

# PMMLD LINK

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

**Spring 2008**

**Families**

PMMLD Link

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

## Families

<b>Guest Editorial:</b>	<b>Beverley Dawkins</b>	1
<b>Supporting Families: What do they want from the voluntary and statutory sectors</b>	Loretto Lambe	2
<b>Facing the Challenges: Some examples of past, present and future issues for parents of a young child with complex disabilities</b>	Brett Millett	5
<b>Day Service Redesign – the future?</b>	Jessie Lindsay	7
<b>Please remember - we never cease to be carers</b>	PAMIS parent member	9
<b>Getting It Right - Together</b>	Sofi Taylor	10
<b>The Challenging Behaviour Foundation</b>	Karen McCane	13
<b>Protecting Body Shape through Postural Care Investment in the Expert Family</b>	Anna Goldsmith	15
<b>Together at Touch Trust: Families' Experiences of a Multi-Sensory Creative Movement Programme</b>	Josephine Lay	18
<b>Communication: Soundabout Family Project: Soundabout and more.....</b>	Sue Simmonds	20
<b>A New Deal for Carers - Raising the profile of family carers as allies in improving the life chances of disabled people!</b>	Dr Phillipa Russell	21
<b>The Learning Disability Coalition</b>	Heather Honour	25
<b>Future Focus: Community Partnerships</b>	Rob Ashdown	26
<b>PMLD Network Email Forum: A Digest of Discussions November 07 - February 08</b>		27
<b>News</b>		30
<b>Resources</b>		34
<b>Reviews</b>		37
<b>Courses and Conferences</b>		39

PMLD Link relies on contributions from practitioners, parents, carers and everyone interested in the field.

**Spring 2008**

# GUEST EDITORIAL

## Spring 2008

### Families

**This edition of PMLD Link has families as its focus.**

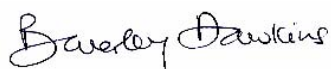
It is especially pleasing to see a number of articles written by parents of people with profound and multiple learning disabilities. Three of these were facilitated by Loretto Lambe (Director of PAMIS) and are written by families supported by PAMIS in Scotland. They highlight the thoughts and concerns families have for the way services are currently developing. Loretto has also provided an article on the evaluation of the services PAMIS provides and why families value them so highly.

We also hear from two further parents and the work that they are doing, from Karen McCane who set up the Challenging Behaviour Foundation, having gained much insight in to what support families need from her own experiences with her son. Also from Dr Phillipa Russell, eminent in the world of learning disability and long term campaigner for human rights, now Chair of the newly established Carers Commission set up by Gordon Brown.

And if all that was not enough, then three excellent contributions from the Touch Trust, Soundabout and the Postural care team providing insight in to how these organisations work with families, are really a great inspiration.

It's been a busy time in the world of policy and campaigns recently so I also hope you will take a look at the News section. You will find information on how you can have your say on cuts through the work of the Learning Disability Collation and news of the new PMLD Network website to be launched soon.

With all the usual round ups of new publications, resources and training, we hope you will enjoy this edition of PMLD Link!



**Beverley Dawkins**  
National officer for profound and multiple learning disabilities at Mencap

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## Supporting Families

### What do they want from the voluntary and statutory sectors

Loretto Lambe  
Director, PAMIS

Eight years on from the publication of *The Same as You? (Scottish Executive 2000)* – the report of the review of services for people with learning disabilities in Scotland – it is high time for organisations such as PAMIS to review their own services to ensure that they still meet the needs of people with profound and multiple learning disabilities (pmld) and their family carers. With this in mind we recently held a consultation day with family carers to find out from them what they wanted by way of services from PAMIS. This was part of an on-going consultation process where we are consulting widely regarding the future work of PAMIS. A similar day with all staff was held a few months earlier and we are also consulting with our Board of Governors, funders and the many professionals who work in partnership with us. We ensured that we had parents from the different geographical areas where we work and also parents of children, teenagers and adults. For me as director, it was a very interesting, stimulating and thought provoking day.

#### Our services - what families valued

We asked participants for their views on our current services, what they wanted us to keep, to drop or to expand and most importantly to identify for us what were their current concerns. The clear message to us was that families wanted us to do more not less and the main strands that emerged were: our *Family Support Service*, which we see as our core service, was very highly rated by all and they wanted us to not only continue but to expand this service; the training workshop programme, where we provide training on a range of health care topics, leisure, and policy and legislation, was seen as vital; campaigning for improved and in some cases additional services, was also seen as a priority and many mentioned our *Changing Places campaign* where we are working in partnership with other organisations, notably Mencap; transitions and in particular our *Futures Project* - which operates in Glasgow - was highlighted and families wanted us to roll this out to the other areas where we work; working on national and international issues was seen as very important and families welcomed the fact that our presence on government and local authorities' committees and working groups kept the issues around pmld on the agenda. Responding to consultations on policy issues and emerging legislation, for example, *The Adult Support & Protection (Scotland) Act, (2007)*, was another key aspect of our work that was valued, as was working with other voluntary agencies and networks.

#### New or additional work for PAMIS to consider

All of the parents present had some burning issues they wished us to take forward and/or work with them individually to resolve, which we will do. They also identified a number of topics/issues where they wished us to expand on our current work or to undertake new work. These included:

**Support to parents of very young children** – a parent mentoring scheme was suggested. We currently provide this in an ad hoc way but they wanted it formalised and if necessary for us to provide training and guidance for parents who would like to take on this role. Additionally, they asked that we provide training and information specifically on children's issues – we do this now in general but it was felt that some initiatives specifically for parents of young children would be beneficial.

**Transitions – all aspects of transition:** home to pre-school services; pre-school to school; school to adult services – referred to as 'the black hole of transition'; and home to supported living. Parents wanted us to provide specific support to them around these milestones but particularly around the move from child to adult services. They felt that it was highly important that this type of support was provided by the voluntary not the statutory sector as we could provide independent, unbiased, advice and support. As noted above we are currently exploring how we can fund and support transition workers in all the areas where PAMIS works.

**Challenging behaviour:** for some families this was their main concern. They felt that although

education services did go some way to address this, adult services were not geared up to providing programmes and strategies to meet needs. It was felt that there really was not the expertise in services to adequately support people with profound and complex disabilities and behaviours that challenge. One parent had received considerable support from The Challenging Behaviour Foundation and she and her daughter had contributed to a DVD on *Communication and Challenging Behaviour (2007)*. The parents asked PAMIS to provide training for family carers and staff, with the help of experts in the field, and to raise awareness of the very specific needs of this group of people who often are missed out in the ever changing pattern of service delivery. We agreed to work closer with the Challenging Behaviour Foundation to develop appropriate training and materials in response to this challenge.

**Support for siblings:** although we had only one sibling present at the meeting, he very clearly made the case for us to work with siblings. He saw himself as a carer for his brother and wanted more involvement with us as an organisation. Parents also supported the need for us to provide information and advice, and where relevant, training for siblings. It was strongly recommended that this should come when the siblings were young but should also be available throughout life, really whenever the siblings themselves wanted help and support.

**Health needs – specifically acute hospital admissions:** The enduring and complex health needs of all people with pml is a prime concern of all parents. Many commented on the additional stress and worry caused when their daughter/son is admitted to an acute hospital. Indeed the parents themselves are also hospitalised. The issues raised in Mencap's *Death by Indifference (2007)* report were very real for the families PAMIS supports. Additionally, the number of Fatal Accident Inquiries (FAIs) in Scotland in recent years and the number that are still on-going clearly show that the avoidable deaths of people with learning disabilities is a real issue of concern for us all – as in the Mauchland case (Dunbar 2003) and the Donnet case (Davidson 2007). As an outcome of the FAIs the Scottish Government have produced a number of recommendations around the treatment of patients with learning disabilities that all NHS Boards must implement. For further details on these – see [www.scotcourts.org.uk](http://www.scotcourts.org.uk)

**Needs of older carers:** parents stressed the need for staff in service settings to recognise the needs of all carers, to respect their views and to acknowledge and recognise the expertise of carers. This was one of the aspects of PAMIS'

work that they valued highly. They felt that when their daughter/son with pml was at school they were consulted and listened to (though not always!) but once they reached adulthood it was a very different story. The situation becomes very much worse when their daughter/son moves from the family home to supported living arrangements. They are often seen as having ceased caring and are expected to have minimum contact with their relative. Parents/carers are often referred to as, overprotective, interfering, concentrating on the negative and having unnecessary worries and concerns. One parent quoted the statistics on both physical and sexual abuse of adults with learning disabilities in managed settings and wondered why staff thought these were unnecessary worries. There is a considerable amount of work going on in Scotland on the needs of older carers, for example, a group of carers from South Lanarkshire have had a debate in parliament on their needs and have published a report (Martin & Johnston. 2005), to highlight the issues to the Government and service providers. We will certainly work with this group of carers to help us improve our support to older carers.

### Next steps

The above are just some of the issues we discussed throughout our consultation day. We have certainly taken note of all the concerns raised and will incorporate them into our future plans. Some can be done quickly and relatively easily, others require a lot of planning and additional funding. The parents present commented on how much they enjoyed meeting parents from other areas and on having the opportunity to raise their views openly with us as an organisation, they also welcomed the fact that their sons/daughters were at different stages in their lives and valued hearing the views of each other. We promised to try to provide more opportunities for parents to meet each other in informal settings though to meet funders' needs this may have to be around a chosen topic or theme!

The following three articles are from parents who attended this consultation day and they specifically wanted to concentrate on issues that are currently of concern to them.

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

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- Community Partnerships -

The copy date for all articles, information and news for the Summer 2008 issue is the 6th June

Please send contributions to:  
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- Money Matters -

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

## Facing the Challenges

### Some examples of past, present and future issues for parents of a young child with complex disabilities

Brett Millett  
PAMIS Parent member

We have at present two major challenges in our life as parents of Ruth. Firstly, our additional long term caring responsibilities. Secondly, striving to access resources which are good for Ruth and may in some instances provide us with a short break from caring. We have found that so far the latter has been the greater challenge and is likely to remain so. Our work backgrounds have helped us face the challenges. Maggie, my wife, is a medical secretary and I am a social worker now working part time in the voluntary sector. I know that every parent's experience will be different primarily as each child is unique but unfortunately also because it is a postcode lottery out there.

Our journey so far is a relatively short timescale and I have found that learning from other parents has helped me make progress. The beginning of my first paragraph was adapted from a recent comment made to me by Isobel Allan a parent and campaigner for carers through Carers Scotland and PAMIS. Isobel impressed on me that when your child needs life long support you never stop planning and working to make the situation better. It is helpful to accept this as part of your life; the challenges are not going to go away.

Our daughter Ruth is five years old, she doesn't speak [so far] but we know from her happy expressions that she loves being at school. When Ruth was nearly one year old we were shocked that she was diagnosed with *Cornelia de Lange Syndrome* [CdLS], a rare genetic condition [1]. At birth and for the first few months everybody considered that Ruth was of typical development. However, she has a severe learning disability, has mobility problems, and needs full support with all her day to day needs and close supervision to keep her safe.

Although I have some major concerns about support services I can also reflect that we are relatively well placed for Ruth in her childhood years. I have split the rest of this article into three headings: Health, Education and Support Services. Other parents I know have serious difficulties in one or more of these areas.

#### HEALTH

Health is probably the most important area and one we can all relate to and sometimes take for granted. Our work backgrounds certainly helped us in the early stages of moving past primary health care into the specialist medical world to find out the cause of Ruth's difficulties. Just after the

diagnosis Ruth suffered from pneumonia and there were a number of difficulties. We were in a spin of specialist health care and therapeutic intervention. Ruth remained on oxygen therapy until last summer. Maggie took the lead in keeping all this together after all she helps to keep three consultants on track in her day to day work. We have experienced excellent healthcare in particular from the community paediatrician and the respiratory consultant who has taken such a keen interest in Ruth's general health and development and beyond. She phoned us one Friday evening to say that she had noticed we were looking really tired at the last appointment and had obtained a short break caravan holiday through the Yorkhill Foundation. It was the first time we had been away for over three years without the oxygen equipment and I have happy memories of Ruth enjoying the space and freedom of Lindisfarne and it was a 'health promoting' experience for us all.

#### EDUCATION

The Pre-school Assessment Team were helpful in placing Ruth part-time in Langlands School Nursery and we had a home visiting teacher who was hands on and gave lots of good advice. Langlands is a special school for children with complex learning difficulties in Glasgow which has just moved into a new building with excellent new facilities. The school has a visiting speech and language therapist, much of the early focus has been on feeding and swallowing and at times we felt that there should be more input on communication. We are working together with the school to develop Ruth's communication system with the PECS system and Makaton. Ruth has learnt her first sign – more! Ruth's teacher is making use of the intensive interaction approach. She seeks to understand Ruth's developing

behaviour which is often repetitive and includes head banging and slapping and shrieking. The developmental approach is essential as the above could simply be interpreted as challenging behaviour and we would end up having meetings about the negatives rather than the positives.

Our experience meant that we did not get into the battle of special schools v. inclusion in mainstream schools. I know from my work experience how difficult that is for all concerned and it can be an unbearable situation for children and their families when a realistic and considered approach is not taken by education services. Baroness Warnock made her position clear that inclusion in mainstream schools is not right for every child [2]. I view that there needs to be a range of choices for families, specialist schools as well as inclusion in mainstream.

Ruth is getting on fine at school but we have been let down by our Education Services with regard to her *additional support for learning*, the term used in Scotland under our Education (Additional Support for Learning) (Scotland) Act 2004 [3]. We had the planning meeting last May and have had quite a job of chasing up the request for a *Co-ordinated Support Plan* [CSP] – a requirement under the Act. Enquire (The Scottish Advice Service for Additional Support for Learning) were a great source of help [4]. I feel that it was only a threat of reference to a tribunal that pushed our local education service to respond. There didn't appear to be any disagreement about providing a CSP for Ruth, the reasons given were restructuring education services, a huge backlog of requests and the long term sickness of the Head of SEN. This bureaucracy and lack of capacity was not helpful as we expected the CSP to be in place in the first term but it will be the summer term. Hopefully, it will be of value in co-ordinating Ruth's support for learning.

## SUPPORT SERVICES

Accessing support through social work services has been the biggest challenge. Social work services do not promote early intervention, they only appear to react to crises, even though economically this is not cost effective.

