

PMMLD LINK

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

Winter 2008

Money Matters

PMMLD Link

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

Money Matters

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GUEST EDITORIAL

Winter 2008

Money Matters

This is my first issue as editor and I would like to say a big thank you to all the authors for providing the content of what I hope you will agree is both an interesting and informative edition. Also thank you to the editorial team for their support, especially to Alice for mentoring me through the editorial process.

With the publication of the review of Independent Budgets (IBSEN 2008) the topic of this issue is of particular relevance. The IBSEN report found that Individual Budgets can improve people's quality of life by giving them flexibility and control over their services and therefore their lives. This is evident in some of the articles in this issue and I hope you enjoy reading them. The contributors discuss the growing empowerment of people with learning disabilities and their families who are increasingly taking control of their services and in doing so improving the lives of all concerned. For people with profound and multiple learning disabilities Individual Budgets are often about *families in control* and whilst no-one writes that this is easy, contributors seem to agree that it is worthwhile. In my opinion when families are in control, services can be more responsive, can offer continuity and ensure that the individual person with PMLD remains the focus of change rather than changes being driven by organisations and service providers.

The final article is about a new service for children with PMLD in India and whilst it is not specifically about 'Money Matters' it is about the importance of the resources of knowledge and time. Whilst money is inevitably needed, access to people with knowledge is always valuable to such projects. This article discusses a volunteer's experiences of service development. I suggest that with charities having fairly good access to the internet there is potential for joint working and support systems that can be provided on-line. Such innovations could enhance emerging services for people with PMLD in less economically developed countries.

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IBSEN (2008) *Evaluation of the Individual Budget Pilot Projects* available from the Department of Health website <http://www.dh.gov.uk/en/SocialCare/Socialcarereform/Personalisation/index.htm>

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The Arts
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The Reality of Being a Deputy Dawg!

David Doggett

I thought it might be useful to write about some of the realities of being a deputy for my nephew under the auspices of Office of the Public Guardian. Others who may be thinking of taking on this role may be interested in my experiences. I have not covered everything I do as that would demand an article very much longer.

The Office of the Public Guardian (OPG) supports and promotes decision making for those who lack capacity, or who would like to plan for their future, within the Mental Capacity Act 2005. This is what the OPG says about being a Deputy for someone who lacks capacity.

The Deputy order you receive from the Court will set out the extent of your powers. It can apply to any area in which the person could have acted or made decisions for themselves if they had the capacity to do so.

Your powers might relate to:

- *finances;*
- *personal welfare, such as giving or withholding consent to medical treatment and/or social care interventions.*

Powers given will depend on the needs of the person you have been appointed to assist and also the Court's decision.

When acting as Deputy the decisions you make can have a major impact on the person who lacks capacity. In order to carry out your responsibilities sensitively, responsibly and rigorously you should always:

- *only make those decisions you are authorised to make by the order of the Court;*
- *adhere to the Act's five statutory principles;*
- *make decisions in the person's best interests;*
- *fulfil your duty to apply certain standards of care and skill (a duty of care) when making decisions; and have regard to all relevant guidance in the Code.*

The Office of the Public Guardian expects that you will keep us informed of any changes in contact details for yourself or the person who lacks capacity.

My nephew has very severe learning disabilities

and autism and I act for him in several capacities many of which relate to money in some way. My nephew does not have parents living, which is why I have been appointed his Deputy.

My Nephew's Financial Circumstances

My nephew has several thousands of pounds which are held in the OPG. Some of this money comes from inheritance when his parents died and some from winning an insurance case in relation to having been left as an orphan at the age of 15 following a car accident. In the OPG, the money earns 6% and the income is sufficient for him to contribute to his support bills, pay his living expenses and for his holidays. In actual fact the income is not really quite sufficient and I am eating into his capital gradually to keep everything afloat. Obviously he will eventually run out of capital and become completely dependent upon the state.

My Nephew's Support Arrangements

My nephew is supported by someone who lives in with him 24 hours a day for several weeks. After this period another person then comes. Ideally he has 2 people who alternate but often the system breaks down and he has to have someone he doesn't know for a while. He goes to a local resource centre during the week, and thus his main supporter can have time off each day. He also has several young people who support him at weekends so the time off is also available at the weekends.

My Nephew's House

One of the most important decisions made by the family (and executed by me) was to buy my nephew a house with some of his capital. We decided that having his own house would be the most secure thing we could do for him. He had tried communal living and this just did not suit him. He is a changed man in his own house, where he can do just what he wants to do when he wants. He had behaviour that was described as challenging in a group home but not in his own home.

The experience of buying his house was not really difficult, just time consuming. I had to sign

everything for him but the house is his and not mine. His name is on all the papers and no-one can arbitrarily decide to move him.

Buying his house was an important decision and it was made easier because my nephew had the funds to do this. It would have been very different if we would have had to go into joint ownership with a housing association. I investigated this possibility so that the housing association would have joint responsibility for repairs and maintenance but my nephew had too much capital to be considered. I am still worried about what will happen when his capital runs out and he is dependent upon benefits. Where will money for repairs and maintenance come from then?

One of the possibilities is that my nephew could take in a lodger to provide some income. His house is situated in a village so attracting a lodger might be difficult. Also as his experience in communal living was not good, the lodger is unlikely to be someone with learning disabilities. Maybe when the time comes, the right person will turn up?

My Nephew's Car

I looked at several ways of providing transport for my nephew. He loves to go out and about and although he loves to go on public transport, there is none that can take him to the resource centre every weekday. He has personal assistants who take him out at the weekends and although they will take him in their cars, it is very expensive to pay their mileage.

I thought about buying a car for my nephew but it seemed to be impossible to get insurance for his carers because when the carers are driving him they need business insurance. They couldn't have business insurance because they didn't own the car. It was very complicated!

The only possible solution seemed to be to use Motability and this was possible because he is eligible for the Disability Living Allowance at the higher rate. Within this scheme, my nephew has a silver Polo to transport him around the countryside. He loves his car and has several different drivers willing to take him wherever he wants!

Getting insurance for the car was quite difficult, firstly because under the Motability scheme they usually insure the client as the driver and not carers. Secondly, it was difficult because Motability restrict the number of drivers to 2. My nephew is driven by several different people, depending on who is supporting him at the time. I have to keep a list of all these people.



Banking Arrangements

I have set up an account that can be accessed in a local bank for my nephew. His supporters can withdraw money for him but he needs to be with them when visiting the bank. Again this was not difficult to achieve but I did have to negotiate it all in person and sort out the difficulties that arose when setting everything up. It all runs smoothly now and the main supporters keep detailed accounts of everything that is spent. They always ask my permission if they want to spend anything outside the usual budgeted amounts. It is very important for them to keep accurate accounts as I must make a return to the OPG every year.

OPG Responsibilities

The most important thing I must keep in mind at all times, is my responsibility for my nephew's money. I must convince myself and the OPG that whatever I do, it is in the best interest of my nephew. I have a responsibility to ensure his money is invested wisely and that I negotiate the best deals. When repairs were needed to the washing machine, I had to work out the most cost effective way of dealing with it.

Annually the OPG need to have the amounts received and spent under a variety of headings. So his accounts are an annual task. This year I was one of a small proportion also to supply all bank statements. Luckily I'm a Type 2 Deputy which entitles me to a 'light touch supervision regime'!

I have been dealing with my nephew's money in this way for several years and during that time the office that is now the OPG has changed its terms of reference from giving advice and taking responsibility for my nephew to merely giving advice. I am now completely responsible. In the early stages, finding out what I could and couldn't do with my nephew's money was very difficult. I had to try something out and ask if it was allowed.

I haven't tested the system recently.

Although this article is about my nephew's money, I must also remember that my responsibilities include making other decisions for him, based on his best interests. I have to sign hospital and dental permissions, attend person-centred planning meetings as part of his circle of support to make decisions about his day-to-day activities, meet his supporters to gauge how well they meet his needs, deal with the support agencies when things go wrong, organise for him to be taken to see his grandmothers, check the state of repair of the house and remember to organise the car servicing..... The list is endless but the rewards are great when everything runs smoothly and my nephew is obviously happy.

Future Considerations

One thing I have not tackled yet is the issues of my nephew making a will. I don't yet know how to go about this. At the moment he not only has his

house, but also some capital and he needs to leave these to someone after his death. Again, I expect the process to be relatively straightforward but no doubt time consuming.

Editors comments. If you wish to find out more about the role that David has described you can visit the OPG website at http://www.publicguardian.gov.uk/forms/customer_service.htm where a range of free information booklets can be downloaded.

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Subscribe for 2009

It is time to renew subscriptions for 2009 and, as usual, a separate subscription form is included with this issue. You will see that we have reluctantly had to increase the prices for next year due to the rising costs of postage and materials, so if you pay by standing order please remember to get your bank to change the amount.

Like many small organizations PMLD-Link is finding it hard to survive and even more difficult to put in place all the initiatives and developments that we would like. We are applying for funding for various projects, but all our income at the moment comes from you – our subscribers. As people with PMLD are a very small percentage of the population we are never going to become rich on this income, but if you know anyone, or any organization who is not a subscriber but would benefit – do encourage them to join.

Thank you to all subscribers who have renewed for 2008 very recently in response to the latest reminder. For you, this renewal for 2009 will seem to be very hot on the heels of the last payment!

Thank you too, to all those individual subscribers who have completed a gift aid certificate. If you have not done so, please send back the gift aid form – it costs you nothing and makes a great difference to us.

Finally, thank you to all those who contribute articles and make it such a wide ranging and informative journal. Happy reading in 2009!

Making Bank Accounts for All a Reality

Di Foxwell

For most people, opening a bank account, once you have demonstrated the necessary credentials and convinced the front of house bank staff that you really are who you are claiming to be, becomes an easy process. However for one group of people, even when a bank account is secured, actually accessing any money becomes a further challenge that has proved insurmountable for some people.

Some parents have been further thwarted by the Mental Capacity Act (2007), since people with profound learning disabilities usually lack the capacity to open an account, and this means that the Office of the Public Guardian (OPG) needs to become involved which can prove to be an expensive time consuming route. Without a bank account people cannot receive individual budgets, direct payments and individual living funds or housing benefits.

One particular group of people are particularly feeling the pinch. This group are just moving from childhood into adulthood, meaning that arrangements are being made for the first time for some of these people to hold a bank account and receive benefits in their own rights as an adult. Yet some are unable to receive benefits until there is an account in the person's name, and at the same time are unable to open an account until there are some monies coming into the account.

The government is aware of some of the problems which have arisen and recognises that

"... direct payments (extended in the Health and Social Care Act 2008, to include those people who lacked capacity to consent to their receipt) are crucial to achieving the Government's aim to increase independence, choice and control for service users and their carers through allowing them the opportunity to arrange their own personalised care".

DH (2008) page 2

In addition, the government is also reviewing the current exclusions to receiving direct payments for those people who are subject to various provisions of mental health legislation in light of the modernisation of mental health law brought about by the Mental Health Act 2007.

The Government will just have completed consulting on regulations relating to these two changes by the time this article goes to print (closure date 11th Nov 2008).

A group called 'Generate' [http://www.generate-](http://www.generate-uk.org/more.shtml)

[uk.org/more.shtml](http://www.generate-uk.org/more.shtml) has carried out a research project to find out about the issues faced in opening and using bank accounts. The Co-Operative Bank funded this, and the project 'looks like it will form the foundation for further work looking at a broad range of access and training issues'.

Meanwhile Barclays Bank has also produced a leaflet for people with learning disabilities and begun a service geared up for people who have learning disabilities and cannot read. Further information is on their web site (details below). Barclays and National Westminster Bank seem to be the leading banks in starting to address the banking needs of people who have learning disabilities but the British Banking Association (BBA) has now produced information for people who lack capacity in relation to banking (see resources at the end of this article). So hopefully now other banks will follow.

Mencap has also worked with the BBA to ensure some of the advice it produces is concomitant with that recommended by the BBA. In fact Mencap has produced lots of information related to many areas to do with finance, benefits etc. (amongst other subjects) which are all available on their web site in PDF formats. This site would be an excellent starting point for parents particularly with young people who are coming up to adulthood and includes some marvellous practical examples of how some people with profound and multiple learning disabilities have received help from their banks. Information is given later in this article. It also contains a wealth of information for professionals.

