her measures of success as: 'if the needs of people with the most complex needs are met in creative and personalised ways'.

However, the PMLD Network recognises that work is also needed to address some gaps, for example, the strategy does not appear to place a priority on improving day services to meet the needs of those

who are not in, or working towards, employment – like people with profound and multiple learning disabilities. And although it recognises that people with complex needs are likely to need highly individualised support packages, it is difficult to understand how this can be supported without a commitment to increase funding.

Beverley Dawkins, Chair of the PMLD Network says, 'Valuing People Now recognises that we must focus on meeting the needs of those with the most complex needs and we welcome the programme of work it is taking forward in this area. But much needs to be done to ensure that the strategy actually delivers the changes needed to improve the lives of people with profound and multiple learning disabilities.'

Read Valuing People Now at [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_093377](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_093377)

Read the PMLD Network briefing on 'How does Valuing People Now aim to improve things for people with profound and multiple learning disabilities' at [www.pmldnetwork.org/resources/VP\\_Now\\_briefing.DOC](http://www.pmldnetwork.org/resources/VP_Now_briefing.DOC)

### Still at Breaking Point

Short breaks are a campaigning priority issue for Mencap. Mencap's surveys in 2003 and 2006 provided the evidence to lobby the Treasury so that substantial extra money is allocated to local councils and PCTs. There is a total of £770m for 2008 to 2011 with most of this funding ring-fenced to create additional fortnightly short breaks for the 100,000 most severely disabled children in England.

Mencap has been tracking the lives of real families with children with profound and multiple learning disabilities to see if this extra funding is reaching the families who most need better short breaks. To read Mencap's findings (Still at Breaking Point) please go to:

<http://www.mencap.org.uk/case.asp?id=542&menuId=557&pageno=>

## Changing Places sets the standard

Campaigners are celebrating after a new British Standard has recommended that fully accessible toilets be installed in new big public buildings.



British Standard 8300:2009 *Design of buildings and their approaches to meet the needs of disabled people* was published on 27th February 2009 and includes recommendations that Changing Places toilets should be installed in larger buildings and complexes, including large railway stations, airports and motorway services; sport and leisure facilities; cultural centres; stadia and large auditoria; shopping centres; key buildings within town centres; and educational and health facilities.

The Changing Places Consortium have been calling for Changing Places toilets - with a hoist, changing bench and lots of space - to be installed in public places since the launch of the Changing Places, Changing Lives campaign in July 2006, and they have played a significant part in securing the addition of Changing Places toilets in the British Standard.

Beverley Dawkins, Chair of the Changing Places Consortium, said, 'We are delighted that the needs of people with profound and multiple learning disabilities are finally being taken seriously. Having access to Changing Places toilets means carers don't have to make the terrible decision between changing their loved one on dirty toilet floors or not going out at all. We want to see more private and public bodies following best practice by installing Changing Places toilets.'

British Standard 8300:2009 *Design of buildings and their approaches to meet the needs of disabled people* is a code of practice, and takes the form of guidance and recommendations. It covers a wide range of impairments and the use of the built environment by disabled people who may be residents, visitors, spectators, customers, employees, or participants in sports events, performances and conferences.

Read further information on BS8300:2009 and find out how to purchase a copy:  
<http://www.bsigroup.com/en/Shop/Publication-Detail/?pid=000000000030153846>

Read policy and legal information:  
<http://www.changing-places.org/legal.asp>

## Get Involved in Learning Disability Week, 22-28<sup>th</sup> June!

### The theme this year is Changing Places, Changing Lives

**Learning Disability Week** is a national awareness week run by Mencap every year. This year it runs from **Monday 22 to Sunday 28 June 2009**.

Changing Places Changing Lives is the theme this year.

Find out how you can get involved at <http://www.mencap.org.uk/page.asp?id=2141>

## Getting it Right when treating people with a learning disability

Prominent health organisations, including the Royal College of Nursing and the Royal Society of Medicine, have joined forces with Mencap to produce a best practice guide for health professionals.

The guide, 'Getting it right', focuses on improving healthcare for people with a learning disability and is accompanied by an interactive website. The health bodies, which represent over one million health professionals in the UK, came together in response to the publication of Mencap's 'Death by indifference' report, which exposed the shocking deaths of six people with a learning disability who died unnecessarily in NHS care.