Ruth started her short breaks last month, just after her 5<sup>th</sup> birthday at Quarriers Countryview, a local respite centre, which is registered for children from 5 years old. Ruth is enjoying the experience especially the sensory room, hydrotherapy and of course time with the staff and the other children. The short breaks will give us more time with our son Sean who is nearly 14 years old.

However, getting there wasn't so simple. I am glad that I made a referral with a couple of years to

spare. It took over a year and a formal complaint to get an assessment. The social work management stepped in with an unwritten block on the request. They wanted us to go on a list for a foster carer even though they didn't have any available. I felt they were probably acting unlawfully but I didn't fancy a legal route and the inequality and lack of resources made it a political matter. I got great support from Johann Lamont, my constituency MSP and Alistair Watson, my local councillor. They had a meeting with the social work management who conceded and we got a contract for short breaks. That process took the best part of last year.

I have built a good relationship with the local generic occupational therapist for adaptations and seating for Ruth. She has been quite open that she doesn't have a great knowledge of disabled children but is prepared to find out information. She has now referred us for a grant to extend the downstairs of our home to make an ensuite bedroom for Ruth. We are on the waiting list as Glasgow doesn't have funding available at present, but at least we are on the list.

Finally, I wanted to mention *Contact a Family* (CaF) [6] and *PAMIS* [7], these organisations provide good advice to families particularly about support services and entitlements. It was through CaF that we found out about the CdLS support group based in Essex. It was great to meet other families and they have a network of clinicians and therapists who also attend the meetings and give specialist advice.

Liz Platt our local *PAMIS Family Support Service* co-ordinator has been helpful in providing information on local services, training and entitlements as well as providing a listening ear. *PAMIS* have family fun days too and I'm taking Ruth wheelchair ice skating in a couple of weeks. This will be a first for both of us and it nicely timed for 4pm just after Ruth's CSP planning meeting. Being on the ice should be fun for Ruth and for me, hopefully a de-stressing and not a leg breaking experience!

Brett Millett,  
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March 2008  
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## Day Service Redesign – the future?

Jessie Lindsay  
PAMIS parent member, Tayside

At a recent *PAMIS* meeting, the parents present were asked to comment on the services we received from *PAMIS*, from other agencies and also the statutory sector. I am very happy with the support I receive from *PAMIS* and want this to continue but, as parents we are all worried about the ever changing pattern of services, particularly services for adults. Although we have many concerns around service delivery and what the future holds, and what will happen to our daughters/sons with learning disabilities when we are no longer there to care for them is one of the main concerns of all parents. But, right now, my priority is around the proposals to make major changes to day service delivery. I am the parent of a young man with complex learning disabilities and epilepsy and I would like to highlight my concerns with regards to the Day Service Redesign that is currently taking place in my local authority.

Learning disability services throughout Scotland are changing, and in my area they are undergoing major changes. A five year action plan for the future of the services has been set in place to look at day opportunities for people with a learning disabilities, assessment and care management, accommodation and housing support needs, and respite and short breaks for carers. The action plan is being supervised by a programme manager appointed for a two year period. I would like to stress that consultations with parents were initially held in all three adult resource centres in my area and parents were invited to talk about how they would like to see services being delivered. As a parent I would also like to stress that I am in no way opposed to changes in the way services are delivered, if they are positive changes that will benefit and enhance the lives of the people who use the services.

### Living with the effects of service withdrawal

However, early moves in the plan have resulted in day service provision being withdrawn from people living in residential accommodation. This is a fundamental change and has a detrimental effect on the lives of people who have been attending the day centres for many years. It will also be seen by parents as a barrier to their son/daughter moving into residential services. As a parent I am worried and very concerned about how the individuals concerned will cope with the speed with which these changes have been imposed on them and the detrimental affect this will have on their emotional and mental well-being. Staff working in the residential settings are being asked to deliver day services but again the speed with which this has been imposed on them has meant they have not had adequate time to prepare for such changes and staffing levels are in many cases not adequate

to provide a quality service. Day Centre staff have been allocated time to support staff working in the residential setting to introduce some day service provision but again this is not ideal nor does it guarantee that staffing levels will be adequate to ensure an appropriate day service will be delivered.

### Community team or Day Centre - the assessment process and what it means

At the moment most people assemble at the day centre before either attending activities within the centre or going to college or to a community based group. The five year plan states there will be assessments carried out by care managers to determine whether an individual will be assessed for a place within a community based team or a place at the day centre. If the individual is assessed for a place in the community based team this means they bypass the centre and go straight to the place where the activity will be provided, ie college. This seems acceptable on the surface until you begin to think about transport, staffing levels and the logistics of providing community based activities within an existing staff team. At the consultation meetings parents were informed that the community team will be formed from the existing staff team working in the resource centres and as the number of people using the day centre would be less the staffing levels within the centres would be decreased.

My fears for my son, whose epilepsy is severe, is that because he attends a sports course at the college and other activities out-with the centre he will be assessed for the community team and this will mean he will have to relinquish his place at the day centre. I have had no correspondence or communication with care management in relation

to his assessment. He has attended the day centre for many years and while he enjoys his outings to various activities, as a parent, I have the security of knowing that he is safe and secure within a day centre setting which he is familiar with. He has drop attack seizures which mean he has to be supervised at all times and I have grave concerns that staffing levels in a community team would not be adequate to provide the care he requires. He often requires rescue medication for his seizures, an invasive procedure that must be administered in a safe environment and in a way that respects his dignity and privacy. I have concerns how this can be accommodated in 'an out and about' service. There is also the question of college. My son attends the college for one morning a week for a sports course. He enjoys this and gains a lot from participation in the activities however I would not like to see the college used as a substitute for appropriate day service provision. At the moment, if there is no provision in the current budget for increased staff support I cannot see my son being supported full time in a community based team as he currently spends half his time participating in activities in the day centre.

### **Service Expectation**

I thought that services were increasingly moving towards constructing services around individuals and ensuring service provision was person centred but to impose such a radical change on vulnerable people without appropriate warning or consideration is insensitive and in my view unacceptable. I would like to be informed as to

how an assessment on my son will be carried out to determine how his day service provision will be delivered. I would also like to be fully consulted about the nature and structure of service delivery he can expect because I consider the quality of the service to be a priority. As carers we receive little enough in the way of respite from our 24 hour, seven day a week, caring role. Therefore, we consider a five day a week placement in an appropriate service is not too much to ask for. The Scottish Government and our local authorities place great emphasis on consulting with parents and in two influential reports (2000 and 2006) stress the need for flexible day services and recognise that for some people with learning disabilities, notably those with profound and complex disabilities, there should be centre based 5 day week services.

Jessie Lindsay  
PAMIS parent member, Tayside

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## Please remember - we never cease to be carers

PAMIS parent member, Tayside

My son, who is in his early 40's, stayed at home with us in our family house in the country until his mid-thirties. He was involved in all aspects of daily living and led a very active and I believe, an enjoyable life. We had always assumed that he would live at home with us, his parents, and like many parents did not think that he would outlive us. As we now know, people with learning disabilities, including those with complex disabilities, are living much longer and parents have to plan for the future. Therefore, a few years ago we took the decision that we should seek suitable supported living arrangements for our son and as best we could we involved him in this decision making. He moved into a small group house with 24 hour support and it became apparent that to secure my rights and expertise as a parent and also keep my involvement in my son's life eg: help him to make decisions, guide and support him to be as independent as he could be, I would need to become his Welfare Guardian under the *Adults with Incapacity (Scotland) Act 2000*.

The move from our home to his new group house was a very stressful time for the whole family. When you care for someone 24 hours a day 52 weeks a year your life totally changes. People say it should be a time when parents can start getting on with their own life, obviously they have no idea of what is entailed in being a parent of someone with profound and complex disabilities. You worry if they are happy, if they are safe, if their needs are being met and you want to continue to contribute to their lives and continuing development. Soon after my son moved home his health deteriorated considerably and he had many hospital admissions. As his Welfare Guardian I should have been consulted about his medical care and any treatments being proposed, but this was not always the case. I feel that the staff see me as an over protective mother and someone who wants control, what I want is the best possible quality of life for my son.

### The Adults with Incapacity (Scotland) Act

This was the first Act that was passed by the Scottish parliament. It is meant to be a very empowering Act both for the person 'deemed without capacity' and also for his/her carers. There are many checks and balances in the Act which is guided by five main principles. Welfare Guardianship is an integral aspect of the Act and this has been seen by parents/carers of people with profound and complex disabilities as most important. PAMIS and other voluntary organisations have provided training for parents on the Act in general and on welfare guardianship in particular. They have encouraged parents to apply for welfare guardianship and supported us in our efforts to secure this.

### What is the status of Welfare Guardianship?

Welfare guardian status provides you with an official document, from the Sheriff's Court, that

empowers the dedicated carer of an individual, who is no longer considered to be a minor and assessed as being without capacity in some aspects of their life, to become their Welfare Guardian. The aim of the guardianship order is to help the carer to guide and support 'the adult' towards making correct decisions in their life. With the right support people with profound and complex disabilities can be helped to make their own decisions. Since becoming my son's Welfare Guardian I feel I do have rights as a parent but I have noticed certain discrepancies in the attitudes of care providers as to how they view this act. I feel that I am often ignored, excluded and to be honest that my status as Welfare Guardian for my son is not being fully acknowledged by care providers and their staff. It seems to me that Welfare Guardian is open to interpretation by care providers and this leads to misunderstandings, upset and confusion. I also feel that my legal rights as my son's Welfare Guardian are being ignored by the staff employed to care for my son and as a result I often feel excluded from my son's life.

I have met and spoken to many other parents and carers who have commented on the same subject. Do we, as carers, need to ensure that all care providers understand the powers of Welfare Guardianship and that this is included in the training of all health care professionals and care providers?. In fact, under the Act, staff from all sectors should receive training on the implications of the Act. From my experience and that of other parents, I believe that what we need now is for the Scottish Government to re-emphasise to all service providers the importance of complying with the Act and to remind them that they must (by law) involve welfare guardians in all decisions around the adult and respect the powers granted to the guardian.

PAMIS parent member  
Tayside

## Getting It Right - Together

Sofi Taylor

Nurse Specialist for Ethnicity and Culture

Getting the best possible support for their relatives has always been a primary concern for families – evidenced by the fact that many of our best known services were started by families. There can be particular challenges if you are not from the majority community in a country, especially if you don't speak the language. Here Sofi Taylor illustrates the importance of mutual respect and close working relationships if we are to get it right for all families. Sofi is originally from Malaysia, but trained in Glasgow and has lived in Scotland for much of her life. She is Nurse Specialist for Ethnicity and Culture and part of the Glasgow Learning Disability Partnership.

Many of the referrals I receive come with additional complexities, such as language problems, cultural and religious issues and difficult family situations. When I reflect on the experiences of clients from the Black and Minority Ethnic (BME) communities, it would be easy for me to think of the lack of services, the stereotyping and the level of discrimination that affects their everyday lives. However, there are many success stories, because good practice *does* happen when everyone pulls together. In my work with families from the refugee and other BME communities within and surrounding Glasgow, I have found that mainstream services can provide effectively for people from different communities if staff are prepared to be flexible, accept training and deal with the unexpected. Culture is also fluid, I believe, and far from being set in their ways, I've discovered that the families involved are open to change and respond well to new experiences. When a client is profoundly disabled, it is imperative for all the professionals involved to work together and focus on their needs rather than ours, if we are to get it right. I can best illustrate this by one of my earliest experiences.

Amy Wong, the third child in a family of four, was born in Hong Kong and had profound and multiple learning disabilities as a result of meningitis. Amy's family came to Scotland when she was 10 years old and she attended school in Glasgow. Deteriorating health meant regular hospital admissions, and eventually, when she was 17 years old, gastronomic feeding after attempts at nasal gastric feeding failed. This operation took place when she was 17 years old and she was under weight. Amy's family are Taoist, her parents do not speak English and at that time her siblings were not confident in their use of the English language. The family was isolated in all aspect of provision of services.

Her mother was the primary carer, but her own health was not good; she suffered from severe

backaches after many years of lifting her daughter on her own. Her feeling of powerlessness was compounded by her lack of English and a feeling that she was unable to advocate on her daughter's behalf. I arrived at her home on the day Amy was discharged from hospital after her gastronomic procedure.

My first few visits were filled with translating the feeding, cleaning and maintaining procedures from English to Chinese. This was done with the dietician, translator and myself. Even though I can speak some Cantonese, Mrs Wong and I speak a different local dialect. From the outset, Mrs Wong was extremely positive in her response, taking in all issues, asking a lot of questions and making suggestions that were appropriate to the care plan. She developed her own routine of care for her daughter that kept Amy well for many years. The physiotherapist and occupational therapist arranged for lifting equipment and advised on exercises for maintaining Mrs Wong's back muscles and on general health and well being.

After a review of medications with the GP, a communication book was established with symbols agreed with all members of the team caring for Amy and her mother. A search for day services and a round of visits commenced. I spent some time with Mrs Wong drawing up the criteria of support that she wished for her daughter. Finally, with social work support, they selected a small unit where they felt Amy would receive the right kind of support. The next steps were a series of training for the day centre staff on Amy's feeding and care routine, and also her hydrotherapy session, supported by a Community Care Assistant. Built into this was also bathing twice a week to support her mother's health.

There were difficulties along the way, of course. On one occasion Amy had to go to A&E as she suddenly became ill. We were all placed into an examination room and no-one came to see us.

Eventually, a nurse appeared and asked Mrs Wong for £46 for the cost of an interpreter before we could proceed. Despite my anger, I suggested I act as interpreter and we managed. When I apologised for this and for the length of time it had all taken, Mrs Wong told me that she was grateful, because the last time they were in this A&E they remained in the examination room for six hours without understanding what was happening, only to have a nurse point to the door at 3am for them to leave. They had never received any explanation of the results of the tests done, but felt powerless to enquire or complain.

One of the most challenging issues we faced was discussing Amy's future, especially as there were cultural issues as well as their relationship. Appearing unable to care for the disabled and elderly members can bring disapproval from the rest of the community. Mrs Wong was very much part of this community and held a respected position. I cannot say that it was easy, more like a step-by-step approach, but our relationship and history of sustaining care paid off. There were few services for the BME communities in Glasgow at that time. Mrs Wong was encouraged to review her situation, her expectation and wishes. Her own parents in Hong Kong were elderly and had expressed their wishes to spend time with her. Her siblings were of the same mind. Arrangements were made for Amy to attend respite and this enabled her parents to take a six week break to visit family. I acted as the in-between person when there was need to translate information from the respite unit to the family and vice versa. This was a success.

