

# PMLD LINK

sharing ideas and information

**Sharing Perspectives**

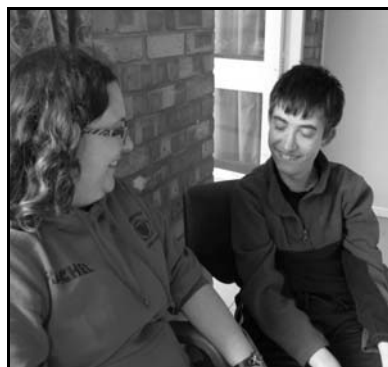
Summer 2011



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

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

## GUEST EDITORIAL

# Sharing Perspectives

**W**elcome to the Summer edition of the new look PMLD Link. This edition covers a variety of topics, sharing perspectives. It gives us an opportunity to discuss and share a wide range of topics. These are discussed from diverse perspectives; parents, teaching assistants, researchers and many more. We hope that this will provide you with interesting reading.

It is enlightening to hear of the passion, enthusiasm and pleasure that are gained from working with and caring for people with PMLD. This is evident in the first article where Rachel, a teaching assistant, describes what provides her with job satisfaction. It has an underlying theme of doing what is best for the young people she works with. This permeates throughout the various topics within this edition, whether it is the health, education or welfare of the people in our care. This is not always a smooth ride as the fight for appropriate adult care and the hospital experiences described in articles by family carers, and also the tortuous route to becoming a deputy, demonstrate.

The work for improvement is not just on an individual level. Rob Ashdown summarises the long awaited government green paper, Support and Aspiration: A new approach to special educational needs and disability. This is supported by the research project that has been carried out by Professor Barry Carpenter and his research team who have developed a framework to engage pupils with complex learning difficulties and disabilities.

There are all the usual sections on News, Books, Resources, Courses and other sources of information. I hope all our readers find things which interest, excite, and help them in their day to day practice. Future Focus introduces the topic for the next issue – Therapy – and all the details for sending articles are given there.

Finally, thank you to all the writers of articles for their contributions to this issue.

Wendy Newby and Carol Ouvry

### Contact Us

#### Subscriptions and advertising enquiries

Carol Ouvry  
31 Birdwell Road  
Bristol BS41 9BD  
Email: carol.ouvry@talktalk.net

#### Reviews

Di Foxwell  
50 Boness Road  
Wroughton  
Swindon SN4 9DT  
Email: di@phonecoop.coop

#### Production

Paul Bramble  
The University of Northampton  
Boughton Green Road  
Northampton, NN2 7AL  
Email: pmlink@northampton.ac.uk

Website: [www.pmlink.org.uk](http://www.pmlink.org.uk)

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## Musings of a Teaching Assistant

Rachel Gale

A friend once asked me how I know when a student that I work with enjoys an activity or stimulant. I gave her the answer that I thought should have been obvious – they tell me. She didn't understand – she wanted to know about the students who cannot talk, the young people who have a very profound disability and limited understanding of how to communicate. But my answer remained the same – if they like something, a person may smile or laugh. If they dislike something, they might frown, cry or push it away. It doesn't matter that they have not looked me in the eye and told me that they "love this track!", the fact that whenever it is played they smile, tells us as staff that it is something they enjoy.

I currently work as a Teaching Assistant (TA) in the Further Education (FE) department of a school for students who have special needs. The students are aged between 16 and 19 and the group covers a wide range of abilities. My experiences as a TA in this school are

different from those of a teacher here because I work with the same group of students for the whole day, whereas teachers tend to teach their specialist subject areas and may teach up to four different groups in one day. I believe that this can give the TAs here a better

understanding of the students' needs and, in some instances, of communication than some of the teachers. I have been in Speech Therapy sessions with students and had to repeat what a child was trying to say when others did not understand - purely because working with that young person every day has given me an "ear" to understand his speech patterns. In addition to that, having been with the student for the entire day, I have encountered the same experiences as he has and can draw upon this information to conclude what he is trying to communicate. If a student has PMLD, that "ear" for a young person's communication which is held by the TA is no different. A "pain cry" is different from a cry of boredom, for example, and if you can identify what the problem is from the pitch of his cry or the way he is sitting, then the solution is easier to find, and the student more smoothly comforted.

Communication is not the only aspect of life where a young person with a disability relies upon his or her TA. For example, a person who is working with a child all day would know whether he or she had eaten at break time and might be hungry – or sickening for something if food had been refused. I once worked with a young man who would be painfully sick if he ate too much, but did not have the understanding to know when to stop eating. It's easy to write "Student X can only eat small portions of food" on a care plan, but everyone's judgement of this is different, and it is the regular staff member that they turn to for advice at this point, allowing the student to eat appropriately and to remain comfortable for the rest of the day.

We are very lucky in our school to have a heavy input from physiotherapists for our students. However, the TAs are relied upon to make sure that W is out of his chair, X has her splints put on, Y gets time in his standing frame and Z has plenty of time in his walker. These events are all essential to assist the child to be comfortable and maintain healthy movement. These children and young people need to be comfortable if any learning is to take

place that day – in fact, maybe that sentence should just read "children need to be comfortable".

As a TA, you unavoidably form close bonds with the students you are working with. These students are reliant upon you for every aspect of their lives. It is because of these close bonds that the TA can be a child's voice when they have had enough – or when they want more! This closeness enables the TA to predict where a pain might be from how a child is seated, or what might explain some erratic behaviour. I firmly believe that the relationship between the TA and the child is what helps the children to feel happy in school, and as a result of this, what helps the parent to relax in the knowledge that their child enjoys coming into school.

I have tried to give an insight into how a TA affects the life of a child in his or her care, but I feel I have merely scratched the surface – after all, it is a school in which we work and I have not even touched upon how we assist these children within their lessons! Not to mention swimming, horse riding, personal care, developing independence...the list of responsibilities is endless, but I would like to end my musings with this; it is nearly impossible to put into words how much I enjoy my job. How many other places of employment can you make somebody laugh just by whispering random quotes from The Lion King into someone's ear? Where else can you make a person's day just because you happen to know all of the words to the musical Joseph? How many average workplaces have people come running in through the door first thing on a Monday morning full of excitement to just be there? And what other environment can you work in where you feel loved and appreciated by at least one person every day?

#### **Contact Details**

Rachel Gale  
Teaching Assistant  
St Rose's School, Stroud  
c/o wendy.newby@stroses.org.uk

## **NEXT ISSUE**

The focus in the Winter issue is on **Therapies**

Do you have any knowledge or experiences to share on this theme?

If so, contact the editors:

Chris Fuller : fuller.chris@hotmail.com

Rob Ashdown: headst.lukes@northlincs.gov.uk

# Having new eyes: engaging children and young people with complex learning difficulties and disabilities in learning

Barry Carpenter, Jo Egerton , Beverley Cockbill and Teresa Owen

‘The only real voyage of discovery consists not in seeking new landscapes, but in having new eyes’. *Marcel Proust*

## The 21<sup>st</sup> century professional challenge

Children and young people are now coming into our schools whose learning difficulties and disabilities are more complex than we have seen before. Many present with previously unknown disabling conditions such as rare chromosomal disorders, or prenatal maternal drug and alcohol abuse. The Department for Education (DfE)’s SEND Green Paper, *Support and Aspiration* (DfE, 2011), explicitly refers to the changes in the child population, and the impact of SEND upon mental health in particular.

If the population of children and young people in our schools is changing, how has their learning changed? Do we have the teaching repertoire to meet the teaching challenges of students with different patterns of learning? If we do not, how then can we teach them?

## The Complex Learning Difficulties and Disabilities Research Project

The Department for Education commissioned the Specialist Schools and Academies Trust (SSAT) to explore with educators how they might develop meaningful pathways to personalised learning for this growing population of children and young people with CLDD (September 2009 to March 2011). The research team worked with 96 schools to support the learning of children/young people with a wide range of complex learning difficulties and disabilities. The schools included special and mainstream (including early years, primary, secondary and transition settings), both in the UK and internationally.

## Engagement for learning

High quality differentiation should be the hallmark of high quality teaching in special educational needs (Carpenter, 2010). However, children with CLDD require something more of us than curriculum differentiation

(Porter and Ashdown, 2002). Our work must be to transform these children with CLDD into active learners by releasing their motivation, unlocking their curiosity and increasing their participation.

Research suggests that engaged behaviour is the single best predictor of successful learning (Iovannone et al., 2003). Unless a child is engaged in learning, there can be no deep learning, effective teaching, meaningful outcome, real attainment or quality progress.

## The Engagement profile and scale

One of the resources developed through the CLDD research project is the Engagement profile and scale, as children/young people with CLDD are often disengaged from learning. The Engagement profile and scale enables educators to use evidence-based knowledge of a child’s successful learning pathways in highly motivating activities to identify strategies, set high expectations, and record incremental progress in activities of low interest. The seven different aspects of engagement – the ‘engagement indicators’ – make engagement an accessible concept which can be addressed in a practical way. The indicators are:

- Awareness / Responsiveness
- Curiosity
- Investigation
- Discovery
- Anticipation
- Initiation
- Persistence

### **The Engagement Profile**

As a first step, educators observe the child or young person in an activity or activities which they are highly motivated by – this can be anything in any setting – and use the engagement profile to write personalised definitions against each of the seven engagement indicators. The child/young person’s high interest activity enables educators to see the higher level of engagement the child is capable of. It allows them to:

1. Develop high expectations of the child/young person’s potential for engagement in other learning areas in which they currently show low engagement
2. Analyse what it is about the high interest task that draws the child/young person in, so that these aspects can later be applied to low interest activities to increase their motivation to engage
3. Use the child/young person’s higher engagement behaviours as a benchmark when scoring on the Engagement scale. All other engagement scores are made in relation to this.

#### **Case study: Alfie’s engagement journey – part 1**

Alfie (not his real name) is a four-year-old boy with PMLD, including global developmental delay, epilepsy and physical difficulties. His high interest activity was watching and listening to pouring water. His lowest engagement activity was food technology – he would self-induce sleep at the beginning of the lesson and wake up at the end! His teacher wanted him to remain engaged and enjoy the lesson.

The class team carried out an engagement profile for Alfie watching and listening to water being poured into a tin from a height. They noted his enjoyment of water, of watching the way the water poured and where it came from, and of the sound. They also noted how his behaviour showed that he was engaged – his body stilled; he paid close attention and tracked the water from its source to its destination; he vocalised.

Alfie’s behaviour during the water pouring activity showed the class staff team how intently he could be engaged. They now knew how he could respond if he was interested in an activity – and they had an idea of what interested him.

[Alfie’s engagement profile and scales can be found online at <http://complexld.ssatrust.org.uk/project-resources/engagement-profile-scale.html> as part of the SEN and Early Years version of the ‘Engagement Profile and Scale document’.]

### **The Engagement scale**

The Engagement scale is carried out with low engagement activities for the child/young person, the first two or three scales being completed before any changes are made to the activity to increase their engagement in it. This provides a ‘baseline’ so that

educators can demonstrate the progress the child/young person has made from when they first started. It is important to note here that ‘progress’ is not just a series of higher and higher scores, but, at specific times, will also include lower scores when the activity is changed to extend the student’s skills (e.g. introducing peer interaction, using more or different materials in the activity, transferring the activity to another setting).

#### **Case study: Alfie’s engagement journey – part 2**

Initially the class team, including the CLDD research assistant, completed an engagement scale for Alfie’s involvement in food technology without making any changes to it, so they had a starting point for their interventions. The first engagement scale showed that Alfie had a very low level of engagement in this activity.

Over a number of weeks, the class team made a series of changes, one at a time, so they could see which changes made the difference to Alfie’s engagement in the activity. In this way, they slowly altered the learning activity so that the context for learning was understandable and meaningful for Alfie, and he was able to achieve. They completed an engagement scale after each change had been made. The changes were as follows:

- The class team reduced aspects of the food technology session that Alfie seemed to find invasive. They moved him away from the busy and noisy main table to a calmer area of the classroom. Instead of having his hands quickly wet wiped with a paper towel to clean them before handling food, he was encouraged to dabble his hands in a bowl of water.
- They overcame Alfie’s confusion by reducing the number of foods they were expecting Alfie to work with from three (bread, butter and sandwich filling) to one (icing).
- They broke down the learning target into steps, so instead of expecting him to watch, touch, make and taste the food within one session, these were spread out over several sessions.
- They transferred some of Alfie’s favourite parts of his high engagement activity to the low engagement one. The icing had some of the properties which had intrigued Alfie about water – it could be poured into a container from different heights, and made a noise while being poured.

Alfie was entranced by the discovery of icing being poured. With support and encouragement, at a pace he could cope with, he became interested in touching the substance to find out what it felt like and, eventually, what it tasted like.

Once Alfie was confident with the icing, the class team slowly re-introduced the elements of sandwich making one at a time: one week the mashed banana filling, and over the next sessions, the bread and butter. Finally Alfie was able to engage fully in the activity which had previously so overwhelmed him.

## Unlocking potential

It is the right of every child/young person to be included as a learner within the curriculum, however great their degree of disability or learning difficulty. The capacity to transform a child's life for the better, and equip them to enjoy active citizenship, is at the heart of education. The Engagement profile and scale, by providing a means of conceptualising engagement (the seven indicators), together with a way of recording increases and decreases in engagement in a learning activity over time, enables educators to address issues of engagement in learning for the child/young person with CLDD in a systematic and deductive way.

Before using the Engagement profile and scale, the teacher working with Alfie had struggled to engage him in anything. He had been completely disengaged both socially and from learning. However, Alfie's own interests, and his mother's suggestions, together with the Engagement Profile and Scale, provided the teacher with a way of identifying and unlocking Alfie's potential for learning and recording his progress. The strategies her team developed to engage Alfie were generalized across all curriculum areas of learning with great success, and these strategies could also be used as a source of ideas in engaging others like Alfie. From being the child in her class who most concerned the teacher, he had become responsive – engaging not only in learning, but also socially, interacting with his staff through eye gaze and body language – where previously he had shown no interest.

In addition to the Engagement Profile and Scale above, the CLDD Project's other resources can be found online at <http://complexld.ssatrust.org.uk>.

### Contact details

Specialist Schools and Academies Trust –  
Wolverhampton Office  
Tel: + 44(0)1902 796067  
Email: [CLDD@ssatrust.org.uk](mailto:CLDD@ssatrust.org.uk)

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Barry Carpenter (Academic Director), Jo Egerton (Research Project Co-ordinator), Beverley Cockbill (Research Assistant) at the Specialist Schools and Academies Trust, and Teresa Owen (Class Teacher) at Chadsgrove School and Specialist Sports College

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# Interactive Sensory Stories: providing a means, a reason and an opportunity to communicate with children with profound and multiple learning disabilities

Laura Blake

As Young and Lambe (2011) described in the previous edition of PMLD Link, story telling is being increasingly recognised as a therapeutic and educational tool for people with profound and multiple learning disabilities (PMLD). As a teacher faced with the wonderful challenge of working with a diverse group of children who fall under the umbrella term ‘PMLD’ I have found interactive sensory storytelling to be an invaluable teaching tool. Interactive sensory stories provide a rich and stimulating experience offering learning opportunities on many levels. At the core of interactive storytelling is communication and social interaction. It is through this interactive dialogue that learning and development takes place.

According to Thurman and Money (1994), in order for effective communication to take place people need: a means, a reason and an opportunity to communicate. When developing an interactive story, these aspects are central: ‘the means’ takes the form of a skilled and responsive communication partner; ‘the reason’ is the sharing of the story using props and resources that the children are drawn to investigate; ‘the opportunity’ is in creating a time and a space where the expectation is that communication will take place.

By communication I mean creating that very special dialogue that can be created through Intensive Interaction. Nind and Hewett (1994) describe Intensive Interaction as being an approach to developing “The Fundamentals of Communication” including; use and understanding of eye contact, learning to enjoy giving attention to another person, learning to concentrate and attend, learning about personal space and learning to read body language, facial expression and gesture. The stories we create provide a framework for shared activity, mutual involvement, repetition and problem solving. These not only give both the child and the adult helper a reason to communicate but they provide opportunities for Intensive Interaction to take place. Props and resources are incorporated into the story to

act as a catalyst. The sound of a “rapper-snapper” being stretched or a wine bag being scrunched causes a reaction to which a sensitive communication partner can respond. From this, an interactive dialogue can develop and the story can evolve.

## The Children

Manor Green Primary School has approximately 130 children aged 2-11 who have learning difficulties and additional needs. Each class has one teacher and at least two assistants. Further support is provided by speech and language therapists, physiotherapists and occupational therapists. Cherry class has eight children and five adult helpers consisting of four special support assistants and one teacher. It is an “additional needs” class with PMLD, SLD and one child who has ASD.

When story telling we share the story as a group with adults allocated to support one or two children. The story teller leads the story, setting the pace and providing various cues. Over a term we repeat the story daily and it forms the basis of topic work in other curriculum areas. With repetition the story develops as both the children and the adults familiarise themselves with it. Sections are tweaked and personalised as we learn from the children how they learn best!

## The Process

As part of our topic “Long, Long Ago...”, Cherry class focussed on traditional tales. We chose *Cinderella* and adapted a version produced by Stan Cullimore (1998). What follows is the ‘translation’ of the text from a language based story to an interactive sensory based story. When devising a story I begin by exploring its essence. I then consider what related props and activities will engage the children and the next step is to build in opportunities for interactive play.

