

# PMMLD LINK

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

**Summer 2008**

**Community  
Partnerships**

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

## Summer 2008

### Community Partnerships

This issue has a focus on 'Community Partnerships', though not exclusively. My opinion is that there is a crying need for many examples in print of effective (an ineffective) partnerships between agencies, parents and carers and person-centred approaches to seeking the views of people with PMLD about the services they require. Currently, we have governments and assemblies that have been seeking for some years to encourage local authorities and local health services to work together to commission and deliver integrated services. In part, ministers and their advisers are concerned about the future cost of services for people with disabilities but there is a real push from the top for 'smarter working' and 'joined up thinking'. There are also genuine attempts to consult. Children's services and services for adults with learning disabilities continue re-organise themselves at local level to deliver new outcome-focussed services and this remains a frustrating time of uncertainty for many who are looking for a coherent pattern to emerge. Regrettably, there is too much 're-inventing the wheel' across the nation and not enough sharing of experiences. This issue contributes several examples of developing partnerships not only among the articles but also with several websites and other resources. In addition, you will find other-themed articles and information of interest, including Alice Bradley's article which reminds us of the poorly-endowed world beyond these islands. Enjoy your reading! I hope that it provides useful links.



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## Community Participation In Learning Disability Nurse Education

Neil Summers, Kim Scarborough, Jackie Clark, Eric Broussine  
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Registered Nurses for People with Learning Disabilities (RNLD) need to be able to respond to the needs of the communities they support, namely people with learning disabilities and family carers. This article will look at changes in Learning Disability Nurse Training at the University of the West of England in Bristol and how these changes were influenced by people with learning disabilities and their family carers. To become a RNLD, students have to complete a course approved by the Nursing and Midwifery Council (NMC) usually a three year university course. Not all courses are the same although the skills nurses have to gain are set by the NMC. This means each university can develop a course that whilst meeting NMC approval can be influenced by local need.

### **Why is working in partnership with the community a good thing?**

The Government worked in collaboration with all stakeholders to publish a new philosophy for learning disabilities services called Valuing People: A New Strategy for Learning Disabilities for the 21<sup>st</sup> Century (DH 2001), recently updated (Valuing People Now DH 2008). This paper had key principles about rights, inclusion, choice, and control. RNLDs need to be able to value both people with learning disabilities and their family carers and to work collaboratively with these communities to realise these principles. Also the publication of a range of government papers and initiatives on working with service users and family carers to improve services means that health and social care professionals have to develop skills in really listening and responding to people's needs (see <http://www.invo.org.uk/>). The way health services work is changing and RNLD training needs to respond to these changes.

In order to be part of the imminent 'sea change', it is clear that we need to look closely at who we are teaching, what we are teaching, where we are teaching and how we envisage students will learn not only facts but a strong value base that reflects new philosophies. In other words, will the new RNLDs be fit for purpose in this new age of delivering care and support to vulnerable people and their families? When asked, families and people with a learning difficulty said that things need to change on all fronts, including educational establishments; they said that along with all other agencies, 'education' had ignored them and their expertise.

### **How did we work with people with learning disabilities and family carers to bring about change?**

When the Learning Disability Nursing programme team reviewed the training programme for RNLDs in 2003 the need to improve the programme by re-developing the practice and theory modules was acknowledged in light of policy and practice shifts. One of the aspects that was considered by the team to be an essential aspect of these developments was the inclusion of family carers and people with learning disabilities in reviewing and developing the programme. How to involve people was carefully considered. The university had set time limits for work to be completed and user and carer involvement is not a quick option. The programme team used two methods to ensure that involvement was as meaningful and productive as possible. Family carers who were involved in workforce planning activities were recruited to join the programme team, they participated in meetings often challenging the status quo and brought fresh ideas to the table. As family members they were able to speak up for people with severe and profound learning disabilities and those with challenging behaviour who otherwise would not have been heard. A weakness is that we did not have the skills to involve people with profound communication difficulties in the review of nurse training. We involved people with learning disabilities by linking with user led advocacy groups and asked them what they felt RNLDs needed to be able to do to provide good health care and other support. Two advocacy groups joined the programme team following the review and we changed programme meetings to be more inclusive but during the review we ran separate forums to explore and improve RNLD training.

### **Problems we had to overcome**

We had no problem in identifying people who were enthusiastic and passionate. However there

were, and still are, barriers to overcome. The bureaucracy, including the processes and jargon at the university, proved difficult to understand. Also, the fact that staff were paid and others were not had to be addressed. We produced a jargon buster and ensured that meetings were as accessible as possible (something we continue to review) and people were paid for their involvement. Whilst not wanting to professionalise people we acknowledged that to be more fully involved family carers and people with learning disabilities should be offered learning opportunities themselves. The programme team worked with local health providers and the learning disability workforce group to facilitate learning experiences to support capacity building including supporting people to develop research skills, teaching skills, facilitating groups and citizenship skills. Some people chose to be assessed and are working towards higher education awards such as certificates, diplomas or degrees. This entailed a huge learning curve for the academics which would not have been possible without acknowledging that we were all learners, learning different things in different ways. We do not say we have got everything right, but we review and change what we do to work as partners in

education with an aim to produce the RNLDs that family carers and people with learning disabilities need.