Find out more about the Getting it Right guide at:  
<http://www.mencap.org.uk/news.asp?id=6776&pageno=&year=&menuid=90>

Visit the Getting it Right website at <http://www.mencap.org.uk/page.asp?id=4363>

## Report finds social care provision needs urgent improvement

The Commission for Social Care Inspection (CSCI) has published 'The State of Social Care 2007-08' – which summarises the progress in adult social care over the last 6 years.



The report indicates some movement away from traditional residential care to community based services and the increased functioning of person-centred care. However the report shows the developments are patchy and that many local authorities are falling short of the national strategy and failing service-users.

The second part of the report pays particular attention to person-centred social care for people with multiple and complex needs.

The report confirms the PMLD Network's understanding that the personalisation agenda is not being implemented by local authorities for people with profound and multiple learning disabilities.

The PMLD Network welcomes CSCI's efforts to highlight specific and practical ways for local authorities to improve.

Read the full report and summary at [http://www.csci.gov.uk/about\\_us/publications/state\\_of\\_social\\_care\\_08.aspx](http://www.csci.gov.uk/about_us/publications/state_of_social_care_08.aspx)

Read the PMLD Network briefing on part 2 of the report: Personalised support for people with multiple and complex needs at [http://www.pmldnetwork.org/resources/state\\_of\\_social\\_care.pdf](http://www.pmldnetwork.org/resources/state_of_social_care.pdf)

## Government doubles funding for disabled children

The Government has given £340 million to Primary Care Trusts to support disabled children and their families. This matches the money already allocated from the Aiming High programme. The funding was announced as part of the Government's new Child Health Strategy.



The strategy includes the commitment that by 2010, all children with complex health needs will have an individual care plan and there will be improvements to community equipment services.

Read the Child Health Strategy at [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_094400](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_094400)

## MPs discuss the Human Rights of People with a Learning Disability

Last March the Joint Committee on Human Rights published a report which found that 'for many adults with a learning disability, the violation of their human rights is seen as a normal part of their everyday lives'. A year on, the Committee hosted a Parliamentary debate to discuss the findings of the report.

12 MPs turned up to discuss the need for more better social care funding and how to reduce inequalities faced by people with a learning disability in health and criminal justice settings. The Minister Phil Hope committed the Government to ensuring greater equality and to act on the report's findings.

Read the transcript of the full debate at <http://www.publications.parliament.uk/pa/cm200809/cmhansrd/cm090305/hallindx/90305-x.htm>



## REVIEWS

**Title:** Health Action Planning and Health Facilitation for people with learning disabilities: good practice guidance

**Publishers:** The Department of Health

**Pub date:** 2009

**Price:** free

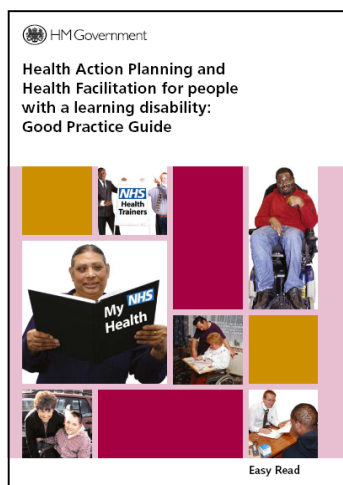
[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_096505](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_096505)

This latest document can be a bit heady. It goes beyond the basic premise about setting up health action plans at the individual level and moves onto the organisational level of implementing health action plans, including the responsibilities of the partnership boards and the PCT as the commissioners of services. This said if you want to make the system work for you as a carer, or for someone you work with who has profound and multiple learning disabilities, then this document is a must.

Besides laying out the responsibilities for implementing and evaluating health action plans this document goes further providing action points and several examples of best practice.

As the latest resource booklet on health action planning as well as the above, this document appears to be a document of substance and is available in an easy to read format too.

Di Foxwell. Book Review Editor PMLD Link.