The essence refers to a feeling or a sense of the story. When planning *Cinderella* I used a chant to emphasise all of the work that *Cinderella* had to do which contrasted with both the “magical” element of the fairy godmother appearing and the liveliness and freedom of the music at the ball. The sounds and props at these stages reflected these contrasts.

Playfulness is key. Nind and Hewett (1994) highlight the importance of play and enjoyment being an essential part of learning for this group of children. Corke (2011) agrees; she explores playfulness in great detail and explains that an ‘open’ inviting presence and playful facilitation encourages a child to enter the learning arena with a positive frame of mind. In addition she describes beautifully the “ten commandments of quality interaction”.

### *The Ten Commandments of quality interaction:*

1. Actively listen with your heart as well as your ears.
  2. Provide listener feedback (positive body language and facial expression) to ensure that the learner knows you are listening.
  3. Make others feel valued.
  4. Be genuine.
  5. Learn your partner’s “language” and consider adopting their style during the interaction.
  6. Consider proximity.
  7. Observe the outer “story” but reflect upon the “inner story”.
  8. “Tune in” at an emotional level.
  9. Respect yourself and others.
  10. Smile, play, relax and enjoy each other’s company.
- Corke (2002: 49)

In *Cinderella* we developed opportunities for interaction through tearing, scrunching and throwing newspaper, banging drums, face-painting, squeezing feet, dressing up, tickling and sobbing. The sensitivity of the adult helpers determines the success of these games. They can appear simple, however when facilitated effectively, they provide a framework for fun, enjoyment and dialogue in which the children are able to explore free from concepts of “the right” way to do something. They support the children to experience their contribution being noticed and valued and learn ways in which they can influence the world around them. With these elements in place, we can begin the story.

## The Story: Cinderella

*“Wash, scour scrub and clean those ugly sisters are really mean, really mean, really mean!”*

We start the story with a lively animated chant, I move around the group, scraping a rhythm on a washboard. The team members support one or two children to engage using individualised props: sparkly scourers for some; sandpaper to make a scrubbing sound for others; a bright purple soft brush for another. As we chant and beat out the rhythm, Michelle looks up to watch, smiles and begins to wiggle her shoulders in her own dance, Justin reaches for my washboard. Ryan slowly raises his head.

*“Cinderella slaved all day doing all the work in the house. One day the newspaper said that the Prince was going to have a big party. He wanted to find a bride”*

Justin pulls the paper, tears it and throws it, I reach down and grab it and throw it back. He grabs it again and an interactive game takes place, he watches as he throws, he laughs and he makes lots of different sounds. I mirror the sounds and laugh as I let him take the lead in an activity he loves. Ryan spreads his fingers on the newspaper and moves them. The newspaper scrunches and wrinkles. He watches his fingers at work. When he pauses his helper mirrors his actions and pauses waiting for him to respond. Joseph grabs the paper and vocalises, he scrunches it up and mouths it. He then throws it away. His helper offers him more and this time joins in with the scrunching and vocalising.

Between each stage of the story we go back to the chant as this helps to pull the group back together. Each time the children respond through movement, vocalisation and gaze.

*“We’ll go the Ball” said the ugly sisters, “but Cinderella you must stay here and work”. They got themselves ready to go and off they went to the ball.”*

We all pretend to get ready for the ball by using face paints and scented moisturiser as “make-up”. I brush paint on Justin’s arm. He reaches initially to push me away but then notices the mark on his arm. He watches as I apply it, rubs it and brings it to his nose to smell it. Michelle holds out her hand enjoying being tickled by the brush, she giggles, “more?” we ask, she smiles and more is applied. Ryan responds to the sensation of the brush on his hands and turns towards his adult helper. He gazes at her as she talks gently to him. Joseph moves his hands away and an “I’m coming to get you” game develops.

*“Scrub, scour, wash and clean, those Ugly sisters are really mean, really mean, really mean!”*

*“Cinderella wept.”*

We pass around Big Mack switches which when activated produce a crying sound. Justin reaches and gives the switch an almighty whack. He laughs and then listens to the sound of weeping. We leave a switch on Ryan's tray and wait for him to reach it. His gaze falls upon it and after some time and several attempts his right hand knocks it and we cheer!

*"Scrub, scour, wash and clean, those ugly sisters are really mean, really mean, really mean!"*

*"Suddenly a Fairy Godmother appeared."*

I drape silver fabric over my shoulders, appear with a fairy wand with streamers trailing and throw sparkly confetti over the children. The children track the confetti, some reach for the streamers, Justin watches me as I say:

*"Oh Cinderella, don't be sad, It really isn't all that bad. My magic wand will set things right, you shall go to the ball tonight!"*

Back to the chant, then:

*"Cinderella went to the ball and danced all night with The Prince."*

This is the cue for lots of noise. We play recorders and drum, moving around the children. Justin reaches and bashes the drum. Ryan lifts his head and turns towards me. I place the drum against his legs as I play. Michelle begins to dance again.

*"Scrub, scour, wash and clean, those ugly sisters are really mean, really mean, really mean!"*

*"The clock struck 12.00."*

I strike a chime bar twelve times. I move around the group as I do so, watching all the time for responses. The children all go silent and still, listening as the sound rings around the classroom.

*"Cinderella ran.....and dropped her glass slipper."*

I hold the slipper up high and count 1...2...3 and then ...."boom!" it lands on a large bass drum. Some of the children learned to cover their ears as they watched, others laughed in anticipation (after having heard the story a number of times). For some it's a surprise every time!

*"Scrub, scour, wash and clean, those ugly sisters are really mean, really mean, really mean!"*

*"The Prince wanted to find Cinderella – he wanted everyone to try on the slipper."*

Each child has their feet squeezed. Some like it and want more, others tolerate it. Justin finds it funny!

*"It fits, it fits! The Prince found Cinderella. They got married and lived happily ever after."*

The story ends with a dance to Bach, "Brandenburg Concerto no. 5". Joseph smiles when he hears the music and laughs as we count 1..2..3 and then spin him round.

*"The End!"*

As we repeat the story we notice how children anticipate parts of it, show preferences for particular resources and develop expectations of the routines they engage in. They learn to attend, to reach, to track and to wait; they are using and developing their gross and fine motor skills. Thus it can be seen that they are developing many of Longhorn's "prerequisites for learning" (Longhorn 2000) as well as developing "the fundamentals of communication" outlined earlier.

Interactive sensory stories are primarily vehicles for interactive play and social engagement. The process of telling the story is so important. The true value of Interactive Sensory Storytelling lies in the nature and the quality of the dialogue that the story creates through shared experience. The story provides a means, reason and an opportunity to communicate. It is through this communication process that learning and development takes place. Whilst we may measure problem solving abilities, reaching and tracking, the motivation to develop these and the value of their development is enhanced by the human quality of interaction and shared pleasure.

### Contact details

Laura Blake  
lblake14@wsqfl.org.uk

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- The Baby Einstein Music Box Orchestra, *Brandenburg Concerto No.5 BWV 1050*, The Walt Disney Company

# Working Together to find New Ways to Communicate

Rosanne Tyas, Signe Dimitriadis, Seeta Shah, and Holly Hitchen

It is an important basic human right to communicate, but for learners with profound and multiple learning disabilities (PMLD) and complex health needs who communicate non-verbally, it is important to find new ways to help them express themselves. Music and sensory exploration have always proven popular with the learners at The School for Profound Education (formerly St. Margaret's School). Creating a specific group focusing on encouraging self and social awareness, each learner's own communication styles and sensory exploration through music has helped them to actively engage with their peers.

**T**he School for Profound Education is one of the few residential special schools in the UK that provides education, therapy and care for children and young people with PMLD all on one site. The school aims to provide a safe, caring, organised and happy environment in which each learner's individual needs can be met and their intellectual, physical, emotional and social development embraced.

All learners follow the school's specially-developed Profound Education Curriculum which combines education with different types of therapy including music therapy, occupational therapy, speech and language therapy and physiotherapy. This combination means learners with complex health needs, degenerative conditions and additional sensory impairments still have opportunities to learn. Therapy is integrated into the school day, in both group and individual sessions, to enable learners to access their learning. Progress, even small steps, is continually recorded, monitored, evaluated and celebrated.

## Music and Sensory group

**C**ombining music therapy, speech and language therapy and occupational therapy, the session was specifically set up for a group of learners in the Further Education class of the school. One of the challenges of this client population is generating new ideas that are appropriate to this age group. This group was set up as a new venture to meet these demands. Sessions took place once a week over the course of 19 weeks in the same venue and with a similar session structure for continuity. The pilot group ran with six learners.

The group aims focused on non verbal communication such as turn-taking, eye contact, listening and looking at

peers, encouraging active engagement and participation, depending on the individual learner's level of ability.

Opportunities were given to each learner to access musical instruments individually and explore their properties whilst the rest of the group members listened to them. There was also the chance for learners to participate in group improvisations using their voice or instruments and having the opportunity to hear their sounds reflected back to them musically. Sensory props and body movements were introduced to accompany and enhance the musical properties and to encourage the learners to express themselves through their own non-verbal methods.

The Individual Education Plan of each learner was used to set specific aims for them to work towards in the session. These individual aims were identified from the communication, social, sensory, cognitive and motor sections of the Profound Education Curriculum as the group incorporated activities and goals from each of these sections. These learner specific aims were measured and interpreted into a percentage at the end of a block of sessions, reflecting their level of achievement. This information was also reflected at their annual review.

## Planning a session

**A** similar session structure was followed each week in order to encourage learners to anticipate activities and participate with more confidence. The general structure of the group was as follows:

**Greetings** – using drum and voice

The learners requested a turn at being sung to through their own vocalising or non-verbal behaviours. Learners

were also encouraged to greet each other in their unique communication style e.g. fleeting eye contact.

### **Passing on song**

A learner chose what instrument was to be passed around from a choice of two e.g. tambourine or bells. A familiar song was then sung as a framework for this activity, incorporating the pace of each learner's playing. An anticipatory phrase cued learners to pass the instrument to the next person, encouraging their awareness of others. This activity also supported learners to use their hands to play or explore instruments as independently as possible utilising their individual movement patterns.

### **Holding and pulling**

Props were used to physically engage the learners with the music and sounds e.g. co-operband (a stretchy band of material). All learners were supported to hold on to the band by a staff member whilst the band was moved to the rhythm of the music. Learners were encouraged to hold onto the co-operband in order to promote group cohesion. The pulling action followed the musical lead of either the violin or flexatone with different speeds and intensities in playful interactions. This activity connected the group together as well as promoted the experience of holding, tension, responding to sounds and building anticipation through facial expression, vocal inflection and musical changes. The key to this activity being successful was the dramatic and energetic presentation of the therapists and teaching staff.

### **Sensory explorations and playful interactions**

This section of the session provided an opportunity for people to explore different props such as the parachute or bubble wrap within a musical context. A parachute was floated up and down with musical accompaniment of either the violin or keyboard. The parachute rose and fell to the rhythm of the music and could also be used in playful interactions, hiding one member of the group and calling them into engagement. This was a multisensory experience maximising the potential for learners to respond to stimuli through visual, auditory and movement modes.

### **Vocal expression and encouraging different use of voice e.g. loud, quiet, whisper, echoes during music and singing**

The therapists began by producing a range of sounds or vocalisations with drum accompaniment to encourage learners to initiate the use of their own vocal sounds. Each learner was given the opportunity to vocalise, with staff then imitating the learner's vocalisations to develop their self-awareness. This activity encouraged skills usually found in the development of early communication and principles of intensive interaction. \*\*

### **Movement interaction to CD or improvised music**

Learners had an opportunity to dance or move to the music by themselves or with their peers. Wheelchair users indicated the type of movement that they liked through non-verbal responses such as smiling or vocalising. Ambulant learners could walk around the room and choose who they wanted to interact with.

### **Goodbye song**

A goodbye song was sung to the group as a whole and to each individual in turn to mark the end of the session.

## **Resources**

- musical instruments e.g. keyboard, violin, drum, tambourine, chimes etc.
- different materials
- co-operband (stretchy band of material)
- parachute
- fans
- bubble wrap
- vibrating objects

## **Roles with the group**

**M**ultidisciplinary working is key to the success of a music and sensory group. The **music therapists** provided the musical stimuli as a framework for other sensory experiences. Individual responses were reflected by changes of dynamics, intensity, harmonic structure etc. The music gave an impetus, energy and emotional atmosphere to each section of the group.

The **occupational therapist** facilitated the exploration of sensory stimuli and enabled all learners to physically access the activities that were presented during the group. The occupational therapist also worked jointly with the other therapists to facilitate choice making, awareness of self and others and enable social communication.

The **speech and language therapist** supported and facilitated the learners' communication through interpreting the non-verbal responses of the learner as well as looking at the consistency of responses. The speech and language therapist also supported the learners' abilities to request and signal, both of which are key skills in early development. They worked with the other therapists to encourage peer awareness and social interaction.

**Teaching staff** completed the group working one to one with learners to encourage them to actively participate in the session, and encourage social interactions and communication throughout the session whilst providing physical support where necessary.

### ***What has worked well?***

- Staff have strengthened their mutual respect for colleagues and gained a solid understanding of what each profession had to bring to the group to make it a success for the learners. Each professional felt comfortable to make suggestions and take the lead in specific activities within the session.
- The presence of structure was helpful but being flexible with this in order to respond to what was being brought from the learners was essential.
- The length of the programme allowed learners to progress at different paces e.g. some learners required longer to adjust to the structure and activities.
- Using a multi-sensory approach meant sessions could be tailored to meet the varying learner needs within one group.

### ***What we have learnt***

- It is important that a core group of staff are able to attend the group consistently on a weekly basis and ensure that learners are able to attend consistently whenever possible.
- Our learners attend most of their sessions in two classrooms so it may be a good opportunity to introduce a new environment that has been specifically set-up to meet the needs of the group and further develop their anticipation of the session .
- The opportunity for learners to get out of their wheelchairs will enable them to explore activities at a different level and move freely.
- It is important to have an initial meeting with class staff to explain the function of the group and their role.

## **A brief discussion of the journey that one young man made throughout the course of the group.**

### ***How the group helped Robert***

**R**obert is a visually impaired young man with PMLD who is also a wheelchair user. Specific aims drawn from his individual education plan and measured at the end of the block of sessions were:

- To use a specific action to cause an effect – measured as 40 percent (aim is evident)
- To give distinct signals to request ‘more’ of an object or activity – measured as 40 percent (aim is evident)
- To respond to his name being called – measured as 70 percent (aim achieved)
- To take more than one turn in any sequence which has been initiated by an adult -measured as 29 percent (working towards this aim).

### ***Responses***

Initially Robert was a little wary of the group setting and held back, listening to the others. However, he began to relax and engage more as he became used to the structure of the group. He was mostly attentive and involved in the session, especially as he had one-to-one support from a staff member throughout the session.

Robert often smiled to his name being sung and engaged in the hello song and ‘passing on an instrument’ activity. He acknowledged awareness of vibrating stimuli e.g. a drum. He enjoyed being moved around in a circular motion during the movement section of the group and showed this through smiling and lifting his head to look around.

He used his voice in the vocal section and sometimes vocalised to request ‘more’ of a particular instrument or activity, often turning his head to locate sounds (although he did require some time to respond). Initially he grimaced at the feel of the parachute material but eventually smiled at the feel of the wind on his face and allowed the parachute to touch his arms without grimacing during the activity. He enjoyed the co-operband, specifically the movement and playful interactions involved in this activity. He showed interest in a variety of musical instruments used by the therapists within the session and stilled when exploring their properties.

The group encouraged him to be more relaxed and responsive. The music and sensory group has worked well with the learners at the school who enjoyed the opportunity to explore their own communication styles and senses in a new way.

\*\* Intensive interaction: <http://www.interact.org.uk/>

### **Contact details**

Rosanne Tyas, Music Therapist  
Signe Dimitriadis, Occupational Therapist  
Seeta Shah, Speech and Language Therapist  
Holly Hitchen, Music Therapist

The School for Profound Education  
Email [profoundeducation@the childrenstrust.org.uk](mailto:profoundeducation@thechildrenstrust.org.uk)  
Tel 01737 365 810.

# Support and Aspiration: A new approach to special educational needs and disability

Rob Ashdown

On the 9th March, the Government published its long-awaited Green paper *Support and Aspiration: A new approach to special educational needs and disability*. It has been presented by the Children's Minister, Sarah Teather, and other ministers, as a comprehensive set of proposals for the biggest programme of reform in the education and health support for children with special educational needs (SEN) and disabilities in 30 years.

The Government wants to address persistent and often reported problems including:

- parents having to battle to get the support their child needs
- SEN statements not joining up education, health and care support
- children falling between perceived gaps in services or having to undergo multiple assessments.
- bureaucracy adding delays to getting support, therapy and vital equipment
- a confusing and adversarial assessment process for parents.

Among the proposals of more interest to those working with children and young people with PMLD are those to:

- introduce a legal right, by 2014, to give parents control of funding for the support their child's needs
- replace statements with a single Education, Health and Care plan so that all services are combined in the package of support
- ensure assessment and the Education, Health and Care plan run from birth to 25 years of age
- overhaul teacher training and professional development to better help pupils with SEN.