The move to respite care made it possible for the family to begin to think about Amy, as a young adult with her own life, moving on from the family home. It took nearly a year to find a home for Amy which met all the necessary criteria. There was a series of overnight and weekend stays before moving.

Teamwork between the family and the professionals was an integral part of the process, especially as there were so many people involved. At different stages, Amy's support team involved input from the occupational therapist, physiotherapist, community care assistant, dietetic service, epilepsy specialist nurse, interpreting and translating service, voluntary sector services for the Chinese Community, care managers, day service and residential care staff. My involvement lessened over time, but it took six years from my first meeting for us to reach a stage where my support was no longer needed. Last year I received a phone call to let me know that, sadly, Amy had passed away at the age of 27. I attended the

funeral and saw the family for the first time in many years. Mrs Wong spoke of the rich life her daughter had and thanked all the people involved in making it so.

Given the importance of family advocacy for people with profound and multiple learning disabilities, the quality of the relationship between the family and the professionals in this situation was crucial, as it always is. But how confident do managers and practitioners feel in building such relationships with families from communities other than their own? A primary aim of the Race Equality Steering Group from the Glasgow Learning Disabilities Partnership is to continually improve their service delivery to people from BME groups. In 2006, this group decided to evaluate information on race and culture (ethnic monitoring) in the Single Shared Assessment process and its effectiveness in contributing to the care plans of BME service users. Responses from a sample of staff in Adult Learning Disability Teams across the city indicated that they felt comfortable asking questions about ethnicity and religion in line with legal requirements. However, the majority felt that they lacked cultural and religious awareness and needed more information, support and training in their contact with BME communities. Requests were for advice and support, especially in the initial stages and in working with interpreters, as well as mentoring outside of line management. There was concern about the lack of diversity in the workforce and the feeling that practice and clinical team leaders may not be in the best position to support staff in their work with BME communities. Several people felt the need for additional race equality training, and support in translating training into practice.

Good communication between families and professionals is fundamental if they are to work well together. Studies shown that poor communication is a key factor in misdiagnosis, inappropriate assessments, non-receipt of welfare entitlements and the blocking of opportunities for disclosure of abuse.(Ahmed and Atkin, 1996; Baxter, 1997; CVS, 1998). Beliefs and values are integral to people's self-concept and affect their willingness to access services. However, stereotyped assumptions about different cultures can disadvantage people by failing to acknowledge individuality and choice (Ahmed and Atkin, 1996; Chandra et al 1998; Bignall and Butt, 2000). The lack of BME staff sends negative messages about status to professionals and families alike. A more diverse workforce can improve access to services and advise organizations on developing appropriate policy and practice. Professionals who feel ill-equipped to respond to people from BME communities indicate that they welcome the

support that can be offered by colleagues from other ethnic communities (Azmi et al, 1996a; Baxter et al, 1990).

A key piece of research by Hester Adrian Research Center (Azmi et al, 1996b) found that between 5 and 34 years of age, the prevalence of severe learning disabilities is approximately three times as high in the Asian (Pakistani, Indian and Chinese) communities as in the non-Asian communities. This study suggests a steady absolute and proportional growth of people with learning disabilities from BME communities from 2001 to 2021. By 2021 one in ten of all people with learning disabilities might belong to a BME community. With this to consider, the Glasgow Learning Disability Partnership is exploring further the future needs of these communities.

Sofi welcomes discussion with other people involved in similar work.

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## The Challenging Behaviour Foundation

Karen McCane

The Challenging Behaviour Foundation

*“My four year old has started biting the backs of her hands and head butting the wall. My GP told me not to worry about it “they don’t hurt themselves” and offered no help. I was so upset by his attitude - of course she is hurting herself, she has bruises and lumps to prove it! There must be something that can be done. Where can I get help?”*

*“My son goes to a residential school during term time but he’s home for half term. Yesterday he started smashing the house up and throwing furniture downstairs. I’m on my own and to be honest I’m scared. What can I do?”*

*“My son has challenging behaviour and is attending a residential school. The journey to visit him is a 7 hour round trip, so we usually stay several days in a month, see him intensively then return home. Now we are being told that when he leaves school there is no suitable provision for our son anywhere in the South East of England. They want to move him to a residential care home in Devon! But my husband is in his seventies and we cannot continue like this. How can we get our son back closer to home?”*

*“My daughter is so up and down. She has a severe learning disability and autism but no consistent support programmes due to the different settings she attends. We do have respite but it’s not enough. I’m on my last legs; I don’t think I can cope anymore....”*

These are just some of the types of calls taken on a regular basis by Gemma Honeyman, the Challenging Behaviour Foundation’s family support worker.

Gemma hears on a regular basis some of the nightmare issues facing families caring for individuals described as having challenging behaviour.

While not able to generate individual solutions for every caller, the role of the Challenging Behaviour Foundation Family Support Worker is to provide information, support and signposting around understanding and managing challenging behaviour for families caring for individuals with severe learning disabilities.

The work of the Challenging Behaviour Foundation has grown out of the direct experience of one family carer, founder of the Challenging Behaviour Foundation, Vivien Cooper.

Twenty one years ago, when Vivien’s son Daniel was diagnosed with the rare genetic condition Cri du Chat syndrome, the only information she was given was a single sheet of paper. This wasn’t much help when Daniel was pulling his curtains down, ripping his mattress open and eating the stuffing, or banging his head against the wall.

Like many parents of children with challenging behaviour, Viv and Steve struggled for years without adequate support. By the time Daniel was nine his special school said they were unable to meet his needs. At home, family life was disintegrating.

With specialist help, children like Daniel can learn ways to communicate that mean they don’t need to resort to challenging behaviour. But Viv and Steve received no help until they reached crisis point.

Vivien was so frustrated at the lack of information available to families, that she set up the Challenging Behaviour Foundation in order to provide information and support to other parents caring for children with severe learning disabilities and challenging behaviour.

Various professionals were approached and persuaded to write information leaflets on topics in which they had expertise. These leaflets, provided free of charge to parents, provide factual information, explanations and practical guidance.

Today the Challenging Behaviour Foundation now has a range of information sheets and DVD resources, website and regular newsletter and is in contact with over 900 families across the UK and nearly 2,000 professionals. The Challenging Behaviour Foundation also runs a professionals’ email network, an active family linking scheme and a parents’ email network.

“Many families caring for individuals with severe learning disabilities think they are the only ones dealing with severely challenging behaviour such as self injury, aggression, destructive and disruptive behaviours,” observes Gemma. “As well as the wealth of practical tips, ideas and information gleaned from other families, parents

often tell us that just knowing they are not the only ones is the biggest 'boost' they can get."

While currently operating nationally with just two full time members of staff, the Challenging Behaviour Foundation is now wanting to grow its team in order to take forward its work supporting families in obtaining specialist local support for their sons and daughters.

If a child or young person has been identified as displaying challenging behaviour, it is likely that he/she will have difficulty accessing many local community services. Many local authorities have traditionally responded to this by purchasing 'out of area' specialist places. These are places that may be able to meet the individual's needs but could be a long way from the family home.

Vivien knows from personal experience the huge impact this has on a family – her son Daniel spent ten years at a specialist residential school 270 miles away from home. And research has shown

that children placed out of area are more likely to move to adult services out of area. Daniel, when he left his specialist residential school, moved back to his home town – but this was only achieved through Vivien's hard work and determination.

Vivien's goal for the Challenging Behaviour Foundation is both to empower families with the information they need and to provide a catalyst for families and professionals to learn from each other.

"We need to get together, families and professionals working as partners, and support each other to make things happen."

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## Protecting Body Shape through Postural Care Investment in the Expert Family

Anna Goldsmith  
Course Manager

Postural care is *gentle, respectful* and *effective* at protecting and restoring body shape, muscle tone and quality of life for those people with a movement difficulty. By protecting body shape through Postural Care we can help to avoid secondary complications for individuals who have movement problems. Anecdotal evidence suggests that through empowering families and Personal Assistants we can protect people from secondary complications such as scoliosis, and respiratory and digestive failure. We mean to challenge the assumption that distortion of body shape is inevitable and we want to raise everyone's expectations for people with complex and continuing healthcare needs.

### The Principles of Postural Care

Out of 8,760 hours of the year, someone with a movement problem will spend approximately:-

- 1,140 hours in school or day care – a bit longer if you go to work
- 7,620 hours with the family
- 3,640 hours in bed

People spend 3 times longer in bed than they do at school or work and so it is here that we can really improve people's body shape, muscle tone and quality of life. At present people are left in easily *avoidable* damaging positions which can distort their body but through therapeutic night time positioning families can help to protect body shape and improve people's quality of life. The really exciting part of this is that we do not need specialist equipment either! If families know what the end game is they can use ordinary household items and make one extraordinary difference.

### Coleen's Story

Coleen's lying position used to be very destructive and she had very high muscle tone. Coleen's chest was distorting and she was experiencing a lot of chest infections and respiratory problems. Her family, gently and respectfully, altered Coleen's sleeping position and used household items to support her in bed. Coleen's muscle tone reduced, as you can see from the picture here, and the number of chest infections she had reduced dramatically. Coleen's family are incredibly proud of their success as Coleen's quality of life was much improved through this simple intervention.

The bottom line is that without good working relationships and adequate investment the chances of protecting body shape are very slim indeed. A failure to invest in families and PAs does

not make humanitarian or economic sense as surgery, specialised equipment, aids and adaptations are very expensive. Through giving families and Personal Assistants the right information and skills they can safely and humanely self manage Postural Care and protect people's body shape. We need to acknowledge that unless we are there at 3 in the morning our role is limited and families and PAs are the ones who will be doing the work.

Through measurement of body symmetry we can ensure that Postural Care is effective in protecting and restoring body shape, muscle tone and quality of life. The Goldsmith Indices of Body Symmetry are the only validated, objective outcome measures which do this (*Physiotherapy, 1992*). Through taking the Goldsmith measurements we make sure that we are accountable for protecting body shape and ensure that the approaches we are taking are effective. The use of a robust



postural care pathway is fundamental because there are a number of areas open to litigation at present (Bolitho vs. City and Hackney Health Authority). The suggestion that services require

development is not in any way a reflection on hard working and often frustrated staff, but rather an indication that this area may have been neglected in the past.

No one in services is currently accountable for protecting body shape and so families are having to do it for themselves. The following piece is written by two family carers who have been trained in Postural Care. They intend to support families in the North West to protect body shape and improve the quality of life for those they care for.

#### Pauline's Story

All his life my son has had intervention from physiotherapists, occupational therapists and orthopaedic consultants. They have all given advice and explained different theories and used different equipment and medication in supporting him to keep and develop a range of movements and to prevent contractures developing. We went along with all this, but suspected something wasn't as it should be when he was 9 and he started developing a marked scoliosis and a tightening of one of his arms. We did some research and persuaded our therapist that an assessment for a dynamic Lycra body suit wouldn't do any harm. She supported us in finding funding for the suit for 6 years. He sat straighter and his scoliosis improved, as did his digestion, elimination and the amount of coughs he picked up.

The shock came when in conversation, when he was 11 years old, we talked about him not being able to straighten his legs any more and that we didn't want him to become wheelchair shaped; we had already stopped him going in his standing frame as he became really agitated. The casual reply from the therapist was that he was already wheelchair shaped. This absolutely devastated us and we wanted to know why...we had followed all their advice, strapping him to a prone sleeping system at night and changing his position during the day at home. If he hadn't used a wheelchair, he wouldn't have become that shape.

Our therapist invited us to a demonstration of a different type of sleep system, which advocated supine sleeping with the body gently supported in as straight a position as possible. The theory behind it was that the chest was squashed and the body had no choice but to go into a windswept position in prone lying. We understood the logic behind it and our therapist ordered one for us. The rep came out, explained what to do and went away. We were left to use the system with no ongoing support and as my son had slept on his tummy since birth, in the neonatal unit, we found it difficult to get him to sleep on his back. This

caused a lot of friction in the family, as we agreed what we should be doing, but were often too tired to persevere when we weren't sure what we were doing. It also meant our younger son was often disturbed.

We did a little more research and found a study day on Postural Care. We went along and were excited. Here was something that made sense and explained what we were trying to do and why. We realised that all we needed was the day to day support and to know that it was a journey we were on and that it had to progress at our son's pace. I enrolled on the Postural Care Tutor course with another parent who was also struggling to use the sleep system and with day to day positioning. Once we started taking simple but objective measurements of body symmetry and using the sleep system how it should be used, it became obvious that changes were taking place that were undoing the damage that had been caused by my son lying on his tummy. But the biggest thing that made the difference was that we knew what we were trying to achieve and there was support for the days things didn't seem to go to plan.



This is what we want for all families who support someone who has movement difficulties and finds it difficult to change their position at night. We know this is gentle, respectful and that it works. It can be a slow process, but it has taken my son 13 years to become "wheelchair shaped". Based on the results and the effects of Postural Care so far, and the change in him, this is now part of our life and essential to his wellbeing.

#### Tricia's Story

My interest in postural care began in 1989 when we fostered a boy of 15 years who had received no postural care. He demonstrated every aspect of body asymmetry; His knees were contracted, hips dislocated, windswept body, fixed rotated scoliosis, greatly reduced lung capacity and severe problems with digestion and elimination of body waste. At the time I did not know this could have been prevented, or that it would still have been possible to improve his asymmetry. This young man died aged 18 years having suffered pain and discomfort throughout his life.

The child who is with us now came when she was 2 years old. Her body was symmetrical and I was determined to keep it that way. I followed all the advice given by therapists to the best of my ability, but the assumption was always that “nature would take its course” and that for some children asymmetry was inevitable. A mixture of high and low muscle tone has made positioning difficult through the years but we have tried and have had some success. I now know that our success would have been greater had we had more knowledge and training in postural care. Our expectations were limited therefore we accepted “the inevitable” to some degree.

A few years ago I went to a presentation on Postural Care and saw the sleep system being demonstrated. It made perfect sense to use night positioning as well as day time when so much of our time is spent in bed. With the support of our therapist we were given a sleep system and one hour’s instruction on how to use it. We persevered for nearly a year but without the expected benefits. Yes, it made a difference, but not to the extent we had hoped. The opportunity to attend a presentation by John and Liz Goldsmith was the turning point in our attitude to postural care. Finally someone was saying poor body shape was not inevitable. It could be prevented and a lot of damage already done could be corrected. It was never too late. Music to our ears!