**Title:** Understanding Nonverbal Learning Disabilities

**Author:** Maggie Mamen

**Publishers:** Jessica Kingsley Publishers

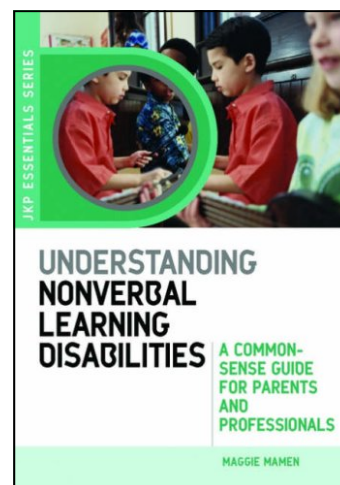
**Pub date:** 2007

**Price:** £12.99

The first thing to say is that this book is not particularly useful for those working with people with PMLD. It focuses on supporting people with nonverbal learning disabilities (NLD), a term that was new to me. The author defines a person with NLD as someone with at least average thinking and reasoning skills who has a deficit in visual, spatial and /or motor functions. This recently recognised condition and can be confused with Dyspraxia or Aspergers Syndrome. Therefore this book would be particularly useful for those who are diagnosing and assessing people with these or associated conditions.

This book is a useful, practical guide. It defines NLD very clearly and provides information on assessment and diagnosis. Different sub types are introduced and explained and strategies for intervention are clearly outlined with lots of handy tips. Although not a useful resource for those of us working with people with PMLD this book provided an interesting overview of NLD. For those working in this area "Understanding Nonverbal Learning Disabilities" will prove to be an invaluable resource.

Peter Burgess (Teacher)



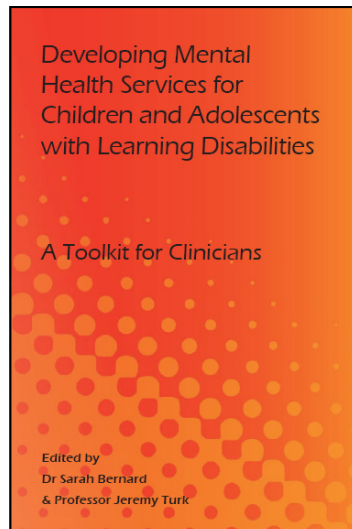
**Title:** Developing Mental Health Services for Children and Adolescents with Learning Disabilities—A Toolkit for Clinicians

**Edited by:** Dr Sarah Bernard & Professor Jeremy Turk

**Publishers:** Jessica Kingsley Publishers

**Pub date:** 2009

**Price:** £10.00



*List of abbreviations*

Epidemiological overview  
Multidisciplinary mental health assessment  
Clinical psychology  
Speech and language therapy  
Occupational therapy  
Nursing  
The social work contribution  
Medical  
Multi-agency working  
Working in partnership with families  
Service tiers and models

This book is easy to read and although written for clinicians (presumably psychiatrists) would be a useful resource in schools and wider care settings in terms of which professional to refer too and who to ask advice from. Needless to say this book would also be a useful resource for students from any of the professions to.

Di Foxwell Reviews Editor PMLD Link

This booklet is produced by the royal society of psychiatrists and is an excellent resource.

As a nurse I am often asked what nurses do with people with learning disabilities?

In relation to mental health issues this toolkit provides a clear description of several professionals' roles. The chapters of this toolkit are listed below so that the reader can form an idea of the types of areas addressed.

Summer Vol. 21 No. 2 Issue 63

- General Issue-

The copy date for all articles, information and news for the Summer 2009 issue is the 5th June 2009

Please send contributions to:  
Carol Ouvry  
Carol.ouvry@talktalk.net

Winter Vol. 21 No. 3 Issue 64

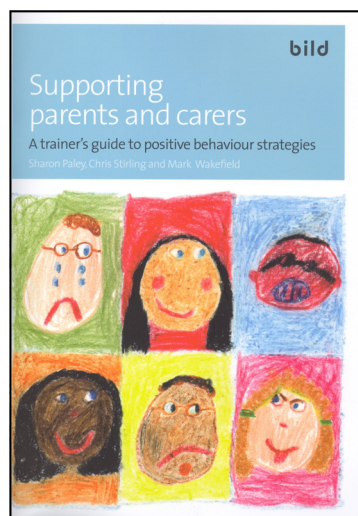
- Health Issue-

The copy date for all articles, information and news for the Winter 2009 issue is the 6th November 2009

Please send contributions to:  
Loretto Lambe L.lambe@dundee.ac.uk  
Ann Fergusson ann.fergusson@northampton.ac.uk

Articles can be long or short and they are welcomed from carers or professionals alike – we value YOUR experience and views. Please contact us if we can help you in any way. If you have any pictures or photos to include we would love to see them (providing we have permission).

