

PMMLD LINK

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

Winter 2009

Health Care

PMMLD Link

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

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GUEST EDITORIAL

Winter 2009

Health Care

Welcome to this Winter edition of PMLD Link revisiting the crucial topic of health. It's not long since we explored this area before (Winter 2007) but again, we have an issue bursting with articles to inform and challenge you.

Our contributions offer a real balance in their perspective; there are too many to describe in any detail here! They explore and challenge service provision and policy, they tell us about resources, events and opportunities which may help to increase our understanding of health and well-being issues and then we have some very practical suggestions for improving our day to day caring or practice when supporting people with PMLD.

All of the articles are advocating the need to become more responsive in meeting the complex health care needs of individuals with PMLD. To be proactive in preventative healthcare at every level rather than risk compromising health and well-being. Carnaby's powerful introduction to this issue explains this simply - better services, better outcomes.

Without a doubt, we all know that enhanced quality of health and well-being leads to improved quality of life. We still have a way to go – but maybe this issue will enable us to move on in some way – at least to the next step on that road.

This year we will be bringing news of our new website. Among other things, this will give you an opportunity to read some of the back issues- so you may want to see the Health Matters issue from 2007. We'll keep you posted!

Wishing you all a happy *and healthy* new decade!

Ann Fergusson & Lorretto Lambe

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Good healthcare for people with profound and multiple learning disabilities: complex means to meeting complex needs

Steve Carnaby
Consultant Lead Clinical Psychologist

According to the Disability Rights Commission (2006), people with learning disabilities are 2.5 times more likely to have health problems than other people, with four times as many people with learning disabilities dying of preventable causes as people in the general population. This is clearly of concern when considering the evidence that people with PMLD are very likely to experience a wide range of complex health issues, often associated with particular conditions. This paper explores some of the thinking that informs how services meet health needs and makes suggestions for how a more creative – i.e. person-centered and collaborative – way of working might lead to more effective outcomes for individuals and their families.

People with PMLD: a growing population

The development of better supports combined with advances in medical care means that the number of people with profound learning disabilities and fragile health is increasing in the developed world (Nakken & Vlaskamp, 2007). This increase brings with it the concept of 'older' people with PMLD; while there is increasing acknowledgement of the ageing nature of the wider learning disability population, there also needs to be recognition that people with PMLD are also reaching adulthood and beyond, with individuals now needing ever-increasing levels of complex technology to ensure that they not only survive, but do so enjoying an acceptable quality of life.

Multiple disabilities, additional needs

It is always important to see the person and their personhood first, and the disability rights movement's success can be seen largely in terms of the extent to which this notion has become central to government policy through documents such as *Valuing People Now* (2009). However, for people with PMLD, there can be a risk that without being transparent about the nature and extent of an individual's needs, those needs will at best be partially met. *Valuing People Now* (2009) and *Death by Indifference* (Mencap, 2007) spell out all too clearly the ways in which the health care system can fail people with learning disabilities, particularly those with the most complex needs.

There is clear evidence that people with PMLD are more likely to experience a range of significant issues. Disabilities associated with particular syndromes can lead to related vulnerabilities - for

example issues with the digestive system are linked with Cornelia de Lange Syndrome and diseases of the nervous system are often seen in Angelman Syndrome. Sometimes the course and prognosis of these health conditions means that early detection and regular monitoring are needed. Even when this is in place, some individuals are still likely to require significant intervention (Berg *et al*, 2007).

Studies in the Netherlands have reported that at least 85% of people with PMLD have some form of visual impairment, in most cases caused by damage to the visual cortex in the occipital lobe (e.g. Van Splunder *et al*, 2003), and between 25% and 35% experience hearing loss (e.g. Evenhuis *et al*, 2001). Dysfunctions of taste and smell can be common (Bromley, 2000), along with impaired sense of touch, pressure, temperature and pain (e.g. Oberlander *et al*, 1999). Seizure disorders are reported to be 50% higher than that mentioned in the literature (e.g. Arts, 1999) and people with PMLD generally have a higher risk of developing medical complications (e.g. Zijlstra & Vlaskamp, 2005).

The 'invisibility' of people with PMLD

People with PMLD are largely invisible on many levels, be that in the literature describing best practice in supporting people with learning disabilities, within services themselves or in terms of citizenship and taking a rightful place in society. Invisibility might be seen as a concrete symbol of discrimination. The idea that a group of people is so unimportant that their very existence is more or less unknown to the general population is a powerful one. This phenomenon has been observed by

The material in this paper was developed in close collaboration with Jill Pawlyn, Lecturer Practitioner, School of Health & Social Care, Oxford Brookes University and is adapted from Pawlyn, J. & Carnaby, S. (eds.) (2008). *Profound intellectual and multiple disabilities: nursing complex needs*. WileyBlackwell.

others (e.g. Samuel & Pritchard, 2001; Mencap, 2007) and is certainly borne out by my own clinical experience over the years. However, wider society perhaps takes its cues on how to understand, think about and respond to people with PMLD from those responsible for their care and support or otherwise representing them in some way. The messages conveyed by services and professionals working within them are therefore crucial if there is to be any attempt at addressing discrimination.

One way of thinking about the tendency for people with PMLD to be invisible within services and the literature describing and evaluating them concerns the principles upon which service supports are built. The development of community-based service models aiming to promote social inclusion necessarily involves the implementation of normalisation and ordinary living principles, which by definition focus on independence, skill acquisition and age-appropriateness (see Szivos, 1992; Carnaby, 1998). For many people with intellectual disabilities, the increasing emphasis on social integration and citizenship has led to a wider range of opportunities and access to an enhanced quality of life that aims to be directly comparable to that assumed and enjoyed by the general population. The 'ordinariness' of everyday life is emphasised, aiming to avoid stigmatisation of those with disabilities – in practice by avoiding where possible any references to 'special' or 'different' treatment.

However, people with PMLD are more likely to lead what has been described as 'extraordinary' lifestyles (Smith, 1994), requiring particular consideration. In the context of healthcare, thinking about people with PMLD in a 'different' way to the general population does not have to be stigmatising, but can come down to - in some cases - a matter of preserving life.

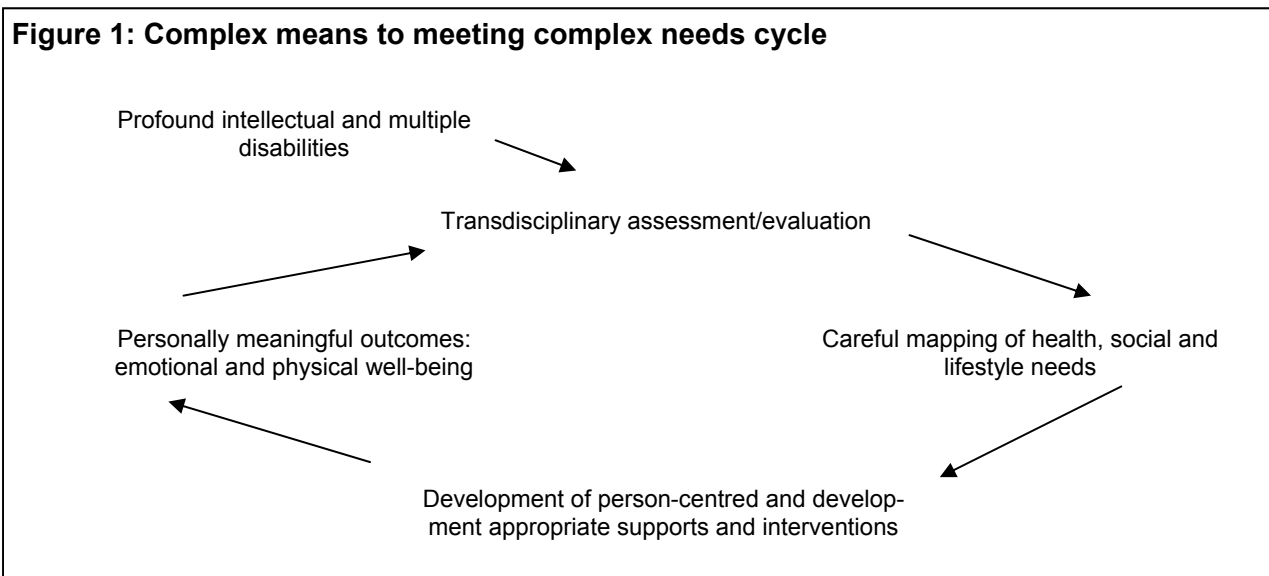
'Good' physical and mental health: Complex needs, met by complex means

The relationship between physical health and mental

health has been well rehearsed in the literature, and it is important that this understanding is equally applied to people with PMLD. Emotional well-being and a positive emphasis on achievement and attainment are just as important as thorough assessment of dysphagia, respiration and postural management. Artificial positioning of the social model as being diametrically opposed to the medical model is thankfully outdated when applied to the lives of people with mild or moderate intellectual disabilities; however, it can be the case that when support for people with PMLD is being considered the integration of health and social care becomes more difficult. Local implementation can lead to intervention being primarily about providing clinical input to address identified health concerns to the detriment of considerations about rights and quality of life, or such medical issues are hidden beneath the drive towards ensuring that the individual concerned is living an 'ordinary' lifestyle, compromising risk management and appropriate healthcare provision.

Jill Pawlyn and I have attempted to provide a framework for addressing this issue of integrating health and social care models by advocating for a more sophisticated approach to meeting needs. 'Complexity' in this context relates to interconnected or interwoven ideas, the principle that 'complex' is not just about 'difficulty' but more about relating concepts and phenomena to each other in ways that provide meaning.

In order for this to be achieved and translated into person-centred action, there may need to be certain adjustments to the ways in which support services are delivered to people with profound and multiple learning disabilities, something of a journey towards a more systemic way of working. Figure 1 attempts to represent this idea of a 'complex means to meeting complex needs' cycle.



Finally, here are some of our practical suggestions for helping to make increase good practice in meeting the health needs of people with profound and multiple learning disabilities:

1. Professionals will need to work alongside families and informal carers in a truly collaborative – rather than tokenistic - relationship, which is likely to require good facilitation in order to address any disagreements and differences in opinion. Steering groups that enable joint discussion and sharing of ideas and experiences can help to foster this collaboration.
2. Clinical staff will need to reconsider their criteria for referral towards a more proactive, preventative model rather than only be involved once issues have been brought to their attention.
3. When measuring outcomes, more flexibility will be needed to design individualised tools and ways of measurement that attempt to capture the unique nature of what is likely to be in place.
4. Setting up and maintaining databases can help to monitor people with PMLD in a named area and track interventions and assessments, flagging up pathways for continuing care.
5. Commissioners may need to review decision-making processes regarding priority of need and the competences required by tendering providers.
6. Training officers will need to develop programmes that are able to cover the wide range of issues and concerns raised by working proactively with people across professional boundaries using a developmental approach.

Conclusion

Some might say that this re-emphasis on health needs could be said to be a return to the medical model, a 'medicalisation' of people that risks an overshadowing of individuality and personhood. This is not the case at all. The progress made in society's drive towards introducing social inclusion *for all* is not being pushed to one side, but instead needs to be carefully combined with an honest and detailed acknowledgment that people with profound and multiple learning disabilities will, almost by definition, require proactive and ongoing healthcare that works preventively as well as addressing issues as they emerge. Being a citizen is surely about being well and comfortable in order to really enjoy one's rightful place in the community.

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Running head: Invasive procedures and people with PIMD

PAMIS Investigates Invasive Procedures in Scotland

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The health needs of people with profound intellectual and multiple disabilities are complex and a majority may require at some time, some form of invasive medical procedure to ensure their well-being. Barriers to the administration of such procedures are prevalent, while issues concerning consent and capacity present further difficulties to the paid carer. The voluntary organisation *PAMIS* is engaged in a national research project supported by the Scottish Government to determine what leads to problems of delivery of invasive procedures in Scotland. Preliminary findings from professional and carer workshops are presented and the objectives of a national postal survey described. A process of dissemination and consultation will then be initiated with a view to ensuring greater consistency of policy and practice throughout Scotland leading to greater equity and effectiveness of practice. Such measures will enhance the well-being of people with PMLD and increase the confidence and peace of mind of both family carers and paid carers.

Introduction

People with profound intellectual and multiple disabilities (PIMD) present with a range of complex and significant health care needs. As a consequence many require a diverse range of invasive health care procedures in order to maintain their health and well being. Among such invasive procedures are for example:

1. The administration of rectal anticonvulsants for the management of epilepsy
2. The management of baclofen implants for spasticity
3. Ventilators and tracheal suction for the management of respiratory disorders
4. The management of non oral feeding
5. The management of tracheotomies.

Despite the evidence of the range of health needs and clear government policy frameworks directed at enabling all people to live inclusive and independent lives in the community (Department of Health, 2009; Scottish Executive, 2000), significant variation and challenges exist in enabling this to be a reality for people with PIMD. This lack of clarity leads to particular challenges in relation to the delivery of invasive procedures in non-healthcare settings. This is supported by MENCAP'S *Death by Indifference* enquiry report (Mencap 2007) and a number of other

reports from across the UK, notably: *Healthcare for All* (Department of Health 2008), *Equally Well* (Scottish Government 2008), the *Same as You?* (Scottish Executive 2000), *Valuing People Now* (Department of Health 2009) and, the recommendations of a number of Fatal Accident Inquiries in Scotland, notably Mauchland (Dunbar 2003) and Donnet (Davidson 2007). Disparities in practice in this area need to be addressed and standardised implementation of policies and procedures need to be in put place to ensure that the needs of people with PIMD are met effectively in the future.

There are also significant ethical issues that need to be considered in the context of the capacity of people with PIMD to consent to treatment. Such ethical issues need to be viewed within the context of the Scottish legal system with attention paid to the Welfare Guardianship orders under the *Adults with Incapacity (Scotland) Act 2000*. These orders allow appointed guardians to act on behalf of people lacking capacity. When functioning correctly the Welfare Guardianship order ensures that the issue of consent is addressed and allows treatments and interventions to be undertaken appropriately. Although a framework addressing the issue exists in Scotland, there appear to be different approaches, across the country, in relation to the implementation of invasive procedures.

The Invasive Procedures Research project

In response to these imperatives *PAMIS* has been funded by the Scottish Government to carry out research on the issue of invasive procedures in Scotland. A project group has been established to support the *PAMIS* research team in undertaking the research, and this is supported by a national expert reference group made up of practitioners, research workers and family carers.

The work is being undertaken in two related phases, first a consultative conference establishing the views of a wide range of stakeholders, and second, a national postal survey of views and practice.

Invasive Procedures: Breaking barriers and achieving control for people with profound & complex disabilities

This conference was held in Dundee June 2009. Delegates from a wide range of social, education and health care backgrounds, as well as family carers, attended. Experts provided evidence on a range of issues and a series of workshops identifying the views of practitioners and carers was held. Possible solutions for the future were considered.

A wide range of issues was identified by the delegates (Hogg et al., 2009). Models of good practice as well as barriers to the effective delivery of invasive procedures were identified, including:

1. lack of training of staff required to implement the procedures
2. poor communication across professional groups and agencies
3. legal and liability issues in relation to non-health care practitioners undertaking invasive procedures
4. absence of clear operating procedures through failures of senior management to take a decisive leadership role.

Recommendations included:

1. the need to undertake an audit of training and resource requirements
2. identification of the transferability of skills to optimise effective delivery
3. development of joint collaborative training programmes across health, social care, the independent sector and with family carers
4. identification of the training needs of family and paid carers to deliver invasive procedures.

It was also recognised that there is a need to commission a review of the legal position regarding the delivery of invasive procedures and to clarify the role of Welfare Guardians when consenting to

invasive procedures for those without capacity. Poor communication was a theme that was identified throughout the workshops particularly across agencies at the time of transition between services. The workshops highlighted the need for continuity of care across the life span and for health services to ensure that there are protocols in place to support this. It was agreed that *PAMIS* has a key role in the effective dissemination of best practice.

The findings from the conference and the research will inform best practice and continuity of care in the future.

The national postal survey of views and practice in relation to delivering invasive procedures

The Invasive Procedures Survey is being undertaken by *PAMIS* and the White Top Research Unit, University of Dundee. The questionnaire has been distributed throughout Scotland to family carers and professionals and data are at present being analysed. These survey findings will be integrated with those arising from the conference.

Conclusion

Completion of the national survey will complement and elaborate the recommendations made at the conference leading to recommendations the Scottish Government. A process of dissemination and consultation will then be initiated with a view to ensuring greater consistency of policy and practice throughout Scotland leading to greater equity and effectiveness of practice. Such measures will enhance the well-being of people with PMLD and increase the confidence and peace of mind of both family carers and paid carers.