Following that meeting I got the opportunity to train as a Postural Care Skills Tutor. I have since completed my training and am able to put what I have learned into practice with our own child. We are seeing the results despite the growth spurt she has had over the last year. Without 24 hour postural care, we would have been on the same road as our first boy and her life would have been poorer for it.

Now that I’ve trained as a Tutor I want to share what I have learned and help other families to acquire the knowledge and skills to protect their children’s body shape. No child should have to suffer when it is possible to stop the destructive forces acting on the body. It is never too early to start good practice in postural care. A baby or young child with expected limited mobility can be protected from body asymmetry with minimal intervention. Body distortion can be prevented, it is not inevitable and it is never too early or too late to intervene.

We are now both qualified Postural Care Support Tutors. We have presented our work to the Wirral Learning Disability Partnership Board and are waiting to hear from the Primary Care Trust about how we can work together to support families to achieve effective Postural Care Support for children and adults who have limited movement.

For a copy of the first Family Led Postural Care Pathway please email [annagoldsmith@posturalcareskills.com](mailto:annagoldsmith@posturalcareskills.com) or you can download it from the National Electronic Library for Health – [www.library.nhs.uk](http://www.library.nhs.uk) and search for Postural Care where you will find the pathway ‘I Got Life!’.

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Course Manager  
PCSP (UK) Ltd

## Together at Touch Trust: Families' Experiences of a Multi-Sensory Creative Movement Programme

Josephine Lay

Research Development Coordinator and Touch Session Leader

The Touch Trust is a pioneering arts charity based in the Wales Millennium Centre. It offers people (our guests) with profound and multiple disabilities (PMLD), autistic spectrum disorders (ASD) and complex needs, touch-based creative movement opportunities within our multi-sensory session room. The philosophy underpinning the Touch Trust is to make a space to enable self and relationship development through unconditional positive regard and praise for every choice, sound, movement and achievement made by each individual guest. For a more detailed description of the programme, please refer to our article in an earlier issue of PMLD Link; Aubrey & Price (2006).

In this paper we will look at the experiences of families supporting their children (young and adult) to be a part of Touch Trust and how these experiences compare to the programme's aims.

### **Aims of Touch Trust in relation to relationship development**

Throughout a Touch Trust session we encourage and enable connections between guests and their partners (family members/ carers). This can be through a multitude of interactions and subtleties including: making eye contact; using or mirroring facial expressions, sounds or creative movements; as well as by creating beautiful partnerships from the outset of the session through relaxation with gentle touch and massage.

Touch Trust draws parallels with Intensive Interaction (Hewett & Nind, 1994) in that it also derives from early infant-primary caregiver interactions to support the development of some of the "fundamentals of communication" with people with PMLD or ASD. Touch Trust also intends to use activities to stimulate guests' social, emotional and creative development and well-being to in turn support self and relationship development.

I had a recent, chance meeting with a child and his family visiting the Wales Millennium Centre. They arrived at the Touch Trust session room and were delighted with what they saw. As I welcomed them in, the child raced immediately over to a comfy, colourful mattress, lay down and began to make happy, contented sounds with his voice. His mother and grandmother then too began to visibly relax and sink into a bean bag each.

The mother then started to express her wish to be a part of a creative activity *with* her son. She reflected on the fact that as her son had got older-

he was now a teenager and in full-time special education, there seemed to be less and less opportunities available to them to enjoy activities *together*, as a family. What was also realised was the general lack of recreational activities available to children with disabilities and their parents.

As I described our new Saturday groups and our summer holiday sessions where children and their families/ carers come and have such fun for an hour, the mother became excited and enthused, saying, "That's exactly what we need!"

The chance meeting with this family led me to think about whether parents of children with learning disabilities and complex needs sometimes felt that they were viewed by some professionals/ or of society as care-givers primarily, which meant that the resources left for FUN, enjoyment and relationship development between them and their children were scarce. I then thought about what it is the Touch Trust offers not only to the guests but their circles of support so I reviewed the wealth of testimonials (letters; open-ended questionnaires; newspaper articles) we have had from parents about their and their children's experiences of attending sessions with us over the years. Here is a summary of that feedback and the themes that it suggested to me.

**Touch Trust appears to have enabled relationship development between parents and children both within and outside of the sessions:**

*"Our daughter would never let us give her a cuddle, but since Touch Trust, she allows us to hold her."*

*"We have lovely eye contact during the session and during the day before the session"*

**Developing an awareness of the Touch Trust session and in turn, further connecting with the world and people within it.**

*"My son is autistic and does not use speech. His world was bleak." "However, Touch Trust has given him a way of further connecting with his environment and the people within it therefore he himself is less isolated."*

*"At Touch Trust ... there are no limits to her progress. She seems to notice where she is, the lights and recognises everyone's voices."*

*"Touch Trust has taught her she is safe and has allowed her, in her own time, to make sense of the world. I used to long to hold and comfort her and now she's inviting us to do that."*

*"She is slowly starting to realise that there is a world out there that she is a part of."*

*"It (Touch Trust session format) encourages waiting turns and enjoyment of other peoples' achievements too."*

*"Everyone benefits from the praise and joining in the session."*

**Communication gains:**

For one individual guest, their parents suggest that the Touch Trust sessions have supported their adult daughter's recent communication developments, which has obvious benefits for both their child and them: *"We are finding our daughter is far more alert, using her eyes more and trying to speak more. The Touch Trust has helped us as parents immensely. If she is happy, we are happy."*

Reports from a local Special Education school trained in the Touch Trust programme highlight that, *"the programme is highly valued by parents and staff. Both report a wide range of benefits including pupils' improved social interaction, increased confidence... and reduced anxiety."*

**Relaxation/ energy changes:**

*"My daughter is calmer throughout the day knowing that she will be attending (Touch Trust) at the end of the day. Overall, she is happy during the session, leading up to it and after it."*

*"It (Touch Trust) gives her energy and relaxes her all in the same night!"*

*"I (parent) thought it was very relaxing. My son is calm and happy."*

*"My son relaxes for the whole hour and thoroughly*

*enjoys it."*

**For some families, Touch Trust has been a support and message of genuine warmth and positivity when they have felt isolated or otherwise surrounded by negative medical opinions:**

*"You were always so positive that it helped me (Mother) to cope."*

*"The sessions enable my daughter to be herself."*

*"With profound and multiple disabilities, you come away quite depressed from hospital visits. Touch Trust is in total contrast to that."*

A father writes about what he sees Touch Trust has done for his wife and baby daughter; *"Your optimism has lifted my wife and daughter's spirits-you did not accept the medical opinion of her virtually "vegetative" state and nor did we. The sessions at Touch Trust have proved that diagnosis wrong as does our daughter everyday."*

*"(At Touch Trust) she is valued as a human being and applauded for what she can bring to each session." "You and your staff have looked beyond her disabilities and recognised the beautiful human being that she is. May we say that yours is the first professional body to do this."*

It appears that not only our guests but their families and carers, as partners within the sessions, benefit greatly from coming to Touch Trust. The Touch Trust actively encourages individuals to express themselves freely, giving unconditional positive regard and praise. This holistic philosophy seems to be a "breath of fresh air" for guests and their families and can lead to developments in guests' self-perceptions and in their relationships with loved ones. With the space available to us at the WMC expanding, we hope to reach even more families and offer them these unique creative opportunities, which are so clearly needed and enjoyed by all.

Josephine Lay  
Research Development Coordinator and Touch Trust Session Leader  
Touch Trust Ltd.

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## Commusication: Soundabout Family Project Soundabout and more.....

Sue Simmonds  
Soundabout trainer

Many of you will be familiar with the work of Soundabout in schools. Soundabout believes that music has a powerful impact upon each of us and conjures up a space for feelings and creative expression, and that we can all use simple musical ideas in our shared interactions.

### Commusication: Family days

Only a few of you will know about some of the other work that Soundabout is involved in. One of our long standing projects takes place on several Saturdays in each term when the Soundabout base is open to families with children with a range of disabilities, especially those with profound and multiple learning disabilities and their whole family. More recently our sessions have embraced a much wider ability range.

If you were to come along on any of those Saturdays you would experience a welcoming and flexible atmosphere in which each person has the space and time to move, vocalise and creatively express themselves in an environment of improvised sound. The improvised nature of the session accommodates their preferences desires and their pace. The circular and flowing nature of the music created allows any person to contribute a sound at any time.

A use of verbal language which limits words to names and simple songs created from pupils initiations and around their actions means that the sessions are personalised to suit the members of the group. There is always an outline plan ....but plans are loose and can change. There are always a broad number of experiences to encounter and fabulous instruments to explore and listen to. Often the voice may be the main instrument and powerful microphones can pick up the smallest of sounds amplifying them or echoing them back.

The Saturday sessions which are now known as 'Commusication' sessions have been running for ten years. When we were thinking of designing sessions for families we invited parents to a taster session to discuss their own family's needs. We were particularly keen to create an opportunity for whole families to be welcomed in to the sessions and with this in mind set up sessions in four venues around Oxfordshire. A Soundabout trainer ran two sessions in different venues on each Saturday. This gradually changed as our numbers grew and a decision was made to use one venue which would become a very familiar destination for the children involved.

We now run all of our sessions at Thomley Barn the Soundabout base which is a beautiful Barn conversion set in rural Buckinghamshire, a safe and welcoming venue for families.

Sessions are designed for particular age groups and also divided if possible to create groups of children and young adults who will enjoy the experience of interacting with one another.

We run two sessions on each of the Saturdays, which may be for under eights or over eights, and an over sixteen's group called 'Songquest' as well as a newly formed group for young adults with Autism called 'Sound Space.'

The whole team is committed to providing a safe, empowering and enjoyable experience for each of our families.

It is difficult to choose who will work on those Saturdays. We all want to! Strong relationships have been forged over the years.

Soundabout offers training in Communication through Sound and simple music for staff working with those children who are functioning at the earliest stages of development.

Aside from the human element, the resonance board has become the main resource for Soundabout training. It is a fantastically simple piece of equipment which enables children to come out of their wheelchairs and relax and move as they choose on a surface that resonates with every movement: A wonderful experience for self expression, making a impact on your environment, body awareness and even better, a chance to be close to other pupils in the group.

If you would like to know more about the work of Soundabout or would like to find out more about our groups or help us in our work please make contact.

Sue Simmonds  
Soundabout trainer

[www.soundabout.org.uk](http://www.soundabout.org.uk)  
e-mail:info@soundabout.org.uk

## **A New Deal for Carers - Raising the profile of family carers as allies in improving the life chances of disabled people!**

Dr Phillipa Russell  
Chair, Standing Commission on Carers

### **Background**

'Carers are the bedrock of our society, remarkable people, a lifeline for the millions who rely on their compassion and dedication. As people live longer and disabled people lead fuller lives, greater numbers of people will find themselves in the role of a carer at some stage in their lives. The needs of carers and the future of social care are therefore priorities for all our citizens and for every community.' (Gordon Brown, 2006)

In 2006, the Department of Health's White paper, *Our Health, Our Care, Our Say*, announced *A New Deal for Carers*, an ambitious programme to improve the life chances of family carers. There was widespread recognition that the nature of family care was changing. An ageing population, improved survival rates of severely disabled children and changing family structures all posed new challenges – not least because expectations were higher and the personalisation of social care raised importance issues about the roles, rights and responsibilities of families.

The *New Deal for Carers* consists of four key components:

- A National Strategy on Carers
- New provision (and resources) for local authorities to provide emergency and other breaks from caring
- An Expert Carers' Programme
- A National Advice Line

The programme aims to achieve seven outcomes for adult social care services, namely:

- Improved health and emotional well-being
- Improved quality of life
- Making a positive contribution
- Choice and control
- Freedom from discrimination
- Economic well-being
- Personal dignity

The announcement of the *New Deal for Carers* (to be formally launched later this year) was followed by what has been described as the largest survey of carers' views in this country. Carers told us that they wanted:

- Recognition of their unique role as family carers, with respect for their own expertise alongside a recognition of their need for emotional and practical support.

- Information, advice and advocacy – a 'one stop shop', with streamlined assessment arrangements to avoid delay and duplication.
- Access to services – many carers referred to a 'post-code lottery'.
- High quality care for their relative (with a trained and competent workforce to deliver it).
- Regular planned breaks – and reliable emergency cover.
- Action to end the financial disadvantages associated with caring.

The responses were remarkably consistent across the country and across the different care sectors. They also underlined the challenge of transforming social care, not least because of inter-related policy initiatives and developments such as the *Independent Living Review* and a number of reports from agencies such as the Healthcare Commission and CSCI, which showed variable quality and quantity of care and support.

### **The creation of the Standing Commission on Carers**

The new National Strategy will have a ten-year life cycle, a period of time sufficient for significant change. But there was widespread recognition of the need to monitor progress and ensure ready access to emerging demographic trends or policy issues around family care. Therefore, in September 2007, Gordon Brown announced the creation of a new Standing Commission on Carers with the aim of:

- Ensuring that the voice of carers is central to the development of Government policy
- Contributing to, and monitoring, the development, drafting and implementation of the National Carers Strategy and the New Deal for Carers
- Exploring how carers will be affected by long-term issues such as changes in patterns of disability and related care; changing family

structures and of course the preferences of families themselves with regard to practical care and support.

I feel both immensely privileged and humbled to be appointed as the first Chair of the new Commission. As a family carer of nearly 40 years, I can look backwards (and forwards) and reflect on the 'family carers' agenda' - in the certainty that if we work in partnership, we can indeed improve the lives of family carers and those they support.

The past decades have seen major changes in the life chances of disabled people like my son. There are higher aspirations for 'ordinary lives'; there is commitment to access and equality within disability discrimination and human rights legislation. Disabled people expect to enjoy the same rights of citizenship, access to education and employment and enjoyment of personal relationships as the rest of us. We have seen the closure of many institutions and a vision of personalised services and individuals 'in control' of their own budgets and lives.

But what about family carers? As Lord Beveridge said when drafting his plans for a welfare state, '*The debate about what constitutes social care in a civilised society can never be static.*' And the nature of social care for families like our own has changed. The institutions (mercifully) are closing. People with learning disabilities like my son no longer live in long-stay hospitals. They are also not dying prematurely – even people with the most complex disabilities and health needs are now often living a normal life expectancy. This is real progress – but it also challenges our traditional assumptions about family care.