## PUBLICATIONS



**Authors:** Sharon Paley, Chris Stirling and Mark Wakefield

**Publisher:** BILD

**ISBN:** 978-1-905218073

**Pub Date:** 2009

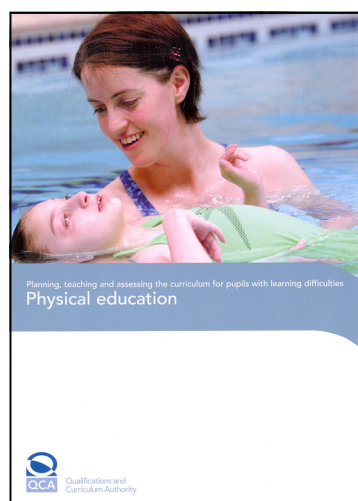
**Price:** £25.00

### A trainer's guide to positive behaviour strategies

Parents and carers are often the most important influence on a child's life and yet they very rarely receive training in strategies to help them deal with challenging behaviour. Training delivered by people who are in, or have been in, the same situation as themselves is likely to be more meaningful and produce a more positive response.

This trainer's guide is intended to provide parents and carers, as well as professional trainers, with materials to deliver training in positive behaviour strategies.

The guide includes a CD-ROM with PowerPoint presentation and handouts and, with the clearly set out session plans, provides a comprehensive course that is designed to be easily understood by those who may have limited formal training.



**Publisher:** QCA

**ISBN:** QCA/09/4118

**Pub Date:** March 2009

**Price:** Free

### Planning, teaching and assessing the curriculum for pupils with learning difficulties

A pack of 15 booklets: General guidance, Developing skills, Art & design, Design & Technology, English, Geography, History, ICT, Mathematics, MFL, Music, PE, PSHE and Citizenship, RE, Science.



**Author(s):** Lorraine Petersen, Ann Fergusson

**Publisher:** Routledge

**ISBN:** 978-0-415-43791-2

**Pub Date:** 1st December 2009  
(Available for Pre-order)

**Price:** £18.99

### P Levels in Mainstream Settings Meeting the Needs of all Pupils

This practical book with QCA endorsement will be an invaluable resource for SENCOs and other staff to learn how to use the P levels effectively. The P scales help teachers to set appropriate and achievable targets for pupils with special educational needs and also provide a framework of common performance measures for benchmark information.

This useful book provides practical, step-by-step guidance on how to use the P levels in mainstream schools to plan for pupils working below NC Level 1 and effectively meet their learning needs.

## Short Courses and Conferences 2009

### April

Date: 30th  
 Title: Capita's National Learning Disabilities Conference  
 'Implementing 'Valuing People Now'  
 Location: Central London  
 Provider: Capita  
 Contact: Web: [www.capitaconferences.co.uk](http://www.capitaconferences.co.uk)  
 Tel: 0870 400 1020

Date: 20th  
 Title: Making the Move - Transition from children's to adult services for young people with learning disabilities  
 Location: ORT House Conference Centre, London  
 Provider: OLM-Pavilion presents:  
 Contact: Tel: 0844 880 5061  
 Web: [www.olm-pavilion.co.uk](http://www.olm-pavilion.co.uk)  
 Email: [info@pavpub.com](mailto:info@pavpub.com)

### May

Date: 14th  
 Title: Getting in Touch—a practical workshop on the use of interactive whiteboards with SLD/PMLD Pupils  
 Location: Royal National Hotel, London  
 Provider: EQUALS  
 Contact: See Provider Details

Date: 19th  
 Title: Sherborne Developmental Movement level II  
 Location: Sunfield PDC  
 Provider: Sunfield PDC  
 Contact: See Provider Details

Date: 19th  
 Title: Profound & Multiple Learning Disability - engaging children and learning  
 Location: Birmingham, Edgbaston, The Portland Hotel  
 Provider: Concept Training  
 Contact: See Provider Details

Date: 20th  
 Title: Sherborne Developmental Movement level I (Taster Day)  
 Location: Sunfield PDC  
 Provider: Sunfield PDC  
 Contact: See Provider Details

Date: 21st  
 Title: Intensive Interaction  
 Location: Leicester  
 Provider: Concept Training  
 Contact: See Provider Details