From this point onward this article relies mainly on the comments and personal experiences of families. This information has been mainly obtained from comments they have openly written on the Profound and Multiple Learning Disability Network which is part of the Foundation for People with Learning Disabilities <http://www.learningdisabilities.org.uk>

It would appear that a number of families, carers

and advocates have managed to work a way around the problem and there are examples where the banks pulled out all the stops to make the banking system work for the people concerned. The National Westminster Bank provided a stamp that it was prepared to accept instead of one person's signature who could not write. Barclays Bank too provided one lady with a cheque book and stamp, the stamp bearing her 'signature', and inkpad. Barclays also provided her with a letter of authentication of the stamp.

One mother wrote,
"I requested an interview at Barclays bank and explained the situation. They opened two accounts for my daughter who cannot really understand or sign her name. They were happy for her to sign with my hand over her hand guiding it to write her name."

However this method of facilitated communication is criticised by some, who urge carers/ families using this method to also seek the extra protection of the Mental Capacity Act.

The commonest way that families found around the problem was having two people named on the account with either one being able to 'sign'. A number of people also had two accounts with different banks to keep different funding/benefits separate for ease of management.

"I did a joint account and either party can sign that way there was no problem, the account is in the other persons name with me as second signature."

(About the NatWest Bank. – Anon)

The same bank also helped three further unconnected parents with their respective offspring in a similar way. Although most comments about this bank were positive, regrettably a small number related to this bank (and other banks) were not.

In putting this article together, I was impressed with the ways that banks and families had worked together, although in many of the examples given above there was also another thread which emerged too – that was that many of those in the successful examples had already established a good relationship with their banks beforehand (a useful tip I thought worth sharing with parents of children).

The BBA does seem to be helping banks to implement the Disability Discrimination Act (DDA) and the Mental Capacity Act (MCA) to the benefit of people with profound and multiple learning

disabilities and early signs seem positive. However the MCA has some way to go yet in terms of the lengthy process and costs involved to realistically address the needs of those who lack capacity. Hopefully some of this will be addressed by the recent reviews.

Contact details

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References

DH (2008) Putting People First. Transforming Adult Social Care.
Consultation on Direct Payments Regulations [online] available from
http://www.dh.gov.uk/en/Consultations/Liveconsultations/DH_087108

Useful Resources

Barclays Bank - Accessible services /Learning Disability
http://www.barclays.co.uk/accessibleservices/learning_disability.html or
<http://tinyurl.com/5977ko>
Banking for people who lack capacity to make decisions [British Bankers' Association](http://www.library.nhs.uk/learningdisabilities/ViewResource.aspx?resID=279465)
<http://www.library.nhs.uk/learningdisabilities/ViewResource.aspx?resID=279465>
Banking on good decisions
<http://www.choiceforum.org/bankleaflet.pdf>
Banking on good decisions (full report)
<http://www.choiceforum.org/bankreport.pdf>
Banking on good decisions Easier Read
<http://www.choiceforum.org/bankinggder.pdf>
Banking on Change
<http://www.choiceforum.org/bankchange.pdf>
Making Decisions - Public Guardian
<http://www.publicguardian.gov.uk/docs/making-decisions-opg605-1207.pdf>
Mencap Bank Account Factsheet
<http://www.mencap.org.uk/document.asp?id=1721&audGroup=&subjectLevel2=57&subjectId=11&sorter=1&origin=subjectId&pageType=&pageno=&searchPhrase=>
Mencap
<http://www.mencap.org.uk/landing.asp?id=5>
Banking on good decisions easier read cover Re Mental Capacity Act 2005



Looking for Value for Money & Better Outcomes for People with Profound and Multiple Learning Disabilities? Then invest in Person Centred Planning and Implementation Training for Families

Barbara Coles

Person Centred Planning is a central theme of most current policy guidance and the crucial fact is that families are central to its effectiveness. Given this fact there is a clear expectation that families will need to be supported to learn about planning and what it could mean for their loved ones and themselves. Yet funding specifically for the learning and development of family members is becoming much more difficult to obtain as opposed to funding for professionals. Such an imbalance doesn't bode well for stimulating partnership working.

Even so most family members want to be able to work successfully with professionals and have a process whereby their expertise around the person they love and support can be recognised. More often than not however, these relationships have broken down. Local Authorities and Independent Providers who have invested in 'Families Leading Planning' courses and the experiences of family members who have participated on them have enabled these relationships to be reformed in a proactive and positive manner that recognises everyone's contributions.

This is particularly pertinent to family members supporting their loved ones who have profound and multiple learning disabilities (PMLD) as illustrated by Val, Mum of a young lady living in Cheshire, who participated on our 'Families Leading Essential Lifestyle Planning' course:

"At first I wasn't sure what I would get out of it but I did see it through and I really enjoyed it and believe that both myself and my daughter benefited from it. It has made a BIG difference in as much as I had all this information about her stored in my head and it was just great to get it out there in a user friendly way. It has made me feel more at ease about facing the future and having to make the 'big' decisions' that we all worry about as family carers. I look at my daughter in a different way now too – it's all about the things she needs and wants now, not what I think she needs and wants! Carers and other professionals have read it and have found it very useful and say that they understand her as a person in her own right now rather than just understanding her needs – they also don't see

me as a moaning mother any more, instead they now see me as an 'information giver' so yes, it was very much worth my effort".

For Val, having an opportunity to learn in a friendly environment, with other family members, and having a family member as a trainer was key to a more confident future for herself and her daughter. The importance of having family trainers, is echoed by a Mum from Coventry whose daughter also has PMLD:

"You know what we are talking about. Just hearing what you have been doing to support your son and the struggles and barriers that you encountered means that we will listen to you whereas you (addressing a non-family trainer) although you are kind and supportive and say all the right things, it's not the same. You don't really know what it is like for us and anyway I expect you will be moving on to a new job soon and we'll never see you again whereas she will be around for as long as her son needs her."

Likewise, Anna, a Mum from Dorset welcomed the opportunity to develop a Person Centred Plan for her daughter Rosie who has PMLD. Anna said:

"...with the benefit of your support and guidance Rosie now has a very detailed plan in place containing all the information about her life and needs which is essential for all who care for her now and in the future. The plan has also highlighted areas in Rosie's life that needed to be improved or developed and moved forward.

As you know Rosie had just transferred to adult services and by using many of your ideas she is now enjoying a full and active life which may not have otherwise happened. In particular we looked at how Rosie would be able to use her 1:1 time more positively. She now attends several work experience placements each week, enjoys aromatherapy sessions and has joined a local social club (for people with special needs) which enables her to meet up with some of her old school friends. Also plans are now well underway for a small self contained flat for Rosie adjoining the family home and we are also looking at ways in which she can have some independence from the family within her own home as you would wish for any young person.

For myself I think this was probably an opportunity to actually sit down with other parents/carers and share thoughts, feelings and anxieties etc. This I found very emotional but equally very rewarding. You also gave me the confidence to ask for and pursue things on Rosie's behalf and you have opened my eyes as to what can be achieved for a person with PMLD. I now have a more positive outlook for our future and will be making sure Rosie continues to have a fulfilled life.

It is essential that every family carer caring for a person with special needs has the opportunity to attend a course like this and I would urge them if they get a chance, to do so."

Even though some families are having an opportunity to take the lead in the planning process the evidence we are finding is that although they are very able to develop the skills to effect change for their loved ones by using person centred planning approaches, they are often held back by the distinctly traditional beliefs and practices of professionals and by lack of funding. We are therefore beginning to work with local professionals to give them an opportunity to work with families in different ways and reflect on their own learning. The feedback these professionals have given so far is that families:

- Have valuable information that needs to be shared
- Are more confident in questioning services
- Are challenging 'bad practice'
- Are more knowledgeable of what is available and are not settling for traditional services
- Are breaking down communication barriers
- Are wanting to become family mentors/trainers which will lead to services becoming more responsive.

And that:

- Service providers have learned more about the individuals they support
- It is challenging professionals to be flexible in their thinking and to find new ways of supporting people
- Professional culture has got to change from 'we know best' to it becoming a 'shared view'.

But in spite of these enlightened views there are still those professionals whose attitudes can hinder the process of person centred planning led by families and in doing so often risk duplication of efforts when scarce resources prevail! So what can be done to redress the funding imbalance of training for families and professionals?

Local Authorities and Service Providers must encourage and support family members who want to take the lead in planning by commissioning specific training as outlined above that enables them to learn alongside each other with a view to develop and implement person centred plans for their loved ones. And they need to invest in their staff by giving them opportunities to learn alongside these families if they really are concerned about better outcomes for people with PMLD.

Contact details

You can find out more about Families Leading Planning UK by contacting Barbara on:

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Web: www.familiesleadingplanning.co.uk

Editors comments

If you are considering self/family directed support CSIP have produced a newsletter that is well worth a read. It can be found on the Valuing People Website at <http://valuingpeople.gov.uk/dynamic/valuingpeople60.jsp> it is the pdf called "April 08 Family Newsletter". As well as stories it outlines the common terms used when developing support packages demystifying the jargon. Hope you find it useful.

Individual Budgets - Making It Work For Everyone

Lesley Barcham
Development Manager BILD

Marketing people use the term innovators and early adopters to describe the two groups of people who are the first to take up new services or products as soon as they are available. Many of the innovators and early adopters of self-directed support have a lot to teach us as we move towards the situation where individual budgets are available for all people who are using social care support. We need to pay attention to what they can teach us about how the new system actually works, its opportunities and challenges. We need also to hear stories and understand the changes from a range of different perspectives.

The two articles which follow, from Tina Cooper and Jenny Pitts, show that some people with profound and complex needs, many with strong support from their families, already have more choice and control over their support through using an individual budget. Government social care policy, particularly in England, is clearly signalling a growth in individual or personal budgets. The launch of *Putting People First* in December 2007 sets the direction for adult social care. This is towards everyone who receives support being empowered to shape their own lives and the services they receive in all care settings through greater choice and control in how the money for their support is spent.

In publishing *Putting People First*, the government acknowledged that this policy is heralding a "total transformation of social care". The existing systems for allocating resources, contracting and purchasing support, planning support, recruiting and training workers and more will all need to change. Things will be different at all levels and for most people involved in the social care systems, from people using support, family carers, support workers, advocates, managers right through to directors of social services and chief executives of providers. In addition, new roles may evolve as the new systems are set up such as support brokers, providers of secondary support etc. Currently less than 1% of the 1 million plus people in England who receive social care support have an individual budget, but this number is set to rise rapidly in the next few years.

To understand how more people with profound and complex needs can get the life they want and need with the right support using individual budgets we need to learn more from those with early experiences. Listening to their stories, experiences, challenges and opportunities and the stories of other key people such as family carers and friends, local authority workers, care providers and support workers we can bring together a wider picture so that others can follow a similar path.

More information on all aspects of the personalisation agenda is available nationally through key websites, through DVD materials and reports. In addition, each local authority is or will be providing information about their work on individual budgets

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References and further information

Details about In Control can be found at www.in-control.org.uk together with factsheets, stories etc and a wide range of information on all aspects of individual budget.

Details about the Department of Health individual budget pilots can be found at www.dh.gov.uk/en/SocialCare/Socialcarereform/Personalisation/Individualbudgets/index.htm

Department of Health (2007) *Putting People First* available from www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081118

DVDs and film stories from individuals and families using individual budgets can be found on:

How to be in control (DVD) from In Control Individual Budget holders tell their stories.

Presented as examples of In Control's 7 step process. Price: £12.00 inc. P&P from www.in-control.org.uk or ring 0121 708 3031

HFT DVD *Getting In Control* Made with families in mind, this DVD explains the differences between the present social care system and that of using an Individual Budget. It also explains, through families' experiences: Options for money, the practicalities of planning support, ongoing responsibilities, views of the future and other related issues. The DVD costs £12 a copy including postage and packing. You can order a copy by contacting 0117 930 2608 or from the HFT website at www.hft.org.uk

Free film clips available on the internet at <http://networks.csip.org.uk/Personalisation/Topics/tags/?tag=Stories>

Doing It Your Way: How people with a learning disability in Worcestershire are being supported to take control through Individual Budgets

Jenny Pitts

'Doing It Your Way' Development Manager, Worcestershire County Council

A growing number of Local Authorities are embarking on helping people who use social care to have the opportunity of much greater choice and control over their care and support. This is done through offering 'Individual' or 'Personal' Budgets. The government's support for greater personalisation of health and social care services was a key tenet of the White Paper 'Our Health, Our Care, Our Say' (DH 2006) and was reinforced in the concordat 'Putting People First' in November (DH 2007).