The issues related to representation have not been easy and it is always difficult to ensure that all groups in local communities are represented. An example of some of the issues we encountered is related to trying to mix representation on a broad programme that looks at people with learning disabilities across the life span. Carers representing other families have particular issues related to their and others' experiences of service provision. Whereas adults with learning disabilities that represent advocacy groups have other issues that at times clash or counter carer issues. The representation was drawn from the local communities but did not include all the groups that are currently active.

### What changes have come about?

A new programme emerged that incorporated changes recommended by people with learning disabilities and family carers. The programme looks like this

Year	Theory	14 week Placement	Theory	14 week Placement
1	Introduction to Learning disability, planning care, Biology Psychology Inter-professional working (IP)	Placement in residential services  1 day a fortnight at UWE linking theory to practice	More about learning disabilities including communication skills, PMLD, clinical skills, sensory loss	Placement in services for people with severe and profound learning disabilities  1 day a fortnight at UWE linking theory to practice
2	Working with families, community learning disability services & voluntary, independent, private as well as statutory service. IP	Placement 1 day a week with a family Part time placement with RNLD and Community learning disability team (CLDT) throughout 14 weeks Placement within community networks including advocacy groups, FE, schools, day occupation  1 day a fortnight at UWE linking theory to practice	Working with families, community services	Placement 1 day a week with the family Placement with RNLD and CLDT throughout 14 weeks & networks  1 day a fortnight at UWE linking theory to practice
3	Working with people with complex needs such as challenging behaviour IP	Challenging behaviour, dual diagnosis (mental health and learning disabilities) placement  Elective placement when students can choose a specific service they want to experience nationally or internationally	Working with people with complex needs such as challenging behaviour Teaching, research, management	Placement in an area where students can develop management skill, this might be challenging behaviour or PMLD services
Any year		2 week placement in Croatia in services for people with autism and other learning disabilities		

Aspects of this curriculum that family carers and people with learning disabilities are involved in are:

- the management committee for the programme
- providing teaching and learning opportunities in classrooms
- providing family placements so students can experience the real lives of people with a range of disabilities including PMLD and get a feeling for both the joy and the problems
- providing placements in advocacy organisation led by people with learning disabilities
- giving feedback to students about their skills and knowledge
- leading conference days about topics such as epilepsy, mental health and PMLD
- developing scenarios for clinical skills sessions
- research which informs teaching / practice
- publishing activities including conferences and articles
- participating in evaluation of modules (separate parts of the programme)
- involved in review of programme
- employed as occasional lectures and contracted visiting lectures
- involved with School of Health and Social Care activities so they can influence the wider health education community including people with learning disabilities teaching all student nurses (adult, mental health, children's, midwives and learning disabilities, about learning disability)

**Benefits of this development**

This has enabled the learning disabilities academics at UWE to develop close links with the local community and both the students and

academics benefit from this partnership working. Also family carers and people with learning disabilities are supported to participate in learning opportunities to increase their skills and knowledge or research, teaching, group work, managing difficult groups, becoming citizens and leaders, and public involvement.

This process of community participation in teaching future RNLDs has taught us that although difficult at times it can also be both powerful and satisfying. We make mistakes, but we trust each other to be honest and non-judgemental and help improve our practice. There is still reluctance to let go of power, but there has been progress in understanding and empathy on all sides. The outcomes we see now are all heading towards greater efficiency, value and sustainability. A workforce fit for purpose with the ethical values and practical skills that family carers and people with learning disabilities are helping to shape.

**Conclusion**

Developing RNLDs for the future is a big responsibility made easier by working as partners with the community they will eventually serve. This is not easy and we are constantly learning, however the learning disability programme team at UWE hope that by role modelling inclusion alongside clients and knowledgeable, passionate family carers, students will learn to respect people's expert knowledge.

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

## Transition Planning in Special Schools

Rob Ashdown, Headteacher, St. Luke's Primary School  
with Bridget Lee, Teacher, and Chris Darlington, Headteacher,  
St. Hugh's Communication and Interaction Specialist College

Nobody likes change and young people with PMLD deserve and need purposeful, coordinated support at times of change. Moving into or out of schools can be a stressful time for these young people and their parents or carers. This article looks at how the staff of two special schools have endeavoured to smooth the process of transition at key points in the lives of the pupils and their families.

St. Luke's Primary School is a special school for pupils with a range of moderate to severe learning difficulties, often compounded by physical, sensory and other disabilities, aged 3 to 11 years; St. Hugh's Communication and Interaction Specialist College has similar students aged 11 to 16 years and 16 – 19 provision for those students with PMLD and other complex needs who cannot access specialist provision in local colleges. An account of the special school reorganisation project that led to the creation of these two schools is provided elsewhere (Ashdown and Darlington, 2007).