**Support and  
aspiration:  
A new approach  
to special  
educational needs  
and disability**

**A consultation**

Department for  
**Education**

## Assessment

The introduction of one single assessment process and plan to give children and young people with SEN all the help they need should mean that education, health and social services must work together to give families one comprehensive package of support, tailored to their individual needs. This has the potential to avoid parents having unconscionable delays to getting the help their child needs and being caught in the middle when local services don't work together. Importantly, new plans for the NHS will introduce 'health and wellbeing boards' which are intended to bring together the social care, health and children's services. The strong focus in the green paper on personal budgets together with the push to develop the range of health services might jointly serve to force change and lead to better services.

Ensuring that assessment and plans run to 25 years has profound implications for the further education system and adult learning disability services and other organisations that must play a crucial part as young adults with complex learning disabilities progress from school into adult life. As is known too well, the transition from school to further education and adult education services can be a source of bitter frustration and profound uncertainty for parents and young people with PMLD.

By and large, the green paper has been welcomed. The green paper has a pleasing emphasis on training and development for staff in schools. Already, developments are underway to develop training opportunities for teachers and others working with pupils who have complex learning disabilities. Schools and other organisations desperately need more staff who are trained and confident to identify needs and barriers to learning and provide the right support for them.

## Parents

It is not clear how parents will be enabled to participate fully in the development of services for their child from 0 to 25 years, i.e. at the pre-school, school and post-school phases of education. Parents will need support to ensure that they have, and understand all of the information they need to make the correct choices for their child. Cuts in local authority funding have forced a reduction in key personnel who would have been knowledgeable advisers to whom parents may turn. The green paper proposes to give parents a personal budget to spend on services such as equipment, including laptops and wheelchairs for their child, in order to give greater control to families. But there is not yet any clarity on how the personal budget option will work for parents. What will happen if the child needs provision that costs more than the budget allocated to parents? Will parents really have a genuine menu of choices or is the reality

that the parents of children and young people with PMLD will have Hobson's choice?

## Conclusion

There has long been a need for a more coherent joined-up approach to the assessment of needs and provision of services for children and young people identified as having SEN. The previous government's Every Child Matters agenda tried to bring together multi-professional teams to support the child and deliver multi-agency delivery to meet their needs. The resultant systems differed between authorities and many parents encountered inadequate information about services, bureaucratic and inefficient systems and a lack of funds to meet children's needs sometimes exacerbated by arguments between agencies about who should pay for what. The proposals for an Education, Health and Care Plan to replace the statement of SEN could ensure that all those providing services are fully involved and commit to providing services in the plan.

At a time when more and more autonomy is being devolved to a local level, giving schools and other services more freedom and flexibility, it is more important than ever that there should be a Government vision about how they must support these vulnerable children and young people and their families from 0 to 25 years. Many of the principles outlined in the green paper are to be commended. The consultation period, which ends 30<sup>th</sup> June, provides a very useful opportunity for debate about whether the proposals will really meet the needs of these children and young people and their families.

The green paper and the consultation form may be accessed via SEN section of the Department for Education website:

<http://www.education.gov.uk/schools/pupilsupport/sen>

## Contact details

Rob Ashdown  
St. Luke's Primary School  
Grange Lane North  
Scunthorpe  
DN16 1BN

E-mail: [head.stlukes@northlincs.gov.uk](mailto:head.stlukes@northlincs.gov.uk)



# Pershore Day Care Centre

John Bradley

Pershore Day Care Centre is a small unit specifically catering for the needs of young people, above school age, who have profound and multiple learning disabilities. There has been very little turnover in staff since it opened 23 years ago, which means that the staff have built up a rapport and understanding of the needs of the group that they care for on a daily basis. Because of this experience they are able to interact with the service users, who cannot speak and have poor communication skills.

The Centre is supported by a registered charity 'The Friends of Pershore Care Centre', who have contributed over £135,000 to the centre for equipment, vehicles, landscaping the garden and funding day opportunities to improve the quality of life for the service users.

## History

The 1944 Education Act prevented people with a low I.Q from attending school, so those individuals had to be cared for at home until they were 16, when they could attend an adult training centre. The Training Centres often followed a work model and efforts were made to teach woodwork, pottery, cooking, knitting, gardening and manual skills, sometimes light assembly work. They were not very well geared for people who had high levels of dependency and for this group of individuals it was more like a sitting service, where they would be fed and changed but not stimulated.

The 1970 Education Act, which was enacted in 1971, placed a responsibility on local authorities to compile a register of young people over 5 and provide school places for all children. Gradually new special schools were built and graduate teachers employed to develop skills and get the best out of children who had learning disability. School nurses were employed with some physiotherapy input and a holistic approach was used for the first time for children with a learning disability.

So the school system moved forward with teachers having a B.Ed. Degree and a level of training in psychology, Sociology, Child development and language and communication skills. Unfortunately the training centres did not move forward at the same pace, although some of them became less work orientated and more social day centres.

Teachers and parents began to realise that when children with PMLD left school at 16 years of age (later 19 years of

age) and then went to a Day Centre, that the PMLD service users began to regress and some showed signs of distress and developed rocking movements. So in the Worcester area, parents, teachers and councillors began to discuss the idea of forming a specialist centre for PMLD service users, who were being let down by the system. Once this was agreed in principle, and funding was established, the County Council looked around for suitable premises and found it in an empty children's home at 48 Station Road, Pershore.

So on the 7<sup>th</sup> December 1987 the Pershore Day Centre opened its doors.

## The first 20 years

Pershore Day Centre initially started with 4 school leavers aged 19, and over the years the numbers increased to its capacity of 7 service users by the introduction of more school leavers and transfers from the Day Centre in Worcester.

The Centre raised the standard for PMLD care. It had its own nurse and it offered physiotherapy and with the help of the 'Friends' the centre obtained specialist equipment and wheelchair carrying vehicles.

It was also used as a resource facility. Each year a nurse in training would be seconded to the Day Centre to broaden their experience and they would work with the staff for four weeks of their training. Every year the local high school would send pupils on work experience and the Centre would hold seminars for staff from other day centres in the region.

## The County Council's Grand Plan

In 2005 the County Council issued instructions to the transition team not to send any more service users to Pershore Day Centre because the Council planned to close the Centre. The 'Friends' were not aware of this at the time but it came to light over a year later when the 'Friends' were involved in a consultation process with the County Council. In 2007 the 'Friends' interviewed a father who had looked around Pershore Day Centre in 2005 and was keen for his son to go there. However, he was told that his son could not go to Pershore because it was going to close and consequently his son was placed with a private company in Bromsgrove. This doubled the journey time for his son and increased the cost of his care, but this was being paid for by the NHS instead of Social Services

In December 2006 the Adult and Community services department sought permission from the Council Cabinet to investigate the future of Pershore Day Centre with a view to expanding it, closing it, or letting it stay as it was. The 'Friends' entered into consultation in good faith, believing that the Council officers were professional and honourable people and that in the course of discussions the officers would come to realise what a valuable resource Pershore Day Centre was, and would therefore wish to keep it open. To our dismay we soon realised that the County Council had a hidden agenda to close Pershore Day Centre and it became apparent to the 'Friends' that the data used in the consultation was inaccurate. Not only that but the same information was subsequently submitted to the Council Cabinet to persuade them to close Pershore Day Centre.

With the help of a senior member of the Cabinet the 'Friends' were able to have a meeting with the Head of Finance and find out the true financial costs for the Day Centre.

The 'Friends' asked ourselves, what is the function of the Adult and Community Services Department? We came to the view that the purpose of that department was to look after the interests of disabled and vulnerable people in their care to the best of their ability, within the resources available to them. We found it very difficult to accept that the County Council could contemplate destroying a valuable service on the basis of inaccurate financial figures. In spite of our protests the Cabinet followed the advice of their officers and approved the closure of Pershore Day Centre. It did appear on the face of it that the Council's grand plan was to combine day care services into one building and reduce the numbers of staff.

## Legal issues

Sadly, it became apparent that the 'Friends' could not rely on the Council Officers to discuss the issues fully, openly and with transparency. The welfare of the PMLD service users was the prime issue for us, so the 'Friends' turned to the Law for justice. It transpired that County Councils have a duty to meet the assessed needs of the service users, and in the event of a closure of a unit, a care plan must be in place to demonstrate how the Council had calculated what resources were required to meet the assessed needs of the individual.

The PMLD service users at Pershore Day Centre were receiving income support and they qualified for Legal Aid. With the help of Public Law solicitors the 'Friends' were able to serve an injunction on the County Council, which prevented them from closing Pershore Day Centre until the 'Friends' application for a judicial review was obtained. Because Legal Aid involves the use of public money the case had to follow two principles:

- **Transparency** - Both the "Friends" and the County Council had to openly disclose all the evidence that they would use in the judicial review so that the process was fair. It was also intended as a means to allow both parties to be fully aware of all the facts so that a compromise might be achieved without going to court.
- **Substance** The evidence is reviewed by an independent judge before it goes to judicial review so that the judge can satisfy himself that there is sufficient substance in the case to warrant it going to court. Approximately 40% of cases fail at this stage and do not proceed to High Court. The purpose of this is a desire not to waste the court's time dealing with a frivolous case.

The fact that the independent judge was of the opinion that the 'Friends' had substance to their case should have been a warning to the County Council.

## High Court

All the parents of the Pershore service users attended the High Court in London for the one day judicial review. We were surprised that the court room was like a small seminar room with three rows of tables and chairs and a raised dais for the Judge. When the Judge entered the room we all had to stand and wait until he sat down before we could resume our seats. Only the barristers were allowed to speak to the Judge and the parents and the solicitors communicated by passing notes to each other.

The 'Friends' barrister made the opening presentation and to our amazement she spoke all day outlining our

case. We were impressed that someone who did not know Pershore, did not know us, apart from correspondence, could grasp the finest minutiae of our case and lay it all out in logical sequence. The Judge was not so impressed because about 4.00pm he drily observed that it was unlikely that we would finish the case that day and he reminded both barristers that it had been booked as a one day case and now he would have to turn round and try to book a courtroom and usher for the following day. When the Judge asked for a forecast of the time when he could expect to hear all the evidence they were both very apologetic and assured him that they would conclude the case the following day if his lordship pleases.

So we had to make arrangements to stay overnight and we had not brought any spare clothes.

The following morning at 9.30am the case got underway again and the barrister for the defence set out the case on behalf of the County Council and she took all day to do it, so there was no time for summing up. The Judge began to get a bit waspy and said that he had made it clear to the Barristers to present their case precisely and he pointed out how inconvenient it was to commit another day to the case both for his time and the difficulty in getting a court room free at short notice and also the services of an usher. Both barristers apologised profusely and were very subservient in speaking to the Judge.

So we had to arrange another night in London and start wearing our underwear inside out. On the last day of the judicial review the judge said that he had intended to give a verdict at the end of proceedings but because the case had dragged on for so long they would have to wait for his decision. The Judge was getting his own back because until the Judge had reached a verdict they could not close their files on the case nor claim their fees nor argue about costs.

## Summary

The County Council decided to close Pershore Day Centre without developing a business case and without producing a care plan for the service users. The Council Officers compounded their malpractice by feeding inaccurate evidence to the Cabinet to bring about the closure of the Day Centre.

Under scrutiny in the High Court, the County Council's defence unravelled, with their Barrister trying to claim that the Council had not fully investigated the matter because they just knew what they were doing.

Four months later the judge handed down his verdict and found in favour of the 'Friends, quashed the Cabinet's decision to close Pershore Day Centre and

awarded costs against the County Council

## Déjà vu

Six months after having their decision overturned by the Court, the County Council announced that they would be looking at Pershore Day Care Centre again. The 'Friends' have just completed months of consultation with the Officers of the County Council and again the Officers are feeding us inaccurate information and our fear is that we shall have to go through the whole process again.

## On reflection

This unsettling situation has been going on since December 2006 and it has been very difficult for the parents to cope with the strain of all the uncertainty. Our strength has been that we have stuck together as a group and supported each other through difficult times with a determination that we will not allow the Council to ride roughshod over us and the knowledge that our sons depend on us to look after their interests.

## Contact details

John Bradley  
Treasurer & Trustee Friends  
Pershore Care Centre  
Email: johnbradley33@madasafish.com

# Involve Me

Louisa Whait

Dedicated to Richard (2011)

Involve Me aims to increase the involvement of people with PMLD in decision making and consultation. Funded by the Renton Foundation, Mencap have been working in partnership with Bild on this three year project.

The Involve Me project is crucial, as people with PMLD are still amongst the most excluded from society. It has taken a practical approach to exploring the concepts and ethos around involvement of people with PMLD. Legislation such as the Mental Capacity Act (2005) and the Human Rights Act are of particular importance for people with PMLD. Involve Me aims to support staff and organisations to explore how they can work in a way that upholds the law and respects each individual's human rights.

Involve Me has worked at two main levels – with frontline staff who are delivering support to people with PMLD on a daily basis and at a management level to ensure organisations understand the importance of involving people with PMLD, along with the challenges and suggestions for what needs to be overcome to truly involve people.

Working with four sites across the country – the Coronation Centre in Ellesmere Port, Hammersmith and Fulham Mencap, the Rix Centre with Eastway Care and Turning Point in Salisbury, each of which have been working with a different approach to communication.

## Communication Approaches

The approaches used keep the person at the heart of the communication process. They were already known to work, whilst the Involve Me project was not exploring the approaches themselves, it was looking at how aspects of the approaches - the commonalities - supported involvement. Each of the approaches support the person's own way of communicating and build on opportunities for communicating.

The commonalities of the approaches are:

- Choice
- Relationships - Friends
- Relationships - Staff
- Dialogue interaction
- Memory Recall
- Sensory Input

- Meaning and what is important
- Fun, interest and engagement
- Creativity and Imagination
- Staff Support
- Consistency
- Ownership by individual
- Ethical and cultural implications
- Build on existing communication
- Involvement of Family and Friends
- Process/Product

The communication approaches used were: Storysharing, Creative Communication, Multimedia Advocacy and Peer Advocacy.

**Storysharing** was facilitated by Dr Nicola Grove of Storytellers Unlimited.

It is an approach to developing "personal event narratives" with adults and children who have severe and profound learning disabilities. Personal event narratives are the small stories and anecdotes that we tell every day to our friends and family.

**Creative Communication** was facilitated by Kate Burns of CAN Communicate and Doncaster Advocacy.

Creative Communication is the use of the creativity to enhance and develop communication and consultation. It aims to develop methods of communication appropriate to individual needs and to enable people with profound and multiple disabilities to participate in decision-making processes affecting their lives via creative communication and consultation.

**Multimedia Advocacy** was facilitated by the Rix Centre. Multimedia Advocacy uses digital photography, video, audio and computers to help people with learning disabilities to communicate more effectively. Using these tools they are able to articulate and express their preferences, choices, likes and dislikes, have more of a say in how they are supported and so participate more actively in their communities. The multimedia advocacy process provides a framework for professionals and service users with learning disabilities to work together

with friends and families, learn from each other and improve the exchange of information.

**Peer Advocacy** was facilitated by Hammersmith and Fulham Mencap. Hammersmith and Fulham Mencap were funded to employ an advocacy co-ordinator whose role was to recruit and train a team of peer advocates. Peer Advocates are people who have a common experience - in this case of having a learning disability and being in receipt of services.

The Peer Advocates spend time developing their own skills around communication, getting to know their advocacy partner and working with those who know the person with PMLD well to explore a range of choices

### Sites in Practice

All sites received a day of Involve Me concept training – the day covered Communication with people with PMLD, preference, choice and decision-making, active listening, reflective practice and the policy and legislation into which Involve Me sits.

The original plan was for each site to receive initial training in the approach they were using with monthly visits by their facilitator with access via email and telephone.

In practice, it became evident that staff needed to be able to model their practice on the actions and experiences of the facilitator. Each facilitator worked with their site to establish the best way of modelling the approach.

Each site was actively encouraged to work with those who knew the person well – family and support staff in other settings - to build up a picture of what it was thought was known about the individual. Just the act of improved communication between the support network improved the knowledge of some individuals.

### Involve Me Evaluation

Involve Me has been evaluated by the Foundation of People with Learning Disabilities, led by Hazel Morgan, with Molly Mattingly and Dr Paul Swift.

The evaluation involved visiting sites before the sites began using their approach, mid-term and end-of-practice phase along with telephone interviews and ongoing reviews of the reflections of staff and the Involve Me project team. The evaluation team were looking at:

- What contribution is made by the different approaches to involvement in decision making?

- What are the barriers/challenges to enabling people with PMLD to participate in decision-making in the different areas? (In everyday decisions, in decisions about support and services, about the local community and about national policy.)

#### Case Study

Tanya is a young woman who likes sensory experiences. In discussion with staff who support her at home, it was thought that Tanya might enjoy a session in a white room including butterflies, feathers, lights and projected images. She liked the feathers, particularly when dropped down on to her from behind, giving an element of surprise. Kate also blew feathers off her hand on to Tanya's face.

When Kate was doing something else, Tanya made a sound like a raspberry being blown. Taking this as an indication that she wanted the blowing of feathers to continue, Kate resumed. This was thought to be a new sound for Tanya and an intentional one, which, it is reported, she has continued. Tanya now has a film, a talking photograph album and a sensory box so that she can tell others about her preferences. In the box are things that she enjoys, including butterflies made from silver paper in which she can catch her reflection, a mirror, feathers and chimes. Tanya and a staff member went to a learning disability partnership board outside her area with her film to show them how creative communication works. Tanya also showed her film and demonstrated her session at the final celebration event at the site. This so obviously gave her pleasure.