Having an Individual Budget means that following a self-assessment, (usually done in conjunction with a professional assessment), the person is informed of how much funding they are entitled to. They are then invited to develop a Support Plan that shows how they intend to use the fund to achieve the things they need to in order to live their life the way they choose. There should be very little restriction on what the person can choose to use their Budget for; the key is that they need to be able to demonstrate how they will maintain their safety and wellbeing and achieve desired outcomes. The Support Plan needs to be approved by the Local Authority (and any risks are looked into at this stage). Once the Plan is agreed, the Local Authority enter into a contract with the person (or someone acting on their behalf) and the money is paid according to how they have chosen to be in control.

In the previous system many people with disabilities have used Direct Payments to have control over their care and support. This remains one way of receiving some or all of the Individual Budget. However, many people do not want the responsibility or work that comes with managing a Direct Payment and therefore can choose other options, whilst still remaining in control. They can choose for some or all of the money to be paid directly to a support provider of their choice. They are the purchaser and the money is paid on their behalf; the money can also go to an independent third party to manage on their behalf, or they can still choose to receive Local Authority provided services. These, as with all services, need to be costed so that people can make informed choices.

The changes, challenges and advantages that self directed support and the transformation of social care bring cannot be underestimated. To date a minority of people using social care are able to

have an Individual Budget but the government has set a target for Councils to achieve 'significant moves towards fundamental system-wide change' by March 2011 with funding available to support this transformation (DH 2008).

There are many different ways that Local Authorities are approaching this change in how they deliver social care. Many are piloting small projects before rolling it out to all social care users. In Worcestershire the Learning Disability Service is working in partnership with the British Institute of Learning Disabilities (BILD) to offer families and individuals the opportunity and the support to have Individual Budgets. This project, called 'Doing It Your Way' involves a small team working in both the County Council and BILD (funded by the Learning Disability Partnership Board) who provide expert support and information to families and individuals. This includes expertise in relation to housing options, benefits and welfare, employment and work opportunities, person centred planning and importantly a Family Carer Link Worker to support and work with carers, building their own networks and sharing information.

The team works independently with families and individuals to support them through the process as much as is needed. This may include explaining what it is all about and how it works, supporting people to do the self assessment and to do the person centred planning that informs how it is they want to live their life and what they want to achieve. Supporting people to plan in a creative way how they can use their Budget is an important function of the team and, depending on what it is people want to achieve, they can draw on team members' knowledge and expertise to support them through the process.

To date the project has supported just over 50

people to have an Individual Budget. This includes people with a diverse range of care and support needs, from those who need very little support to be independent to those with profound and multiple disabilities. Some people have used their Budget to continue to be cared for in the family home, others have been able to move into their own home, sharing with friends or on their own, whatever is right for them. Some people have chosen to get support to do voluntary work, go to the gym or pursue hobbies and activities. The project has resulted in disabled people remaining in their communities and strengthening family and social networks rather than being 'placed' in segregated services. It is also demonstrating that when empowered to make their own decisions, people can achieve value for money because they become the experts who know best what it is right for them or their relative and they know what they need to have a happy and fulfilled life. In this way, the project supports people to use their Budget to 'get a life' rather than get a service.

The partnership with BILD has been a critical factor in the success of this project. Not only have BILD been able to bring their own expertise to this project, but the people employed in the team who work for BILD have been able to guide and support people independently. The project Development Manager is a member of the Learning Disability Senior Management Team in the County Council and has been able to directly influence procedural and system changes that have been necessary. The project will continue to develop over the next 12 months as Worcestershire continues to promote personalisation, along with the partnership and empowerment of people who rely on social care and support. 'Doing It Your Way' has

demonstrated that when local government is transparent and works in a fair and equitable way, people who need support and those who care for them become equal partners treated with dignity and respect to make their own decisions and be in control.

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Links: www.worcestershire.gov.uk/learningdisabilities

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Department of Health (2006) Our health, our care, our say: a new direction for community services DH:London

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Change Of Carer - Change Of Life

Tina Cooper

OK let's put the record straight. It was a big birthday; my fiftieth birthday was looming, time to reflect, look back and take stock of what life was all about. So where had all the years gone? It did not seem like I had been married for thirty years, daughter at university. I should be out there enjoying life. But life is often not like that. I had been caring for my 25 year old son James, who has profound, and multiple learning disabilities, severe physical disabilities and complex health needs, for all his life and what's more the future looked just the same, with no foreseeable end to my caring responsibilities.

I felt that I had given up so much, career, friends, holidays, and family occasions. Everything that I seemed to do all had to centre on my caring responsibilities. The rest of the family shared my caring role and helped out whenever they could, but it was always me who looked ahead and took the brunt of all the problems. It was me who slept with one eye open, planning for every eventuality. It was me who did the same things over and over again, always putting James first.



Things had to change; I just had to find a way to free myself from my day to day caring responsibilities, as time would fly by and I would be celebrating another big birthday, ensuring that James would be safe, happy, having a good life and being well cared for all the time.

So after a lot of soul searching and family discussion and then a lot more discussion and even more soul searching, the decision was taken. It was time to speak with social services. Things were going to change and change for the better.

Social services advised all the options, from residential care, shared ownership, live-in carers or carry on as we were. In the end we decided on shared ownership (yes James could share/own a property) with 24 hour seven days a week support provided by a local support agency of our choice. This was no easy decision - it was one of the hardest that we had ever taken. It was life changing, not only for James but the rest of the

family as well, me included. James was to become a home owner, but how was I to retain control and ensure that James was well looked after?

The answer to my concerns came in the form of an Individual Budget for James. As James is unable to control the budget himself I was appointed to administer it.

I am in control - on James's behalf - of how the money is spent. I write the cheques to the support agency, maintain standards and make sure all is well before I part with the cash. James is having lots of fun and living his life to the full. No, it has not been that easy a journey; because of James's complex needs, I had to apply to the Court of Protection, Public Guardianship Office, to become James's receiver; to enable me, on James's behalf, to buy a property and to have a mortgage. Yes, a mortgage. I know it does sound farfetched, but it is possible. I had to apply to the local council for a Disabled Facilities Grant to make alterations to James's property, project manage the builder on the alterations to James's property and then - the biggest challenge of all - move James into his new home! The actual move was not a problem but oh boy did I feel so lost when he moved in. I stayed with him on his first night in his new home. He slept for 10hrs - I slept for 2! He has now been living in his own property for 23 weeks. I still wake up at night to check he is OK - I forget he doesn't live with us anymore, (It is getting better; only woke up three times this week) James is having a wonderful time, living a full life, has become part of his local community, and having lots of fun, going out with his friends and is very happy. Although I will say I still worry about him and I don't think that will ever go away. He is my son and still a very vulnerable young man.

Now my life has changed. I still monitor James within his new home environment. He comes to visit us. I stay at James's new home and support him; we meet him in the pub for a meal on occasions, go places with him and have quality time with him without having to worry about the

housework or the washing, The amount of support that I provide is up to me. I have my life back. I can arrange a social life safe in the knowledge that James is safe and being well cared for.

It's not that simple. There are addition tasks with an Individual Budget, support plans to be written, meetings to go to, but you owe it to yourself to at least find out about an Individual Budget – it might just change your life. It has changed mine for the better. I am me again not just James's carer.

Now my birthday party's come and gone, and how things have changed. James has settled very well, my husband and I are a couple again. I even have found time to restart my career, you know - salary, office gossip and even a Christmas party to attend. Yes it has been a journey I thought would never happen but it has.



Tina Cooper 30th October 2008

Contact details

Tina Cooper works as a Family Carer Link Worker, part of the 'Doing It Your Way Team' in partnership with BILD (British Institute Learning Disabilities) and Worcestershire Learning Disabilities Partnership Board. She can be contacted at t.cooper@bild.org.uk

Editors comments

There are many resources about individualised budgets, below are some you might find useful.

The Care Service Improvement Partnership (CSIP) Personalisation pages have information about the Personalisation Toolkit. <http://networks.csip.org.uk/personalisation/index.cfm>

The Community Care website has links to articles about Direct Payments, Individual Budgets and Personalisation
<http://www.communitycare.co.uk/Articles/2008/12/19/102669/direct-payments-personal-budgets-and-individual-budgets.html>

The Department of Health website provides papers related to the governments commitment to individual budgets <http://www.dh.gov.uk/en/SocialCare/Socialcarereform/Personalisation/Individualbudgets/index.htm>

Peter Beresford points out some possible problems with Individual budgets in this article published in the Guardian <http://www.guardian.co.uk/society/2008/apr/16/nhs.health1>

The Mencap website has information about Individualised Budgets <http://www.mencap.org.uk/page.asp?id=1813>

In Control has a myth busting page <http://www.in-control.org.uk/site/INCO/Templates/General.aspx?pageid=33&cc=GB>

And fact sheets <http://www.in-control.org.uk/site/INCO/Templates/General.aspx?pageid=30&cc=GB>

Working for Calcutta Rescue

Karen Gleave
Nurse volunteer

Initially started in 1979 by Dr Jack Preger on the streets of Calcutta, with the charity itself becoming registered in 1991, Calcutta Rescue is a medically orientated charity which also provides support and education for slum children. It has four outpatient clinics, two schools and a handicraft project as well as various outreach programmes within urban and rural communities. Early last year I saw an advert in the Calcutta Rescue Newsletter, advertising for a nurse for people with learning disabilities to work in Kolkata. What a fabulous opportunity I thought, and applied for the post.

Once successful I signed up to a nine month contract and was supported by my NHS employer to have unpaid leave. I had travelled in India a few times but this would be my first experience of working within a completely different culture. India is a very rich, beautiful, spiritual and vibrant country, as are her people. Once I stepped outside the airport, on my night of arrival, India suddenly came flooding back to me, all the smells, sights and tastes. It really is an assault on all of your senses and I was excited at the thought of the challenge ahead.

Once I had settled in, I had a tour of the clinics, schools and various projects that are currently being undertaken by CR and then it was on to meet my new colleague. Even though my Bengali wasn't up to much, we soon began to form a very good working relationship, which, as you will read, proved very useful when visiting people within their homes and villages.

The disability services in Kolkata were initially assessed by Teresa Hassall. Calcutta Rescue wanted to improve upon the logistics of this newly developing project and thereby improve the service delivery. It had been identified that there were a number of people with disabilities who attended the clinics whose needs were not being fully met by the current medical services on offer. Our job was to identify these people, assess their needs and support them in whatever way that we could. Also to direct them to other services around the city that might meet their needs.

We worked mainly from three of the clinics as the fourth clinic was a specialist Leprosy clinic and didn't have people who just "dropped in". When we first started out, we were told that around 20 people in total had been identified as needing our services. As you can probably imagine, once we had set up our corner of the clinic to start to meet with our clients we quickly became aware that

there was a slight under estimation in the numbers!! In one clinic alone when I left 9 months later there was 125 people, 90 in the second and around 50 in the third. This number continues to rise as people become aware that finally something is happening for people with disabilities and primarily people with learning disabilities.

The majority of referrals came from the Mother and Child Health Project within Calcutta Rescue including many babies with Cerebral Palsy, whose needs were not being addressed. We spent a lot of time in people's homes looking at the environment that people lived in which included homes on the pavement, under plastic sheeting or with one of the large slum areas of Kolkata. As you can probably imagine this in itself threw up all kinds of difficulties for people with Learning Difficulties, particularly with regards to access. How can you keep a wheelchair safe when you live on the side of a main road? What do you do during the monsoon when you live in an area where around your living space there is just mud? These and many more hurdles were what we endeavoured to tackle plus the ever ongoing stigma issues within the various communities.

