

PMLD LINK

Supporting people with profound and multiple learning disabilities

Winter 2010

Lifelong
Learning

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

Lifelong Learning

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GUEST EDITORIAL

Winter 2010

Lifelong Learning

Welcome to the Winter edition of PMLD Link with a focus on lifelong learning. We are delighted to be able to include a rich array of articles which provide insights into how we enable people with profound and multiple learning disabilities to continue to learn and fulfil their potential.

Our opening article by Professor Jim Mansell sets the scene by highlighting the good practice and the barriers that need to be addressed if adults with profound disabilities and their families are to benefit from personalised support and be able to participate as active and valued members of their community.

We move on to a parent perspective by Dreenagh Lyle who discusses the challenges of supporting her daughter Odessy to access the day time opportunities which are meaningful to her and the review of the support available to people with profound and multiple learning disabilities living in Lambeth.

Moving on Michelle Morrison from PAMIS in Scotland writes about the resource bases that have been developed in Lanarkshire, more news on the Inclusive Libraries projects by Penny Lacey and a very inspiring article on story telling by Nina Martinez complete with the active participation of a lizard!

We then consider some of the challenges of transition from the experience of Wendy Newby and an update on the factors affecting access to Further Education for young people with profound and multiple learning disabilities by Jane Alltimes. In our last article Speech and Language therapist, Lucy Van Walwyk, looks at the use of technology and how to ensure this is used effectively and does not end up in the cupboard!

With our usual array of news, reviews, resources, training and the PMLD Network digest that concludes the winter edition. Enjoy!

Beverley Dawkins

PMLD LINK Contacts

Subscriptions, information and enquiries

Carol Ouvry
31 Birdwell Road
Bristol BS41 9BD
Tel: 01275 394621
carol.ouvry@talktalk.net

Reviews

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

Production

Paul Bramble
The University of Northampton
Park Campus
Boughton Green Road
Northampton, NN2 7AL
Paul.bramble@northampton.ac.uk

Future Issues

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Copy date
28th January 2011
Please send your contributions to:
Alice Bradley
alicebradley@talktalk.net
Or
Ann Fergusson
ann.fergusson@northampton.ac.uk

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Carol Ouvry
carol.ouvry@talktalk.net

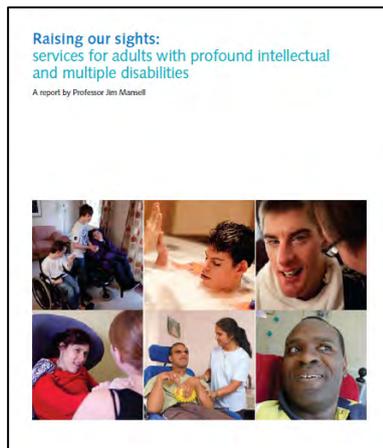
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Raising our sights: services for adults with profound intellectual and multiple disabilities

Jim Mansell

Raising Our Sights is a review of services for adults with profound intellectual and multiple disabilities (sometimes referred to as profound and multiple learning disabilities) carried out as part of the implementation of Valuing People Now. The report and its accompanying DVD looks at good practice and the barriers that stop people getting the support that they need.

People with profound intellectual and multiple disabilities are among the most disabled individuals in our community. Faced with such undeniable need, why is it that they and their families have such difficulty getting help? The evidence from



families themselves is that prejudice, discrimination and low expectations underlie why families have such difficulty getting help. A common experience appears to be that families are told that they cannot have the services they need because their needs are too great – that the amount of money involved is 'better spent' meeting the needs of a larger number of people with less severe needs. As well as prejudice and discrimination, expectations of what it is possible to achieve are very low.

Raising Our Sights

Although people with profound intellectual and multiple disabilities are very disabled and do experience a much higher mortality rate than the rest of the population, it is evident that many live well into adult life, do recognise people around them, do respond to circumstances and do enjoy activities and relationships. Irrespective of the difficulties, and just like any other parents, most families love their disabled child and want the best for them. They want to protect them from harm, and to provide love and security for them. New models of providing services in a person-centred way should make us raise our sights. Examples of good practice show that, in general, the 'personalisation agenda' (Prime Minister's Strategy Unit 2005; Department of Health 2007) - the framework of person-centred planning and highly individualised services, increasingly funded through individual budgets - is providing what people need and want.

A second reason for revising our expectations is the coming revolution in information technology. Research suggests that people with profound intellectual and multiple disabilities can learn to use microswitches to indicate a preference or control an event (Lancioni, Reilly and Basili, 2001; Lancioni et al 2008). Such microswitches may need to be adapted so that they are operated in different ways, depending on the physical impairments of the disabled person. Similarly, electric wheelchairs have been adapted to follow a track and their controls are replaced by motion sensors or other microswitches tailored to the disabled person's skills. This provides a means by which people with profound intellectual and multiple disabilities can move around their environment (Nilsson and Eklund 2006; Odor and Watson 1994). The intelligence built-in to the wheelchair makes it safe to use in spite of the person's disability.

Such technological aids offer the prospect of enabling people to communicate with others and to control aspects of their environment such as where they are. For people often dismissed as unable to communicate the possible impact on the attitudes of others, being able to control aspects of their environment is at least as important as the direct effect on the person's quality of life. These technological developments, are beginning to make an impact in schools and colleges and so some people with profound intellectual and multiple disabilities will have had experience of them. They appear, however, to be almost unknown in services for adults with profound intellectual and multiple disabilities.

Elements of good services

Good services are individualised and person-centred

All the examples of good practice involved designing and delivering arrangements tailored to the individual person's needs and preferences. Some families had achieved personalised arrangements before individual budgets were possible, through lobbying to shape services in the way they needed. Others were using individual budgets to achieve the same result. In both cases, good services also

overcame organisational barriers (for example between health and social care) to deliver the services the individual needed in a coordinated way.

Good services treat the family as expert

In all the examples of good practice families had taken a leading role, often battling against the perceived indifference of public services to get what they needed for their disabled family member. In most cases families had used self-directed services involving individual budgets to control and direct the main services they needed. Some families were playing a large part in recruiting and managing staff, whereas others were leaving most of this part to service providers. These families were also being treated as experts by other services they used. For example, in using hospital and other health services they described how professionals listened to their advice about how best to serve their disabled family member, making adjustments to appointment times and approaches to assessment and treatment as required. Recognition of the expertise and commitment of the family means that these services are not only person-centred, but they are also family-centred.

Good services focus on quality of staff relationships with the disabled person

Sufficient personal assistance is essential, both to provide safe care and support and also to enable the person to have as good a quality of life as possible. In describing the staff who provided support to their disabled family member, there was remarkable consistency in family views about what was important. The key attribute was that staff should have a warm, respectful and caring relationship with the person. This was viewed as much more important than the particular background or training that staff had: as a mother explained

“Often – not always but sometimes – the best people have been people who have come with the right values and attitudes and with no experience whatsoever...That’s why it is so important that the person understands and has that ability to build a relationship, to see the person as a person. You can teach all the rest.”

Families did, however, put a lot of effort into ensuring that staff learned how to support the disabled person in the best way, using written policies and procedures, modelling by more experienced staff, supervised practice and attendance at training courses. Communication is fundamental to these skills. Staff need to be able to recognise and respond to the full range of communication, including eye-movements, facial expression and body language.

In addition, research suggests that there is scope for better support from personal assistants given more

access to training: as one professional interviewed explained “I see too many people being wheeled round shopping centres for hours at a stretch, by poorly paid and insufficiently trained staff.”

There is great potential to provide a better quality of life for the person with profound intellectual and multiple disabilities, if staff are helped to build on the foundation of a good relationship with the person they support by using person-centred approaches.

Good services sustain the package of care

Families described the importance of reliability and continuity in the provision of basic supplies like incontinence pads, rubber gloves and medicines. They were clear that if these were to fail, they undermined the quality of life of their disabled family member. Having achieved the package of services they wanted, some families were confident that they would continue to be supported. Others were anxious that they had to repeatedly justify the package in the face of pressures to make financial savings or that restrictions might be imposed on how they could use their individual budget.

Good services are cost-effective

There appears to be no research on the cost-effectiveness of services specifically for adults with profound intellectual and multiple disabilities. The families using services identified in this report as providing good practice, reported that they were similar in cost to the alternatives they had considered or had experience of. The cost of care packages ranged from £62,952 to £179,000 a year. It is self-evident that services for adults with profound intellectual and multiple disabilities will be more expensive than those for people with less severe disabilities: the major element of costs is personal assistance and these people will need personal assistance most of the time if they are to have a good quality of life.

The cost-effectiveness of good services for adults with profound intellectual and multiple disabilities is therefore much more likely to be reflected in:

- higher quality of life
- lower costs on families (including non-monetary costs)
- lower needs in other areas (eg health)
- or in the future,

than in lower costs of the package of care. On this basis all the families, and the commissioners they were working with, thought that the arrangements they had in place were cost-effective.

Extending good practice

Government plans to continue to extend self-directed services will provide the opportunity for more families to experience the benefits. As this happens, a number of risks or potential problems can be identified which need to be dealt with and in

the course of reviewing good practice, a number of more specific obstacles to improvement have become apparent. These obstacles particularly affect people with profound intellectual and multiple disabilities.



Alex shares a 3 bedroom bungalow in an ordinary residential street with Simon. The bungalow was the property of Alex's family and when it became available it was decided that it would become Alex's new home. Alex's father

approached SENSE to ask them to find someone else to be a tenant in the property and so Simon (who has less severe disabilities) joined him. They had not known each other particularly well before living together as they went to different schools. The families knew of each other but had not had much previous contact.

Simon and Alex have one bedroom each and the third is used as an office/sleep over room for night staff. The bungalow has a small kitchen and this includes some adapted equipment, such as a drinks level indicator and a talking microwave. It has a garden which is paved with raised flower beds (good for both young men as they both have visual disabilities) and a garage. Additional hand rails were put on the steps in the garden.

Both families receive funding for the package of care as a direct payment. This pays for 1:1 staff support but includes only one sleeping member of staff at night. In addition Simon and Alex receive housing benefit, incapacity benefit and upper rate Disability Living Allowance which are used for rent and living costs. They are both tenants and both pay monthly rent. Alex and Simon also attend a SENSE Resource Centre for 5 days per week which they attend with their support staff. The Learning and Skills Council fund 3 days per week and social services fund the other 2 days per week.

Alex and Simon appear in the film accompanying the Raising our sights report.

Conclusion

Adults with profound intellectual and multiple disabilities are a relatively small, easily identified group of people with undeniable needs for care and support. Despite these needs, they and their families have often not been provided with services to adequately meet them.

The 'personalisation agenda' expressed in government policy does appear to provide a better quality of life for adults with profound intellectual and multiple disabilities and their families. Continued progress in widening access to these kinds of services will enable more people to benefit from them.

No amount of investment is going to radically change the need for support for this group of people. Greater efficiency in other aspects of health and social care may free up resources which can be spent on them but they are not going to be the source of savings. Their services are relatively expensive because their needs are high. Greater cost-effectiveness will come from getting the most out of those resources, in terms of the quality of life experienced by them and their families, and through the reduction of harm and ill-health to them and their carers.

Most of the work required to tackle the obstacles identified does not require large amounts of extra resources. It requires reasonable adjustment to policies, procedures, rules and priorities to ensure that adults with profound intellectual and multiple disabilities get the support they need. In general, adults with profound intellectual and multiple disabilities require such substantial amounts of support from staff that person-centred services are not likely to be significantly more expensive than the old congregate models of care.

Where extra resources are required (as for example in the application of technology to empower and enable people) these will be difficult to find during the current world economic crisis. Hard times should, however, dictate the pace at which we can achieve our objectives, not the nature of the objectives themselves. In the words of the United Nations (2006) Convention our obligation is to work towards "achieving progressively the full realization" of the rights of this group of disabled people.

To order a copy of the *Raising our Sights* report and film email publications@mencap.org.uk or telephone 020 7696 6900. (Please note there is a limit of one per person, three per organisation).

To view the report and film on-line visit:
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_114346

Jim Mansell
Professor of Learning Disability in the Tizard Centre
at the University of Kent
J.Mansell@kent.ac.uk

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Box 1 Extending good practice

- Continued leadership from government will be required to ensure that personalisation is not compromised.
- Families should be able to get help in securing and running self-directed services from user-led organisations or self-help groups of other families.
- Independent advocacy arrangements suitable to represent the interests of adults with profound intellectual and multiple disabilities should be funded.
- Government should continue to lead the development of more effective transition arrangements so that there is proper planning and timely provision of appropriate services as people move into adulthood.
- Up-to-date information about the number, needs and circumstances of people with profound intellectual and multiple disabilities in each area now and in future should be collected to enable effective planning of services.
- Sufficient numbers of personal assistants should be available, trained in person-centred approaches to communication and support that meet the needs of adults with profound intellectual and multiple disabilities, through training that involves families and adults with profound intellectual and multiple disabilities in its delivery.