Being part of Involve Me has had a significant impact on Tanya's life. It was working with Tanya that provided 'the biggest learning curve for staff.' (Manager) Through her creative session it became clear that Tanya likes surprises. Previously it had been thought that she liked peaceful activities, 'soft things', but she enjoyed Richard's session about horses. If she became upset it was thought she was in pain. It has become apparent that she was expressing boredom. It is important to build on experiences. For example, staff are thinking how she could attend an event with hot air balloons. She has also shown by her body language that she likes being supported by young women who share her love of fashion.

At the time of print the evaluation is being finalised but excerpts include:

*“At the beginning of the project participants were often making decisions or involved in decisions about some everyday things like what to eat and drink and possibly what to wear. Sometimes they were involved in decisions about daytime activities, leisure and holidays. Their control over their lives was limited. They communicated mainly through facial expression, body language and sounds. Some were only able to make their wishes known through their reactions and behaviour. Some could indicate an everyday choice, such as what they would like to drink for example, by pointing or looking; some could choose from two or three options. A few could say a couple of words. It was clear that they were on a spectrum. Staff were keen to know more about their likes and dislikes.*

*Involve Me has shown that where staff, peer advocates and others appreciate the different ways in which people communicate, where they recognise the importance of their own role in communicating creatively and are prepared to spend time with people with PMLD, they find out so much more about their preferences. This greater responsiveness can then influence what happens in individual lives.*

*... Through storysharing and through visits and activities, Tim and Dave are able to influence what is going to happen in planning a garden to the flats where they live. Wayne has been supported to develop a multimedia profile which enables him to communicate with others about his likes and dislikes. Martin is Jonathan’s peer advocate. He attended his review and is supporting him to expand his activities in the evenings.*

*The enthusiasm of staff and peer advocates has been a crucial factor. They have often been excited by the opportunities to listen creatively to people with PMLD and to give them a voice. They have felt time pressures, but have persevered. Communicating with each person in a way that is appropriate for them should be an essential component of support, so that it is part of personal care and everyday activities. In the sites it is becoming embedded in practice. The support of management is crucial in developing involvement in decision-making, in ensuring relevant communication training for staff and allowing time for reflection. There also should be time to engage with families and others in the person’s life to learn from them and to ensure consistency of approach.*

## Summary: Impact on participants

Through the introduction of different communication approaches, participants to varying degrees have been able to express their preferences which have led to changes in their lives and enhanced their well being. Some approaches were more suited to one person than to another. Sometimes the changes have been the result of people spending time with them and observing their expressions, sounds and body language and were not the direct result of the approach. However, in these instances, it was because of the focus on people with PMLD that what the person likes or would like to happen, could be established.

The main changes have been in everyday matters, what to eat, what to wear and especially how to spend their time. Directly or indirectly, participants have begun to influence services and policy, but this is at an early stage. In all sites Involve Me is expected to be ongoing.

## Impact on services

A major impact has been on the support staff. In each site they have been excited to improve the ways in which they listen to those they support, using the approach in their site; interpreting what they know of the person, checking this out and then having this validated or finding a new way of seeing what the person likes. It contributed to job satisfaction and enabled staff to have a more exciting and rounded view of their role beyond personal care.

Involve Me has worked particularly well where management is actively engaged in supporting Involve Me. Where this happens consistently these approaches are more likely to be embedded.

Services have begun to change internally because of this project with a shift towards empowering people with PMLD.

The full Evaluation outlines a range of impacts, challenges and key recommendations. Once published the Involve Me evaluation will be available from [www.mencap.org.uk/involveme](http://www.mencap.org.uk/involveme)

## Contact details

Louisa Whait  
National Manager –  
PMLD National Support Unit  
PO Box 9861  
Shepshed  
Loughborough  
LE11 9GG  
Tel: 07944 931433  
Email: [Louisa.Whait@mencap.org.uk](mailto:Louisa.Whait@mencap.org.uk)

# Collaboration Comics: The possibilities for individuals with PMLD

Caroline Winstanley

Collaboration Comics are a visually appealing communication tool that I developed as part of my PhD study (Winstanley 2010). In this study, young people with severe learning disabilities chose and used the comic book format to express their thoughts, feelings and ideas during their transition planning meetings. Although Collaboration Comics were developed for individuals with SLD, I believe that there is potential for this tool to be used with individuals with more profound difficulties. In this article, I will suggest how this may be possible.

There is plenty of evidence demonstrating that people with learning disabilities benefit from the visual presentation of information (Lewis & Porter 2004, Cameron & Murphy 2006). However, no research has assessed the benefits of comic books for individuals with learning disabilities. When comic books were used with slow learners in a mainstream context, Sonnes (1944) and Haugaard (1973) found that young people had a natural attraction to the format; and that this increased their motivation to learn and participate in activities. I therefore wondered if this would also be true of individuals with learning disabilities.

The use of Collaboration Comics became an important part of my study, in which two different types were developed:

**Research Comic** This helped me to explain my research to the young people in an accessible way. I used the comic to introduce myself and the research process, and to gain consent.

**Transition Comic** These comic books were produced by each of the young people with support. The young people used them to express their ideas to others, particularly at their transition meeting, which enabled the young people to be included in a collaborative decision-making process.

Figure 1 shows some pages of the research comic that were used to gain consent. Figure 2 shows pages from two of the young people's transition comics.

## Creating a Collaboration Comic

The Collaboration Comics were produced using a computer application named "Comic Life" (Plasq 2006), shown in Figure 3. This application allows you to

create comics, story books and brochures. It is designed to be intuitive to use and I found that the young people in the study could use it with minimal support. The young people were able to control how their comic looked by selecting different page layout templates and dragging their own pictures into the comic's frames. To make the comic even more fun, speech bubbles or caption boxes could then be added.

In my comic, I used single words or simple phrases to explain what the photographs depicted. The comic books were generally made up of colour symbols and photographs. A maximum of six pictures were put on a page to ensure that people with visual impairments could see each picture. This also ensured that only the most vital information was included which made the comic more accessible for everyone.

The photographs used in the transition comics were taken with a digital camera by the young people or found by them on the internet. It was crucial that the young people selected their own pictorial vocabulary and this gave them control over how they represented themselves in their transition comic. The process of choosing their own vocabulary was empowering and encouraged the development of self-identity and self-expression. If, on the other hand, I had provided the vocabulary it would restrict the young person's decision-making opportunities, as they would only be permitted to choose within a limited range of options.

Collaboration Comics have some similarities with communication passports. Both approaches aim to show individuals with learning disabilities in a positive way and share their views with others. What makes Collaboration Comics unique is the greater potential for the young people to be involved in the creative process.

Figure 1: Pages from a research comic

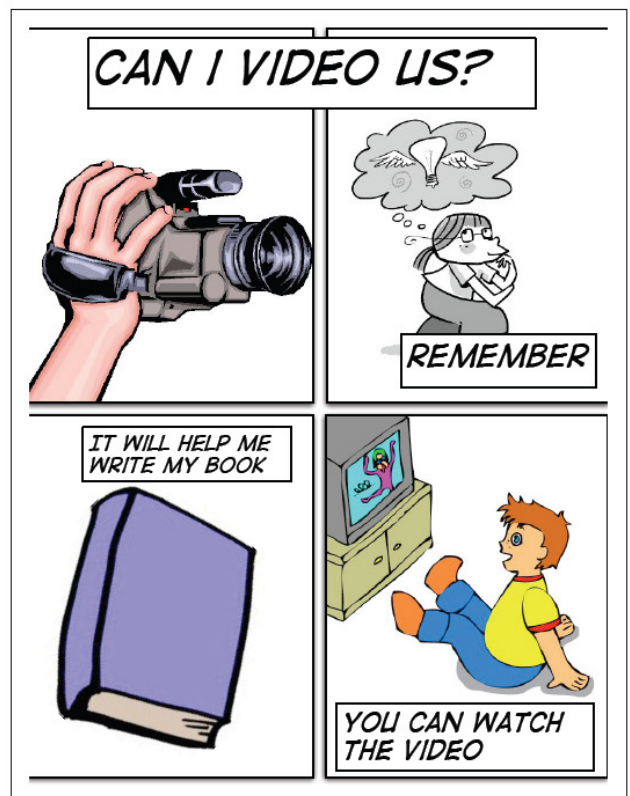
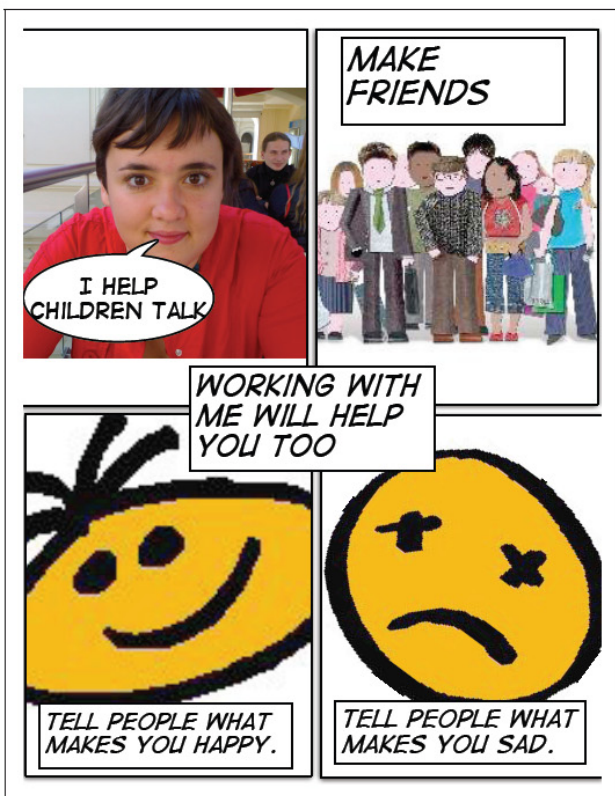
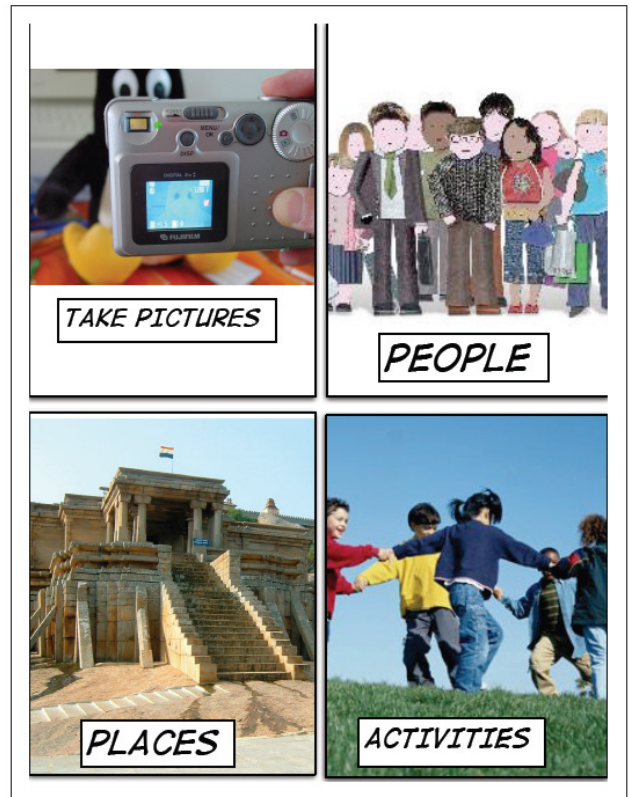
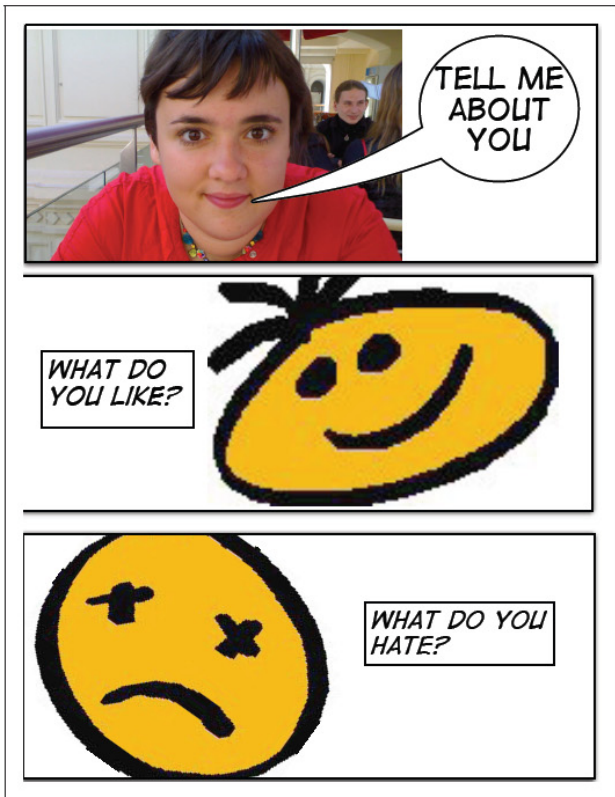







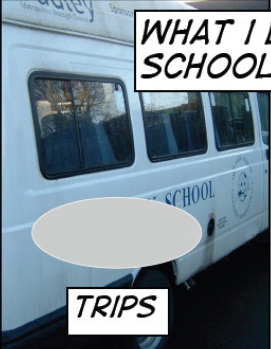


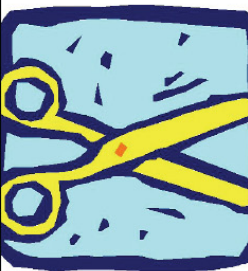
Figure 2: Pages from transition comics

<b>WHAT I LIKE AT SCHOOL....</b>	
<b>swimming</b> 	 <b>THE PIANO</b>
<b>GOING ON THE BUS</b> 	<b>GOING TO MERRYHILL</b> 

Anna - Interests

<b>WHAT I LIKE AT SCHOOL...</b>	
 <b>ASSEMBLY</b>	 <b>KEYBOARD</b>
 <b>COOKING</b>	 <b>ENGLISH LESSONS</b>

Anna - Interests

<b>WHAT I LIKE AT SCHOOL....</b>	
 <b>TRIPS</b>	<b>dance</b> 
 <b>COOKING</b>	 <b>CLIPPING</b>

Terri - Interests

3

<b>MORE THINGS I LIKE AT SCHOOL...</b>	
 <b>PAINTING</b>	 <b>SINGING</b>
 <b>SCIENCE</b>	 <b>ENGLISH</b>

Terri - Interests

Figure 3: The Comic Life application



In contrast, the content of a passport has a greater bias to the written word rather than pictures. For instance, the Scope communication passport template would not be accessible to an individual with a learning disability. Maybe this is the reason that communication passports are typically created by staff working with individual's with learning disabilities.

### Collaboration Comics for PMLD

Collaboration comics could potentially be created by individuals with PMLD. It is likely that an advocate would be required to spend time with the individual, learning of their likes and dislikes, and then supporting them to produce their comic. The support of an advocate will be essential if the person has pre-intentional communication. Finding the right advocate will be crucial to allow the people to communicate their views. There is a risk that the views of the individual could be lost in the process through the advocate acting in what they believe to be in the individual's best interests.

In my study, the young people were often able to use the Comic Life program with minimal support. It is likely that individuals with PMLD will also have some level of physical difficulty which would make using a computer more challenging. Comic Life could be operated with adaptive technology, for instance a roller ball mouse or a Liberator switch. Although the young person would still require support, it may help them to be more involved in the process.

Digital photography is increasingly used with individuals with PMLD and was specially recommended in the Bercow Communication Review (Bercow 2008). Digital photography can be useful to show others how the young person communicates: subtle communication cues, such as facial expressions, can be captured. Comic Life is an ideal program to easily incorporate photography into an individual's comic.

In my study, the young people's comics were presented in a paper format. However, there are greater possibilities for creativity. A comic could be presented as a cloth book and include a sensory element such as different textures or odour patches. Or, a large comic book template could be printed onto a board, and then objects of reference could be attached. Collaboration comics could also be combined with a speech output device, such as a talking photograph album, so that sound can be incorporated into the comic. Once the comic has been completed it could be attached to the young person's wheelchair so that they have constant access to it, as well as assisting new people to learn about the individual preferences.

In summary, the way that collaboration comics were used in this study would require some modification to become accessible for individuals with PMLD. However comics could still become a powerful tool. The process of identifying the likes and dislikes of individuals with PMLD can be lengthy, especially when preference may be communicated through slight changes in facial expression or body movement. However, if new people have a straightforward way of learning about the young person's preferences, it will encourage a rapport to develop more quickly and ultimately improve the young person's quality of life.

### Contact details

Caroline Winstanley  
Email: [caroline.winstanley@googlemail.com](mailto:caroline.winstanley@googlemail.com)

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# Good Health! What carers say about hospital care for their learning disabled family members

Michael Ormian and John Gurney

Lincolnshire's County Carers' Group supports parents and other family carers of people with learning disabilities. Committee members spend a lot of time talking to family carers and there is a constant underlying disquiet concerning healthcare for their learning disabled family members. The County Carers' Group has conducted a survey that captures the thoughts and opinions of family members who have supported the learning-disabled person in hospital.