Malnutrition played a very large part in this and many young babies do not achieve their milestones due to this reason so it is vitally important that we tried to give these children the best support and start to their lives. Other issues included when a family has say 6 children and the sixth child has a learning difficulty and cerebral palsy, then that child in the eyes of the other members is not able to contribute to the daily life of that family as the other children would be assigned tasks eg: collect water, look after the babies, washing the pots etc. The family lives for today and feeds itself for today as they may not know where tomorrows rice is coming from. So when it comes to meal times the stronger family members will have the "lions share". Part of our role was talking to families and discussing the

benefits of having a child/young person with a learning difficulty within the family. Children and adults who were able to mobilise seemed to be able to go out and engage in the local community, make relationships with peers and gain some independence. Children and young people with more complex and physical needs as well as their learning disability had little or no exposure to this and the families themselves found very little or no support that they could access. After spending some time researching services that the city had to offer people with disabilities, we quickly realised that we needed to set something up to reach the families who had children and young people with complex needs.

One of the things that we set up was an "Early Intervention Programme". This was an opportunity for the people plus their family members to come along to the clinic after the main clinic time had ended. They could see the various health professionals that they needed to access and come together as a group and discuss issues with other mothers, brothers, sisters etc. The children and young people with complex needs also started to form relationships and engage in play and activities. We looked at buying some equipment (which is still in the process of being purchased) for example large mats and primarily physiotherapy equipment to enable therapy through play. I also spoke to a local guy from Kolkata who was working at the Indian Institute of Cerebral Palsy as an Occupational Therapist and asked him if he would help out with this project as we desperately needed someone with his skills to join our team mix. It was and continues to be a great success although it has only been running some 6 months its advantages have been quickly realised by all working and using the programme. The Indian Government has introduced new legislation for people with disabilities so hopefully more people will come forward.

On one occasion I was asked by a social worker to visit a young girl in a large slum area in the north of the city. My colleague came with me not only as my interpreter but also as a kind of "minder" as it is not usual for a "foreigner" to be wandering through a massive slum area. Eventually we managed to find the right home by which time about 50 children were in tow and very eager to see what we had come to do. We met with the mother and at the back of the very small room that herself her husband and three other children lived, slept, ate etc. we found the young girl. I picked her up from the bed area and she immediately started to have a seizure, her mother said that she had been doing this for months possibly years now and didn't know what to do. The young girl had cerebral palsy and severe learning difficulties and needed a complete

assessment at the clinic. We arranged for a jeep to come and collect her and her mother as they were unable to afford the transport to the clinic. We



Karen working for Calcutta Rescue

followed her progress through and she is now receiving medication and has her seizures controlled and is attending intensive physiotherapy sessions at the Early Intervention Programme. Just before I left we also looked at various schools for people with special needs who would be able to accommodate this young girl. Before we left the area where the young girl lived we must have seen about a dozen other people. As we walked through the "slum" and word got around as to why we were there people started to bring out their children and siblings and wanted to engage in our services.

Calcutta Rescue now has a rapidly growing project that needs a lot of support and manpower to help it along its journey. Within the last two month three people have offered their services from Europe and are in the process of travel to Kolkata. One is a Learning Disability nurse, one is an Occupational Therapist and the other has worked in various Learning Disability settings. Calcutta Rescue has also identified the need for a special needs teacher and hopes to fulfil that post in the future.

This is the start of a very much needed and worthwhile project, and as I said earlier aims to give people with disabilities in Kolkata the best start they can have. If anyone would like to keep up with how the project progresses, then please have a look at the newsletter on the website below. Or if you can offer support in any way please get in touch. The resource of knowledge is needed, eg: by being available to e-mail for advice also by supporting the project as a volunteer or however you feel you could help then please get in touch.

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Hearing from the seldom heard

Sue Thurman
BILD

People with learning disabilities face many barriers in being able to complain about the services they receive. Simons (1995) pointed out that complaining is harder when:

- People are **vulnerable** due to stress, illness, inexperience or lack of knowledge
- People have **difficulty expressing their views**
- There is a big **disparity in status** between complainant and those complained about
- Those being complained about having **continuing power** over the person complaining
- People are **isolated**

The report 'A life like any other' (House of Lords 2008) which explores the human rights of people with learning disabilities says that many do not complain because:

- The complaints system is **confusing** and difficult to understand
- Some people do not have the **confidence** to complain

People with complex needs can't complain because people don't know how to **communicate** with them.

People with profound and multiple learning disabilities face all these barriers and more. The scandals of Cornwall (CSCI 2006), Sutton and Merton (CSCI 2007) and Death by Indifference (MENCAP 2007) are sad reminders of the potential for abuse and neglect and infringement of human rights that can result when people's voices go unheard. Nationally there is a drive to improve access to complaints procedures in both health and social care through 'Making Experiences Count' (Department of Health 2007). However people with profound and multiple learning disabilities are not going to be greatly helped simply by the production of an integrated complaints procedure or an 'accessible' complaints leaflet, however well designed. The wider issue of ascertaining views from people with profound and multiple learning disabilities is complex (Ware 2004, Thurman et al 2005.) Being able to complain about services needs to be seen as part of a whole culture in which people's human rights are upheld and promoted. That is why, for example, the promotion of a human rights based approach to health care (Department of Health 2008) is so welcome.

In the light of these concerns the British Institute of Learning Disabilities is undertaking a year long project funded by the Department of Health to look at how we might begin to overcome these barriers

and create listening cultures within organisations where the voices of people with profound and multiple learning disabilities and other complex communication issues are heard, respected and responded to. At the end of the project a pack will be produced and shared widely containing good practice recommendations, resources and links to examples of innovative work.

I am acting as manager for this project. So far I have heard from many people across the country (indeed the world!) who share the concern that people with profound and multiple learning disabilities in particular are not being listened to. I have heard moving real life stories of where things have gone well or gone badly wrong as well as examples of where people are trying innovative ways to improve how we are all listening to people with profound and multiple learning disabilities.

The good practice suggestions that people have made so far fall into five broad categories

- Getting to **know people really well** so you can see things as far as possible from their point of view and spot when they may be unhappy. (The 'I'm Talking – are you listening?' project reported in PMLD Link in Winter 2007 is an example of this)
- Staff and families learning ways in which they can **communicate with people better** (as my professional background is a Speech and Language Therapist I view this as a vital component of any approach to listening to people's views and feelings)
- **Teaching staff and others about complaining**, about the entitlement that everybody has to 'complain' in whatever way they can and how organisations should respond when somebody is unhappy – creating a responsive culture around the person that does not merely 'jolly' people along or ignore their signals of distress or

unhappiness

- Improving access to forms of **advocacy** such as citizen and non-instructed advocacy to all who are unable to represent their own views and feelings easily
- Making sure everybody has a **complaints buddy** – somebody who can look out for them and take action on their behalf. This could be a family member, a friend, another person with learning disabilities or a paid worker but all will need support and resources to help them maintain independence and carry out this role.

Although time is running short for the project I am still keen to hear from people who have stories or ideas to share. **I would welcome hearing from anybody who can share ideas about approaches that have worked or share your experiences about people with profound and multiple learning disabilities whose 'complaints' have been taken seriously (or not).** Any ideas used in the final project will of course be fully acknowledged and any stories shared about individuals will be anonymised to respect confidentiality.

Please contact me either by post at the BILD office or if you prefer by e-mail on the address given below. I look forward to hearing from you and reporting back on the final outcomes of the project when it is complete.

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Spring Vol. 21 No. 1 Issue 62

- The Arts-

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

Please send contributions to:
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Summer Vol. 21 No. 2 Issue 63

- General Issue-

The copy date for all articles, information and news for the Summer 2009 issue is the 8th May 2009

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

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).

RETRO!

Penny Lacey

I have been collecting information for a research article on teaching children (and adults) with severe and profound learning disabilities to think. My intention is to make recommendations for curriculum content and suitable teaching approaches. As I gathered information, I found myself going further and further back in time to find the relevant research and practice to review. Research undertaken in the 1950s and 60s was very useful as was some of the practice in 1980s. My article has taken on a really 'retro' feel! The article is intended for one of the research journals but I will be writing a version for PMLD Link that picks out the particular aspects of teaching thinking that relate to PMLD. For the moment, I shall just outline my main argument.

One of the most important points I want to make in my article is that teaching thinking has been largely ignored in the nearly forty years since children with SLD/ PMLD were allowed to have an education (following the 1970 Education Act). The 1970s and 80s were very dominated by behavioural techniques in which children were taught isolated skills which they did not always know when and how to use and the 1990s and 2000s were devoted to trying to adapt the national curriculum subjects to those functioning at what are called P-levels (pre-national curriculum). Throughout all of this time, we seem to have little time for concentrating on teaching children to think and solve problems more effectively. My argument is that we should be focusing on how to teach these skills, not in isolation but as part of everyday living and learning.

Children with PMLD seem to spend so much of their time in national curriculum subject lessons waiting for something to happen that engages them and I feel that they would be better starting off being engaged at a level they can understand. This is unlikely to be recognisable as a national curriculum subject but it is much more likely to be helping them to develop their capacity for thinking and learning the fundamentals of how to learn. They are more likely to be learning how to pay attention, how to scan objects, how to connect cause with effect, how to influence a person to keep repeating an activity, how to control their environment. They should be concentrating on developing an understanding of how the world works, noticing patterns that make up the world and making sense of what is happening to them. They need to learn to think!

So how does looking backwards help us to move forwards? The experiments undertaken with people with learning disabilities from the 1950s onwards suggest that although individuals have different abilities in their thinking, they basically go through the same developmental sequence of any

person. However, it is not helpful to suggest their development is 'delayed' as that implies that they will catch up if they live long enough, which clearly they do not. Experiments on memory, especially with people with down syndrome help us to understand difficulties in learning. It is very hard to learn anything if your working memory is so small everything you do appears to be as if the first time you have done it! People with PMLD may have very little of a working memory at all. We cannot know that for certain.

Some of the experiments on teaching people to improve their memories was encouraging, although there was always the difficulty of helping people to generalise strategies they learned. They became better at doing the tests in the experiments but not necessarily at using their memories in real life situations. There were ideas for teaching for generalisation but these were not adequately developed at the time.

There is so much more to explore in this area and I need to complete my review. If you want to know more about my ideas for developing the thinking and learning skills of people with PMLD then look out for my finished article here in a future PMLD Link!

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PMLD Link: Future Focus

The Arts

Alice Bradley

I remember as a young teacher, new to working with children with learning disabilities, being both amazed and inspired by a drama class for children with profound and multiple learning disabilities. Drama, for children with such severe disabilities – I was sceptical to say the least, which just goes to show how much I knew! The session involved lots of props – hats, fabrics, everyday objects and so on – lots of laughing, lots of movement and lots of participation. I've never forgotten it.

Our Spring issue of PMLD-Link is about 'The Arts'. From your own experience, both as an individual and as someone who supports people with profound and multiple learning disabilities, you'll be well aware of the pleasure and fulfilment that comes from exploring those aspects of ourselves that can be hard to put into words. Perhaps this is where many people with profound and multiple disabilities have the advantage – who needs words when there are so many other different and exciting ways to express and experience ourselves? The advent of multimedia has brought new and exciting ways of working with – and just sharing time with – the people we support.

So please let's have your thoughts, ideas, tips and experiences about:

- Events and activities involving painting, drawing, sculpture, drama, music, dance, movement, storytelling, film and other related areas
- Multisensory and multimedia stories, events and activities
- Making visits to public places like museums, cinemas, art galleries and theatres more accessible to and enjoyable for people with profound and multiple learning disabilities
- New and creative ways of making The Arts come alive for people with profound and multiple learning disabilities

We'd also like to hear about any books, DVDs, CDs, websites or organisations you have found particularly useful – and anything you might have produced or developed yourself, with individuals or groups.

Please send your articles, short or long (maximum 2000 words) to alice.bradley@virgin.net by 6th March 2009.

Thank you! It promises to be an exciting read.