### June

Date: 2nd  
 Title: Understanding the Multi Sensory Concept  
 Location: Cardiff  
 Provider: Concept Training  
 Contact: See Provider Details

Date: 4th & 5th  
 Title: Advanced Sensology Skills reinforcing good practice  
 Location: Space Centre, Preston  
 Provider: Florich Productions  
 Contact: See Provider Details

Date: 10th  
 Title: Intensive Interaction  
 Location: Wolverhampton  
 Provider: Concept Training  
 Contact: See Provider Details

### Providers Details

#### BILD

**British Institute of Learning Disabilities**  
 Campion House, Green Street,  
 Kidderminster, Worcestershire DY10 1JL  
 Tel. 01562 723025  
 E-mail: [learning@bild.org.uk](mailto:learning@bild.org.uk)  
 website: [www.bild.org.uk](http://www.bild.org.uk)

#### Concept Training

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

Date: 12th  
 Title: Profound & Multiple Learning Disability - engaging children and learning  
 Location: Chorley, The Woodlands Conference Centre  
 Provider: Concept Training  
 Contact: See Provider Details

Date: 12th  
 Title: National Training for EQUALS Moving On Programmes including Literacy and Numeracy for 14-19 year olds  
 Location: The Executive Centre, Bristol  
 Provider: EQUALS  
 Contact: See Provider Details

Date: 12th & 13th  
 Title: *TEACCH UK Conference 2009: Theme - A Culture of Autism*  
 With Mary E. van Bourgondien, Ph.D. Professor and Clinical Director, Raleigh TEACCH Center and Ros Blackburn  
 Location: The University of Northampton, Park Campus  
 Provider: The University of Northampton  
 Contact: Patsy Hollingum  
 Conference Administrator,  
 The University of Northampton  
 Tel: 01604 893447 or email  
[patsy.hollingum@northampton.ac.uk](mailto:patsy.hollingum@northampton.ac.uk)

Date: 16th  
 Title: Intensive Interaction  
 Location: Sunfield PDC  
 Provider: Sunfield PDC  
 Contact: See Provider Details

Date: 16th  
 Title: An Introduction to Puppetry with Tess Hills  
 Location: National Centre for Early Music, York  
 Provider: EQUALS  
 Contact: See Provider Details

Date: 17th  
 Title: Intensive Interaction  
 Location: Warrington/Haydock  
 Provider: Concept Training  
 Contact: See Provider Details

Date: 24th  
 Title: Understanding & Managing Sensory Related Behaviour  
 Location: Sunfield PDC  
 Provider: Sunfield PDC  
 Contact: See Provider Details

Date: 26th  
 Title: An Introduction to Conductive Education  
 Location: Sunfield PDC  
 Provider: Sunfield PDC  
 Contact: See Provider Details

Date: 29th  
 Title: Understanding the Multi Sensory Concept  
 Location: London, The IBIS Hotel (Euston Station)  
 Provider: Concept Training  
**Contact:** See Provider Details

## July

Date: 1st & 2nd  
 Title: An Introduction to PMLD  
 Location: Sunfield PDC  
 Provider: Sunfield PDC  
 Contact: See Provider Details

Date: 3rd  
 Title: Activities for communication for people with profound learning disabilities  
 Location: London  
 Provider: BILD  
 Contact: See Provider Details

Date: 8th  
 Title: Person centred storytelling  
 Location: Kidderminster  
 Provider: BILD  
 Contact: See Provider Details

## Providers Details

### EQUALS

PO Box 107, North Shields,  
 Tyne & Wear, NE30 2YG  
 Tel. 0191 272 8600  
 Email: [admin@equals.co.uk](mailto:admin@equals.co.uk)  
 Website: [www.equals.co.uk](http://www.equals.co.uk)

### Sunfield PDC

Clent Grove, Clent,  
 Nr. Stourbridge,  
 West Midlands DY9 9PB  
 Tel. 01562 883183  
 E-mail: [pdc@sunfield.org.uk](mailto:pdc@sunfield.org.uk)  
 Website: [www.sunfield-school.org.uk/courses.htm](http://www.sunfield-school.org.uk/courses.htm)



## September

Date: 24th & 25th  
 Title: Advanced Sensology Skills reinforcing good practice  
 Location: Chester Zoo  
 Provider: Florich Productions  
 Contact: See Provider Details