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Some useful References & Resources provided as part of the Workshop Participants' Pack:

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RNIB produces a range of Factsheets and Information. Leaflets on all aspects of visual impairment. www.rnib.org.uk and a journal called - **Insight: supporting blind and partially sighted young people** which contains lots of useful articles. *PAMIS* subscribes to this journal and copies are available in the library.

Mary Codling discusses epilepsy and its management in people with profound and complex disabilities

Mary Codling
Primary healthcare liaison nurse

In this article I will be discussing the impact of epilepsy on people with learning disabilities particularly those with profound and complex disabilities. I will not however detail the classification of epilepsy as there is sufficient literature surrounding the classification of seizures. Instead I will share how my colleagues and I sought to explore need pertaining to epilepsy so we could provide evidence to influence and improve services for people with learning disabilities in Berkshire.

Epilepsy is the commonest serious neurological condition-affecting people of all ages. However, the frequency of epilepsy occurring in people with learning disabilities is higher than in the population generally and increases with severity of disability. For example, the occurrence in those with mild to moderate learning disability is around 30% whereas in people with severe learning disabilities at least 50% will have additional epilepsy and in those it will be even with PMLD greater.

Epilepsy itself is not a single disorder but is often the result of an underlying condition. For example in people with learning disabilities there is underlying brain damage occurring at birth or in the first five years of life. Some causes of learning disability are genetic such as Fragile X, Downs Syndrome, Tuberous Sclerosis, Angelman Syndrome and Retts Syndrome. These are just a few of a number of genetic disorders where ultimately most will present with epilepsy.

There are particular challenges in providing support and information to people with profound and complex disabilities and often there are times when they cannot make their own decisions. Therefore the care often falls to carers. It is becoming increasingly clear that carers play a pivotal role in the lives of people with learning disabilities who have epilepsy. People with profound and complex learning disabilities normally depend on others to negotiate the experiences that most people take for granted (Kerr & Rogan 2006). Therefore the management of epilepsy for people with learning disabilities invariably falls to a third party, notably their carers. Carer is a term that encompasses not only family but also relatives or paid carers.

When people with profound and multiple learning disabilities and complex needs experience seizures it is their carers who are their most frequent observers. Consequently carers present with a range of concerns about epilepsy that extend beyond the number of seizure events (Espie et al 1998). The knowledge and skills of carers have an impact on the individual been cared for, thus their perception of need may influence their contact with appropriate services.

Within Berkshire little was known about the range of services specifically for epilepsy that were accessed by people with learning disabilities and their carers. Clinical evidence from practice demonstrated that no clear process or structure existed for mapping the care of individuals with learning disabilities and epilepsy. Although the assessment of epilepsy in people with learning disabilities does not differ from people with epilepsy generally, evidence from research suggests that people with learning disabilities have a lower than average satisfaction with services for epilepsy (Bradley 1998). Further evidence from Paxton & Taylor (1998) from findings of their study in primary care suggests there was little evidence of monitoring or reviewing of epilepsy for people with learning disability. One of the main difficulties identified by Jenkins and Brown (1992) is the overall assessment of epilepsy and issues relating to diagnosis amongst people with learning disabilities. This is further compounded by communication difficulties and lack of skills of medical professionals in communicating in particular with people with profound and complex disabilities. These findings are consistent with that of other researchers such as Branford et al (1998), Espie et al (1999) and Kerr & Todd (1996).

The evidence from both research and practice highlighted the need to develop a framework that could address existing barriers around access to services and hence improve the standards of care for this group of people. In view of the presenting evidence we decided to conduct a survey to find out how many people with learning disabilities have epilepsy and the services they accessed. In obtaining the information required we used the same questionnaire as that used in the Branford et al 1998 study. Permission was sought and obtained from the authors to use the questionnaire. The questionnaire sought information on the following key areas:

- Does the person have epilepsy
- The nature of epilepsy
- The treatment of epilepsy / frequency of injuries
- Current access to services for epilepsy

The questionnaire was distributed to 600 people with learning disabilities attending day centres, living in residential homes, attending further education establishments, respite care centres, assessment and treatment units and supported and independent living style accommodation. Details of the survey was also advertised in local newspapers, charity newsletters such as Mencap and the Autistic Society to enable others to participate who may use different services than those described. We also provided opportunities for people with complex disabilities who were unable to read or write to engage in a one-to-one meeting where a member of staff or their carer could also be present in helping them to communicate their responses. However, a number of people with complex disabilities were unable to answer the questions despite using a range of user friendly resources as well as communicating via carers and staff. Therefore much of the information obtained from the survey came from carers.

For example of the 600 questionnaires sent, 487 were returned for which 67% were completed by carers, 24% by relatives and 8% by others. Of the 487 returned questionnaires, 28% confirmed they had active epilepsy. In the case of a further 2.5% the respondent was not sure whether the person had epilepsy, e.g. when the person had perhaps had one or two seizures or had been diagnosed with epilepsy in childhood but not had a seizure for many years. Respondents provided information about the age of onset of seizures for which the findings showed that the majority of participants were diagnosed with epilepsy in childhood, which has continued into their adulthood.

Access to services as shown in the findings from the survey did not reflect any pattern of particular services that people may access for treatment of epilepsy. The lack of cohesion in patterns of care is in itself worrying, reflecting perhaps a lack of knowledge of parents / carers or the lack of clarity from services on the most appropriate service in meeting the needs of people with epilepsy. The aim of this survey was to explore the needs of people with learning disabilities and epilepsy for which the findings reflect that people with learning disabilities and epilepsy were not accessing appropriate services. For people with profound and complex disabilities this was left to parents and carers for whom the findings reflect that they too, do not, or may not know where to seek help.

Utilising the findings from the survey

The outcome of the survey showed that once people with profound and complex disabilities were diagnosed with epilepsy there was no clear process for accessing services and receiving treatment. In view of this we decided to set up a working group to formulate a pathway that would signpost people with learning disabilities, their carers and staff to services

for epilepsy. Collectively, a team of multi-professionals who currently provide care for people with epilepsy were selected for the purpose of planning the Care Pathway for Epilepsy. Included in the group were representation from psychology, learning disability nurses, speech & language therapy, learning disability psychiatry and dietitian. The aim of the group was to discuss current care provided and explore areas for improvements. The objective was to agree a pattern as to when care should be provided and by whom, and to develop an integrated pathway focusing on best practice. Patterns of care may be evident amongst professionals themselves but it can cause immense confusion to users and carers of services. By mapping a process of care it would enable users and carers to have a clear focus of the care expected. The group devised a Care Pathway for people with learning disabilities and epilepsy that consisted of six stages. Each stage is outlined as follows:

STAGE 1: Referral made to the Community Team for People with Learning Disabilities (CTPLD) by user, carer, GP; other professional. Referral would be discussed amongst a group of professions resulting in a multiprofessional decision being agreed. If there were an indication that the needs are related to epilepsy then the referral would be passed to the next stage of the pathway.

STAGE 2: Referral is discussed and allocated to the Learning disability nurse. The rationale for this is that the nurse has the skills and knowledge of epilepsy from a medical aspect and can further assess the need for input from other professionals.

STAGE 3: Learning disability nurse to undertake initial assessment. At this stage 'The Epilepsy Outcome Scale' (Espie et al 1998) would be completed if the initial assessment indicates movement onto the next stage. The Epilepsy Outcome Scale is a health measurement scale developed specifically for use with adults with epilepsy and learning disabilities and their carers. It reflects concerns about seizures, their impact and their treatment. The scale can be completed in 5 – 10 minutes and can give an account of concerns held by the person with learning disabilities and their carer in the management of epilepsy. Once completed it would be kept with the individual's records for comparison with the same measure that would be conducted again on completion of the Pathway to measure intervention. This would be used for the purpose of evaluating whether intervention altered areas of concern documented at the start of the pathway.

STAGE 4: The Epilepsy Assessment (formulated by the Pathway group) would be completed. This assessment serves as the baseline in identifying current need and interventions required such as

referral to other professionals. Previously assessments were developed as separate components rather than seeing the inter-relationship between different dimensions. It was agreed collectively that the learning disability nurse would complete the assessment due to the medical nature of the condition. Also having a designated professional for particular stages of the pathway enables acceleration of the referral. Referrals to other professionals are co-ordinated at this stage and arrangements are made between the individual with epilepsy and the professional. Monitoring & reviewing and producing care plans are also part of this stage.

STAGE 5: Recommendations arising from the assessment that may require further action are documented and forwarded to the GP who can act as the gatekeeper for referral to appropriate services.

STAGE 6: The pathway is complete and may require no further input apart from a review date. In some instances the pathway may be completed but there may be a need to review and monitor interventions for a set period of time. The Epilepsy Outcome Scale (Espie et al 1998) would be completed again at this stage.

Summary

In summarising, the process of care developed in Berkshire for people with learning disabilities and epilepsy has greatly improved. This was achieved by conducting and utilising the outcome of the survey to involve professionals, users and carers in the development of a plan of care that in turn has guided access to appropriate services. The use of the care pathway has combined the process and practice for delivering care that can be audited with changes incorporated where necessary. Having a clear pathway equally sets standards for the delivery of care and promotes partnership working with primary care services through the facilitation of a standardised process that identifies the needs of people with learning disabilities and epilepsy in a structured and co-ordinated manner.

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PAMIS Healthy Lifestyles Project

John Shields
PAMIS parent member, Tayside

My Experience

The Healthy Lifestyles Project run by *PAMIS* and was a series of health and leisure related topics. The work brought together good practice and research on improving the health of people with profound and multiple learning disabilities (PMLD) and their carers in order to enhance the quality of health in this disadvantaged group. The project was funded by a grant from the Big Lottery Fund, with complementary funding from six statutory agencies across Scotland. The project was delivered to families with input from health, local authorities and *PAMIS*. A team of Project Development Workers were appointed to set up and deliver the programme of work in the six areas of Scotland where the project operates.

I am a father of a young man with a genetic condition and profound learning disabilities and I attended several of the workshops held by *PAMIS* as part of this project and I would like to share my experience of the practical outcome that I achieved for my son after attending one of the workshop titled, *Vision: Seeing, Knowing and Understanding*.

Vision: Seeing, Knowing and Understanding

In March 2009 I attended this *PAMIS* Workshop where the principal tutor was Professor Gordon Dutton.

Gordon Dutton is Visiting Professor of Optometry and Vision Science at Glasgow Caledonian University and Honorary Professor at Glasgow University. He initially trained in Bristol and then came to Glasgow to carry out a research project on toxoplasmosis*, which is the subject of his MD. He was a consultant senior lecturer with the University of Glasgow for nine years and has been working as a consultant paediatric ophthalmologist at Yorkhill Children's Hospital for the last 17 years years. He has developed a particular interest in the visual problems of children due to brain damage and is currently carrying out a number of research projects in this field.

**Toxoplasmosis is a disease of animals and humans, transmitted by exposure to the faeces of cats. If symptoms occur, they can in their most extreme form result in extensive damage to, for instance, the brain and the eyes.*

Professor Dutton has led a number of workshops on the topic of vision for *PAMIS* for the Healthy Lifestyles and also for other *PAMIS* initiatives.

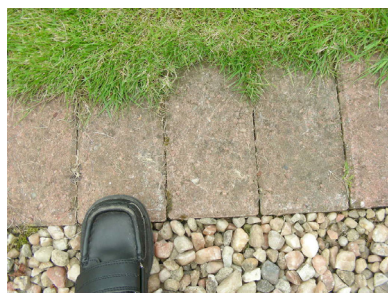
The aims of this particular workshop were to:

- develop an understanding of the nature of vision.
- appreciate the close links between vision and communication.
- understand what can go wrong when the visual process is disturbed by damage to the brain.
- understand the meaning of medical terminology used to describe visual difficulties.
- be aware of the legal requirements for the registration of blindness and partial sight.
- understand the role of professionals specialising in visual difficulties and of voluntary agencies.
- know about different visual assessments.
- develop skills in assessing and recording our daughter's or son's visual behaviour.
- draw up an individual action plan, to help the person they care for overcome visual difficulties and make the most of the vision they do have, in order to appreciate and enjoy the world.
- find ways of adapting or highlighting aspects of the home, school or centre environment to make it more 'visible'.

I attended this workshop along with my son John, who I knew had a co-ordination problem but I was not convinced that this was related to a visual impairment. However, during this workshop when Professor Dutton was talking about lower visual field impairment and impaired visual guidance of movement of the feet leading to problems with steps,

I realised that this was relevant to my son. Practical advice from Professor Dutton such as; when walking, holding hands with someone with lower visual field impairment, holding one's arm slightly backwards, gives advance notice of changes in the height of the ground ahead, and keeping the arm straight, gives the guidance to the height itself. Professor Dutton explained that the view someone with lower field impairment has going downwards gives less information, than the view going upwards, where the side of pavement or step is also visible, which can lead to stepping off the edge of a pavement.

John in his garden – note some of the visual obstacles he has to deal with



area. My son John will travel to RNIB in Kirckaldy for his assessment and this will be paid for with money from his care package. The assessment will be based on John's needs and will be person centered with staff doing the assessment getting to know John. Once the initial assessment has been completed support will be provided by RNIB Pathways for John to have a fuller clinical assessment carried out aided by the information contained in the initial assessment, which can take as long as twenty weeks. Once the process is complete a plain language report will be produced, containing all the information relevant to John's vision requirements. This will help both us as a family and staff supporting John to better understand his visual needs and make life easier for us all.

Thanks to the *PAMIS* workshop I now have a better understanding of my son's vision and I am able to access RNIB Pathways services to carry out his assessment. I also have an invaluable training resource in the form of a detailed training pack containing the information discussed at the workshop, which both myself and support staff working with my son can access and refer to for information.

I fully appreciate the value of the information I received from this workshop and am indebted to both Professor Dutton and *PAMIS* for the opportunity to have access to a workshop that provided material that enabled me to better understand my son's visual problem and that empowered me to take steps to make a referral to the RNIB Pathways service for my son to have a Functional Vision Assessment carried out.

As I mentioned this was just one of a series of training workshops on health related topics as part of the *PAMIS* Healthy Lifestyles Project. Further information on the whole programme can be obtained from Maureen Phillip, *PAMIS* Co-ordinator for Tayside. She can also pass on any queries on this article to me. Her contact details are:

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Tel: (01382) 385 154

This very practical example is only one of many that Professor Dutton talked to me about and as a result of attending this workshop I decided to arrange for my son to have a Functional Visual Assessment carried out. My son has a Self Directed Support Care package and with the help of *PAMIS* I made a self-referral to RNIB Pathway Visual Impairment and Learning Disability Services (VILD) - in Kirckaldy in Fife as there is no equivalent adult service in my

Children with Complex Health Needs in Schools and Early Years Settings

Rob Ashdown
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This paper focuses specifically on children with learning difficulties, including children with PMLD, who have complex health needs and as a consequence require additional support and care at school. For example, at St. Luke's Primary School, Scunthorpe various care or health needs of the children have been experienced: restricted mobility and postural problems necessitating specialist seating and regular repositioning as well as opportunities for movement and standing; difficulty in breathing which may be improved by repositioning and/or periodic oxygenation and/or regular suctioning during the day to remove excess saliva; problems with eating and drinking, with children requiring minced or pureed foods and thickened drinks and several children requiring gastrostomy feeds or drinks at regular intervals throughout the school day as well as at lunch time; susceptibility to infection, particularly chest infections; epilepsy requiring careful monitoring, record keeping and giving routine and emergency medication; asthma requiring use of inhalers and nebulisers; and diabetes requiring regular testing of blood and on occasions giving insulin. This single school's experiences can be illustrative only; other schools will be dealing regularly with children with other complex needs, e.g. continence problems where children require assistance with bladder emptying and may need catheterisation, tracheostomy care, inserting suppositories, etc.

For several years local authorities across the country have been developing partnership arrangements with the local health providers and they are evolving joint policies and protocols. At St. Luke's Primary School the staff have enjoyed good partnerships for many years at 'grass roots' level with local health professionals, e.g. paediatricians, nurses, physiotherapists, occupational therapists, speech and language therapists, dieticians, etc. The strategic developments within our area should help to cement these school-level partnerships which in the past have depended more on personalities than planned systems and joint funding arrangements. However, it is worth remembering that the joint strategic planning is not yet fully in place and it remains to be seen what impact it will have for the pupils and their families.