Box 2 Specific obstacles to improvement

Housing	Revise arrangements for capital subsidy from the Homes and Communities Agency to remove the disincentive to provide adequate housing for adults with profound intellectual and multiple disabilities; resolve the apparent contradiction between social care policy and housing policy created by the Turnbull judgement.
Access to community facilities	Amend Part M of the Building Regulations so that all newly built major public buildings provide a Changing Places toilet; identify and disseminate good practice in the provision of access for adults with profound intellectual and multiple disabilities to public swimming pools.
Health services	NHS bodies should pay particular attention to meeting the needs of adults with profound intellectual and multiple disabilities in implementing the government's response to the Michael Report and the report of the Local Government, Parliamentary and Health Service Ombudsmen; they should ensure they provide health services to adults with profound intellectual and multiple disabilities in each area which focus on protection of body shape, dysphagia, epilepsy and investigation and resolution of pain and distress; the Board of each NHS Trust should consider a report specifically focused on the adequacy of health services for adults with profound intellectual and multiple disabilities and approve an action plan to ensure adequate treatment.
Wheelchairs	Reform the wheelchair service; provide powered wheelchairs where family members, paid staff or others need them in order to move the disabled person; people who have used powered wheelchairs (eg 'smart' wheelchairs) at home or at school during childhood should have the option of continuing to have them provided in adult life, where this sustains or enhances their quality of life; other people should be provided with powered wheelchairs, suitably adapted with 'smart' technology, where this sustains or enhances their quality of life.
Communication aids and assistive technology	Decide whether funding the provision and repair of communication aids for adults with profound intellectual and multiple disabilities is the responsibility of the National Health Service or of Local Authority social care services; review and disseminate the available research and practice; fund research and demonstration projects in each region; commission organisations which have expertise in this area, to advise families and agencies about new opportunities presented by these communication and control aids; to offer opportunities for people to try out different equipment; and to train staff.
Further education	State as policy the goal that everyone with profound intellectual and multiple disabilities should have access to further education, in order to help funding bodies develop appropriate objectives and plans; monitor the volume and quality of provision; create incentives for specialist colleges to partner with local non-specialist further education colleges to increase the quality and amount of local provision for adults with profound intellectual and multiple disabilities.
Employment and day activity	Ensure that adults with profound intellectual and multiple disabilities are able to take part in a wide range of meaningful activities – including employment, education and leisure activities; continue to provide places which can be used as a base from which adults with profound intellectual and multiple disabilities can take part in different activities during the day.
Short breaks	Provide a range of short break services in every area with staff with sufficient skills, expertise, equipment and facilities to meet the needs of families supporting adults with profound intellectual and multiple disabilities. No family supporting an adult with profound intellectual and multiple disabilities at home should be denied regular short breaks.

Training	Offer subsidised or free places to families and personal assistants on any training courses relevant to the care of adults with profound intellectual and multiple disabilities. Individual budgets should include provision for training of personal assistants.
Clinical procedures	Adapt policies and procedures already used in children's services for use in services for adults, involving representative bodies of the relevant professions and agencies; base these on the principles that (i) arrangements will be designed so that they sustain and enhance the quality of life of the disabled person by enabling clinical procedures to be carried out when and where needed, and (ii) arrangements will be coordinated and consistent between agencies, avoiding unilateral exclusions and consequent service gaps; focus on procedures identified by families as currently problematic, including all relevant care settings, such as hospitals, community services and people's own homes. These policies should specify who is responsible for carrying out clinical procedures in different situations and should deal with issues of clinical governance, legal liability and insurance.
Funding	Health and social care services should always work in close partnership both in planning and commissioning services and in providing them. Local authorities should continue to play an active part as the lead agency for learning disability services in all service development and should continue to lead individual assessment and planning, even when continuing health care funding is provided. However funded, services for adults with profound intellectual and multiple disabilities should be developed in line with the government's personalisation agenda. They should be designed around the individual and be person-centred, they should treat the family as expert, they should focus on the quality of staff relationships with the disabled person as the key to service quality and they should sustain the package of care.

Mark Gray Associates

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Lambeth PMLD project: Understanding the Lives of People with PMLD in Lambeth

Dreenagh Lyle

As the parent of an adult woman with 'PMLD' and as the local Learning Disability Partnership Board's 'High Support needs' champion, I have been increasingly concerned about what I see as the *informalising* of care and support for individuals with profound intellectual and multiple impairments. This is especially evident when one starts to look at self directed support, but is also evident in the community inclusion agenda, which has been incorporated into local Day Centre and Specialist College programmes.

In Lambeth, we decided one way to examine the impact of this Valuing People (DOH, 2001) policy, on people with PMLD, would be to do a collaborative piece of work with Mencap, Lambeth Council, NHS Lambeth and 'I Count' Register Services to specifically look at the real life needs of this population. This eventually became ***'The Lambeth PMLD project; understanding the needs of people with profound and multiple impairments'***.

The Report, just published, sought to identify local numbers of this section of the population, and surveyed family carers and support workers to find out more about the needs of people with PMLD and how they are spending their time. We were especially interested to hear about people's daily activities. What were people doing all day?

The findings very much reflect the national picture of what life is like for people with PMLD.

Of those who responded to the survey there were family carers of people with PMLD living in the family home, family carers of people no longer living in the family home and support workers who supported people in and out of borough. Not surprisingly perhaps, the Report found there were not enough meaningful activities available for people with PMLD to do in Lambeth. I say not surprisingly because, as a mother and constant carer, this is an area I have struggled with for a long time and increasingly now, as the informal manager of my daughter's Individual Budget and her support staff.

When person-centred planning was first being rolled out, it was easy perhaps for people to concentrate on the big exciting stuff; like climbing Mt Everest or, to a lesser extent, planning holidays and outings. But the reality of a life is in the detail of the day to day living and if this policy is to have any impact on individuals with PMLD, then it is beholden on us to find ways to make the day-to-day living meaningful at some level for individuals. How to do this?



There are two day centres in Lambeth which include people with PMLD. They provide structured programmes including sessional activities, both within the day centre and now at various sites in the local community. More recently, for example, they have begun to access a mosaics group at the site of a former secondary school. There is also a branch of Orchard Hill, a specialist college that caters for adults with PMLD. Their courses are now very much geared to the idea of 'community access'.

There are very few, if any individuals attending any of these places for a full 5 day week. Mostly people may attend 1, 2 or 3 days for 3-5 hours per day. This leaves a substantial amount of hours in the week, with no structured input. How are they filled?

There are also a number of people living in the borough in residential care or in the family home, who do not have access to the day centres or to the college. Again, how do they spend their time?

Is it appropriate, as some have responded in the survey, to spend 7 hours a day 'chilling' or 5 hours a day 'watching television'? Is this an informed choice by the individual, or is it the end result of family/staff burn out? Not burnt out from providing the care and

What are meaningful activities?

- They are stimulating and meaningful to the individual.
- People's physical and health needs are supported in a dignified manner.
- The person can access the community by taking part in activities that they find genuinely enjoyable.
- They recognise that many people with PMLD experience the world largely on a sensory level and take this into account.
- People are included in community activities in ways that are meaningful to each person.
- Manual handling policy and practice don't act as a barrier to the person taking part in community activities.
- They recognise the importance of one-to-one interaction, with a workforce who are skilled in meeting complex health needs, and trained in non-formal communication techniques.
- Suitable and flexible transport is provided that enables people to physically move around their community.

*Lambeth
PMLD project:
understanding
the lives of
people with
PMLD in
Lambeth*

support, but from struggling to come up with ideas about what to do from day to day.

If the individual is someone with very complex health issues, it can be easy for this to override everything else. I certainly remember the days when my own daughter's seizures were so severe; she could take anything up to 5 days to recover. Behavioural issues associated with autism can also limit someone's ability to access activities. Again, speaking from experience, my daughter has been excluded from college courses, pottery sessions, music groups, respite centres, etc. She has great difficulties accessing 'the community' due to the combination of her hyperacusis, her autism, her neurological and total blindness and her profound learning disability.

Whilst 'community activities' in the mainstream may be absolutely appropriate for one individual, for another they can mean the worst levels of anxiety. If all you can cope with in life is dependent on successfully predicting what happens next, how appropriate are informal outings that vary each time

and have no set order?

Another concern of mine is, if the individual in question is living in residential care and has no family or advocate, how are we to know how limited their life actually is? I am also very concerned that so many of these people receive their support from agency staff who have no possibility of getting to know the individual never mind developing a relationship with them. This is essential in order to provide meaningful support, never mind activities, to an individual with PMLD.

I believe the first step to providing meaningful activities is to acknowledge the difficulties. I believe if we are going to use a concept like person centred planning, we must be very clear about the difference between 'person centred' and 'staff centred'. Working with people with PMLD can so easily be all about maintenance that the fulfilling side of lived experience becomes overlooked.

I am especially concerned about the 'community inclusion' agenda, as it assumes 'the community' has the facilities to accommodate people with PMLD. We all know this is not the case. Why else would there be such a massive nation wide campaign for Changing Places? It concerns me that there is no actual space where individuals across the spectrum of PMLD can access structured therapeutic inputs. Physiotherapy, hydrotherapy, music therapy and art therapy are all appropriate and meaningful activities for this population, yet their provision is scant or non-existent.

A number of recommendations came out of the project about how to increase meaningful activities for people with PMLD. They included:

- To explore how ideas for meaningful activities can be shared via a local forum
- For more Changing Places toilets to be installed in public buildings
- For staff to receive training in how to communicate with, and meaningfully involve, people with PMLD in person-centred planning.
- For there to be a strategy group to focus on how to increase meaningful activities for people with PMLD in Lambeth. This would involve family carers as well as different council departments such as health, education, leisure and parks. They should work together to see how the community can be more inclusive for people with PMLD and other groups.
- For the council to explore a place in Lambeth that could be used as a base, by people with PMLD and their supporters, from which they can access the community. It should also consider what activities could take place at the base and how other community groups could be included.

For me, a base is very important. I personally feel there should be somewhere under one roof where people with PMLD can access respite, day activities, therapies and information and support. When people are children there are children's centres – where you can go and access services and information and advice. But there is nothing like it in adult services, which is ridiculous as the needs of people with PMLD haven't changed. They still need the same support they had before.

I hope the project leads to improvements for people with PMLD in Lambeth and that other local areas take on board the recommendations and work to improve things for their population of people with PMLD. This involves ensuring people have the support they need to take part in meaningful activities and live life to the full.

For more information about the Lambeth PMLD project and to download a copy of the report, visit: <http://www.mencap.org.uk/page.asp?id=19495>

Dreenagh Lyle, carer representative on Lambeth Learning Disability Partnership Board

New style day services in South Lanarkshire: Providing opportunities for lifelong learning and inclusion for people with PMLD

Michelle Morrison

Review of Services for People with Learning Disabilities in Scotland

The Same as You? The review of services for people with learning disabilities published in 2000 by the Scottish Executive heralded a change to services and attitudes across Scotland. This report made 29 recommendations, among them that day centres needed to modernise, become more flexible, allow people with learning disabilities to engage in learning, create social involvement and meet the needs of people with profound and multiple learning disabilities (PMLD).

Local authorities across Scotland interpreted this recommendation in different ways. Some opted for a service without walls, that is providing a flexible service but not from a building; some kept their day centres but changed the way they provided services to people using them.

In South Lanarkshire, they carried out independent research (Kane, K. 2000) seeking the views of people using services and family carers alongside the Best Value Reviews of Residential Care and Day Opportunities which the local authority led. The message came across loud and clear that people wanted to keep a centre base. This was particularly the view of people caring for someone with PMLD. Family carers often feel that a building base provides the best option for their daughter/son for the following reasons: it offers them security; provides a safe place where their son/daughter can be able to rest when tired; recover from a seizure; have a gastrostomy feed and other procedures, and their intimate and personal care tasks can be dealt with, all within a safe and private environment; have the opportunity to socialise with their peer group and others; have a service that provides predictability, consistency, repetition; and the prospect of participating in on-going learning and development. There is wide agreement that a structured environment facilitates and enhances development and learning and this view is equally applicable to people with PMLD (American Psychiatric Association, 2000) and (Scottish Executive, 2000).

Modernising Day Opportunities

South Lanarkshire Council responded to the feedback they received by giving a commitment that they would continue to offer services from day centres for adults with learning disabilities. They applied a model where their day centres would become community buildings offering a service not only to people with a learning disability but to the wider community. Essentially they would be a

community building first, a day centre second. They would feature high quality design alongside a themed approach – Lifestyles! The first of these new centres opened in 2003 and was a community hall and Internet Café as well as having a dance studio, multi-sensory room, various work rooms and two personal care toilets that met the then Changing Places criteria. Everyone entered through the same front door regardless of why they were using the building. The community hall allowed community groups and members of the public to access the building for a variety of uses i.e. weddings, functions, fitness classes and art classes. This meant that people with learning disabilities using the day centre could also access classes that members of the public were attending.



The next centre opened in 2004. This incorporated a swimming pool, leisure centre and café as well as various workrooms and personal care areas again meeting the Changing Places criteria. This allowed people accessing the day centre the opportunity to become a member of the gym, swimming pool and exercise classes. What both of these centres proved was the importance of sharing integrated facilities with members of the public.

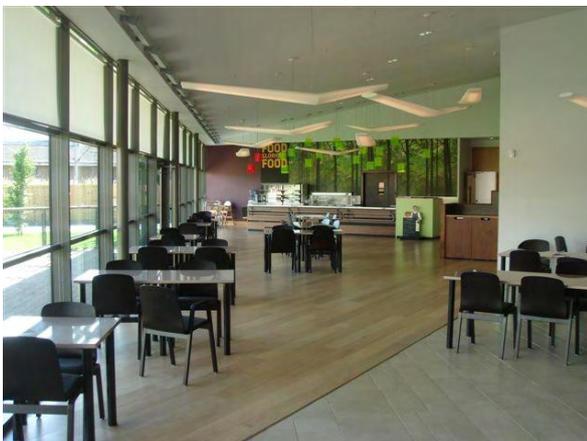
The Scottish Executive produced a report *Make My Day!* (Scottish Executive 2006) on how day services had changed as a result of the *Same as you?* By this time South Lanarkshire Council had proven how successful keeping their day centres buildings based

had been. Social integration was truly happening within these buildings with people being given opportunities that they had never been given before. This report also confirmed that family carers saw education and learning as being a valued activity.

Services evolving

People with PMLD were able to access both of these community based day centres because they had accessible environments and personal care areas. Whilst a variety of activities was offered both within the centres and out in the community true social integration was generally limited to people who were more able. This was due to them being able to be a gym member or active enough to join a fitness class. This has evolved as centres have been developed with the realisation that people with PMLD can be involved in lots of activities at various levels, i.e. joining a line dancing class even though they are wheelchair users.

South Lanarkshire Council appeared to have their model of building right and so they continued to build a further three centres using the same philosophy. These buildings have various community facilities such as a cinema room, snooker rooms, Starbucks Café, hydrotherapy pool, community hall, fitness gym (one of very few in Scotland with equipment for people with physical disabilities) and a swimming pool. The community as a whole feels valued by these new buildings as they are designed to a high standard with light, airy reception areas, lots of windows and furnished with high quality furniture.