This survey has been undertaken by the County Carers Group (Learning Disabilities) Lincolnshire, a group of carers working for carers in their quest for health care improvements. It is partly in response to the numerous published reports, such as 'Death by Indifference', 'Six Lives' and 'Raising Our Sights' that have put hospitals and health care under intense scrutiny, and partly in response to members' own concerns. It is hoped that the findings reported here will assist hospitals in their quest for improvement.

The survey was based on a questionnaire, sent to a membership of approximately 600 members. 113 family carers responded and we were able to collate their levels of satisfaction in respect of their support for people with learning disabilities who made 163 separate hospital visits, including day visits, hospital stays and A&E visits. 137 of these visits were to United Lincolnshire Hospital Trust (ULHT) hospitals; 100 being in the last 4 years.

## The Questionnaire

The questionnaire comprised five sections, as follows:

1. **Where and When:** This identified information about which hospital was visited and in which year.

2 & 3. **Carer's Satisfaction:** These sections presented 10 positive statements and asked carers to indicate their level of agreement or disagreement with each. There were 4 possible answers to select from, as indicated in the scoring strategy below.

## 4. Overall Opinion and Additional

**Comments:** An overall impression was asked for in terms of whether they would or would not recommend the hospital. It also provides an opportunity to record details of any good or bad experiences in a 'Relevant Comments' section.

5. **About the Person with the Learning Disability.** In addition to age and sex, this section identifies the nature of the learning disability and any communication difficulties. It also asks about the information accompanying the patient on admission, such as Hospital Admission Documents, Communication Passports or 'Traffic Light' Information.

## Scoring Strategy

To provide a convenient way to make comparisons, a scoring system has been applied to the 'Carer's Satisfaction' section. For each of the possible responses to the 10 positive statements the following points were allocated:

- Strongly Agree 4
- Agree 3
- Disagree 1
- Strongly Disagree 0

*The allocation of points is designed to give greater difference between 'Agree' and 'Disagree' than between 'Strongly Agree' and 'Agree', or 'Strongly Disagree' and 'Disagree'. There was also an opportunity to make a nil response.*

An overall score of 50% (i.e. an average score of 2 out of 4) represents a balance of positive and negative feeling. It should be noted however that, whilst this percentage score provides a useful method of comparison, it should not replace the consideration of the actual number of positive and negative responses. Clearly a balance of positive and negative responses cannot be considered to be a satisfactory outcome.

## Survey process

Approximately 600 questionnaires were distributed by post with a covering letter and a reply-paid envelope to members of the County Carers Group (family carers of adults with learning disabilities). The Parent Carers Council (family carers of children with learning disabilities) was also asked to distribute questionnaires to their members. Carers were asked to complete the questionnaire, focusing on one recent visit/stay in hospital, but were invited to make separate responses for up to 3 visits/stays.

It is not known what proportion of those receiving a questionnaire had not had any hospital visits during recent years, so a meaningful response rate could not be identified.

For the purposes of this article we will concentrate on the outcomes of the questions posed in the questionnaire. For example, when we asked the respondents to indicate whether they 'strongly agreed', 'agreed', 'disagreed' or 'strongly disagreed' to the following positive statement:

### 1. 'My needs as a carer/supporter were appropriately catered for'

47 respondents 'strongly agreed', 61 'agreed', 28 'disagreed' and 21 'strongly disagreed'. Using our scoring strategy this translated into 399 points out of a maximum of 628 points, which gave a satisfaction level of 63.54%. We feel it is important to indicate the satisfaction scores for the other nine questions:

### 2. 'The admissions procedure was sympathetic towards the special needs of the person'

Satisfaction score = 67.8%

### 3. Nursing staff and other ward/clinic staff were fully aware of the person's special needs'

Satisfaction score = 62.8%

### 4. 'Doctors/Consultants understood and were sympathetic towards the special needs arising from the person's disabilities'

Satisfaction score = 66.7%

### 5. 'The person's views and preferences were sought and appropriately acted upon, in the person's best interest'

Satisfaction score = 60.8%

### 6. 'Treatment and care were delivered in an appropriate way (as defined in the person's 'hospital information document' where this exists)'

Satisfaction score = 63.9%

### 7. 'Where appropriate the person was consulted in a manner they could understand (possibly through you) before decisions were made'

Satisfaction score = 67.1%

### 8. 'I, as parent/supporter was fully consulted before decisions were taken'

Satisfaction score = 70.4%

### 9. 'I was recognised as the expert carer, and listened to'

Satisfaction score = 66.7%

### 10. 'Any agreed follow-up was acted upon in an appropriate and timely way'

Satisfaction score = 65.1%

It is important to note that the satisfaction scores for each of the above statements included visits/stays at hospitals outside Lincolnshire.

By analysing Lincolnshire hospitals only, we noted a decline of around **10 percentage points** in satisfaction scores. The greatest difference was in question 9, where the decline was **11.1 percentage points below**.

An analysis of time trends showed that in all but one satisfaction question, the score was at its highest (around 70% - 80%), in 2006 or 2007 and reduced to a low of around 55% to 65% in 2009, before increasing slightly in 2010.

The County's Hospital Trust must decide what an acceptable level of satisfaction is, but it is reminded that a 50% score represents a balance of negative and positive feedback, 0% and 100% being the negative and positive extremes respectively.

## Overall Opinion

We asked respondents whether they would recommend the hospital they had experienced to a friend.

There was clear evidence that the smaller hospitals gave greater carer satisfaction. Our two major county hospitals performed poorly, with 49% and 64% of carers respectively, unwilling to recommend these hospitals. It also emerged that carer satisfaction was much reduced where the patient was either below 19 years of age or over 60.

**The survey also captured other data about the person being supported, included gender, age and disabilities.**

- There were 83 males and 78 females
- 33 people were under 19, 121 were between 19 and 60, and 7 were more than 60.
- 22 people had profound intellectual and multiple disabilities.
- 62 had severe learning disabilities
- 42 had moderate learning disabilities
- 14 had mild learning disabilities
- Additional disabilities included epilepsy, autism and significant communication difficulties.

**We asked how the learning disabled person communicated:**

- 90 had normal speech
- 42 had limited recognisable words
- 16 used sounds
- 14 used a signing system
- 3 used communication aids
- 82 used non-verbal communication e.g. body language, facial expressions, eye pointing

**We asked whether the person had any sort of hospital information document that identified such things as medication and any special needs.**

- 44 said YES
- 110 said NO

We used 'Easi-Quest', a specialist questionnaire design and analysis software package to produce our data. This gave us the opportunity to analyse many aspects of the respondent data and to draw some interesting, and sometimes alarming, conclusions.

Probably the most concerning outcome from the analysis of satisfaction scores was the overwhelming evidence that the more severe or more complex the disabilities, the lower the level of satisfaction. Where the disability seriously compromised the ability of the patient to communicate (thus putting greater reliance on the carer to maintain the link between patient and medical professionals), the level of satisfaction dropped considerably, compared to that where the patient had 'normal speech'.

**Hospital Information Documents:**

Only 29% of patients had any documented information relating to their special needs when they went to hospital, but where there was a document in place, carers satisfaction was reduced, *suggesting that the documents are often not sufficiently referred to.*

One issue here is that such documents can take many different titles and forms, from simple 'grab sheets' to more complex and detailed documents named Hospital Passports or Hospital Admissions Documents, sometimes

based around traffic light coding.

**Conclusions and Recommendations:**

Clearly carers are often dissatisfied with the standard of care and consideration received during hospital visits supporting their learning disabled family members. This is particularly the case where the nature of the disability is severe and complex and where the carer's support is vital in providing the communication link between health professional and patient.

This seems to be further compounded if the patient is young or older. It is hoped that the findings in this report are used by the Trust to bring about improvements and to avoid any serious outcomes such as those reported in publications such as 'Death by Indifference' and 'Six Lives'. The County Carers Group will support any initiative to work cooperatively with the Trust or individual hospitals to bring about improvements. It is recommended that action planning is undertaken to address the main issues identified through this survey.

The following recommendations are aimed at bringing about such improvements:

- **Recommendation 1:** Include a statement in the Carers Charter that ensures the needs of the carer/supporter are appropriately catered for, thus maximising the effectiveness of their support.
- **Recommendation 2:** Introduce mandatory annual training, delivered by Acute Liaison Nurses and carers, to improve understanding of learning disabilities (including communication problems and autism/asperger's syndrome) amongst health professionals, and to raise awareness of the value of carers' expertise.
- **Recommendation 3:** Develop a single model information document that will be recognised by all as being important in meeting care needs. This should include the 'Passport' and Assessment & Care Planning and must be used by all.
- **Recommendation 4:** Include the satisfaction statements from this one-off survey within a rolling carer satisfaction survey process.
- **Recommendation 5:** Develop and adopt carers' performance indicators as part of a quality improvement process.

The full Satisfaction Survey, produced by Lincolnshire County Carers' Group, runs to 34 pages and contains many illustrative graphs.

There are also five closely-typed pages of comments from parents and supporters of people with learning disabilities. Some are good, many are bad, but they are illuminating and alarming in equal measure. If you would like a PDF copy please send your email request to the details below.

### Contact Details

John Gurney  
Email: [j.gurney@ntlworld.com](mailto:j.gurney@ntlworld.com)  
Michael Ormian  
Email: [michael.ormian@metronet.co.uk](mailto:michael.ormian@metronet.co.uk)

# RESOURCE

## BRINGING ABOUT A SENSE OF CALM

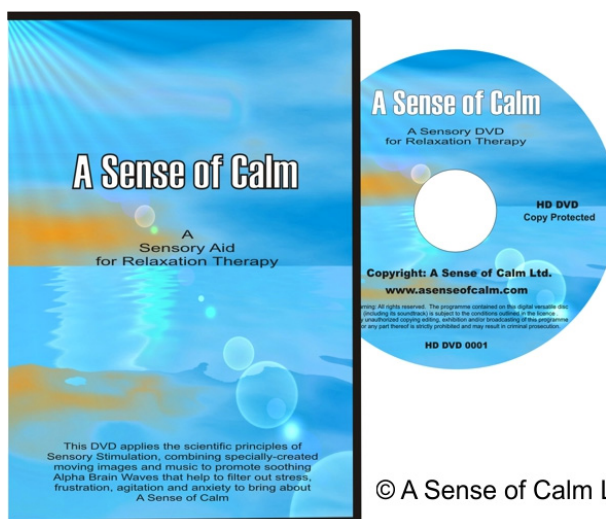
"A Sense of Calm" is a pure form of relaxation therapy, presented in the convenient form of a DVD. It can help to calm anyone who is stressed, anxious, or agitated and is being successfully used as part of a holistic approach for the wellbeing of people living with dementia, Alzheimer's, autism, Asperger's, Down's syndrome, ADHD, strokes and learning difficulties, where the nature of their condition can lead to frustration, agitation, anxiety and sometimes rage.

The DVD is 60 minutes long and features 6 videos of specially-created, flowing images, set to specially-composed music, designed to promote relaxation through sensory stimulation.

"A Sense of Calm" DVD is £32.50 and for each DVD purchased from this website we will donate £2.50 to the charity of your choice from the charities listed below.

Alzheimer's Society - Dementia UK - Mencap - The National Autistic Society

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# Improving Health and Lives – the Public Health Observatory for People with Learning Disabilities

Sue Turner

The Improving Health and Lives (IHaL) Learning Disability Observatory is a three year government funded project which aims to reduce the health inequalities faced by all people with learning disabilities in England.

Sir Jonathan Michael said that one of the major obstacles to providing good healthcare was the lack of information about people with learning disabilities and their care. He recommended that:

*‘To raise awareness in the health service of the risk of premature avoidable death, and to promote sustainable good practice in local assessment, management and evaluation of services, the Department of Health should establish a learning disabilities Public Health Observatory’ ( P.44)*

The project involves three organisations; the North East Public Health Observatory, the Centre for Disability Research at Lancaster University and the National Development Team for Inclusion, and is designed to:

- Make health information about people with learning disabilities more easily available
- Work towards having better information about the health of people with learning disabilities
- Help commissioners, providers, families and people with learning disabilities make better use of the information.

## Making health information about people with learning disabilities more easily available

Improving Health and Lives has a website [www.ihal.org.uk](http://www.ihal.org.uk). The website includes information about how different areas are doing. It has information about the health self-assessment that each region does, and information about the number of health checks people with learning disabilities have had in each Primary Care Trust area. This means that staff and families can compare their area with others.

The website also includes all the reports that Improving Health and Lives has written. For example, it has a report about the number of health checks that were done in 2008/9 and 2009/10 (we don't have the figures for 2010/11 yet). Of course, this just tells you about the numbers, so there is another report which tells you what we know from research about the effectiveness of health checks. The research tells us that health checks are good at identifying unmet health needs and leads to actions to address health needs. This is not really surprising as we know that people with learning disabilities, particularly those with profound and multiple learning disabilities, are not able to say when something is wrong or take themselves to the doctor. However, it helps to have the evidence to back up what we know.

IHaL also runs events. To continue with the health check theme, there are three events on increasing the quality and quantity of health checks. They are running in the first half of the year as the Directed Enhanced Scheme (which pays GPs to do health checks) and this has now been continued for another year; and the plan being to give people as much information as possible so that they can get going and improve the situation locally.

## Working towards having better information about the health of people with learning disabilities

A lot of the information collected either doesn't identify people with learning disabilities at all, or is not very good. IHaL are working with organisations like the NHS Information Centre to think about how to get better information and data in the future.

## Helping commissioners, providers, families and people with learning disabilities make better use of the information

Using the data and the evidence from research, IHaL writes guidance for commissioners. One of the guidance papers is about increasing the quality and quantity of health checks. We talked to those areas that had done well with providing health checks and identified what worked. We also got a number of examples from practices to illustrate how things could be done. For example, in Gloucestershire a man with learning disabilities and complex physical impairments requested an examination to determine the cause of abdominal pain. The surgery did not have a suitable hoist and therefore offered a telephone consultation with the carer. The specialist learning disability service and PCT argued for a home visit on the grounds of reasonable adjustments. As a result of the home visit, a number of health issues were resolved, greatly improving the man's health and wellbeing.

As well as writing guidance, IHaL works with six 'local partners'. There is information about them on the website. The local partners commented on draft guidance, with particular regard to how useful and useable it is. They also provide some of the examples of good practice. In addition, the sites get some development time from the project to tackle health inequalities in their area.

## Advisory groups

IHaL has three advisory groups. There is an international group which helps particularly with the research side of things. For example, other countries may well have done research on aspects of health care and people with learning disabilities that are relevant to this country. There is also a wider stakeholder group made up

of representatives from different interested parties like Mencap, the Care Quality Commission, the Department of Health and others. Finally, there is a group of people with learning disabilities and family carers. The group is based in the eastern part of the country and includes family carers of people with profound and multiple learning disabilities. The group comments on the work of the project and makes suggestions about other things that IHaL can do.

If you have any comments or thoughts about the project please contact me.

## Contact details

Sue Turner  
Email: [sue.turner@ndti.org.uk](mailto:sue.turner@ndti.org.uk)

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# Becoming a Deputy

Written by a Family Carer

For 10 years I bumbled along being a Receiver now called a Deputy - appointed by the Court of Protection (COP) and supported by the Office of the Public Guardian (OPG). In those days I knew the name of the person allocated to help me if I had any queries or requests. It was all very reassuring and supportive. I was even able to make an appointment and speak to The Master of the Court when really concerned and anxious about making the right decision. Every year I got to take out rusty maths skills, prepare and send off the accounts. Periodically I filled in a questionnaire letting the service know I was very satisfied, and initially visited by a representative of the Court to make sure we were coping with the system. It all ran like clockwork - jollied along, all very civilised and charming.

As time passed I noticed in the then, regular, useful newsletters - references to people complaining about the system, various changes were made - all having very little impact on how I did things. Like most people I'm healthily averse to paper work and as things were running smoothly I took very little notice of changes that didn't seem to impact on me. I thought things were looking up. I loved the language and principles of the new Mental Capacity Act (MCA).

All this came to an abrupt end. The Forms Changed. The Order Changed. My son was no longer a child. Still oblivious to what was coming, the only onerous part of the process - plopped on the door mat - the annual accounts. They looked half the size of the previous ones and had a reassuring letter saying they were NEW, Improved, simpler. I was given a new title - a deputy. I no longer had to send off all the bank statements - and there were a number of lovely very comforting questions - as a loving Mum it was delightful explaining how I had involved my child in making decisions - watching his body, listening to his intonations, waiting for his wonderful laugh, grimace or just a look of for goodness sake Mum, and just plain knowing him. Off course I included all the people who supported him in making major decisions. Why wouldn't I? I want the best for him. The questions were also placed in reassuringly small boxes. Nevertheless, it was a form that also involved adding up - why fill in a form today if it can be filled in tomorrow - especially with adding up?

Several weeks later the deadline was still a month away - but in sight. The improved form was taken out. Horror - it made absolutely no sense, especially the adding up - it bore no relevance to my child's life. With much thought, a lot of work and huge amounts of worry I could adapt

what I had done previously. It's not easier and there is nothing nice about the so called protection of the vulnerable in the new system.