Health and safety responsibilities

Health and safety legislation places responsibilities on employers to ensure the health and safety and welfare of school staff and pupils. The local authority that maintains St. Luke's Primary School has fulfilled its obligations by developing a health and safety policy and guidance and making it available to all its schools but there is little in the guidance that specifically identifies good practice in meeting the health and safety needs of pupils with complex health care needs. Yet schools need to act to safeguard all their pupils. Teachers have a duty of care towards their pupils and are expected to act like any reasonable parent. Schools also have to prepare and review regularly a disability equality scheme which will include plans for improving

accessibility for disabled pupils to the curriculum and the physical environment wherever practicable. So where can schools find appropriate advice and information about the children's needs and meeting them? One obvious source of information is the children's parents and information gathering at the time of the child's admission to school and at subsequent reviews has proved to be invaluable. But, understandably, some parents do not always fully understand the health care needs of their own child. For 'triangulation purposes', another invaluable source of advice and information is the range of professionals who are supporting the child and their family. St. Luke's Primary School pupils and staff have benefited immeasurably from cultivating contacts with the health services professionals in particular. Finally, there is also information on various websites: there are national organisations supporting individuals with a specific condition and Contact a Family has a directory of conditions (www.cafamily.org.uk).

Schools should develop policies which reflect their responsibilities, the needs of their pupils and the local resources. There is guidance for this in *Managing Medicines in Schools and Early Years Settings* (DfES/DoH, 2005) which sets out the roles and responsibilities of the various parties. The same responsibilities will apply when managing complex health needs. Complementary guidance and case studies are easily accessed in *Including Me* by Jeanne Carlin (Carlin, 2005). This practical book is downloadable from the publications page of the Council for Disabled Children (www.ncb.org.uk/cdc).

It gives guidance about developing policies and procedures drawing on examples of good practice from different parts of the country. Medical Conditions at School: A Policy Resource Pack is a free pack produced by the Medical Conditions at School Group (2007) that can be downloaded (www.teachernet.gov.uk/medical). It provides information about the most common medical conditions: anaphylaxis, asthma, diabetes and epilepsy. It is aimed more at helping primary and secondary schools to implement a tailored and effective medical conditions policy and provides, after registration, resources for teaching people about these conditions.

Roles and responsibilities of staff

Teachers' conditions of employment do not include giving or supervising a pupil taking medicines. St. Luke's Primary School is lucky in that all of the teachers voluntarily participate in such activities and a range of other health care procedures besides because they can see that they are of benefit to the pupils. However, when the job descriptions of the teaching assistants were revised several years ago, care was taken to ensure that the administration of medicines, physiotherapy and invasive care procedures were included in the job description for one of the higher grades of teaching assistant as part of their duties.

The Royal College of Nursing has provided advice (January, 2008) about which clinical procedures may be safely taught and delegated to non-health staff. Significantly, the College has also advised that some tasks should not be undertaken by them including re-insertion of nasogastric or gastrostomy tubes, deep suctioning (oral suctioning tube beyond back of mouth), ventilation care for an unstable and unpredictable child and intravenous injections. This advice can only be a general guide since innovative ways of managing health conditions are still being developed. It can be accessed at the website for the Council for Disabled given above. The advice stresses that best practice is that any delegation of clinical tasks to non-health qualified staff is undertaken only after they have received initial training and preparation and when their competence has been properly assessed and recorded by an appropriately qualified person. Carlin (2005) suggests that the 'Staff training record – administration of medicines', taken from the Managing Medicines In Schools And Early Years Settings Guidance (DfES,/DoH, 2005) can be used for records of training and competencies.

Risk Assessments, Staff Training and Health Care Plans

There is an element of risk involved with many of the tasks carried out to support children with complex health needs. Risks cannot be eliminated completely, but it is possible to manage them. Risk

management will include identifying the risks and ensure that written plans and training are available to enable tasks to be carried out in the safest possible way. For instance, a key St. Luke's Primary School policy relates to moving and handling. Several teaching assistants have been trained as risk assessors for moving and handling by Centaur Training (www.centaur-training.co.uk) and not only assess and reassess the risks involved in moving and handling the children with physical disabilities but write and regularly update moving and handling plans and provide training for a staff both at a general level and in relation to specific children. The school is expensively equipped with mechanical hoists and adjustable beds and other devices which are used to minimise the risks to staff and children. The visiting occupational therapist and physiotherapist also provide their specialist knowledge and expertise with regard to equipment and procedures that children may require.

Staff supporting children with complex health needs require appropriate training and continuing support from health professionals in order to carry out clinical procedures. At St. Luke's Primary School initially this training was done by members of the nursing team on the children's ward at the local hospital but now this is done by a full-time paediatric nurse, funded through the Primary Care Trust, who is shared between this school and the local secondary special school, St. Hugh's Communication and Interaction Specialist College. Training takes two forms: (a) general training for all about complex health needs, and (b) training for class teams related to the needs of a specific child and the procedures or care that child requires. Incidentally, school staff retain some concerns about taking on total responsibility for supporting children with the most complex health needs because they fear that one day they may do something incorrectly and a child could be harmed. After all, they do not have in-depth medical training and experience. However, the provision of the paediatric nurse, albeit shared between the two schools, has provided a great deal of reassurance and given staff an accessible person to whom they can refer problems and concerns.

Importantly, each child with complex health needs has a health care plan which is specific to them. The plans vary in their content depending on the needs of each child but follow a common framework. In the past, health care plans were drawn up by the paediatrician but currently they are developed and maintained by the paediatric nurse who serves the two special schools. The plans are written in non-medical language which the school staff can understand. Where children require routine and emergency medicines the health care plan provides details about when and how to administer these and dosages. For children with the most complex health care needs, the plan will detail other forms of

support besides. The health care plans have proved invaluable because of the clarification they provide for staff, parents and others, including emergency paramedics who are called to the school from time to time because of concerns for the health of specific children. The health care plan is drawn up prior to the child starting at a school and the paediatric nurse ensures the training required for particular procedures is given to relevant staff. The plan is a working document and is reviewed at least at the time of the annual medical review and the annual review of the child's statement of SEN. Details of drawing up a health care plan are outlined in *Managing Medicines In Schools And Early Years Settings* (DfES/DoH, 2005) and *Including Me* (Council for Disabled Children, 2005).

Emergency treatment

Like all organisations, St. Luke's Primary School has its 'first aiders' – staff who must complete an approved training course – whose main duties are to give immediate help to casualties with common injuries or illnesses that can arise in school and, when necessary, ensure that an ambulance or other professional medical help is called. The school has also invested heavily in child-focused first aid training for a somewhat larger group of staff. *Guidance On First Aid In Schools; A Good Practice Guide* (DfEE, no date) can be found on the Teachernet website (www.teachernet.gov.uk/firstaid).

A relatively recent challenge for the school is the existence of 'do not resuscitate orders' for a few children. A 'Do Not Resuscitate' order (DNR) is an agreement drawn up between a child's parents and the medical staff with clinical responsibility for the child. It authorises or denies treatment where it is agreed that this is in the best interests of the child. A DNR order does need to be discussed and agreed with the parents and health service professionals and the health care plan amended appropriately. A copy of the DNR order is kept with the health care plan so that it can be accessed in an emergency. School policy is that in an emergency situation staff must phone for an ambulance, inform the paediatric nurse and any relevant health professionals who are available and notify the parents. The problem is that making decisions about treatment for a child in an emergency situation is a clinical matter and not one that can be made by school staff. Whilst the school respects the reasons for the DNR order, the staff understandably feel that they cannot make decisions to deny standard first aid treatment to the child when health service professionals are not immediately available to take over. This is an area where more debate and guidance would be welcome.

Funding Issues

Funding to meet health care needs is a complicated issue. To what extent should the local authority provide funding for additional support staff and technology not to mention the considerable costs involved in providing appropriate training? Certainly, the level of support required by a child should be clearly stated in their statement of SEN. To what extent should funding for this additional support come from the health services (the Primary Care Trust) or be jointly funded? These are issues still being explored by the local authority and the children's health care commissioner in our area. The reality for St. Luke's Primary School with its stretched budget is that staff time spent on meeting a child's complex health care needs inevitably means less staff time spent on meeting the educational needs of the child and others, possibly to their detriment. However, up to a point, the school can and should meet many health care needs without expecting, say, health service funding for health care assistants. Equally, it would not be cost-effective, if not impossible, for the paediatric nurse to take over the whole range of clinical procedures from the school staff. Our local experience suggests that there are probably discussions ongoing in many parts of the UK to agree thresholds beyond which additional health care support is required for schools and how to apply for this additional support from children's health care commissioners and/or relevant professionals or agencies.

The Children's Voice

In all of the above, the views of the children themselves have not featured at all. The focus has been upon the complicated issues surrounding the development of policies and guidance at local authority and school level. However, Carlin (2005) reminds us quite rightly that we are doing all this for the sake of the children and they should have an opportunity to express their views, even those who cannot communicate conventionally through speech or signing. She provides examples of how to do this in case studies and shows how a 'communication passport' carried by the child could help ensure a more child-centred approach.

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Medical Conditions at School Group (2007) Medical Conditions at School: A Policy Resource Pack (available online after registration; visit www.teachernet.gov.uk/medical).

Royal College of Nursing (2008) Managing Children With Health Care Needs: Delegation Of Clinical Procedures, Training And Accountability Issues (available online from www.ncb.org.uk/cdc)

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**

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“ for all your specialist communication training & sensory function assessment in PMLD” for details contact Mark Gray on 0115 9732540 web site www.markgrayassociates.com



MarkGrayAssociates

The British Society for Disability and Oral Health (BSDH)

Selina Masters
Clinical Director of Dental Services (Eastern Locality)

In this article, Selina describes the work of the BSDH and then shares an example of their practical guidance and information for service users, parents and carers.

The British Society for Disability and Oral Health (BSDH) was formed in 1976 with the following aim and objectives:-

Aim

To bring together all those interested in the care of people with disabilities.

Objectives

- To promote the oral health of disabled people of all ages.
- To promote links with organisations representing disabled people.
- To consult with disability groups to identify their needs and demands.
- To study the barriers relating to the provision of oral health care for disabled people.
- To develop undergraduate and post graduate teaching in the subject.
- To encourage research in the field of oral health care for people with disabilities.

The Society has many functions:-

1. Educational

Two conferences are run each year, a Spring and a Winter Conference, details of which can be found on the website:- www.bsdh.org.uk. The last conference was held at School of Oriental and African Studies (SOAS) on Friday, 4th December 2009; the title was "Broadening Horizons" and it covered how developments in dentistry can be applied to special care groups. It also marked the launch of the *BSDH Professional Consensus Statement on the Provision of Oral Healthcare under General Anaesthesia in Special Care Dentistry*. The programme was run back to back with the British Society of Gerodontology conference (3rd December 2009) on the subject of "Medical Challenges – Management of the Medically Compromised Older Patient".

2. Guidelines

The Society has been very active producing many Guidelines which can be viewed on the website and are updated every 5 years. *The Clinical Guidelines and Integrated Care Pathways for Oral Health Care of People with Learning Disabilities* was mainly funded by the Diana Princess of Wales with additional funding from RTR Foundation (formally MCF) and The Bailey Thomas Fund. It was a joint initiative by BSDH and the Faculty of Dental Surgery – Royal College of Surgeons of England and can be accessed on the BSDH (<http://www.bsdh.org.uk/guidelines.html>) or Royal College of Surgeons of England websites. These Guidelines are currently under review but should be available in their updated

format within the next few months. The chapter on oral care practice is included at the end of this article.

3. Journal

The official publication of BSDH is the Journal of Disability & Oral Health. It is also the official journal of the International Association for Disability & Oral Health and the Irish Society for Disability and Oral Health. The journal includes research, articles, clinical audits and case reports. The March Journal included two articles on Oral Health Risk Assessments for adults with learning disabilities which examined current practice and attitudes of dentists and care staff.

4. Information for the Public

There is a section on the website for the public to access information e.g. how to locate a local dentist with experience and skills in treating people with special needs. There are also information leaflets on a variety of conditions and issues.

5. Practical Oral Health Information for Service Users, Parents and Carers

The dental team play an important role in the overall care of the mouth but the day-to-day care provided in the home environment is the key to a healthy mouth. These guidelines are designed to help maintain a good standard of oral hygiene by optimising toothbrushing techniques and overcoming some of the difficulties, which may be encountered during toothbrushing procedures.

Mouthcare Advice—Toothbrush

Electric toothbrushes are more effective than manual ones and should be used when individuals can accept them.

- If a manual toothbrush is used, it should have a small head with smooth and rounded tufts
- A child's toothbrush is suitable for reaching awkward areas of the mouth in an adult.
- Whichever method is used, all surfaces must be brushed effectively

Brush size to use / Age

- Toothbrush for infants - 0-2years
- Small child's toothbrush - over 2 years
- Child's toothbrush - 7 years to adult

Toothpaste

- Always use fluoride containing toothpaste
- Non-foaming toothpastes are available (e.g. for people fed by tube or those intolerant of foaming agents)

Chlorhexidine Gel

- This is clinically effective in reducing plaque bacteria over short periods
- It should be used as recommended by the dentist or hygienist

Denture Care

- Dentures should be removed from the mouth for cleaning
- Hold the denture over a bowl of water to avoid damage if it is dropped
- Brush thoroughly using a small, soft brush and unperfumed soap or toothpaste
- Plastic dentures should be soaked in hypochlorite cleaning solution, (Metal dentures should be soaked in an alkaline peroxide solution) for 30 minutes rinse, brush and rinse again before storing dry overnight
- Dentures should be marked with the person's surname and initial
- Carers need to assume the same responsibility for denture care whether individuals and/or people in their care have partial or full dentures
- If the person has no natural teeth, it is important that carers clean the oral tissues daily with a soft toothbrush or gauze to remove plaque and so maintain good oral health.
- Professional carers assisting someone to clean
- their teeth or mouth should wear latex free gloves

Overcoming Specific Problems in Oral Care

- **Biting on the toothbrush:** Allow person to continue biting the toothbrush whilst the teeth are cleaned with another toothbrush.
- **Aids to toothbrushing:** Finger shields have a small head of soft latex tufts and may be useful for some people. Fingerstalls are small so their use is limited to people with small hands. They are less effective than a toothbrush for removing plaque.
- **Strong tongue thrust:** A mobile tongue or tight lip may tend to push the toothbrush out of the mouth, or away from the front teeth. A flannel or gauze-square wrapped around the forefinger to gently retract or hold back the tongue or lip may be used. It will need patience and perseverance.
- **Gagging or retching on brushing:** In order to reduce gagging and retching it may be helpful to start brushing from the back teeth and move forward.
- **Reduction in oral sensitivity:** Some children who have disabilities may require a considerable amount of oral de-sensitisation. Various appliances are sometimes suggested by occupational therapists and speech and language therapists for this procedure. However, they do not remove plaque if used for cleansing.
- **Reduced cooperation:** A different area of the mouth can be brushed on different occasions keeping note of the area brushed each time (i.e. several short brushing sessions). Other distractions such as music and videos can be used, and brushing whilst in the bath can be of benefit.
- **Lack of co-operation:** A degree of physical assistance may be required to accomplish satisfactory toothbrushing, such as holding hands or lying a small child back into the lap. The parent or carer may need to take care not to be accidentally bitten. A second person may be required to hold hands to prevent the individual from pulling the toothbrush out of their mouth.

General Dental Advice for Service Users**Diet**

- Keep foods and drinks that have sugar in them to mealtimes.
- Between meals, avoid snacks and drinks that contain sugar are carbonated or fruit flavoured. Choose bread, toast, nan bread, chapatti, poppadums, cheese, fresh fruit and vegetables instead. Drinks could be milk, water, tea or coffee (without sugar) or acknowledged as "tooth kind".
- Always ask your doctor or chemist for sugar-free medicines.
- Moderation and infrequent consumption of food and drink, which contain sugar is a good regime to follow.

Oral Hygiene

- Brushing teeth and gums helps keep the mouth healthy.
- Clean teeth and gums twice every day – you may need some help to get them really clean.
- Choose a small sized toothbrush – you may find it easier to use an electric toothbrush.
- Use a toothpaste with fluoride.
- If your gums bleed – keep brushing – gently and thoroughly.
- If your gums continue to bleed contact your dentist

Visiting the Dentist

- Visit your dentist at least twice a year.
- Tell the dentist if you are having any trouble with your mouth.
- Find a dentist you can talk to – ask your family or friends.
- You may want someone you know to accompany you to the dentist.
- Tell the dentist about any tablets or medicines that you are taking.