As these buildings are community buildings this has meant that they don't belong to the Social Work Department. This has had its difficulties i.e. Social Work Department having to explain the importance of personal care rooms. However, it has also had a very positive impact on the wider departments of the local authority i.e. South Lanarkshire Leisure and Culture in that they recognise that people with learning disabilities aren't just the responsibility of the Social Work Department and now take their specific needs into consideration. This has evolved as the departments have worked together over the last 10 years on designing the new buildings.

Need for specialist resources

Prior to this new model of building only some of the day centres had personal care areas. This meant that people with PMLD who required the use of a changing plinth and hoist had to use specific buildings, not necessarily the one closest to home or the one where their friends went. Now all the new buildings meet the recommendations from British Standard BS 8300: 2009 with two Changing Places toilets in each. Changing Places toilets are an important facility, as more people with PMLD cannot use standard accessible toilets, as they need support from one or two carers, either to use the toilet or to have their continence pad changed on a changing plinth.

Standard accessible toilets do not provide changing benches or hoists. Most are too small to accommodate more than one person. Changing Places toilets are different to standard disabled toilets with extra features and more space to meet these needs. They provide the right equipment, including a height adjustable changing bench and a hoist. See www.changing-places.org



Even though these Changing Places toilets are in day centres, they are open to members of the public who benefit from these facilities. As the building is a community facility they are open longer hours. Some of the buildings are open 7 days a week, some from as early as 7.30am and some as late as 10pm. These facilities are extremely valuable for people with PMLD and allow them more freedom to explore their local community knowing that they are not time limited by having to go home to have their incontinence pad changed.

Opportunities, choice and inclusion

Having a good building does not necessarily mean that you are providing a good service. However, due to the model of these buildings there has been increased opportunity for people with PMLD to learn. Whilst centre staff offer people choice there is also a timetable of activities. The benefit of routine and

predictability is recognised as important in helping people with PMLD to learn (APA, 2000; and Scottish Executive, 2000). There are new, interesting and exciting activities on offer. Some of the centres have lecturers coming in from college providing sessions such as pottery, gardening and cooking. These are open to people with PMLD. In some of the centres the computer suite is located in the library giving people with PMLD the chance to use these alongside the general public. Some specialist local authority services such as the Arts Development Team come into the community halls offering sessions to the public which again, people with PMLD are encouraged to take part in.



As these are integrated facilities there is continued opportunity for social contact. Members of the public access the gym, swimming pool, library, café, community hall etc. Through this people with PMLD are given the opportunity to be a member of their local community, to get to know people coming in to use other services. Some activities that the day centre service users can join in are not organised by the day centre but are community groups e.g. art sessions which service users with PMLD are able to access. All of the new centres also offer a drop in service. This allows for further choice, for example a service user with PMLD can access an activity in a

different centre or for someone who chooses not to use a day centre all of the time to pick and choose activities that they like.

Despite the day centres still having a low ratio of staff to service users they say that they do not rely on Independent Living Fund to support someone's package.

This model of community integration has opened the door for new relationships to be formed. People with PMLD have been introduced to members of the public that they wouldn't otherwise have met and it



has been a very natural process. This has allowed for learning in relation to developing communication and social skills. The opportunity for learning here is a two way process as members of the public have been learning too. They have involved people into their activities, taken time to help people develop/experience skills, invited people to have coffee with them in the café. Through this they too have learned how to engage with someone with PMLD. Day centre staff have commented on how members of the public have built up relationships with some of the service users (Partners in Practice, 2006, DVD). Initially there was some resistance to people with a learning disability sharing services in the heart of the community but now people are embracing this change that has led to the development of real friendships.

South Lanarkshire Council Social Work Resources is currently carrying out a Best Value Review of Day Opportunities. This goes wider than just looking at day centres but includes the views of people accessing services, family carers, staff and partners. These views were obtained by FMR Research Ltd who carried out an independent consultation exercise. It is anticipated that the outcomes of this review will be known by early 2011. Informal feedback suggests that this new style of building is still welcomed by people using the building and family carers.

It is still unknown how the personalisation agenda will change how people use these centres but it is anticipated that people with PMLD and their family carers like having a base from which they are given the opportunity to learn through routine, predictability, consistency and the opportunities which this model of day centre offers. It is clear that South Lanarkshire Council has more than met the recommendation on day services which was set out in *The same as you?* Review, carried out in 2000, in that, they are modern, flexible, provide social involvement and can meet the needs of people with PMLD in an environment that embraces learning.

Michelle Morrison
Co-ordinator, PAMIS Family Support Service, South Lanarkshire
Email: michelle.pamis@btconnect.com

Websites

www.changing-places.org
www.pamis.org.uk
www.southlanarkshire.gov.uk

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Inclusive Libraries in Practice

Penny Lacey and Penny Smith

The Inclusive Libraries research is now complete and it has been very exciting to be part of the project. The University of Birmingham worked with the central public library and with Quinton community library in Birmingham to develop their capacity to meet the needs of children and adults with severe and profound learning disabilities. The British Institute of Learning Disabilities have also been involved and will put on their website a short film on the project and a downloadable booklet for interested libraries and learning disability services.

Background to the project

From previous research at the University of Birmingham, we know that there are ways in which children and young people with severe and profound learning disabilities can be involved in the world of books and literature. We called this 'inclusive literacy' and it consists of a range of resources and activities from sensory stories and interactive games through to picture books and books with simple accessible texts (Lacey et al, 2007). Following this research, we felt that whilst children with learning disabilities (LD) can have their inclusive literacy needs met at home and at school, it was not clear how this could be achieved for adults with LD. It seemed as if public libraries could have an important role for that group.

We wanted to study good practice in inclusive literacy within public libraries but when we looked at the literature we were not convinced that we could find very much good practice to study. Libraries seemed to be slow to respond to the Disability Discrimination Act (Ineson and Morris, 2006) and even relatively well-known resources for those who cannot manage print are not universally available (AFB, 2005). Attitudes of staff to disabled library users are crucial and disability awareness training is essential but not always available (McAuley, 2005; Charles, 2005).

Because of the lack of widespread good practice to study, we felt that this was an opportune moment to contribute some of our own. We wanted to spread the ideas we had gleaned from studying inclusive literacy in schools to a more public environment and thus asked, and subsequently answered the question:

'How can we develop the use of inclusive literacy in public libraries so they can meet the needs of children and adults with severe and profound learning disabilities?'

Methods

We used action research as an approach to the research. Action research enables you to identify a problem, imagine a solution, devise a plan of action

and evaluate how well the plan worked, over and over again in cycles. It is a research approach that is specifically about making a series of changes and evaluating how well they have worked. We worked in a cyclical way with the two libraries in Birmingham for just over a year.

Firstly, we used a survey which enabled us to learn more about current strategies in public libraries. We telephoned representatives from 32 local authorities to ask them how they meet the needs of people with LD. We were also looking for examples of good practice which we then followed up with more telephone conversations and for some, a visit. We visited four libraries around the country: Bexley, Bradford, Leeds and Burnley and were able to share their innovative practice with the staff in the Birmingham libraries.

As part of the action research, Our Way self advocacy group from Kidderminster were employed to carry out an evaluation of the libraries. They visited twice: once before the changes had been effected and once after. They wrote two accessible reports with support from a facilitator.

Staff at the Birmingham libraries were at the centre of all the research and nothing would have been achieved without their enthusiasm. The researchers provided support, information and encouragement. It took a while to find a leader for the project from the libraries but once one was identified activities followed each other quickly.

Activities included:

- Developing a strategy
- Training
- Building relationships
- Changing the environment
- Purchasing resources
- Developing activities

From the data we collected in all the libraries we are able now to present the factors we feel can lead to an inclusive library.

Developing strategy

Few local authorities have a strategy for specifically developing a response to the needs of children and adults with LD, although all had a general strategy relating to disability in general. This usually referred to physical access such as lifts and ramps and access for those not able to use print such as those who have a visual difficulty or a specific literacy difficulty such as dyslexia.

A strategy that includes people with LD should also include ways of engaging with people for whom the library environment and most conventional books are cognitively inaccessible. The few libraries that were specifically meeting the needs of people with LD had individuals who were leading the changes that needed to be made. From our experience in the Birmingham libraries, very little happened until a leader was identified. If no-one is responsible for developing the strategy and making the necessary changes, they are unlikely to occur.

Funding is also an issue and unless funding is set aside for this group their needs will be subsumed into other disability considerations. In the project our grant from the Esmee Fairbairn Foundation and the Rayne Foundation contained £5,000 for each of the two libraries. This money was for purchasing resources identified as suitable for people with LD. These are described later in this article.

Strategically this is an opportune moment for public libraries to be considering how to include users who have particular needs. The whole service is in the midst of huge change as they adapt to the demands of the digital age and the decline in use of books. Birmingham Central Library is shortly to move into a new building and they can now plan into the new environment the needs of people with LD.

Training

As part of the project Open Storytellers were engaged to provide training for the library staff. The training included general learning disability training but also training in how to engage with storytelling at a level suitable for people with severe and profound learning disabilities.

As with many members of the general public, staff at public libraries should learn to understand the needs of children and adults with LD, especially those who do not communicate using words or who may have unconventional behaviour. They require advice on how to approach people who come into the library and how to find out what their needs might be. Staff from the Business Library in Birmingham went to a local day service for people with LD and got to know a group of people who then visited the library. The visit to the library is described below in the section on 'Activities'.

Relationships

As can be seen from the previous section, building relationships between public libraries and people with LD is essential. All of the successful libraries in the project had regular visits from particular groups or individuals with LD and this had led to increased commitment on both sides. Once carers and supporters can see the benefits of visiting the library, the relationships can develop.

Not only do relationships need to develop between libraries and users with LD, but relationships between library staff are crucial as well. The Central Library in Birmingham is huge with many different departments and communications between them are hard to achieve unless they are deliberate. Even in Quinton community library it was hard to get the project going as many staff work part-time and do not have a chance to discuss policy and practice together. This meant disseminating good practice was difficult to achieve.

As mentioned before the presence of a leader is very important. As with all initiatives, a champion who is well informed and committed can make all the difference. In one of the surveyed libraries the project was led by a librarian who had a relative with LD and in another a parent approached a librarian for a particular piece of software and that person took on the initiative and helped it to grow. Someone has to lead.

Changing the environment

So once a leader has been identified and funding set aside, what can libraries do to meet the needs of people with LD, particularly for children and adults with severe and profound learning disabilities? One of the most important considerations is the environment.

Our Way self advocates had the job of considering the environment in terms of their less able peers. They were very complimentary about the Centre for the Child in the central library, approving of the bright colours and interactive displays. They liked the amount of physical space to move around and the height of the books; accessible to people in wheelchairs. They approved of the changes made in the adult lending library where new display shelves enabled books to be set up with their front covers visible. It is much easier to see if the book is right for you if you can see the pictures on the front. The staff had chosen accessible books to place on this shelving and had labeled it 'Easy Reads'. They are considering whether to have a spine sticker for the ordinary shelves that denotes an accessible book. Stickers on spines with symbols for different genres can be seen at most libraries and an accessible sticker would fit in with this system.

Although there are some accessible symbols already used in public libraries, Our Way felt that there could be more and they should be clearly visible, especially when negotiating a large central library. Staff at Birmingham Central Library plan to increase the symbols and pictures to help users find their way around. They are also planning to produce a pictorial guide to the library which will be available at the front desk. Quinton library only contains one room and is so much easier to negotiate once the different areas have been located.

The favourite area of the library for the Our Way self advocates was the music library. They found that very accessible with CDs and DVDs easy to find. They liked the 'listening post' where they could try CDs and appreciated the few that were selected on a particular theme. They thought their less able peers would find it easier to choose music from a small set of suggestions. They spent a long time in this department!

Purchasing resources

As was mentioned £5000 was available to each library for the purchase of new resources and this money was spent on the display shelving, accessible books and a touch screen computer with accessible software. Both libraries already had some accessible books but most were related to dyslexia or adult literacy and thus were cognitively too demanding for people with severe learning difficulties. The Central Library had some Bag Books but these were not available for lending to families. From their purchases they are now able to lend some out.

Staff at the central library are considering ways in which they could make their own sensory stories and have discussed how they might get volunteers involved in achieving this. There are other ways in which volunteers might be able to support the needs of people with LD. For example, a volunteer has offered to work with a group, perhaps around a project on photography. Purchasing loan cameras was a possibility for the future.

The computer was very popular with Our Way and they spent some time playing simple games specifically designed for people with LD. They thought the touch screen would be very useful for their less able peers. The computer is still rather limited in software, especially for people with PMLD but they can access simple cause and effect games from the internet. This is an aspect that requires more training.

Although the libraries did not need to buy more CDs and DVDs as they already had a large collection, these resources are very important. Small community libraries do not always have CDs and DVDs but if they are to be able to meet the needs of people with LD then they need to have at least a

small selection. The collection could be shared between a group of community libraries and rotated.

Developing activities

The survey libraries gave several examples of activities that they have undertaken with individuals and groups of people with LD. In one library a group of able people with LD run a café for library users and in another they provide a welcome and directions for users. One group uses the Wii in the library to play games and another had sensory story sessions.

In Birmingham central library there were two specific activities set up as part of the project. The first was a sensory story in the music library. The staff chose the 'Tempest' as the stimulus and they devised a range of sensory experiences for a group of people with LD, especially music. The group contained people with PMLD and they seemed really to enjoy the session. The librarians were very pleased with the result and were intending to put together a 'Tempest' pack for other staff to use.

The other activity was carried out by the Business Library and was related to shopping. The group consisted of people with severe learning disabilities and they were involved in quizzes and games about buying a birthday present. Both the staff and the library users with LD enjoyed the session.

The success of the two activities have been very encouraging for library staff and they are looking forward to offering more and to developing their relationship with regular groups of people with LD.

Although they were not specifically arranged for the project, the Centre for the Child also organized activities for children with LD. They had a storyteller come to tell a sensory story from Bag Books. Two librarians told a sensory story themselves to another group of children and they organized a group from a special and a mainstream school to come together to enjoy a music session with a musician from the City of Birmingham Symphony Orchestra. These kinds of activities are already part of the general library strategy for including children with Special Educational Needs.