Alice Bradley

PMLD Network Email Forum A Digest of Discussions July 08 - October 08



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

1. Hearing from the seldom heard

This is a one year a project being run by BILD to look at barriers faced by people with a learning disability (particularly those with complex communication and other needs) when wanting to complain about the levels and quality of services they receive. It will result in a pack of good practice recommendations and resources. They have already gathered some examples of approaches to help people complain more effectively including complaints forms, Dvds and buddy systems. They wanted to know if anyone else had any good practice examples, resources or experiences of complaints to share. Responses included:

- Someone suggested getting in touch with PAMIS who have done some work in this area. Someone else suggested contacting Mencap who are doing some work around communicating with individuals with PMLD.
- Someone said she should look at the 'I'm Talking – Are you Listening?' resource which addresses issues like pain, discomfort/displeasure through to complaints or signs of possible abuse, in people who have limited communication. (This was featured in an earlier issue of PMLD Link)
- Someone suggested contacting the people at Talking Mats www.talkingmats.com
- Someone said they have a very good complaints procedure at the White Horse Care Trust (WHCT) which provides residential care for people with learning disabilities. It is a postcard system and there is a video using staff and residents which explains how it works. Basically each resident has a postcard with a symbol on the back of a person with their thumb pointing down. The postcard is stamped and has the address of the Chief Executive on the front. If a resident has a complaint they can send - or be supported by a member of staff to send - their postcard. The Chief Executive will then arrange to meet with the person to discuss the complaint (he can identify who the resident is by a personal number on the postcard). To see a copy of the Dvd contact Helen@whct.co.uk
- Someone who investigates complaints independently for local authorities said it is really helpful for people to be specific about time place and person. People may need support with this though.
- 'Say it Works' has produced a picture library to help with communication. In developing this they spoke to many people and organisations and asked what they wanted to make their messages clear. For more information see www.sayitworks.co.uk

2. Further education and complex needs

Someone who is supporting a local education authority in developing an improved education offer to young people with complex needs aged 16 to 19 was looking for examples of good practice. He asked if anyone knew of further education colleges or other post 16 providers who have developed good courses. Some comments and suggestions were:

- Nash College in Bromley specialises in this. For more information contact info@nashfecollege.org.uk
- Schools and colleges are increasingly using an interactive cd-rom called 'My Life Plan' to build a picture of what is important to young people with them central to the process. For more information see www.information-plus.co.uk/mlp.htm
- A special needs provision for 16 to 19 year olds in East London has a curriculum based on the development of Independent Living Skills, Communication and Community Access. They notice excellent progress in the young people as they do not have to follow the National Curriculum. Learning activities are based on the students' strengths and preferences. The aim is to equip them with the necessary skills to move on to adult life within the community. They work closely with all agencies involved with the young people. The students' reviews are all person-centred planned and they produce a multimedia profile for all their leavers.
- Linkage Community Trust in Lincolnshire

which have one campus in Grimsby and one in Toynton: www.linkage.org.uk

- City College Plymouth offer individualised programmes for learners with PMLD/ complex needs as part of a range of Skills Development Courses: www.cityplym.ac.uk/

3. Top tips for being with or supporting a person with a learning disability

Someone was putting together a list, for training events, of hints and tips about being with or supporting a person with a learning disability and asked people on the forum to share their top 3 tips – for example, around communication, teaching new skills or attitudes. Responses included:

- Someone said their top tip is to treat everyone as an individual. They said that because everyone is different, general tips about how to communicate might not be that useful. They suggested universal truths about 'good communication for all' might be better.
- 'Shared understanding is absolutely vital in any successful communication'
- Someone suggested that people stop talking and start acknowledging their partner's communication - and respond to it using the same language, and take it from there (based on the principles of intensive interaction)
- 'I agree with 'not talking' and using intensive interaction.'
- 'Communication is everything someone does in their life. Each time anybody does something they are trying to communicate whether there is someone there or not.'
- 'If you are working with someone with PMLD they might look towards the door because they either saw a light change or heard footsteps. This person is telling you they are observant about their environment and they can tell light change. We can use this as evidence to develop skills.'
- Someone said to talk to people with a learning disability of all abilities to get tips about how they want to be supported and to invite them to the training events.
- Someone said that people will often teach you everything there is to know about themselves through their behaviours, choices, like and dislikes.
- 'When supporting someone with a learning disability it is important you work with their lifestyle. They are a unique person and deserve respect.'
- Someone said it is important to give service users the opportunities to participate in everyday life eg. cooking, going swimming, choosing clothes.

- 'Find out about the person from those who already know them. See if they have a communication passport.'
- 'Be patient'
- 'Share your experiences with them and share theirs and have fun.'

4. Successful Person-centred planning

Someone said they were having difficulty finding good quality training in person centred planning. They wanted advice or good examples of successful plans.

- Someone said it is important to find a way of working which makes sense to the person, engages them and puts them at the centre for example through creating videos.
- There are some videos from Inclusion Distribution which could inspire people wanting to plan in a person-centred way. See www.inclusiononline.co.uk
- Someone said they had accessed training, information and support from Partners in Policymaking on Merseyside which included PCP, MAP and PATH. The training was in small groups and was participative, easy to understand and with lots of hands-on practice. The Circles Network deliver the Partners in Policymaking courses and they have lots of experience in supporting people to understand and apply the principles of PCP in real life. See www.circlesnetwork.org.uk for more information about the training they provide.

5. No mention of parents who broker

A parent said that in all the discussions and reports about Brokerage she can find no mention of parents who broker. She has been managing her daughter's individual budget for three years and says no one will enter discussion about her role. Her comments and some of those from other parents are below:

- 'Can I be paid or not?'
- 'If brokerage is so worthy of all these reports and so many people gaining accreditation as brokers, why is there resistance to recognising we parents do the same? Or are all these newly trained brokers working for free?'
- 'I provide many hours of support in connection with my son's individualised service. The question you need to ask yourself is 'would someone else in my absence, do what I do without payment?' – if the answer is no, then you need to pay yourself!'
- 'As two out of work parents caring for our profoundly disabled daughter, we would like to be recognised for what we do. But the real world is that the system would collapse if all

family carers were recognised in the same way as employed carers or any other roles ie. Brokers.'

- 'We have requested specialist expertise from a broker, but the Authority won't pay for it. They haven't set up that system themselves, but won't pay for an independent one either. We continue free of charge, no choice.'
- There is a chance the system could change if and when Individual Budgets become established and money is provided as part of the planning and implementation process.'

6. I've started a photo library!

- Someone said they had realised how few positive photos are available that depict people who use social care so started a photo library. She said that people looking for images to use on publications, websites and publications could be directed to the website:
- www.flickr.com/photos/charlottesmorse/collections. She said all people have signed consent forms and are happy for their photos to be used.
- Her email generated a lot of debate. Although a couple of people voiced concerns over the safety of the web, the majority felt the photo library was a good idea and welcomed positive images of people with a learning disability. There was lots of discussion about it being the choice and right of people with a learning disability to have their photos on the web. There was also lots of discussion about consent including working in line with the Mental Capacity Act 2005 when someone lacks capacity to make a particular decision themselves.

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

Please note: The new PMLD Network website is launching in mid-April. The website address will be www.pmldnetwork.org

The PMLD network discussion forum, (www.pmldnetwork.org), is run and maintained by:

Foundation for people with Learning Disabilities
7th Floor, 83 Victoria Street,
London SW1H 0HW.
Tel: +44(0)20 78020301
Email: nmorris@fpld.org.uk
Website: www.learningdisabilities.org.uk
Registered Charity No: 801130 Company
Registration Number: 235 0846

Report Back

The Whale's tooth

A performance with bite



The Whale's tooth was on at the Unicorn Theatre, London in July. It was an interactive and sensory performance for people with profound and multiple learning disabilities.

The story was about a girl called Canny who lives in the Arctic Circle with her grandfather. Canny's father had left home many years before when her mother had died and Canny and her grandfather presumed he was now dead. But after finding his name carved on a whale's tooth they realise he must still be alive and go on a long and dangerous journey to find him.

The performance took place in an igloo where the performers interacted with a small audience of people with profound and multiple learning disabilities and their supporters. Other people were able to watch the performance on a screen outside the igloo.

Use of different music and lights helped create a fantastic atmosphere in the igloo. The audience were involved all the way through. At one point each person was supported to put a fish onto a hook and watch it being lifted up during a scene where Canny and her grandfather were fishing. Wind machines and sprays of scented water were used to create the atmosphere of a storm and a warm fur glove and heavy whale's tooth were passed around for people to feel at other points during the play. Each of the performers spent time communicating parts of the story in sensory ways to each member of the audience.

Leroy Binns, a member of the PMLD team at Mencap was watching the performance on screen outside the igloo, he said 'It was such a good play because it really involved people with PMLD. There should be more like it.'

We are delighted to hear that another performance is planned for 2009-2010 due to the success of this one.

Further information

The Whale's tooth was a Nottingham Playhouse Roundabout production. Education resources for the play can be downloaded from the Nottingham Playhouse website: www.nottinghamplayhouse.co.uk.

Report Back

Penhurst Conference 2008 Communication and PMLD Developing Intentionality?

Under an unusually cloudless blue sky, around 100 delegates gathered at Penhurst School in Chipping Norton on 26th September for the school's fourth biennial conference. There was a buzz of anticipation at the start of the day, and delegates were not disappointed, as the programme was packed with interesting and stimulating items.



Our Keynote Speaker was Dr. Mark Barber, Consultant in Profound Intellectual Disability & Severe Communication Impairment (Melbourne, Victoria, Australia). Mark is not only suitably qualified to express and explore the theory of the development of communication in those with PMLD, having studied for his PhD under Juliet Goldbart at Manchester Metropolitan University, but is also hugely experienced practically as a teacher and as an advocate for the implementation of Intensive Interaction.

Mark held our attention completely in his keynote speech and workshop, as he gently but thoroughly challenged our preconceived ideas on how to develop intentionality in our pre-intentional learners. He questioned our unswerving focus on promoting proto imperatives (requests for objects or action) as being needs-led, and persuasively argued for promoting proto declaratives, i.e. interactions designed to achieve joint attention or social closeness. Thus we need to look beyond the learners' physical needs to their core human needs for social interaction and relationships, even though (uncomfortably for professionals) the consequences might not be as concrete or obvious, and outcomes harder to measure.

Many video examples of stunningly good practice of Intensive Interaction illustrated the theory perfectly, and left us all inspired to redouble our efforts to achieve and support the use of Intensive Interaction in our places of work. Mark also, tantalisingly briefly, touched on his work in Australia, where he advocates the embedding of Intensive Interaction into the curriculum. We wished we had had another few hours to learn about that too!

Five other workshops maintained the quality of presentations throughout the day. Tony Jones, training and development manager for Liberator, is an old friend of the conference, and led a popular session on Multi-sensory Referencing. Judy Robertson, Independent Specialist Speech and Language Therapist and a familiar face in the world of AAC, had lots of motivating ideas on active participation in communication. We were also privileged to benefit from the expertise of two Music Therapists, Bob Heath and Judith Henderson, who led inspiring workshops on Creative Songwriting and Music and the Secure Base respectively.

Cath Irvine, Specialist Speech and Language Therapist, had been at Penhurst School all week, training our Intensive Interaction Advanced Practitioners, who then themselves (very bravely!) took a turn at presenting some of the case studies they had been compiling over the last six months. Penhurst School has been on a journey, to find a way not only to train staff in the use of Intensive Interaction, but also to record and evidence the progress that students make, and Cath's input has been invaluable for us to achieve our goals. Cath finished her week by contributing a stimulating workshop on the implementation of Intensive Interaction at the conference.

Penny Lacey, from the University of Birmingham, has enthusiastically supported the conference on previous occasions, and we were delighted to hear this time of her Inclusive Libraries project, which (funding permitting) will inform and train public libraries to offer more appropriate material and activities for those with PMLD.

Time was precious during the conference, but breaks were used to the full – not only for eating and drinking the delicious fare on offer, but also to browse round displays by Liberator, QED and Bag Books, and network generally with like-minded people from all over the country.

A great day – thankyou to everyone who made it possible!

Janet Trebilcock
Speech and Language Therapist

NEWS

CSCI report condemns 'flawed' eligibility system

'Cutting the Cake Fairly', a report by the Commission for Social Care Inspection (CSCI), examines the mandatory eligibility guidelines laid out in the government's Fair Access to Care Services (FACS).

The report recommends that the current eligibility criteria should be scrapped with immediate effect and replaced with criteria that take into account the urgency of each situation. It also states that eligibility criteria should be applied consistently across the country.