Practical Advice for Carrying Out or Assisting with Toothbrushing

- Always explain what you are going to do first; brushing someone else's teeth is an invasive procedure and can be frightening.
- Choose a suitable time, when carer and person are relaxed.
- Professional carers should wear latex free gloves for cross infection control when assisting with toothbrushing.
- Gloves should be changed for each individual.
- Partial dentures should be removed before cleaning natural teeth.
- Work in a good light, e.g. use a desk lamp if necessary.
- Make sure the person is comfortable (e.g. seated in front of a washbasin, in their wheelchair, or on the bed or floor) and their head is well supported. Consider working with two carers for toothbrushing.
- Stand behind the person, slightly to one side, but this position may have to be varied, according to what is comfortable for client and carer.
- Toothbrushes can be adapted in many ways for those who have limited manual dexterity. Consider using alternative toothbrushes, e.g. 'Superbrush' or 'Collis Curve'.
- Gently draw back the cheek and lips with forefinger on one side of the mouth to first gain access to upper teeth. Brush teeth and gums

using short scrub motions paying particular attention to gum margins.

- Carry out the same procedure for the rest of the mouth, so that all teeth have been brushed.
- An 'order of brushing' should be decided to ensure no areas are missed, but if cooperation is limited, brush different areas of the mouth each day, recording what has been achieved at each session.
- If possible brush the inner and biting surfaces of all teeth to ensure all plaque and food debris has been removed.
- If teeth are loose, brush them carefully but try to clean them every day.
- Do not stop brushing if you notice gums bleeding; leaving plaque behind on the teeth and gums will only increase gum problems.
- Help the person to rinse out with water or clean round with a damp swab. Consider encouraging spitting out but not rinsing away the fluoride toothpaste.
- Straws can be useful for some people, to help people rinse their mouth.
- If possible, gently hold and brush the tongue.
- Encourage the person you are assisting to do as much as they are capable of themselves. Be prepared to prompt, encourage or assist as necessary.
- Use disclosing tablets on the teeth to check the effectiveness of toothbrushing and in removal of plaque.
- Use a chart to record when teeth are brushed and when it has not been possible.

If you have any problems, ask the dentist for advice.

Tooth Brushing**Manual Tooth Brush vs Electric Tooth Brush**

An oral assessment consists of an inspection of the mouth to ascertain the oral health status of the individual. A simple oral assessment may be carried out by carers and is recommended for all people with learning disabilities on admission to residential care, including community group homes.

An example of Good Practice

Development of a protocol for staff to assess residents' oral health status, to act as guidance in reaching ethical decisions and to create a model for residents requiring assistance and support.

Adult Healthy Mouth / Child Healthy Mouth - pictures

Gums that are healthy are generally firm in texture. They should not bleed on brushing. Pigmentation of the gums may be normal for some individuals.

Gums that are inflamed will usually appear swollen and will often bleed on brushing. An oral assessment recorded on a chart is useful for carers to identify any oral problems that might occur e.g. ulcers, soft tissue trauma and any changes. It helps familiarise carers with that person's specific daily oral care needs (including denture care).

More complex assessments involving oral examination require training to recognise signs and symptoms of pathology and need to be carried out by the dentist. It would be useful to have an oral care plan written up following each dental visit.

The oral care plan should include a record of both the professional care to be carried out by the dental team, and the preventive care to be carried out at home. This will help to promote partnership between the people with learning disabilities and the carers and professionals.

Example of Good Practice:

An Oral Health Care Plan

(Community Dental Services Solihull HealthCare NHS Trust)

Name

Problem Goal Specific Materials Staff Date identified in Action Required Informed conjunction Planning with dental specific staff methods
I agree to the above programme taking place.
. Next Review Date
The person's dentist should be contacted if any changes are noticed in the mouth or if there are any unexplained changes in behaviour. Cancer can occur in the mouth but is treatable if detected early.

Recommendations

1. An oral assessment should be recorded on a chart.
2. Every person with a learning disability should have an individual oral care plan.
3. Carers should seek professional help and advice to carry out daily oral care procedures.
4. Individual carers should not make the decision to discontinue oral hygiene practice.
5. Trust and good working relationships should be developed.
6. The frequency of sugary drinks and snacks should be limited in the diet to mealtimes.
7. Healthy snacks should be encouraged as an alternative.
8. Sugar-free medicines should be used whenever possible.
9. The consumption of fizzy drinks and citrus fruit should be limited to mealtimes.
10. All people with learning disabilities should be registered with a dentist and attend regularly.
11. Carers should provide appropriate levels of support during dental appointments and liaise with

the dentist and service user about day-to-day oral care.

For more information about BSDH or for other info on oral health see website www.bsdh.org.uk

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Fluid – the forgotten nutrient

Siân Burton

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When we think about a balanced diet we automatically think of food, looking at variety, energy and fat content but often miss out a vital component- fluid. In order to keep healthy we need to achieve both a food and fluid balance. Indeed we are unable to survive much longer than ten days without fluid (Barasi,2007) and water makes up around 60% of the body weight in an adult and higher in children (Whitney et al, 2002).

Fluid balance

Quite simply this is the relationship between fluid intake (drinks and food) and fluid loss through urine, faeces, skin and lungs. In general fluid intake is controlled by the individual, though in people with PMLD this is not necessarily the case. Therefore carers need to be vigilant and ensure that:

- Drinks are offered and encouraged at regular intervals.
- Plenty of time is given as people with PMLD can take up to 3 times as long to drink.
- Thickeners are used correctly at all times if prescribed by the Speech and Language Therapist.
- Fluid intake is recorded on a daily basis especially if the person is a poor drinker.
- Additional drinks are given in warm weather and/ or if person loses a lot of sweat.

There is not a recommended daily intake for fluid and for most people an intake of 1200 to 1500ml/day (8 – 10 drinks) will be sufficient (Burton et al 2008). However constipation and diarrhoea will increase requirements from this baseline. Another 1000ml will be provided from foods within a typical varied diet.

Signs & symptoms of dehydration include:

- Dark /odorous urine
- Dry continence pads
- Low urine output
- Frequent urinary tract infections
- Dry loose skin
- Dry mouth
- Sunken features—particularly eyes
- Constipation

Other less detectable signs and symptoms include increased thirst, frequent headaches; fatigue and changes in concentration and co-ordination.

Monitoring for dehydration

1. Fluid intake and output charts
2. Pee chart (see Appendix 1)
3. Food intake charts if client is a poor drinker.

8-10 drinks a day helps keep dehydration at bay

- Tea
- Coffee
- Juice
- Milk
- Water
- Milk shakes
- Smoothies
- Flavoured water

Also encourage intake of foods that contain fluid:

- Fruit
- Vegetables
- Soups, sauces & gravy
- Cereal & milk
- Ice cream
- Ice lollies
- Sorbet
- Yoghurt
- Custard
- Milk puddings

Fluid guide

| | |
|--------------------------------|-------|
| 1 Teaspoonful | 5ml |
| 1 Dessertspoonful | 10ml |
| 1 Tablespoonful | 15ml |
| | |
| Mug | 200ml |
| Tea Cup | 150ml |
| Glass (tumbler) 200ml | |
| | |
| Average bowl of Soup | 200ml |
| Average portion of Jelly | 120ml |
| 1 scoop of ice-cream | 50ml |
| 1 ice cube | 20ml |
| Milk on cereal | 100ml |
| Yoghurt(125gpot) | 100ml |
| 1 large tablespoon gravy/sauce | 20ml |

Summary

Thirst is not always a good indication of dehydration as it begins after mild dehydration has already occurred. Encourage a variety of frequent drinks especially in warmer weather. If you have a choice of at least three different types of drinks each day you are more likely to have a good fluid intake. Should you be concerned, keep a record of food and fluid intake.

However, as in all things, moderation is important. People drinking more than three litres regularly (water intoxication) can be a problem for people with PMLD often causing reduced appetite and leading to a poor nutritional intake. Generally if fluid intake is often less than 1000mls or more than three litres this indicates the need to contact the dietitian for advice.

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Resources:

Pee charts available from: Sports Dietitians UK. PO Box 176 Stockport SK7 1XZ

APPENDIX 1

Pee Chart

| | COLOUR |
|---|--|
| 1 |  |
| 2 |  |
| 3 |  |
| 4 |  |
| 5 |  |
| 6 |  |
| 7 |  |
| 8 |  |

Reproduced with kind permission of Sports Dietitians UK

The colour of urine is a good indicator if someone is dehydrated. Aim for colours 1-4. Dark colours indicate dehydration though remember that urine is darker first thing in the morning.

Menu planning - basic ingredients for success

Siân Burton

Head of Nutrition & Dietetics for Learning Disabilities

Sue Cox

Specialist Dietitian for Learning Disabilities

The aim of this article is to look at the reasons for menu planning and provide the reader with tips for planning successful menus for people with PMLD. Many people with PMLD require softer foods and may experience difficulties in eating enough to satisfy their nutritional needs. Achieving a suitable weight can also be problematic. Menu planning in this paper will focus on the provision of smaller more frequent meals for those who struggle to meet their nutritional requirements.

People with PMLD are dependant on others for food choice and have a higher prevalence of health problems than in the general population. Many of these health problems are nutritionally related. This is where the specialist Learning Disability Dietitian (LDD) has a key role.

Specialist Dietitians in Learning Disabilities are small in number with only 0-2 working in each county, in our region. Referrals are made by community teams, but may also come from GPs and hospital consultants. In a consultation the dietitian will make a nutritional assessment of the individual and decide if an alteration to the diet is necessary. This may be by means of increasing food frequency, food types, texture changes, hydration and various other changes. If these changes are not enough to remedy the situation then the recommendation of various food supplements may be necessary. Dietitians work closely with the Speech & Language Therapist as dysphagia (difficulty in swallowing) is commonly found in people with PMLD. The dietitian is able to advise carers on the most nutritious foods to comply with an individual's eating and drinking guidelines. Menu planning makes the provision of a good variety of suitably textured meals much easier for the carer.

Why plan a menu?

Forward planning in life helps make our lives run more smoothly. A plan gives a backbone from which we may deviate but return to or re-plan should circumstances change.

A nutrition plan for people with PMLD can similarly be applied. If we eat at erratic times this may eventually lead to poor digestion. For example if over a long period of time we consume a lot of processed food, a lack of vital minerals and vitamins may occur. Therefore a plan is needed to help prevent the onset of disease.

The National Minimum Standards for Care Homes 2003 (Department of Health,2003) advises that

people with learning disabilities should be offered a healthy diet and an effort be made to enable them to enjoy their meal and mealtimes. It also states that people should receive a choice of suitable menus in which they are actively supported to participate in planning. *Editors note: See also the Scottish Executive (2002) National Care Standards. Edinburgh: Stationary Office.*

There has been a recent moving away from using menu plans in community homes as it is deemed too institutionalised. Very little research has been carried out around the benefits of menu planning in the UK. However, a recent America study has shown that meal planning significantly improved nutritional adequacy in adults with a range of learning disabilities (Humphries et al, 2009)

PMLD resident's participation in menu planning can be greatly aided by pictures on a large board of particular meals or food items. Sometimes smelling foods is necessary for them to be able to determine their favourites. Just noting what people enjoy is a way of insuring their participation in the food selection in the rotational menu plans.

Some people with PMLD are not interested in eating meals and therefore finger foods are appropriate and should also be included on the menu plan.

As dietitians, we know optimum nutrition in PMLD is essential and the following section is of a snapshot of reasons why and what essential ingredients are needed to meet those requirements. Finally a sample menu plan is included.

ADVANTAGES OF MENU PLANNING

These are three fold with benefits for all concerned but first and foremost for the person with PMLD they are more likely to have....

- A balanced diet that supplies all the necessary nutrients

- More variety in food choices
- An opportunity to participate in menu choice
- Increase in food intake as client receiving foods they like
- Increase enjoyment in meal times
- Feel good factor

FOR CARERS

- Saves time as makes shopping easier and quicker
- More cost-effective, less food wastage
- Reduces too frequent repetition of meals
- Gives carers better grasp of the clients food intake
- Opportunity to engage with client and other staff

FOR HEALTH PROFESSIONALS

- Dietitians can see at once if the nutrition is sufficient and considered a balanced healthy diet.
- Other professionals can spot if ready meals become an increasing item on the menus, it might indicate that the carers need to improve on their cooking skills

TOP TIPS FOR MENU PLANNING – GENERAL ADVICE

Variety: Including a variety of foods in the menu is important because no one food or group of foods can provide everything for a healthy diet. Variety also makes menus interesting, appealing and reduces taste fatigue which can occur if similar foods are served too often.

Portion size: Small frequent meals to assist those with small appetites to obtain sufficient nutrition for their needs.

Colour: Chicken mashed potato and cauliflower may be a nutritious meal but lacks colour contrast and may look unappetising. Using broccoli in place of the cauliflower will considerably improve the aesthetic appeal of meal. If a person likes food of one colour then add contrast with different coloured crockery or tablecloths.

Nose & Eye Appeal: Food has to look good enough to eat and also smell good to stimulate the taste buds. The smell, aroma of foods will also make the meal more appealing for those with visual impairment.

Flavours: Too many mild flavours can make food too bland and lead to taste fatigue.

Environment: Too noisy or too quiet? If not right can have a negative affect on nutritional intake.

THE DIETITIAN'S TOP TEN

1. **Frequency:** - of meals needs to be 6-7 small meals daily
2. **Texture:** - needs to be soft and moist or pureed (meat, vegetables and potato should be separate)
3. **Energy:** - often needs to be fortified with full fat products. There is rarely a need for low fat or diet products.
4. **Fruit:** - no tough skins. Remove stones and pips.
5. **Vegetables:** - cook to soft consistency.
6. **Fibre:** - wholemeal bread, pasta, baked beans, pulses etc are desirable daily as they help alleviate constipation.
7. **Puddings:** - custards, ice cream and trifles etc are an important source of easy eating that can be enjoyed daily.
8. **Meat:** - red meat should be eaten 2-3 times weekly to help provide iron and zinc – low blood levels have been documented in people with PMLD.
9. **Fish:** - use a variety such as white and oily. Good source of essential fatty acids.
10. **Dairy:** - in cheese sauces, yoghurts and milk. Good for teeth and bones.

Summary

Menu planning saves time, money, and stress but do not be tempted to overcomplicate the process, as this will become a burden. Because you buy only what you need, less food is wasted and planning ahead helps avoid frantic cooking sessions and over reliance on ready meals and tins of soup. By providing a good variety of meals you will help to improve the health of the person with PMLD. Behaviour may be reduced if there are less unpleasant food. For clients who are nutritionally at risk individual care plans can be implemented with the assistance of the specialist dietitian. Menu planning doesn't mean that you can't be flexible and adapt your plan for special occasions. It can be fun and opens the door to new culinary experiences for all concerned.

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the Scottish Executive (2002) National Care Standards. Edinburgh: Stationary Office.

Useful websites for menu planning:

www.bristollearningdifficulties.nhs.uk
www.photorecipes.co.uk

Subscribe for 2010

It is time to renew subscriptions for 2010 and, as usual, a separate subscription form is included with this issue. This year we are pleased to be able to keep the cost at the 2009 level.

Thank you to all subscribers who have renewed for 2009 very recently in response to the latest reminder. For you, this renewal for 2010 will seem to be very hot on the heels of the last payment!

Thank you too, to all those who have opted to pay by standing order and also to those personal subscribers who have completed a gift aid form. If you are a standard rate taxpayer and have not already done this it would be very much appreciated – it costs you nothing but helps us.

Spring Vol. 22 No. 1 Issue 65

- International Perspectives-

The copy date for all articles, information and news for the Spring 2010 issue is the 5th March 2010

Please send contributions to:
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Summer Vol. 22 No. 2 Issue 66

- Sensory Experiences -

The copy date for all articles, information and news for the Summer 2010 issue is the 4th June 2010

Please send contributions to:
Di Foxwell
di@phonecoop.coop

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).

Home Enteral Tube Feeding – A consensus statement

Siân Burton, Anne Laverty and Marjory Macleod

In December 2008 a professional consensus statement on home enteral tube feeding for adults with a learning disability was published by the British Dietetic Association (BDA). The BDA working group consisted of 5 Dietitians and a Community Nutrition Nurse specialising in Adult Learning Disabilities Services from England, Scotland, Wales and Northern Ireland. The statement is of particular relevance to adults with PMLD who have complex health and social care needs requiring appropriate person-centred interventions and support (Fairclough et al 2008). Three of the statement's authors provide an overview here of the document as well as a sample of carers' concerns taken from their practice.

What is a professional consensus statement?

It is a recommended dietetic clinical guidance for a specific condition where there is no robust published evidence base so the document is the result of a consensus view from dietitians with experience and expertise in the subject. Professional Consensus Statements are produced by British Dietetic Association (BDA) Specialist Groups and validated by the Clinical Governance Committee (BDA 2009).

Why is it needed?