From consultations with parents, the governors and staff of both schools were keenly aware of their concerns that there should be continuity of education and personal welfare provision between the two schools and that the staff should work together to ensure that there should be no barriers to progression for the pupils or differences in levels of support for and communication with parents and carers at times of transition. There is plenty of evidence that young people, and their families and carers, can experience many real difficulties at key transition points in their school career, i.e. on entry to preschool services, entry to primary education, entry to secondary education, entry to college and access to adult education. These difficulties are often compounded by the fact that they require a combination of education, health and support services in order to access a good quality of life and that the various services seem to find it a struggle to plan jointly meet their needs. The Government envisages dramatic transformation in inter-agency working but this seems to be moving at a frustratingly slow pace. Yet there are positive developments. There is now a *National Service Framework for Children, Young People and Maternity Services* which sets standards for health, social care and education services and the *Complex Disability Exemplar* (Department of Health, 2004) offers best practice guidance for professionals across all statutory and voluntary

agencies. The *Children's Plan* published by the Department for Children, Schools and Families (2007) is just one of a string of Government publications that stresses the need for joint planning and improving the lives of disabled children and their families.

The children with PMLD mostly arrive in the primary special school between two and four years. Typically, prior involvement with families has been from educators and therapists working at the local children's development centre, Early Years SENCOs in preschools, health visitors, social workers, and/or Portage home visitors going into the family home. When the local authority requests a place for a child, a teacher from the school arranges a home visit with a professional who knows the child and parents. Parents are given the information they need about the school, the rights of parents, the school's open door policy, home-school transport, etc. and the teacher gets the information the school requires about the parents' hopes for their child, their child's needs and interests, health care strategies, contact persons, etc. and essential information for the local authority to communicate to the transport providers.

The local implementation of the Early Support Programme has set a benchmark for providing helpful information and support for parents. To date, only a few parents have had the support to develop comprehensive family-held records but the primary special school needs to build on and continue to support these records and help coordinate service delivery for families after entry to school. In principle, the working practices, especially as regards working in partnership with parents, developed by the Early Support Programme are transferable to further up the age scale but they demand a heavy investment of time from staff to develop school practices. Currently, the school's deputy head is beginning to explore with Early Years officers and children's services

staff the integration of Early Support and Common Assessment Framework activities. Other teachers are trialling the use of communication passports that build on family-held records in consultation with therapists and other educators, including staff from the secondary special school, with a view to achieving authority-wide implementation.

In response to the Government's Sure Start strategy, there has been an increase in the number of children's centres locally, including one opened this year at the primary special school. It is planned that this children's centre will begin to contribute to the development of provision for children with 'low incidence needs' in the other nine children's centres and in other early years provision. School staff are able to contribute to local authority training to develop inclusive provision which represents a considerable challenge given the variable baseline of knowledge and skills among early years practitioners. A complimentary strategy is that the primary special school is now able to release staff to help provide developmental opportunities in the children's centre for parents of 0 to 3 year olds with low incidence needs that cannot be met in mainstream provision even with targeted support.

As regards the transition from Key Stage 2 to Key Stage 3, there has been heavy investment in joint planning between the two special schools. The minimum requirements are, of course, set out in the *Special Educational Needs Code of Practice* (Department for Education and Skills, 2001). At the primary school, the Year 5 annual review of every pupil's statement focuses upon agreeing a 'transition plan' to identify the pupil's personal emotional, social and health needs and appropriate strategies, the pupil's main educational needs and approaches that work best, and the people who need to be involved in the advance planning which is essential for a successful transition. An interim review is held in the Autumn Term of Year 6 to review and revise as necessary the transition plan and this meeting is usually attended by the headteacher of the secondary special school. This is a good time to give information to parents about the organisation of the secondary school and try to answer any queries and concerns that they may have. In the past these reviews have been held at the primary school, but from Autumn 2008 they will be held at the secondary school to allow an opportunity for parents to have a supported visit to the new school site. In addition, the student's future class teacher from the secondary school attends the final ordinary review of a child's statement and transition plan held at the primary school.

The secondary school has a clear induction process for new students and their parents: information meetings for the parents of Year 6

pupils around Easter; follow-up meetings in the Autumn Term of Year 7 to check on how each pupil is experiencing the transition; and a questionnaire survey to get the views of the parents of the Year 7 pupils about the process. The Year 6 and Year 7 teachers meet in the Spring term to share information about each Year 6 pupil. Finally, after opportunities to visit the secondary school in the Summer Term, the Year 6 pupils transfer fully in the last week of the Summer term and this gives them a chance to get to know staff and have a positive experience of the new school before the lengthy summer holiday closure. Year 6 pupils with PMLD have a more in-depth transition experience which takes the form of half day and full day visits over the last six weeks of the final term before transfer. These visits are fully supported by staff from the primary school to allow a sharing of key information between staff as well as allowing the pupils to become more familiar with the environment, the classroom and the staff in secondary school. The support from the primary school staff is withdrawn when all involved feel that the time is right and, usually, the pupils work with the secondary school staff only for the penultimate and final visits before transfer. During this process the staff from both schools must work closely with each other and other professionals, especially the various therapists, specialist advisory teachers and specialist nurses. Parents are mostly reassured by this process as evidenced by the positive comments from questionnaire surveys of the parents of the Year 7 students.