Conclusions

We feel we can say that everyone involved in the Inclusive Libraries project really enjoyed the experience. Library staff built up understanding of the needs of people with LD, engaged with children and adults with severe and profound learning disabilities and felt that their efforts were successful and worthwhile.

There were difficulties in the project, particularly with the lack of a leader at the beginning and with changes in staff at Quinton. There were also delays

with ordering resources and with getting the computer set up. All the changes took longer to achieve than was anticipated and we all know that this is only the beginning of a whole new strategy for including people with LD.

Perhaps PMLD-Link readers can help to spread the ideas and encourage changes in public libraries? You could go to your library and talk about sensory stories and a touchscreen computer with interactive stories and cause and effect games. They probably do not know such things exist. Try to enthuse one person. That's how things got started in one of the survey libraries. When the film and booklet are on the BILD website, you can direct them to that. Hopefully the changes experienced by public libraries at the moment will be encouraging librarians to look for new ways in which they can engage their users. This could be the project they have been looking for!

Contact

Penny Lacey
School of Education
University of Birmingham
p.j.lacey@bham.ac.uk

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Life Long Learning With Bexley Library Service

Nina Martinez

Bexley Library Service started working with Carlton Road Day Centre three years ago. The Centre helps adults of all ages with physical disabilities, medical needs and profound and multiple learning difficulties to access different activities during the day. Initially their photographic club came to Sidcup Library to use the computers to produce calendars, consisting of their own photographs taken during their weekly outings.

This led to an extremely successful exhibition of their framed work in Sidcup Library. During that time the local press and Councillors viewed their work and many items were bought by the general public. To date they have successfully held another three displays and are currently creating new work to exhibit in Central Library, Bexleyheath.

A group from the Centre now join myself and a colleague for Nintendo Wii sessions. The group are of very mixed ability and age. They all have a severe learning disability and a combination of physical or medical conditions, some profound. Initially, some members of the group found the whole concept of using the Wii controller an impossible and daunting task, but with regular weekly visits, laughter and fun, the group has now doubled in size and many need very little support to enjoy playing the game.

Recently we secured Aiming High funding to purchase two portable hoists for use in the accessible toilet. One of these resides at Sidcup Library and gives staff from the Centre the confidence to use the library for a longer period of time, knowing that personal care can be easily accommodated. The other hoist is currently at Welling Library. This library and Sidcup have the



largest accessible toilets and space for wheelchair manoeuvre but the portable nature of these hoists means they fit in the boot of a car and can be transported to any library as needed. The hoists can also be used by members of the public for anyone with additional needs.

In December 2009 Bexley Library Service held an Inter-Centre Wii competition at Welling Library. The three Day Centres in Bexley were invited to enter a team and we all enjoyed lunch together halfway through. Carlton Road won the competition with much pride but all participants left with a medal. Let us see if they can hold the title again this year!

Along with these events we work with many other organisations to provide activities in Bexley Libraries. Examples of these are The Mini Beast Man, Spud and Yam and Knex [workshops](#).

Spud & Yam specialise in developing material which is both educational and entertaining. Kate's (Spud) professional background in language teaching, acting and singing - together with Winston's wealth of experience as an accomplished percussionist, singer and dancer serve to enrich their collaborative

work.

K'NEX is one of the most successful construction kits in the world, second in popularity only to Lego. It is based around a series of "Rods", which can be joined together by "Connectors". Once participants have mastered using these simple components, children and adults can use their imagination to make potentially millions of different working models.

The relationship between Bexley Library Service and the Centres has gone from strength to strength resulting in closer contact with all members of the community with profound and multiple learning difficulties. I deliver regular Bag Books story times in our libraries for this group of people. Bag Books are multi sensory, tactile stories for people of all ages with multiple difficulties. Although Bexley Library Service encourages and welcomes them into libraries for these sessions we are also extremely mindful that sometimes this is impossible for Centre staff, and outreach work becomes the reality.

I have trained Library staff and other Council employees in using Bag Books and Disability Awareness training is now mandatory within the Library service. Bag Books are loaned just as a bound book would be but the loan period is slightly longer. Bag Books stories are on card with

appropriate objects attached that are handled by the listeners, thus making for an interactive experience. On their return they are checked to see that all pages are intact and all items that require disinfecting are wiped over.

Positive partnerships between Bexley Library Service and children and adults with complex disabilities have encouraged people who are unable to read, to find the library a welcoming and fun place to be. We strive to continue to think of new ways to deliver lifelong learning to these valued members of the community.

Nina Martinez
Study Support Coordinator
Bexley Libraries
nina.martinez@bexley.gov.uk

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- Communication - Speak Up Speak Out

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Please send contributions to:

Ann Fergusson
ann.fergusson@northampton.ac.uk

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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).

A Case Study – Lifelong Learning in a Further Education Post 16 Unit

Wendy Newby

Life-long learning is vital for pupils with profound and multiple learning difficulties (PMLD). Within this article I aim to provide a brief insight on how we foster life-long learning for young people with PMLD within the further education 16-19 unit in the school where I work.

Learning Situations

The starting point of our provision is the learners themselves. It is essential that all learning at any level is intrinsically motivating to the young people. This requires knowledge of previous experiences, likes and dislikes. We draw upon these to provide meaningful experiences for the students. This is achieved through a wide range of contexts through, lessons, massage, hydrotherapy, physiotherapy, music therapy, horse riding and so on. A good example of a meaningful experience was one that I was very lucky to observe within the school, a massage session from our massage therapist with Bill (pseudonym).

There were considerable empathy and respect for Bill throughout the whole session and his responses were what led the therapist. Bill took an active role and was not passive. A passive learner, I believe is when the teacher or, in this case, the therapist decides what is to be learnt and sets the criteria by which the learner's success and failures are judged. This can restrict the learner's contribution and affect their lifelong learning. Learners need to have the opportunity to be personally involved in the session, like Bill was. I feel that the session I observed allowed Bill to be personally involved, as it gave him the opportunity to make choices. An example of this was that the therapist put her hand out inviting Bill to place his hand on hers and it was only then that she took his hand in a sandwich and gently but firmly stroking it towards her. There was no sense of the therapist controlling the session as they were interacting together. The power was shared, in that there was a meaningful dialogue.

The expertise of the therapist was evident in her gentle calm approach to the session. She had clearly built up a trusting relationship with the Bill, which is vital. This example of a meaningful dialogue within a trusting relationship led me to consider the importance of communication.

Communication

I feel that communication not only allows us to connect with the people within our learning environment but also it permeates our life and provides us with a sense of living. It fosters our emotional and social development by allowing us to express ourselves. This, therefore, becomes imperative in promoting lifelong learning, as it avoids

the danger of our students experiencing a sense of isolation, a danger that is all too apparent for pupils with PMLD.

Communication is an integral part of everyday life within the learning of our students and it would be impossible to tell you about everything we do. Therefore, I aim to share one example of an approach that is used within lessons and social occasions. This is the use of intensive interaction. Harry (pseudonym) specifically benefits from this. For Harry to communicate, I believe it is essential to have a reciprocal interaction and that he takes an active lead role. He enjoys sharing his personal space with me and interacts through touch, eye contact, body language and verbal sounds. By experiencing an active interaction that he leads, I am taking into consideration Harry's subjective view of himself and the world around him. It allows Harry the opportunity to seek out and develop a mutual relationship with me. This was due to the fact that it was a fun activity for both of us that was open-ended.

Relationships and Friendships

Having fun and enjoying life is of paramount importance and is a main focus within our Post 16 unit. If a student with PMLD is actively involved, is having fun, is communicating, is taking lead, is making choices, feels valued, cared for and included, and is making relationships, they are learning. We hold in high regard what the young people like to do and have great fun in joining in their world. I have watched learning support workers lying on the trampoline with students, during a rebound session, where both are giggling; water play where everyone gets wet; discos where everyone is all dressed up; singing where everyone smiles; swinging where the squeals of delight can be heard across the whole unit ... the list is endless. It is this unreserved regard, acceptance and empathy that allow the development of relationships. This, in turn, I feel contributes to learning about the world around them. I feel that it is a privilege to join in the exploration of this world and learn alongside the students.

Wendy Newby
 St Rose's School
 Straford Lawn
wendy.newby@stroses.org.uk

Further Education and training for people with a learning disability

Jane Alltimes

With the Government's spending review, there has for some time been speculation and rumour about how the Treasury will curtail public spending and where cuts will fall. There are real concerns for the Further Education sector, with a recent report by the Association of Colleges predicting a total cut of 16% in 2010-11. However, for learners with a learning disability, this is not a new issue. Cuts in courses for this group of learners have been happening for some time and recent changes in the funding and commissioning of further education provision is causing further confusion and uncertainty about what the future holds for learners with a learning disability. The concern is that things could get worse.

Currently, there is little reliable data about the numbers of people with a learning disability accessing further education or training. While there are over 600,000 learners with a self-declared learning disability and/or difficulty (LDD) across all parts of the post 16 sector, it remains unclear the number of people with a learning disability specifically within the wider LDD cohort of learners – or the associated funding streams attached to this group of learners. There is therefore little known about the numbers of people with profound and multiple learning disabilities (PMLD) accessing learning opportunities – or the quality of this provision.

The coalition government recently launched its consultation on *Skills for sustainable growth*. This has some welcome elements, outlining a vision of a skills system that sees learning both as a means of meeting the needs of a successful economy, as well as something much broader, in relation to personal growth, enrichment of life and ensuring an inclusive society. As it states, *“learning promotes personal growth, enriches our lives, enlarges our understanding and broadens our interests. It is an asset to our cultural and community life.”* But while the previous government invested substantially in further education, it would seem that the prioritisation of certain groups of learners (for example, those learning at Level 2 or above, young people aged 16 -18 and employment outcomes) has adversely badly impacted on learners with a learning disability, including PMLD.

In addition, a focus by the Learning and Skills Council (the agency who, until 2010, was responsible for post 16 learning in England) on – quite rightly – the *quality* of provision for LDD, committed to stopping 'inadequate' and 'non-progressive' courses. This led to cuts in courses for people with a learning disability, leaving many learners with no alternatives. There was confusion about what was being deemed as 'non-progressive'

in the context of course cut-backs which seemed to be having a particular impact on people with more severe learning disabilities and PMLD.

Despite this, the policy framework and the underlying principles behind the focus on learners with a learning difficulty and / or disability have been welcome. This has included the development of a more inclusive credit qualifications framework and the continuation of support for high quality informal and non-accredited educationally driven programmes for this group of learners. But this clearly needs to be inclusive of *all* learners with a learning disability, including those with the most complex and profound and multiple learning disabilities. It is essential that the government supports a system of education and training opportunities which considers 'learning' in the widest possible sense, taking into account the fact that most people with PMLD will be learning skills that generally appear at a very early stage of development and where learning will take place very slowly. A focus on 'progression' needs to be all encompassing, recognising the importance of progression that is 'lateral' as well as linear. The learning requirements facing learners with PMLD, for example, are very specific and should be heavily focused on communication – working through the senses, using touch, taste and smell. There are many good examples of such provision – and in some cases, attempts to accredit such provision, but the key is always about good support and an approach that is person centred, taking into account any additional needs, such as sensory needs, so that the best approach to learning can be established.

The LSC was replaced in April of this year by two new agencies - the Skills Funding Agency and the Young People's Learning Agency. Alongside the government's skills strategy, the new arrangements provide an opportunity to take a step back and review planning and funding in further education and

training to ensure participation, progression and the promotion of equality of opportunity for all. The recent *Skills Investment Strategy*, however, suggests significant cuts to the developmental learning budget for 2010-11 which is to be reduced by £144m – impacting on 370,000 learners – many of whom are likely to be people with a learning disability.

The vision is clear: educational and learning opportunities should enable people to maximise their potential. The skills strategy needs to consider the range of learning opportunities that can benefit people, including informal education for personal and community development. But it is perhaps useful to consider the role of further education and training within the wider policy context, taking a broader and more holistic approach which considers the range of options available to people. What exactly are adults with a learning disability doing with their time? What support are they getting to access meaningful opportunities, whether that is in

employment, education or out and about in the community? This clearly feeds into much of the current debate around cuts to social care, as well as cuts to welfare benefits, and potentially means that people with a learning disability could lose out on a number of fronts over the coming months and years.

Without doubt, the current financial climate presents a threat to funding for learning disability across the board. Government will need to think carefully about spending more effectively and considering the vital role that education and training can have in transforming and enhancing people's lives.

Jane Alltimes
Senior campaigns and policy officer MENCAP
(policy lead on employment and further education)

A Method for Evaluating the Use of Switches and Voice Output Communication Aids within a Special School

Lucy Van Walwyk

Over the last fifteen years, switches and simple Voice Output Communication Aids (VOCA's) have become an important tool in the education of children with severe, profound and complex learning difficulties. Research and practice have shown how they can help children gain some control over their environment, fulfil their cognitive potential and learn about intentional communication.

In April 2007 I joined a team providing the speech and language therapy service to 'Brookside School'. A new, purpose-built special school, Brookside caters for primary aged children with moderate, severe or profound and complex learning difficulties. Since the school was new, it was necessary to build up provision for children using switches and VOCAs almost from scratch. Two years on, I felt it was time to audit the service both to celebrate what had been achieved and to identify necessary areas of development.

In order to make the audit effective, I needed to develop a set of criteria which I could use to evaluate the existing service. To achieve this, I reviewed relevant literature concerned with the beneficial use of switches/ VOCAs in education. Since switches and VOCAs form part of ICT for this population, literature concerning the effective use of ICT was also covered. In addition, I considered individual priorities for the school through discussion with management staff, teachers and others and by incorporating my own experience as 'knowledgeable professional' in this field.

As I completed this process it became clear that the features considered important both by literature and school staff could be classified at different levels. I used a framework adapted from Lacey (2001) to describe these as:

- **Strategic** – Applying to overall management and organisational issues.
- **Operational** - Policies and aims applied to individual planning (e.g. IEP's).
- **Fieldworker**: - Practicalities of input (e.g what is done and by whom).

Finally I ended up with an audit tool consisting of a set of questions to be addressed (see Table 1).

