

PMLD LINK

sharing ideas and information

Human Rights

Summer 2013



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www.pmldlink.org.uk

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

GUEST EDITORIAL

Human Rights

Welcome to the Summer edition of PMLD Link. This edition focuses on the human rights of people with profound and multiple learning disabilities. When we think of human rights our thoughts often understandably turn to the really big issues like the right to life. After all, we know from the Mencap report 'Death by *indifference*' (2007) and the recently published 'Confidential Inquiry in to the premature deaths of people with a learning disability (2013) that people with the most severe and profound disabilities are more likely to die because they didn't receive the right health care. Within this work we also know that people's rights not to experience inhumane and degrading treatment are often violated in the failure to recognise that people are in pain or to attend to their most basic care needs, such as nutrition.

All of this is of course of fundamental importance. However, as you will see from the array of articles in this edition there are very many ways of upholding human rights in all the ways we support people in their every day life. We can provide respectful and dignified personal care and ensure that communities are accessible and equipped with the facilities like Changing Places toilets-that not only meet people's care needs but make the statement that everyone has a right to be included. We can think about our day to day interactions and make sure that people are valued and have meaningful opportunities to learn and to play. We can support people to be heard and have influence.

There are many barriers to the human rights of people with profound and multiple learning disabilities being achieved and maintained. Some quotes from people we asked about this can be found throughout this edition.

This edition continues to celebrate and reflect on 25 years of the PMLD Link Journal and share with you the brilliant event we held to celebrate this summer. We also said goodbye to Carol Ouvry, a founder member and long term editor of the journal over many of those years. We presented her with a variety of yellow rose called PMLD link for her garden

The edition also comes packed with a range of new resources and news items, such as the launch of the 11 'Raising our Sights- How to Guides'. Enjoy!



Above: Carol Ouvry, founder member who retires after 25 years

Sue Thurman and Beverley Dawkins

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Making a difference?

The United Nations Convention on the Rights of Persons with Disabilities in low and middle income countries in Africa and Asia

Alice Bradley

Over the last thirty years or so, in addition to working in the UK, I've been involved in international development initiatives in several countries across Africa and Asia. In situations where resources are limited the challenges for disabled people and their families are considerable, not least for those who always seem to be the last to have their rights acknowledged, people with profound and multiple learning disabilities.

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which came into force in May 2008, is a milestone in the development process. It is not the first human rights instrument relating to disability but it offers disabled people unprecedented levels of protection. The convention is described by the UN (2007) as '... the response of the international community to the long history of discrimination, exclusion and dehumanization of persons with disabilities. ...'. Its purpose is to '... promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity' (<http://www.un.org/disabilities/default.asp?id=261>).

To date the Convention and the Optional Protocol have been ratified by 77 countries and well over a hundred have ratified the convention alone. (The Optional Protocol is a side-agreement which allows parties to recognise the competence of the Committee on the Rights of Persons with Disabilities to consider complaints from individuals) (<http://www.un.org/disabilities/latest.asp?id=169>). A map showing the countries which have signed or ratified the convention and a list of these countries can be found at <http://www.un.org/disabilities/index.asp>

The CRPD is based on respect for individual dignity and difference, freedom of choice, non-discrimination, participation in society, equality of opportunity, accessibility, gender equality and respect for the evolving capacities of disabled children, as well as their right to preserve their identities.

Interestingly, the Convention uses the term 'persons with disability', common across many countries, as opposed to the official UK terminology 'disabled people', which is based on the social construction of disability. This always seems to me to be a contradiction of the 'paradigm shift' claimed, i.e., that disabled people are acknowledged in the CRPD as 'subjects' with rights, rather than 'objects' of charity, medical treatment and social protection (<http://www.un.org/disabilities/default.asp?navid=14&pid=150>). However, it isn't easy to change global terminology and the existence of the Convention is what matters.

The CRPD and low income countries

At a recent international event I took the opportunity to discuss the CRPD with two colleagues, Sunanda Mavillapalli and Jennifer Liew, and get their impressions its impact on the lives of people with profound and multiple learning disabilities and their families, as well as its potential for future development at international, national and local level.

At global level

Sunanda is Head of Programmes for Asia in the International Department of Leonard Cheshire Disability and has extensive experience of working with disabled people, families, organisations and government bodies across both Asia and Africa.

'The Convention has engendered a lot of momentum and been adopted by many different countries. At UN level there is definitely more awareness of disability, more discussion, and disability is in more policy documents

than ever. At global level there are a lot of initiatives. In all the countries it varies as to how the Convention is being used to change their own country policies. In some countries a lot more is happening with disability than ever before so it's a good time to put pressure on for the post 2015 framework (The Millennium Development Goals: a framework to galvanize development and guide global and national development priorities).

In terms of whether it's had an impact on people with profound and multiple disabilities, I'm not sure – they are still at the end of everything. Few organisations look at severe or profound learning disabilities specifically, though there are NGOs that provide support. I keep questioning this in our own organisation. In most countries there are no services or people go to alternative services.

The challenge is that there is no collaboration or integration between the ministries. Children with severe or profound learning disabilities are dealt with by social services - the Ministry of Education has nothing to do with them, so if they do not appear in statistics they lose out on education. When we started educational work one of the objectives was always increasing the numbers of children into mainstream – hugely positive because for first time our children had access to education but then we found the gaps – children with severe disabilities didn't get counted because they were outside the system parameters. So there is still a long way to go. But there is increasingly more awareness of education and parents feeling that their children have a right to education. More children with severe disabilities are at least being brought out from their homes, though there is probably more acceptance of people with mild to moderate disabilities. It isn't just to do with attitude, but also access to transport, care, protection, especially for girl children, to being safe. It requires resources being targeted and that doesn't happen often. We are told that the 'per child' cost is too high. In health they are left out completely – no accessible services, parents don't have information, they don't know where to take their child, so they keep them at home.

Even in CBR (community based rehabilitation) children with the most severe disabilities aren't often included. They were always the hardest to reach and remain the hardest to reach. Where there is intervention, it is at the family level so either the mother or someone else is included in self help groups or micro-finance groups, or helped to get a disability card or pension or certificate. Whether the benefits ever reach the child is always a question – the hardest to reach, the poorest of the poor are always left out. I haven't really seen a truly inclusive programme.

But there are examples where countries are trying to reach those with the most severe disabilities. In India, for

example, they have set up the National Trust for people with learning disabilities, multiple disabilities and autism under the Ministry of Social Justice and Environment. They have community groups all over the country and NGOs (non government organisations) are invited to register with the Trust. There are insurance and social protection schemes to help families look after their children with profound and multiple disabilities and to support them at home rather than looking for a residential institution.

And technology has made a difference especially in terms of alternative and augmentative communication. Children who couldn't communicate before now have ways to do so."

At service level

Jennifer Liew is the manager of Sabah Cheshire Home in Malaysia. Currently the home provides services for people with a wide range of disabilities in the form of residential, respite and day care, community based family support and early intervention. They are in a period of transition and will become a Disability Resource Centre, operating on a rights based framework and providing a wider range of services both on their own premises and in communities across the state. Jennifer told me of the challenges faced in her country.

"The main challenge is lack of awareness and also education for society. Society still feels that people with profound disability will not be able to learn and the system does not really support them. Most children with profound disabilities who go to school go to special school which is run by non-government agencies or go to community based rehabilitation.. To be able to go to normal special school they must be able to look after themselves, toilet training for example. In rural areas CBR is the only choice. The government are doing CBR but many programmes do not cater for children with multiple disabilities. Also there is never enough money and not enough CBR teachers and carers — most families with children with profound disabilities have no service at all. The government is shifting responsibility to NGOs but they have to be responsible as well or things won't change.

Parents are not aware of their rights. They think that when they have a child with profound disability they need to look after that child. They want to protect that child because they are not well informed of the programmes we have outside. Another thing is that we do not have enough assistive devices or equipment to be able to deal with people with profound disability, for them to be able to get education and to go out. That's why we use young people now (the international Young Voices movement) to advocate for the rights of persons with disability – what kind of thing they require to be able to live a normal life. You have to make the

community be responsible for the things you want to happen but you have to go slowly to raise that awareness and open the way.

Working in a residential home I see people coming in and actually treating our residents, most of whom have profound disabilities, in a different way. They come without knowledge, giving them attention that is not respecting their value. People will sympathise. They don't need sympathy, they need empathy. We spend lot of time helping people to create a good quality home; a home with no care and feeling of belonging is not a home. By providing good quality facilities we are giving residents what they deserve and also changing other people's perspectives.

With the UN Convention and the Disability Act (Malaysia, 2008), I hope more will be done and there will be more awareness. Malaysia is paving the way, doing lots of things at national level, but they have to go to the roots of the problem.

More rehabilitation services will have to be established. The government have asked us to start an early education centre, a nursery, to cater for disabled children from three years old. Starting with the child at the right age is very crucial. It's a big responsibility and we need money, resources, staffing, all sorts, but if we don't do this there will be no examples for others to follow so we hope we will be able to do a good job. It will be the first in Sabah. I have high hopes. Once we start people will start opening their own (nurseries). This will help families to keep their children at home. If parents have this support and see that the child can have a good quality life, they will not want to put their children into a residential service.'

Concluding comment

Obviously, what I've presented here is a snapshot of a very complex, diverse subject. There are wide variations not only from country to country, but also within countries. Factors such as poverty, class structures, political systems and stability, the availability of resources and educational and health infrastructure are significant. In essence, these issues are not so very different from those we face in the UK and other countries of the North, but they differ considerably in degree, which is where the challenge lies.

There are also many excellent examples of NGOs in low and middle income countries – often started by parents - providing high quality services to sections of the population. These organisations are the first to acknowledge the extent of the need – and to do something about it.

Despite the challenges, I feel that the CRPD has the potential for improving the lives of people with profound

and multiple disabilities, not least because it recognises disability at global level, unites nations in their efforts to provide the support needed and provides additional opportunities for international cooperation and collaborative development. Countries ratifying the Convention are required to file country reports after two years, so this is both a spur to development and an indication of what is happening worldwide, which, no matter how imperfect, can't be a bad thing.

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United Nations: Enable. Development and human rights for all <http://www.un.org/disabilities/>

United Nations. The Millennium Development Goals (MDGs) and Disability <http://www.un.org/disabilities/default.asp?id=1470>
Sabah Cheshire Home website <http://www.sabahcheshirehome.org/online/>

Leonard Cheshire Disability (International) <http://www.lcint.org/>

"I think the communication bill of rights is a part of the whole rights approach ... using that as a framework for supporting people... being aware of their communication rights, their right to be listened to, their right to be included, the right to be responded to ..."

Jules McKim
Intensive interaction coordinator, Southern Health NHS Foundation Trust



Milestone for Changing Places campaigners

Beverley Dawkins

Hannah is in her twenties and works for a company that makes people more aware of disability issues. She enjoys dancing, going to the theatre, listening to music and meeting up with her friends. Because of her disability, she is also one of 230,000 people across the UK that need access to Changing Places toilets so that she can do the things she loves to do.

Changing Places are of course used by people who need assistance and special equipment in order to go to the loo, including people with severe and profound learning disabilities and other severe disabilities. They are larger than a standard disabled toilet and include a height-adjustable changing bench, a hoist and room for up to two carers so that continence pads can be changed easily.

Without these specialist toilets, carers and families are often forced to change and care for their loved ones in highly undignified and unsuitable conditions, such as toilet floors. Understandably, some choose not to visit public places where they are not available, or limit the time they spend out of their homes.

In May, Hannah was proud to open the 500th Changing Places toilet at The O2 in London. As well as being great news for disabled visitors to the world's largest music venue, it was a key milestone for Changing Places campaigners - campaigners who have for the past seven years been calling for an increase in the numbers of these fully accessible toilets in public places so that the people who need them can enjoy the same things as everyone else.

Over the years, our biggest campaign successes have been won by the disabled people and their families who have shared stories about how the lack of Changing Places impacts on their lives.

People like Margaret, the mother of Julie, a 39-year-old woman from the West Midlands. Julie has profound and multiple learning disabilities, and needs 24-hour support with all aspects of her care, including going to the toilet.

They found that trips to the airport posed the biggest problem. At one airport Margaret was asked to change Julie on the floor of the strip and search room, and at another in the immigration office. But she said the worst had got to be when she had to change Julie on the floor of the body bag room. She was furious but the attitude was 'well it's that or nothing'.

At first Margaret was embarrassed about making a fuss but then she found out about the Changing Places campaign and became a powerful campaigner herself. Together Margaret and Julie have become a force to be reckoned with, delivering powerful presentations to big corporations in the UK and as far away as Canada about the importance of Changing Places.

Margaret says that it doesn't take long before the audience are visibly moved when they talk about the indignity that Julie has had to suffer. "I think it just isn't on people's radar. As soon as we tell people about what we have to go through they realise how important it is – it's about awakening people to the problem."