The transition to adult services can prove even more problematic for students and their parents and carers as documented, for instance, by the report *Improving the Life Chances of Disabled People* (Prime Minister's Strategy Unit, 2005). There is guidance based on existing good practice: for instance, from Wheatley (2006) and the former regional SEN partnerships (Department for Education and Skills, 2003). Such documents provide a few examples of good practice from special schools. However, it has to be said that the point of exit from school both locally and nationally confronts students and their families with a reality of less well-endowed provision for adults with learning disabilities.

The secondary special school closely follows the *SEN Code of Practice* advice that transition planning arrangements must start at the year 9 annual review of the statement. For many students 'preparation for adult life' starts as soon as they arrive in Year 7. However, the minority of students with PMLD cannot benefit from the school's strong links with local colleges and its work experience programme. These students are supported by staff in a three year transitional programme to access



appropriate day services operated by the local authority for adults with learning disabilities. Students are fully supported by school staff within the adult service provision for one day per week in Year 12 and two days per week in Year 13 and the families are kept fully informed of all achievements and challenges during this process. There may also be some experience of respite provision for adults during this period. The school staff work closely with the staff of the adult service but gradually withdraw their support when students reach 18 years of age so that the adult service's staff begin to take the lead. The students attend the adult services provision full-time for six weeks prior to finally leaving school. All of this requires careful transition planning from the time of the Year 10 annual review of the student's statement and the school has had a vital role in supporting the development of a multi-agency group of professionals that has developed these processes over several years.

We are sure that special schools up and down the country are involved in similar work and it is a shame that these collective experiences are not more widely reported. We know that we could learn much from others, for instance, about empowering parents so that they have the confidence and resilience to cope with transitions, or about how to communicate with and understand the young people with PMLD themselves. But we have learned a lot. We know that children's services and services for adults with learning disabilities are still reorganising themselves to deliver new outcome-focussed services and this will continue to be a frustrating time of uncertainty for many parents and professionals. However, there are many positive signs locally and nationally that give us cause for cautious optimism of future, coherent approaches to transition planning.

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## **The Therapeutic and Educational value of Hydrotherapy as an intervention for young adults with PMLD**

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Hydrotherapy offers people with special needs many more advantages in addition to the benefits of warm water therapy. Many disabled people have conditions that can limit the therapeutic support given "on land" but, within water, can access a safe freeing and responsive environment.

Whether used in the context of an educational intervention or more loosely, it can also enable successful interaction sequences through Intensive Interaction. Hewitt and Nind (1994) state "*Intensive Interaction is about accepting the person and offering her/him new opportunities.*" Hydrotherapy can offer such opportunities.

The use of hydrotherapy dates back to around 2400 BC where Proto-Indian cultures made hygienic installation. Later the early Egyptians used mineral waters for curative purposes, whilst the Hindus used water to combat fever. It was not until the 1920's that "exercise in water, as opposed to immersion only began to develop". Epps (2007) explains that:

*"Current hydrotherapy practices involves utilising the properties of water to maximise an individual's level of function be it physical, physiological or psychological"*

Nowadays there are two general approaches to working with disabled people in the hydrotherapy pool. One is with the support of flotation aids and the other called "Halliwick" (created by James McMillan in 1949) is without flotation aids. It is "based on scientific principles of hydrodynamics and body mechanics" (Reid Campion, 1997). It is a technique set out by the "Halliwick Association of Swimming Therapy" suggesting that through the "Ten point programme" the following could be observed:

*".....a process of development through mental adjustment, balance, control and movement leads to personal independence in the water ..... essential components of motor learning"*

The second technique is via the support of flotation aids such as arm bands and body supports. Flotation aids offer the support often needed with severe physical disabilities or those over a certain weight.

Due to the nature of the needs of the students attending hydrotherapy we use the flotation approach but offer "swimming" in a public pool for those students who are more physically able and do not require access to changing beds. "Swimming" gives the students the opportunity to progress to learning through the Halliwick technique.

Planning and ensuring the safe delivery of hydrotherapy is an ongoing multidisciplinary activity. It involves a variety of professionals within the college in assessing the students, and the consent of parents and pupils on each occasion (this may vary dependant on current medical state, particularly if epilepsy is a feature since recent seizures may have left the pupil exhausted). Class teachers give the up-to-date picture and together with the hydrotherapy coordinator extend the classroom curricula into the therapy pool. The senior physiotherapist and the hydrotherapy coordinator identify and assess students able to access a public pool and those requiring hydrotherapy. This has mainly been through the risk assessment the physiotherapist regularly carries out regarding the moving and handling requirements of each individual. It is then decided whether certain students require 1:1 or 2:1 support in the water as this has implication on the staffing levels required. The next major factor in the planning is with the nursing team to ensure the student's health is not an issue for withdrawal from the activity – this is also ongoing on a daily basis.