To answer the questions posed by my audit tool I gathered information from a number of sources. Using multiple sources in this way can strengthen the qualitative validity of a small scale study (Gersten et al, 2000; Lloyd, 2002) and can provide a solid baseline for ongoing evaluation as part of action research.

Table 1: Audit Tool used to evaluate switch/VOCA use at Brookside School

Strategic Level
<p>Are there any policies reflecting organisational support for switch/VOCA use? Is there identifiable managerial support for switch/VOCA use? Is there a budget ring-fenced for equipment? Are a range of staff involved in maintaining the service for switch/VOCA users? Is there multi-disciplinary collaboration? Is training provided? Are other stakeholders (including parents) involved?</p>
Operational Level
<p>Are aims, appropriate equipment and positioning determined by a multi-disciplinary team? Does written documentation clearly outline; equipment to be used, the best switching position for an individual, the reasons and aims for switch/VOCA use, suitable activities? Do Individual Education Plans and lesson plans reflect the use of switch/VOCAs? Is there evidence that switches/VOCAs are used to support learning across the curriculum? Is there a clear framework for observation/ recording of progress?</p>
Fieldworker Level
<p>Who organises the use of switches/VOCAs on an everyday basis? Has everybody who supports the use of switches/VOCAs received training? Are switches/VOCAs used frequently and consistently? Are the necessary resources available and easily accessed?</p>

The sources I used were:

- Direct observation of a sample of children using switches/ VOCAs.
- Structured interviews with teachers of these sample children.
- Analysis of written documentation concerning the sample children.
- A parental questionnaire.
- An analysis of strategic/managerial support for switch use including evidence from policies, correspondence and meeting minutes.

Using information from these sources, I was able to answer the questions within my audit tool. As a result, I was able to pinpoint areas of good practice as well as those which needed further development (see Table 2).

Whilst the idea of conducting an audit might seem like a somewhat ‘academic’ task there is no doubt that our audit has had some very lively and practical benefits so far.

Firstly, it has highlighted our areas of good practice – the managerial support in terms of allocating staff time and budget to this area and the existence of our multi-disciplinary ‘AAC working party’. This is helpful, not just in terms of raising morale, but as a source of evidence to justify the continuation of this managerial support, budget and the release of staff to participate in the working party.

Secondly, the audit has shown us where to focus our efforts for improving our service further. So far this has prompted us to run a successful ‘switching day’ where equipment, information and multi-therapy input was set up so that switch-users could come along and use it accompanied by hands-on staff and parents. It has also led to the setting up of our ‘switching trolley’ which contains a variety of switches toys and essential equipment (such as spare covers, leads and jacks) so that equipment is easily accessible and shared.

Service offered to Switch/VOCA Users following Audit

Conducting an audit involves taking some time out from everyday activity, stepping back and evaluating what you are doing. My experience on this project has shown me how focused academic reading and data collection can be translated into real hands-on benefit for the children I work with.

Lucy Van Walwyk
Independent Speech and Language Therapist
lucy@walwyk.fsnet.co.uk

Table 2: Recommendations for the Improvement of

Strategic Level	
1.	Draw up a policy addressing the use of switches/VOCAs within the school.
2.	Broaden the range of staff taking responsibility for the implementation of switch/VOCA use.
3.	Increase the involvement of parents and other relevant stakeholders.
4.	Explore the possibility of offering further on-going training to teachers.
Operational Level	
1.	Improve joint goal setting for switch/VOCA users which can be incorporated into IEPs.
2.	Develop a framework for observing and recording progress in switch/VOCA use.
3.	Focus on integrating the use of switches/VOCAs into everyday curriculum activities.
Fieldworker Level	
1.	Provide training opportunities to Learning Support Assistants.
2.	Develop a system to improve access to shared equipment.

References

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Lacey, P. (2001) *Support Partnerships: Collaboration in Action*. London: David Fulton.
Lloyd (2002) Developing and changing practice in special educational needs through critically reflective action research: a case study, *European Journal of Special Needs Education*, 17(2) 109-127.

Future Focus: Spring 2011

Speaking Up - Being Heard!

We all know there is no non-communicating person. There is no one who cannot **Speak Up** or **Be Heard**, albeit in their own way. Despite this truism - people with PMLD, their families and their champions continue to encounter great difficulties in establishing an automatic right to be heard. **Speaking Up - Being Heard - Communicating.**

When understanding and acceptance does happen it's thrilling, poignant and humbling as the example below illustrates - a willingness to 'listen' makes a real difference:

'She had a body brace mould made without anaesthetic...took us two hours, and they all had to sing to her, but we did it. See that's good practice. Because she couldn't have anaesthetic any more....so if they listen, really listen and believe in us, and listen to her team as well' (Mansell, 2010, p11)



This example of **Speaking Up** and **Being Heard** - takes us beyond the glib, pretty platitudes into the world of real life communication. Choosing the right hair brush or the speed at which someone wants to eat, through to ensuring the best outcomes from complex hospital procedures, takes real responsiveness and sensitivity. It's all in the detail - it's about the right pace, the right skills and value base, but most of all it needs a genuine '*wanting*' to hear what's being '*said*'. Small or subtle changes can have big impact on the lives of people with PMLD, their families or those who support them.

The next issue of PMLD Link - will be about Communication; **Speaking Up - Being Heard.** Are you willing to share your experiences?

We are looking for examples – especially where you've had some success [however small or great]. We want to hear about the day to day stories... as well as inspiring practice in the whole range of settings and services – stories of overcoming the challenges of achieving a big voice. Please also share your photos [with appropriate permissions]. Do speak up – *we want you to be heard!*

Please send us your contributions - have your say to: to Annie Fergusson and Helen Daly [Guest Editors] ann.fergusson@northampton.ac.uk or c/o Centre for Special Needs Education and Research, The University of Northampton, Park Campus, Boughton Green Road Northampton. NN2 7AL **All contributions by XXX XXXXXX 2011**

Reference

Mansell, J. (2010) *Raising our sights: services for adults with profound intellectual and multiple disabilities* London: DH Publications

PMLD Network Email Forum A Digest of Discussions July 2010 to October 2010

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. Your views on Inclusion

Someone asked for people's views and experiences of inclusion for children with disabilities.

Responses included:

- A teacher from a special school working in a partnership setting in a mainstream primary school with pupils with needs ranging from moderate to PMLD, said that for the majority of the class the benefits of inclusion are social, so instead of accessing the mainstream classes - which would not meet their educational needs - they arrange for pupils to spend time and share activities with their mainstream peers including sitting with them in assembly.
- 'Much of what people advocate as successful inclusion is very tokenistic and does not maximise teaching and learning opportunities for those pupils who have the greatest learning needs whose learning is slower.. They also tend to spend much of their day with the least qualified staff, with teachers having little input.'
- 'It is important that the needs of the child are what count, not a philosophical bias in one direction.'
- Someone said that services local to them tend to work on inclusion for the most able disabled people in the area first. They said: 'It is said that if you have got it right for the most vulnerable members of society you have got it right for everybody. This is not a reality in our locality. An example: it is possible to go canoeing locally. There is a place where 2 canoes have been strapped together so they can not roll over. But my daughter can not get in the canoes as no hoist has been provided and there is no supportive seat in the canoe. A less disabled person can access this opportunity.'
- 'I was recently involved in a 'Festival of Togetherness'. Our planning started with the question:- how can we make people with profound disabilities and their families feel so welcome that they won't want to leave? It was an amazing day. We also enjoy a monthly 'togetherness walk' - a walk and roll round the local park with relaxed time in the cafe. We invite people first who are usually left out. What we are noticing is generosity - this is happening with very little money because people want to help each other and (when we get beyond initial fears) they want to know each other. There is an article due in *Learning Disability Today* about this 'togetherness' thinking and you can find out more at www.frameworks4change.co.uk
- Someone said that near Rickmansworth in Hertfordshire there is a very active special sailors group called Colne Valley Special Sailors at Bury Lake, which many people with PMLD access.
- Someone said that they find that disabled people without a learning disability are no more able to get their heads round PMLD issues, such as non-verbal communication and lack of capacity, than non-disabled people. As a result they said that that you will rarely see this tackled in a sympathetic way in magazines, where the issue is usually presented in a cut-and-dried manner: inclusion is good, special schools are bad, and the many complexities specifically relating to PMLD children aren't appreciated. The person added 'having said that, even though my son is too old for school now, I do know how he loves the sound and presence of other children and young people, and how wonderful it would be to have some inclusive measures which don't segregate our PMLD children.'
- Prof. Jim Mansell suggested using the concept of 'and' instead of 'or'. He said: 'People who support special schools do so particularly because they believe that they can provide the expertise their children need to get a good education; people who support inclusion do so mainly because they believe that inclusion brings social benefits for the individual and for society. Why should we have to choose? Why can't we have special classes or units located in mainstream schools, so that every child gets both expertise and inclusion?'
- 'I guess the current reality is that many mainstream schools actively struggle with being truly inclusive, expecting children to fit into there system rather than making reasonable adaptations. The support systems around mainstream schools tend to have little learning disability expertise and I would question whether the money that is provided in terms of a support, not just personnel but bricks, mortar, expertise, outreach support and technologies is transferred to mainstream schools to support their provision'.
- 'For some with special needs, mainstream works fine if the resources, expertise, staffing, training, etc and everything needed are right and in place. For some, a special unit or strategically resourced

facility within a mainstream school might work. But for some neither of those are enough to meet their needs. The problem is that mainstream schools often do not have the teaching accommodation, staffing and resources needed. The special facilities in mainstream schools which already exist are also often under-resourced. The staff in them can become isolated because their colleagues in the mainstream part of the building often do not understand the difficulties or needs being faced by either the pupils or the staff in the specialist facility. For some children with special needs, the best way of including them is in a special school or residential special school which can offer the 24 hour therapeutic curriculum and respite care for parents and siblings which are needed to keep the family unit from breaking down. Special school staff build up a pool of expertise greater than the sum of its parts over a period of years which cannot be replicated by bolting a special unit onto the side of a mainstream school.'

- Someone made a general point about the ongoing inclusion debate. They said 'could we please stop talking about it as if it is one issue... the issues surrounding inclusion into mainstream for pupils with PMLD would be totally different from those for the more able.'

2. Holiday accommodation

Someone said that they were seeking planning permission to build accessible self catering holiday accommodation. They need to demonstrate the need for this type of accommodation in their planning application and they asked if anyone knows of any ceiling hoisted accommodation and if people think this type of accommodation is needed.

Responses included:

- The HFT Family Carer Support Service 2010 Holiday information Brochure
- can be viewed and downloaded at www.Hft.org.uk/Family_Carer_Support (click on the link in the family carer news column on the right hand side)
- 'I am so pleased that someone has thought about adapting their accommodation for those with more complex and hoisting needs...Our home is not perfect but it's getting there. But we would love to have something like that when we go on holiday, even if it's for a couple of nights.'
- Some people flagged up some things that need to be considered, for example:
 - 'armchairs – if you have a portable hoist instead of ceiling hoist then the legs on the armchair need to allow the legs of the hoist to go underneath and to be able to place the person into the armchair!'
 - 'When we go on holiday we have to make sure that we have a large enough family

room, we shift the furniture out of the way and place sheets, blankets, duvets, and pillows on to the floor for support and safety. That way our son can't roll out as he is already at floor level. So he needs either a very high sided bed or a low level bed on the floor or a low level bed that still allows a floor hoist to go underneath'.

- 'With bathing or showering, we feel that a shower table isn't ideal for someone with scoliosis (back problems) as it is rather hard and our son shouldn't move around so it is harder work on a table surface. We would have preferred to have a bath but would need some seating inside with some straps or belts or some kind of support to stop our son sliding down or falling over as he can't sit up on his own inside a bath. A ceiling hoist would obviously be very useful to lower him into the bath'.
- 'Hopefully you will go for the 'H' frame x-y tracking which means people can be moved anywhere in the open plan setting (rather than having a fixed track) and a toilet area on the lines of the 'Changing Places' campaign where there is a good sized changing surface.'
- People made suggestions about where they could go for information about suitable equipment:
 - Disabled Living Foundation (DLF): www.dlf.org.uk
 - Local mobility shops, larger disability events like Naidex at the Birmingham NEC.
 - Occupational therapists and physiotherapists at hospitals, schools, disabled living centres, and various other places could also be consulted.
 - 'Yes there is a need for this type of accommodation.'
 - Some people shared accessible holiday venues they had been to:
 - 'Kingfisher Barn near Abingdon in: <http://www.kingfisherbarn.com/>
 - Vitalise: <http://www.vitalise.org.uk/>
 - Livability self-catering holidays: <http://www.livability.org.uk>
 - Crathie Opportunity holidays: <http://www.crathieholidays.org.uk>
 - Newlands at Southwold guesthouse, Suffolk: <http://www.newlandsofsouthwold.co.uk/>
 - Casa Ourico do Mar villa just outside Loule town, Algarve, Portugal:
 - www.ouricodomar.com
- The HFT Family Carer Support Service 2010 Holiday information Brochure can be viewed and downloaded at www.Hft.org.uk/Family_Carer_Support (click on the link in the family carer news column on the right hand side)

3. Planning and assessment

Someone said they work at a special educational needs school and they have more children with PMLD starting to attend. They asked for any support with planning for foundation/infant children working on the p levels from p1 to p4. They are very interested to know how other special educational needs schools are planning for and assessing children with PMLD.