One of her proudest moments came after she saw the name of a local MEP on a leaflet that came through her door. She got in touch and they discussed the Changing Places campaign. As a result of what she told him, a new bill has gone through all four stages of the European Parliament, which will mean all airports in the EU will have to have a Changing Places toilet. That's quite a success.

Five hundred toilets as a result of our joint campaigning activity is a great starting point, and we hope to reach 1000 or more within the next three years. Key to this will be getting more local campaigners like Margaret and Julie on board to help persuade the people designing and managing public places to provide Changing Places as standard.

As Hannah put it as she opened the 500th toilet at The O2: "A toilet opening might seem like a weird thing to get excited about, but having access to one of these is a huge deal to people like me."

www.changing-places.org

Contact details

Beverley Dawkins OBE
Policy Manager at Mencap and Co-chair of the Changing Places consortium

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Culture or absolute?

Changing places - the international perspective

from the blog of Sheridan Forster
(<http://pimda.blogspot.co.uk> — Monday, October 31, 2011)

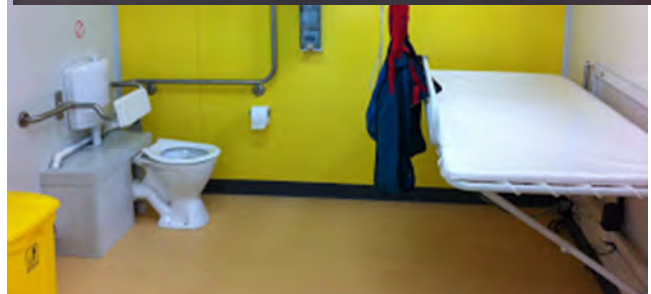
One of the things that struck me while visiting Biwako Gakuen was the amazing bathroom that I went into. There was submersible bath, a plinth that got pushed into a cavern to which a spray shower could be used, and a plinth for washing all in a large room. I heard the statements in my head that may be made by people in Australia "oh terrible, what about privacy". But in Japan concepts of privacy are very different. Communal bathing is not uncommon in the steaming hot Japanese bath.

It took me back to my visit to an institution in the Netherlands where shared bedrooms were used. I was challenged with the perspective of in whose best interest was it to be in a "private" bedroom particularly when you had a physical disability, vision impairment, and intellectual disability. I've been struck by this thought - what is the difference between a seclusion room and a private bedroom.

Travelling to different cultures is enormously challenging. What are the absolutes in life quality? What are our culturally imposed norms? What is in the best interest of the person with PIMD - what matters to them?



passionate about getting Changing Places happening here. It was great to check out the mobile Changing Places loo and see how popular this has been for councils. It was also great to hear about the upcoming bathrooms for Ringwood.



WEDNESDAY, NOVEMBER 28, 2012
Changing Places Victoria - A great success

I had the pleasure of attending the Changing Places Victoria launch on Monday. It was very exciting to see a great number of people attending the launch and

Let's hope that, like UK, in 5 years time we'll be able to announce the many hundreds of places where people with disabilities can go to because they now have access to an adult height adjustable change table, hoist and real space for assistance.

Playfulness and children with PMLD: going beyond the 'statutory minimum' to reach the child

Debby Watson

Playfulness in children with PMLD is an inspiring and wonderful phenomenon, bringing untold benefit both to the child and the person who is supporting them to be playful. From a professional's point of view, Jill Goodwin illustrated this when she wrote in the last edition of PMLD Link:

An entire week of stressful work can be made totally worthwhile by just five minutes of engaged and playful contact between myself and one pupil'

I have heard similar views from professionals throughout my PhD research study on playfulness and children with PMLD, with one professional describing playfulness as a 'lifesaver'. So far in the study I have conducted: a survey via the PMLD Network, ten interviews with people or groups who have extensive experience with children with PMLD, observations on four children with PMLD, including three with significant health issues and interviews with their parents and teachers or teaching assistants. Although I have not carried out a thorough analysis of the findings yet, it is becoming clear just how essential playfulness is to children with PMLD and to those who work or live with them.

For the child with PMLD, considering the odds stacked against them regarding their impairments and the incomprehensible situations in which they can find themselves, the drive to be playful is nothing short of remarkable. At times during my study, I have felt that the desire to be playful is almost as strong as the urge to breathe and have wondered why this is so. Although I haven't solved this, and probably never will, I am finding clear reasons why playfulness is so important for children with PMLD. Some of the suggested reasons that people have given for encouraging playfulness are that it can: enable children with PMLD to be engaged in an activity that they have some control over; increase their well-being; raise arousal, communication and engagement levels; be a springboard to other types of interaction; and, importantly, elevate their lives beyond the mundane. An example of the benefit of playful arousal

was provided in an interview with the teacher of one of the children in my study. She wasn't sure that the child had displayed any intentional behaviour, although his mother was convinced that he had at home. When she found a playful activity that got him really excited and motivated she said:

'he was very, very, very interested and excited by that and ...he's definitely now making a link between - he's not just hitting the switch (demonstrates hitting switch over and over) and that's the effect, it is cause and effect. Hitting the switch but watching and then we had it on a timer, so it did 10 seconds and then stopped and he hit it again and then watched again so he is making that connection, definitely.'

Playfulness enriches lives that can otherwise be dominated by positioning, feeding, medicating and changing - things that sometimes we feel more comfortable doing than trying to reach that 'inner child', the playful one rather than the disabled one. It is also a 'way in' to discover the personality of the child, a rewarding and meaningful way to engage. One participant, from an arts-based organisation said of playfulness in their work:

'you could sort of exquisitely adjust it to what was liked at a particular time and then you would get people just flowering, unfolding and flowering. It was very, very effective.'

The need to reach this 'flowering', or as it has previously been described, the ability of children with PMLD to 'shine' (<http://www.debbywatson.co.uk/downloadable-resources/>), is the reason why I have developed a 'Passport to Play', a type of communication passport which focusses on playfulness. People who know a child with PMLD well are, in my experience, generally extremely skilled in reaching that child's playfulness. For the young work experience student, however, or the care worker in a short break service, being presented with a child who doesn't appear to 'do' much can be daunting. A mother in the study said:

'I would say my daughter is very facially expressive, but if you don't know how to interpret those expressions...quite often I know (child's name) is grimacing and people will interpret that as a smile, I have that a lot. So there are other things, and I guess this is where a passport, or play passport and those kind of things becomes a shorthand for people who may not know your child very well to say 'oh that's what they can do.'

The 'Passport to Play' can be accessed from my website – www.debbywatson.co.uk and is a freely downloadable and editable Word document. It is hoped that the Passport will encourage people who support children with PMLD to focus on the child's need and ability to be playful, recognising that the child's impairments are significant only in that the supporter needs to be creative in how they overcome difficulties with positioning, attention to comfort and so on in order to observe, interpret and develop playfulness.



A final word from a parent who spoke very movingly about the role that she feels society should play in the lives of profoundly disabled children:

'If I could get a message out to all the professionals in this: For whatever reason the children are saved... let's not go into the ethics of all that. As a consequence of whatever it be - a condition or born very, very early and born very profoundly disabled- I do think we have a moral responsibility to provide those children with everything they need and that goes beyond the discharge date of the hospital. We have made a promise to that child when we saved that child's life.....Saying you can have a bed and you can have nursery chair and that is it, is just to me - we're talking about environments and what evokes playfulness and comfort and being able to access the toys, accessible toys. Quite often what you're given, your statutory minimum, isn't enough.'

It is in looking beyond the 'statutory minimum' that we will discover the joyous, resourceful and resilient side of children with PMLD, something well worth finding.

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Society values skills, intellect, materialism and aesthetics. People with PMLD teach us about a different kind of beauty which comes from connection with others, acceptance, a smile or the shared pleasure of enjoying a piece of music or a moment in the sun. Many people fail to see this. Therefore whilst people with PMLD are more human than most of us could ever be, they are seen as less human and not valued and afforded the same rights as the rest of us.

Julie Calveley
Practice Development Co-ordinator, Mencap

A Life's Experience

Elaine Shipway

I am a specialist teaching assistant that has been working in a school for special needs children for the last 37 years. Within the first few weeks of my work at St Rose's I realised I was drawn towards the children with the most profound disabilities. I am at my happiest when I am working with these children as no two days have ever been the same within those 37 years.

The children I work with usually have significant challenges to face on a daily basis. They have their own ways of communicating and making their needs known and have their own individual personalities and sense of fun. To understand these children the adult working with them need to know them very well. This comes by forming and developing a bond with them and gaining their trust. This can only be achieved as you build up your knowledge, skills and experience of each child. This is added to everyday you work with them. Through time and developing a relationship you begin to recognise their way of communicating. This requires patience, awareness, understanding, a sense of fun and a lively personality.

Working with the families of these very special children is a very important part of my job. Communication with the parents on a daily basis is crucial to the well-being of their children. They all have complex medical, physical and emotional needs. Parents have a right to know about their child's day and how they have been. This is achieved in a variety of ways, through home-school books, text and phone messages and the fact that the parents are welcome in the classroom at any time. A good relationship with the parents is crucial to the care and education of their child.

The fact that we work as a close team allows continuity and promotes a holistic approach that is individual to each child's needs. This is further enhanced due to my involvement in writing Individual Education Plans, target setting and close work with the therapy team. Most of all my involvement in strategic planning as part of the senior management team allows me to contribute to the school lives of the children.

Part of my job is to assist the therapy team with therapy programmes and to work closely with the lead nurse to maintain the children's well-being. As a specialist

teaching assistant I work directly with the children throughout the whole day. This includes classroom lessons, during 1:1 therapeutic sessions and personal care during break times. This gives me the opportunity to develop the relationships needed for the children to express themselves, to communicate and be understood. The high adult child ratio enables the pupils to encounter, experience and, most important, be involved with a wide variety of life experiences. It allows me to celebrate the mutual fun times and gives me pleasure and job satisfaction. I especially relish the trust a child places in me during a session in the hydrotherapy pool, as you give them the opportunity to float for the first time; when a child recognises you in a room and seeks to interact with a smile; the recognition on a child's face that they have control within an intensive interaction session by trying a new sound, giggling and physical touch; the eye contact and recognition in a 1:1 session; making a child comfortable. The list is in fact endless.

Working with these very special children brings many rewards, as previously mentioned. However, it does bring occasional sadness. The hardest part of my job is when a child is unwell, unhappy, uncomfortable or is experiencing emotional difficulties. These times challenge me but the fact that I have developed such a close relationship and in-depth knowledge of the child's needs allows me to recognise when these happen and enables me to act quickly assisting the child in the appropriate way. This at times prevents the situation from getting worse and allows the team of professionals I am part of to act and meet the best needs of that child. The hardest part of my job is when a child passes away, which is very rare but something that I have experienced. Even these times bring back good memories of time spent with the child. This is because they bring such joy to my life.

My job is the best job in the world. The pupils have taught me patience, understanding, empathy and given me immense job satisfaction. These children reward me daily with their trust, the relationships we have and the enjoyment we share. They give me more than I give them.

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I have had the pleasure of working with Elaine for the last seven years, just a short time of her 37 years of work with youngsters with PMLD. Her experience is invaluable to the children she works with and reiterates the idea that continuity, experience and familiarity is vital to the development of relationships and communication with pupils who have PMLD. These relationships are essential when considering the rights of the child. They have the

right to be able to express themselves in whatever way they to be understood, to live a fulfilled life and play an active role in the community. Experienced specialist teaching assistants, such as Elaine, facilitate this and have a significant effect on the lives of pupils within schools that have PMLD. I, as a teacher, recognise the significance of their role as the members of staff who have the most direct contact with the pupils.

Wendy Newby - wendy.newby@stroses.org.uk

A useful informative website
A summary of the United Nations Convention on the Rights of the Child http://www.unicef.org.uk/Documents/Publication-pdfs/UNCRC_summary.pdf

NEXT ISSUE

Summer Vol. 25 No. 3 Issue 76

- Well Being -

Do you have any memories of PMLD Link to share?

If so, contact the editors:

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The copy date for all articles, information and news for the
**Winter 2013 issue is the
Friday 15th November**

Leicester, Leicestershire and Rutland



IF YOU LISTEN YOU WILL HEAR US

People with profound and multiple learning disabilities

If You Listen You Will Hear Us

Jane Parr

For many years our local Learning Disability Partnership Boards have been debating the best ways to involve people with profound and multiple learning disabilities. In 2012, with the ending of funding on the horizon, Leicestershire and Leicester Partnership Boards decided that it was essential that guidelines were available to support the new commissioners and policy makers, as well as providers of services, on how to gain the views of people with PMLD. As the lead of the communication sub group I was asked to take this work forward.