The most recent National Survey of People with Learning Disabilities shows us that 52% of adults with a learning disability live with their parents, a further 12% with other relatives. Many others are heavily dependent on friends and family for quality of life. We know from the *Epicure* and other studies that the population of very severely disabled children is growing. The '*new survivors*', as they were described in the Nuffield Bioethic Committee's working group on critical care in the neonatal period, are now living into adult life. But their health and well-being (and that of the families who support them) will be challenged without a range of appropriate services. We also know there are new groups of family carers - the Disability Rights Commission's Learning Disability Action Group has found that many people with learning disabilities are themselves becoming family carers – for partners, elderly relatives, friends and siblings! There is increasing awareness of the growing army of young carers – many concealing

their caring roles for fear of teasing and bullying at school and possible break-up of the family if social services get involved.

The reform of adult social care should also be seen in the context of similar developments in children's services. *Aiming High* sets out new expectations for disabled children and their families, with a strong personalisation theme and with an emphasis upon families as strategic partners. The life chances of many disabled adults are profoundly affected by their life chances as children and there are challenges in managing transition to adult services better for children (in particular those with PMLD).

But perhaps the greatest challenge lies in how we balance the 'life chances' of both family carers and disabled people. We know that many family carers experience financial hardship in carrying out their caring roles. In a survey for the Elizabeth Nuffield Educational Fund (2006), which preceded my guide to the Carers Equal Opportunities Act, I found that 85% of respondents of working age wished to either work (often part-time) or to study (often to gain qualifications for a different form of employment more compatible with caring responsibilities). We know that 80% of family carers are of working age, but 58% give up work in order to care. At a time when there are major demographic changes, an ageing population and a significant skills gap as identified by the Leitch Review, it must make sense to enable those family carers who wish it to remain in the workforce. Premature retirement damages pension prospects, it diminishes quality of life for carers and cared-for and as noted above, it damages the nation by diminishing the workforce.

And of course, paid work is simply not an option for some families. Recognition of the financial consequences of caring came '*top of the list*' during the consultations on the National Strategy. In particular, the Carers' Allowance was felt to be '*not fit for purpose*' and carers felt passionately that they should be regarded and recognised as *working* in the best interest of their relatives. Income and employment are two key themes under discussion in the four Task Forces which were created to help provide an evidence base for the National Strategy. There is general agreement that financial disadvantage and poverty should not be the consequences of family care (vital in a changing population of older and more severely disabled people).

The creation of the Standing Commission on Carers is crucial in encouraging family carers, the voluntary sector, local and national government and the health service to work together to find



better solutions and to genuinely raise the profile of family carers as 'partners in policy-making'. Partnerships matter as never before within the Government's transformation agenda.

We have unique opportunities ahead of us! The 'New Deal for Carers' includes a revised and revitalised National Strategy for Carers. The *Expert Carers' Programme* and a *National Help-Line and Information Service* should raise the profile of family carers as experts in their own right and hopefully ensure that they receive the high quality information, advice, advocacy and practical support that they need for their caring roles. There is also additional money to address the long-term challenge of providing essential short breaks and emergency cover for carers.

A radical review about definitions (and funding) of 'social care' will be challenging. Money matters and the Government's commitment to a Green Paper on the future funding of social care is vital in acknowledging the growing diversity of family carers and the greater complexity of disability now cared for at home. For many families with children or other relatives with PMLD, transformation of social care cannot be achieved without significant changes in the way in which health needs are met. The Darzi Review offers an important opportunity to consider the interface between health and social care (not least because of the wider trends across the NHS to reduce dependency on hospital treatment and deliver a wider range of treatment programmes and care in the family home).

Family carers must indeed become 'partners in policy making', not least to avoid the misunderstandings and low expectations of people with complex disabilities and health problems as identified by MENCAP in *Death by Indifference*. The development of the *Expert Carers Programme*, as part of the *New Deal for Carers* offers a new opportunity to build on existing good practice but also to recognise the importance of shared training in order to build confidence in a wider range of community services and to maximise health and well being. As one mother of a child with PMLD commented:

*'Families and staff in the services they use must be trained, must understand risk management and must work together to ensure that everybody has maximum quality of life. We found that the short break staff were willing, but afraid of providing intimate care. They saw 'litigation' hanging over their heads! But shared training meant shared confidence. 'Rebecca' enjoys her short breaks as much as we do. Personalised support is the way forward – but how can we ensure that the skills are*

*there for people with the most complex needs? Individual budgets will mean a huge expansion in the workforce – and people with PMLD must have high quality and trained supporters if they are to have the kind of life envisaged for disabled people in the 21st century.'*

[Personal communication, 2008]

### Looking to the future – exploring future options for family carers

In developing new systems for supporting carers, we will also be looking at international experience – the UK shift to personalised services with an emphasis on individuals being 'in control' of their own lives and of course the budget which underpins them is mirrored in some of our European and North American counterparts. Some Governments provide some financial support for carers similar to our own DLA for *disabled people*, ie non means-tested, awarded on nationally agreed criteria, acting as a 'passport' to other allowances and benefits. In other countries, local authorities can access regional or national funds to meet the additional care needs of people with complex disabilities.

Many other European nations have clear expectations about the respective roles and financial contributions of the local authority or health service *and* the disabled person or family carers in the provision and funding of any support. Some provide tax incentives – or tax credits – in order to support carers who wish to remain in employment. We already have enhanced tax credits for disabled children, which have been widely welcomed. But every new option means careful scrutiny and we need to explore what is working well now for carers – and of course for disabled people in the context of the United Kingdom. In particular, we must ensure that the international commitment to personalisation of services acknowledges the additional needs of people with PMLD and ensures that families are appropriately supported (and respected) as carers.

And finally – we are hopefully looking for a more equal society where disabled people and family carers have real value and are able to lead 'ordinary lives'. As noted above, the nature of social care is changing. If we want to avoid crisis-intervention, family breakdown and (dare I say it!) the reinvention of institutions, then we have to re-focus on the *life chances* and *health and well-being* rather than the mere *maintenance* of family carers in their caring roles.

In December 2007, the Government published *Putting People First: a shared vision and commitment to the transformation of adult social*

care. As this concordat notes, we are all now working towards the creation of a *'high quality, personalised system, which offers people the highest standards of professional expertise, care, dignity, maximum control and self determination'*. Families matter – to everyone. If we are to achieve positive change, we need to work in partnership – with local authorities, with providers and of course with the NHS service and national government – in order to find good solutions to big problems. The Standing Commission should provide a real and constructive forum for an informed debate about these issues. In particular it should raise the profile of family carers as important allies of disabled people and recognise both their long-term commitment to giving their relatives valued lives *and* (importantly) ensuring that they are not exhausted and financially disadvantaged because of their caring roles.

The launch of the Prime Minister's National Strategy and the *New Deal for Carers* later this year mark an important and growing interest in the health and well-being of both family carers and

those they support. The test of a more proactive approach to family carers (and a recognition of their roles) will be the quality of life experienced by those with the most complex needs. The Standing Commission on Carers, the inspection and regulatory bodies and the outcomes of the Darzi review, *Valuing People Now* and *Aiming High* (combined with the Children's Plan) all offer real opportunities for a long-term programme of service development and improvement.

Further information on the Standing Commission on Carers and on the New Deal for Carers can be found on [www.scoc.dh.gsi.gov.uk](http://www.scoc.dh.gsi.gov.uk) or e-mail the secretariat at [scoc@dh.gsi.gov.uk](mailto:scoc@dh.gsi.gov.uk).

## The Learning Disability Coalition

Heather Honour  
Campaign Manager

Some of the country's leading learning disability organisations have come together in a new alliance, the Learning Disability Coalition, which was officially launched last year.

The coalition consists of 10 organisations – People First, the National Forum for Learning Difficulties, Mencap, Sense, Turning Point, the Downs Syndrome Association, the Association for Real Change, United Response, the Foundation for People with Learning Disabilities and the British Institute of Learning Disabilities.

Its main aim is a very simple one: to make sure there is enough public funding to enable people with learning disabilities to have the same opportunities and choices as everyone else. And there is growing evidence that, despite all the warm words and fine policies from central government, this is not happening at the moment.

The recent Commission for Social Care Inspection report on the State of Social Care indicated that most local authorities are tightening their eligibility criteria for those receiving social services. More than two thirds now only provide support to those whose needs are 'substantial or critical'. Three are funding critical care only. Three quarters of authorities are facing significant cost pressures in services for people with learning disabilities.

What this means is that the quality life for people with learning disabilities, and their families, is under threat because of funding shortages. All this has been compounded by cuts in college places, growing evidence of unequal health care treatment – as highlighted in Mencap's 'Death by Indifference' report – and restrictions on a range of local services by cash-strapped councils.

Yet this is happening at a time when the government's commitment to the needs of people with a learning disability has apparently never been greater.

*Valuing People Now* is revamping the original White paper which stressed the importance of rights, independence, choice and inclusion. It enshrined the principle that people with a learning disability should be at the centre of all decisions made about them and *Improving the Life Chances of Disabled People* in 2005 laid down vital principles about equal rights and treatment for people with a learning disability and sets a target for all disabled people to have genuine equality by 2025.

Putting People First sets out a policy of self determination for users of social services and

promotes personal budgets, previously known as Individual Budgets. And the Prime Minister has set up a Standing Commission on Carers under the chairmanship of Philippa Russell and will publish a carers' strategy in the Spring.

Another initiative, the cross government Independent Living Strategy sets out to improve disabled people's experiences and life chances. The strategy aims to improve access to health, housing, transport and employment as well as promoting the personalisation of services. But like the important report of the Joint Commission on Human Rights there is an awareness of a gap between national policy and people's real experiences.

The Report of the Joint Committee on Human Rights into the human rights of people with learning disabilities sets out an appalling account of how they are deprived of their fundamental human rights. It says that adults with learning disabilities are more liable to social exclusion, poverty and isolation...and that limited resources are undermining efforts to implement the aims of Valuing People Now. On the money front it says that the question of resources must acknowledge "legal obligations to respect the dignity and rights of service users". This is exactly what the Coalition has been saying.

There are two strands to our work:

### 1. Making the case for more funding for services for people with learning disabilities

We need hard evidence about why and how the demand for services for people with a learning disability has increased so that Government cannot ignore the resource that are needed to meet their policy promises.

This means looking at demographic and social trends such as :

- Improvements in neo-natal care which have led

to an increase in the number of babies surviving with profound and multiple learning disabilities;

- The higher prevalence of learning disabilities among South Asian communities;
- The large increase in the numbers of people living past the age of 50 when their families may no longer be around to care for them in the family home;
- Single parent households;
- The changing views amongst carers about a life time's commitment to caring for their family member;
- Increasing expectations amongst people with learning disabilities coming through transition, and as a result of Government policies like Valuing People.

## 2. Cuts to services

- Finding out what is happening on the ground and demonstrating a system under pressure by highlighting cuts to services, the extent to which people are excluded from services and the effect that under-funding has on individuals.

The Coalition has been highlighting cuts to services at a local level and drawing attention to the impact of tightening eligibility criteria.

We are undertaking two surveys. The first is a survey called "Tell It Like It Is" is to get a clearer picture of what the impact is on individuals of cuts to services. We need to be able to demonstrate the hardship encountered by people with learning disabilities and their families. We also need case studies with which we can confront Government. Our second survey is looking at what is happening to learning disability budgets in local authorities so that we know which councils are likely to cause difficulties for their residents. We hope to have collected this information by the end of March and if you are interested in taking part please contact [info@learningdisabilitycoalition.org.uk](mailto:info@learningdisabilitycoalition.org.uk).

The strength of the new coalition – which is completely independent - is that for the first time all the major learning disability organisations will be speaking with one voice on strategic issues that affect the sector. We will focus on just a few key issues. And we hope this means our views will have greater political clout than if they came from a single organisation.

For more information look at our website on [www.learningdisabilitycoalition.org.uk](http://www.learningdisabilitycoalition.org.uk) where you will find the latest news on what cuts are taking place where.

Heather Honour Campaign Manager

## PMLD Link Future Focus

### Community Partnerships

Rob Ashdown

The Summer edition of PMLD-Link has the all-inclusive theme of 'community partnerships'.

As you know the editorial team likes to receive articles from practitioners, parents, carers and everyone interested in helping people with profound and multiple learning disabilities. We would especially like to hear from you if you have any examples of people working together to improve the lives of children and adults with profound and multiple learning disabilities and to make things easier for their families and carers and others who work with them.

Community partnership can denote a range of activities. Do you know of an interesting case of a particular service or voluntary organisation working in innovative ways with parents or carers? Do you have an example of several agencies talking to one another so that they can deliver coordinated provision? Are you aware of local community groups coming together to bring about a significant change in people's lives? We are interested to know of anything big (for example, innovations across a whole county or region) or small (for example, supporting advocacy for a single individual). Do you know of any other examples of partnerships that are worth sharing with other readers? We would like to have clear accounts about why these partnerships developed, what worked and what did not work so well, and what they may achieve in future.

Articles should be no more than 2000 words. Equally, we would be happy to receive short articles that are only a few hundred words or news items about forthcoming events. We do get really good articles from PMLD-Link readers and we look forward to receiving your contributions.

Please send your articles to me by 9<sup>th</sup> May at:

[rob.ashdown@ntlworld.com](mailto:rob.ashdown@ntlworld.com)

Rob Ashdown

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**PMLD Network Email Forum  
A Digest of Discussions  
November 07 - February 08**



The PMLD Network Forum is an open email discussion group who focus on issues relating to PMLD. It has been as busy as ever over the last few months. Here is a summary of the key themes that have come up:

### 1. Sensory budgets

Someone who works at a residential unit asked for information about funding for sensory equipment. Suggestions included:

- They could try and get funding from their local authority.
- They might be able to get grants for individuals from local charitable trusts (The local Community Learning Disability Team might have a list).
- The parents could form a group and apply for funding. A funding officer at the local council might be able to advise them.
- They could set up a social enterprise company and make the sensory service available to others at cost. They might be able to get funding for this through the Department of Health.
- They could do some fundraising locally, for example run an event or link up with a local radio station or Rotary club. This would help raise awareness as well.