- Lack of knowledge specific to learning disabilities in field of enteral tube feeding.
- Variations in practice throughout the country.
- Increasing numbers of children with complex needs surviving into adulthood.
- Differing requirements – many adults with PMLD tend to require enteral feeding throughout life.

What was the process?

The consensus statement is based on a systematic review of the available literature undertaken between October 2006 and August 2007 as well consultation and peer review at regular intervals. The views of carers were also taken into account and are used throughout the document.

What is in it?

The statement looks at the following areas:-

- **Decision-making:** Assessments need to be carried out and it is good practice to involve carers in the assessment process and to communicate openly. In order to treat, the issue of gaining informed consent must be fully explored and worked examples of recent legislations have been incorporated into the statement.
- **Nutritional Assessment and monitoring:** Research has shown that people with severe

neuro-developmental disabilities may have lower energy needs though there is insufficient evidence to influence dietetic practice. However dietitians specialising in learning disability have had the opportunity to share practice and contribute to the statement.

- **Training and education:** Co-ordinated care from the multi-disciplinary team (NICE, 2006) is essential to ensure that correct and timely assessment, referral and pre and post enteral tube placement training and education happens.
- **Areas for future multi-agency research:** Includes the development of reference standards applicable to this client group.

Who is it written for?

- Dietitians
- Nurses
- Other professionals
- Students

Carers may also find the Statement useful even though they were not part of the original target group. Details on how to access the document can be found at the end of this article.

We feel that the Statement is a valuable resource for dietitians, nurses, other professionals and students to guide them through the issues that are commonly encountered in practice. Feedback from service users illustrate the dilemmas and experiences of this client group and have been used to inform recommendations within the document. We have taken the opportunity to expand on some of the more common queries raised by carers and share these concerns with you in the following Q&A section:

Frequently Asked Questions (FAQs) by carers:

How long will the PEG tube be in place for?

Generally life long but this will depend on individual circumstances. Some people may have a transient loss of swallowing ability related to a physical

condition such as stroke, a change in mental state or as a side effect of medication. Following a period of enteral feeding they may recover sufficiently for the tube to be removed. Some may recover sufficiently to eat orally but find it difficult to achieve an adequate fluid intake so the PEG tube may remain in place in order to give adequate fluids.

I felt really close to my daughter when I was feeding her. With the PEG tube I feel I will lose this degree of interaction and she will become distanced from me. Is there a way around this?

While attending to your daughter's personal care take longer and give more attention. Contact through hand and foot massage can be very relaxing for both of you. Story telling, looking at pictures can be another way of bonding and interaction or extend a pleasurable interaction that involves you both.

He used to enjoy mealtimes, won't he miss having food?

Not every instance of PEG placement means nil by mouth (NBM). Some people may manage a small amount of pureed diet but not sufficient to meet their needs. In such cases the PEG feed will make up the bulk of the nutrition. This means they can also receive the tastes that they did enjoy but in smaller and safer amounts. Often meal times can be more relaxed because the stress is removed by no longer having to worry about the quantity eaten, time it takes to feed or risk of choking. In cases where the feeding regimen provides all the nutrition the client easily adapts to the new way of feeding and the scientifically designed feeds provide fullness/satiety as well complete nutrition.

How will I know if she is getting enough food?

The dietitian will work out the feeding regimen for you. Regular weight checks may be necessary to check that the energy intake is sufficient to maintain a good weight. Blood tests can be undertaken but are not always practical as they can be very traumatic for the individual. However if blood has to be taken regularly for anticonvulsant levels as an example then a little more can be obtained to carry out a full blood profile at the same time. Additionally there is the Subjective Global Assessment (SGA) where appearance is often a good guide especially when observed by a regular carer. Clothing becoming loose or tight is an indicator of weight change. Other indicators of nutritional insufficiency include observing skin condition and pallor. If the skin is breaking down the individual client will have increased requirements for protein, energy and micronutrients.

What about medication - can it go down the tube?

Yes it can and you will be given specific training from the team. Flushing the tube between each

medication is very important as it will ensure that the tube remains free-flowing. Some medications such as Phenytoin can interact with the feed so a rest period between administration of medication and the feed is required. Again this will be documented on the individuals feeding regimen. It is important that you follow the timings stated on the regimen.

How do I clean his/her teeth?

Oral hygiene is very important to keep mouth area including teeth and gums healthy and reduce infections. There will be local guidelines which will vary across the country but it is important to get advice and record the procedure so everyone who is involved in providing care follow the same guidelines. Some areas use a low foaming toothpaste i.e. avoiding brands which have sodium lauryl sulphate as an active ingredient. *Editors note: See Selina Masters article in this issue on oral health case).*

Where will we get the feeding equipment from?

In general the feeding sets and syringes for feeding and flushing will be provided by the nutrition & dietetic department and syringes for medications by the district nursing service. There are local variations but all this will be part of the discharge documentation and training package for each person.

Where are we going to put everything?

This can be quite a problem! Being faced with where to store boxes of feed, sets and syringes can be a headache especially when deliveries are routinely organised on a monthly basis. Delivery of equipment may need to be adjusted to suit the storage space available.

What if something goes wrong - the tube blocks or the tube comes out?

Carers should be informed and provided with various scenarios and a suitable plan of action to be follow in such instances. This 'trouble-shooting' is usually covered during initial training and guidelines are given as well as contact numbers for such emergencies.

Will my son be able to go to the Day Centre and attend Respite?

Day care and respite placements may need to be reviewed as it is crucial that staff are willing and able to provide the correct support. Training and ongoing support will be available for all appropriate key staff. *Editors note: See article by Brown and Miller in this issue.*

There is so much to learn – how will I ever cope?

Short frequent training sessions with input from all disciplines involved are preferable to trying to cram everything in at once. Carers should be assured that they are not alone in feeling anxious about the

whole process. There is a lot of information to take on board and only repetition over time in different formats will reinforce it. Often it is not until the person is home and carers have to put techniques learned into practice and gradually build their confidence that it all falls into place. Continual reviews by all involved with the persons' care are essential and carers should always be able to contact a professional by phone. Refresher training for existing staff, as well as training for new staff is always available so do not be afraid to request this when required. Training for family carers should also be provided. Also remember that practices change over time and do not be alarmed if you are introduced to new techniques or equipment.

Concluding remarks:

Communication between professionals and carers involved in home enteral tube feeding is vital for continuity and consistency of high standards of care for people with PMLD. Our persons' needs are evolving as too our knowledge of the practicalities of providing what is in essence 'artificial nutrition'. We need to ensure that not only are our practices evidence-based but that we also take a pragmatic approach by listening and learning from the experiences of our clients and carers.

There is little worth in providing services based on scientific principles unless practices are shared and robust channels of communication, education and training are in place to support our service users and carers.

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NICE (2006) *Nutrition support in Adults, oral nutrition support, enteral tube feeding and parenteral nutrition*. Quick Reference Guide. Clinical Guideline 32. Available at: <http://.nice.org.uk>

Resources

1. The statement:
Place cursor over sentence in blue and follow 'pop-up' instructions to download a copy of the consensus statement,

Home Enteral Tube Feeding for Adults with a **Learning Disability**

NB: Downloading may take up to 5 minutes as the document is quite large.

2. **Profound and Multiple Learning Disabilities** (2009) edited by J Pawlyn, and S Carnaby. Wiley- Blackwell

Future Focus: International Perspectives

Penny Lacey

For the next issue of PMLD Link, we have approached people from a range of countries to ask them to write about what is happening for/ with children and adults with PMLD in those countries. So far we have asked folk in Australia, Greece, Ireland, Kenya, Japan, Rumania, Northern Ireland and there have been suggestions of possibilities in the Philippines, Germany, Mexico, Taiwan, USA, Florida and Armenia!! If all the articles arrive then we will have enough for 2 or even 3 issues! Despite the possibilities of several articles already, if you have any contacts abroad whom you could ask or experience yourself in another country, then please let me know on p.j.lacey@bham.ac.uk.

In many countries in the world, people with PMLD do not survive into childhood, let alone adulthood and those who do are often hidden away from the public eye. We have students at the University of Birmingham from many different countries, particularly African and far eastern countries and they often know nothing of what happens to/ for the most severely disabled children as any who exist are hidden away. One government officer from Nigeria is conducting his research for his master's dissertation on the attitude of Nigerians to severe disability. His experience in Nigeria is that people traditionally regard severely disabled people as cursed and should be feared and shunned. He is concentrating his data collection on Nigerians who live in the UK, and is particularly interested in whether and how Nigerians who live in the UK change their attitude from that traditionally held in their mother country.

Other students at the University are interested in educational inclusion but rarely in the inclusion of pupils and students with PMLD. In many countries, those with mild difficulties and disabilities are still not fully included in schools and colleges and there is yet little or no interest in those with profound disabilities.

Looking through the English language published literature on PMLD or PIMD (Profound Intellectual and Multiple Disabilities), there is little written about countries other than the UK, USA and Australia. There are, however a group in the Netherlands who have published research. They write about Dutch special education centres and how to give effective education and care to children with PIMD (eg: Fonteine, Zijlstra and Vslakamp, 2008; Tadema, Vlaskamp and Ruijsenaars, 2007). Another group of researchers, in Greece, have focused on children with PMLD, in particular on the use of IEPs (Individual Education Plans) to encourage collaborative multidisciplinary work (Stroggilos and Xanthacou, 2006). Ireland has been represented in recent publications, for example with a paper on training teachers to use ICT with children with PMLD (Ware and Holmes, 2007).

It is even harder to find English language papers on adults with PMLD/ PIMD. I located a paper by Lim (2005) regarding the use of psychotropic medication for people with PIMD in institutions, showing that many people are given medication inappropriately. I hasten to add that a similar conclusion was arrived at in this country (Kroese and Holmes, 2005).

So information about people with PMLD/ PIMD from other countries, in English, is quite sparse and I look forward to the articles we get for the next issue of PMLD Link to increase my own knowledge and understanding. Do help us to make this a very exciting edition.

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PMLD Network Email Forum A Digest of Discussions August – October 09

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. FE colleges/ Post 16 providers for young people with complex needs

Someone requested information about FE colleges/post 16 providers who offer courses & programmes for young people with complex needs. They also asked for information about any FE colleges that demonstrate good practice around the inclusion of young people with complex needs on their mainstream courses.

Responses included:

- Newbury College in Berkshire has a sensory based course www.newbury-college.ac.uk
- New courses are currently being set up at Berkshire college of Agriculture & Wick Hill College, Bracknell.
- Someone said there are many specialist colleges around the country, see National Association of Specialist Colleges: www.natspec.org.uk
- Regent College: www.regentcollege.org.uk
- Percy Hedley Foundation: www.percyhedley.org.uk
- Someone said that the Touch Trust provides an Open College Network course for students with complex needs. Their work is based around movement, sound music and the arts. They think it has recently gained further education status. They are piloting their work with Rhondda Cynon Taf Local Authority Day Services. They said that individuals won't be working towards the qualification but will take part in the program. The staff at Day Services will be trained to undertake the program themselves.
- Someone suggested looking at the case study of Blackburn College on the National Transition Support Team website: http://www.transitionsupportprogramme.org.uk/resources/case_studies.aspx

2. Funding suggestions for a service for people with PMLD

Someone wanted suggestions of potential funders for a service for people with PMLD: the Music Gym in Hastings (they now have a permanent site for this

and want to make it attractive and accessible).

Responses included:

- You could try www.grantnet.com
- Check with your local authority they may have a funding search service, many do.
- www.governmentfunding.org.uk (but there is a charge for registering on this site)
- Princes Trust www.princes-trust.org.uk
- Look at www.sussexgiving.org.uk (a community foundation in the area where the service is)
- You could see if you have a local 'Besom' group in your area www.besom.com

3. Safeguarding/ Protection of Vulnerable Adults (POVA/ SOVA)

A parent of a daughter with PMLD who lives in her own home with 24-hour one-to-one support asked for advice. She said her daughter's support workers are worried about the issues of comforting her when she is distressed, unwell or depressed.

She said it seems that POVA/SOVA is designed to prevent the sort of human contact that we all thrive on. She said she had heard stories of people being deprived of even having their hand held - presumably because the action might be misconstrued. She asked how organisations get over these problems? She said that surely it is a basic human right to experience love, comfort and support.

Responses included:

- 'It goes right to the heart of the danger of the reactive and over simplistic nature of POVA.'
- Someone suggested a simple written policy around the value of touch to her daughter and the kinds of circumstances in which she welcomes it. This would free up and empower both her daughter and the people who support her.
- Many people with complex support needs rely upon use of touch to help meet their day-to-day communication and emotional needs, and this can and should be justified as a 'therapeutic intervention'.
- Detailed Person-Centred planning and positive risk assessment can address this by involving everyone who knows her best in collating and recording information about: -types of touch that she prefers, and dislikes, and

reasons for this, if known -how she indicates her consent (or otherwise) if possible -how she benefits from particular 'interventions' using touch -risks to your daughter and others, and how risk should be minimised when physical touch is used -when, where and why it is - and is not - appropriate to use different kinds of touch with your daughter.

- Someone suggested looking at 'Learning Disabilities: Towards Inclusion' 4th Edition Chapter on Complementary Therapies'.
- Someone suggested looking at Diana Kerr's 'Understanding Learning Disability and Dementia: Developing Effective Interventions' Chapter 6 on Therapeutic Interventions'.
- 'Touch is something as humans we have a fundamental right to choose. A useful article to read is the work of David Hewett in the following article. Hewett, D. (2007) Do touch: physical contact and people who have severe, profound and multiple learning difficulties. Support for Learning, 22 (3): 116-123.'
- 'Some organisations do err on the side of caution and when you have investigated as many cases of abuse as I've been involved with I understand perfectly well why they do. This can then promote services that are no longer person centred or based on a humanist approach.'
- Someone said the issue is not 'touch' but 'inappropriate touch' and this is where the misunderstanding occurs. 'If holding your daughter's hand when she is distressed alleviates her distress than this is 'appropriate touch', if on the other hand the 'touch' is causing her distress than this would then become 'inappropriate'.
- 'One way of assessing 'touches' is by considering what might other people do in these circumstances and if you were judged by your peers would they consider this touch appropriate. Our justice services (if any thing went this far) often consider that three different professionals agreeing on any actions as being valid. So one way forward might be having a plan that is approved by three professionals.'
- 'Perhaps a referral to your local Community Learning Disability Team for help and support is needed.'
- 'Practical tools of person-centred planning should have a very important role to play, and also more broadly in ensuring that the views, feelings, desires, values and wishes of the people are taken into account.'
- 'How can Valuing People talk about real choice, independence and well being when clearly they are not achievable for lots because of policy and

red tape?'

- 'It is another example of parents, carers loved ones etc having to hope/rely that they get a service which has someone working with their son/daughter who is - understanding, empathetic, aware of human rights/legislation on a scale to challenge policy, aware of ridiculous/restrictive interpretations of policy, has a positive approach to risk, someone willing to go that extra mile, dogged/determined, strong, charismatic, creative the list goes on....and get this....all for the hourly rate you can get working in most fast food shops!'
- 'When considering an adult in residential care with 24 hour high level support, this carer has to be an extension of the family and friend in their role, the careful employment and monitoring of safe practice alongside protection of vulnerable adults awareness training, will minimise risks of abusive care.'
- 'Withholding touch and cuddles in itself would be an abuse, deliberate institutional neglect.'
- Someone said she believed experiencing touch as a form of communication is vital to both adults and children who have PMLD. She suggested having a policy agreement that includes what Mary Kellett describes, (SLD experience, Issue 52, Autumn 2008) as 'a circle of consent'. She said 'this is where there is a circle of people protecting your daughter's best interests, which may include carers, friends, therapists, siblings, parents etc., and they all have the right to intercede when they feel your daughter is indicating dislike or withdrawal of consent. These people are the people that know the idiosyncratic forms of communication your daughter shows. She said that surely this would fulfil the pre-requisites of the Mental Capacity Act (2005).'
- Someone said they will raise this issue with the Chief Executive of the Social Care Association (SCA) to see if the SCA is in a position to progress this at a national level. This organisation focuses on good practice.
- Someone said: 'The message that distancing cold policies send is that people are not worthy and should only be touched when this cannot be avoided.' They said they would like to create a film called 'The Right to an Intimate Life'. They said people could get in touch if they would like to be involved: <http://frameworks4change.co.uk/>
- Someone suggested that care issues like this could be taken to the Care Quality Commission.

The parent responded to thank everyone for their contributions. They said that as suggested they formed a 'circle of consent'. Their daughter contributed by indicating how she consented or dissented to touch on a daily basis, as interpreted by her supporters. She said a set of guidelines has

been drawn up, agreed by all parties and now forms an integral part of her Personal Support Plan.