Getting started

Our group involved Speech and Language Therapists, members of the Valuing People team, a member of the local Mencap, family carers and people providing services. Our first task was to clearly define the people we wanted to write the guidelines for as locally a range of terms had been used and complex needs had been used to cover both people with PMLD and those with autism and challenging behaviour. We decided to focus on those people with PMLD, using the definition from the PMLD network, as we considered this group of people to be those most vulnerable to being excluded.

During the discussion in the first few meetings the family carers articulated a strong view that fundamentally changed the direction of our work. They were very clear that they only wanted to be involved in this work if it was going to make a real difference to the lives of people with PMLD. This view was clearly based on previous projects they had been involved in where papers, guidelines or standards were produced but then never really implemented.

Developing the guidelines

The first step was to carry out a literature review and also find out what other people were doing in this area. It was clear that the aspirations of Valuing People to improve rights, independence, choice and inclusion had not been achieved for people with PMLD and that the 'personalisation agenda' was not improving their quality of life (Mansell 2010). The literature, however, was clear that people with PMLD communicate about the same things as everyone else but their methods of communication were very personal to them (Goldbart, J and Caton S.2010). It was also apparent that a range of formal approaches were being used to support people with PMLD to communicate their preferences and therefore be involved in their everyday lives. The group were initially supported by Louisa Whit who was leading the work on the Mencap 'Involve Me' project where four creative approaches to involvement were evaluated and key messages and recommendations produced to support people with PMLD in decision making.

Given the body of work and resources already available and several examples of local good practice, the group then had to consider the specific outcomes that our work would achieve. Our focus was on

- Sharing good ideas, practice and resources locally.
- Helping people to evaluate their approaches to communication and involvement for individuals. The aim was to move away from blanket approaches to more person centred approaches.
- To develop systems locally to ensure the views of people with PMLD were collected and then used to help with planning, delivering and evaluating services.

What do the guidelines say?

The main focus of the guidelines is on building the views of people with PMLD into service planning and commissioning. This process is divided into three steps

- Capturing and sharing the best ways to communicate with an individual and how they express their preferences. This information is often collected as a Communication Passport or Profile or is in part of a Person Centred Plan.
- Building up a picture of the person's preferences about the most important things in their lives. It was acknowledged that gaining the views of people with PMLD can involve a lot of guess work and we have to be honest about the limitations of what can be achieved (Ware 2004). It is therefore essential that this is an on-going process and involves the people that know the person best
- Following this there needs to be systems in place to ensure that the views of people with PMLD are included in commissioning and planning services, in day to day delivery and in evaluation. This is the step that is missing locally with involvement processes not being accessible to people with PMLD. To ensure these guidelines do make a difference to people with PMLD and their families, considerable work will be needed at this level.
- Finally families and carers will need feedback on how the views have been used to improve services.

Communicating the guidelines

In order to ensure that these guidelines got out to as many people as possible a decision was made to develop a DVD of local people and venues to demonstrate the key points. The Mencap guidance on consent was followed with all participants in the DVD who could not give informed consent. The guidelines were then launched at a local theatre to an audience of people with learning disabilities, their families, service

providers and commissioners. The guidelines are also on a website: http://www.leicspart.nhs.uk/_InformationLibrary-Easyreadinformation.aspx and included on YouTube: https://www.youtube.com/watch?v=Hp4PW17U_h8 which to the groups surprise means they have been viewed across the world.

Making a difference

The final stage is now to support local services and communities to use the guidelines to listen to the views of people with PMLD. Talks and presentations have been given to the three local Learning Disability Partnership Boards and to local service providers. With the changes in Commissioners we now need to start working with them to implement the guidelines.

A local network for anyone interested in all aspects of working with and caring for people with PMLD has been set up. The aims are to share good practice, ideas and resources, and build a group of champions to keep spreading the word about the guidelines in order to really give a voice to people with PMLD.

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How are people with PMLD affected by dignity?

Julie Calveley (nee Clark)

As families and carers are aware, intimate and personal care is integral to the care that many people with profound and multiple learning disabilities (PMLD) require. For many of us, the idea of being dependent on others to carry out activities such as bathing and continence care would be difficult to accept and cope with, but this is something that people with learning disabilities experience on a daily basis.

Intimate care is important for maintaining hygiene, and as it often takes up a large part of daily life, it also offers an opportunity for interaction between the care-giver and care-receiver. Despite its apparent importance, this area of care has received little attention by researchers and policy makers and carers have been left to grapple with issues around how to carry out these activities with little or no guidance.

I therefore decided to conduct a study to attempt to answer the question 'how do adults with severe and profound learning disabilities experience intimate care?' (Clark, 2008). This research focussed on care provided by paid care staff in residential homes.

Observations of staff providing intimate care indicated that there was variation in the extent to which dignity was maintained throughout the provision of intimate care. For example, at times there was a failure to

maintain privacy and at times staff spoke in ways, which could have been interpreted as disrespectful. Findings were compared to other studies of dignity in health and social care and it was found that, although dignity is a subjective and value laden concept, there was consistency in the kinds of interactions that are thought to compromise dignity. For example, it is widely accepted that being unnecessarily exposed naked to others and being exposed to ridiculing comments and actions leads to a loss of dignity.

The question of how people with PMLD are affected by the extent to which they are treated with dignity had not been addressed in the existing literature. It was therefore necessary to examine theoretical ideas about how dignity might affect the general population, and then to consider whether these ideas applied to the lives of people with PMLD. This article discusses how dignity might affect people with PMLD and gives examples of how dignity

might be promoted in the provision of intimate and personal care.

Studies on dignity in health care settings have given some indications about the kinds of emotional reactions that the general population experience when their dignity is compromised. These reactions include anger, anxiety, humiliation and embarrassment (Walsh and Kowanko, 2002; Franklin et al, 2006; Lundqvist and Nilstun, 2007). In one study, faecal and urinary incontinence were found to affect emotional well-being, by leading to lowered self-esteem, shame, embarrassment and despair, and the authors argued that the negative impact this has on quality of life cannot be underestimated (Buckley et al, 2007).

Loss of dignity is related to humiliation and shame, and these feelings have been regarded as particularly wounding to the self-concept (Kaufman, 1985). According to Haddock (1996), dignity is connected to the self-concept and self-esteem.

Self-esteem is largely dependent on the way that others see us and is closely linked with feelings of social inclusion (Leary and Downs, 1995).

'It is a plain fact about human beings that their sense of personal worth is shaped to a large extent by what other human beings think about them and the treatment they receive.' (Statman, 2000, p535)

The impact of dignity on self-esteem is important because self-esteem underpins psychological and physical health (Rosenberg, 1965; Meisenhelder, 1985; MacInnes, 2006). Loss of dignity can lead to low self-esteem, which in turn can lead to depression and anxiety (Rosenberg, 1979).

For a person to experience loss of dignity as damaging to their self-esteem, they must have developed a sense of 'self'. This article argues that people with PMLD are susceptible to experiencing damage to their self-esteem because the self emerges at early stages in the course of development and does not require advanced intellectual functioning.

The development of the self-concept requires a person to have differentiated their self as a separate entity. It is from this social process of 'self-other differentiation' that infants come to grasp another person's intent and view themselves as a recipient of another person's actions (Müller and Carpendale, 2004).

From birth, infants are social beings (Piaget, 1963). The findings that new-borns react differently to social stimuli and non-social stimuli and engage with emotional exchanges with others have been taken as evidence that

the ability to differentiate self from other emerges in early infancy, or perhaps is even present from birth (Müller and Carpendale, 2004). Furthermore, the ability to attribute mental states to self and others has been identified in infants as young as nine months old (Müller and Carpendale, 2004).

Neuropsychological findings support this idea that the self-concept develops at an early stage of development because the self is distributed into images and objects at an early phase in the process of object realisation (Brown, 1999), which typically develops at around 8 months.

Therefore, although people with a learning disability are more likely to have problems understanding emotions on an intellectual level (Arthur, 2003), the possibility that they experience the same range of emotions as the rest of us in response to the way that others treat them cannot be disregarded. This is also supported by the findings that people with PMLD show psychophysiological emotional responses to stressful triggers (Chaney, 1996).

However, this does not mean that everyone's response to being treated in a certain way will be the same, and it has been suggested that self-esteem will only be damaged if the way that others treat us is incompatible with our self-concept (Goffman, 1961; Haddock, 1996; Nordenfelt, 2004; Hannover et al, 2006). This implies that whether or not a person experiences loss of dignity not only depends on having a sense of self, but also on having a sense of self-worth. Whether or not we have developed a sense of self-worth also depends on the way that others see and treat us.

Therefore, paradoxically, for an individual to experience loss of dignity as an insult to their self-esteem, they must have, at some time, been treated with dignity. So, if an individual with PMLD does not experience a loss of dignity in response to an event that the majority of people would consider to be demeaning, that could be because the person does not have a sense of self-worth.

Understanding that dignity involves other-regarding and self-regarding dimensions (Gallagher, 2004) is important for working with people who have PMLD. Arguably support staff have a duty to bestow dignity, even if they think that it is not felt, because it is through treating someone with dignity that they are able to develop a sense of worth.

Furthermore, dignity is a right for everyone, and therefore it is a fundamental characteristic and requirement of 'care' that the person giving care does so in a way that promotes dignity.

Drawing on psychological and social development theories, this study concluded that loss of dignity could affect a person with a severe or profound learning disability, in a similar way to anyone else, because the sense of self develops early in infancy and does not require advanced cognitive functioning.

Ideas for promoting dignity in intimate and personal care

Intimate and personal care should always be carried out according to person centred support plans, which take account of a person's known preferences, ethnicity, culture and health needs. These are some ways of promoting dignity, which although may seem common sense and obvious, were found not always to happen in the study this article is based on.

- Holding up a towel when someone gets out of the bath
- Ensuring that someone is covered up (i.e. wearing a bathrobe) whilst shaving, brushing teeth, brushing hair, waiting to be dressed etc.
- Keeping doors shut during personal and intimate care
- Knocking on bathroom and bedroom doors whilst other people are carrying out personal and intimate care and waiting to be invited in before entering
- Talking about personal and intimate care in privacy and only with those who 'need to know'
- Ensuring good continence care so that there is no need for people to have a 'special seat' due to a risk of it being wet
- Providing good shaving to avoid cuts
- Using respectful language and a respectful, caring tone of voice

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Illustration by Rachel Mahala Calveley

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“I believe it’s the lack of flexibility and it’s a one size fits all society approach that is taken by too many staff You need a lot more flexibility in order to provide much more of a person centred approach”

Adrian Hartley
Family carer

SUBSCRIPTIONS AND PASSWORDS

Thank you to all readers who have already renewed their subscription for 2013. If you know people who have not done so, tell them that it is never too late in a year to renew a subscription and they will receive all issues in the year.

The time line for access to member’s pages of the website was extended to the end of March of this year because we recognise that subscribers may be late with their subscriptions all sorts of reasons. People renewing after the end of March may find that their passwords have been cancelled but they will be issued with a replacement one.

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25 Years of Education Articles in PMLD-Link

Rob Ashdown

This paper reports coverage in PMLD-Link over the 25 years of its history in relation to teaching and learning for pupils with PMLD. A trawl of all 73 issues was done to identify articles concerned with an aspect of teaching and learning for children in early years settings, schools and further education establishments. Brief conference reports or articles that were less than one page in length were discounted even though these could sometimes be informative and thought-provoking. Also excluded from the survey were at least twenty articles concerned with partnership with parents/families of children and the experiences of parents/families, even though these contained some profoundly moving and inspirational stories and observations with huge implications for schools. Similarly, several articles written about inter-agency working and articles related to services and interventions with adults with PMLD were discounted, even where it was plain that they presented potentially useful information for professionals working with pupils. These decisions were made because the intent was to see what people had been writing about ideas, interventions and issues directly affecting teaching and learning in UK classrooms and to keep the survey relatively simple. There were 168 articles that met these criteria for selection.

Since the mid-90s, there has been a theme for each issue of PMLD-Link: for instance, there have been themed issues on the use of Multisensory Environments (MSEs) (36), Arts (21), Music Movement and Drama (32), Professional Development and Training (57) and Literacy and Drama (35) that have each provided several relevant articles. (Note that the issue number is in brackets here and below.) Yet some important themes have not; for instance one issue was focussed on Advocacy (33) and another on Quality Services (48) but incredibly there were no articles related to schools in these issues. Nevertheless, this is clearly a good strategy for the PMLD-Link editorial board to maintain if it wants to encourage articles on particular themes.

Aspects of provision

A very few articles debated how and whether children with PMLD should be educated in special classes or in mainstream classes within the special

school. There has only been one article about this in the past 22 years. Ten articles relate in some way to links with peers in mainstream settings demonstrating all kinds of benefits for all and different types of links. There has not been a themed issue on Inclusion since 2003 (45) and only a few articles since then. It remains important to share more accounts of continuing, successful and unsuccessful, links with mainstream schools as schools networking is becoming increasingly important.