### 2. Post 16 Transition in education for young people

Someone carrying out research wanted to hear people's views about the issues faced by young people with PMLD at the transition stage from school to post 16 provision. Here are some key points and quotes from the forum members:

- Many people said there was a lack of any real choice and the person often has to fit the provision rather than the other way round.
- Someone said there was a lack of local FE which could support her daughter's needs. She wanted continued educational input for her daughter up to 25 but day services could not offer this. She said her daughter was unstimulated in day services.
- Others said that FE provides social opportunities for young people and a break for

carers and that if local provision does not meet needs then you can look out of county.

- Someone said that at school a lot of effort is put into developing communication skills and then there is not commitment to carry this on when they leave.
- 'To achieve her own potential she needs to continue in a multi-sensory environment to develop her communication skills'.
- The level of physiotherapy and speech and language therapy and other services are not maintained once the young person leaves school and goes to college.
- Whereas clinics for wheelchairs and orthotics might have been on-site at special school, at college people have to miss a day for an appointment.
- Adult services are not becoming involved in future planning early enough.
- Transition services and post transition services vary widely according to local resources.
- Blatchington Court Trust is based in Sussex and works with young people who are blind or visually impaired. They are concerned with continuing education, skills development and advocacy <http://www.blatchingtoncourt.org.uk/>.
- National Education Advocacy Partnership works with and advocates for individuals who are either blind or visually impaired T: 01959 522094.
- Funding is a barrier to post 16 provision in an FE college: changes in Learning and Skills Council (LSC) funding means that colleges are less able to run courses at low costs. The LSC is also less willing to permit non-accredited courses which particularly affects learners with PMLD. Even when courses are available there might not be the funding for 1:1 support. There are also problems of access eg. there might not be a Changing Places toilet in the college.
- Someone said that people tend to stay where they are between 16 and 19 so the real change is the post 19 transition to adult services.

### 3. The extension of direct payments

There was a Department of Health press release announcing that the Health and Social Care Bill

helps to deliver the government's commitment to extending direct payments to 'those groups who are excluded under the current legislation'.

Currently direct payments are not available to people lacking capacity, as defined by the Mental Capacity Act 2005. A person who lacks capacity is, however, able to access direct payments via an independent service user trust.

If the Bill becomes law then it will allow a direct payment to be made to a 'suitable person' who can receive and manage the payment on behalf of a person who lacks capacity.

#### 4. PMLD service user involvement project

Someone working on a project to look at ways of involving adults with PMLD in meetings and planning services asked if anyone was doing similar work or had information to share. She hopes to produce a toolkit with practical information to help people with PMLD become more involved. Here is some of the information and quotes from forum members:

- An intensive interaction approach can begin the process of supporting individuals to develop engagement, take the lead in their communications with others and express their preferences. Visit [www.intensiveinteraction.co.uk](http://www.intensiveinteraction.co.uk). In combination with this approach a range of materials and resources can help people with PMLD begin taking control and communicate choices, eg. objects of reference, photos, art, music, video. Regular 1:1 opportunities to explore these is important.
- Similarly someone else said that they have 1:1 sessions where different experiences are tried and responses recorded and analysed. The choice is then integrated into the person's life. These ensure that the person has some say in the things that directly affect them eg. trying different fabrics and establishing that someone likes silky materials and then incorporating this choice into the person's life. It has a direct impact and does not involve sitting in long meetings. The agenda is set by the findings of these experiences.
- Useful articles: 'Creative Groupwork: towards self-advocacy' by Vic Forrest in the book 'Voices of the Voiceless: Person-centred approaches and people with learning disabilities' by Jan Hawkins and 'From the Inside Looking Out: an Intensive Interaction Group for people with profound and multiple learning disabilities' B Learning and T Watson (2006).
- 'We must be realistic about how much people

with PMLD understand the process and think very carefully about the personal and observational evidence that families/supporters can provide when big decisions are being made.'

- 'To enable individuals with high support needs to participate authentically in meetings: it will take time – no deadlines to tick someone else's boxes and everyone involved in the meeting will need to be totally present, person-centred and proceed at the pace of the individual concerned'.
- Some were concerned that actually being at a meeting might not always be appropriate – it could be tokenistic.
- Someone said it is good to make the person who the meeting is about 'real' to those who are making decisions for them eg. if the meeting is about services there could be some video footage showing what they like and don't like. Someone else suggested that photos of video of the person could be sent in advance of the meeting illustrating the important issues and needs to be dealt with at the meeting.
- 'It is useful to make sure that people who are discussing young adults with PMLD do meet the person: perhaps a short introductory session with them at the start of the meeting.'

#### 5. Shifting up of the term PMLD

- The discussion about PMLD service user involvement prompted someone to comment that 'in the past few years there seems to have been a shifting up of what the term PMLD means and as a result those at the bottom end of the scale are being even further marginalised':
- Some people said that other terms such as complex needs, high support needs are not helpful as they are even broader terms.
- The PMLD Network agrees that the above terms are not helpful. They think the term PMLD is useful if used correctly. See the PMLD Network definition of profound and multiple learning disabilities (PMLD): [www.mencap.org.uk/html/campaigns/PMLD/Meet\\_the\\_People\\_definition.pdf](http://www.mencap.org.uk/html/campaigns/PMLD/Meet_the_People_definition.pdf)
- Someone said 'it is almost like any child with multiple impairments that cannot follow the standard curriculum is now called 'PMLD'. The end result being that none of the children have their needs met.
- Someone had done some research on PMLD provision and had a large number of mainstream schools say they had PMLD students which turned out not to be the case. They said it showed the term wasn't understood and this painted an inaccurate



picture of what provision was available in the area.

## 6. Wheelchair Vouchers

Someone asked how Wheelchair Vouchers work and what the pros and cons of them are. Later in the discussion they also expressed concern that people were expected to accept a certain style of wheelchair 'that is driven by current policy rather than lifestyle and care needs.'

- Someone said that the voucher scheme might not be suitable for people who are growing as they are expected to keep the wheelchair for 5 years.
- A couple of wheelchairs were recommended: The Panther wheelchair which is produced by R82 (it is a child's wheelchair but R82 produce larger wheelchairs too) and the Foam-Karve wheelchair from Delichon which is custom fitted to fit the individual and can be attached to a variety of bases.
- Someone shared the concern that the needs of carers and the person's lifestyle weren't considered. Someone said they had to fight to get a Panther wheelchair as it wasn't one that was usually supplied.

## 7. Writing in 1<sup>st</sup> person

Someone wanted comments on the use of writing in the first person in documents for people with PMLD. This prompted much discussion. Information and quotes from the forum were as follows:

- People said it depended on the purpose of the document and the intended audience. A number of people said they use the first person for personal communication passports and that they would write professional reports in the third person
- A small scale study carried out by Sense Scotland over 10 years ago showed that 100% of the parents surveyed liked the use of the first person in Passports.
- 'One of the functions of a passport is to help the person make themselves known and understood...so it should be as direct as possible'.
- Writing in the first person means 'not hiding behind detailed professional language to cover up gaps, but taking responsibility for finding out things you don't know.'
- People said it was important to be clear where information came from - how much evidence is direct and how much inferred.
- Concerns included that in speaking for people

with PMLD we 'may indeed be presuming an awful lot and again not valuing the person'.

- Someone said that Care Plans and Lifestyle Plans often 'speak in two voices at once' – this can be useful when 'it is difficult to be sure that some aspects of a person's communication behaviour are being interpreted accurately'.
- It was mentioned that a personal communication passport needs to follow best practice guidelines on all fronts. See [www.communicationpassports.org.uk/index.html](http://www.communicationpassports.org.uk/index.html) (then Resources, then Good Practice/ Auditing Passports)
- 'A report or passport is not worth anything whether it is written in the first or third person if the process of collecting and interpreting and cross-checking the content is not rigorous' – 'See what I Mean: guidelines to aid understanding of communication by people with severe and profound learning disabilities' BILD:Kidderminster. ISBN 19021519418 was recommended.

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

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

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

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

## NEWS



### Changing Places campaign - Update

The Changing Places campaign is calling for Changing Places toilets – with a bench, hoist and plenty of space - to be installed in all big public places in the UK.

Changing Places toilets are needed by people with profound and multiple learning disabilities (PMLD), their families and carers, and other people who need assistance to use the toilet. Without Changing Places toilets thousands of disabled people and their families have to return home after a few short hours, or are forced to carry out changing on dirty toilet floors.

#### New Changing Places toilets

At the end of 2007, the Tate Modern and a public toilet block in Westminster opened Changing Places toilets - the first in central London. There are now 44 Changing Places toilets on our UK map.

#### Policy

We hope to hear soon whether our proposals to incorporate Changing Places toilets into the revised British Standard 8300 for public building design have been accepted. This would be a significant step towards securing a change in planning regulations.

The Department for Communities and Local Government (DCLG) recently published their public toilet strategy 'Improving Public Access to Better Quality Toilets: Strategic Guide'. This includes information on Changing Places toilets (see page 34).

#### Awards

At the end of 2007 Martin Jackaman, a member of the Changing Places Consortium, won the Guardian Public Servant of the Year award for his work on Changing Places both in Nottingham and nationally. This really helped to raise the campaign profile.

The Loo of the Year awards presented special Changing Places awards for the second year running. The Trafford Centre won the overall Loo of the Year award - fantastic news for us as they provide a Changing Places toilet. This should send an important message to other venues.

#### Consortium news

The Centre for Accessible Environments has joined the Changing Places Consortium, bringing their valued expertise on accessible design with them. See [www.cae.org.uk](http://www.cae.org.uk) to find out more about them.

#### Get Involved!

There is still much to be done to achieve our goal of having a Changing Places toilet in every big public place across the UK. Find out how you can get involved at [http://www.changing-places.org/get\\_involved.asp](http://www.changing-places.org/get_involved.asp)

### New strategy for children's palliative care services

The Department of Health has recently published 'Better Care: Better Lives'. It announces a new investment of £20 million to improve palliative care services for children with life-limiting or life-threatening conditions. This is in addition to funding already allocated to PCTs to improve palliative care services, as part of the 'Aiming High for Disabled Children' programme.

For more information see the Every Disabled Child Matters (EDCM) website: [www.edcm.org.uk](http://www.edcm.org.uk) (Go to the news section and read the news item posted on 19<sup>th</sup> February).



## Death by Indifference - Update

March marks the first anniversary of the publication of *Death by Indifference*, Mencap's hard-hitting report about the unequal health care people with a learning disability receive in the NHS, and the tragic consequences this can have. A lot has happened in the year. Most importantly that people are talking about healthcare people with a learning disability.

The Health Secretary, Alan Johnson, met with Jo Williams and David Congdon from Mencap in December to discuss the campaign, and the government is waiting to hear the results of the Independent Inquiry that has been taking evidence from all over the country on the healthcare treatment of people with a learning disability.

Learning disability is in the NHS operating framework, and doctors, nurses and other health professionals across the country are developing and sharing good practice in treating people with a learning disability. And the families of those whose deaths were described in *Death by Indifference* will be receiving the results of the health ombudsman's investigation shortly.

We need to use this momentum to get meaningful change to the way people with a learning disability are treated in the NHS. We still need to see national action on:

- Training on learning disability for all NHS staff
- Annual health checks for all people with a learning disability
- Monitoring of people with a learning disability

The bravery of the six families who shared their loved ones stories to make *Death by Indifference* such a powerful report has had a big impact. Mencap is working to make sure it also leads to big changes.

For more information please visit [www.mencap.org.uk/deathbyindifference](http://www.mencap.org.uk/deathbyindifference) or call 020 7696 6918.



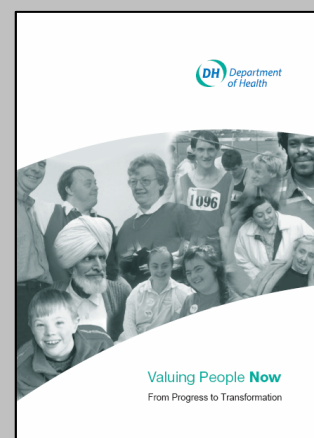
## Valuing People Now Consultation

The government finally launched its *Valuing People Now* consultation in December 2007. The original *Valuing People* white paper, published in 2001, set out the government's strategy for people with a learning disability. Most people thought that the policies in *Valuing People* were good, but while some things have got better, the lives of many people with a learning disability have not changed, particularly for those with profound and multiple learning disabilities (PMLD).

*Valuing People Now* is designed to improve the policies behind 2001's White Paper.

The PMLD Network submitted a response to the consultation which closed at the end of March 2008. The response focused on the needs of people with PMLD.

To get a copy of the PMLD Network response please contact [bella.travis@mencap.org.uk](mailto:bella.travis@mencap.org.uk) or T: 020 7696 5549



## Local Cuts: Help us to 'Tell it Like it is'

Mencap, as part of the Learning Disability Coalition, is looking for personal stories about how people with a learning disability are affected by cuts to their services.

From all over the country Mencap and other coalition members get facts and figures about cuts and lost choices. But they do not get to hear enough personal stories that can be used to remind decision-makers that their decisions affect real lives, not just budgets.

The Learning Disability Coalition has developed a form called 'Tell it like it is' which you can use to tell them your stories. They want to hear from you, for example, if the person you care for or support has lost a service that they used to receive, if they have started being charged more for services, or if they now have to pay for services that used to be free.

If you have a story to tell, please request a form by calling Mencap on 0207 696 6952 or emailing [campaigns@mencap.org.uk](mailto:campaigns@mencap.org.uk). Your story or name will not be used without your consent.



## Joint Committee on Human Rights report on learning disability

The Joint Committee on Human Rights has published their report, 'A Life like Any Other? - Human Rights of Adults with Learning Disabilities.' The report highlights the appalling lack of respect for the human rights of people with a learning disability.

To read the report: <http://intranet/html/businessunits/ccf/campaigns/documents/JCHR.pdf>

## National Family Carer Network (NFCN) - Update

National Family Carer Network (NFCN) links groups and organisations across England, that support families that include an adult with a learning disability, by maintaining a database of organisations, running events and consultations, and sharing information.

It was established by HFT Family Carer Support Service in 2004 with Section 64 funding from the Department of Health, and for three years the work was coordinated by Helen Dorr. Helen worked with HFT and NFCN's steering group to develop the project's important role and activities, giving family carers a strong voice, and during this period NFCN made an important contribution to raising the profile of family carers at a national level.

With the support of the Valuing People Support Team and national charities, NFCN is now establishing itself as an independent organisation. In July 2007 it was registered as a company, with three initial trustees from the project's steering group, and should soon be registered as a charity. Joan Cox came into post as Director in January this year, to work with the trustees to manage and develop the new organisation, and to maintain its activities.