Date: 28th  
 Title: Sensology—A One day sensory journey  
 Location: Leeds  
 Provider: Florich Productions  
 Contact: See Provider Details

## October

Date: 14th  
 Title: Sensory Play and Leisure in the Multi Sensory Environment  
 Location: Glasgow  
 Provider: Concept Training  
 Contact: See Provider Details

Date: 19th  
 Title: Sensology—A One day sensory journey  
 Location: London  
 Provider: Florich Productions  
 Contact: See Provider Details

Date: 19th  
 Title: Intensive Interaction  
 Location: Liverpool  
 Provider: Concept Training  
 Contact: See Provider Details

## November

Date: 14th  
 Title: Sensory Play and Leisure in the Multi Sensory Environment  
 Location: London, The IBIS Hotel (Euston Station)  
 Provider: Concept Training  
 Contact: See Provider Details

Date: 9th & 10th  
 Title: Advanced Sensology Skills reinforcing good practice  
 Location: Glasgow  
 Provider: Florich Productions  
 Contact: See Provider Details

Date: 7th & 8th  
 Title: Profound & Multiple Learning Disability Meaningful Activities to Support & Engage Children & Adults with PMLD  
 Location: The Imperial Hotel, Blackpool  
 Provider: Concept Training  
 Contact: See Provider Details

Date: 17th  
 Title: Sensory Play and Leisure in the Multi Sensory Environment  
 Location: Birmingham  
 Provider: Concept Training  
 Contact: See Provider Details

Date: 18th  
 Title: Profound & Multiple Learning Disability - engaging children and learning  
 Location: London, The IBIS Hotel (Euston Station)  
 Provider: Concept Training  
 Contact: See Provider Details

## Providers Details

### Florich Productions

Tel. 01524 42 63 95  
 Email: [flocatalyst@aol.com](mailto:flocatalyst@aol.com)  
 Website: [www.multi-sensory-room.co.uk](http://www.multi-sensory-room.co.uk)

### RNIB Children's Services

58-72 John Bright Street  
 Birmingham B1 1BN  
 Tel: 0121 665 4235  
 Email [children@rnib.org.uk](mailto:children@rnib.org.uk)  
 Website: [www.rnib.org.uk/shortcourseschildren](http://www.rnib.org.uk/shortcourseschildren)

## LONGER COURSES (with accreditation)

Updated April 2008

### MA in Education

#### **SLD1 & SLD2: Pupils with Severe and Profound and Multiple Learning Difficulties (Contexts & Understanding)**

This module addresses the requirements of the Teacher Development Agency (TDA) National Special Educational Needs Standards (Core 1a – 1e, Extension 2.i – 2iv.). It is directly related to the module Curriculum and Teaching – Pupils with Severe and Profound and Multiple Learning Difficulties which addresses further standards. 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 severe and profound and multiple learning difficulties.

**Module: EDUM081**

**For further Details:** The University of Northampton. Tel: 01604 892192. E-mail: [admissions@northampton.ac.uk](mailto:admissions@northampton.ac.uk)

### MA in Education

#### **Physical Disabilities: Contexts & Interventions**

This module provides opportunities for those with QTS and professional qualifications & 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 module encourages both the development of enhanced understandings of the dimensions of physical disability, with regard to both their theoretical bases and the policies and practices invoked in meeting identified needs.

**Module: EDUM058**

**For further Details:** The University of Northampton. Tel: 01604 892192. E-mail: [admissions@northampton.ac.uk](mailto:admissions@northampton.ac.uk)

### MA in Education

#### **Physical Disabilities: Curriculum Issues**

This module provides students with opportunities to investigate, critique and evaluate a range of curriculum approaches in the field of PD. It engages students in debates concerning the relevance and practical efficacy of recent guidance & legislation in PD-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 PD.

**Module: EDUM059**

**For further Details:** The University of Northampton. Tel: 01604 892192. E-mail: [admissions@northampton.ac.uk](mailto:admissions@northampton.ac.uk)

### MA in Education

#### **Understanding Multi-Sensory Impairment**

This module addresses the requirements of the Teacher Development Agency (TDA) National Special Educational Needs Standards (Extension 2.i – 2iv.). 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.