The majority of our students have epilepsy and this is not a reason for exclusion from hydrotherapy, as Reid Campion (1997, p.155) explains:

*“It is interesting to note that epileptic seizures are uncommon in water provided undue excitement and tension, flickering lights and reflections on the water are eliminated, a fit is unlikely to occur”.*

It is important that precautions are taken and training given to ensure safety at all times. I have also received training in administering rescue medication for epilepsy, CPR and First Aid. A key factor is the staff accompanying each student. I liaise with the students' tutor and care unit managers, regular staff who, besides knowing the students, have also attended the training course for hydrotherapy. Each session planned has 1:1 (or 2:1) support per student, one person pool side and the support of the physiotherapist in the water. The role of the physiotherapist is invaluable as she is able to support the team individually whilst working with the students and showing correct movements and support. There are certain movements that must not be attempted for people with spinal rods and this information must always be disseminated before entering the pool. It is important to have time for feedback after each session; not only on how the students were but to discuss the overall session to see if changes are required.

Hydrotherapy can help physiologically, psychologically and therapeutically and the “uniqueness of water lies mainly in its buoyancy.....relieves stress on weight-bearing joints and permits movement to take place” (Reid Campion 1997). This is why it is beneficial to our students. Hydrotherapy is often the only time disabled people can experience freedom and move freely allowing them more control during the activity. The therapeutic effects of exercising in the water as described by Reid Campion (1997) relate to:

- The relief of pain and muscle spasm
- The maintenance or increase in range of motion in joints
- Increase in tolerance to exercise
- The maintenance and improvement of balance, co-ordination and posture

Whilst attending hydrotherapy our students are able to experience a range of movements to the body not experienced elsewhere and this is achieved by moving through water turbulence. One exercise in particular is “snaking” which offers movement left and right against the natural flow of the water. The density of the water offers our students improved co-ordination and balance which allows students with limited weight bearing

ability on land to “walk”, often unaided, for several minutes at a time in the water building on their confidence and this can then be transferable to land activities. The additional physiological effect of water is the reduction of muscle tone, Epps (2007) explains:

*“... muscle tone (spasticity) is reduced, the sympathetic nervous system is suppressed and relaxation enhanced. ... often calmer during hydrotherapy than similar land based activities and sleep better .... easier to perform stretches to the muscles and joints”*

John (pseudonym) is one such student and, due to his physical deformities, he is unable to lie on a mat to receive stretches; he also has the brittle bone condition so special care is required in his handling. After additional risk assessments he is now successfully attending hydrotherapy on a regular basis and the staff on his team are now more confident in his handling both in the water and on land. The benefits of hydrotherapy as an intervention for physiotherapy over land based activities include the following for John and echo Epps (2007)

- Ease of handling and movement in an unencumbered environment
- Free from equipment, wheelchair, splints, aids and can be independent
- Learn/experience new skill, such as standing
- Reduces pain in joints especially in weight bearing

But Epps (2007) goes on to point out the advantages of the hidden curriculum:

*“Hydrotherapy plays an important role in the holistic approach to the child’s learning. It involves life skills, such as dressing and showering, communication... intensive interaction and switching (multi sensory pools) through to enhanced vocalisation, attention ... social interaction ...choice ... empowerment and turn taking”*

Hydrotherapy can be a tool as an educational intervention but never forgetting that it should remain fun, inclusive, and enabling for all those attending.

Many hydrotherapy pools are now designed as a multi sensory environment and is particularly of benefit to children/adults with PMLD. Spacekraft, make multi sensory pools and refer to the environment as a way of “introducing all the imagery and colour of a multisensory area giving a total unique, exciting and stimulating experience”. These multi sensory pools have sound and lighting and can offer education to children and adults with

profound learning difficulties. The previous headteacher of Bleasdale House (sadly now deceased) which has one such pool said:



*"All our children have profound and multiple learning difficulties, physical difficulties and other associates sensory difficulties, and this equipment provides a combination of effects that we can use in themed approaches with the children in lessons. When they're in the water, they're not just swimming or doing a water activity. The aim is to embellish activities, to accentuate all learning experiences. Our aim is to provide as many experiences as possible for this particular group of children. It's about the pupils affecting their own environment, it's about control and it's about learning."*



An alternative to Spacekraft is a Multi Sensory environment designed by Snoezelen. The concept is to create a non-threatening environment with an atmosphere of calm and relaxation offering a "feeling of sensory well-being". This style of environment offers support to the education value of the activities applied in the hydrotherapy pool.

Davis (2001) talks about when and where to deliver a sensory curriculum and explains that all activities can have the potential for teaching and learning and draws on the Snoezelen environment when discussing her idea of a "fun" environment and

refers to the enjoyment of an activity being the motivating factor and not the outside pressure of achievement. During the "fun" time it is important for both student and staff member to enjoy themselves and she points out that:

*"... these can be times of real communication and bonding ..."*

and this is beautifully illustrated in the attached picture reproduced here from the Worcester Snoezelen web site.



The hydrotherapy pool offers the learner the opportunity to engage in cause and effect activities but, as experienced at the hydro pool we attend, the position of the switches need to be accessible for all abilities and unfortunately, if placed along the water line or slightly below, the ability for adults with PMLD to visually locate these can prove difficult, the preferred position would be just above the water line and this is where expert advice is needed.