Commenting on the report, co-chair of the Learning Disability Coalition, Dame Jo Williams, said: "We welcome many of the recommendations, particularly around the proposal to scrap existing eligibility criteria and the postcode lottery. But, as the report admits, it will be futile without the money to back it up. Services will still be unfairly restricted



The following abridged announcement was received on the Learning Disabilities Forum in October 2008.

'Welsh Assembly Government Ministers have announced new funds worth £2.75m to raise awareness of benefit entitlement, provide more play opportunities for disabled children and offer short break services for children with complex disabilities. Dr Gibbons said:

Families with disabled children face a real risk of poverty due to having to buy specialist support or equipment or because they struggle to earn a full-time wage due to their caring commitments. To compound the problem many parents miss out on benefits and tax credits which can mitigate the greatest poverty risk.

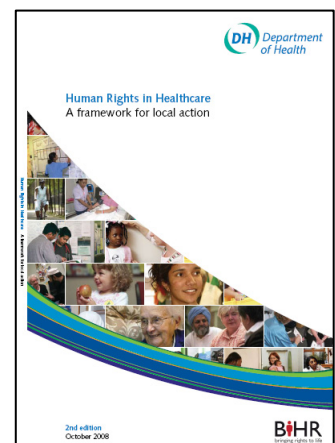
The Welsh government acknowledge the additional financial difficulties facing parents with disabled children and want to ensure that all families are claiming the benefits and tax credits available to them, making a difference to those families living in, or at the margins of poverty. Additional funding of £1.5m is being made available by the Deputy Minister for Social Services Gwenda Thomas to fund short break services for children with complex disabilities.'

If you experience new or improved services as a result of this please let PMLD Link know, we would love to report successful projects both in Wales AND also in other parts of the country.

Framework for Local Action on Healthcare published

The Department of Health, the British Institute of Human Rights and 5 NHS Trusts have worked in conjunction to produce a framework to assist NHS trusts to develop and apply human rights based approaches in their organisations to improve service design and delivery.

You can read the framework - 'Human Rights in Healthcare - A Framework for Local Action,' on the [Department of Health's website](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_088970):
www.dh.gov.uk/en/Publicationsandstatistics/Publications/
PublicationsPolicyAndGuidance/DH_088970



Independent Review of the Primary Curriculum: Interim Report

Sir Jim Rose has written an interim report following his review of the primary curriculum. We are invited to respond to his review by

So what does the review offer to young children with PMLD? Directly, of course, it offers nothing but those of us working in primary education can see how we might be able to adapt what Rose is saying to meet the needs of children with PMLD.

1. Rose recommends that teaching the subjects of the national curriculum should be balanced with a cross-curricular approach. He is a great pains to explain that he does not mean that we should return to old-style projects but we should combine the best of cross-curricular work with rigorous subject teaching.

2. He proposes to combine the subjects into areas of learning to reduce the curriculum demand on primary schools. The new areas are: Understanding English, communication and languages;

- Mathematical understanding;
- Scientific and technological understanding;
- Human, social and environmental understanding;
- Understanding physical health and well-being;
- Understanding the arts and design.

3. Literacy, numeracy and ICT will continue to be at the centre of the primary curriculum but Rose suggests that speaking and listening should have more prominence.

4. Rose suggests that personal development should be an important part of the curriculum to promote the spiritual, moral, cultural, mental and physical development of pupils.

5. Rose recommends that there should be earlier access to school and he thinks dividing the curriculum into areas of learning (rather than subjects) will provide better transition from EYFS to KS1. He sees play as an important aspect that needs to continue throughout KS1.

6. He also suggests that at least one modern foreign language should be taught in primary schools.

We can see how much of this is likely to be helpful for primary schools educating children with PMLD. The emphasis on developing communication is very good news as is the interest in personal development. These are fundamental aspects of a curriculum suitable for educating children at a very early stage of development. Dividing the curriculum into areas of learning is certainly superficially, a good idea for children with PMLD as the subjects of the curriculum were always difficult to access for them. However, we will wait to see what the programmes of study will look like before getting too excited!

Emphasising the important of play further up the school seems to be another important change, although I suspect the kinds of play Rose has in mind is likely to be much more adult-led than is recommended for approaches such as Intensive Interaction, where the adult follows the child's lead and lack anything resembling specific teaching. Again, we will have to see what is recommended in terms of details.

All-in-all, the new primary curriculum looks to be PMLD-friendly. Let's hope the Government is willing to listen and sanction the changes.

For more information regarding the report please visit <http://www.dcsf.gov.uk/primarycurriculumreview/>



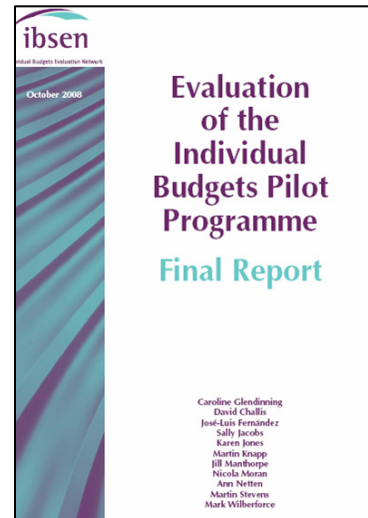
Individual budgets 'offer control over lives'

People with a learning disability choosing to use individual budgets are more likely to feel in control of their lives, a new report has found.

The Individual Budgets Evaluation Network (IBSEN) carried out the research. It evaluates the outcomes of individual budget pilots across 13 local authorities in England, which took place between November 2005 and December 2007.

The report finds that the effectiveness of individual budgets differs between groups, such as older people, people with mental needs and people with physical disabilities. For people with a learning disability, 68% of those surveyed for the evaluation said that individual budgets had changed their view on what could be achieved in life.

Responding to the findings, the Department of Health (DoH) said it is "encouraged that the overall results for social care outcomes were positive." It said that the research confirmed that the introduction of individual budgets to social care is the right approach, and that the Valuing People Now strategy will prioritise personalisation.



Mencap's head of campaigns and policy, David Congdon, welcomed the report and said that Mencap supports the introduction of individual budgets. However, he called for greater transparency over how they are calculated and said that the system must be properly funded.

"Any local authority that puts a maximum upper limit for people who need more complex packages of care are treating individual budgets primarily as a money-saving scheme, rather than a way to give people more control over their lives," he said.

Read the IBSEN evaluation report and the Department of Health response:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_089505

BSc hons, BSc, Diploma HE with Nursing and Midwifery Council validated Registered Nurse for people with Learning Disabilities (RNLD)

The University of the West of England are taking applications for the RNLD course commencing September 2009. This 3 year course includes practice placements in a range of services in the South West Region (Swindon, Bristol, Bath, Weston Super Mare, Gloucester etc.) and during the 2nd year with a family. Opportunities for some overseas practice experience can be negotiated. The course is based on the values of rights, choices, independence, inclusion and personalisation. Academic content includes a wide range of learning opportunities in relation to adults and children with learning disabilities including person centred planning, communication, health, health inequalities, challenging behaviour, complex needs, PMLD, services provision modules (including traditional and emerging) working with families, social policy, biology, psychology, inter-professional working and more. If you would like to find out more contact the programme leader Robert Pardoe or Admissions tutor Matthew Godsell who will be happy to give you more information. e-mail Robert.Pardoe@uwe.ac.uk Matthew.Godsell@uwe.ac.uk phone Robert Pardoe 0117 32 88 447

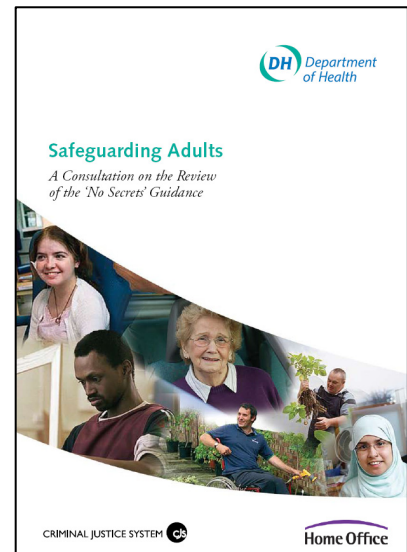
No Secrets consultation launched

The Department of Health has launched a review of No Secrets, its 2000 guidance on preventing the abuse of adults.

The consultation will look at ways to further improve the protection of vulnerable adults and address abuse in all its forms within the care system. The review will also focus on personalisation, and promises to empower people to recognise and manage, rather than minimise, risk.

David Congdon, head of campaigns and policy at Mencap and part of the advisory group for the review, welcomes the consultation, but calls for a commitment to implementing the necessary legal powers and duties to ensure real protection:

"To keep vulnerable adults with a learning disability safe from abuse, the systems designed to protect them must be backed by legal powers. Without this much-needed legal framework, we will continue to see more horrific cases of abuse against vulnerable adults with a learning disability, like the tragic case of Stephen Hoskin who was abused and brutally murdered in Cornwall last year."



The consultation closes on 31st January 2009. Read the consultation document on the Department of Health website:

<http://www.dh.gov.uk/en/Consultations/Liveconsultations/index.htm>

Annual health checks announced

A new part of the contract between government and GPs means all people with a learning disability who are known to social services should get an annual health check.

People with a learning disability who are on the local authority register will be invited to come to their GP surgery for a health check.

The check will include:

- Physical health
- Medication
- Mental health
- Transition reviews (where appropriate)
- Epilepsy (where appropriate)

To be able to give the health check doctors, nurses and receptionists in the surgery will have to have training in learning disability. This training must include people with a learning disability, their families and carers.

Although most surgeries are expected to carry out health checks, the new scheme can't make them do it.

At the moment the money for health checks is only planned for 2 years. It is hoped the scheme will be a success and go on after the 2 years.

It may take a while for GP surgeries to get organised and start giving health checks to people with a learning disability in their area.

Changing Places going for gold at Olympics

Designs for the 2012 Olympic Park promise to be the most accessible yet – featuring Changing Places toilets in every venue.

As part of its Inclusive Design Strategy, the Olympic Delivery Authority (ODA) has announced that it will include accessible Changing Places toilets in each of the Olympic Park's venues.



For thousands of people – including 40,000 people with profound and multiple learning disabilities – standard accessible toilets do not meet their needs. Changing Places toilets provide a height adjustable changing bench, a hoist system and plenty of space.

Margaret Hickish, principle access officer for the ODA said: "We have published our Inclusive Design Strategy which sets out the framework for how the Olympic Park will be designed and constructed to be inclusive for people of all cultures, faiths and ages, and accessible to disabled people. As part of this commitment, we will have accessible Changing Places toilets in every venue, both front and back of house."

This announcement is a huge achievement for the Changing Places Consortium, who have been lobbying for the Olympics to be made accessible to people with profound and multiple learning disabilities.

As a further result of the Consortium's lobbying, the Community and Local Government Committee has called for all local authorities to provide consistent and evenly distributed public toilets, recommending that there should be more disabled facilities.

Commenting on the report, Changing Places Consortium spokesperson Beverly Dawkins, said: "The report recommends the need for better provision of disabled toilets. The government must accept this recommendation and encourage more local authorities to provide Changing Places toilets that cater for severely disabled people."

Read the [ODA Inclusive Design Strategy](#):

www.london2012.com/about/the-people-delivering-the-games/the-olympic-delivery-authority/oda-priority-themes/design-and-accessibility.php

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

Planet X

Planet X is a fun, tactile, interactive installation space created to stimulate the senses of young (3-16yrs) people with disabilities through sound, light, colour & texture.

It has exciting areas to explore and interactive gadgets all themed upon space travel and strange planets. There are trained facilitators to encourage the participants around the space, helping to enhance the experience.

Parents and siblings are welcome to also take part and enjoy the shared event.

So far, the dates planned for 2009 are:

Saturday 31st January, Saturday 28th February, Saturday March 28th.

You can drop in anytime and stay as long as you want from 12 noon to 4pm. It is £1 on the door per person.

Please do come along and enjoy a journey into outer-space.