Responses included:

- Someone suggested 'The Equals Guide to Teaching Mathematics' which is about supporting access for pupils working towards the National Curriculum, including teaching pupils at the earliest levels of development www.equals.co.uk/
- Information was given about the curriculums being used in some schools with pupils with PMLD:
 - Castle Wood School, Coventry said that their curriculum for PMLD consists of Communication, Cognition, Physical, Personal Care. Children have 3 targets – one is Communication, one is Cognition and one other which is usually either physical or personal care. These are then placed within a context of wider curriculum experiences encompassing things such as music, dance, drama, art, sensory stories, swimming, outdoor exploration etc - anything that is motivating for individual pupils. They said that they acknowledge that children at an early stage of development are not best served by a curriculum of subjects but need a curriculum based on early development. They said they are led by identifying individual children's strengths and needs using a range of observations and assessments - but particularly the 'Routes for Learning' assessment materials from Wales: <http://wales.gov.uk/docs/dcells/publications/090915routeslearningbookleten.doc>. Castle Wood School, Coventry said they would be willing to share their curriculum once they have got past the first draft.
 - Information was also given that Whitefield School in London and Victoria School MSI Unit in Birmingham are willing to share their curriculums and the curriculums used at Barrs Court in Herefordshire and St Margaret's in Tadworth can be purchased.
 - 'At St Rose's (Stroud) assessment is carried out in a broadened sense for pupils with PMLD. We use routes for learning as a formative assessment and use the guidance to help us pin point response to activities. As we are a school that has a multi-disciplinary team the therapists incorporate their targets into the curriculum and they are assessed by
- the therapists. Unfortunately we are all constrained with the necessity of summative assessment and although it is not ideal - as pupils with PMLD do not necessarily follow a linear progression and often do not achieve targets set - we use B-Squared small steps as a summative assessment tool. The data from B-Squared is then annually put into CASPA that is a software that quantifies data and maps progression and value added. This full-fills our accountability to the wider community such as Ofsted. However as a school we recognise that pupils are individuals and so IEPs and provision maps provide an individualized approach that is multi-disciplinary.'
- 'I enclose a brief description of the Key Skill Assessments we have developed here at Rosewood School. The assessments cover pre-intentional, intentional and formal learners (P1-P4) and are known collectively as ImPACTS. Each assessment is backed by a curriculum. Please feel free to contact us if you are interested. ImPACTS Introduction: <http://www.choiceforum.org/docs/impacts.doc>'
- 'In Leeds we have written policy and guidance that recognises that the learning needs of pupils assessed as below P3ii are significantly different than their peers resulting in them having their own personalised learning plans to address their learning needs (if you use our materials please acknowledge our work):
 - Curriculum policy for pupils with Complex learning needs: www.choiceforum.org/docs/curric.doc
 - Curriculum Guidelines for Pupils and Students with Complex, Multiple Learning Needs: www.choiceforum.org/docs/curricgd.doc
- 'I hear from my own child's school a lot of persuasion is required to convince those on high that things don't always fit neatly into specific categories - some of our children may take a very long time to progress, even on P levels, and some may even stay at the same level. But I know everyone does their very best to make sure each child progresses in one way or another. And it is good to see some evidence of this. I do hope that some time in the future parents/carers and teachers can come together on a 'P level conference' to look at the good work, celebrate everyone's achievements.'
- 'I don't know if anyone mentioned Asdan in their responses. My son's school has used this in the last year...as a carer I like it because at the end of the school year I have a folder with photos and information of what teachers did with my son, and there is visual evidence of work being done in the different areas.'

4. Friendship and people with PMLD

A research student working on a thesis on the significance of friendship in the lives of adults with PMLD said that as part of her fieldwork she has been spending time with people with PMLD who have friends – or more accurately, with people with PMLD who have people in their lives who are spoken of as their friends, by their parents or carers, or by the friends themselves. So far she has not found many people with PMLD who fall into this category of people with identified friends. She asked if people think this rings true or whether there are lots of people with PMLD and their friends out there who she hasn't met yet.

Responses included:

- 'My daughter certainly has children her own age, who know her through church or other activities, who call themselves her friends. She has people in her life who bring her pleasure, people of all ages who make her life richer by spending time with her; people for whom she reserves her most special of smiles.'
- Someone said there are lots of people and organisations out there where friendship is supported, encouraged and enabled. For example befriending projects where peers are encouraged to come forward to go out to places like the pub or cinema with disabled young people on a peer level rather than a careworker role. They also mentioned 'circles of support' - where people have people around them who support them, including friends.
- People tend to have friends linked to an activity or establishment, particularly school. Once a person leaves school they often won't see friends again unless they happen to meet accidentally. Any continuation of friendships is often based on others making arrangements and taking them to see one another, this may happen more often when people live with parents and parents have a friendship themselves through shared experience. Generally speaking when people live in staffed homes little effort is made to find out if any friendships existed let alone maintain them.
- 'I am a parent of a young woman who has profound and multiple learning disabilities. I think she does make friends independent of me if I give her opportunities. For example by sending her to college or on a holiday without me and with a PA. She does seem able to make new connections with people without my help. But she can't do it without any help. She does need an enabler who might be me...Her friends are not all other people with disabilities, some of her friends are elderly. This is because the elderly are also available to go out in the day! Again she goes out with these people without me but with the help of 2 PAs. She has a devastating smile and once people have experienced this they are done for and will do anything to be rewarded with another.

I think this is how she does it.'

5. Depression scales within learning disabilities

Someone said they were beginning their degree in health and social care and as a registered nurse in learning disability, they have been asked to implement an assessment to use in practice. She asked if anyone had come across the Becks Inventory Scale screening tool and found it useful when working with people with leaning disabilities and mental health who had experienced depression and/ or anxiety.

Responses included:

- Someone said that they had not come across this scale but they strongly feel that all mental health issues including depression are overlooked in people with learning disabilities.
- Someone said they thought there was an adapted version of the Becks Inventory Scale – although they do not think it has been standardized. They mentioned other scales that might be used such as the Glasgow Depression Scale, Adapted Hospital Anxiety and Depression scale etc. Although they said these scales generally rely on the self-report of the client, to some degree. However they said that if you are thinking about clients who are unable to give some form of verbal self-report, the Glasgow Depression Scale has a carer's supplement, that might be helpful. They said a paper by Lowry (1998: Journal of Developmental & Physical Disabilities, 10(4), 387-406) also looks at behaviours that might be symptomatic of depression.
- 'Here in Australia through the Bridging Project we have been working on a tool/scale for people with complex communication needs. We have used the Becks Inventory Scale and adapted it. We have developed it in collaboration with people with intellectual disability and are currently piloting it. For more information about it go to www.bridgingproject.org.au'
- 'I've never come across this scale before and certainly don't think it was available as a tool when my daughter was in a deep state of depression following her operation about fifteen years ago as it might have been of help to us. At that time no advice was available and due to her severe level of cognition and communication the only way we could provide any form of help for her was to give lots of TLC, cuddles, talking to her with one to one involvement and common sense.'
- 'I have used Beck's inventory before but I would not think it suitable to use with people with profound disabilities because of their cognitive ability. We have a PMLD pathway in the trust and use a tool called the Mood, Pleasure and Interest Questionnaire [MIPQ] I have found this tool very

reliable in assessing people's Mood, Pleasure and Interest.'

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

Visit the PMLD Network website at www.pmldnetwork.org



EQUALS is a registered charity committed to supporting the work of teachers of pupils with Learning Difficulties within special and mainstream education. We produce curriculum support materials, organise national conferences/workshops and influence educational policy at local, regional and national levels by acting as a voice for practitioners.

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NEWS

Local government funding cut in CSR



Cuts to local government funding put social care services at risk.

Chancellor George Osborne has announced a 7.1% annual cut in local council budgets over the next four years in the Comprehensive Spending Review (CSR). Over the four years, this will be over a quarter of their funding.

He also said that the government will remove ring-fencing of local government grants, which means that local authorities will no longer be obliged to protect funding for specific areas. Core grants for people with a learning disability, including the Learning Disability Development Fund, the Carers Grant and Supporting People will not be protected.

"The spending review confirms that the war on cuts has become a reality," says Mencap's chief executive Mark Goldring. "The severe 7.1% year on year reduction in funding to local councils and removing ring-fencing to local government grants will inevitably mean significant pressures put on care budgets. These savings cannot be made by efficiencies and they will impact on services and care for those with disabilities. With an ageing population and growing numbers of people with disabilities, social care needs more money not less."

Although the chancellor promised an extra £2 billion for social care, Mencap believes that this will not be enough to secure the social care services that people with a learning disability need. "The extra money transferred to the social care budget is a drop in the ocean compared to annual care costs and will have a limited impact on protecting the most

vulnerable," said Mark Goldring.

Reacting to the cuts, Mencap staff member Ismail Kaji, who has a learning disability, said: "My question would be: where is the £2 billion going to? They mentioned elderly people when I saw it on TV but it is not only elderly people who need support. People with physical and profound disabilities might need 24 hour care or have problems with communication that stop them getting the care they need."

Changes to benefits

George Osborne also announced changes to the welfare system, including time limiting Employment Support Allowance to one year for some people, and ending the payment of the mobility component of Disability Living Allowance to claimants in residential care.

"We are concerned about the impact of this policy," said David Congdon, Mencap's head of campaigns and policy. "The mobility component of DLA can help to ensure that people with a learning disability living in residential care get the individualised support they need to access the community. For example, people with mobility difficulties may use the benefit to pay for adapted taxis to go to activities like arts classes or shopping.

"If this benefit is removed, it is crucial that this does not result in people with a learning disability finding it harder to access meaningful activities. An unintended consequence could be a step back from choice and control."

Enhanced eye services for people with a learning disability

In parts of the UK, enhanced eye examination services are ensuring that people with a learning disability receive the eye care they require. These services offer longer



appointments which are carried out by an optometrist with specialist training and equipment. This helps to overcome some of the eye care barriers faced by people with a learning disability

such as communication difficulties and inaccessible testing methods. Improved access to appropriate eye care will lead to an increase in the quality of life for people with a learning disability and reduce future health and social care costs.

An enhanced eye examination scheme can fit in with the Directed Enhanced Service, a national scheme that rewards GPs for offering annual health checks to their patients who have a learning disability and are known to the local Learning Disability Team. When a person with a learning disability has their annual health check, the GP or nurse will ask specific questions about their eye care but won't provide a comprehensive eye test. People who are not getting regular eye care can be referred on to the local enhanced service to see their optometrist, as part of their Health Action Plan.

For more information, including how this sort of service can be taken forward in your area, read the press release from Seeability: http://www.pmldnetwork.org/resources/Enhanced_eye_tests_press_release.pdf

Challenging Behaviour Charter

The 'Challenging Behaviour' - National Strategy Group has launched a charter to promote the human rights of individuals with a learning disability who are perceived as challenging.



Up to 27,000 people with a learning disability in the UK may have been given a label of 'challenging behaviour', resulting in this group of people being:

- stigmatised and socially excluded
- denied the right to ordinary lives in the community, education, recreation and employment
- placed in institutional settings a long way from home and families.

The label challenging behaviour has become misused over time. Rather than being used as a term to encourage carers and professionals to understand the underlying reasons for a person's behaviour, 'challenging behaviour' has been used as a diagnostic label, viewed as being intrinsic to the person.

The Challenging Behaviour - National Strategy Group want people (and organisations) to sign up to the charter to register their support for the principles it contains and to commit to action to improve the lives of children and adults who are labelled as challenging. We need as many people as possible to

support us, so please ask your friends and family to sign up too.

Read the standard and easy read version of the charter:

<http://www.thecbf.org.uk/campaigns/Charter.htm>

Celebration time at The School for Profound Education, Tadworth

Students took centre stage when The School for Profound Education in Tadworth (formerly St Margaret's School), celebrated the achievements of its hardworking learners and college students.



The school, one of the UK's only to cater exclusively for pupils with profound and multiple learning disabilities (PMLD) and complex health needs, held a special awards

ceremony to congratulate 13 of its students who gained certificates as part of the Accreditation for Life and Living (ALL) scheme certified by Oxford, Cambridge and RSA Examinations (OCR).

The students, all of whom have PMLD, gained certificates for modules covering a variety of areas including creative arts, ICT, home management, communication and personal skills. All students in the school's further education and college classes gained at least one certificate each this year.

The ceremony was also an opportunity to celebrate the school's new name – The School for Profound Education – which took effect on 1 September 2010.

The modules allow each student to build an evidence-based profile of their own achievements which reflects their own needs and skills. The school selects ALL modules which will fit within its own specially developed curriculum, emphasising sensory awareness and promoting the inclusion of therapy procedures within the classroom.

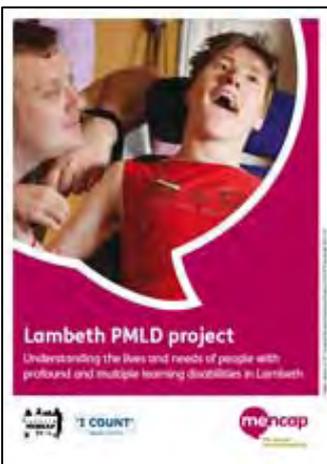
Jan Cunningham, The School for Profound Education's head teacher, said: "The awards

ceremony has shown just how hard our learners work and what a credit they are to the school. It is wonderful that we have been joined by so many parents, family members and friends who want to share in our celebrations."

Pictured: Dr Mary Greenaway, chair of governors at The School for Profound Education presents college student Joshua with his certificate.

Lambeth PMLD report: understanding the lives and needs of people with profound and multiple learning disabilities in Lambeth

Mencap has launched a report exploring the numbers and needs of people with PMLD in Lambeth. It was a collaborative project, with family carers in Lambeth, Lambeth Council, NHS Lambeth, Lambeth Mencap and 'I Count' Register Services.



The report will not only help Lambeth Council and NHS Lambeth better plan for this part of the population but we hope that the project and 31 recommendations that have come out of it will help other local areas to focus on the needs of people with profound and multiple learning disabilities and ensure their plans for people with a learning disability are inclusive of those with the most complex needs.

Focusing on the needs of people with PMLD so that they don't miss out is something that Professor Mansell said that all local areas should be doing in his report Raising our Sights: services for people with profound intellectual and multiple disabilities, which was commissioned as part of the Valuing People Now delivery plan:

"Local authority social care services, together with their education and health partners, should keep up to date information about the numbers, needs and circumstances of people with PMLD in their area currently and projected future to enable effective planning of services."

Findings

The findings in the Lambeth PMLD report reflect the national picture of what life is like for people with

PMLD.

A priority to come out of the project is to ensure that family carers who are caring for someone with PMLD in the family home in Lambeth get the support they need - help from support staff with the right skills, reliable, high quality respite, better information and advice about local services and how to manage direct payments and individual budgets. Findings indicated that people with PMLD living in the family were less likely to have a person centred plan or health action plan which suggests family carers need more support with these.