**Module: EDUM054**

**For further Details:** The University of Northampton. Tel: 01604 892192. E-mail: [admissions@northampton.ac.uk](mailto:admissions@northampton.ac.uk)

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

During the course we will be looking in detail at the needs of learners who are known to have severe or profound and multiple learning difficulties. They 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: 01604 892192. E-mail: [admissions@northampton.ac.uk](mailto:admissions@northampton.ac.uk)

### **BSc in Professional Practice (Learning Disability Pathway)**

The School of Health & Social Care, University of Chester, BSc in Professional Practice (Learning Disability Pathway) - includes forensic, mental health/learning disability, challenging behaviour, older person with LD and epilepsy modules (plus others)

**For further details:** University of Chester

Telephone: 01244 511471 (Pat Palser), 511472 (Monica Davies) or 511473 (Ann Ashford)

Email: [p.palser@chester.ac.uk](mailto:p.palser@chester.ac.uk), [monica.davies@chester.ac.uk](mailto:monica.davies@chester.ac.uk), [a.ashford@chester.ac.uk](mailto:a.ashford@chester.ac.uk)

### **PGCert, AdCert.**

#### **Early Years: Sensory and Multiple Needs—This programme begins in January**

*Distance education.*

This programme enables professionals to work more effectively with young children with sensory and multiple needs. Participants may be teachers, who may already hold a specialist qualification in visual impairment, deafness or multisensory impairment; specialist speech and language therapists; health visitors; social workers; carers or others working with young children with sensory and additional needs.

**For further details:** University of Birmingham Dr Liz Hodges on 0121 414 4873 or email: [E.M.Hodges@bham.ac.uk](mailto:E.M.Hodges@bham.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.

The modules are as follows:

1. Understanding Learning Difficulties and Disabilities
2. Interventions for People with Learning Difficulties and Disabilities
3. Learning Difficulties and Disabilities: Communication and Behaviour
4. Working Together to Meet the Needs of People with Learning Difficulties and Disabilities
5. Learning Difficulties and Disabilities: Life Long Learning
6. Either: Special Studies in Special Education or Practitioner Inquiry in Education

**For further details:** University of Birmingham Dr Penny Lacey, phone: 0121 414 4878 or email: [p.j.lacey@bham.ac.uk](mailto: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](mailto:e.m.hodges@bham.ac.uk)

### **MSc and Graduate Diploma in Learning Disability Studies - Distance Learning**

If you are currently working with people with a learning disability and are interested in updating and expanding your knowledge of theory and practice, this course provides an opportunity to learn alongside other experienced professionals from a wide range of backgrounds.

- Is designed for experienced professionals involved in the care of adults and children with a learning disability.
- Is a distance course, involving the use of specially-prepared texts, annual weekend schools, and local tutorial groups.
- Assesses ability through small practical assignments and a dissertation of 15,000 words based on original research.
- Can be completed in one-year (full-time) or between two and five years (part-time).
- Leads to a Masters of Science degree after the completion of all assignments and the dissertation, or a Postgraduate Diploma for the completion of the assignments alone.

**For further details:** University of Birmingham Dr Stuart Cumella, Division of Neuroscience on 0121 414 4507 or email: [S.Cumella@bham.ac.uk](mailto:S.Cumella@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](mailto:mc1@st-andrews.ac.uk)

**Postgraduate Certificate/Diploma Profound Learning Disability and Multi-Sensory Impairment Programme**  
**MSc Learning Disability and Multi-Sensory Impairment Programme**  
*Programmes available by Distance Learning at The University of Manchester, School of Education*  
**Programme Aims**

- To provide an increased knowledge and understanding of children and adults who have complex needs and/or sensory impairments.
- To empower those directly concerned with this group to advocate for the rights of the individuals concerned.
- To enable this to happen by providing current information relating to cognitive, emotional, physical, sensory and social needs.

**Programme Structure**

Courses are delivered by Distance Learning over a period of 1 - 3 years (including an extra year of independent study for MSc. students undertaking their dissertation). The MSc and Postgraduate Diploma are also available full time (distance learning) over 1 year. The written materials are underpinned by a variety of Study School formats during this time. Student support is also provided by telephone contact with the academic tutors. There are no examinations and the course requires approximately 3-4 hours private study per week.

**For further details:** University of Manchester Janet Grimshaw, Phone: 0161 275 3463, Email: [janet.grimshaw@manchester.ac.uk](mailto:janet.grimshaw@manchester.ac.uk)

**MSc in Advanced Practice (Learning Disabilities)**

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).