Groups and organisations supporting family carers are encouraged to make contact by email: [joan.cox@hft.org.uk](mailto:joan.cox@hft.org.uk), phone 0117 968 6698 or writing to NFCN, c/o HFT, Merchants Landing, Bristol, BS1 4RW

Website (being redeveloped): [www.familycarers.org.uk](http://www.familycarers.org.uk)

The National Family Carer Network is hosted and managed by



## **Inquiry into the Government's carers strategy**

The Work and Pensions Committee have launched an inquiry to examine the effectiveness of the Department for Work and Pensions' existing approach to carers. The deadline for written evidence was 3 April 2008 and oral evidence sessions will take place in the summer.

Key areas likely to be covered by the inquiry are:

- Information, guidance and advice
- Income and Carer's Allowance
- Employment strategy and training opportunities
- Equality, recognition and discrimination

For more information about the Work and Pensions Committee and to read its published reports visit [www.parliament.uk/parliamentary\\_committees/work\\_and\\_pensions\\_committee.cfm](http://www.parliament.uk/parliamentary_committees/work_and_pensions_committee.cfm)

## **New Short Break services for families with disabled children**

Government ministers have announced the start of a 3 year transformation in short break services for families with disabled children.

Last year, 'Aiming High For Disabled Children' was published by the government. It contained a commitment to spend £280 million on short break services. Another £90 million will be spent on improving equipment, transport and facilities for short breaks.

21 local authorities have been selected to receive the majority of this funding in the first year. These local authorities will make immediate improvements to their short break services. They will deliver best practice, which will be rolled out across the country by 2011.

The 21 pathfinder authorities are Bradford, Bolton, Bournemouth-Dorset-Poole (joint pathfinder), Brighton, Dudley, Derbyshire, Enfield, Gloucestershire, Gateshead, Halton, Kent, North Yorkshire, North Tyneside, Nottinghamshire, Norfolk, Sutton, Sunderland, Telford and Wrekin.

All other local authorities will receive an average of £50,000 to help them prepare to transform their short break services from 2009.

This is an important step by the government towards providing much-needed support for families with disabled children. However, it is important that this funding paves the way for more and better short break services for families with an adult son or daughter, who often get no short breaks at all.

Read about the new plans on the Every Disabled Child Matters (EDCM) website: [www.edcm.org.uk](http://www.edcm.org.uk) (Go to the news section and read the news item posted on 28 January 2008).

## **New guide on relationships and caring for a disabled child**

Caring for a disabled child can put a strain on relationships. Contact a Family have produced a new guide 'Information for Families: Relationships and caring for a disabled child' for parents and professionals with information and ideas about looking after family relationships.

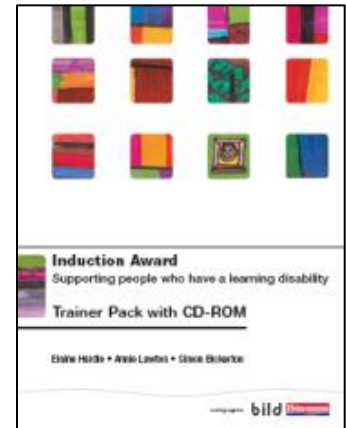
Download the guide at <http://www.cafamily.org.uk/relationships.pdf>

## RESOURCES

### Induction Award: Supporting people Who Have a Learning Disability

The pack includes:

- introduction with information on:
  - learning disability qualifications and standards
  - supporting assessment
  - involving people with learning disabilities and family carers in training
- session plans
- CD-ROM containing:
  - activity sheets
  - PowerPoint presentations
  - video clips
- pdfs of all four study books
- guidance on how to link learning to the relevant NVQ/SVQ



ISBN 978 0 435500 04 7

Price £293.75

For a copy telephone BookSource on 0845 370 0067 with the book name and ISBN number.

### Specialist Curricula

Authors: Barrs Court School

Price: £360 + £12 P&P for the first two areas

Info from: [raird@barrscourt.hereford.sch.uk](mailto:raird@barrscourt.hereford.sch.uk)

Because children who have severe, profound and multiple learning difficulties (SLD/PMLD) have learning needs that stand outside of the learning matter contained within the National Curriculum, additional, specialist curricula has been developed at this school to ensure that all pupils will have the opportunity to achieve and attain at optimal standards. The learning matter contained within the specialist curriculum has also been reinforced by adding links to relevant subjects of the National Curriculum and to distinctive teaching approaches which include best practice in the use of valuable resources and facilities.

When completed, the specialist curriculum will be made up of four "subjects" or curriculum areas:

Early Thinking Skills Curriculum  
 Early Communication Skills Curriculum  
 Early Mobility Curriculum  
 Early Emotional Literacy

Article about it with pictures is on—<http://www.barrscourt.hereford.sch.uk/Policies/specialist%20curriculum%20info.doc>

**Disabled Go** is a useful website that provides detailed, well researched information on access to a range of venues such as hotels, cinemas, restaurants, tourist attractions, pubs, train stations, leisure centres and so on across the UK. From March 2008 it will also include the 'Changing Places' logo in its list of symbols. Visit it at [www.disabledgo.info](http://www.disabledgo.info)

## Quest for Learning

These materials are intended to support teachers/classroom assistants of learners with PMLD, providing ideas for and pathways to learning. They are supported by research regarding developmental processes in infants and children and other key theories regarding the current approaches in the assessment and teaching of learners with PMLD.

This guidance:

- offers an overview of the main theories and background information underpinning effective teaching and assessment;
- considers the complex interaction between the sensory impairments, motor disabilities, medical problems and cognitive processing difficulties experienced;
- takes a more holistic view of learners by focusing on how they learn and by acknowledging their different abilities and achievements;
- takes account of preferred sensory and learning channels and ways of processing information;
- focuses on those early communication, cognitive and sensory skills that are the foundation to all future learning and crucial to an improved quality of life;
- supports the development of learner-centred approaches and the focus on emotional well-being through all the Key Stages from the Foundation Stage through to Key Stage 4;
- celebrates the different abilities of learners with the most complex needs, rather than trying to fit them into an existing framework not developed with these needs in mind;
- recognises interactions in new settings and situations as valid progress in the same way as the learner's development of new skills;
- is aware of atypical patterns of PMLD development which impact on:
  - the processing of new information and stimuli
  - the ways in which new experiences are accommodated into existing schemes
  - the learners' approaches to problem solving situations
  - the ability to form attachments and interact socially
- recognises external environmental factors/family circumstances.



For a copy of this publication: [www.nicurriculum.org.uk/inclusion\\_and\\_sen/index.asp](http://www.nicurriculum.org.uk/inclusion_and_sen/index.asp)



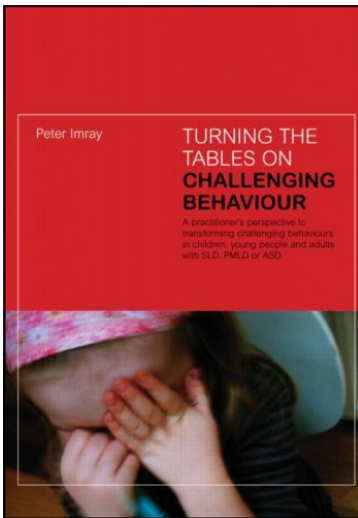
## Reaching Out: working with Black and Minority Ethnic Families

This report is based on research commissioned by Royal Mencap Society and Birmingham Mencap. The research was carried out to gather information about the experiences of families affected by learning disability among BME communities in Birmingham. The researchers particularly wanted to find out about difficulties in accessing services, especially among elderly carers. And they wanted to find out about levels of awareness and perceptions of Mencap. Finally, they wanted to evaluate the work that Birmingham Mencap has done in these communities over the past two years, following the appointment of a BME development worker.

For a copy of this publication: [www.mencap.org.uk/download/150906\\_Reaching\\_out\\_report.pdf](http://www.mencap.org.uk/download/150906_Reaching_out_report.pdf)



# PUBLICATIONS



**Author(s):** Peter Imray  
**Publisher:** David Fulton Publishers Ltd  
**ISBN:** 9780415437585  
**Pub Date:** 2007  
**Price:** £20.99

**Turning the Tables on Challenging Behaviour**  
 Containing real-life case studies, strategies for identification, and handy hints and tips throughout, this is "the" authoritative guide to tackling challenging behaviour and working effectively with children, young people and adults with severe learning difficulties (SLD), profound and multiple learning difficulties (PMLD) and autistic spectrum disorders (ASD). With a unique approach, the author stresses the need to diagnose not only the correct difficulty but the degree of learning difficulty for a lasting resolution, as well as tackling common behavioural problems such as attention seeking and task avoidance.

# Useful Websites

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



Although this site is aimed at children with SLD, there are a few games and stories that appeal to someone with PMLD who likes colourful things happening on the screen.

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

This site is not specifically for children with SLD/ PMLD but there are some games that are very simple and engaging. The contents change quite frequently.



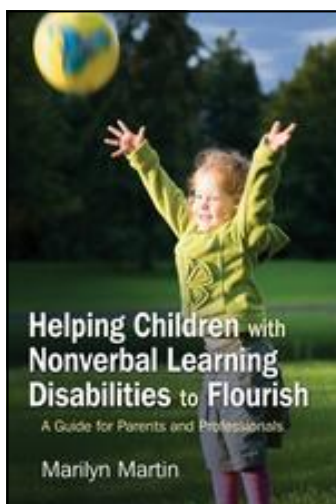
## REVIEWS

**Title:** Helping Children with Nonverbal Learning Disabilities to Flourish: A Guide for Parents and Professionals.

**Authors:** Marilyn Martin

**Pub date:** 2007

**ISBN:** 978-1-84310-858-0



Before I read this book, I was unsure what the title really referred to; on finishing it I feel I understand the disability both from a professional point of view, and mostly from a holistic perspective. This book really makes you think about how many things we take for granted related to language.

Martin managed to provide a descriptive account of the condition through a case study, her own daughter's, and their feat to function within the disability to create an able person. The alternating texts between practical points, and recalling what her daughter went through, makes this book an ideal read. The language used in the book is simple enough for every reader to understand, whatever their knowledge background; as the title implies, it is truly a guide for both professionals and parents.

I particularly liked Chapter 10 that provides a brief on possible interventions with these children. After you read the whole book, as a professional, you may feel you need to improve your intervention approaches to cater fully for these children, and Martin has provided some excellent advice that is worth taking note of. Most highly prized is the fact that hints given are applicable to all, whatever the language or background of the child with a non-verbal language disability.

All in all, I believe this book is a successful one, a book that inspires optimism, hope and a feeling that anything can be achieved if we just look harder for the appropriate answers.

Daphne Farrugia, Malta  
*Speech-Language Pathologist*

**Title:** Three Stories

**Authors:** Office of the Public Guardian

**Pub date:** 2007

DVD from the Office of the Public Guardian.

The DVD can be ordered from the Office of the Public Guardian customer services on 0845 330 2900. It can also be downloaded from the website <http://www.publicguardian.gov.uk/mca/three-stories.htm>



The DVD is in English but has Welsh subtitles and British Sign Language options

The Mental Capacity Act brought fully into

force in October 2007 safeguards the interests of people who may lack capacity to make decisions for themselves, now or in the future. This includes people with a learning disability, although it also refers to people with dementia, mental health problems and medical conditions such as a stroke or brain injury.

The DVD 'Three Stories' is a documentary depicting three real life stories. It shows how the Mental Capacity Act can empower and protect them. None of the people in the film have PMLD but there are aspects of all three lives that help families with a member with PMLD to understand what the Act is about and what they are able to do as a result of the legislation.

The first section contains Lucy's story. Lucy has learning disabilities and, with the help of her parents, has set up in her own home. She tells us how she likes the freedom to do what she wants in her own house. She also recounts how she spent too much money at first but gradually learned to be more careful with her funds. Lucy is very proud of her own keys!

Jack's story comes next. Jack has Alzheimer's and his son talks about using the powers of the Office of the Public Guardian to manage his father's money affairs. He talks about a Lasting Power of Attorney and how he is a Deputy for his father, enabling him, for example to have access to his father's pensions for his mother's living expenses.

The last story is Ned's. Ned has Motor Neurone Disease and is gradually losing control over his body. The main point made in his story is how Ned can go on making decisions about what happens to him for as long as possible. The commentator suggests that the Mental Capacity Act promotes ways of sustaining dignity at the highest possible level throughout the person's life.

So although PMLD is not specifically addressed, the film shows how advocates might function to ensure the best interests of the people they are representing. People with PMLD can live in their own houses and have personal budgets, especially when their families and advocates make decisions based on their knowledge of those people. Their money needs managing by Deputies and the work of the Office of the Public Guardian can help with this.

I think the DVD would be useful for training purposes as it could precede discussions about how to interpret the Mental Capacity Act for people with PMLD. Families could find it a useful introduction to the demands of the Act. It was certainly very interesting to hear the stories of the 3 people involved.

Penny Lacey  
Senior Lecturer Severe and Profound Learning  
Disability



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

This web site is absolutely packed, and soon to have even more resources added to it. The site has four main areas, which are Communication, Resources, Independence, courses, and Links

On this site there are a wealth of communication aids such as assessments, ideas, templates, quiz and booklet plus more ideas. These also cover facilitated communication and those who have motor problems too.

The Independence part covers direct payments, help with claiming this and a case study of Dan and his person centred plan plus photos of him.

The Links section often lead onto other exciting areas and are well worth exploring including dance and video clips.

On the Courses section there is also information on the team and how they can help you too.

This is an easy, none fussy site but absolutely packed yet easy to negotiate around.

Di Foxwell. Coordinator of Clinical Education and Practice Development – Berkshire Healthcare NHS Foundation Trust.