- Someone said 'It is such a shame that you had to go to the lengths you did to achieve, what is a relatively straight forward process. It is indicative of the continued lack of awareness in this area by professionals, both within LAs and Providers (of which I am one).'

4. Testicular screening

A student learning disability nurse wanted to know about any health screening projects involving testicular cancer, especially with regards to people with PMLD. They are looking to design a training session for staff and a communication book for service users.

Responses included:

- Looking after my balls' is the new title in the Royal College of Psychiatrists' 'Books Beyond Words' Series of picture books for use by people with learning disabilities. Available at a cost of £10.00 from the Publications Department, The Royal College of Psychiatrists, 17 Belgrave Square, London SW1X 8PG.
- Someone suggested speaking to Grapevine in Coventry who do work around health and creative ways of learning www.grapevinecovandwarks.org/
- Someone said 'Why do we persist in producing documents and booklets 'aimed at' people with PMLD, let's be frank here, who are they really for? ...We all know its far more complex than that, surely a better strategy would be to be taught how to desensitise and try to avoid anxiety...'
- Someone else said they were particularly interested in finding out about any testicular awareness projects involving young men aged between 11-19 with severe learning disabilities. They said they were yet to find specific projects aimed at this group.
- Someone else said that all people are different and therefore we should be making more individualised resources available to teams.

5. University of Kent specialist to review services for adults with profound and multiple intellectual disabilities

It was announced that the Department of Health has commissioned Professor Jim Mansell, Director of the Tizard Centre at the University of Kent, to carry out a review of services for adults with profound and multiple intellectual disabilities. The review will form the basis for policy guidance to local authorities and the NHS next year. Professor Mansell will be assisted by the PMLD Network..

A number of people responded to this announcement. Responses included:

- Someone asked where the statistic in the press release of 28, 000 adults with profound and multiple disabilities had come from? They also wanted clarification about the body of people he will be studying: people with Profound and multiple learning disabilities (PMLD), people with profound and multiple intellectual disabilities (PMID) or people with Profound Intellectual & Multiple Disabilities (PIMD)? As they said there are considerable differences between each.
- Professor Mansell later clarified on the forum that he tends to use 'profound intellectual and multiple disabilities' because this is the term used internationally and because members of this group don't necessarily have multiple intellectual disabilities - they have multiple disabilities in addition to their intellectual disability. He said he sees this term as referring to the same people identified as having 'profound and multiple learning disabilities'. He said he has not yet decided which term to use in his report - he recognises that the term 'profound and multiple learning disabilities' has become widely used in the UK. However he confirmed that he will be using the PMLD Network definition of PMLD. He also said that since the original press release, Professor Eric Emerson has completed his work estimating the number of adults with profound intellectual and multiple disabilities using the School Census. He estimates that there are just over 16,000 adults with profound intellectual and multiple disabilities in England now. Professor Mansell said 'that this is a relatively small, easily identifiable group with undeniable needs for support should make improving services easier'.
- The issue of housing was brought up. Tim Clements who has co-authored 'Group Homes for People with Intellectual Disabilities: Encouraging Inclusion and Participation' said the book focuses on the lives of people with severe and profound intellectual disabilities living in these settings. (A group home is defined as being accommodation for between 4-6 people) <http://www.jkp.com/catalogue/book/9781843106456#>. He said the book 'takes a pragmatic and practical stance; that we have this type of accommodation; that people with severe and profound intellectual disabilities are not going to be re-housed in supported living options in the near future, so we might as well get on and produce the best outcomes we can.
- Someone said that people with PMLD are being given supported living options now, for example his son who has just bought his own flat. The author replied to say he thought it was great that this young man is moving into a supported living environment but said he believes this is going to be the exception rather than the rule. He said a point Jim Mansell makes in the book's foreword is

that it will be hard to resource and organise a new wave of service development.

- Jim Mansell said on the forum that he is in the process of visiting people, services and organisations, looking for examples of good practice. He said that there are some areas where he does not feel he has yet found really good examples. He asked for the Forum to help identify them. They are:
- Self-directed support, either enabling people to live with their family or to enable them to live elsewhere.
- Use of technology to assist communication and control. For example a smart electric wheelchair that knows it's way round their home and can be driven without complicated control, an electronic communication aid that turn simple non-verbal acts into a phrase eg. I'd like a drink. He also asked if there are people who had this as children, and if so what has happened since they moved into adult services.
- Further education and employment . He asked if anyone with profound intellectual and multiple disabilities doing any work – paid or unpaid?
- Someone said they don't know of anyone using a smart electric wheelchair in the home but the technology is all ready out there for SMART wheelchairs that are operated with a single switch press and follow a light reflecting line. They said they use a programme called MOVE which focuses on developing functional sitting, standing and walking skills. They said there is very little opportunity in many areas for this to continue once pupils have left school as there is little money within adult services for training and equipment. They said the same is true for Intensive Interaction as this again requires dedicated staff time.
- Someone said they were interested to read this comment about Intensive Interaction needing dedicated staff time to be effective, and the challenge of this continuing after school. She said it does takes good training and a supportive attitude from management to keep it going but that there are many examples of this happening throughout the UK. She said the Intensive Interaction Newsletter is a good place to find out the various ways people are finding to make this happen: www.intensiveinteraction.co.uk
- Someone said that in their experience the sudden abrupt change from children's services to adult provision causes a lot of problems for the young people receiving the service. They have had great difficulty finding day provision and respite care which meets their daughter's needs.
- 'As these people get older their needs increase, their mobility however limited decreases if they do

not receive the correct amount of input.'

- Someone from the organisation Clear said they use 2 approaches to promoting inclusive communication with people with PMLD. One is the use of multimedia in developing communication passports, the other is a self advocacy tool which they have called 'sensory asking'. She said this uses a range of sensory material to discover what people do and do not like and to crystallise how people might be telling you this. They use this information to help build life enhancing opportunities.
- Someone said that their Communication passports have been developed over the last five years and are the result of the development of Key skills assessments in five areas – Communication, Cognition, Environmental Control Technology, Physical Skills and Personal, Social and Emotional Well Being. They said these assessments are supported by curricula which include advice on target setting for the individual. They focus on PMLD learners working between P1 and P3 /4. They said they will be publishing this shortly but are already working with a number of schools nationally.
- Someone said they look forward to reading Professor Mansell's report as it will help everyone to understand the nature, extent and needs of this group of people..

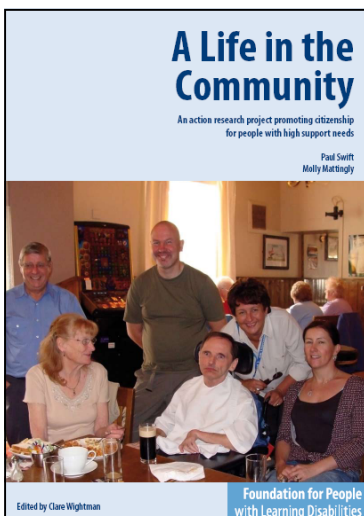
To take part in discussions please join the PMLD Network Forum at http://www.pmldnetwork.org/about_us/join.htm

Visit the PMLD Network website at www.pmldnetwork.org

NEWS

Life in the Community' project

The Foundation for People with Learning Disabilities has worked with a number of third sector service providers over the last three years to develop more opportunities for people with high support needs in their local communities. An important part of this has been to develop community connections.



Some of the key messages from the 'Life in the Community' work are:

- Circles of support, where a group of people come together to plan around a person and implement ideas, offer an effective way of finding out what a person with high support needs might like changed in their life
- Having their own pot of money (and the support to use it) leads a person with high support needs to have more choice and control about what they do, when they do it and how they do it.
- For people with high support needs to meet and spend time with people, other than paid staff, support staff need to work in a different way and develop skills to be good community connectors.
- Commissioners and care managers have a key role to increase these opportunities through personalised funding as well as funding services that have a community connecting role.

Community Connecting

Our work with the service provider organisations highlighted the need for staff to develop the skills of a 'community connector'. Staff working in this role helped people with high support needs and their families to turn plans into action by getting to know their gifts and interests and then looking for opportunities to use these to link with other people in their local communities.

Booklets and videos

The Foundation has produced a booklet about the 'Life in the Community' project and a video showing the work of the service provider organisations ([http://](http://www.learningdisabilities.org.uk/publications/?EntryId5=32795&char=L)

www.learningdisabilities.org.uk/publications/?EntryId5=32795&char=L)

The Foundation has also produced a booklet about community connecting and a DVD (<http://www.learningdisabilities.org.uk/publications/?EntryId5=32798&char=C>). These include the stories of people with high support needs. The booklet was written by Clare Wightman and both products are based on the work of Grapevine, in Coventry, which participated in 'Life in the Community'.

The DVD tells the story of Anne, who was supported to have a magazine swapping service amongst her neighbours. This resulted in them seeing Anne in a very different way and Anne enjoying the contact with them.

ADVOCATE 4 HEALTH: HELPING PEOPLE WITH A LEARNING DIFFICULTY TO BE HEALTHIER

My name is James Box and I am in the Advocate 4 Health group. I am writing this article for the group.

Advocate 4 Health launched their health website on 11th June 2009. (www.advocate4health.org.uk)

The website was made by the Advocate 4 Health group with help from a guy called Ashley Garner. Ashley is a professional web designer.

The website is to help people with a learning difficulty to understand information about being healthy. It is also useful for service providers across Greater London and Kent. The Advocate 4 Health project works in Bexley, Bromley, Croydon, Greenwich, Sutton and Wandsworth.

Matthew, a member of Advocate 4 Health says:

"The website is colourful and easy to use. I think it will be useful. It has things like news and what the group has done."

For service providers there is a 'local info' section that they can use to find other providers, activities and events. Service providers in the 6 project boroughs can upload their details for free.

The Advocate for Health project is run by Bexley and Bromley Advocacy and is funded by London Councils. The project is called a 'self advocacy' project, which means it encourages its members to speak up for themselves and have control over how

the project is run.

The group meets once a month in Bromley to talk about health and to get involved in healthy activities. There is also a monthly focus group that shares ideas and helps to plan the project.

The group is now running workshops for other groups in the 6 boroughs on how to use the website. People with learning difficulties are able to teach other people with learning difficulties. This gives people lots of confidence. Laura Wilkin says:

“It’s given me more confidence to go out and speak to people in other boroughs about what we do.”

The group are very proud of what they have achieved so far and they are really enjoying meeting new people through their work. Next year the group are going to make a DVD all about health and it will feature lots of exciting projects that are going on in the 6 project boroughs. They would love to hear from anyone who would like more information about the project or who would like to be on the website. Please contact Naomi Rose on 020 8300 9666 or email naomi@bbadvocacy.org

Specialist curriculum available for pupils with PMLD

The new edition of a curriculum designed specifically to meet the needs of pupils with profound and multiple learning difficulties (PMLD) is now available. The Profound Education Curriculum, developed by St Margaret’s School in Tadworth, Surrey, enables users to make detailed assessments of pupils’ achievements and measure them against the National Curriculum P Scales.

St Margaret’s is one of the UK’s only schools to cater exclusively for pupils with PMLD and complex health needs. Recognising that the National Curriculum was unable to measure adequately the small but significant developmental steps made by its pupils, the school began developing its own curriculum over ten years ago. The curriculum was originally published in 2006 and has since been purchased by over 40 special schools in the UK and internationally.

The new edition, renamed The Profound Education Curriculum, features updated content, new colour-coding that links each developmental area to National Curriculum P Scales 1-4 and a CD-ROM of assessment sheets so that pupil records can be maintained electronically.

Jan Cunningham, St Margaret’s School’s Head

Teacher, said: “We are very proud to have produced this new and updated version of our curriculum. The Profound Education Curriculum is a vital tool for us here at St Margaret’s for assessing and measuring the achievements of our pupils. By making it available for other schools we hope that many more children and young people with PMLD will benefit from the expertise that my team has developed.

“Profound Education as a whole is the overarching educational approach behind everything we do at St Margaret’s, including our curriculum. It places each pupil at the heart of their learning experience and gives them the opportunity to achieve and succeed regardless of their level of disability.”

Copies of The Profound Education Curriculum can be purchased from the school for £280. For more information please contact Elaine Lush on 01737 365810 or elush@thechildrenstrust.org.uk.

St Margaret’s School is hosting a special one day conference for specialists working with children and young people with PMLD on 24 October. For more information visit: www.thechildrenstrust.org.uk/pmldconference.

Personalisation and learning disabilities: A review of evidence on advocacy and its practice for people with learning disabilities and high support needs

Evidence suggests that people with learning disabilities and high support needs are likely to be left behind in social care services provision while those who are more independent have more choice and control over social care services.

The Social Care Institute for Excellence (SCIE) Position Paper 6,

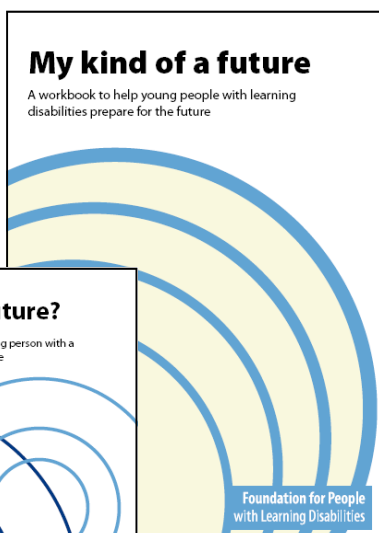
Supporting self advocacy (Lawton, 2006a), indicated that a lack of skills, understanding and provision of advocacy for people with high support needs could mean this group missing out on opportunities to shape not just their individual support but also wider planning.



This review was commissioned by SCIE to identify and consolidate the available evidence of progress and innovation in advocacy practice in relation to people with learning disabilities and high support needs.

The Foundation for People with Learning Disabilities has published a new workbook

The workbook is for young people with learning disabilities to help them plan their future after school or college, as well as an information booklet



for their parents. The materials were developed in consultation with young people with learning disabilities and their families.

Moving forward

The Easier Read workbook, My Kind of a Future, covers a range of topics including Staying Healthy, Getting Around and Getting Ready for Work. My Kind of a Future was developed to encourage young people to plan their own lives independently and think about their future.

Jill Davies, Research Programme Manager for the Foundation explained the thinking behind the project:

"Young people were telling us that there wasn't a good source of information available to help them think about their future. We hope My Kind of a Future will fill that gap. Young people with a learning disability have dreams and hopes for the future and we hope this workbook will help make it bit easier for them to go about following those dreams."

Help for parents

Prepared for the Future? has been written specifically for parents, siblings and other family members who want to help a young relative to lead a fulfilling life after leaving school. The booklet covers a wide range of topics in jargon-free language, including: getting support different opportunities available after school moving from the family home health, and getting support in your caring role

Jill Davies added: "Working with the young people and their families who were actually going through this transition allowed us to put together really valuable resources to help others in the same position. The families were very keen for their child to get the most out of life as they grow older but the choices available can sometimes feel overwhelming. Many parents are really concerned as to how their child would cope with living away from the family home and managing their own money. The resources are easy to use for both young people and their families and will help smooth what is a bumpy transition for any young person".

Both My Kind of a Future and Prepared for the Future? can be downloaded for free from www.learningdisabilities.org.uk

Good Learning Disability Partnership Boards: making it happen for everyone

This guide provides best practice examples from around the country and proposed ways of working, based on the evidence that the most effective Partnership Boards are those with strong links to other local boards and work programmes; where there is delegated or shared financial



and commissioning responsibility; and where there is meaningful representation of people with learning disabilities and family carers from all local communities.

UPDATE: The treatment and management of depression in adults with chronic physical health problems (partial update of CG23)

This guideline is published alongside 'Depression: the treatment and management of depression in adults (update)' (NICE clinical guideline 90), which makes recommendations on the identification, treatment and management of depression in adults aged 18 years and older, in primary and secondary care

This guideline (and CG90) update recommendations made in NICE technology appraisal guidance 97 for the treatment of depression only. The guidance in TA97 remains unchanged for the use of CCBT in the treatment of panic and phobia and obsessive compulsive disorder.

Study into the dietary pattern and depressive symptoms in middle age released

Commenting on the 'Dietary pattern and depressive symptoms in middle age' study by researchers from University College London, Dr Andrew McCulloch, Chief Executive of the Mental Health Foundation, said:

"This study adds to an existing body of solid research that shows the strong links between what we eat and our mental health. The mind and body are often separated but the brain, just like the heart or liver, is an organ that needs nutrients to stay healthy and functional."

Research studies important

"Major studies like this are crucial because they hold the key to us better understanding mental illness, which enables us to find out how we can both treat and prevent widespread mental health problems like depression, anxiety and dementia.