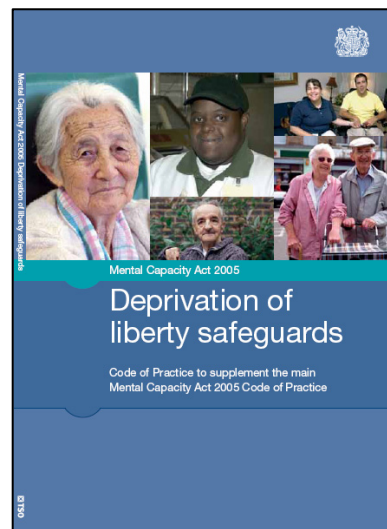
For further information, email: shaun@turtlekeyarts.org.uk or telephone: 020 8964 5060

New code to protect the liberty of those who cannot consent

There is a new code of practice to protect people who do not have the capacity to consent to treatment, but have a mental disorder that means they need to be kept under the care of a hospital or care home. The new code will come into force in April 2009.

The safeguards ensure that there are systems in place to make sure that if a person cannot consent, their freedom is not restricted by the care home or hospital more than necessary, and any restriction is in their best interests. Any third party can say if they think someone is being deprived of their liberty, and prompt checks will then be made.

You can find out more on the [Department of Health website](http://www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/MentalCapacity/MentalCapacityActDeprivationofLibertySafeguards/index.htm):
www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/MentalCapacity/MentalCapacityActDeprivationofLibertySafeguards/index.htm



Parenting Fund: call for projects

Maximum grant value: Discretionary

The Parenting Fund assists not-for-profit organisations undertaking parenting support work where parents, families and children face significant challenges. (This includes parents who have children with disabilities). Funding is available for work in 23 localities (<http://www.familyandparenting.org/PF3Localities>). The Parenting Fund has launched a funding round in October 2008, projects will be funded from April 2009 to March 2011. Projects should be expected to deliver training and outcomes that can be picked up nationally although the projects themselves should be more local. Visit <http://www.familyandparenting.org/ParentingFundHome>



Welcome

Anne Williams, newly appointed National Director of Learning Disabilities commenced her new role in October. She takes over from Rob Greg and will be driving forward the Valuing People Now agenda.

PMLD Network Website

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

Have you visited this website yet? There are a range of resources from personal stories, news and events, campaigns and links to many useful reports, presentations, publications and positive images of people with PMLD.

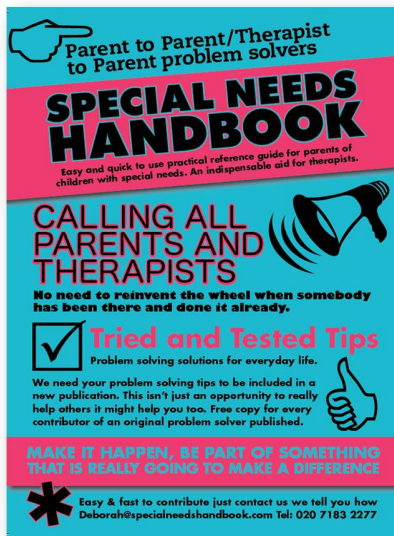
INTERCONNECTIONS ELECTRONIC BULLETIN

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. To view the listings www.icwhatsnew.com

Peter Limbrick
 Interconnections
 E-Mail: p.limbrick@virgin.net
 Web: www.icwhatsnew.com

RESOURCES



Special Needs Handbook

Call all Parents and therapists

We need your problem solving tips to be included in a new publication. This isn't just an opportunity to really help others it might help you too. Free copy for every contributor of an original problem solver published.

If you would like to contribute just contact us we tell you how = Deborah@specialneedshandbook.com Tel: 020 7183 2277

DVD Review

People with Learning Disabilities, AT & Telecare

DVD produced as part of the TATE project (Through Assistive Technology to Employment)

This DVD gives examples of how Electronic Assistive Technology can support people with learning disabilities at home and in the workplace. Most of the ideas relate to more able people than those with PMLD but there are applications that are useful for more severely disabled people.

One of the case studies on the DVD is about a residential home for eight people with severe to profound learning disabilities and this part of the film shows a range of devices that can help the residents to be more independent. One man who hated going in the shower now has flashing lights set off by a sensor which attract him and now the problem is getting him out of the water!

There is a paging device which can help staff know where they are wanted. They can respond quickly to residents' needs. Other devices can let them know when residents come out of their rooms at night so staff can go and help where needed or can tell when someone has got out of bed unexpectedly. Fingerprint technology can help give privacy to residents who cannot manage to use keys for their rooms. One resident on the film is using a simple message device to help her communicate to staff that she would like her TV turned on.

The central message from this DVD is that technology can help to enable people with learning disabilities to be more independent. Staff can support more at a distance and only when required. A more able man is seen travelling about on his own knowing that in his pocket is a phone that can connect him immediately to a supporter. If he is unsure of his location, the phone will indicate where he is.

The DVD is part of the TATE project and you can find out more about that from the website http://www.tateproject.org.uk/tate_project.php

REVIEWS

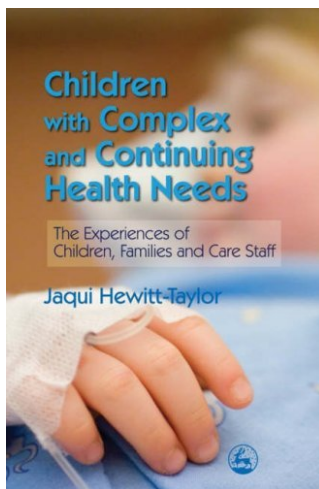
Title: Children with Complex and Continuing Needs: The Experiences of Children, Families and Care Staff

Authors: Jaqui Hewitt-Taylor

Publishers: Jessica Kingsley Publishers

Pub date: 2007

Price: £18.99



Jaqui Hewitt-Taylor has written a text and captures the real experiences of families that support children with complex and continuing health needs. The frequent narrative accounts of parents and care staff, illuminates and supports the factual and discursive chapter content in this book. I would have welcome some contributions from the

children themselves but understand the difficulties associated with developing narratives when many of the children referred to in this book appeared not to use language.

The author explores the experiences of children, families and care staff via 12 chapters that are easy to read, informative and often offer practical advice and links to other useful resources. What this text doesn't do is relate the groups' experiences to the wider disability literature. For example chapter 6 (Diagnosis) only uses two references in area that has a significant body of literature.

There are a number of accounts that explore the experiences related to children that have additional learning needs associated with autism, cerebral palsy and Rett syndrome. These accounts could appear confusing to some readers as these additional learning needs are not explored or developed. This may leave some families confused about the relevance of this text as not all children with additionally learning needs have complex health problems.

This book is moving and offers readers an insight into the difficult challenges families and care staff

face when developing and supporting this group of children. I would recommend this book to parents, care staff and students that have limited knowledge and experience in this specialised area of support. This is not a text that offers in-depth technical or theoretical explorations, but is none the less a compelling read!

Neil Summers
Senior Lecturer
UWE-Bristol UK.

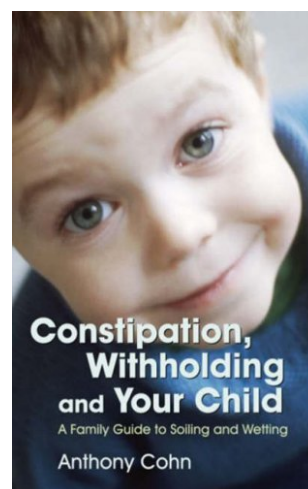
Title: Constipation, Withholding and Your Child: A Family Guide to Soiling and Wetting

Authors: Anthony Cohn

Publishers: Jessica Kingsley Publishers

Pub date: 2007

Price: £9.99



This book comprises 20 very short chapters beginning with an introduction explaining how common toileting problems are and which emphasises how stressful they can be for the whole family. The author (a paediatrician) carefully explains medical terms, rendering it easy to read and accessible to all. One of the book's appealing features is the author's direct

appeals to children through stories: these illustrate Cohn's belief that youngsters can be encouraged to accept some responsibility for their toileting behaviour from an early age. These stories are well devised and could be adapted for various ages.

A central theme to the book is the fact that many children withhold stools rather than experience real constipation. The author explains that this often relates to anxiety and can become habitual. Information about digestion is provided in straightforward ways using visual props to outline

the variety of problems children might experience. A series of child-friendly questions are also posed and these are aimed at eliciting information from those who might find the topic "taboo." The author is reassuring about when parental anxieties might suggest a medical problem and how rare these are. A chapter on the "signs of withholding" is particularly helpful in alerting adults to indicators of problems when children cannot explain their symptoms

Cohn offers general tips related to toilet training, all of which serve as sound reminders of some children's fears and habits. He follows this by advice on healthy foods and fluids, especially fibre. The use of reward systems and diaries is explored before a section on medication (a last resort, although this section does contain a helpful outline of advantages and disadvantages of laxatives). This is followed by a short section focused on enuresis (wetting) and its relationship to bowel problems.

The penultimate section of the book looks at some of the theories about why children might continue to have toileting problems despite intervention. Again this is contextualised by considering parental approaches to their child's toileting and by addressing the child directly. Brief information is offered about the relationships between bowel problems and conditions such as autism, ADHD and Cerebral Palsy. Finally, the book ends with a brief section on the role of schools which is thought provoking but brief.

In summary, this is essentially a book for parents and carers or teachers who are at the early stages of worrying about a child's bowel problems. It adopts a predominantly behaviourist approach but also acknowledges the child's role in toileting and how family dynamics may prolong issues. It is informative, accessible, well supplemented by visual explanations and one which I would highly recommend to anyone who works with young children.

Sue Sanderson. Educational Psychologist - Cumbria

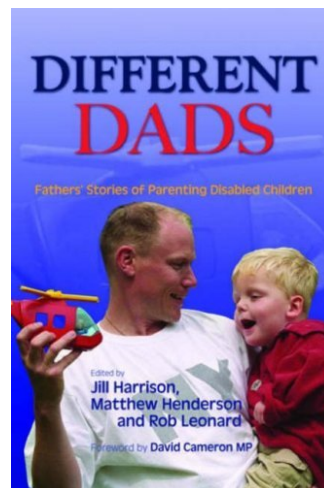
Title: 'Different Dads' – Fathers Stories of Parenting Disabled Children

Edited by: Jill Harrison, Matthew Henderson and Rob Leonard

Publishers: Jessica Kingsley Publishers

Pub date: 2007

Price: £12.99



When I received this book, I wasn't quite sure of what to expect. Historically, men don't like to show their feelings and try to appear the strong person in a relationship. As I started to read I realised just how thought provoking and deep the book was going to become.

Short accounts of 'Dads' experiences show how they have come to deal with their child's disability and how they felt going through the process of adjustment and acceptance.

Throughout, there is a passion and sense of positivity, which I feel, will benefit other fathers.

I found the tips and web links at the end of each story a real help and could see how this would empower people to look if they didn't know where to start.

My husband read the book but only really felt he could relate to the stories about Autism, which he has knowledge of having two sons with the condition. This may be a bit of a disadvantage if others feel the same, but the insight into feelings would hopefully help 'Dads' share an empathy of their daily lives.

Altogether, I found the book really helpful, especially as a mother to be able to try and understand how the partners may feel in comparison to my own thoughts.

I would recommend the book as a informative, insightful collection that could help many families travelling the same road.

Dawn Rooke

Website Review



This web site gives exactly what it says it will give – easy access to information that is health related. There are 6 main windows which are :-

- About the site
- Health leaflets
- Short films about visits to certain health professionals and departments, plus some explicit health problems explained.
- An area for patients about improving health and well being
- An area for health professionals about improving ways of working
- Useful people, websites and help-lines.

Each of the above area opens up to reveal deeper layers of further information.

This site contains a wealth of information for anyone who cares for either children or adults who have profound and multiple learning disabilities, but as the title states is confined to the health arena. The information whilst aimed at people who have learning disabilities, covers more general health needs at the moment but as this site grows it, if the present standards are maintained, this could become a compulsory first site destination for all those wanting to find out more about meeting the health needs of people who have learning disabilities.

The site is currently inviting comments and has a number of set questions.