Many people need reassurance during the whole activity and this can be offered through general conversation. However, the majority of the students are unable to express their fears or concerns regarding the change in environment, or about entering the water. Intensive Interaction has played an important part in forming the reassurance needed and I encourage its use with all staff attending and supporting, as mentioned earlier.

Employing Intensive Interaction has enabled the continuation of students attending hydrotherapy, when initially during their first and second visit they showed distress and concerns whilst in the water. However, by the third session, the transformation and enjoyment was evident and I believe this was due to engaging with them using the principles of

## Intensive Interaction.

During our evaluating the use of hydrotherapy we kept arriving at the same positive outcomes of how/ why the activity works. These were:

- Organisation
- Team work
- Training
- Consistency of staff
- The working together of Therapy and Education
- Enjoyment by all

As mentioned previously, John a young man with severe physical deformities was unable to receive the level of physiotherapy intervention required on land. Through attending hydrotherapy and an increased awareness by staff on handling John, his physical well-being is reported to have improved and now staff are attempting more stretches and handling out of the water. The mobility of other students has been increased. Daisy (pseudonym) has the ability to walk unsupported but was reluctant to do so. Now when she attends hydrotherapy, after gaining her initial balance, she lets go and “walks” in the water – this has been transferred to land recently, and she requires only one person to support her around the college.

At present, we have not successfully accessed the switches, but the students have shown awareness of the dolphin murals on the walls and of the changing lights. The benefits of using Intensive Interaction has been evident with Charlotte and Simon (both pseudonyms) who are both unable to tell us how they feel apart from being able to show their distress through changes in vocal responses. Five sessions on and both students, respond completely differently. We start our interaction during the changing stage and immediately continue it in the water, allowing the direction to come from the student. During the time when the therapist joins us to stretch the lower limbs I increase my level of positive “chat” with them to distract from the therapist – this has proved successful.

However, we appreciate and recognise that hydrotherapy or swimming is not suitable or wanted by all and it does need to be by student choice as

well as taking into account parental or health issues. Finally, the joint working relationship between the physiotherapist and myself has proved successful and beneficial to both the students and the college.

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## Assessment for Real Learning

Wendy Newby

“Teachers should avoid ‘quick fixes’ focusing on the most observable behaviours. Any skills achieved must be underpinned by real learning which leads to permanent change in behaviours.”

(Qualification and Curriculum Group, 2006, p.13)

McNicholas (1998) found that the targets set for pupils with PMLD tend to be long term and generalized and, in some circumstances, a ‘best fit’. This article reflects upon my own experiences of assessment and target setting for pupils with PMLD in the school where I work and considers the implications for my own practice.

### What assessment is carried out?

Assessment has been a focal point in my school’s development plan for the last three years. In February 2007, a computerized assessment package called *B-Squared* was introduced. This is a criteria referenced summative check list of small steps that will be familiar to many teachers. The small steps are derived from the Performance Scales (P Scales) and National Curriculum Attainment Targets. But is *B-Squared* relevant? Initially I was quite excited by the package, as it seemed to fulfil all the areas needing development within my assessment practice, as both a teacher and also as a subject leader. It appeared to empower me to make standardized judgements with clearly defined objectives. As the Mathematics subject leader, I found the *B-Squared* data also allowed me to monitor attainment within my subject. This allowed me to address the problem of my accountability for progress within the subject. This is especially relevant as the collection by the DCSF (Department for Children, Schools and Families) of P Scale data becomes mandatory in July 2008.

However, even though P Scales provide a standardized statement of attainment, Aird (2001, p.5) describes them as a “curious hybrid of developmental/behaviourist/academic criteria”. Moreover, when I started to use *B-Squared* I discovered that the small steps were not achievable for the pupils with PMLD that I was assessing. The small steps are intended to be in line with the DCSF’s model of SMART targets (Specific, Measurable, Achievable, Realistic and Time-related) in that they are achievable within a time scale. I found that targets remained ongoing over several reviews suggesting that the pupils were not progressing at all. Lacey (2006, line 2), also suggests that children with PMLD are “poor consumers of SMART targets” and states that it takes too long for pupils with PMLD to achieve these measurable skills. It appears that they are

not learning when, in fact, they are.

*B-Squared* could be used to inform the target setting for the pupils’ IEPs (Individual Education Plan), reinforcing the idea that assessment is an integral part of the learning process. However, at present another computerized programme called *IEP Writer* is used to create the pupils’ IEPs. The *IEP Writer* package contains thousands of SMART targets in progression but also includes success criteria, teaching resources and strategies that teachers and support staff can use. It is a good starting point but the targets within *IEP Writer* do not relate to the small step subdivisions of *B-Squared*. This inconsistency has led me to feel that the IEPs I am writing in school could become just paper-based or computer-based activities to satisfy the requirements of the *SEN Code of Practice*. Even though using computer-based IEP writing packages can save valuable time, I found that I had to find the ‘best fit’ target and edit it for pupils with PMLD. This contradicted my belief that the IEP should be a positive tool that leads to the enhancement of the pupils’ learning.