## **INTERCONNECTIONS ELECTRONIC BULLETIN About Children and Young People (0 - 25) with Disabilities / SEN**

**Note: You can receive the whole bulletin as an e-mail attachment if you request it by sending a message to [p.limbrick@virgin.net](mailto:p.limbrick@virgin.net). To view the listings [www.icwhatsnew.com](http://www.icwhatsnew.com)**

**Peter Limbrick  
Interconnections  
E-Mail: [p.limbrick@virgin.net](mailto:p.limbrick@virgin.net)  
Web: [www.icwhatsnew.com](http://www.icwhatsnew.com)**



## Short Courses and Conferences

### May

Date: 7th

Title: **Personalised learning using supportive strategies in and out of the classroom**

Provider: BILD

Location: Loddon School, Surrey

Contact: See providers' details

Date: 8<sup>th</sup> & 9th

Title: Improving practice in challenging behaviour (Conference)

Provider: BILD

Location: Glasgow

Contact: See providers' details

Date: 9th

Title: **Living Stories and Key Skills**

Provider: **Concept Training**

Location: **Glasgow**

Contact: See providers' details

Date: 14<sup>th</sup>

Title: Person centred coaching and mentoring for staff

Provider: BILD

Location: Kidderminster

Contact: See providers' details

Date: Various workshop dates

Title: Understanding the multi-sensory concept

Provider: Concept Training

Locations: Belfast, London, Dublin

Contact: See providers' details

Date: 12<sup>th</sup>, 22nd

Title: Sensory play and leisure in the multi-sensory environment

Locations: Chorley, Winchester

Provider: Concept Training

Contact: See providers' details

Date: 14th

Title: **Developmental Movement in Early Years**

Provider: BILD

Location: Kidderminster

Contact: See providers' details

Date: 15th

Title: **Sherborne Developmental Movement (SDM) Level 2**

Provider: Sunfield PDC

Location: Sunfield

Contact: See providers' details

Date: 16th

Title: **Mental Health Awareness Training**

Provider: Fife Employment Access Trust (FEAT)

Location: Dunfermline Athletic Football Club, Fife

Contact: See providers' details

Date: 20th

Title: **Supporting people to make choices**

Provider: BILD

Location: Sunfield

Contact: See providers' details

Date: 22nd

Title: **Autism and Sensory Issues**

Provider: BILD

Location: Kidderminster

Contact: See providers' details

Date: 23rd

Title: **Every Disabled Child matters - Do They? Issues & Evidence (Conference)**

Provider: Sunfield PDC

Location: Sunfield

Contact: See providers' details

### Providers Details

#### BILD

**British Institute of Learning Disabilities**

Campion House, Green Street,  
Kidderminster, Worcestershire DY10 1JL

Tel. 01562 723025

E-mail: [learning@bild.org.uk](mailto:learning@bild.org.uk)

website: [www.bild.org.uk](http://www.bild.org.uk)

#### Concept Training

15 Beach Street,

Morecambe,

Lancashire LA4 6BT

Tel. 01524 832 828

E-mail: [info@concept-training.co.uk](mailto:info@concept-training.co.uk)

Website: [www.concept-training.co.uk/](http://www.concept-training.co.uk/)

## June

**Date:** Various workshop dates  
**Title:** Understanding the multi-sensory concept  
**Provider:** Concept Training  
**Locations:** Leicester, Warrington, Birmingham  
**Contact:** See providers' details

**Date:** 4th  
**Title:** Inclusion Summer Institute  
**Provider:** Inclusive Solutions  
**Location:** Nottingham  
**Contact:** [inclusive.solutions@ntlworld.com](mailto:inclusive.solutions@ntlworld.com)

**Date:** 5th  
**Title:** **Assessing the Mental Health Problems of Young People on the Autistic Spectrum**  
**Provider:** Sunfield PDC  
**Location:** Sunfield  
**Contact:** See providers' details

**Date:** 13<sup>th</sup>  
**Title:** Meeting the needs of people with profound learning disabilities  
**Provider:** BILD  
**Location:** Kidderminster  
**Contact:** See providers' details

**Date:** 17th  
**Title:** *Forgotten Citizens Conference*  
**Provider:** Scottish Consortium for Learning Disability (SCLD) /Open University in Scotland  
**Location:** Glasgow  
**Contact:** SCLD  
 Tel: 0141 418 5420  
[administrator@scld.co.uk](mailto:administrator@scld.co.uk)

**Date:** 17<sup>th</sup> & 18<sup>th</sup>  
**Title:** 'Not So Ordinary Living' (Conference)  
**Provider:** Support for Ordinary Living  
**Location:** Lanark  
**Contact:** Tel: 01698 276206  
[Conference@forliving.org](mailto:Conference@forliving.org)

**Date:** 18<sup>th</sup>  
**Title:** Understanding challenging behaviour for parents and families  
**Provider:** BILD  
**Location:** Kidderminster  
**Contact:** See providers' details

**Date:** 20th  
**Title:** Sherborne Developmental Movement (Level one)  
**Provider:** Equals  
**Location:** Birmingham  
**Contact:** See providers' details

**Date:** 20<sup>th</sup>  
**Title:** Managing Behaviour Positively in Autistic Spectrum Disorder  
**Provider:** Joint conference: autism. west midlands and BILD  
**Location:** Birmingham  
**Contact:** See providers' details

**Date:** 23rd & 24th  
**Title:** **26th National Network for Learning Disabilities Nursing Conference at The School of Nursing and Midwifery**  
**Provider:** National Networks of Learning Disability Nurses, NNLDN  
**Location:** Trinity College Dublin  
**Contact:** Events Team Tel: 01225 757488 Email: [office@NNLDNConference.com](mailto:office@NNLDNConference.com)

**Date:** 25<sup>th</sup>  
**Title:** Person centred story making  
**Provider:** BILD  
**Location:** Kidderminster  
**Contact:** See providers' details

**Date:** 27th  
**Title:** Non instructed advocacy (Toolbox' of ideas and practical suggestions relating to people with high support needs)  
**Provider:** BILD  
**Location:** Kidderminster  
**Contact:** See providers' details

**Date:** Various workshop dates  
**Title:** Very special mathematics  
**Provider:** Concept Training  
**Locations:** Belfast, Dublin, Birmingham  
**Contact:** See providers' details

### **Providers Details**

#### **EQUALS**

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

#### **Sunfield PDC**

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

## July

**Date:** 2<sup>nd</sup>, 3<sup>rd</sup>

**Title:** Very special mathematics

**Provider:** Concept Training

**Locations:** London, Leicester

**Contact:** See providers' details

## August

**Date:** 22nd-27th

**Title:** *Listen to Me*: the 4th Listen to Me conference for deafblind people and their families.

**Provider:** Sense Scotland

**Location:** Glasgow

**Contact:** Sense Scotland

Tel: 041 429 0294 Fax: 0141 429 0295

Text: 0141 418 7170

[info@sensescotland.org.uk](mailto:info@sensescotland.org.uk)

**Date:** 28<sup>th</sup>, 29<sup>th</sup>

**Title:** Understanding the multi-sensory concept

**Provider:** Concept Training

**Locations:** Edinburgh, Glasgow.

**Contact:** See providers' details

## September

**Date:** 12<sup>th</sup>, 13<sup>th</sup>

**Title:** Quality Communication: Maximising Opportunities for People with Multi-Sensory Impairment

**Provider:** University of Northampton

**Contact:** Patsy Hollingum Tel: 01604 893447

[education@northampton.ac.uk](mailto:education@northampton.ac.uk)

**Date:** Various workshop dates

**Title:** Understanding the multi-sensory concept

**Provider:** Concept Training

**Locations:** Taunton, Birmingham, London

**Contact:** See providers' details

**Date:** 16th

**Title:** Very special mathematics

**Provider:** Concept Training

**Locations:** Glasgow

**Contact:** See providers' details

## October

**Date:** 13<sup>th</sup>, 21<sup>st</sup>

**Title:** Sensory play and leisure in the multi-sensory environment

**Locations:** London, Birmingham

**Provider:** Concept Training

**Contact:** See providers' details

## November

**Date:** 11th

**Title:** Sensory differences and the role of positive touch

**Provider:** Concept Training

**Location:** London

**Contact:** See providers' details

**Date:** Various workshop dates

**Title:** Very special mathematics

**Provider:** Concept Training

**Locations:** St. Helen's, Enfield, Wolverhampton

**Contact:** See providers' details

### Quality Communication: Maximising Opportunities for People with Multi-Sensory Impairment

Friday 12<sup>th</sup> & Saturday 13<sup>th</sup> September

9.30 – 4:00 pm -Includes Lunch and Refreshments  
£30 per day

(The conference is subsidised by the East Midlands Special Educational Needs Regional Partnership - Innovation Grant)

Paul Hart – SENSE Scotland  
Melanie Nind – Professor of Education  
University of Southampton  
Gail Deuce – SENSE Consultant Teacher  
David Brown - Education Specialist California  
Deaf-Blind Services

The conference is suitable for teachers, advisory and support teachers, intervenors, teaching assistants, parents, health and social services workers and other professionals who work with people with Multi Sensory Impairment. The two days have been subsidised by the East Midlands Regional Partnership. The conference will take place over two days and participants are welcome to attend either or both days. Overnight accommodation information can be provided on request.

For more information phone Patsy Hollingum – Conference Administrator, University of Northamptonon: 01604 893447 or e-mail [patsy.hollingum@northampton.ac.uk](mailto:patsy.hollingum@northampton.ac.uk)

## LONGER COURSES (with accreditation)

Updated April 2008

### MA in Education

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

This module addresses the requirements of the Teacher Development Agency (TDA) National Special Educational Needs Standards (Core 1a – 1e, Extension 2.i – 2iv.). It is directly related to the module Curriculum and Teaching – Pupils with Severe and Profound and Multiple Learning Difficulties which addresses further standards. The module provides students with an opportunity to gain an understanding of those influences which impact upon the learning, development and management of pupils with severe and profound and multiple learning difficulties.

**Module: EDUM081**

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

### MA in Education

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

This module provides opportunities for those with QTS and professional qualifications & experience in services for children to engage in structured critical reflection, exploration of key substantive issues and overarching policy determinants in respect of children and young people with physical disabilities. The module encourages both the development of enhanced understandings of the dimensions of physical disability, with regard to both their theoretical bases and the policies and practices invoked in meeting identified needs.

**Module: EDUM058**

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

### MA in Education

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

This module provides students with opportunities to investigate, critique and evaluate a range of curriculum approaches in the field of PD. It engages students in debates concerning the relevance and practical efficacy of recent guidance & legislation in PD-related issues, and offers an in-depth series of curriculum-focused activity which is intended to enhance both the understanding and the practice of those working with children and young people with PD.

**Module: EDUM059**

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

### MA in Education

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

This module addresses the requirements of the Teacher Development Agency (TDA) National Special Educational Needs Standards (Extension 2.i – 2iv.). It is directly related to Pupils with Multi Sensory Impairment (MSI) The module provides students with an opportunity to gain an understanding of those influences which impact upon the learning, development and management of pupils with multi sensory impairment.

It provides professional development for teachers and other professional colleagues working in an area of low incidence need and addresses priorities established by Local Authorities, individual teachers and others working with children and young people who experience MSI.

**Module: EDUM054**

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

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

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

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

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

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

**For further details:** University of Chester

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

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

**AdCert, BPhil, PGCert, PGDip, MEd.  
Learning Difficulties and Disabilities (Severe, Profound and Complex)**

*Distance Education*

This distance education programme has been developed for the range of staff who work with people with severe, profound and complex learning difficulties, for example teachers and lecturers, nurses, therapists, psychologists and support staff.

It is primarily about the learning and development of children and adults with severe, profound and complex learning difficulties, particularly in the areas of cognition and communication. Education, in its broadest sense, is seen as a key topic but other areas covered include health, therapy and social care. An important central theme is multi-agency collaboration and course participants will be expected to develop and reflect on their collaborative work as part of course. All the course assignments are grounded in reflective and evidence-based practice and are driven by the individual professional development needs of participants.

The modules are as follows:

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

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

**AdCert, BPhil, PGCert, PGDip, MEd.  
Multisensory Impairment (Deafblindness) - Distance Learning**

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

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

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

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

**PGCert, AdCert.**

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

*Distance education.*

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

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

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

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

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

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



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

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

**Programme Structure**

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

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

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

The School of Health & Social Care, University of Chester, MSc in Advanced Practice (Learning Disabilities) - includes generic modules in research and inter-professional working plus 3 LD specialist modules (socio- political themes in LD; developmental perspectives on LD; profound & complex needs).

**For further details:** University of Chester

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

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

**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 next intake is October 2006.

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

**For further details:** University of St. Andrews <http://psy.st-andrews.ac.uk/people/personal/mc1/>

Dr Martin Campbell email: [mc1@st-andrews.ac.uk](mailto:mc1@st-andrews.ac.uk)

**BPhil, PGDip and MEd**

**Inclusion and SEN**

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

Year 2 Autism (Children) or Autism (Adults)

*Distance Education*

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

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

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

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**PMLD-Link** is an informal journal for practitioners and carers working with people with profound and multiple learning disabilities (PMLD), of all ages and in all situations. It is published three times a year and covers a wide range of issues of interest and practical use in the day-to-day work of practitioners, parents and carers in schools, colleges, adult provision, in the home, and many other settings. In recent years the scope of the articles has been widened to include all professions and services, and to cover issues pertaining to all groups, including occasional articles by practitioners and parents from overseas.

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

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

**PMLD-Link** also includes:

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

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

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

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

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

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

Subscription prices for 2007 are:

<b>Annual Subscription</b>	<b>United Kingdom</b>	<b>Outside United Kingdom</b>
Personal/individual	£12	£17
Organisation	£17	£25

(NB. Subscriptions run from January and copies of all issues already mailed this year will be sent)

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

Carol Ouvry, **PMLD-Link**, 31 Birdwell Road, Long Ashton, Bristol BS41 9BD.  
Telephone: 01275 394621 e-mail: PMLD@mansell.wyenet.co.uk

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

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# PMMLD Link

## IN THIS ISSUE

Guest Editorial:	Beverley Dawkins
Supporting Families: What do they want from the voluntary and statutory sectors	Loretto Lambe
Facing the Challenges: Some examples of past, present and future issues for parents of a young child with complex disabilities	Brett Millett
Day Service Redesign – the future?	Jessie Lindsay
Please remember - we never cease to be carers	PAMIS parent member
Getting It Right - Together	Sofi Taylor
The Challenging Behaviour Foundation	Karen McCane
Protecting Body Shape through Postural Care Investment in the Expert Family	Anna Goldsmith
Together at Touch Trust: Families' Experiences of a Multi-Sensory Creative Movement Programme	Josephine Lay
Communication: Soundabout Family Project: Soundabout and more.....	Sue Simmonds
A New Deal for Carers - Raising the profile of family carers as allies in improving the life chances of disabled people!	Dr Phillipa Russell
The Learning Disability Coalition	Heather Honour