**For further details:** University of Chester

Telephone: 01244 511471 (Pat Palser), 511472 (Monica Davies) or 511473 (Ann Ashford)

Email: [p.palser@chester.ac.uk](mailto:p.palser@chester.ac.uk), [monica.davies@chester.ac.uk](mailto:monica.davies@chester.ac.uk), [a.ashford@chester.ac.uk](mailto:a.ashford@chester.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](mailto:p.j.lacey@bham.ac.uk) or Helen Bradley [h.bradley.2@bham.ac.uk](mailto:h.bradley.2@bham.ac.uk)

**MSc Profound and Complex Learning Disability and**  
**Postgraduate Certificate/Diploma Profound and Complex Learning Disability**  
*Distance Learning*

**Course aims**

- To provide an increased knowledge and understanding of children and adults who have complex needs and/or sensory impairments.
  - To empower those directly concerned with this group to advocate for the rights of the individuals concerned.
- To enable this to happen by providing current information relating to cognitive, emotional, physical, sensory and social needs.

**Course Structure**

Courses are delivered by Distance Learning over a period of 1-3 years (including an extra year of independent study for MSc. Students undertaking their dissertation). The MSc and Postgraduate Diploma are also available full time (distance learning) over 1 year. The written materials are underpinned by a variety of Study School formats during this time. Student support is also provided by email and telephone contact with the academic tutors. There are no examinations and the course requires approximately 3-4 hours private study per week.

**For further details:** The University of Manchester, Emma Hardy Phone: 0161 275 3463 Email: [emma.hardy@manchester.ac.uk](mailto:emma.hardy@manchester.ac.uk)

# PMLD-Link

Subscription Year 2009

## Volume 21 Nos. 1,2 and 3

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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 is published three times a year and 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 many other settings. In recent years the scope of the articles has been widened to include all professions and services, and to cover issues pertaining to all groups, including occasional articles by practitioners and parents from overseas.

**PMLD-Link** is a grass roots publication and depends on written contributions from parents and carers, teachers, psychologists, special support assistants and workers in all settings. The contributions may be:

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

**PMLD-Link** also includes:

- information and reviews of resources or publications and reports on conferences and research
- listings of courses and events relevant to the area of PMLD.

It enables readers to create networks, and provides a forum for contact with others involved in the field.

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

<b>Rob Ashdown</b>	Head Teacher at St. Luke's Primary School, Scunthorpe – a special school for children with complex learning difficulties aged 3 to 11 years.
<b>Alice Bradley</b>	Freelance training and development worker.
<b>Beverley Dawkins</b>	National officer for profound and multiple learning disabilities Mencap.
<b>Julia Dixon</b>	Early Years Advisor and parent of young adult with PMLD.
<b>Ann Fergusson</b>	Family member with learning disability; research and teaching in severe / profound and multiple learning difficulties at the University of Northampton; Research Associate for University of Cambridge <i>What About Us?</i> Project.
<b>Di Foxwell</b>	Coordinator of Clinical Education and Practice Development – BHCT NHS Trust and Distance Regional Tutor for Birmingham University on two learning disabilities programs.
<b>Penny Lacey</b>	Co-ordinator of the University of Birmingham course in severe, profound and complex learning difficulties; freelance consultant; family member with severe learning difficulties
<b>Loretto Lambe</b>	Director of <i>PAMIS</i> - an organisation in Scotland working with people with profound and multiple learning disabilities, their family carers and professionals who support them.
<b>Carol Ouvry</b>	Special education teacher and freelance consultant in the field of PMLD. Editor and administrator of <b>PMLD-Link</b> for many years until retirement.
<b>Kim Scarborough</b>	Nurse with 25 years experience in working with people with SLD/PMLD and their families. Have 2 nephews with PMLD. Programme leader for BSc (Hons) in learning disability studies University of the West of England.

There is also a consultation group to assist in commissioning articles from all regions of the UK and overseas and, to ensure a wide coverage of topics. The administrator of **PMLD-Link** is Paul Bramble, The University of Northampton, e-mail: paul.bramble@northampton.ac.uk

**Information for Subscribers:** **PMLD Link** is published in three issues per year.

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**If you wish to subscribe, or to receive a sample copy of *PMLD-Link* please contact:**

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

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# PMLD Link

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