At the time it felt as if there was more than a whiff of Kafka in its new officiousness and Dickens in its new labyrinthine bureaucracy, and then there are the costs. My previous experience was no longer relevant. The mood wasn't helped by plummeting confidence and increasingly infantilised need, sometimes required, to seek paid professional advice.

We are several years into the new system. I am used to it. **It can be managed.** Was my reaction and were my feelings merely a response to the Shock of the New? I do genuinely think the new system has had some unintended consequences. It has stripped away the personal, supportive partnership between the Court of Protection and the deputies and produced a process that commodifies the individual, the personal and the complexities of people lives.

**So why become a deputy?** Any parent with a child with PMLD knows their child cannot make many of the decisions that the rest of the population take for granted. They have never had the capacity to make the decision to visit a solicitor or get a form from WH Smith and make out a Power of Attorney for the time when they lack such capacity. They may not have the capacity to decide what to wear on a hot day. A parent, other family member, friend, lawyer or other professional can however apply to the Court of Protection to become a deputy. Being a deputy will give you permission to make decisions in someone's best interest when they lack capacity.

**Where do I go to become a deputy?** To become a deputy you must get a Court Order from the Court of Protection. The Court will make this decision but the Office of the Public Guardian will be the body that deals with the ongoing administration of the order.

**What will it cost?** If you do it yourself - The Court fee is currently £400, there will be a further £100 to pay in the first year. There are also fixed costs that solicitors can charge as an appointed deputy or if they help you complete the forms to become a deputy yourself. Go to [www.justice.gov.uk](http://www.justice.gov.uk) - once on the Justice home page click on guidance, then protection of the vulnerable. This will take you to the area you need to be in.

**How do I make an application?** This will depend on a number of variables - but there is excellent official Guidance in a document called a **COP42**. This Guidance is available from [www.hm.court-service.gov.uk/courtfinder/forms](http://www.hm.court-service.gov.uk/courtfinder/forms). **COP42** will tell you which forms to complete. All the forms are on the same website. It is possible to complete the forms yourself.

If you ask for help to complete the forms this is okay - remember

- 1) you have every right to be the deputy
- 2) the forms can still be filled in using plain English
- 3) paid professionals fill in these forms all the time so don't feel you cannot be a deputy because you needed help with the forms. It is a good idea to download the forms for yourself and think about what you want the Order to say before you see a solicitor. Once the Deputyship has been set up it should be fairly straight forward.

**What do I need to know?** A family member or close friend who loves and cares for a person who lacks capacity has as much right to be a deputy as a paid professional. If you use a paid professional to help you make the application make sure you are fully aware of everything they do. They will be paid for their expertise. As professionals they do this sort of thing everyday so you can expect them to be effective and efficient. See the Justice website above for fees including fixed rates for solicitors.

Your Order will tell you what you can do.

Always act in the person's best interest - if in doubt there are 5 principles in the Mental Capacity Act - see the OPG Guide below for further details.

There is an excellent Guide published by the OPG, called **A Guide for Deputies appointed by The Court of Protection - my advice** - read this before you make an application. Available on the [www.directgov.uk](http://www.directgov.uk), once into the home page click on Government Citizens and Rights, now click on Mental Capacity and the Law - on this page you will see the heading Making Decisions for someone else. You can also find the Code of Practice in this section.

Keep receipts. An old envelope will do. This doesn't have to be too onerous.

Complete annual accounts as directed by the Court - again these are not as bad as they sound. The paperwork tends to favour Care Homes - but it is possible with simple adjustments to alter the form to meet your needs.

Don't read Bleak House by Charles Dickens before you make your application.

Once your order is set up carrying out your duties is a privilege, and very rewarding.

Good luck.

Written by a family carer

### Contact Details

Email: [pmlmlink@northampton.ac.uk](mailto:pmlmlink@northampton.ac.uk)

# FUTURE FOCUS

## Therapies

In the next issue of PMLD-Link we would like to publish accounts of 'therapies' that have been used to try to improve the quality of life of children and adults with PMLD.

The term 'therapy' has different meanings for different people. For many, therapy is synonymous with the word 'treatment' which is the attempted remediation of an identified health problem. Yet, it can be extended to refer specifically to some form of psychotherapy where a psychologist aims to increase the individual's sense of their own well-being.

In fact, there is a huge range of therapies with potential benefits: treatment can be by matter (a drug, a medical device, a hormone, even some kind of organism as in botox therapy), by some form of energy ( e.g. light, heat, cold, manual handling as in physiotherapy or massage therapy), by human interaction (e.g. counselling, physical therapy, lifestyle modifications such as eating more healthy foods). The list of therapies is as long as a piece of string: physiotherapy, occupational therapy, speech and language therapy, hydrotherapy, massage therapy, art therapy, music therapy, drama therapy, psychotherapy, behaviour therapy, aromatherapy, sensory integration therapy, etc. The skilled way in which therapists work with individuals with PMLD can be very impressive and can have immediate effects – but sometimes the long term outcomes are not so obvious. Also, we all have to be wary when the claims made for a

therapy cannot be substantiated because there is little or no evidence to either support or refute them.

We are keen to know your experiences and views about therapies that you use or that have been used with people you know. Do they result in improvements in the quality of life of the person who is being treated? Tell us about the situation in which the treatment is used and the goals of the treatment, and do you have any illustrative photos that may be used with the permission of the individuals concerned?

Also, we do not want to limit your accounts to the more traditional ideas of what constitutes 'therapy'. Many everyday activities in the community (e.g. at home, at school, at a day centre, during a community-based activity) can provide many opportunities for learning with genuinely therapeutic outcomes. After all, we all know the benefits of retail therapy!

Please contact us and send your contributions on anything related to 'therapies' preferably in RTF (Rich Text Format) or 'Microsoft Word' by 28<sup>th</sup> October. Thank you.

Rob Ashdown:  
St. Luke's Primary School  
Scunthorpe  
DN16 1BN  
E-mail: head.stlukes@northlincs.gov.uk

Chris Fuller:  
Email: fuller.chris@hotmail.com

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

# REPORT BACK

## Complex Learning Difficulties and Disabilities Research Project: Dissemination Conference

Dame Philippa Russell, Chair of the Government Standing Commission on Carers, chaired the conference and the day began with Sarah Teather MP, Minister of State for Children and Families speaking on the SEN and Disability Green Paper and its aim of joining up services for families with children with special educational needs and disabilities. She said that families need to have information which says "This is what we normally provide, what else is it that you need?" and to have a personal budget so that they can choose which schools and services will provide for their aims and ambitions for their child.

Holly Lawson speaking later on the family perspective, reported only 6% of the UK's children with disabilities receive any regular support and 8 out of 10 families are at breaking point.

Sharing the outcomes from SSAT'S (Specialist Schools and Academies Trust) research into education for children with Complex Learning Difficulties and Disabilities (CLLD), Barry Carpenter described the project focus as "engagement based" and gave the full definition of CLLD which defines the children and young people as presenting "a range of issues and combination of layered needs - e.g. mental health, relationships, behavioural, physical, medical, sensory, communication and cognitive."

He spoke of these children as having "a spikey profile of learning" and referred to a parent who had described her child as "being wired differently." He said that as the school system becomes more diverse, the importance of specialist knowledge would increase, with special schools needing to be leaders in teaching and learning practice for children with PMLD and CLLD. He also reported a marked increase in numbers, with 950,000 families in the UK having a child with a disability, an increase in a five year period of 250,000 children and a 29% increase of those with CLLD.

We heard from Viv Hinchcliffe about child engagement; how does this child engage, being a question crucial to their further learning, together with the need to focus on "the things that matter," and the video case studies shown later were very useful for closely examining this question of true engagement and appropriate targets.

He declared that teaching is a research profession and Jo Egerton, Research Officer, spoke on the need for "developing an inquiry based culture" within schools. Involving the whole school by creating practitioner research circles, gathering evidence to provide classroom based research, staffroom anecdotes, university research etc. to develop preferred ways of teaching, affect school policies and generally empower staff within an environment that fostered a feeling of whole school development and engagement. Dr Tamara Brooks also highlighted the need for collaboration across transdisciplinary teams including health and social care.

Headteachers of schools which had taken part, including schools in New Zealand, believed that the project had enhanced student learning, that teachers and teaching assistants were pleased to have been involved and that staff had a clearer understanding of how children with complex needs engage. One Head of a mainstream secondary school described the approach as "like looking at a jumper inside out and trying to sort out the pattern on the outside!"

Chris Fuller, PMLD-LINK Editorial Group

To find out more and download the Briefing Sheets visit:  
[www.ssatrust.org.uk/specialschools](http://www.ssatrust.org.uk/specialschools).

## **PMLD Network Forum A Digest of Discussions February 2011 to May 2011**



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:

### **Coping with death of parents**

Someone asked for advice on how adults with a learning disability can best cope with death of parents, and how to assist with memories. Their niece has recently lost her mother and the family has been advised that she should not have any photos of her as she might become "confused" as she uses pictures to communicate.

Responses included:

- 'Whilst seeing photos of her mum may upset her, this is an inevitable part of the grieving process, and she needs the opportunity to deal with her feelings about her loss. Preventing her from communicating about her mum could leave to additional frustration or anger, and could cause greater confusion.'
- Someone said that photos of the person who has died are generally considered a good means of helping individuals cope with the loss.
- Someone said 'I think it's really important we give people the opportunity to be supported through this loss - as best we can. Too many people just 'disappear' in the lives of people with PMLD. How do they know when they won't see someone again - or whether they'll be back on shift the next day? Maybe there are some other things that help think about Mum but reinforce the 'remember when..' bit. For example, her perfume, a scarf she wore, music they listened to together'. They suggested creating a memory box about mum.
- Someone suggested they get additional support from the local Community learning disability team.
- Resources suggested to help with bereavement:
  - Someone said that for people who are able to recognise and relate to images, 'Books Beyond Words' series might be useful. There is one called 'when mum died'. They are published by the Royal College of Psychiatrists: <http://www.amazon.co.uk/When-Somebody-Books-Beyond-Words/dp/1901242900>
  - Someone said an organisation which supports children who have lost someone close: [www.winstonswish.org.uk](http://www.winstonswish.org.uk) may have some useful ideas which could help children and adults.
  - Down's Syndrome Scotland have a useful booklet 'Let's talk about death': <http://www.choiceforum.org/docs/ta.pdf>. You can also order their factsheet with useful tips called 'Coping with loss' from [www.dsscotland.org.uk](http://www.dsscotland.org.uk)
- Mencap has a factsheet on bereavement. Visit [www.mencap.org.uk](http://www.mencap.org.uk) and go to resources and search for 'bereavement'.

### **Transition from children's to adult's services**

Someone said they were seeking feedback about difficulties being experienced in transition from children's to adult services.

Responses included:

- Someone said that the research from the Social Policy Research Unit (SPRU) at the University of York seems to capture many of the issues that young people and their families have experienced in their area. Download the research, 'Transition to adult services for disabled young people and those with complex health needs' at <http://php.york.ac.uk/inst/spru/pubs/1888/>
- Someone said 'I wonder how many more reports are needed before any of the systems are actually improved'.
- Someone said 'on a personal level, transition from children's to adult services has been awful for a whole range of reasons. The most shocking part of the transition has been to find that parents' views are not valued and the financial implications of meeting needs is paramount. Person centred planning and choice are a farce: money is everything'.
- 'It saddens me that with all the talk of 'Valuing People' and personalization that actually nothing has changed in twenty years. In fact I would go as far to say that it has got worse, much much worse'.
- Someone said people might be interested in reading the progress reports by the National Transition Support Team for the Transition Support Programme (TSP), which is part of Aiming High for Disabled Children. Regional reports from year 2 of the TSP can be found here: [http://www.transitionssupportprogramme.org.uk/resources/self\\_assessment/year\\_2\\_saq.aspx](http://www.transitionssupportprogramme.org.uk/resources/self_assessment/year_2_saq.aspx). A full report looking at the TSP and what works well in transition will be published towards the end of the programme.
- Someone said that they agree that things have gone from bad to worse. They said that they think direct payments and the Independent Living Fund can make a person with PMLD isolated. They said they are concerned that day services and residential care settings are being done away with.
- Someone said about the importance of having options available for respite when the child becomes and adult. They said that social services should provide

good signposting/ information about all types of respite provision, including those provided by charities, private companies and community agencies (not just the statutory sector).

### Ordinary residence

Someone asked what rights a PMLD young adult has regarding ordinary residency if the Borough funding their placement with an adult placement provider, wishes to move the case to the Borough they were placed in and thereby put at risk the whole placement. They said that within the boundaries of the mental capacity act, the young person has no capacity whatsoever. They said that the family providing the placement feel that this is not in the best interests of the young person and this action risks a long standing placement.

Responses included:

- 'You need a 'best interests' advocate such as myself to be commissioned or to work with the person in order to forensically assess the situation and apply the Human Rights Act - and in particular the right to a normal family life.'
- Someone said 'I was advised by one source to seek an IMCA for some issues concerning my daughter but when I applied I was refused an IMCA because it was said that IMCAs are only available to those people who do not have a parent or similarly connected person to speak for them.'
- Someone asked for clarification about the situation. The person who posted the original query confirmed that the borough funding the placement was where the person was born. And that the person was placed in an adult placement home out of borough because there was no alternative in-borough. The person seeking clarification then said it sounds like the placing original authority wants to transfer the funding responsibility to the receiving authority not move the young person to another residence/area. They said they didn't know why this would put the placement at risk as it sounds like just a dispute about which authority should fund the placement and not a dispute about whether the place is appropriate or what the person wants.
- Someone else said they think this sounds like an issue between the authorities about their funding boundaries and should not really affect the care the person receives.
- Someone said that what is clear in the ordinary residence guidance is that funding battles should never affect the person's progress or their plans going forward
- Someone said there is background information about the Government's 'ordinary residence' policy at [http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Ordinaryresidence/DH\\_079346](http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Ordinaryresidence/DH_079346)

### Gross contravention of his fundamental human rights

Someone said their son is being grossly discriminated against by the LA. They said that the LA refuses to acknowledge he has PMLD, by constantly writing letters to him, asking for his input on consultations etc. They said they have discussed this with them politely for over 20 years but they keep doing it. They said they believe this is a gross contravention of his fundamental Human Rights; i.e. the Right to be afforded dignity and respect, based on who he is as an individual. He said he wants to take the LA to court and asked for advice from the forum.

Responses included:

- I am also the parent of a person with PMLD. She is in her twenties. I completely agree that people with profound disabilities have a right to be treated with dignity and respect. Attempts should be made by professionals and ourselves to understand the viewpoint of our adult children. This is not easy to do. I feel my daughter does have opinions but she might not express them conventionally. For example she has clear musical preferences, she likes some foods more than others and loves going shopping. I think she is also clear about how she would prefer that she is treated by staff in for example a hospital. I find myself often acting as her advocate. Any letters addressed to her have to be read by me and I have to try to work out how she would respond if she could use words.' She suggested that other people could ask her daughter's opinion by sending a letter addressed to both the parent and the adult child asking if they would like to participate in a consultation. She said 'to ask her directly in a letter she cannot see to read seems to me to be a clumsy attempt to do this.'
- Someone said that people still don't understand what a learning disability is and that in some cases they will need to listen to the carer. They said 'they don't believe us when we say our children and young people don't understand or speak for themselves until we turn up on their doorstep and suddenly it dawns on them.'
- 'In accordance with Article 10 of the Human Rights Act (Right to Freedom of Expression - to receive and impart information and ideas...) your son is entitled to be included in consultations especially about services he receives. May I suggest that correspondence is addressed to him c/o yourself and attempts are made to find out his perceived views by considering his choices/likes and dislikes. This could be achieved with the involvement of an independent advocate. There are a number of organisations now providing 'non-instructed' advocacy.'

To take part in discussions please join the PMLD Network Forum at [http://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)

# Obituary

## Professor Chris Kiernan (1936-2011)

Professor Chris Kiernan died on April 23 2011 at the age of 74 after a long illness. Chris was one of the leading figures in the UK and internationally in the area of intellectual disability research. His commitment was always influenced by the consequences of a serious and damaging illness to his infant son, Jim, in the late 1960s when he lectured at Birkbeck College. His experience of the rewards and challenges of raising Jim had a profound effect on his research and on his strong philosophical and ethical commitment to people with intellectual disabilities. Never, however, did this undermine his objectivity and certainly he never allowed his personal experience to intrude into his professional activities.



While Deputy Director of the Thomas Coram Research Unit in the Institute of Education, University of London, in the 1970s and 80s he began detailed work that focused on the neglected area of a curriculum for people with profound intellectual and multiple disabilities. The resultant *Behaviour Assessment Battery* was, and is, one of the most sustained and comprehensive documents ever produced in this field. From this emerged *The Pre-verbal Communication Scale* which still plays a valuable part in the difficult task of assessing non-verbal individuals. His interest in non-oral communication and the use of signs and symbols for people with autism and intellectual disabilities yielded critiques of the misuse of such approaches that have yet to be heeded by practitioners.

From 1984 to 2001 he directed the Hester Adrian Research Centre, University of Manchester, where he developed collaborative research into challenging behaviour. He contributed significantly to a cross-UK study on the reduction of antipsychotic medication for people with intellectual disabilities. The co-authorship of these streams of work read like a roll-call of the major contributors to this field.