For Community Nurses on

<http://www.choiceforum.org/gennurse.doc>;

For GP on

<http://www.choiceforum.org/gengp.doc>

For parents and carers on

<http://www.choiceforum.org/gencarer.doc>

There is also an Easy read feedback form

<http://www.choiceforum.org/gen.pdf>

or you can just email comments to Jo Giles email: Jo.Giles@generate-uk.org

Di Foxwell - Reviews editor PMLD Link

Other Useful Websites

If you were looking for Pete Well's sensory stories then you will find them on

<http://www.sunderlandschools.org/portland/PetesStuff.htm>

There are no new stories yet but you can still enjoy the old ones!

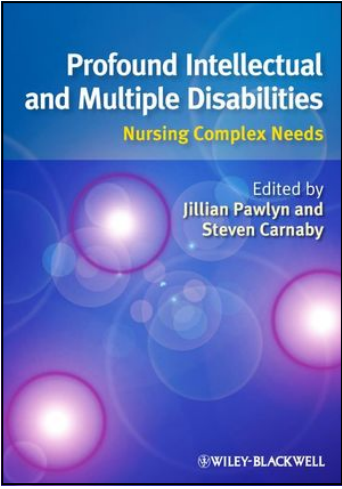

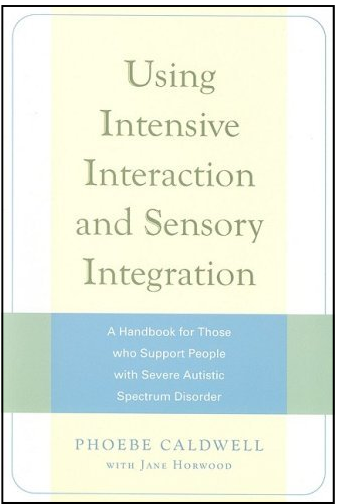
Don't forget the Priory Woods School site. There are lots of simple one switch games.

<http://www.priorywoods.middlesbrough.sch.uk/>

And Poisson Rouge adds new games frequently. Have you been to the website recently? Some of the games are very simple and can be used with a touchscreen or a single switch.

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

PUBLICATIONS

	<p>Authors: Jillian Pawlyn & Steven Carnaby</p> <p>Publisher: Wiley-Blackwell</p> <p>ISBN: 978-0-415-46315-7</p> <p>Pub Date: 2008</p> <p>Price: £27.99</p>	<p>Profound Intellectual and Multiple Disabilities: Nursing Complex Needs</p> <p>Children and adults with profound intellectual and multiple disabilities (PIMD) are among the most marginalised people in society. They have some of the highest support needs and are most reliant on services. This accessible text presents and promotes current best practice regarding interventions to meet the complex health needs of a person with profound & multiple learning disabilities. Practical in focus, this text provides evidence-based guidance on meeting the complex needs of a person with PIMD.</p>
	<p>Author(s): Richard Byers, Jill Davies, Ann Fergusson & Claire Marvin</p> <p>Publisher: Foundation for People with Learning Disabilities</p> <p>ISBN: 978-1-906162-23-8</p> <p>Pub Date: 2006</p> <p>Price: £Free to download</p>	<p>What about us?</p> <p>Report sets out guidelines for improving the experiences of young people with learning difficulties in mainstream education. Young people with learning difficulties who attend mainstream schools and colleges need to feel safer and more secure between lessons, new research has found.</p> <p>http://www.learningdisabilities.org.uk/publications/?EntryId5=31325</p>
	<p>Author(s): Phoebe Caldwell, Jane Horwood</p> <p>Publisher: Jessica Kingsley Publishers</p> <p>ISBN: 978-1843106265</p> <p>Pub Date: 2008</p> <p>Price: £12.99</p>	<p>Using Intensive Interaction and Sensory Integration: A Handbook for Those Who Support People with Severe Autistic Spectrum Disorder</p> <p>People with PMLD can also be on the autistic spectrum and whilst this book is not about profound disability it has transferable information about the use of Intensive Interaction and sensory integration. Its focus on building relationships by learning the individual's language and communicating in a way that makes sense to them continues to build on Phoebe Caldwell's earlier publications.</p>

Short Courses and Conferences

January 2009

Date: 23rd
Title: RE in the SLD/PMLD Classroom
Location: Sunfield
Provider: Sunfield PDC
Contact: See Provider Details

Date: 28th
Title: **Capita's 3rd Annual Conference Transforming Services for Disabled Children and Their Families**
Location: Central London
Provider: Capita
Contact: For further information please contact Kamil Hussain on 020 7808 5292 or email kamil.hussain@capita.co.uk

Date: 30th
Title: Flonghorn Master Class
 Emergent Literacy and Numeracy
Location: Hartlepool
Contact: 0845 127 5281
patcerl@aol.com

February 2009

Date: 4th
Title: Play matters for young children who have poor sight, including those with additional needs
Location: Leeds
Provider: RNIB Children's Services
Contact: See providers' details

Date: 4th
Title: **Intensive Interaction**
Provider: Concept Training Ltd
Contact: See Providers Details

Date: 5th
Title: **Enhancing Communication in Special Schools**

Provider: Concept Training Ltd
Contact: See Providers Details

Date: 5th & 6th
Title: **Sensology A Practical Guide to Multisensory Education**
Location: MIC London
Provider: Florich Productions
Contact: See Provider Details

Date: 5th
Title: All Aboard: Special / How teaching assistants can promote the learning and participation of blind and partially sighted children
Location: Leeds
Provider: RNIB Children's Services
Contact: See providers' details

Date: 9th
Title: **Play for People with Autistic Spectrum Disorder**
Provider: Concept Training Ltd
Contact: See Providers Details

Date: 9th
Title: **Working with A D H D**
Provider: Concept Training Ltd
Contact: See Providers Details

Date: 10th
Title: **Success with People with Autistic Spectrum Disorder**
Provider: Concept Training Ltd
Contact: See Providers Details

Date: 10th
Title: Developing Motor Skills with Children who have Severe, Profound & Multiple Learning Difficulties
Location: Sunfield
Provider: Sunfield PDC
Contact: See Provider Details

Providers Details

BILD

British Institute of Learning Disabilities
 Campion House, Green Street,
 Kidderminster, Worcestershire DY10 1JL
 Tel. 01562 723025
 E-mail: learning@bild.org.uk
 website: www.bild.org.uk

Concept Training

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

Date: 10th
Title: Empowering Staff to Work Effectively with Children and Young People who Experience Behavioural, Emotional & Social Difficulties (B E S D)

Provider: Concept Training Ltd
Contact: See Providers Details

Date: 11th
Title: Flonghorn Master Class
 Emergent Literacy and Numeracy
Location: Birmingham
Contact: 0845 127 5281
 patcerl@aol.com

Date: 11th, 12th
Title: Understanding the Multi-sensory Concept
Provider: Concept Training Ltd
Contact: See Providers Details

Date: 26th
Title: Successful Multi-sensory Sessions
Provider: Concept Training Ltd
Contact: See Providers Details

Date: 27th
Title: Creating Exciting, Low Tech, Multi-sensory Sessions
Provider: Concept Training Ltd
Contact: See Providers Details

Date: 27th
Title: PMLD – Engaging Children in Learning
Provider: Concept Training Ltd
Contact: See Providers Details

Date: 27th
Title: Musical Activities to Support Key Skills Across the Special School Curriculum
Provider: Concept Training Ltd
Contact: See Providers Details

Date: 27th
Title: Mental Capacity Act
Provider: Concept Training Ltd
Contact: See Providers Details

March 09

Date: 5th, 17th
Title: Success with People with Autistic Spectrum Disorder

Provider: Concept Training Ltd
Contact: See Providers Details

Date: 16th
Title: Promoting Developmental & Social Skills Using Body Music
Location: Sunfield
Provider: Sunfield PDC
Contact: See Provider Details

Date: 9th
Title: Play for People with Autistic Spectrum Disorder
Provider: Concept Training Ltd
Contact: See Providers Details

Date: 10th
Title: Successful Multi-sensory Sessions
Provider: Concept Training Ltd
Contact: See Providers Details

Date: 11th
Title: P.M.L.D – Engaging Children in Learning
Provider: Concept Training Ltd
Contact: See Providers Details

Date: 16th
Title: Flonghorn Master Class
 Emergent Literacy and Numeracy
Location: Manchester
Contact: 0845 127 5281
 patcerl@aol.com

Date: 16th
Title: Sensology A Practical Guide to Multisensory Education
Location: Tate—London
Provider: Florich Productions
Contact: See Provider Details

Providers Details

EQUALS

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

Sunfield PDC

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

Date: 20th
Title: **Creating Exciting, Low Tech, Multi-sensory Sessions**
Provider: Concept Training Ltd
Contact: See Providers Details

Date: 16th, 25th
Title: **Music, Rhythm & Movement for Communication & Language**
Provider: Concept Training Ltd
Contact: See Providers Details

Date: 16th
Title: **Sensory Differences and the Role of Positive Touch**
Provider: Concept Training Ltd
Contact: See Providers Details

Date: 18th & 26th
Title: **Intensive Interaction**
Provider: Concept Training Ltd
Contact: See Providers Details

Date: 19th
Title: **Successful Delivery of Personal and Social Development**
Provider: Concept Training Ltd
Contact: See Providers Details

Date: 19th & 26th
Title: **Improving the Skills of Children with Asperger's Syndrome**
Provider: Concept Training Ltd
Contact: See Providers Details

Date: 20th
Title: **Children and Adults with Complex and Continuing Healthcare Needs Conference**
Contact: Bev Lally
 PCSP (UK) Ltd
 email: bevlally@posturalcareskills.com

Date: 23rd
Title: **Understanding the Multi-sensory Concept**
Provider: Concept Training Ltd
Contact: See Providers Details

Date: 26th
Title: **Musical Activities to Support Key Skills Across the Special School Curriculum**
Provider: Concept Training Ltd
Contact: See Providers Details

Date: 26th
Title: **Enhancing Communication in Special Schools**
Provider: Concept Training Ltd
Contact: See Providers Details

April 09

Date: 22nd
Title: **Sensology A Practical Guide to Multisensory Education**
Location: Cheltenham
Provider: Florich Productions
Contact: See Provider Details

Date: 28th
Title: **Sensology A Practical Guide to Multisensory Education**
Location: Cheltenham
Provider: Florich Productions
Contact: See Provider Details

June 09

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

Providers Details

Florich Productions

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

RNIB Children's Services

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

LONGER COURSES (with accreditation)

Updated April 2008

MA in Education

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

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

Module: EDUM081

For further Details: The University of Northampton. Tel: 01604 892192. E-mail: admissions@northampton.ac.uk

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

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

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

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

BSc in Professional Practice (Learning Disability Pathway)

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

For further details: University of Chester

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

Email: p.palser@chester.ac.uk, monica.davies@chester.ac.uk, a.ashford@chester.ac.uk

PGCert, AdCert.

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

Distance education.

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

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

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

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

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

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

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

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, monica.davies@chester.ac.uk, a.ashford@chester.ac.uk

BPhil, PGDip and MEd

Inclusion and SEN

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

Year 2 Autism (Children) or Autism (Adults)

Distance Education

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

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

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

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

Course aims

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

Course Structure

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

For further details: The University of Manchester, Emma Hardy Phone: 0161 275 3463 Email: emma.hardy@manchester.ac.uk

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:

Rob Ashdown	Head Teacher at St. Luke's Primary School, Scunthorpe – a special school for children with complex learning difficulties aged 3 to 11 years.
Alice Bradley	Freelance training and development worker.
Beverley Dawkins	National officer for profound and multiple learning disabilities Mencap.
Julia Dixon	Early Years Advisor and parent of young adult with PMLD.
Ann Fergusson	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.
Di Foxwell	Coordinator of Clinical Education and Practice Development – BHCT NHS Trust and Distance Regional Tutor for Birmingham University on two learning disabilities programs.
Penny Lacey	Co-ordinator of the University of Birmingham course in severe, profound and complex learning difficulties; freelance consultant; family member with severe learning difficulties
Loretto Lambe	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.
Carol Ouvry	Special education teacher and freelance consultant in the field of PMLD. Editor and administrator of PMLD-Link for many years until retirement.
Kim Scarborough	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 2009 are:

Annual Subscription	United Kingdom	Outside United Kingdom
Personal/individual	£15	£20
Organisation	£20	£30

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

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