How the project was done

The well maintained learning disability register in Lambeth helped us identify the population of people with PMLD in this area. Criteria were developed using the PMLD Network definition of profound and multiple learning disabilities and applied to the register information to identify who was likely to have PMLD. 81 people were identified. This fitted in with the local estimate given in Emerson's report Estimating future numbers of people with profound and multiple learning disabilities in England. Lambeth will continue to be able to use the criteria developed to identify people with PMLD on the register and analyse their needs, and use this to better plan for people with PMLD.

In addition to information from the register, we surveyed and interviewed family carers and support staff for the project. This enabled us to get a picture of what life was like for people with PMLD in Lambeth.

Beverley Dawkins OBE, national officer for profound and multiple learning disabilities at Mencap and Chair of the PMLD Network said:

"We are delighted to be part of this 'good practice' project – a local area finding out about its PMLD population. We hope it will encourage other local areas to do the same. It will also help us increase our understanding of the issues we are campaigning on nationally."

The project was initiated by family carer representatives on the Lambeth learning disability partnership board.

Further information

Read the Lambeth PMLD report

http://www.pmlDnetwork.org/resources/Lambeth_PMLD_report.pdf

For more information about the project contact the Mencap campaigns team by email: campaigns@mencap.org.uk or telephone: 020 7696 6019.

Needless deaths continue

The Department of Health has highlighted continuing failures in care for people with learning disabilities

The Department of Health has published its findings on the progress of 'Six Lives' – last year's report containing evidence that hospitals are failing to provide proper healthcare to people with a learning disability.



'Six Lives' was published by the health ombudsman in March 2009, in response to Mencap's 'Death by indifference' campaign. It revealed 'significant and distressing failures' in health and social care services and that people with a learning disability experienced 'prolonged suffering and poor care'.

Since 'Six Lives' was published, a further 14 deaths have been reported to Mencap, which families blame on hospital blunders, poorly trained staff and indifference.

In the introduction to the report, care services minister Paul Burstow says: "People with learning disabilities and family carers still report experiences of care that fall well short of the standards we should all be able to expect."

The report highlights a number of areas that need improvements, including complaints procedures and advocacy support for people with a learning disability. It highlights the need for more, better quality annual health checks (currently 60% of people with a learning disability are not receiving them). And it calls for more training for mainstream staff on communication and making reasonable adjustments.

"This report is a stark warning that too many parts of the NHS still don't understand how to treat people with a learning disability," said Mark Goldring, Mencap's chief executive. "If attitudes, training and clinical practices aren't overhauled across the board people will continue to die needlessly."

"Health professionals need to properly understand how to apply the Mental Capacity Act as too often decisions are not made in the best interests of the patient. Doctors should be trained to intervene early to treat people with a learning disability, rather than waiting.

"It is also essential that funding of the Confidential Inquiry and Public Health Observatory continues so that people with a learning disability do not keep dying needlessly. The failure by some hospitals to act reflects the deep-seated discrimination against people with a learning disability that still exists in the NHS."

Mencap is calling on all health trusts to sign up to and implement its nine-point 'Getting it right' charter. It is also asking the health ombudsman to publish a follow up report on NHS Trusts' progress in 2012.

Help fight the DLA cuts

Mencap has launched a campaign against the cuts to Disability Living Allowance.

October's comprehensive spending review included the decision to remove the mobility component of Disability Living Allowance (DLA) for people living in residential care homes.



This change will affect 58,000 disabled people, who use the benefit to access their community. Mencap believes that the government has misunderstood how this benefit is used – by removing it, people living in residential care will only have around £22.19 a week personal allowance.

Mark Goldring, Mencap's chief executive, explained that the mobility component of the DLA helps people living in residential care to get the personal support they need to take part in activities and live a fulfilled life: "This cut will take us back to the days when people were left in care homes with just four walls for company and will undo decades of progress."

The help fight these cuts, Mencap has launched a campaign. It calls on people to email their MP, asking them to write to disability minister Maria Miller, urging her to get the decision reversed.

Find out how you can get involved in the campaign : <http://talkld.mencap.org.uk/2010/11/05/stop-the-cuts-to-dla/>

The coalition government's vision for social care

Increased use of personal budgets announced as part of care reform plans.

The Department of Health has published its plans for adult social care in England.

'A vision for Adult Social Care: Capable Communities and Active Citizens' sets out seven core principles for reforming social care.



It includes plans to roll out personal budgets to one million people by 2013. Personal budgets were introduced in 1996, and are currently used by 213,000 people. Through the In Control programme and as a result of Valuing People's focus on personalisation, the use of personal budgets among people with a learning disability has been high compared with other groups of social care users.

The vision also promotes 'big society' ideals, including the belief that local communities are best placed to watch over those who need care.

Carers

The plans call carers 'the first line of prevention' and propose that they are assigned personal budgets to let them take a break from caring responsibilities. In a statement, Care Services Minister Paul Burstow announced £400 million over the next four years to support carers' breaks.

Announcing the plans, Mr Burstow, said: "Often people find the social care system confusing, inflexible and not suited to their needs – that's not good enough. I want to see the vision brought into practice at a local level. Councils can offer more choice, control and flexibility over care, which is what people tell me they want."

David Congdon, Mencap's head of campaigns and

policy, said: "Personal budgets empower people with a learning disability to live more independent lives, a luxury the rest of us take for granted.

"While the government's plans are a positive step towards people having more control over their lives, October's spending review has dramatically tightened local authority budgets so it's going to be hard for them to deliver this vision for social care. We hope that councils will do all they can to protect the frontline."

Timeline for reform

The current vision, along with a consultation paper, will be followed by key milestones towards the reform of social care in England

The current vision, along with a consultation paper, will be followed by key milestones towards the reform of social care in England:

- End 2010 - Public Health White Paper
- Spring 2011 - Report from Law Commission on social care law
- Summer 2011 - Commission on Funding of Social Care report
- End 2011 - Care and Support White Paper (social care)
- Spring 2012 - Social Care Reform Bill

RESOURCES

Raising our sights report and DVD - copies available

Hard copies of the 'Raising our sights' report and DVD are now available. This report about services for adults with profound intellectual and multiple disabilities was written by Professor Jim Mansell for the Department of Health.

To order a copy email

publications@mencap.org.uk or telephone 020 7696 6900. (Please note there is a limit of one per person, three per organisation).

View the report online at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_114346

Raising our sights:
services for adults with profound intellectual
and multiple disabilities
A report by Professor Jim Mansell



REVIEWS

Title: Choosing a School for a Child with Special Needs

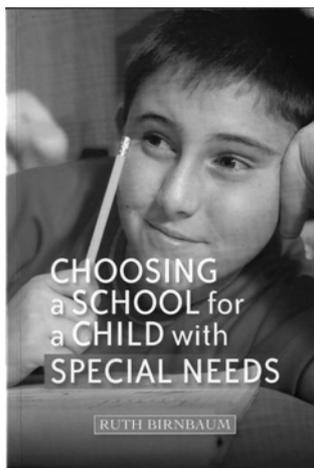
Author: Ruth Birnbaum

Publisher: Jessica Kingsley Publishers

Pub date: 2010

Price: £14.99

ISBN: 1843109875



Ruth Birnbaum's aim "to try and make education as accessible as possible for the children who often rely on others to be their advocates," is the key to the success of this book. She places herself firmly with the child and hopes "that by alerting parents and professionals to the sort of questions they need to ask and the types of provision which will be suitable, the children will benefit."

The result is a book that has in-depth information together with questions and checklists, on just about everything a parent or carer will need to be aware of as they approach the daunting task of selecting the educational provision which will best support their child with special educational needs.

The author begins by defining a range of special educational needs from dyslexia through to profound and multiple learning difficulties and includes behaviour, emotional and social development difficulties and sensory and physical needs.

There were instances when I wondered if parents would be able to cope with the shock of seeing their child's condition laid out before them. For example, a diagnosis of cerebral palsy would mean that "the impairment in movement does not resolve with time" and "[It] may take several years for the full impact of a child's cerebral palsy to become apparent." For the parent of a young child, still hopeful of seeing progress, this could be hard to take on board. However, this is a very minor point when considering the practical usefulness of the whole book.

The outline of the main areas of the current law on special educational needs which will affect parental choice, the importance of assessment in defining the child's needs, the list of schools and looking in advance at school documentation, the Prospectus, School Magazine, School Profile, Policies and Procedures and Ofsted report, will all prove very useful for parents and carers starting their search.

Equally helpful is the section on "Setting up a Visit", finding the best time in the school timetable so that they will really see what their child will experience, and looking at the physical school environment to assess whether there will be access to the whole curriculum as well as the potential for inclusion in after school activities and school trips etc.

There are clear descriptions of teaching for specific learning difficulties, dyslexia and dyscalculia etc; visual, hearing and dual sensory impairment and autism and of the roles and qualifications of specialist teachers and therapists. Issues in regard to religious beliefs, equality and discrimination, co-education, school size and transition are also explored.

Finally the author takes us through the different school models; Mainstream, Special units, Special Schools etc. and includes Home Education, Studio Schools and Virtual Schools. To conclude, there is a format for evaluating all that has been seen, heard and learnt during the school visits together with a chart for documenting the findings and helping to make the final choice.

This book is a comprehensive survey and guide from an educational psychologist with a wealth of knowledge and experience to share. It will be invaluable to parents and carers and a most useful resource for educational professionals, schools and students.

Reviewed by:
Chris Fuller
PMLD Link Editorial board member

Title: Autism and Intensive Interaction Using Body Language to Reach Children on the Autistic Spectrum

Author: Phoebe Caldwell

Publisher: Jessica Kingsley Publishers

Pub date: 2010

Price: £19.99

ISBN: 978-1-84905-088-3



This DVD is the latest publication of Phoebe Caldwell. Phoebe has worked for over thirty five years with people with severe and profound learning disabilities and autistic spectrum conditions of all

ages. She believes passionately that as many people as possible, especially family members, should be aware of the simple ways in which they can interact with people considered difficult to reach. Intensive Interaction is one powerful way of doing this. The DVD focuses on her use of this approach in a school for children with autistic spectrum disorders and learning difficulties. Her previous DVD 'Creative Conversations' focussed on the use of Intensive interaction with people with multiple disabilities.

The pack itself is well produced and contains well filmed examples of Phoebe and staff at the school using Intensive Interaction with some of the children in classroom settings. Included in the pack is a simply written leaflet giving some background and providing a guide to the film. The DVD itself is broken into three parts, each with further sub sections, easily navigated on screen by the menu – very useful when using the DVD in training for example.

The first two sections cover issues related to sensory differences in people with autism and issues of age appropriate behaviour and the use of touch. Both have application to people with profound and multiple learning disabilities as well as autism. The third section is a completely unedited piece of film where a young child, Jamie, moves from an apparent disinterest in interacting with the adults present in the room into a delightful exchange with Phoebe using a range of non verbal interactions.

Although not specifically aimed at people with profound and multiple learning disabilities this DVD is a useful addition to a range of DVD material now available illustrating the use of Intensive Interaction. This DVD illustrates an approach that can be of real value to any person marginalised from important human contact due to their complex communication needs and will be of interest to anyone interested in the emotional and communicative well being of people with complex communication needs.

Reviewed by:

Sue Thurman
Communication Concerns
Speech and Language Therapist and freelance consultant and trainer

Title: Learning to Tell: A Handbook for Inclusive Story Telling

Author: Nicola Grove

Publisher: British Institute of Learning Disabilities

Date: 2009

Price: £30

ISBN: 978 1 905218 09 7



Storytelling is a very old art form. In the distant past when communication was mainly by word of mouth rather than through writing, stories were an important means of entertaining and informing. Nicola Grove tells stories but not just for these reasons. She has experience of 30 years in storytelling with children and adults with learning difficulties. She has used this experience to develop an approach to inclusive story telling which enables these persons to develop skills in narrative and story in group situations. Rather than being listeners of stories, she wants to make them the providers of stories. She aims to make stories fun and interesting and help them to use them as a vehicle for making friends, understanding the world and developing their imagination.

This book and accompanying DVD have been specifically designed to help people to develop inclusive story telling with adults who can enjoy and understand short stories, who have awareness of the needs of others and who are able to adjust their behaviour to accommodate their needs. They should be able to understand sentences at the three key word level and have expressive skills at a similar level through speech or signing or other augmentative communication systems. With modification the activities could be used with older children as well as adults but they are not suitable for people with PMLD. The materials can be used flexibly with groups of adults for a day per week over a year. The book contains all of the practical information required to set up a story telling course and a range of games, activities and suggestions for stories. The accompanying DVD brings the book alive by giving easy access to video footage of a group of adults with learning disabilities carrying out activities set out in the book. The DVD also has PDFs of a range of planning and recording forms.

Nicola Grove presumes that the lead workers will have experience of teaching children and adults who have special educational needs as well as an interest in stories and storytelling. The book itself does not contain much guidance about the practical

ways of modifying the suggested activities so it is good that the DVD shows individuals being supported to join in activities and participate in story telling. This is an interesting and well-constructed package of activities that is well worth exploring.

Reviewed by:

Rob Ashdown
Head Teacher
St. Luke's Primary School
Scunthorpe

Title: The Profound Education Curriculum

Publisher: The School for Profound Education, The Children's Trust.

Pub date: 2009

Price: £280

The School for Profound Education, formerly St. Margaret's School caters exclusively for 40-plus learners with PMLD aged between 5 and 19 years. The school's website (www.thechildrenstrust.org.uk) states that the Profound Education Curriculum is used with all pupils and is now in use in over 40 schools in the UK and overseas.