The introduction of the National Curriculum and debates about its relevance and ways of providing access accounted for as many as 15 articles between 1988 and 1995. Whereas, for 15 years between 1995 and 2009, no articles specifically about the National Curriculum appeared – probably to everybody’s relief. It remains to be seen whether much will be written about the new National Curriculum for 2014; there has only one to date. Yet there must be concerns about the relevance of the new programmes of study to pupils with PMLD and SLD.

Not much has been written about assessment for learning either although some important tools have been described: for instance, 'Affective Communication Assessment' by Mark Barber (39), 'Sounds of Intent' by Adam Ockelford (66), Engagement Scale and Profile by Barry Carpenter and others (69) and the development of the Welsh 'Routes for Learning' assessments by Jean Ware and Verity Donnelly (49)

Only four articles have been written about the organisation of Further Education provision and none in the past 15 years. There have only been a half dozen articles on the whole vexed process of transition from school to adult services.

Aspects of Communication

There has been a sustained interest in Intensive Interaction over the years with nine articles specifically about the use of this approach with children (not to mention several other articles about its use with adults). Particularly useful accounts have been provided by Carol Ouvry (2), Dave Hewett and Melanie Nind (4), Phoebe Caldwell (22), and Mark Barber (52, 56). The most recent account is by Coryn Memory (70).

In relation to communication an important article by Nicola Grove and Keith Park (17) explores the relative neglect of declarative behaviours compared to behaviours that are emphasised by 'functional communication' that relate mainly to making requests or expressing choices. Alternative communication systems (AAC), including objects of reference, have been surprisingly neglected with just a few articles written.

The printed word is important for communication but Penny Lacey (55) reminds us of the various forms that 'inclusive literacy' may take – it is not just about books. She also reports on the Inclusive Libraries project (60,63,67). Nicola Grove explores story telling (62) and in the same issue Chris Fuller describes the "Story Go Round Project" and how children with complex needs have been given access to story telling in community libraries. Nicola Grove and Keith Park (28) discuss giving access to literature – stories, plays and poetry – to people whose language development is severely limited, even to people with PMLD. In a later article, Keith Park describes a performance of Shakespeare's "The Tempest" (41).

Almost 30 articles on computer-based technology and/or MSEs have appeared and many have relevance to fostering communication as well as thinking and exploration. The extensive developments in MSEs as illustrated in PMLD-Link articles and other literature has been discussed most recently by myself and Nick Howard (74). PMLD-Link articles illustrate the development in ICT and software and its use with pupils with PMLD from the

early stages with primitive BBC Acorn computers and switch technology by Richard Walters (8) and Nick Pronger (10) right through to the latest themed issue on "Technologies" with articles about the promise held out by proponents of interactive tablets and apps (73).

Healthy living and healthcare

About a dozen articles have appeared about movement, dance and other physical development activities, although in truth these are more about communication and enjoyment than about healthy living. Cyndi Hill has made positive contributions about Sherborne Developmental Movement (9,10,32) but this is an area of work where it would be good to have more descriptions of people's experiences. Indeed, in the past 15 years there have been just one or two articles on dance and the use of Soundbeam technology.

More about physical development might have been expected. There have been articles on Postural Care (53, 59), one on physiotherapy (70) and just two on hydrotherapy (60, 70). There have been one or two articles on massage and aromatherapy but nothing since 1992. However, there has been an excellent article by Peter Limbrick and colleagues (70) about therapy and what therapists do and their concerns surrounding the lack of evidence and the aggressive marketing of some therapies.

In the past 15 years there have been a small number of articles relating to aspects of health care; notable have been articles on moving and handling (41), oral healthcare (41) enteral feeding via PEGs (47,52), sleep management (48), clinical care procedures (64), and one on medical technologies for sustaining life and improving health by Jeanne Carlin (73).

The number of articles about mental health and challenging behaviour is surprisingly small. There are standout articles by John Harris and Margaret Cook on a long-ago project working with schools to manage challenging behaviour (15) and by Penny Lacey (68) on 'listening to challenging behaviour'. Stuart Gent and Wendy Newby (60) describe six years of work to encourage a child to accept touch and communicate. If only, we had more examples of these successes.

The school curriculum

Not surprisingly, there have been a dozen articles on sensory approaches and the sensory curriculum. There have been almost twenty articles about access to the Arts. In contrast, there is really very little written about encouraging children's early cognitive development but there are important articles by Roy McConkey on the potential of developing play for learning (55), the role of touch in development by Mike McLinden and Steve McCall (66), and a review of the

literature on teaching early thinking skills by Penny Lacey (63).

There are several interesting articles in a themed issue about RE and spirituality (22). There have been just a few articles about empowerment and advocacy. Christina Tilstone wrote about the ethical concerns inherent in observational methods of research (31). Another themed issue collated articles about professional development and training (57) and in one of these Barry Carpenter expressed widely-held concerns about the implications of current teacher training for pupils with PMLD. He was voicing similar concerns twenty years ago – see his letter in Issue 18. Teachers now have access to some good downloadable or online training materials: e.g. the Welsh 'Routes for Learning' materials (www.wales.gov.uk/topics/educationandskills/schoolshome/curriculuminwales/additionaleducationalneeds/routeslearning/?lang=en), the Northern Ireland 'Quest for Learning' materials (www.nicurriculum.org.uk/inclusion_and_SEN/assessment/pmlid.asp), and the English online 'Training materials for teachers of learners with severe, profound and complex learning difficulties' (www.education.gov.uk/complexneeds) It would be good to have some accounts of their use and use of other training materials in schools.

Future Trends

Over the years, PMLD-Link has moved from being a way of linking schools and education professionals working with pupils with PMLD to being a journal supporting parents and a whole range of adults working with and caring for both adults and children. The journal has changed in its format, presentation and its content in many ways over these years. 1992 saw the first of a number of articles by students on university courses – an article by Celia Foote on the use of affective communication assessment (13). There have also been many articles by accomplished professional researchers

working in higher education or local authorities. Importantly, there have been articles by practising teachers and therapists – but nowhere as many as would be wished.

There is a need for more case studies exemplifying teaching and learning in schools. The PMLD-Link journal is an ideal place to publish such articles and any articles are welcome. Listed below are aspects of teaching and learning where it would be especially good to see more articles with evaluations of actual practices and their rationale in future issues:

- Use of AAC, including objects of reference, for communication
- Developing thinking skills, exploratory and investigative skills
- Teaching and learning through play
- Developing social communication and interactions, including use of approaches like Sounds of Intent, Sherborne Development Movement, Intensive Interaction
- Assessment for learning
- Delivery of elements of the whole school curriculum, including the National Curriculum 2014
- The use of new technologies for communication and cognitive development
- Meeting complex health care needs and mental health needs
- Professional development and training for teachers, support staff, therapists and others

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A Life Like Any Other

Vicki Raphael

Back in 2008 a House of Lords Special Committee gathered to reflect on how adults with learning disabilities were being treated in respect of their Human Rights. A large number of people with Learning Disabilities were interviewed or consulted and asked questions such as

Was it hard to have relationships?
Was it easy to do things in the community?
Did people have a say in their lives?
Did people complain if things went wrong?
What would help people to be treated more fairly?

200 people gave evidence at day activities, at home, in college and in self-advocacy Groups.

Reading the report again five years later, it is difficult to know how many people with Profound and Multiple Difficulties, Complex Needs or Family Carers were consulted and had a voice. I do know that in 2008, as a member of the Government's Learning Disability Task Force, I was actively campaigning for

people with complex needs to be much more high profile in the refresh of Valuing People Now, the then Government's Policy Guide for people with Learning Disabilities. Many groups also spoke up and their voices were heard and reflected in the revised Policy.

As the current and still full time carer of someone who has complex needs and a severe learning disability, I am not sure that my life for the last quarter century has been "A Life Like Any Other". As a family carer, I have been keenly aware of isolation, discrimination and negative assumptions associated with my son's disability. So how much more keenly has this been felt by my son, Christian? His rights have to be fought for, checked up on and tested in the reality of his day to day life.

Looking back at the list of questions posed by the House of Lords Committee, I can trace some threads of campaign, action, reflection and planning which have supported Christian .." a man without words"..to speak up for himself and others and to activate his rights. We began with investing time and energy in supporting Christian to build a Circle of Support. Friends and family who knew him well and worked on detailed person centred plans ,keeping them up to date and charting Christian's skills, experiences and his "non negotiables", things which were essential to wellbeing, safety and communication. As someone who does not use words, signs or symbols, Christian's Circle of Support used a large catalogue of photos, films and diaries to check out the integrity and suitability of the planning that was done and to check back on how things changed and progressed. Christian then spent some time securing a personal budget, finding suitable accommodation and inevitably learning a lot about barriers, inclusion and rights. He also went out and about a lot, travelled and became a familiar face in his community....all valuable experience for becoming a campaigner!

Having complex health needs including the challenge of living with intractable epilepsy has meant that Christian and his family and support staff have spent much time in hospital or accessing medical services. This is an area where health inequalities are well documented and where Christian has been particularly active in exercising his rights. He has been supported to complain when things have gone wrong and to make useful suggestions about how to put them right. This includes sharing his story in pictures in training and staff awareness sessions. He also met his MP at the hospital to present him with a photo folder evidencing the paucity of disabled parking available and to point out that there was no Changing Place toilet.

Active campaigning has been something that Christian has been able to participate in. He has " taken to the streets" with his placards and leaflets for the 'Hardest Hit' March in London, set up a stall outside the local City Council to campaign for a Changing Places toilet and was there for the Flush Mob in Trafalgar Square. All of these events have been enjoyable, socially rewarding and have had a great sense of common purpose.

In defending the rights of a group of people at great risk of being denied those rights, every opportunity has to be taken to speak up, share experience and inform others. With his Circle of Support actively engaged, Christian is able to be seen and to be heard in his locality on the Partnership Board, regionally at meetings and training events and nationally as the representative of people with Complex needs on the National Forum of people with Learning Disabilities. Christian has to be there to be heard.....presence is essential and inclusion is the message.

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Mother of Christian and family campaigner

Sounds of intent music project

Victoria Hubbard

Adam Ockelford and his colleagues have previously written about the Sounds of Intent (SOI) framework of musical development for PMLD-Link (Summer 2010, Issue 66, 7-10). SOI was designed particularly (for children and young people with learning difficulties, including autism and sensory and motor impairments). Adam has recently publicised the fact that SOI is available at www.soundsofintent.org. This freely available software package — which operates on any platform and with any device, from PCs to iPads — has been designed to enable teachers, therapists and others to assess where their children are at, musically, and to download appropriate materials for use with them. Children's achievement and progress can be recorded in just a few clicks and downloaded in visual form or as data for use in other packages.

The music-education charity Soundabout (www.soundabout.org.uk) is leading on the roll-out of SOI across the UK. There are a number of people across the country that are supporting this process and are organising seminars and conferences in your region. Funding has been obtained to offer free training and support to schools in the coming months. For further information, please contact Jacqui Malone at jacquimalone@soundabout.org.uk.

The University of Roehampton is currently producing a PGCert in the use of SOI, which will function as a stand-alone qualification or can be used as credits towards a Masters degree. Contact Jacqui Malone if you want more information about this unique course.

Soundabout can provide a range of in-house training packages for schools including a one day 'Introduction to SOI' which will allow schools to begin using the SOI framework confidently and to create a baseline assessment for their children's developmental levels in music. It will include a focussed music session with pupils for observation and feedback purposes. The training package/day will be tailored to suit the needs of individual schools, primarily to fit in with how music is delivered. The training is suitable for teachers, music specialists and classroom staff working with pupils up to P levels 4/5 for use during music sessions, and musical interactions throughout the school day.

Contact details

This information was provided by Victoria Hubbard who is a teacher who has been seconded as a trainer to the project from St. Luke's Primary Special School in Scunthorpe. She can be contacted via e-mail: victoriahubbard@soundabout.or.uk or tel: 07834232250.

I'd say we have the technology to support people's human rights and to enable people to have valued and active and meaningful lives – what we **don't** have is the political will, to provide the money, in order to enable people to have that kind of life, so I think the biggest barrier to people's human rights being made meaningful is the political will to make it happen."

Rachel Fyson
Nottingham University

The Right to Touch

Wendy Newby

When considering the rights of people with PMLD I believe touch is of primary importance, due to the underpinning belief that touch is a vital sense when considering how human beings interact with their environment. It is a means of communication, physical and social development and as a guide to exploring the external world. So why is it especially important to people with PMLD? I also believe that it is significant because it is, in fact, the first and foremost form of communication. Touch develops in the uterus before any cognitive, expressive and receptive communication. Streri (2000, p. 51) supports this, stating “Human beings possess tactile sensitivity from the first weeks of foetal life.” When people with PMLD are at very early developmental stages, it can be suggested that touch is vital for them to make sense of the world. Developing relationships and communicating provides the essence of what is of value when considering quality of life. Life depends on the mutual awareness of each other.