Let’s take the example of Harry (pseudonym) who is a 15 year old pupil with PMLD. From the assessment of his previous teacher he appears to be functioning at about P3(i) of the P Scales. The first thing that struck me, as Martin (2006) points out, is that the P Scales up to P3 are generic and not subject specific, yet *B-Squared* has the small steps broken into subject based behavioural targets. This compartmentalizes the achievement of the pupil and I feel that this could lead to these small steps becoming only what is taught, leading to a narrow curriculum. None of the targets generated for the IEP relate to how Harry interacts with the people around him and I feel that these targets would be a ‘best fit’ for what pupils such as Harry need to learn.



### Behaviour, Skill or Knowledge ?

Assessment is a vital part of the learning cycle and has several purposes. The purpose of assessment for pupils with PMLD is the same as for any individual; it is a gathering of information that allows decisions to be made about the individual's education. I feel, therefore, it is from the individual we need to start, not from a checklist of behaviours. Willis (1993) suggests that, even though pupils may be able to learn behaviours, it does not necessarily mean they understand it or can apply it to other situations. For example, Harry is able to squeeze my held up fingers one at a time while I count, but this does not mean he can count or understand the concept of number. He does it in anticipation of the clapped hand on five, something he has learnt to expect when this stimulus occurs.

'Behaviourism', as a learning theory, suggests that learning is the acquisition of bits of knowledge in a hierarchical sequence in which mastery of one objective leads to the next (Shepard, 2000). This is reflected in the structure and the sequence of small steps of both *B-Squared* and *IEP Writer*. During the 1980s behaviourist psychology offered a way of linking assessment with what happened within the classroom for pupils with learning difficulties (Elliott, 2000). The development of small steps, criteria referenced assessment was of great help to struggling teachers during the 1980s, as it gave them support and a basis for a curriculum. As noted by the Welsh Qualification and Curriculum Group (2006) behaviourist approaches provided clear aims and objectives, such as those within *B-Squared* and *IEP writer*, and emphasised the process of determining baselines and ongoing collection of evidence. This has benefited my practice, especially when reporting progress and achievement: for example, to parents at annual reviews, during my performance reviews and to Ofsted inspectors.

But my main concern is how to avoid the temptation to take the small steps of *B-Squared* and *IEP Writer* as the taught curriculum. This would lead to a narrow curriculum since the small steps of *B-Squared* and *IEP Writer* do not incorporate all of the aspects that contribute to a broader curriculum, such as therapy. With the advent of the National Curriculum and there is an increasing knowledge of the need for a broader curriculum. Elliott (2000) points out that the behaviourist form of assessment concentrates on 'what' is learnt, and does not consider how the learner has learnt. Marvin (1998) suggests that this puts the pupil in a passive role of what she describes as a 'follow the lead'.

In contrast '*interactive approaches*' emphasise the pupils' interaction with the environment and the

people within it. The focus is on the learning process and not on fragmented parts of it or behaviours as presented within *B-Squared* and *IEP Writer*. Importance is given to Vygotsky's '*Zone of Proximal Development*'; that is, the difference between what a learner can do with assistance and what they can do independently, with the emphasis on the interaction between the pupil and the support (Shepard, 2000). It follows that assessment for pupils with PMLD should be more child-orientated and result in their active participation. However, interactions may be difficult to measure and this repercussions when considering accountability. The idea of levels of support is not considered within the *B-Squared* or *IEP Writer* packages. Lacey (2006, line 2) offers an alternative to SMART targets that is more pupil-led. She describes them as SCRUFFY targets (student-led, creative, relevant, unspecified, fun for youngsters). Such targets seem far more appropriate for pupils with PMLD.

### Linear or Non-Linear ?

*B-Squared* and *IEP Writer* provide hierarchical assessment, that is, assessment related to progressive levels and sequences of small steps (Martin, 1996). But do all pupils progress in a hierarchical manner? Hierarchical learning or linear progression would be indicated if all of the targets were achieved at one level before targets within the next level were achieved. In contrast, Harry's progression record does not show this. Aird (2001) points out that, due to the idiosyncratic nature of pupils with PMLD, they tend not to achieve in a linear manner and that the belief that they can follow a hierarchical developmental pattern is both naive and flawed.

An exciting new development has been the publication of a programme of assessment for pupils with PMLD called '*Routes for Learning*' that has been developed by the Welsh Qualification and Curriculum Group (2006). In contrast to *B-Squared* and *IEP Writer*, it provides a means of baseline and ongoing assessment with clear objectives that are not linear. *Routes for Learning* recognises that pupils with PMLD may not progress in a linear manner and that there is a need for assessment to consider lateral learning. It provides a route map allowing the assessment and target setting to be tailored to the individual.