"We need to take notice of international dietary studies. People living in some countries in other parts of the world have very different diets to people in the UK. There is a lot to be gained from researchers around the globe assessing the impact that different diets can have on mental health."

UK population is consuming less nutritious, fresh produce and more saturated fats and sugars

"The UK population is consuming less nutritious, fresh produce and more saturated fats and sugars. Significant changes in the way food is produced and manufactured have reduced the amounts of essential fats, vitamins and minerals we consume. New substances, such as pesticides, additives and trans-fats have also been introduced to the diet. This imbalance combined with a lack of vitamins and minerals is associated with depression as well as concentration and memory problems.

"We are particularly concerned about those who cannot access fresh produce easily or live in areas where there are a high number of fast food restaurants and takeaways. Groups to which we need to pay real attention include those on a low income and the unemployed."

Government needs to educate the general public

"The findings of this study will come as a surprise to many because the links between diet and mental health are still relatively unknown. The Government, as part of its ten year plan to tackle mental illness by 2020, needs to educate individuals and families more about how they can look after their mental health to prevent common problems such as depression and dementia.

"There are things that people can do to ensure that they eat the necessary nutrients to keep the brain healthy. The same diet that is widely accepted to be good for your physical health is also good for your mental health. A healthy balanced diet includes lots of different types of fruit and vegetables, wholegrain cereals, nuts and seeds, meat and dairy from extensively reared sources and oily fish from sustainable fisheries."

Findings taken from Feeding Minds, a report from the Mental Health Foundation:

Over the last 60 years or so there has been a 34 per cent decline in UK vegetable consumption with currently only 13 per cent of men and 15 per cent of women now eating at least five portions of fruit and vegetables per day

People in the UK eat 59 per cent less fish - the main source of omega 3 fatty acids - than they did 60 years ago.

Women reported eating healthy foods, including fresh vegetables, fruit or fruit juice and meals made from scratch, more often than men, who tend to eat more takeaways and ready meals.

Younger people are more likely than older people to report daily mental health problems, as are those in social class DE, those on a lower income, those who

are not in paid employment and those who are not married.

Nearly two thirds of those who did not report daily mental health problems eat fresh fruit or fruit juice every day, compared with less than half of those who did report daily mental health problems. This pattern was similar for fresh vegetables and salad.

Nutritional advice

A web guide providing recipes and nutritional advice to help people manage their mental well-being can be found at www.mentalhealth.org.uk/feedingminds

PMLD Network responds to Social Care Green Paper

The PMLD Network has submitted a response to the Government's consultation on the social care green paper. It welcomes the green paper and its proposal to create a National Care Service.

But it says it is crucial that the government understands that people with profound and multiple learning disabilities (PMLD) will need lifelong complex packages of support to meet their health and social care needs. There needs to be a strong commitment to fully meeting the needs of people with PMLD throughout their lives and not just at times of crisis. The Government needs to ensure that there is enough funding in the system to do this.

Beverley Dawkins, Chair of the PMLD Network said, "We welcome reform of the care and support system. Currently most people with PMLD are not getting the care and support they need to have an 'ordinary life' and their human rights are largely ignored. The new system must fully support the equal rights of this vulnerable part of society."

Read the PMLD Network response to the Social Care Green Paper:

http://www.pmlidnetwork.org/resources/PMLD_Network_response_green_paper.pdf

Read the Social Care green paper, 'Shaping the Future of Care Together':

http://www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_102338



Better support for children with SEN

Children's secretary Ed Balls has promised to change the way schools support children with special educational needs (SEN). He has announced a new right to appeal for parents if they are unhappy with decisions about their child's statement of SEN and a new duty for OFSTED to inspect the quality of education provided for children with SEN.

These announcements follow on from recommendations from the Lamb Inquiry and Mencap welcomes them as a step in the right direction to meet the needs of young people with learning disabilities.

David Congdon of Mencap said "All too often parents of children with a learning disability have to fight to get the educational support their child needs. The proposed 'right to appeal' will take a parent's knowledge and understanding of their child into account, strengthening their rights as parents. It is a major step towards addressing the needs of children with a learning disability more accurately and effectively.

Find out more about support for children with special educational needs:
<http://www.dcsf.gov.uk/lambinquiry/>

Ed Balls commissions review into SEN teacher training

Children's Secretary Ed Balls has commissioned an independent review into the supply of teachers trained to meet the needs of children with severe learning disabilities.

Toby Salt, deputy chief executive of the National College for Leadership of Schools and Children's Services, will look into the supply of teachers trained to meet the needs of children with severe learning disabilities (SLD) and profound and multiple learning disabilities (PMLD).

The Specialist Schools and Academies Trust will also be running a £550,000 project to share good practice in teaching and learning for children with the most complex learning disabilities

Find out more on the Children and Young People now website:

<http://www.cypnow.co.uk/bulletins/Daily-Bulletin/news/941624/?DCMP=EMC-DailyBulletin>

Funding at breaking point

Carers organisations have written to the chief executive of the NHS to ask where £150 million promised for carers' breaks has gone. They are worried that the money - outlined in June 2008 in the national carers' strategy - is not being used for its intended purpose.

Research carried out by Carers UK found that PCTs were still unaware of the funding, unclear about how much had been allocated to them, or denied having any new money allocated.

Mencap's breaking point campaign showed how 8 out of 10 parents and carers are being stretched beyond their limits in trying to care for their loved ones. Families of children and adults with severe or profound learning disabilities love the people they care for. They care for them willingly, but they need help to do so in a system where a carer's full time job is sometimes viewed as suitable a suitable break and respite from providing care. The funding for breaks set out in the national carers strategy was seen as a key part of the support for carers.

Read about Mencap's Breaking Point campaign
<http://www.mencap.org.uk/case.asp?id=542&menuId=557&pageNo=>

Find out about the reaction by Carers UK
<http://www.carersuk.org/Newsandcampaigns/News/1246978705>

originally published in 2006 and has since been purchased by over 40 special schools in the UK and internationally.

The new edition, renamed The Profound Education Curriculum, features updated content, new colour-coding that links each developmental area to National Curriculum P Scales 1-4 and a CD-ROM of assessment sheets so that pupil records can be maintained electronically.

Jan Cunningham, St Margaret's School's Head Teacher, said: "We are very proud to have produced this new and updated version of our curriculum. The Profound Education Curriculum is a vital tool for us here at St Margaret's for assessing and measuring the achievements of our pupils. By making it available for other schools we hope that many more children and young people with PMLD will benefit from the expertise that my team has developed.

"Profound Education as a whole is the overarching educational approach behind everything we do at St Margaret's, including our curriculum. It places each pupil at the heart of their learning experience and gives them the opportunity to achieve and succeed regardless of their level of disability."

Copies of The Profound Education Curriculum can be purchased from the school for £280. For more information please contact Elaine Lush on 01737 365810 or elush@thechildrenstrust.org.uk



Specialist curriculum available for pupils with PMLD

The new edition of a curriculum designed specifically to meet the needs of pupils with profound and multiple learning difficulties (PMLD) is now available. The Profound Education Curriculum, developed by St Margaret's School in Tadworth, Surrey, enables users to make detailed assessments of pupils' achievements and measure them against the National Curriculum P Scales.

St Margaret's is one of the UK's only schools to cater exclusively for pupils with PMLD and complex health needs. Recognising that the National Curriculum was unable to measure adequately the small but significant developmental steps made by its pupils, the school began developing its own curriculum over ten years ago. The curriculum was

University of Kent specialist to review services for adults with profound and multiple intellectual disabilities

The Department of Health has commissioned Professor Jim Mansell, Director of the Tizard Centre at the University of Kent, to carry out a review of services for adults with profound and multiple intellectual disabilities.

The intention is that the review will form the basis for policy guidance to local authorities and the National Health Service next year. Professor Mansell will be assisted by The Profound and Multiple Learning Disabilities (PMLD) Network, which includes families, professionals and voluntary organisations.

Professor Mansell explained: 'There are thought to be about 16,000 adults with profound and multiple intellectual disabilities in England. They are among the most disabled people in our society. The government recognises that services and support for these people and their families are not improving

fast enough. My review will look at what needs to be done.'

Beverley Dawkins, national officer for profound and multiple learning disabilities at UK learning disability charity Mencap and Chair of the Profound and Multiple Learning Disabilities (PMLD) Network, commented: 'We welcome this announcement and the recognition by the government that improvements need to be made for people with profound and multiple learning disabilities. People with profound and multiple learning disabilities are among the most excluded and disadvantaged people in today's society and all too often their needs are ignored. The PMLD Network will be delighted to play a full part in the review.'

Anne Williams, National Director for Learning Disabilities, said: 'We are committed to making sure that the benefits of Valuing People Now are experienced by those with the most complex needs. Professor Mansell's work will set out what needs to be done to provide good quality services. I am sure it will be of great benefit to people with learning disabilities and their families.'

The Department of Health views improvements in services for people with profound intellectual and multiple disabilities as a major part of its learning disability strategy (Valuing People Now).

Involve Me



'If we listen to what is important to people with PMLD we can better meet their needs.'

Involve Me is a 3 year project about how to creatively involve people with profound and multiple learning disabilities (PMLD) in decision making.

The project is supported by the Renton Foundation and is being run by Mencap in partnership with the British Institute of Learning Disabilities (BILD).

Most people with PMLD don't use formal communication like words and symbols. This makes communication very difficult and can mean people with PMLD are not involved in important decisions, such as where to live. But people with PMLD should be involved in all decisions which affect their lives. They have important preferences and experiences to

share. We just need to give them the opportunity to do this.

Staff and people with PMLD at 4 sites are taking part in the Involve Me project. Each site is using a different creative approach to involve people with PMLD.

An interactive DVD and training guide will be produced at the end of the project. They will show how the creative approaches have been used at each site. They will show how everyone including staff, families and policy makers can start involving people with PMLD in decision making. We will also be running training workshops and conferences.

Find out more about Involve Me:
www.mencap.org.uk/involve
 involve@mencap.org.uk
 079 4493 1433

Websites

www.videoprofiling.co.uk

A multimedia interactive and updatable communication passports that can be easily shared with professionals around the adult (or child) on a need to know basis

www.voiceuk.org.uk

Is a national charity supporting people with learning disabilities and other vulnerable people who have experienced crime or abuse. We also support their families, carers and professional workers.

We provide a telephone helpline, the line is attended from 9am to 5pm Monday to Friday and Wednesday 9 am to 7 pm.

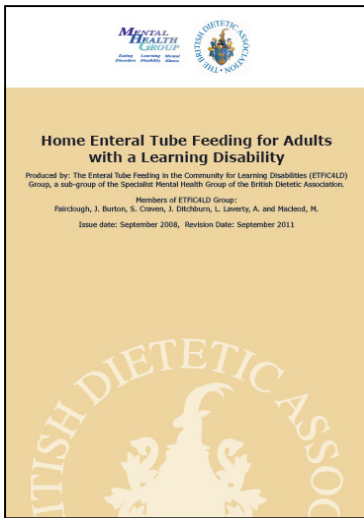
OUR NEW HELPLINE TELEPHONE NUMBER IS 080 880 2 8686

Calls to this number will not show up on your telephone bill and are free from mobiles and most landlines.

RESOURCES

Home Enteral Tube Feeding for Adults with a Learning Disability

Produced by: The Enteral Tube Feeding in the Community for Learning Disabilities (ETFIC4LD) Group, a sub-group of the Specialist Mental Health Group of the British Dietetic Association.

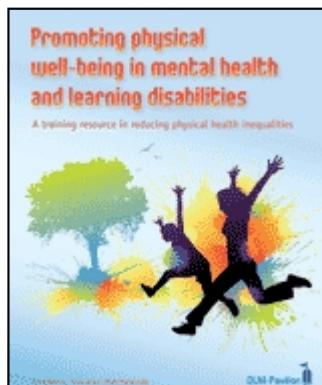


This Consensus Statement is intended to inform and support the practice of dietitians who are not undertaking a specialist learning disabilities (LD) role but do care for adults with a LD within their caseload. The Statement may be a useful resource for other professionals and student dietitians.

http://www.rcn.org.uk/_data/assets/pdf_file/0006/206448/Home_Enteral_Tube_Feeding_for_Adults_with_a_Learning_Disability.pdf

Promoting Physical Well-being in Mental Health and Learning Disabilities

Do you want to organise and run a healthy living group? All it takes is a little information, good sense, and the ability to help and support your service users to make a few healthy changes to their lifestyles.



This pack is a facilitator's resource, which will enable you to set up and run a healthy living group that will be fun and interactive for community groups and individuals, including adults with specific conditions such as mental health illnesses and learning difficulties.

The pack contains vital information for: community support workers, occupational therapists, community psychiatric nurses, social workers, voluntary bodies and charities, local community support groups, carers and service users.

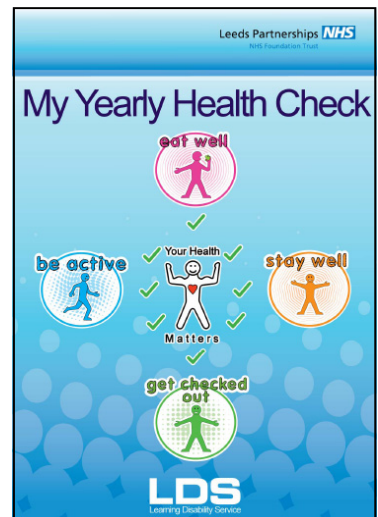
Format: Ringbound materials (approx 200pp) plus CD-rom containing a healthy living folder, exercise pack and session worksheets and handouts.

Price: £95
 Order Code: E002
 ISBN: 978 1 84196 254 2

An accessible annual health assessment called 'my yearly health check' document

<http://www.choiceforum.org/docs/healthassessment.pdf>

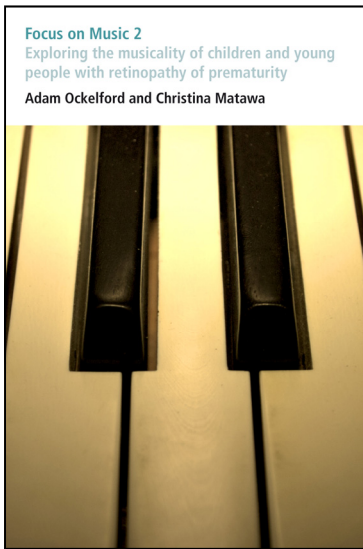
Since it was put up on the forum resources pages we have had lots of enquiries about other trusts, services and organisations using it. We are now able to offer the documentation for a one-off licence fee of £220. This covers some basic re-design in terms of putting your organisation's logo on (as supplied by yourselves) and any minor changes you may require. For this fee you get



a PDF and Word copy for you to use throughout your organisation for all service users.

Email me at learning.disabilities@leedspft.nhs.uk if you have any queries or wish to place an order. Alternatively you can call me on 0113 305 5128 to discuss.

PUBLICATIONS



Author(s):
Adam Ockelford and Christina Matawa

Publisher:
Institute of Education Publications

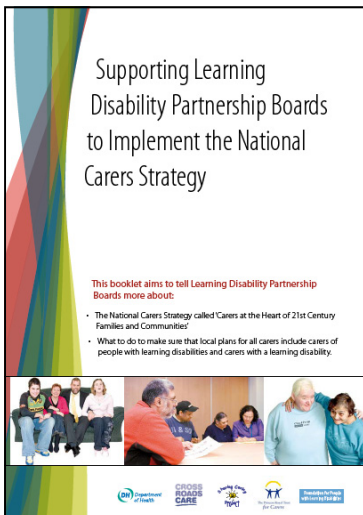
ISBN:
978-0-8547-861-8

Pub Date:
2009

Price:
£12.99

Focus on Music 2: Exploring the musicality of children and young people with retinopathy of prematurity

This study is the second in a series that is planned to examine the impact of different forms of visual impairment on the developing musicality of blind and partially sighted children and young people. Each volume will focus on the effects of a particular medical condition, which can cause varying degrees of sight loss, may result in learning difficulties, and which has been reported anecdotally to be associated with an unusual prevalence of exceptional musical abilities or interests.



Author(s):
Dalia Magrill, Christine Towers and Hazel Morgan

Publisher:
Crown

Gateway reference:
12456

Pub Date:
2009

Price:
Free
http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_106394.pdf

Supporting Learning Disability Partnership Boards to Implement the National Carers Strategy

This booklet offers guidance to Learning Disability Partnership Boards to help them ensure carers of people with learning disabilities, and carers with learning disabilities are:

- supported in their own right, and
- involved in local service developments which affect their lives, and the lives of the people they care for.