Touch is a source of ultimate knowledge. To live without the ability to perceive touch would be a denial of reality. It has a significant effect on the social and emotional well-being of human beings. It is vital that the internal milieu of a person promotes a feeling of safety and the development of relationships. The neurobiological systems, such as the limbic-hypothalamic-pituitary-adrenocortical (LHPA) system, control the body’s fight or flight response (Carter et al, 2006). It is vital that touch is used not only to learn about objects in the world, but to develop a neural connectivity that promotes a feeling of safety (Hewett, 2007).

Touch is a delicate subject when considering interaction with people with PMLD who are considered vulnerable. Touch is a near sense. These are the senses from where information is gained through close contact with the body. It can be intimate. Because of this, I feel there is a danger that this leads to people with PMLD becoming the ‘untouched’ and only experiencing functional touch. I believe it is important to avoid this and improve the use of touch within a multi-sensory approach to life for people with PMLD. Touch helps build up relationships and provides a mutually positive experience. It is vital when trying to promote interaction with their environment. Promoting interaction with both their environment and the people within it, is what I believe underpins a positive life experience for people with PMLD.

There is a need for a personalized, individual-led approach to touch that is consistent. What one person will enjoy, another will not. It is therefore vital that there is consent to touch. Thurman (2011) supports this by emphasising the importance of communication as a human right. I completely support this and feel that it is essential to ‘listen’ to all forms of communication. If communication is a human right, then it is vital that people with PMLD are given the right to communicate their wish to withdraw their consent. Touch must not be coercive. The individual needs to be understood, to be able to communicate and need time to interact. It is essential that there is flexibility, intuitiveness, responsiveness, familiarity, a trusting relationship and, most of all, the conviction to start where the individual is and be led by them. It requires the strong belief in wanting that person to experience the joys of being able to explore the world and people in it using touch.

Contact Details

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Thurman, S. (2011) Is Communication a Human Right for People with Profound and Multiple Learning Difficulties? PMLD Link. 23 (1): 10-14

People with PMLD cannot argue for their own rights or fight their own battles. Communication difficulties make them easy targets.

Matt Calveley
Police Officer

NEXT ISSUE

Winter Vol. 25 No. 3 Issue 76

- Well Being -

We would like to hear from you if you have any examples of people working together to improve the physical and mental health and health care of children or adults. We are keen to have full articles, letters and short reports – anything that could inspire or inform others.

If so, contact the editors:

Rob Ashdown
rob.ashdown@ntlworld.com

or

Jeanne Carlin
jeanne@jcarlin.karoo.co.uk

The copy date for all articles, information and news for the
Winter 2013 issue is the
Friday 15th November

Top 10 websites for Human Rights

Some useful websites

1. Changing Places

<http://www.changing-places.org/>

2. PIMDA: Profound Intellectual & Multiple Disability Australia

<http://pimda.blogspot.co.uk/>

3. Passport to Play

www.debbywatson.co.uk

4. PMLD Network

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

5. Equality and Human Rights Commission

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

6. Supporting and meeting the needs of people with PMLD: top tips

http://www.devon.gov.uk/nhsenglandsouth_pml_d_version2.pdf

Now available free as a smartphone app on App Store, Google Play (Android) and Blackberry

7. Total communication

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

8. If you listen you will hear us

www.leicspart.nhs.uk/Library/GuidelinesforinvolvingpeoplewithPMLDfinalversion2.pdf

9. Involve Me

<http://www.mencap.org.uk/involveMe>

10 Hearing from the Seldom heard

<http://www.bild.org.uk/about-bild/ourwork/seldom-heard/>

FUTURE FOCUS

Well-Being

The Winter issue will be the third issue in our year of celebration of 25 years of PMLD Link. This issue will have the theme of 'Well-being' in the broadest sense of the word. We would be very pleased to receive articles or news items from practitioners, parents, carers - anyone involved and interested in helping people with PMLD. We would especially like to hear from you if you have any examples of people working together to improve the physical and mental health and health care of children or adults.

This is not the first issue with the theme of 'Well-being': the first was in Spring 2004 (Issue 47). There have been issues on 'Health Issues' (Spring 2001, Issue 38), 'Health Matters' (Winter 2007, Issue 58) and 'Health Care' (Winter 2009, Issue 64) and there have been various articles related to health care and well-being over the past 25 years. However, we make no apologies for returning to this important topic since we are sure that it is essential that we should return to it again and again in coming years.

In past articles, we have glimpsed how developing medical technologies (new medical interventions) and clinical care procedures (e.g. to manage respiratory and feeding problems) are sustaining life and optimising health for increasing numbers of people with PMLD. What has been your experience of the impact of these new technologies and care procedures on the lives of people with PMLD and their families, carers, educators and others? More and more adults with PMLD are now being funded through Continuing Healthcare. You may like to write about your experiences.

Many people with PMLD can have severe physical disabilities leading to complex postural problems and very limited movement. Surprisingly, there have been relatively few articles in PMLD-Link on postural care, physiotherapy and hydrotherapy or on massage and aromatherapy. There have been just a few articles on mobility and moving and handling. Can you add to our knowledge base about effective and successful methods?

Even less has been written about the mental health problems of people with PMLD. Do you have any suggestions about systematic approaches to ensuring that living and learning environments meet their mental health needs? When needs are not met, real distress and harmful or disturbing behaviours may develop and we

would like to know more about positive approaches to the management of these challenging behaviours. It would be especially good to know more about people's experiences of managing sleep disturbance and developing relaxation.

People with PMLD can experience serious pain due to their physical disabilities or other medical problems or menstruation and it would be informative to hear more about the assessment and management of physical pain. Does anybody have any experience of providing palliative care at home or in a hospice or other setting for people coming to the end of their lives or suffering from degenerative conditions?

People with PMLD have severe communication problems and cannot easily express their feelings, needs and emotions, so some professionals and parents have developed personal passports or other ways of sharing information with nurses, doctors, care officers and others who have their temporary care during stays in hospitals or social care settings. Do you have any examples of how these have contributed to people's well-being?

And, of course, we must not forget about the well-being of those people who care for, educate and support people with PMLD who themselves experience physical discomfort and stress in trying to give them best quality living and learning environment. What training, support and attention to their welfare do they receive?

So let us hear about your experiences. Share the things that have worked well so that we can all develop our knowledge and confidence. We are keen to have full articles, letters and short reports – anything that could make a difference to others. We look forward to hearing from you.

Rob Ashdown
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or

Jeanne Carlin
jeanne@jcarlin.karoo.co.uk

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PMLD Network Forum A Digest of Discussions April 2013—August 2013



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.

Is there any support for people with disabilities in countries like India?

Someone got in touch from India. They said they were working with people with disabilities and asked if there was any help to support them.

Responses included:

- Someone said that there are many excellent organisations in India working with people with disabilities, but because of the size of the country, they tend to work in particular regions. They said they are most familiar with the Indian Institute for Cerebral Palsy which is based in Kolkata, but has links with affiliated organisations throughout East India. See www.iicpindia.org. They said this Institute may be able to recommend organisations geographically closer to where the person is based, or which are particularly relevant to the needs of the people they are working with.
- Someone said that the Music Therapy Trust is an Indian organisation bringing music therapy to India. They are based in Delhi, and part of their project is to train Indian musicians to become music therapists, who are able to address communication, developmental and emotional needs in people with a variety of disabilities, illnesses or emotional needs. They said the Trust may be able to advise whether there is someone qualified in the area where the person is based. See www.themusictherapytrust.com
- Someone said that Sense International does a lot of work in India: www.senseinternational.org.uk/pages/sense-international-india.html

Sensory Garden Design

Someone from a school said they wanted to redesign their existing sensory garden. They asked if anyone had had a particularly good service and design that they could share details of.

Responses included:

- 'Timotay Playscapes seem to have a good record and have been helping us with our plans: www.timotayplayscapes.co.uk'
- Someone said that they supported a group of adults with PMLD and their support staff to re-develop their garden space. They said they call the sensory garden 'a garden' as all gardens offer sensory experiences. They said it is about how the supporter assists the person to engage in the space, utilising sensory elements that match the individual's identified sensory preferences and strengths. They said the garden design process involved identifying how each person expresses like/dislike then taking them each week to a garden environment over a 3 month period to explore. Like and dislike responses were recorded and then the sensory elements of those activities that they were responsive to analysed. Some people also had sensory assessments. The garden design was then based on this. They said 'the interesting thing was that what the staff thought would be a great design did not match with what the people with PMLD showed us they liked. Person centred design!'
- They have written articles about the project for newsletters in Australia and London and have presented at a conference in London. Read their article 'Person Centred Design: Engaging people with profound intellectual and multiple disabilities (PIMD) in the process of designing their garden space': www.choiceforum.org/docs/ecaa.pdf

Resources/ information

- New level 3 award in Supporting the needs of individuals with PMLD:
<http://www.nocn.org.uk/assets/0000/4656/T-504-4550.pdf>
- Funding opens to support voluntary organisations that improve health and social care – find out how to apply:
<https://www.gov.uk/government/publications/voluntary-sector-funding-available-for-health-and-care-projects>
- Seeability’s new easy read factsheets ‘Getting the best eye care’ and ‘What to do if things go wrong’ to improve eye care for people with learning disabilities:
www.seeability.org/myeyecare/eye_test
- Guide: Integrating personal budgets – early learning, myths and misconceptions
www.personalhealthbudgets.england.nhs.uk/Topics/Toolkit/MakingPHBshappen/Integrating/index.cfm
- A free print version of Contact a Family’s ‘Holidays, play and leisure’ guide is available - exclusively for families of disabled children. Call freephone 0808 808 3555.
- Contact a Family has published the latest in its range of benefits guides for families with disabled children: http://www.cafamily.org.uk/media/389326/personal_independence_july_low_res-1.pdf
- New elearning course for Postural Care:
http://debramooreassociates.com/index.php?option=com_content&view=article&id=365

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

Visit the PMLD Network website at www.pmldnetwork.org

We Welcome any Contributions to PMLD-Link

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

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

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

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

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

REPORT BACK

PMLD Link conference: celebrating 25 years

On 28th June 70 plus people came together for a special conference at the University of Birmingham celebrating 25 years of the PMLD Link Journal. The University's Department of Disability, Inclusion and Special Needs hosted the conference. Dr. Penny Lacey from the department, who is Chairman of the PMLD Link charity and is on the journal's editorial team, opened the conference with a welcome to all and invited several long standing associates of PMLD-Link to briefly describe the growth of the journal over the years.

Prof. Barry Carpenter, OBE, talked first of all about its genesis as a simple newsletter produced by the Blythe School in Coleshill where he was Head Teacher to facilitate networking following on from a 1987 conference at Westhill College, Birmingham on the education of children and young people with PMLD.

Carol Ouvry described how after several years, she took over the editorship as well as acting as subscriptions secretary and general factotum ably supported by a committee initially of Barry, Christina Tilstone (formerly at the University of Birmingham), Loretto Lambe (now at PAMIS) and Jean Boucher (former HMI). Next, Annie Fergusson (who joined the committee a few years later and is from the University of Northampton which has also provided much support for PMLD Link over the years) illustrated the developments of the journal over



the years into the polished product that exists today plus the development of the new website to meet the needs of people of all ages with PMLD and their families, carers and others who support them in voluntary and statutory education, health and social care organisations. This opening session was rounded off by Christina Tilstone who publicly expressed appreciation to Carol for her 25 years of excellent service. Carol is retiring from PMLD Link work and Penny Lacey presented her with a gift of gardening vouchers and a specimen of a new strain of a yellow rose now named "PMLD Link". The audience was shown a special made cake created specifically for this celebration.

The main speaker was Dave Hewett who delivered an entertaining and thought-provoking presentation on Intensive Interaction illustrated by some remarkable video of interactions between young people with PMLD and their supporters. Dave also covered the importance of 'phatic communion' stressing that communication is not just about making requests and having these satisfied. Also, he talked about the importance of physical touch as an element of communication and deplored schools and organisations which have no-touch policies. He urged all present to go away and write or rewrite their policies to emphasise that physical contact is good and how it should be used appropriately and effectively. In the course of his animated talk he almost sat on the cake but that just added to the entertainment value.

After an excellent lunch (thanks to Karen Turner-Brown for her organisational skills) and huge slices of the celebration cake, short presentations were made by members of the editorial board: Penny Lacey spoke about a range of developments (teaching approaches, materials, ICT, communication aids, etc) in the education of pupils with PMLD some of which simply are not being explored enough in schools; Beverly Dawkins, OBE, from MENCAP, presented details about a new series of publications called "Raising Ours Sights Guides". These are downloadable from the MENCAP



Left to Right: Carol Ouvry, Dave Hewett and Christina Tilstone

website and supporting videos can be viewed. These were produced to counter the prejudice, discrimination and low expectations faced by people with PMLD as highlighted by the late Prof Jim Mansell, OBE in his 2010 report called "Raising our Sights"; Helen Daley is a parent of a young man with PMLD and author of one of the guides on wheelchairs and spoke eloquently about the issues encountered by people concerned with supporting people with PMLD who need more complex seating.