Chris' strong ethical commitment was always apparent in his work, and towards the end of his career found increasing expression in his publications. Characteristically he brought rigour and clarity to key concepts that often fared less well in the hands of others.

Throughout his career Chris supported and enabled the development of many younger colleagues. These, together with the wealth of his publications will continue to influence the field of intellectual disabilities for many years to come. He will be remembered not only by his family, his wife Diana, and children Chris, Nicola and Jim, but by all of us who had the privilege of working with, and learning from, him.

# IN THE NEWS

## The Hotlist: Inspirational people with a learning disability

A recent poll has revealed that just 1% of the British population can name someone who has a learning disability. Mencap's Viewpoint magazine set out to change this by publishing a 'Hotlist' of successful people with a learning disability.

The Ipsos MORI poll, carried out on behalf of Mencap in March, found that while more than half of the population could name a high-profile disabled person, 99% could not correctly name someone with a learning disability.

The most frequently named disabled people included blind Labour MP David Blunkett and physicist Stephen Hawking, who has motor neurone disease. Stephen Fry, who has bipolar disorder, was the third most commonly cited person.

However, when it comes to high-profile people with a learning disability, the public seem to struggle. Even after being given a definition of learning disability, many people incorrectly named celebrities who have dyslexia. Only 1% of those polled could accurately name a high-profile person with a learning disability – most commonly 'Britain's Got Talent' star Susan Boyle.

In an effort to redress the balance, the latest issue of Mencap's Viewpoint magazine (May/ June 2011) highlights 20 of the most inspirational and

successful people with a learning disability. Victoria Willson, a PMLD ambassador, was one of the 20.

"Britain has a wealth of disabled talent but the simple fact is that they are not seen enough in the media," says Mencap's chief executive Mark Goldring. "They have the right to be represented equally in society and people want to see them in the media."

Read the Hotlist in Viewpoint at: <http://www.mencap.org.uk/news/article/viewpoints-hotlist-inspirational-people>



## New Look PMLD LINK

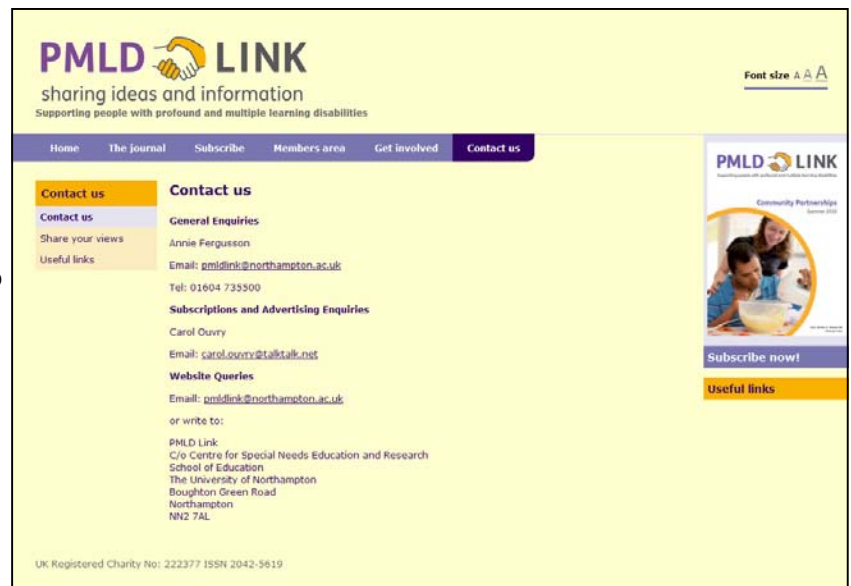
We hope you are enjoying the new look PMLD Link? We are very proud of it and hope that it will go from strength to strength. Please do recommend it to all your contacts in the world of PMLD.

The new look was launched on Friday March 25<sup>th</sup> at the Mencap/ BILD conference 'Raising our Sights' and we introduced our new website at the same time. There was lots of interest in the journal and website during the conference. People were very encouraging, saying that the new look was more inviting than the old look. Someone

described the old look as 'worthy' but added that it didn't invite her to read it. The new look, she felt, was very inviting! Right is a screenshot from the new website. You can see how it mirrors the new look journal! Mencap were amazingly supportive in getting the new website up and running. They gave us a grant and helped us to make good use of the money. At the moment, the content of the website is still increasing as back issues are gradually uploaded for members to access. The whole process will take some time but eventually all issues will be available.

If you are a subscriber you can read all the available journals on screen and download the back issues or articles from them. We won't stop sending a paper copy out though!

Subscribers need to be given a username and password and these are currently being sent out. If you have not yet received yours and you need it urgently please contact [pmlmlink@northampton.ac.uk](mailto:pmlmlink@northampton.ac.uk).



## Dr. Juliet Goldbart promoted to Professor of Developmental Disabilities at Manchester Metropolitan University

Juliet Goldbart's name is well known in the field of profound learning disability research and she recently delivered her Inaugural Professorial Lecture entitled '*Strategy or Serendipity: In Praise of Collaboration*'. The event was attended by a wide range of people from her academic, professional, social and family lives. In particular there were many parents of people with intellectual impairments present.

Throughout the lecture, the impact of Juliet's work, and her enthusiasm and commitment to working collaboratively with people with intellectual impairments, parents, teachers and other professionals, was palpable. In particular, she stated that one of her guiding principles has always included making research accessible. To this end, she described a model of early communication, collaboratively devised, which has become a powerful standard within the field – well known to those who support people with PMLD -enabling even the most restricted communication to be recognised as meaningful.



The fact that so many people attended her lecture indicates how much people have been influenced and inspired by Juliet and her work.

## Brain Injury Awareness Week Tweetathon

For this year's Brain Injury Awareness Week, 9<sup>th</sup>-13<sup>th</sup> May 2011, The Children's Trust, Tadworth decided to try to get everyone talking about brain injury for the day.



Outside specialist settings, paediatric acquired brain injury often remains an under-recognised condition. By providing information and support to parents and professionals, The Children's Trust is working to increase awareness and understanding of childhood brain injury, and thereby improve the lives of all children affected by the condition.

With a twitter following of over 17,000 people - a mixture of families, supporters, media and celebrities - The Children's Trust decided to embark on a social media campaign to raise awareness of this often 'hidden' disability.

Over 12 hours, from 8am to 8pm, The Children's Trust's communications team shadowed some of its doctors, nurses, therapists, teachers and care staff as they worked with children and young people accessing residential brain injury rehabilitation programmes at its national centre in Surrey. Tweeting every 2-3 minutes, the Trust also introduced and followed children and their families as they got up, got ready and got involved in therapy sessions, classes and outings.

At its peak the Trust was reaching around 150,000 people via its updates and the team was amazed at the level of engagement from followers. There were messages of support, 'ask the expert' questions, updates about children the Trust had previously worked with and lovely messages from people who recognised friends or family and wanted to pass on their best wishes.

Over the course of the tweetathon, the Trust recruited over 500 new twitter followers to take its total to 17,701 followers, which, according to a recent report, would put The Children's Trust in the top 10 charities on twitter in the UK. This number has since risen to over 18,000 followers as the profile of the Trust and its work with children and young people with multiple disabilities and complex health needs has increased significantly online.

The Children's Trust also had some great celebrity support throughout the day – for example kind messages from Amanda Holden, Annabelle Karmel, Calum Best and Craig Phillips.

In fact the event was so successful that The Children's Trust is considering hosting a similar day to showcase the work of its on-site special school, The School for Profound Education. Watch this space for more information nearer the time!

To join The Children's Trust on twitter, please visit [www.twitter.com/childrens\\_trust](http://www.twitter.com/childrens_trust) or for existing users, tweet @childrens\_trust.

## Thousands of disabled people protest against cuts

On 11 May, approximately 5,000 disabled people and their families and supporters marched through central London to warn the government of the impact of the public spending cuts on disabled people.

The Hardest Hit march was organised by the UK Disabled People's Council and the Disability Benefits Consortium. It was supported by 40 organisations. Protesters travelled from as far afield as Scotland, Wales, Northern Ireland and the south west of England to take part in what is being hailed the biggest gathering of disabled people in the UK ever. After the demonstration protesters met with their MPs to lobby them on cuts vital benefits and services. Some 2,000 people were hoping to meet an MP.

The night before the Hardest Hit march, a committee of MPs voted on whether to amend the Welfare Reform Bill, to make sure disabled people in residential care continue to get the mobility component of DLA. It was a close vote, but the proposal remains in the Bill.

## New SEN plans for families

Proposals in the SEN green paper include a single assessment and personal budgets.

The long-awaited green paper on children with special educational needs (SEN) was published in March.

'Support and aspiration: a new approach to special educational needs and disability', proposes to replace statementing with a single assessment process and 'Education, Health and Care Plan' by 2014.

Children's Minister Sarah Teather said: "We have heard time and time again that parents are frustrated with endless delays to getting the help their child needs, and by being caught in the middle when local services don't work together.

"Parents and voluntary organisations have given us overwhelming examples where they have felt let down by local services. The new single assessment process and plan will tackle this issue and mean that parents don't feel they have to push to get the services they are entitled to."

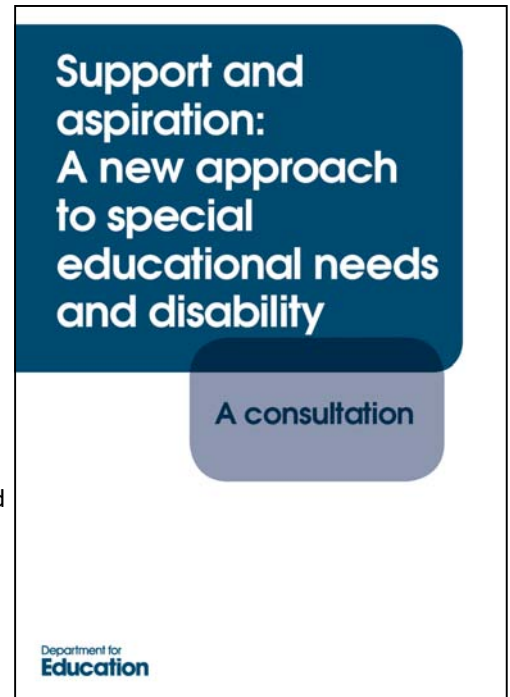
Mencap's chief executive, Mark Goldring, welcomed the single assessment and plan, but warned: "The real test will be how successfully different agencies will be able to work in partnership to deliver services. The system will also need to have appropriate checks and balances in place to ensure that all of a child's needs are properly met and addressed."

In line with the government's localism agenda, the green paper also plans to transfer power to front-line professionals and local communities. Mark Goldring, however, said that localism "may make education for children with a learning disability even more of a postcode lottery unless there is national coordination and leadership".

Other plans in the green paper include:

- introducing greater independence to assessments, perhaps by involving the voluntary sector
- giving parents a legal right to control funding for their child's support (through a personal budget) by 2014
- making easy-to-understand information about all services available from local authorities
- overhauling teacher training and professional development
- making improvements to the range and diversity of schools available for parents to choose from.

The consultation ends on 30 June 2011.



## It's not just about talking

It's the National Year of Communication, and April's focus was on non-verbal communication.

'Hello', the 2011 National Year of Communication, is a campaign to increase understanding of the importance of good communication skills for children and young people. The campaign is being run by The Communication Trust, a coalition of 40 charities, in partnership with Jean Gross, the government's communication champion.

Find out more about the National Year of Communication at <http://www.hello.org.uk/>

## A new zoo loo

Marwell Wildlife in Hampshire has become the 250th location – and the first zoological park – in the UK to install an accessible Changing Places toilet.

Changing Places toilets meet the needs of an estimated 250,000 disabled people in the UK, including those with profound and multiple learning disabilities (PMLD). A Changing Places toilet is larger than a standard disabled toilet, with enough room for at least two carers, and has a centrally placed toilet, adjustable changing bench and ceiling hoist.



Chair of the Hampshire Parent Forum Ray Daniel campaigned for the toilet at Marwell. Ray, who has a 15-year-old son with cerebral palsy, said: "For us as a family, a Changing Places facility means that we can be out for longer than four hours, and spend a whole day at the zoological park."

Beverley Dawkins OBE, Mencap's national officer for PMLD and co-chair of the Changing Places consortium said: "We have achieved great strides in this campaign since it launched; however, there are many more facilities still needed. The Changing Places consortium will continue to lobby for more facilities across the UK to cater for the needs of our most vulnerable citizens."

## Social care crisis highlighted in LDC report

In March the Learning Disability Coalition (LDC) published the findings of its surveys of local authorities in England, and of people with a learning disability, their families and carers.

The report, 'Social care – the continuing crisis', identifies that following the government's comprehensive spending review, local authorities are cutting services for people with a learning disability or increasing eligibility criteria.

It shows that 9 out of 10 local authorities have less money than a year ago. In addition, the number of local authorities making cuts to services has doubled since last year, from 10% to 20%.

The report acknowledges that local authorities would like to be able to offer services that fully meet the needs of people with a learning disability, but that a lack of funding prevents this. It notes that nearly half of local authorities that responded to the survey are likely to cut non-employment day services.

Read the report at: <http://www.learningdisabilitycoalition.org.uk/download/Social%20Care%20-%20The%20Continuing%20Crisis.pdf>



# Government delays removal of DLA mobility component

As part of the Welfare Reform Bill, the government has delayed its decision to remove the mobility component of Disability Living Allowance (DLA) for disabled people living in residential care homes.

The benefit was due to be removed by October 2012. However, an impact assessment document that accompanied the Bill, confirms: 'The DLA mobility component for those in care homes will be retained until March 2013.'

The impact assessment says that any further changes to the DLA will be built into the design of the new Personal Independence Payment. It also confirms that the government will review whether the mobility component of DLA is an overlap of social care funds – a claim that campaigners have been providing evidence against.

The six-month delay has been welcomed by disability groups, who have been campaigning against the government's proposal for the last few months.

If the removal of the mobility component of DLA does still go ahead, it will mean that disabled people in residential care will no longer have the funds to meet extra transport costs, such as an electric wheelchair or an adapted car. This will have a devastating impact on 80,000 disabled people who rely on the allowance to live their lives independently.

Jane Alltimes, Mencap's senior campaigns and policy officer, said: "This change in government policy is a great credit to all of the campaigners who have worked incredibly hard and have forced the government into reviewing their position." However, she warned that the campaign is not won yet. "To ensure the mobility needs of disabled people in residential care continue to be met, we will be continuing the campaign."

The government has also been running a wider consultation on DLA reform, and Mencap has issued a response to this. Alongside the response, Mencap has also submitted a report based on the results of a survey exploring usage of DLA by people with a learning disability. Visit [www.mencap.org.uk/dla](http://www.mencap.org.uk/dla) to download Mencap's response and report.



10am-4pm 20th April 2011,  
Friends Meeting House



## Big Cuts Event - Liverpool

From January to April 2011, Mencap ran a series of roadshow events to tell people about cuts happening in their area, and to explore ways we can fight them together.

The Big Cuts events were highly successful. They have highlighted a range of services being cut across the country, and shown how these cuts are affecting people with a learning disability and their families. Attendees also benefited from advice about accessing support and their rights from Professor Luke Clements, a leading lawyer and expert in community care law.

To watch an interview and read advice from Professor Luke Clements aimed at families facing cuts, and to find out more about Mencap's campaign against cuts and how you can get involved, visit [www.mencap.org.uk/bigcutsevent](http://www.mencap.org.uk/bigcutsevent)

# People with profound disabilities 'being marginalised'

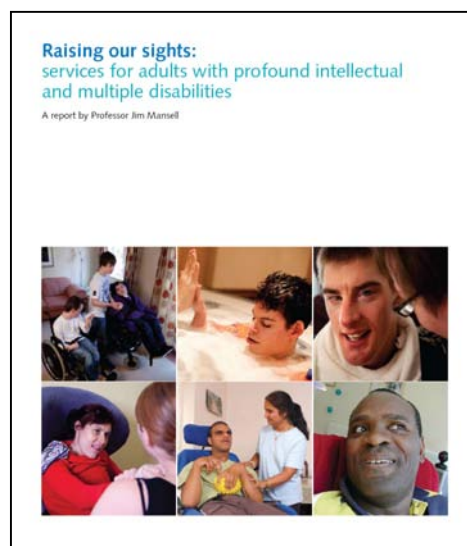
The government responded to the 'Raising our sights' report on services for people with profound and multiple learning disabilities (PMLD) in February, nearly a year after its publication.

'Raising our sights', commissioned by the Department of Health and written by Professor Jim Mansell, was launched on 19 March 2010. It made 33 recommendations across areas such as health, wheelchairs, assistive technology and day activities.

The government's response refers to existing social care documents, like the 'Vision for Adult Social Care' and the personalisation plan 'Think Local, Act Personal', but stops short of introducing new policies and procedures. The responsibility for addressing many of the recommendations remains with local authorities.

Professor Jim Mansell said: "The specific obstacles identified in the report ['Raising our sights'] will not be overcome by listing the government's general policies nor by leaving it all to local decision. There are some obstacles, for example concerning access to housing, which only government can address, but the government has not said how it will do this."