Author:
Nicola Grove

Publisher:
Bild

ISBN:
978 1 905218 09 7

Pub Date:
2009

Price:
£30

Learning to Tell - a handbook for inclusive storytelling

The resource aims to enable people who are marginalised through communication and language difficulties, to develop skills in narrative and story. The role of stories in their lives is the same as for everyone else – stories are fun and interesting, help you to make friends, understand the world and develop your imagination.

REVIEWS

Title: Adults with Learning Disabilities (Having fun, meeting needs)

Authors: Helen Sonnet & Anne Taylor

Publishers: Jessica Kingsley Publishers

Pub date: 2009

Price: £17.99

Simple, Informative, Imaginative!

This book is a fantastic resource, one which has truly inspired and helped us to become more creative when devising activities for adults with learning disabilities and has our full recommendation.

Activities for Adults with Learning Disabilities can be used in a variety of settings and by a range of professionals, such as nurses, support workers and activity co-ordinators, as well as by friends, parents and carers.

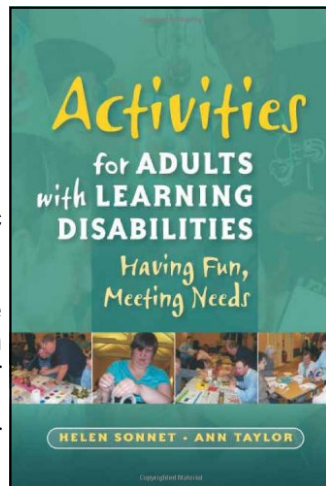
It's suitable for day centres, residential homes, social clubs and hospitals and is ideal for services who have limited resources to aid activities within their environment.

The activities are divided into easy-to-use sections, including cookery, arts and crafts, party games, drama and dance and outside events, all of which are descriptive, well written, self-explanatory and include helpful hints and tips.

This book has over 60 simple, do-able activities that will capture not only the imagination of the reader but of the participants as well, by giving them an enjoyable, fun and fulfilling experience, time and time again.

Using this book will permit the reader to choose an activity where not only will they be able to learn and develop new skills, but they will also be able to implement them in a variety of ways. This book will give the audience an opportunity to learn and share valuable facts about one another through the activities, therefore giving encouragement and confidence to the participants, which is equally important.

The authors are Helen Sonnet and Ann Taylor, two people who have a wealth of experience. Helen is a



teacher and author with over 30 years experience in education. She specialises in working with children with learning and behavioural difficulties and is a volunteer helper at her local Gateway club, a social club connected to Mencap. Ann is a qualified teacher who has experience of working with adults with learning disabilities, she has been a Gateway Club leader for the past 12 years.

In conclusion if you are looking for a book on activities for adults with learning disabilities than look no further, as this is the only book we have come across that is instructive, user friendly and enjoyable.

Kiran Rai (Person Centred Planning Assistant)
Sarah Baxter (Assistant Behavioural Specialist)

Services for People with Learning Disabilities –
Enhanced Support Services Berkshire Healthcare
NHS Foundation Trust

Website Review

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

I have just discovered this interesting little site where there are songs available covering a range of personal issues.

The songs are the brain child of Edwin Humphreys – a nurse and musician and the above site has 6 songs available to download free of charge, however he is currently making a CD which will feature 16 songs.

The songs available on the web site cover such areas as :-

- Feeling good – Masturbation song.
- Checking your testicles for testicular cancer song
- Smear tests song,
- Just say no (use a condom song)
- personal hygiene song,
- Tell someone (vulnerable persons song)

The music is simply arranged though catchy and the words easy to listen to but there are accompanying words as the music plays.

These songs are a marvellous resource to play as an introduction to discussing intimate issues, as well as being informative for some people to listen to privately. The beauty is that they can be played over and over again too.

The personal hygiene song has been specifically written for people who have a severe learning

disability and certainly adds a sparkle to washing.

Whilst not designed for people who have profound learning disabilities, I believe they could have their place. For instance the feeling good song sends an open message that it is okay to masturbate (although the private location will need to be made more explicit). The beauty is that the catchy songs can be used as a teaching / training aid over time. This is a new site and definitely worth visiting.

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

Cerebra Research Unit

<http://sites.pcmd.ac.uk/cerebra/main.php?g=main>

This web site comes from the South West of England and as the name suggests Cerebra's main function is research. Cerebra are a registered

charity for children with brain injuries who fund the research unit attached to the Peninsula medical school.

This group seems to be relatively new and are eager to undertake their research agenda in partnership with families. They are also eager to receive requests from parents and children too.

Their site is very user friendly and is one to keep an eye on in the future – already there is some useful information discussing the evidence base behind some treatments. At the moment mainly related to Cerebral Palsy.

The forums are accessible to browse, though you will need to register to post any comments – an interesting thread there by a few parents on incontinence pants and pads.

This site will specifically be of interest to parents, students undertaking projects and research, professionals seeking (or wishing to share) more information about the validity of treatments.

REPORT BACK

I went to Leicester on Monday 16th November to an East Midlands Multi-sensory Impairment network conference on curriculum for pupils with MSI and/ or PMLD. It was a really informative and inspiring day.

There were 4 curriculum models on which to reflect:

Barrs Court School in Herefordshire
St Margarets' School, Tadworth
Victoria MSI Unit, Birmingham
Whitefield School, London

Each school's curriculum was presented in overview and then later explored in a little more depth in smaller seminars. There was time for general discussion and for questions for each speaker. Unfortunately I had to leave before the end of the afternoon and so can't report on their final 'workshop and practical implications'.

Barrs Court curriculum for pupils with MSI and /or PMLD is divided into 4 areas:

Early Communication Skills
Early Thinking Skills
Early Motor Skills
Early Emotional, Social and Behavioural Skills
Staff can use the curriculum to help with assessment, planning, teaching activities and resources.

St Margaret's curriculum is now called 'Profound Education' and is multisensory in focus. It is defined

developmentally and has fine steps for progress, concentrating on the world around the pupils, social interaction and relationships. It covers education and health to give an integrated approach.

Victoria School MSI Unit curriculum is aimed at more able youngsters with sensory impairments. It does not cover all the needs of pupils with PMLD, although some of approaches will be useful with that population. It offers teaching and learning strategies across a wide range of learning domains from communication and conceptual development to movement and mobility and ownership of learning.

Whitefield's curriculum is offered at three distinct levels, pre-formal (P1-3), semi- formal (P4-8) and formal (NC). The curriculum is based on the school's own documents which set out objectives covering a range of needs, so every child can follow a curriculum that is right for them, whilst still meeting statutory requirements.

What was particularly inspiring about the conference was the obvious total commitment of all presenters to meeting the needs of the pupils in their schools. An enormous amount of work had gone into developing the curriculum documents which will be useful far beyond the walls of those particular schools. It is so encouraging that schools are not only being imaginative about interpreting a curriculum handed down by government but are willing to share their ideas.

Short Courses and Conferences

February

- | | |
|--|---|
| <p>Date: 2nd Title: All Aboard: Special - the particular issues facing Teaching Assistants supporting children with little or no sight and with additional needs Location: Friend's House, London Provider: RNIB Contact: See Provider Details</p> | <p>Date: 5th Title: Developing person centred thinking and working Location: London Provider: BILD Contact: See Provider Details</p> |
| <p>Date: 3rd Title: "But she can't tell you what she wants" – non instructed advocacy Location: London Provider: BILD Contact: See Provider Details</p> | <p>Date: 5th Title: Introducing sensory integration into educational or care settings Location: Birmingham Provider: Florich Productions Contact: See Provider Details</p> |
| <p>Date: 5 day course – 3rd, 25th February, 3rd 17th 31st March Title: Intervenor Training Course Causes and implications of deafblindness, the role of the intervenor, visual and hearing impairment, mobility and orientation, communication, touch interaction, interactive environments Location: Woodside Family Centre, Bristol BS15 8DG Provider: SENSE Contact: Jenny Fletcher Tel: 07980 606951 e-mail: jenny.fletcher@sense.org.uk</p> | <p>Date: 8th Title: Informed and successful target setting Location: Nottingham Provider: Florich Productions Contact: See Provider Details</p> |
| <p>Date: 4th Title: Talking to Families; Listening to Families Location: Sunfield PDC Provider: Sunfield PDC Contact: See Provider Details</p> | <p>Date: 10th Title: Understanding and Managing Sensory Related Behaviour Location: Sunfield PDC Provider: Sunfield PDC Contact: See Provider Details</p> |
| <p>Date: 4th/5th Title: Advanced sensology skills – reinforcing good practice Location: London Provider: Florich Productions Contact: See Provider Details</p> | <p>Date: 10th Title: Sensology – pre-requisites to learning. A sensory journey into embedding pre-requisites into every day curriculum Location: Manchester Provider: Florich Productions Contact: See Provider Details</p> |
| | <p>Date: 10th Title: Physical Interventions: a policy framework – exploring definitions, use of restrictive physical interventions, scope of policy, health and safety issues, relevance to organisational risk assessment Location: Kidderminster Provider: BILD Contact: See Provider Details</p> |

Providers Details

BILD

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

Concept Training

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

Date: 11th
Title: Linking Lives Conference 2010
 From margin to mainstream: using Intensive Interaction to make life better for people with PMLD
Location: The Reigate Manor Hotel, Surrey
Provider: Sunfield
Contact: www.usinabus.org.uk
 info@usinabus.org.uk
 01737 764774

Date: 17th
Title: Aromatherapy and massage for children with complex needs an introduction
Location: RNIB, Liverpool
Provider: Action for Blind People North West
Contact: Sarah Crabb
 0151 298 3224
 Sarah.crabb@actionforblindpeople.org.uk

Date: 25th
Title: Developing and sustaining community connections
 Getting the right support for people with learning disabilities to make real and sustainable connections in the community
Location: London
Provider: BILD
Contact: See Provider Details

March

Date: 3rd
Title: Communication and autism
Location: London
Provider: BILD
Contact: See Provider Details

Date: 4th/5th
Title: Advanced sensology skills – reinforcing good practice
Location: Sheffield
Provider: Florich Productions
Contact: See Provider Details

Date: 8th
Title: Intensive Interaction
Location: Sunfield PDC
Provider: Sunfield
Contact: See providers details

Date: 8th / 9th / 18th / 23rd
Title: Practical & Effective Ways of Using Multi-sensory Equipment
Location: London/Birmingham/Liverpool/Glasgow
Provider: Concept Training Ltd
Contact: (See Providers Details)

Date: 8th / 9th
Title: Inclusive Play
Location: Chorley / Birmingham
Provider: Concept Training Ltd
Contact: (See Providers Details)

Date: 8th / 23rd / 24th
Title: Intensive Interaction
Location: London/Edinburgh/Birmingham
Provider: Concept Training Ltd
Contact: (See Providers Details)

Date: 9th / 23rd
Title: The Autistic Spectrum when things are not straightforward! *Working with children with a complex profile*
Location: Chorley / London
Provider: Concept Training Ltd
Contact: (See Providers Details)

Date: 10th
Title: Choosing staff to support you
 For people with learning disabilities and their supporters
Location: Kidderminster
Provider: BILD
Contact: See Provider Details

Date: 10th
Title: Aromatherapy and massage for children with complex needs – part two – developing good practice
Location: The Gateway Centre, Liverpool
Provider: Action for Blind People North West
Contact: Sarah Crabb
 0151 298 3224
 Sarah.crabb@actionforblindpeople.org.uk

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: 11th
Title: **Successful Multi-Sensory Sessions**
Location: **Birmingham**
Provider: Concept Training Ltd
Contact: (See Providers Details)

Date: 11th
 Title: Confident Parenting
 Location: London
 Provider: EQUALS
 Contact: e-mail: admin@equalsoffice.co.uk

Date: 11th
 Title: Whose choice is it anyway? Supporting choice and decision making
 Location: Kidderminster
 Provider: BILD
 Contact: See Provider Details

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

Date: **12th/24th**
Title: **Positive Ways of Changing Behaviour**
Location: **Birmingham/ Leicester**
Provider: Concept Training Ltd
Contact: (See Providers Details)

Date: 16th
 Title: The International Big event 2010
 Location: BT Conference Centre, Liverpool
 Provider: In Control
 Contact: 0156 482 1650
 admin@in-control.org.uk
 www.in-control.org.uk/bigevent

Date: 15th
 Title: Learning together: developing mutual understanding using touch, sound, gesture and the Canaan Barrie 'on body' signs
 Location: RNIB Birmingham
 Provider: RNIB
 Contact: See Provider Details

Date: 17th
 Title: PSHE, Sex & Relationship Education in the ASD/SLD/PMLD classroom
 Location: Sunfield PDC
 Provider: Sunfield
 Contact: See providers details

Date: 18th
 Title: Current approaches to the education and care of children and young people with Foetal Alcohol Spectrum Disorder (FASD)
 Location: London RSM
 Provider: Royal Society Of Medicine Intellectual Disability Forum
 Contact: Ruth Threadgold
 020 7903 394
 intellectualdisability@rsm.ac.uk

Date: 19th
 Title: Informed and successful target setting
 Location: Birmingham
 Provider: Florich Productions
 Contact: See provider details

Date: 19th
 Title: Mental Health Issues in Persons with Intellectual Disability and Autistic Spectrum Disorders
 Location: Sunfield PDC
 Provider: Sunfield PDC

Date: **22nd**
Title: **Sensory Play & Leisure in the Multi-sensory Environment**
Location: **London**
Provider: Concept Training Ltd
Contact: (See Providers Details)

Date: 24th
 Title: Personalisation – what is it? How personal budgets and self directed support have helped people with learning disabilities get a good life and become involved in their community
 Location: Kidderminster
 Provider: BILD
 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: 24th
 Title: Play matters for young children with visual impairment, and children with additional needs
 Supporting active learning of young children with visual impairment and of children with complex needs
 Location: The Gateway Centre, Liverpool
 Provider: Action for Blind People North West
 Contact: Sarah Crabb
 0151 298 3224
 Sarah.crabb@actionforblindpeople.org.uk

Date: 25th
 Title: Physical Education – An Introduction to Sherborne Developmental Movement – Certificate Level 1
 Location: Northampton
 Provider: EQUALS
 Contact: e-mail: admin@equalsoffice.co.uk

Date: 26th
 Title: Activities for communication for people with profound learning disabilities
 Location: London
 Provider: BILD
 Contact: See Provider Details

Date: 27th
 Title: Sensory Differences and the Role of Positive Touch
 Location: Birmingham
 Provider: Concept Training Ltd.
 Contact: See Provider Details

April

Date: 23rd
 Title: Inclusive Play
 Location: London
 Provider: Concept Training Ltd.
 Contact: See Provider Details

Date: 27th, 28th & 29th
 Title: Intensive Interaction Co-ordinator Courses
 Location: The Together Trust, Schools, Cheshire, SK8 1JE
 Provider: Intensive Interaction
 Contact: Sarah Forde on 07976-778969
 www.intensiveinteraction.co.uk/events/coordinators.php

Date: 28th
 Title: Practical & Effective Ways of Using Multi-sensory Equipment
 Location: Edinburgh
 Provider: Concept Training Ltd.
 Contact: See Provider Details

Date: 28th
 Title: Intensive Interaction
 Location: Chorley
 Provider: Concept Training Ltd.
 Contact: See Provider Details

Date: 29th
 Title: Successful Multi-Sensory Sessions
 Location: Chorley
 Provider: Concept Training Ltd.
 Contact: See Provider Details

Date: 30th
 Title: Very special maths
 Location: London
 Provider: Florich Productions
 Contact: See Provider Details

Date: 30th
 Title: P.M.L.D. – Engaging Children in Learning
 Location: Chorley
 Provider: Concept Training Ltd.
 Contact: See Provider Details

May

Date: 14th
 Title: Intensive Interaction
 Location: The Beeches Conference Centre, Birmingham
 Provider: Interact
 Contact: Helen Janes
 01727 768 726
 07778 178346
 events.made.easy@ntlworld.com

June

Date: 11th
 Title: Intensive Interaction
 Location: Hunton Park Conference Centre
 Watford Junction 20 M25
 Provider: Interact
 Contact: Helen Janes
 01727 768 726
 07778 178346
 events.made.easy@ntlworld.com

Date: 22nd, 23rd & 24th
 Title: Intensive Interaction Co-ordinator Courses
 Location: The Together Trust, Schools, Cheshire, SK8 1JE
 Provider: Intensive Interaction
 Contact: Sarah Forde on 07976-778969
 www.intensiveinteraction.co.uk/events/coordinators.php

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/pclcd

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/pclcd

PMLD-Link

Subscription Year 2010

Volume 22 Nos. 1,2 and 3

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

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

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

PMLD-Link also includes:

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

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

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

| | |
|-------------------------|---|
| 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.

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(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

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

PMMLD Link

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