Jeanne Carlin, also a parent of young woman with PMLD, spoke about her concerns about recent changes that could serve to eliminate the humanity and empathy required for decisive planning and provision of the appropriate and effective services that people deserve to have; Rob Ashdown presented an analysis of 170 articles that have appeared in PMLD Link about the education of pupils with PMLD at school identifying popular themes and areas where more coverage is required; Wendy Newby, who teaches at St. Rose's School in Stroud, used slides of activities in her classroom to illustrate the importance of touch for exploration and learning and enjoyment; Lesley Barcham from BILD talked about the

various activities carried out by BILD and some of its most important publications; and to round things off Annie Fergusson reiterated how much the PMLD Link editors would really welcome articles from readers since the journal relies absolutely on voluntary contributions. She pointed out the guidance that is available on the website to would-be authors and invited everyone present to think about what they could write for the journal.

2013 continues to be a year of celebration of the 25th anniversary of PMLD Link with two forthcoming issues: in the Summer on the human rights of people with PMLD and in the Winter on 'well-being'. This conference was an excellent and enjoyable celebration of the hard work and contributions of the very many people who have made the journal such a success. There was a great deal of conversation and networking and energy on the day which definitely showed the commitment of all to shining a light on people with PMLD and showing their humanity and potential. It was a lovely day all round and many thanks to everyone involved in organising the day. Here's to the next 25 years of PMLD Link.

RESOURCES

Holiday, play and leisure guide

A free print version of our guide for parents Holidays play and leisure is now available from our helpline - exclusively for families of disabled children.

Packed full of useful information to help you plan to keep the kids occupied this summer holiday, the guide covers:

- where you can find suitable play and leisure facilities
- financial help that maybe available in paying for it
- ideas for suitable days out
- your child's rights to access playgrounds and leisure facilities
- finding financial help with holidays in the UK or abroad and finding holiday and travel insurance
- and short breaks for carers

Other printed guides for parents available from the helpline are:

- Relationships (and raising a disabled child)
- Understanding your child's behaviour
- Personal Independence Payments and other benefits at 16
- Aids and equipment
- Fathers

Call freephone 0808 808 3555. Monday-Friday 9:30-5:00pm to order your copy today!



New Contact a Family guide launched on the day Personal Independence Payments start

Contact a Family has published the latest in its range of benefits guides for families with disabled children to coincide with the launch of personal independence payments (PIP). PIP will replace disability living allowance (DLA) for those aged 16 plus from 10 June.



Initially PIP will only apply to those making a brand new claim. Then, from October 2013 DLA claimants whose existing award ends, or who report a change of circumstances, or who turn 16 will be re-assessed under the PIP system.

At first glance the new PIP may seem very similar to DLA. Like DLA it is not means tested and has two components - a mobility component and a daily living component which considers the need for care and assistance. However, PIP uses entirely new rules to decide whether you qualify for the benefit. There will also be a new way of assessing claims, normally involving a face-to-face meeting with a health professional.

Srabani Sen, Chief Executive of Contact a Family said: "Contact a Family has a team of expert benefit advisers who are able to offer detailed, one to one advice to

parent carers who want to find out more about this and the many other planned benefit and welfare changes.

We can also offer parents of disabled children a comprehensive benefits 'check up', to help those who might be missing out on vital income.

We want to reduce any worry and confusion about benefit changes and increase the chances of families with disabled children getting what they are entitled to.

If you are a parent of a disabled child and are worried about benefit and welfare issues or to get a copy of Personal independence payment and other benefits at 16, please ring the freephone helpline on 0808 808 3555 Monday, email us or visit our website. Don't be caught out by benefit changes."

Personal independence payment and other benefits at 16 <http://www.cafamily.org.uk/search-results/?s=Personal+independence+payment+and+other+benefits+at+16>

Alternatively try: <http://sn.im/27e7gw7>

Kidz up North is relocating to EventCity, Phoenix Way, off Barton Dock Road, Urmston, Manchester, M41 7TB (Next to the Trafford Centre)

Free Entry, Free Parking, Fully Accessible! Information on: funding, seating, beds, mobility, accessible vehicles, bathing, communication, sensory; sport and leisure and much more!

Come and join us at this free exhibition for children and young adults with disabilities and special needs, their parents, carers and the professionals who support them!

With more than 130 exhibitors, Kidz up North is a one stop shop offering the most up to date advice and information on equipment, products and services and much more.

The advice and information you gather at the events can help improve independence and quality of life.



Funding Point - In view of the current economic climate the Kidz Team have introduced a Funding Point to all the Kidz events. Here you can access information on alternative funding streams for equipment and much more.

Voluntary and service organisations will also be on hand with information on services, support, holidays, publications etc.

Free CPD seminars – a full programme of free CPD seminars for professionals and parents will be running alongside the exhibition. You will have the opportunity to update your knowledge and understanding on particular topics such as moving and handling, transition, sleep issues, toileting issues and much more. A full timetable will appear on Disabled Living's website and within the visitors free entry ticket as plans progress.

The visitor's free entry tickets will be mailed/emailed to those who have requested them approximately 6 weeks prior to the event. They will also be available to download from the website www.kidzupnorth.co.uk

To pre order your visitor's free entry tickets or for more information on any of our Kidz events contact the organisers: - Disabled Living Tel 0161 607 8200 Email info@disabledliving.co.uk www.kidzupnorth.co.uk

Other dates for your diary:

- Kidz in the Middle – 27th March 2014 – Ricoh Arena, Coventry
- Kidz South – 12th June 2014 - Rivermead Leisure Complex, Reading
- Kidz Scotland – 11th September 2014 – Royal Highland Exhibition Centre, Edinburgh.

IN THE NEWS

Frozen Light

Frozen Light is a new and vibrant theatre company for audiences with PMLD. We wrote about developing our show TUNNELS, in the Spring 2013 issue of PMLD Link. Since then we have had some exciting news and wanted to update the readers. Our work with TUNNELS was so successful that we decided to create a new theatre company out of our collaboration and have called this company Frozen Light. Frozen Light have recently been awarded an arts council grant to develop the business side of the company. This will mean we can lay the groundwork for our organisation to ensure the longevity of the company and bring exciting, cutting edge, sensory theatre productions for audiences with PMLD, to theatre venues across the UK and beyond. We have also received grants from the Odin Charitable Trust and D'Oyly Cart Charitable Trust which means we are able to begin booking our 2014 theatre tour of TUNNELS. If you would like TUNNELS to come to a theatre near you please get in touch via our Facebook page or e-mail below.

[www.facebook.com/
frozenlighttheatre](http://www.facebook.com/frozenlighttheatre)

frozenlighttheatre@gmail.com



Mencap and the PMLD Network launch guides to improve services for people with PMLD

In June, Mencap and the PMLD Network launched a series of how-to guides and films to help local areas better meet the needs of those with profound and multiple learning disabilities (PMLD).

Funded by the Department of Health, the guides are aimed at commissioners, families and those responsible for supporting or developing services for people with PMLD.

The guides address the recommendations made by Professor Jim Mansell's Raising our sights report (2010), which looked at services and support for people with PMLD.



There are eleven guides in the series. One is specifically designed for commissioners and offers practical help and advice on how best to provide services at a local level.

The other ten guides cover key issues relevant to people with PMLD and their families, including communication, support for families, advocacy, and personalisation. They give examples of best practice, and have sections to help families and others challenge and campaign where they are not getting the right support.

Six short films accompany the guides, providing insights into the lives of people with PMLD and illustrating the importance of making the changes outlined by the guides.

The Raising our Sights guides were officially launched at the PMLD Network Conference 2013 in Nottingham. Policy Manager at Mencap Beverley Dawkins, said:

'These guides and films will help raise the profile of people with PMLD, and their families. The stories will inspire families about what is possible in terms of services and support, and the practical information will equip them to ask for this. They are an absolute must-read and must-see for people responsible for commissioning services and other health and social care professionals, who are often not aware of how best to support this group of people.'

Download the how-to guides and watch the films:

www.mencap.org.uk/raisingoursights

Primary assessment and accountability under the new national curriculum

This consultation was launched by the Department for Education (DfE) on 17th July just as most schools were preparing to close for the summer holiday. Was this timing deliberate? It certainly happens a lot. The deadline for responses to the consultation is 11th October so schools should have enough time to comment.

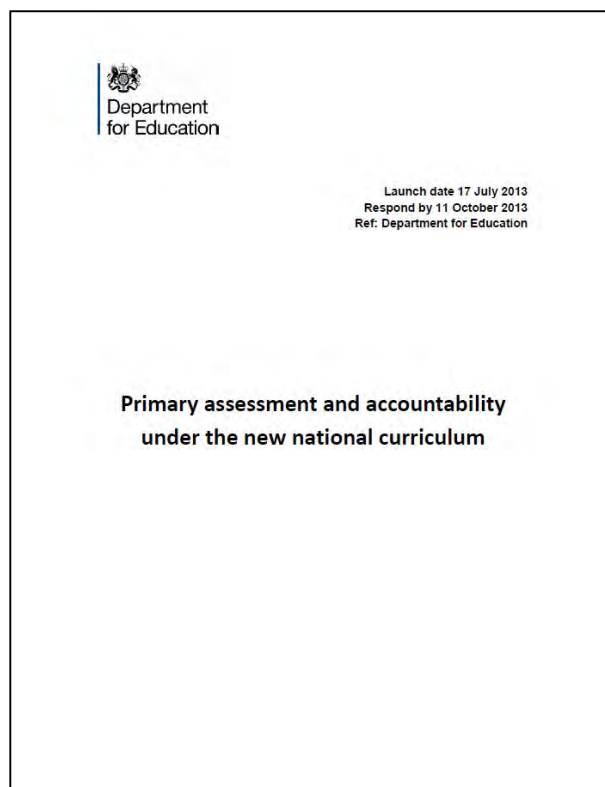
This is an important document ostensibly seeking views on how attainment in national curriculum tests should be measured and reported, whether there should be a new baseline to measure pupils' progress in the Reception year, and proposals for how schools should be held to account, with a particular emphasis on floor standards (but these are not relevant to special schools). It is not an easy read but all school managers and ultimately all teachers are going to have to understand the implications of what is written here.

This document applies to all schools, including academies and free schools. Academies and free schools are required to offer a broad and balanced curriculum, but are not required to teach the national curriculum. Their funding agreements require the academy trust to comply with statutory assessment arrangements as they apply to maintained schools. Pupils in maintained schools, academies and free schools will all be subject to the same statutory assessment system and accountability regime that will evolve after this consultation is complete.

Proposals

The document sets out a number of proposals or intentions, some of which have been in circulation for a while, and some which will be really challenging for schools, including special schools, such as:

- National curriculum levels will be removed and not replaced (not relevant for pupils with severe learning difficulties (SLD) or PMLD but see below about P Scales).
- The new national curriculum programmes of study set out what pupils should be taught by the end of each key stage (though you will be hard pushed to demonstrate their relevance to pupils with PMLD). Teachers will develop a school curriculum which is relevant to their pupils. Schools will be able to



introduce their own approaches to formative assessment.

- Teachers will continue to track pupils' progress and provide regular information to parents. How they do so will be for schools to decide, suited to the curriculum they teach. The DfE will not prescribe a single system for on-going assessment and reporting.
- Statutory national curriculum tests at key stages 1 and 2 will continue (not relevant for pupils with SLD or PMLD)
- It is proposed to report national curriculum test results using a scaled score, and compare pupils against the national cohort by decile. If this does come about, there could be implications for special schools from this model.
- In order to measure pupils' progress, schools will report how each pupil performs at key stage 2 compared to pupils with similar prior attainment
- The department's floor standards (not relevant to special schools) will focus on threshold attainment measures and value-added progress measures.
- Ofsted will focus their inspections more closely on schools just above floor standards (not relevant to special schools) and inspect schools with good performance on these measures less frequently.
- There is a proposal to introduce a baseline check of attainment in the reception year. If this is introduced, to avoid any increase in the overall assessment burden, the EYFS Profile would be made non-statutory. Although schools could still choose to assess using the EYFS Profile, they would not be

required to do so. (Special schools might welcome removal of the EYFS Profile which has no continuity with P Scales.)

As regards children with PMLD, or children with SLD for that matter, they are not mentioned by name but the following two paragraphs in the document are relevant and are worth considering. These are quotes.

Para 7.4. As is currently the case, there will be a small minority of pupils for whom the curriculum and assessment will not be appropriate. These pupils currently do not sit the national curriculum tests. Instead, teachers' judgements are reported, for example using P-scales. We will explore whether P-scales should be reviewed so that they align with the revised national curriculum and provide a clear route to progress to higher attainment.