Mencap and the PMLD Network have also criticised the government for failing to provide leadership. Beverley Dawkins OBE, chair of the PMLD Network and national officer for PMLD at Mencap, said: "People with PMLD are a relatively small group in our society but one of the most vulnerable. We have campaigned hard to ensure that their needs are understood and focused on. I am extremely concerned that the government is not encouraging local authorities to specifically focus on the needs of this group of people. Without this, people with PMLD are at risk of being further marginalised."



# Involving families in workforce development

**G**ood practice in involving families in your workforce development was a project to identify good practice of involving family carers of people with a learning disability in workforce development.

The project was commissioned by the workforce lead of the Valuing People team, and ran for six months. It was supported by an advisory group made up of family carers and carer organisation representatives.

A report collating seven examples from local authorities, health, training and support providers and identifying common principles of good practice is now available to download.

It details how involving families in workforce development can support organisations achieve CQC outcomes, and can help organisations have a healthier, more committed and involved workforce, save money and develop supportive relationships with families built on trust.

The report can be downloaded at: <http://www.mencap.org.uk/document.asp?id=21440>



## Demand for action on Winterbourne View

**P**anorama programme 'Undercover Care: The Abuse Exposed', shown on Tuesday 31 May, exposed a regime of abuse at the privately-run Winterbourne View care unit in Hambrook, near Bristol, a residential care unit for people with a learning disability and autism.

Using secret cameras, the programme's undercover reporter captured a culture where care staff routinely taunted, kicked, slapped and pinned down residents.



The BBC commissioned the programme after Terry Bryan, a former nurse at the unit, approached it. He had tried to raise concerns about the treatment of residents with the Care Quality Commission (CQC), but his complaint was not taken up.

86 learning disability organisations and individuals in the sector have now written to the Prime Minister David Cameron, calling for action in response to the abuse of people with a learning disability at Winterbourne View.

The letter states: "We were disturbed and distressed to see the evidence of abuse and service failure that was shown on the recent Panorama programme but believe that it is an almost unavoidable consequence of the continuing use of inappropriate services to support some people with learning disabilities." It sets out a programme of 15 actions.

For more information about the actions and to read the full letter, visit:  
<http://www.mencap.org.uk/news/article/demand-action-winterbourne-view>

You can watch the episode 'Undercover Care: The Abuse Exposed' on BBC iPlayer  
<http://www.bbc.co.uk/programmes/b011pwt6> (for UK only) (10 months left to watch it from the time of publication)

## Central Valuing People Now team cut

Since the end of March the central Valuing People Now team has ceased to exist.

Prior to this, in a statement, a Department of Health spokesperson said: "The strong foundation which has been established means that delivery [of 'Valuing People Now'] will now no longer be led through the centrally funded programme team, which will cease from the end of the current financial year."

The news of the cut prompted many to question whether the 'Valuing People Now' agenda will lose momentum – a year before it was due to end.

The government says that it is "committed to improving outcomes for people with learning disabilities and delivering the vision of 'Valuing People Now'", but emphasises the role of local leadership. "The programme team has worked hard in recent years to shift power from professionals to people with learning disabilities, to support real local leadership... local action is not dependent on [the central team] and will continue, through local partnership boards and through the cross-government programme board."

Anthea Sully, director of the Learning Disability Coalition, has serious concerns about the new approach: "Good support for people with a learning disability is already patchy, and this is only going to increase the postcode lottery." She points out that this is exactly what 'Valuing People Now' sought to avoid.

"There's a danger that the move to localism and the end of ring-fencing in council budgets means that essential support for people with a learning disability will not be seen as a priority. At the very least, 'Valuing People Now' should remain as a strong framework with delivery measured against it – otherwise it's a strategy without teeth."

# REVIEWS

**Title:** Working with Reluctant Clients in Health and Social Care

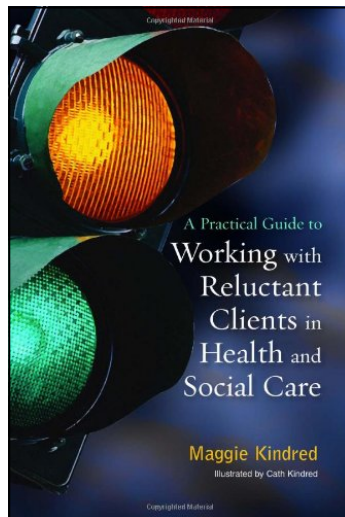
**Author:** Maggie Kindred

**Cost:** £16.99

**Published by:** Jessica Kingsley

**ISBN:** 9781849051026

This book is a basic starting point for professionals starting out on their professional training and would make a good starting point for in-service training for support workers, STAR workers and community support staff. Its content is more applicable to those who work with adults rather than children, however since educational staff also deal with parents as well as the children, it could have application in more specific situations there too.



Human rights, religious differences, and philosophy are covered in the early part of the book where it sets the tone of valuing each other as equals but its strength I believe, are the exercises included throughout along with possible responses.

There is also a guide for how to respond to different types of uncooperative behaviours at a superficial level. Half way through the book it covers 'The first visit' I felt this to be a particularly useful section to those students and staff who were new to the field of community care, home visits and would really stress the value of this particular section of the book for those about to embark on their first visits. Constructing letters for this first visit is also considered in some depth and there are useful exercises again included.

The next section covers making contracts with clients and families and how to approach this along with hidden agendas before proceeding onto the next section covering recording. This is a particularly interesting section which sets it in the context of legal documents and the family before moving onto ways to help you connect with reluctant clients. The last section deals with the rewards.

The book is extremely easy to read and the numerous

exercises throughout help the reader to apply the books contents to a range of circumstances and clientele. My first thoughts on reading this book was that it was too basic – but as I read through it I realised that the contents were often those which are not formally discussed in such depth, how I wish this book had been around in my early days as I embarked upon my first visits.

Whilst not really addressing people with profound and multiple learning disabilities, this book is more about helping to instil in professionals and care staff a good professional helpful attitude.

A good book for libraries in FE and HE who run courses with students training in the health and social care fields as well as a book that at a service level would aid in staff development not least by the application of the exercises.

## Review by

Di Foxwell  
PMLD Link  
Development and career lead for support workers.  
Berkshire Healthcare NHS Trust



The Council for Disabled Children are looking for examples of good practice in two areas:

## Health / hospital Passports

### Material to assist young disabled people to take more control of their health care

This call for information is part of a Department of Health funded project, '**Managing My Way**' exploring ways in which disabled children and young people can take more control over the management of their health needs. This project covers a wide range of disabled children and young people and recognises that children may participate at different levels. For some disabled children it is about being given information in a way that they can understand, for others it is about being able to express their views or influence a decision and for some it is about giving consent to treatment or being the main decider. For most disabled children and young people with PMLD it may be about evidencing how a decision made by others is in the child's best interest. To do this it is essential that the child's method of communication is understood by all the decision – makers.

We would like to know about any Trusts or hospitals who are using 'health / communication passports' so that children and their families do not have to continually repeat their story or where a passport is being used to share information on a child's communication system. Passports go by a number of different names – hospital passports / profiles / All About Me books. You can find an example of what we are looking for by using the following link:

[http://www.ncb.org.uk/cdc/My\\_Hospital\\_Book.pdf](http://www.ncb.org.uk/cdc/My_Hospital_Book.pdf).

Second, we would like to develop a 'tool' or 'aide-memoire' to give young people the confidence to contribute to their appointments or attend on their own. This 'tool' would assist them take part in the discussion on their treatment and be part of decisions made about their care and also look at what feedback methods exist to keep the young person 'in the loop'. If you know of a Trust or practice that has developed such a tool we would like to hear from you.

Please send your examples of good practice to:

Jeanne Carlin (Associate Consultant to CDC)  
jeanne@jcarlin.karoo.co.uk

# SHORT COURSES & CONFERENCES

## 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/)

### EQUALS

PO Box 107, North Sheilds,  
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)

### 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)

### Sunfield PDC

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

## September

Date: 12<sup>th</sup> and 13<sup>th</sup>  
Title: Person Centred Planning and Support Services for Young People with Complex Needs  
Location: Nottingham  
Provider: Inclusive Solutions  
Contact: Tel: 0115 9567305 / 0115 9556045  
Email: [inclusivesolutions@me.com](mailto:inclusivesolutions@me.com)

Date: 12<sup>th</sup> Glasgow **October** 14<sup>th</sup> Ipswich 18<sup>th</sup> Birmingham 17<sup>th</sup> London  
**November** 14<sup>th</sup> Doncaster, 15<sup>th</sup> Leeds  
**December** 2<sup>nd</sup> London 7<sup>th</sup> Glasgow  
Title: Practical & Effective Ways of Using MS Equipment  
Provider: Concept Training  
Contact: See provider details

Date: 20<sup>th</sup> Glasgow **November** 24<sup>th</sup> London  
Title: Intensive Interaction: Connecting with People Who are Difficult to reach  
Provider: Concept Training  
Contact: See provider details

Date: 23<sup>rd</sup> and 24<sup>th</sup>  
Title: Rebound Therapy for SEN  
Location: Newcastle-upon-Tyne  
Provider: Equals  
Contact: See provider details

Date: 27<sup>th</sup>  
Title: Very Special Maths  
Provider: Sunfield PDC  
Contact: See provider details

Date: 27<sup>th</sup> and 28<sup>th</sup>  
Title: Sleep Practitioner Training for health professionals working with families of disabled children  
Location: Birmingham  
Provider: Hansel Trust  
Contact: [joanne@hanseltrust.org](mailto:joanne@hanseltrust.org)

Date: To be arranged  
Title: Infant Massage Teacher Training Programme  
5 day accredited course for professional working with parents  
Location: London  
Contact: [anita@touchlearn.co.uk](mailto:anita@touchlearn.co.uk)  
Tel: 01889 566222

## October

Date: 4<sup>th</sup>  
Title: Intensive Interaction  
Provider: Sunfield PDC  
Contact: See provider details

Date: 10<sup>th</sup> Chorley/Leyland **November 22<sup>nd</sup>** London  
 Title: Inclusive Play  
 Provider: Concept Training  
 Contact: See provider details

Date: 10<sup>th</sup>  
 Title: Bridging the Gap: from sensing and perceiving to thinking and learning  
 Location: Manchester  
 Provider: Florich Productions  
 Contact: See provider details

Date: 11<sup>th</sup> Birmingham **November 29<sup>th</sup>** London  
 Title: The Sensory Curriculum – a practical approach to curriculum planning  
 Provider: Florich Productions  
 Contact: See provider details

Date: 11<sup>th</sup>  
 Title: Sherborne Developmental Movement  
 Provider: Sunfield PDC  
 Contact: See provider details

Date: 12<sup>th</sup> Nottingham **November 30<sup>th</sup>** London  
 Title: Successful Target Setting – building a framework of reference  
 Provider: Florich productions  
 Contact: See provider details

Date: 13<sup>th</sup> Manchester **November 30<sup>th</sup>** London  
 Title: Profound and Multiple Learning Disability – engaging children in learning  
 Provider: Concept Training  
 Contact: See provider details

Date: 14<sup>th</sup>  
 Title: Access to Mathematics for Pupils with Very Special Needs  
 Location: London  
 Provider: Equals  
 Contact: See provider details

Date: 20<sup>th</sup> London and Chorley  
 Title: Successful Multi-Sensory Sessions  
 Provider: Concept Training  
 Contact: See provider details

Date: 22<sup>nd</sup>  
 Title: Conference: Working together for best practice in PMLD education  
 Location: The School for Profound Education, Surrey  
 Contact: Tel: 01737 365810  
 profoueducation@thechildrenstrust.org.uk

## November

Date: 8<sup>th</sup> and 9<sup>th</sup>  
 Title: Sleep Practitioner Training for health professionals working with families of disabled children  
 Location: London  
 Provider: Handsel Trust  
 Contact: joanne@handseltrust.org

Date: 8<sup>th</sup>  
 Title: Hydro and Swimming for Children with Disabilities  
 Location: Newcastle upon Tyne  
 Provider: Equals  
 Contact: See provider details

Date: 9<sup>th</sup>  
 Title: Positive Ways of Changing Behaviour  
 Location: London  
 Provider: Concept Training  
 Contact: See provider details

Date: 11<sup>th</sup>  
 Title: Sherborne @ Sunfield  
 Provider: Sunfield PDC  
 Contact: See provider details

Date: 17<sup>th</sup>  
 Title: Sensory Play and Leisure in the Multi-Sensory Environment  
 Location: London  
 Provider: Concept Training  
 Contact: See provider details

Date: 17<sup>th</sup>  
 Title: Strategies to Promote Sensory Well-Being: How to Make Sensory Integration Work at Home and School  
 Provider: Sunfield PDC  
 Contact: See provider details

Date: 18<sup>th</sup>  
 Title: Sensory Differences and the Positive Role of Touch  
 Location: London  
 Provider: Concept Training  
 Contact: See provider details

Date: 22<sup>nd</sup>  
 Title: Whole Person Communication  
 Location: London  
 Provider: Concept Training  
 Contact: See provider details

Date: 24<sup>th</sup>  
 Title: Sherborne Developmental Movement – Level 2  
 Provider: Sunfield PDC  
 Contact: See provider details

Date: 27<sup>th</sup>  
 Title: Seamless Assessment Transition - *for families and professionals*  
 Location: Sunfield PDC  
 Contact: See provider details

Date: 28<sup>th</sup>  
 Title: Waking the Senses – stimulating the sensory systems into action  
 Location: London  
 Provider: Florich Productions  
 Contact: See provider details

## LONGER COURSES (with accreditation)

### MA Education

Pupils with Severe and Profound and Multiple Learning Difficulties (P1: Contexts & Understanding P2: Curriculum & Teaching)  
The modules address the requirements of the Teacher Development Agency (TDA) National Special Educational Needs Standards  
The course provides students with an opportunity to gain an understanding of those influences which impact upon the learning, development and management of pupils with severe and profound and multiple learning difficulties.

**For further Details:** The University of Northampton. Tel: 08003582232 Email: [study@northampton.ac.uk](mailto:study@northampton.ac.uk)

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

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

**For further Details:** The University of Northampton. Tel: 0800 358 2232 Email: [study@northampton.ac.uk](mailto:study@northampton.ac.uk)

### MA Education Understanding Multi-Sensory Impairment

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

**For further Details:** The University of Northampton. Tel: 0800 358 2232 Email: [study@northampton.ac.uk](mailto:study@northampton.ac.uk)

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

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

**For further Details:** The University of Northampton. Tel: 0800 358 2232 Email: [study@northampton.ac.uk](mailto:study@northampton.ac.uk)

### BPhil, PGDip and MEd Inclusion and SEN

Year 1 Learning Difficulties and Disabilities (Severe, Profound and Complex) Year 2

Autism (Children) or Autism (Adults)

*Distance Education*

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

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

MEd includes a research methods module and a dissertation

**For further details:** The University of Birmingham, Penny Lacey [p.j.lacey@bham.ac.uk](mailto:p.j.lacey@bham.ac.uk) or Helen Bradley [h.bradley.2@bham.ac.uk](mailto:h.bradley.2@bham.ac.uk)

### BSc in Professional Practice

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

**For further details:** University of Chester Tel: 01244 511000 Email: [enquiries@chester.ac.uk](mailto:enquiries@chester.ac.uk)

**MSc in Advanced Practice**

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

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

**Postgraduate Courses in Profound and Complex Learning Disability**

The course is studied by distance learning plus attendance at an Autumn Study School at the University of Manchester.

The course accent is on moving towards increasing choice; developing community presence and participation; and increasing respect for individuals with complex needs. This approach underpins all aspects of course delivery. The course has three aims:

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

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

**AdCert, BPhil, PGCert, PGDip, MEd.**

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

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

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

**AdCert, BPhil, PGCert, PGDip, MEd.**

Multisensory Impairment (Deafblindness) - *Distance Learning*

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

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

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

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

**Adults with learning disabilities who have significant and complex needs**

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

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

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

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

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

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

## About Us

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

- Rob Ashdown** Headteacher of St. Luke's Primary School, North Lincolnshire, for children with complex learning difficulties
- Helen Daly** Mum to a young Adult with PMLD, previous career in Further Education for 20 years - including Curriculum Team Manager for Inclusive Learning and Developing an Improving Choice Programme for people with Complex Needs. Currently involved in carers groups in the Eastern Region, Learning Disability Partnership Board and associated projects.
- Beverley Dawkins** National officer for profound and multiple learning disabilities, Mencap
- Ann Fergusson** Researcher and tutor for severe learning difficulties and PMLD courses at The University of Northampton. Trustee of National Family Carers Network. Ann also has a family member with a learning disability
- Di Foxwell** Works for Berkshire Healthcare NHS Foundation Trust; Distance Regional Tutor for University of Birmingham learning disability courses and a BILD tutor
- Chris Fuller** Founder and former Director of Bag Books: multi-sensory stories for people with PMLD, and previously special education teacher
- Penny Lacey** Coordinator of the University of Birmingham course in severe, profound and complex learning difficulties; freelance consultant; Penny has a family member with severe learning difficulties
- Loretto Lambe** Director of PAMIS an organisation in Scotland working with people with PMLD, their family carers and professionals who support them
- Wendy Newby** Teacher and curriculum coordinator St. Rose's School, Stroud, a school for children with physical disabilities and complex health needs
- Carol Ouvry** Retired special education teacher, trainer and consultant in the field of PMLD. Previously editor and administrator of PMLD Link

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# PMLD LINK

sharing ideas and information

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