The Core Curriculum covers five areas of sensory-motor development:

- Sensory Cognitive
- Communication
- Social
- Motor
- Life Skills

The bulk of the Core Curriculum documentation is an elaboration of the P Scales 1(i) to 4 of the National Curriculum to identify small steps in achievement. Similar assessment tools have been devised by individual schools, consortia and businesses up and down the country ever since the P-Scales came out more than a decade ago. The St. Margaret's School assessment sheets have the virtue of being particularly well-presented and accompanying guidelines do stress that this is not a one-off 'sit down and tick the boxes' assessment tool. A holistic approach is intended, supported by cross referencing of statements of attainment between the curriculum areas. It will be helpful for teachers who are seeking a small steps assessment tool and have not the time to develop one or for teachers who are new to teaching pupils with PMLD. Many schools will be so well ahead in their own assessment development that they will not need it. The

publication does not really advance the cause of curriculum development for these learners since it is primarily a checklist of attainments. For each curriculum area there is a general description in a few pages of organising principles and a few examples of activities and planning and recording sheets for lessons but readers will not find practical guidance about what works in terms of delivering a balanced, meaningful, interesting and relevant curriculum in the classroom. The documentation does make plain the need for multi-agency review of targets and planning and a couple of cases studies are available on the school website that illustrate the approach to personalised learning.

The section on the Extended Curriculum gives an inkling of the range of activities at the school. It would be very interesting to see how these experiences are provided in the school and visits are encouraged. The Extended Curriculum includes religious education, creative arts, leisure activities, topic work (the example given is Ancient Civilisations) and there are some links to National Curriculum subjects.

The curriculum is available directly from The School for Profound Education (e-mail: curriculum@thechildrenstrust.org.uk; or tel: 01737 365810.) The curriculum is presented as a single hard copy in a ring binder with all of the assessment sheets on a CD-ROM. Users can make 50 hard copies or save digital copies from the CD-ROM onto PC to complete the assessment sheets electronically. If this is the kind of assessment tool you want, it does seem to offer good value for money.

Reviewed by:

Rob Ashdown
Head Teacher
St. Luke's Primary School
Scunthorpe

Website REVIEWS

QED online

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

This is a great web site bulging with resources and an online catalogue for you to order from. There are lots of gadgets, switches and aids of all descriptions here ranging from the reasonable and affordable to the expensive but niche market devices to keep people safe who may have impaired memory.

There is an array of communication aids on this website well worth a look.

This firm also advertises several road shows and exhibitions around the UK - its worth looking at to see if there is one happening in your neighbourhood. There are also several links included many of which seem very applicable to our clientele group too.

The site is easy to navigate and clearly laid out ,if a little garish on the home page.



Reviewed by:

Di Foxwell
Reviews Editor



<http://kcbn.org.uk/resources/>

This web site is bulging with links and useful resources. Do not be put off by the title – it includes much, much more than resources for challenging behaviour and a significant amount of information related to health issues too. There are also links to trade firms where specialist heavy duty fixtures and fittings are called for to meet the needs of people who have challenging behaviours.

The links on this site include many of the larger sites with further resources such as SCIE. There are also several reports available to open and read too.

This is an easily navigable site which is well laid out.

Reviewed by:

Di Foxwell
Reviews Editor

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

Have you sent your subscription for 2011 yet?

It is now time to renew your subscriptions for 2011. You will see that there has been a small increase to cover the rising costs but we have kept this as low as possible.

As usual there is a separate subscription form included with this issue. Please send in your renewals as soon as possible so that you continue to receive your PMLD LINK regularly.

Short Courses and Conferences

December

- | | |
|---|--|
| <p>Date: 7th Dec Birmingham / 14th Mar Chorley / 22nd Mar London
 Title: Play for People with Autistic Spectrum Disorder
 Provider: Concept Training
 Contact: See provider details</p> <p>Date: 8th
 Title: Free workshop: Communication and Challenging Behaviour
 Location: Watford
 Provider: Challenging Behaviour Foundation
 Contact: Tom Budworth Tel: 01438 844815
 Email: AHDC.training@hertscc.gov.uk</p> <p>Date: 8th Dec Birmingham / 29th Mar London
 Title: Sensory Play and Leisure in the Multi-sensory Environment
 Provider: Concept Training
 Contact: See provider details</p> <p>Date: 9th Hemel Hempstead / 14th Broxbourne
 Title: Free workshop: In and Out - play activities/ideas indoors and out
 Provider: Oyster
 Contact: Tom Budworth Tel: 01438 844815
 Email: AHDC.training@hertscc.gov.uk</p> <p>Date: 9th Dec London / 28th Jan Glasgow / 3rd Mar Middlesbrough / 15th Mar London / 23rd May London
 Title: Intensive Interaction: Connecting with People Who are Difficult to Reach
 Provider: Concept Training
 Contact: See provider details</p> <p>Date: 9th 10th
 Title: Supporting Children and Young People with Autistic Spectrum Disorders
 Location: Stafford
 Provider: Concept Training
 Contact: See provider details</p> | <p>Date: 9th 10th 11th
 Title: SLD Induction: Day 1 Language Literacy & Communication
 Day 2 Challenging Behaviour. Day 3 Curriculum Development
 Location: Clent, West Midlands
 Provider: Sunfield Professional Development Centre
 Contact: See provider details</p> <p>Date: 10th
 Title: Successful Multi-Sensory Sessions
 Location: Chorley
 Provider: Concept Training
 Contact: See provider details</p> <p>Date: 13th
 Title: Free workshop: Physical Care and Daily Living Activities
 Location: Hemel Hempstead
 Provider: Cool2Care
 Contact: Tom Budworth Tel: 01438 844815
 Email: AHDC.training@hertscc.gov.uk</p> <p>Date: 13th
 Title: Free workshop: Listening & Communicating & Understanding Challenging Behaviour
 Location: Hemel Hempstead
 Provider: Cool2Care
 Contact: Tom Budworth Tel: 01438 844815
 Email: AHDC.training@hertscc.gov.uk</p> <p>Date: 14th
 Title: Exploring the notion of "hard to reach" and improving engagement in services
 Location: Essex
 Provider: Strategic Consult & Co Ltd.
 Contact: Tel: 07762798008 Email: charlotte@strategicconsult.co.uk</p> |
|---|--|

Providers Details

BILD

British Institute of Learning Disabilities
 Champion 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: 14th
 Title: Free workshop: Disability Awareness and the Experience of Families and Disabled Children
 Location: Hatfield
 Provider: Cool2Care
 Contact: Tom Budworth Tel: 01438 844815
 Email: AHDC.training@hertscc.gov.uk

Date: 16th
 Title: Free workshop: Communicating with a range of children
 Location: Stevenage
 Provider: Oyster
 Contact: Tom Budworth Tel: 01438 844815
 Email: AHDC.training@hertscc.gov.uk

Date: 16th and 17th
 Title: Person Centred Planning
 Location: Nottingham
 Provider: Inclusive Solutions
 Contact: Tel: 0115 9567305
 Email: inclusive.solutions@me.com

Date: 10th Dec Manchester / 28th Jan Manchester
 Title: Working Effectively with Children and Young People who Experience Behavioural, Emotional and Social Difficulties (BESD)
 Location: Manchester
 Provider: Concept Training
 Contact: See provider details

January

Date: 14th
 Title: Free workshop: Let's All Communicate
 Location: Ware
 Provider: KIDS
 Contact: Tom Budworth Tel: 01438 844815
 Email: AHDC.training@hertscc.gov.uk

Date: 21st Jan London / 4th Mar Nottingham / 25th Mar Birmingham / 13th May Manchester
 Title: 100 Ideas for Your Sensory Room
 Provider: Florich Productions
 Contact: See provider details

Date: 25th Jan Middlesbrough / 28th Mar London / 29th Mar Taunton / 24th May London / 25th May Leicester
 Title: Practical and Effective Ways of Using Multi Sensory Equipment
 Provider: Concept Training
 Contact: See provider details

Date: 25th
 Title: Tactile Art: teaching art to children who are blind or partially sighted – a practical course
 Location: Liverpool
 Provider: Action for Blind People North West
 Contact: Sarah Crabb. Tel: 0151 298 3224
 Email: Sarah.crabb@actionforblindpeople.org.uk

Date: 26th
 Title: Pre-Requisites to Learning
 Location: Birmingham
 Provider: Florich Productions
 Contact: See provider details

Date: 27th Jan. Chorley / 4th Mar Birmingham
 Title: Creating Communication Rich Environments
 Provider: Concept Training
 Contact: See provider details

Date: 27th Jan Leicester / 7th Feb Manchester / 9th Feb Birmingham
 Title: Successful Target Setting
 Provider: Florich Productions
 Contact: See provider details

Providers Details

EQUALS

PO Box 107, North Sheilds,
 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: 28th Jan Nottingham / 11th Feb Bristol / 5th April London
 Title: The Sensory Curriculum – A Practical Approach to Curriculum Planning
 Provider: Florich Productions
 Contact: See provider details

Date: 28th
 Title: The Sensory Curriculum
 Location: Nottingham
 Provider: Florich Productions
 Contact: See provider details

Date: 31st
 Title: Children and Grief: Supporting the Bereaved Child
 Location: Bury St Edmunds
 Provider: St Nicholas Hospice Care
 Contact: Rachel Brown.
 Email: Rachel.brown@stnh.org.uk

February

Date: 1st
 Title: Free workshop: Communicating Effectively with Children & Young People (including introduction to non-verbal communication)
 Location: Hemel Hempstead
 Provider: Play Doctors
 Contact: Tom Budworth Tel: 01438 844815
 Email: AHDC.training@hertscc.gov.uk

Date: 8th Liverpool / 4th Apr London / 7th Apr Birmingham
 Title: Waking the Senses
 Location: Liverpool
 Provider: Florich Productions
 Contact: See provider details

Date: 11th
 Title: Creativity for All
 Location: London
 Provider: EQUALS
 Contact: Email: admin@equalsoffice.co.uk

Date: 15th
 Title: Free workshop: How to Provide Sensory Play at Little or No Cost (including calming methods)

Location: Watford
 Provider: Play Doctors
 Contact: Tom Budworth [Tel: 01438 844815](tel:01438844815)
 Email: AHDC.training@hertscc.gov.uk

Date: 16th
 Title: Music gets us going
 Location: Liverpool
 Provider: Action for Blind People North West
 Contact: Sarah Crabb. Tel: 0151 298 3224
 Email: Sarah.crabb@actionforblindpeople.org.uk

March

Date: 1st and 2nd
 Title: National Autistic Society's Professional Conference: Delivering Excellence in a Time of Austerity
 Location: Manchester
 Website: www.autism.org.uk/conferences/professional2011

Date: 4th Mar Southampton / 9th Mar Glasgow / 12th May London
 Title: Whole Person Communication
 Provider: Concept Training
 Contact: See provider details

Date: 8th
 Title: Assessment and Pupil Progress in the SLD/PMLD School
 Location: Manchester
 Provider: EQUALS
 Contact: Email: admin@equalsoffice.co.uk

Date: 10th Mar Glasgow / 23rd May London
 Title: The Autistic Spectrum – when things are not straightforward
 Provider: Concept Training
 Contact: See provider details

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

Date: 11th Mar London / 13th May Nottingham
 Title: Introducing Sensory Integration into Classroom or Care settings
 Provider: Florich Productions
 Contact: See provider details

Date: 11th Mar Bristol / 6th May Glasgow
 Title: Very Special Maths
 Provider: Florich Productions
 Contact: See provider details

Date: 16th
 Title: Success with People with Autistic Spectrum Disorder
 Location: London
 Provider: Concept Training
 Contact: See provider details

Date: 17th
 Title: Understanding Attachment Disorders
 Location: London
 Provider: Concept Training
 Contact: See provider details

Date: 17th Mar Birmingham / 18th Mar London / 4th Apr Glasgow
 Title: Positive Ways of Changing Behaviour
 Provider: Concept Training

Contact: See provider details
 Date: 18th Mar Nottingham / 20th May Liverpool
 Title: Multisensory Approaches to Music
 Provider: Florich Productions
 Contact: See provider details

Date: 23rd
 Title: Towards 21st Century working practices in Early Childhood Intervention
 Location: Bristol
 Provider: Peter Limbrick
 Contact: Tel: (0044) 01497 831550 Email: p.limbrick@virgin.net

Date: 24th
 Title: Working with Music and Autistic Spectrum Disorder
 Location: London
 Provider: Concept Training
 Contact: See provider details

Date: 24th
 Title: Communication Passports
 Location: Middlesbrough
 Provider: Concept Training
 Contact: See provider details

Date: 31st
 Title: Physical Education – an Introduction to Sherborne Developmental Movement – Certificate Level 1
 Location: Newcastle upon Tyne
 Provider: EQUALS
 Contact: Email: admin@equalsoffice.co.uk

April

Date: 7th
 Title: Big Macs and Beyond
 Location: Chorley
 Provider: Concept Training
 Contact: See provider details

May

Date: 12th
 Title: Inclusive Play
 Location: London
 Provider: Concept Training
 Contact: See provider details

Date: 11th
 Title: Moving and Handling
 Location: Hadrian School, Newcastle-Upon-Tyne
 Provider: Workshops at Hadrian School
 Email: david.palmer@hadrian.newcastle.sch.uk

LONGER COURSES (with accreditation)

Updated July 2009

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

Undergraduate and Postgraduate Courses in Profound and Complex Learning Disability

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

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

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

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

Information about the course can also be found on the website: www.manchester.ac.uk/education/pclid

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

Website: www.manchester.ac.uk/education/pclid

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 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.
Chris Fuller	Teacher in mainstream and special school with children with PMLD. Founder and director of Bag Books until her very recent retirement.
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.
Wendy Newby	Ten years experience working as a qualified nurse with children with learning difficulties and severe physical disabilities, now teacher and curriculum co-ordinator at St. Rose's School, Stroud and studying for a Masters in learning difficulties and disabilities.
Carol Ouvry	Retired special education teacher, trainer and consultant in the field of PMLD. Previously editor and administrator of <i>PMLD-Link</i> .

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	£18	£25
Organisation	£25	£35

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

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

Carol Ouvry, *PMLD-Link*, 31 Birdwell Road, Long Ashton, Bristol BS41 9BD. Telephone: 01275 394621 e-mail: carol.ouvry@talktalk.net

Publisher: The University of Northampton

Disclaimer: Views expressed by contributors to *PMLD Link* are their own and do not necessarily reflect the policies and opinions of the editorial team
many other settings. In recent years the scope of the articles has been widened to include all professions and services, and to

PMLD LINK

Supporting people with profound and multiple learning disabilities

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