Para 7.5. The accountability system must recognise the achievements of all pupils. Inspectors and others will consider the cohort of pupils when making judgements about a school. They will also consider the progress of pupils with very low prior attainment. We should ensure that data is published that will provide

information about these pupils' progress wherever possible, subject to protecting individual privacy.....

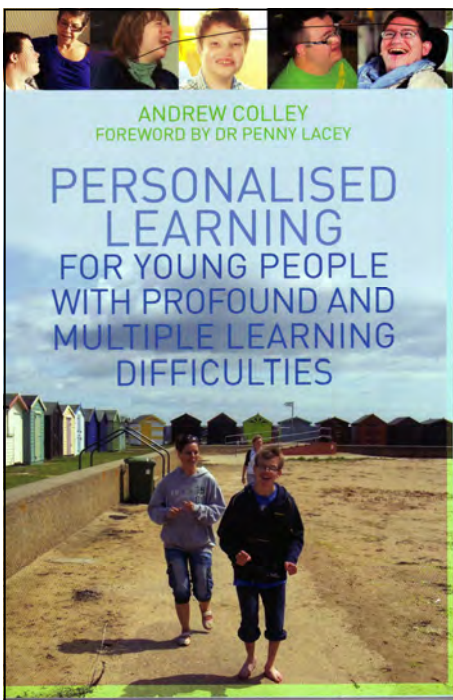
It is interesting that P Scales may not disappear like the national curriculum levels. A lot of effort and money has been invested in recent years in using these to measure pupil progress and also gauge standards of learning in special schools. So it's a case of watch this space to see what develops over the coming year.

Finally, the accountability system is going to be supported by the introduction by the DfE of a new data portal in 2015 which is intended to make the information about schools easier to access and analyse. Again, watch this space.

It is far too early to comment on these challenging developments in assessment and accountability but PMLD Link will bring you relevant information as and when this surfaces.

The document can be read here along with information how to respond to the documentation:

<https://www.gov.uk/government/consultations/new-national-curriculum-primary-assessment-and-accountability>



Title: Personalised Learning for Young People with Profound and Multiple Learning Difficulties

Author: Andrew Colley

Publisher: Jessica Kingsley Publishers

Date: 2013

Price: £19.99

Pages: 168

There will be a full review of this book in the Winter 2013 issue. Dr. Penny Lacey in her foreword applauds "What a lovely commonsense book!" Andrew Colley has written vividly about many aspects of educating pupils with PMLD in schools and colleges with a particular emphasis on teenagers. The book reveals a wealth of personal and professional experience and will surely be of interest to all people working with these pupils. The young people he talks about have PMLD, although most do not have profound physical impairments, and they present many challenges. This is not a dry academic text but a very readable book about appropriate curricula and teaching approaches and about the unique needs of each young person.

Department of Health responds to Confidential Inquiry into premature deaths

In two new publications, the Department of Health says that far more needs to be done across health and care services to improve the treatment received by people with a learning disability.

The reports published in July by the Department of Health were the Six Lives Progress Report on Healthcare for People with Learning Disabilities and the response to the Confidential Inquiry into premature deaths of people with learning disabilities.

These publications show that whilst some improvements have been made, people with learning disabilities are still experiencing poor care, and face unacceptable inequalities in health and social care.

Mencap responded to the Department of Health's report and believes that, whilst the government shows recognition of the inequalities identified by the Confidential Inquiry and expresses support for the majority of the recommendations, the response does not provide any set goals or timescales for tackling the issues highlighted by the Inquiry.

In particular, Mencap feel that the lack of commitment by the government to set up a National Learning Disability Mortality Review Body is a lost opportunity to learn from mistakes. Dan Scorer, Senior campaigns manager said:

'We are hugely disappointed at the government's weak response to the recommendations outlined in the Confidential Inquiry. This clearly shows the continued lack of value they put on the lives of people with a learning disability, especially compared to its strong reaction and detailed response to the Mid-Staffordshire scandal.'

The Confidential Inquiry showed that over a third (37%) of deaths of people with a learning disability were due to them not getting the right health care. How many more deaths at the hands of the NHS do there need to be before the government takes this issue seriously?'

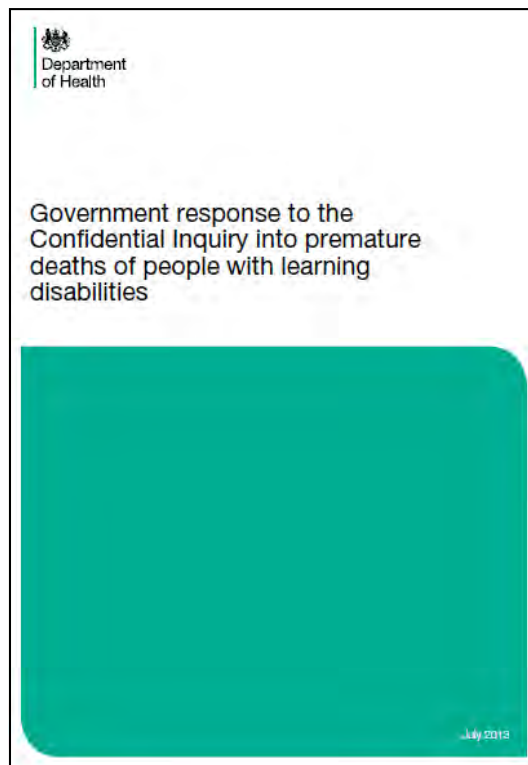
In March 2013, the Confidential Inquiry published the findings of its three year study into the deaths of people with a learning disability, which showed that 37% of the deaths of people with a learning disability in the research area were considered avoidable. Compared with the general population, men with a learning disability died on average 13 years earlier, while women with a learning disability died 20 years earlier.

Following the Confidential Inquiry, Mencap commissioned research from Professors Glover and Emerson of the Improving Health and Lives Learning Disabilities Observatory. The research found that over 1,200 children and adults with a learning disability continue to die unnecessarily every year in England because of discrimination in the NHS.

Mencap has campaigned for many years against discrimination in the NHS. In 2007, the publication of its landmark report, *Death by indifference*, led to an independent inquiry, headed up by Sir Jonathan Michael. Patients with a learning disability experience delays in diagnosis, delays in treatment, lack of basic care and poor communication by health professionals.

Read the Department of Health's Six Lives Progress Report:

www.gov.uk/government/publications/six-lives-department-of-health-second-progress-report



The keys to life

This text is based upon material that is currently on the PAMIS website – www.pamis.org.uk. PAMIS is the Scottish charity working with PMLD and their families. Members of PAMIS have been regular contributors to PMLDLink.

The Keys to Life was launched at Murrayfield on Thursday June 13th 2013 with due ceremony. Over 600 people attended the opening launch. Michael Matheson, the Minister for Public Health, officially launched the new strategy. The strategy includes over 50 recommendations across all aspects of a person's life areas but has a particular emphasis on health services to ensure that all health professionals, not just specialist staff, are working to meet the needs of people with learning disabilities.

PAMIS notes some key recommendations from 'The Keys for Life' that are especially relevant for people with PMLD.

Recommendation 26

That the Glasgow palliative care pathway is evaluated and rolled out nationally by 2015 to improve the care outcomes for patients with learning disabilities. This recommendation responds to the training and resources developed by PAMIS on the key issues facing people with PMLD, their parents and carers, during palliative care.

The Keys to Life also identifies as good practice PAMIS' work on the Bereavement and Loss Project, which provides resources on supporting bereaved people with PMLD.

Recommendation 43

That all stakeholders involved with people with PMLD commit to the implementation of the Scottish Quality framework for the delivery of invasive procedures, which will be launched in Autumn 2013.

Recommendation 44

That a sub group of the learning Disability Implementation Group is set up to increase the number of Changing Places toilets in Scotland to 100 by June 2015 using the conclusions and recommendations set out in the Scottish Government's report 'Changing Places Toilets' and by the implementing the UK-wide Changing Places Consortium's Charter in Scotland.

This sounds like exciting news from Scotland and it is good to hear that the campaigns of PAMIS and others are bearing fruit.

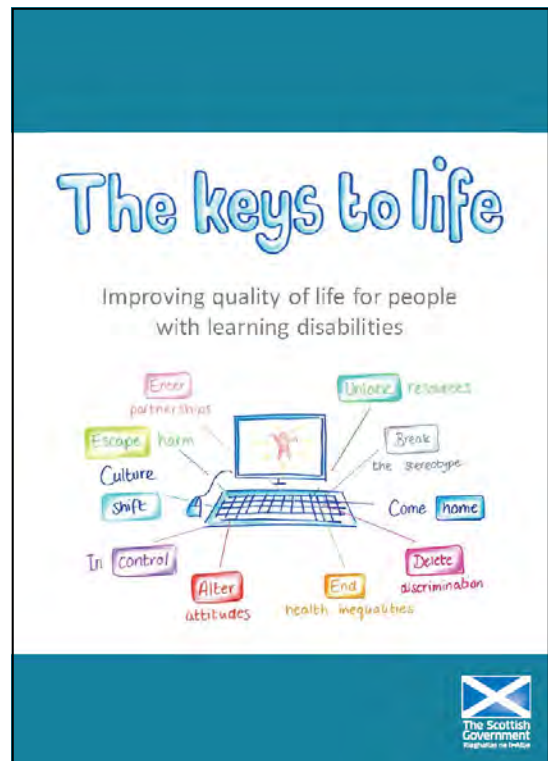
Continued from page 38

Read the Department of Health's Response to the Confidential Inquiry into learning disability:

www.gov.uk/government/publications/response-to-the-confidential-inquiry-into-learning-disability

You can find more information about the Confidential Inquiry and download the full report at the Confidential Inquiry website:

<http://www.bristol.ac.uk/cipold/>



Getting it right
for people with a learning disability

A charter for Clinical Commissioning Groups

All people with a learning disability have an equal right to healthcare.

All healthcare services should be accessible to people with a learning disability, with reasonable adjustments being made where necessary to support them when they are unwell.

All NHS services should value the lives of people with a learning disability, and provide a high standard of care and treatment.

By signing this charter, we pledge to:

- ✓ have a learning disability commissioning lead on our executive committee to monitor and coordinate service improvement
- ✓ provide an ongoing programme of learning disability awareness and mental capacity training to NHS staff
- ✓ meaningfully involve people with a learning disability and their families and carers in the planning and review of health services, and provide evidence thereof
- ✓ commission all NHS providers to implement reasonable adjustments, and use contracting mechanisms to check these are in place
- ✓ encourage and support all GP surgeries to offer annual health checks to people with a learning disability in line with the RCGP recommendations regarding process and consent
- ✓ ensure that all acute healthcare trusts are signed up to the Getting it right charter
- ✓ participate in the National Joint Health and Social Care Self-Assessment Framework (Learning Disabilities) and work closely with social care colleagues to ensure implementation
- ✓ work closely with local authorities to ensure that public health, social services, housing services, education, employment and NHS commissioning are well-coordinated and, where responsibilities overlap, aim to jointly deliver services
- ✓ identify people with a learning disability using NHS services, closely monitor equality outcomes for people with a learning disability and act to improve them when inequalities of outcome are identified
- ✓ strategically plan and commission specialist learning disability services based on sound evidence and best practice
- ✓ commission local services for children and adults with a learning disability and behaviour that challenges, and robustly monitor their quality
- ✓ ensure that the recommendations set out in the Department of Health's final report of the Winterbourne review and the accompanying Concordat are implemented locally in a timely manner
- ✓ ensure that the recommendations set out in the Confidential Inquiry into premature deaths of people with a learning disability are implemented locally in a timely manner

First CCG takes the pledge for equal healthcare

West Hampshire Clinical Commissioning Group is the first CCG to sign up to a charter to eliminate health inequalities for people with a learning disability in the NHS.

Mencap launched the new charter, Getting it right for people with a learning disability, after recent research revealed that there are over 1,200 avoidable deaths of people with a learning disability in NHS care every year.

Mencap has aimed the charter at GP-led clinical commissioning groups (CCGs), which are now responsible for the majority of the NHS budget after replacing Primary Care Trusts in April 2013.

The charity believes that CCGs will be key to eliminating health inequalities within the NHS - inequalities that result in people with a learning disability dying an average of 16 years earlier than the general population, according to the Confidential Inquiry into premature deaths of people with learning disabilities.

By signing the charter, West Hampshire CCG has committed to a number of pledges, including ongoing

learning disability awareness training for NHS staff in their area, supporting all GP surgeries to offer annual health checks to people with a learning disability, and providing evidence of what they do to meaningfully involve patients and their families in the planning of health services.

Dr Sarah Schofield, West Hampshire CCG chair, said:

‘We are delighted to be working with Mencap on this important initiative. West Hampshire CCG is working hard to ensure that people with a learning disability have equal access to good quality healthcare and the charter will help us focus our attention.’

The charter was developed in partnership with the Royal College of GPs, IHaL, Royal College of Nursing, College of Occupational Therapists and the Royal College of Paediatrics and Child Health.

The charter is part of Mencap's Getting it Right campaign, which has been running since 2010. The campaign aims to support local campaigners, health professionals, GP surgeries, hospitals and healthcare authorities to work together to make improvements in the quality of care they offer to people with a learning disability and their families.

For more information about the charter:
<http://www.mencap.org.uk/CCGcharter>

500th accessible toilet opened at O2

In May, the 500th Changing Places fully accessible disabled toilet was officially opened at The O2 by pop music fan Hannah James from Greenwich before The Big Reunion show.

Hannah, 28, is one of 230,000 people across the UK who benefits from Changing Places toilets. Changing Places toilets are larger than a standard disabled toilet and include a height-adjustable changing bench, a hoist and room for up to two carers. Where these toilets are not available, carers and families are often forced to change and care for someone in highly undignified and unsuitable conditions, such as toilet floors. Others simply choose not to visit public places where these toilets are not available.



The 500th toilet at The O2 is a key milestone for the Changing Places campaign, which for the past seven years has been calling for an increase in the numbers of fully accessible toilets in public places so that the people who need them can enjoy the same freedoms as everyone else.

Hannah James said: 'A toilet opening might seem like a weird thing to get excited about, but having access to one of these is a huge deal to people like me who have to worry and stress-out about when and where the next toilet stop will be. They make life so much easier. It was great that I got to celebrate afterwards by watching The Big Reunion show and seeing Atomic Kitten, B*Witched and 5ive perform.'

Top Paralympians, including Ade Adepitan, are supporting the Changing Places campaign. He said: "It was amazing to see so many disabled people cheering on Team GB at the London 2012 Olympic and Paralympic Games last summer. The fact that specially designed Changing Places toilets were available helped make this possible. Without them, many people simply wouldn't have had the opportunity to go along. 500 is a great landmark, but we need thousands to make a real difference."

Rebecca Kane, general manager of The O2 said: "I am extremely proud that The O2 is the host of the 500th Changing Places toilet, which highlights the venue's on-going commitment to accessibility. I am also delighted that as a result of this facility opening Hannah James could enjoy the show here."

The Changing Places Consortium, which runs the Changing Places campaign, consists of Mencap, PAMIS, Nottingham City Council, Dumfries and Galloway Council, the Scottish Government and the Centre for Accessible Environments. The official sponsor of the Changing Places campaign is Aveso Ltd. Aveso hope that its support for the campaign will help it achieve its target of 1000 registered Changing Places toilets within the next three years.

Find out more about the Changing Places campaign: www.changing-places.org

SHORT COURSES & CONFERENCES

Providers Details

Concept Training

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

EQUALS

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

Hirstwood Training

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

Sense

Jackie Bishop and Rachel Johns
Tel: 01179 670 008
Email: jackie.bishop@sense.org.uk
rachel.johns@sense.org.uk

September 2013

Title:	Learning Outside the Classroom
Dates:	<u>October 7th</u> Chorley, 21 st Birmingham, <u>November 11th</u> London, 25 th Manchester
Provider:	Concept Training
Title:	Practical & Effective Ways of Using Multi-Sensory Equipment
Dates:	20 th Edinburgh, 23 rd Belfast, 24 th Dublin, 30 th London, <u>October 1st</u> Birmingham, <u>November 20th</u> Manchester, 21 st Doncaster, 27 th Middlesbrough, <u>December 2nd</u> London, 9 th Glasgow
Provider:	Concept Training

Title:	Scope Early Years Conference
Date:	6 -7 th
Location:	Melbourne, Australia
Provider:	Scope
Contact	Web: www.scopevic.org.au Email: earlyyearsconference@scopevic.org.au

Title:	Conference: New Horizons for Mental Health in Intellectual and Developmental Disabilities
Date:	12 th - 14 th
Location:	Lisbon, Portugal
Provider:	European Association for Mental Health in Intellectual Disability
Contact:	Web: www.mhid.org info@mhid.org

Title:	Conference: A Practical Guide to Safeguarding Vulnerable Adults in Health Services
Date:	10 th
Location:	London
Contact:	Email: gemma@healthcareconferencesuk.co.uk

Title:	Conference: Best friends forever? Tackling 'mate crime' against people with learning disabilities
Date:	17 th
Location:	Nottingham
Provider:	Central Conference Consultants
Contact:	Tel: 0115 916 3104 Web: www.cclimited.org.uk

Title: Open Day for Professionals at the Children's Trust
Date: 19th
Location: Tadworth, Surrey
Provider: The Children's Trust
Contact: Michelle Baillie
 Tel: 01737 365 000
 Email: opendays@thechildrenstrust.org.uk

Title: Intensive Interaction (Phoebe Caldwell) Sensory Issues and Communication Using Body Language
Dates: September 19th Glasgow, October 7th Middlesbrough, 11th Chorley, 15th Manchester, 21st Cambridge
Provider: Concept Training

Title: Rebound Therapy for SEN, Level 2
Dates: 23rd and 24th
Location: Newcastle upon Tyne
Provider: EQUALS

Title: 3rd Croatian Symposium on Early Childhood Intervention
Date: 26-28th
Location: University of Zadar
Provider: In cooperation with the UNICEF Office for Croatia
Contact: Email: simpozij@hurid.hr

October 2013

Title: Building Resiliency: In Children, Families, Community and Professionals
Date: 2nd 3rd 4th
Location: Markham Ontario, Canada
Provider: OAICD
Contact: Email: registrar@ecrtno.ca

Title: Intensive Interaction (Jane Gurney) Connecting with people who are difficult to reach
Dates: 3rd Birmingham, 16th London
Provider: Concept Training

Title: Exploring, listening and talking hands (one-day course)
Dates: October 3rd 4th 8 -10th London, 21 - 25th Birmingham, November 11-15th Manchester
Provider: Sense

Title: Sleep Practitioner Training and 8 UK family stories about sleep deprivation (Special Offer 15% discount quote 'TB12/5')
Date: 7th & 8th
Location: Birmingham
Provider: The Handsel Project (UK)
Contact: Gemma Tel: 0121 373 3747
Gemma@handselproject.org.uk

Title: Developing Special Needs Practice in Early Years Foundation Stage
Date: 8th
Location: Chorley
Provider: Concept Training

Title: Positive Ways of Changing Behaviour
Dates: 9th Chorley, 21st Birmingham
Provider: Concept Training

Title: Intensive Interaction
Date: 11th
Location: Birmingham
Provider: Dave Hewett
Contact: www.intensiveinteraction.co.uk/

Title: **25th Annual Meeting of the European Academy of Childhood Disability 'From Basic Research to Policy'**
 Date: 10th-12th
 Location: Newcastle-Gateshead, UK
 Provider: EACD
 Contact: <http://www.eacd2013.org>

Title: **Autism and complex needs**
 Date: 15th
 Location: Birmingham
 Provider: National Autistic Society
 Contact: Email: nas@nas.org.uk

 Tel: 020 7833 2299

November 2013

Title: **iPods and iPads in Special and Inclusive Education**
 Date: 8th
 Location: Manchester
 Provider: EQUALS

Title: **Intensive Interaction Co-ordinators Weekend – 'catching up & moving on'**
 Date: 8th-10th
 Location: Malham, North Yorkshire
 Contact: www.intensiveinteraction.co.uk/

 Email: graham.firth@nhs.net
 Tel: 0113 3055160.

Title: **Using music and sound to develop interaction & engagement**
 Dates: 11th Manchester, 12th Birmingham, 15th London
 Provider: Hirstwood Training

Title: **FREE Seminars and Exhibition: Kidz up North**
 Date: 21st
 Location: Manchester
 Provider: Kidz up North
 Contact: Disabled Living Tel: 0161 607 8200
 Web: www.kidzupnorth.co.uk

Title: **Early Childhood Care and Education – 3rd Annual International Research-to-Practice Conference**
 Date: 21 – 23rd
 Location: Moscow
 Contact: Irina Morozova
 Email: info@ecceconference.com
 Tel: +7 (499) 946-38-05 (ext.108)

Title: **Multi sensory approaches to reduce Challenging Behaviour**
 Dates: 25th Edinburgh, 27th Birmingham, 29th London
 Provider: Hirstwood Training

Title: **Learning Disability Today: Seminars and Exhibition**
 Date: 28th
 Location: London
 Provider: Pavilion
 Contact: Tel: 01273434943
<http://pavilion-live.couk/learningdisabilitytoday-events/organisers/>

December 2013

Title: **Assessing Pupil Progress and Target Setting for Pupils and Students working at or below Level 1**
 Date: 4th
 Location: Bristol
 Provider: EQUALS

Title: **Past present future special education for learners with sld/ plmd**
 Dates: 6th & 7th
 Provider: florencealonghorn@gmail.com

Title: **Developing Maths Curriculum for Pupils with Very Special Needs**
 Date: 5th
 Location: London
 Provider: EQUALS

LONGER COURSES (with accreditation)

MA Education

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

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

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

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

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

MA Education Understanding Multi-Sensory Impairment

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

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

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

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

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

BPhil, PGDip and MEd Inclusion and SEN

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

Autism (Children) or Autism (Adults)

Distance Education

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

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

MEd includes a research methods module and a dissertation

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

BSc in Professional Practice

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

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

MSc in Advanced Practice

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

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

Postgraduate Courses in Profound and Complex Learning Disability

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

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

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

For further details: The University of Manchester, Lesley Jenkins Phone: 0161 275 33337 Email:

pld.distance@manchester.ac.uk

AdCert, BPhil, PGCert, PGDip, MEd.

Learning Difficulties and Disabilities (Severe, Profound and Complex)

Distance Education

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

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

AdCert, BPhil, PGCert, PGDip, MEd.

Multisensory Impairment (Deafblindness) - *Distance Learning*

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

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

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

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

Adults with learning disabilities who have significant and complex needs

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

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

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

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



Subscription prices for 3 issues are:

UK:	Personal	£18.00	Organisation:£25.00
Non UK:	Personal	£25.00	Organisation:£35.00

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The sum of: £.....

Commencing: and thereafter on 1st January annually until further notice

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We Welcome any Contributions to PMLD-Link

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

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

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

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

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

NEXT ISSUE

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- Well Being -

We would like to hear from you if you have any examples of people working together to improve the physical and mental health and health care of children or adults. We are keen to have full articles, letters and short reports – anything that could inspire or inform others.

If so, contact the editors:

Rob Ashdown
rob.ashdown@ntlworld.com

or
Jeanne Carlin
jeanne@jcarlin.karoo.co.uk

The copy date for all articles, information and news for the
Winter 2013 issue is the
Friday 15th November

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

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

About Us

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

Rob Ashdown	Former teacher and special school head teacher specialising in the needs of pupils with severe and profound and multiple learning difficulties
Alice Bradley	Has worked in schools, universities, health and social care settings in the UK, Canada, Thailand and various countries in Africa and Asia. Currently working in international development and as a volunteer with some UK charities.
Jeanne Carlin	Disability Consultant (freelance) and a parent of a young woman with PMLD.
Helen Daly	Mum to a young Adult with PMLD, previous career in Further Education for 20 years - including Curriculum Team Manager for Inclusive Learning and Developing an Improving Choice Programme for people with Complex Needs. Currently involved in carers groups in the Eastern Region, Learning Disability Partnership Board and associated projects.
Beverley Dawkins	Policy manager - profound and multiple learning disabilities, Mencap
Ann Fergusson	Researcher and tutor for severe learning difficulties and PMLD courses at The University of Northampton. Trustee of National Family Carers Network. Ann also has a family member with a learning disability
Chris Fuller	Founder and former Director of Bag Books: multi-sensory stories for people with PMLD, and previously special education teacher
Rachel Parry Hughes	Lecturer in Social Work, Goldsmiths, University of London, researcher in the field of profound and multiple learning disabilities
Penny Lacey	Coordinator of the University of Birmingham course in severe, profound and multiple learning difficulties; freelance consultant; Penny has a family member with severe learning difficulties
Loretto Lambe	Director of PAMIS an organisation in Scotland working with people with PMLD, their family carers and professionals who support them
Wendy Newby	Teacher and curriculum coordinator St. Rose's School, Stroud, a school for children with physical disabilities and complex health needs
Sue Thurman	Former NHS Speech and Language Therapist for adults with learning disabilities with a particular interest in PMLD. Now writes and trains about communication and is a Registered Intermediary assisting vulnerable witnesses to communicate at police stations and courts.

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PMLD Link publishes 3 issue per calendar year. You will receive all 3 issues no matter what time during the year you start your subscription. The issues are published for Spring, Summer and Winter. Reminders to renew the subscription for the next year are put in the Winter issue.

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If you wish to subscribe to **PMLD Link** please contact: Rob Ashdown rob.ashdown@ntlworld.com or tel: 01724 852818

PMLD LINK

sharing ideas and information

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

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