### Developing a Holistic Approach

Viskamp (2005) stresses that it is essential to involve a multi-disciplinary team to plan an individual education programme. This is an idea that would lead to the whole child being considered. There is an holistic approach and the involvement of the interdisciplinary team in the school where I work. However, the therapists are

only just beginning to be involved in assessing and target setting using *B-Squared* and *IEP Writer*. This development is potentially of great benefit to the individual but will require a huge amount of time and commitment. Also, as Marvin (1998) acknowledges, there may be difficulties when considering the establishment of shared priorities and an interdisciplinary approach requires a commitment of time, effective communication and regular meetings. Nevertheless, this cooperation is essential if we are to achieve the optimum learning situation for pupils with PMLD.

### Conclusion

“A ‘one size fits all’ approach to special educational needs (SEN) is naive. We are working with children in that spectrum of learning difficulties with unique learning profiles...”

(Carpenter, 2007, p.1)

My belief is that pupils with PMLD have unique learning profiles and that these should drive the assessment process. Therefore, systems like *B-Squared* and *IEP Writer* are not the optimum form of assessment for all pupils with PMLD, although they do support accountability and it may be appropriate to use *B-Squared* to provide the P Scales summative assessment at the end of each Key Stage for statutory reporting from July 2008. The idea of ‘best fit’, or trying to fit the pupil to the small steps, is not appropriate, the pupils do not necessarily follow a hierarchical progression in learning and SMART targets are not always achievable.

It has become evident to me that *Routes for Learning* assessment package (Qualification and Curriculum Group, 2006) offers a more appropriate means of formative assessment. It is responsive to the child and allows the child an active rather than passive role. It provides a structured means of assessment that is non-linear with the child following an individual route through life skills and communication. It also advocates a holistic approach which encourages assessment to be an inter-disciplinary process providing a whole broad curriculum. I am sure that this will have a direct and positive affect not only my practice, but the whole school’s development, and especially the provision for these very special pupils.

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## **Simon's Miracle: a six-year journey from isolation to intimacy**

Stuart Gent and Wendy Newby,  
teachers at St Rose's School

### **Emotional numbness and touch aversion: Simon six years ago**

(written by Stuart)

I started working with Simon a little over six years ago when he was eight years old. At the time he joined my class with five other children with severe and profound and multiple learning difficulties. It soon became clear on reading about Simon through his statement of needs that he had had a very difficult start to life. At the age of 18 months old he had contracted meningitis that left him with multiple learning difficulties and a visual impairment. This resulted in his being unable to walk or talk. Subsequently since that time Simon has become a Looked-After-Child and is now in long term foster care.

At this time Simon had huge aversion to any type of touch, even functional touch. He was intolerant of the close proximity of people and objects. He would spend most of his time rocking in his wheelchair, side to side making no eye contact with anybody or anything. He appeared to be emotionally numb. He never cried, smiled or showed any degree of pleasure. As his teacher, I was initially uncertain how to address the issue of touch as well as address the presentation of his curriculum work. It was at this time that I became aware of Tacpac (see Note below). I arranged for Simon to have a daily session in the school's sensory room. Initially Simon's response to the stimulations were as predicted, he was very distressed and would even go as far as screaming.

#### **The first year: Simon begins to accept touch, but only in Tacpac sessions**

After a month of a daily session of Tacpac, it was then reduced to twice a week. He had at this stage during the sessions started to relax more, show glimpses of anticipation and some eye gazing. Simon at this time was still rocking side to side. He became more relaxed during the sessions because of the familiarity and consistency of the routine, the same room, the same member of staff, the same music and the same tactile stimulation. This growing acceptance of touch was not generalised outside of the sessions.

#### **The next 2-3 years: the sessions become an emotional anchor for Simon**

Over the subsequent months small changes were made to the routine, i.e. different staff and different

#### **Note on Tacpac**

Tacpac is an activity pack that combines touch and music to promote communication and social interaction, sensory, neurological and emotional development. It is widely used in with people with PMLD in schools, homes, health care settings, adult day care centres, etc.

Tacpac begins with the simple sense of touch with a familiar, easy-to-get-hold-of, everyday object, such as a kitchen sponge, a wooden spatula, or some furry fabric. The experience is then enhanced through the principle of 'sensory alignment'. Music has been composed specifically to match the texture, character, and even the emotional quality of each touch experience. The receiving partner hears from the CD what they see and what they feel on their skin: sensory alignment - and sensory reinforcement for seeing, hearing and touching. Through linking what becomes familiar music with objects, actions and people in a pattern of different activities, the partners communicate with each other.

To find out more about Tacpac, and read more stories about it, visit [www.tacpac.co.uk](http://www.tacpac.co.uk), or call 01865-772213.

positions e.g. out of his wheelchair and at times in different rooms. I did this, as Simon's teacher, to help him begin to generalise this tolerance of touch and closeness of people that he exhibited during the Tacpac sessions. Gradually, during more sensitive sessions in the classroom, Simon's rocking and lack of eye contact eased. This was only seen when the classroom was quieter and when time was given to him by the staff. However, any prolonged interruptions such as school holidays resulted in Simon returning to his original state of defensiveness. This resulted in us returning to the structure of the sessions. This cycle continued for two to three years.

#### **The 4<sup>th</sup> and 5<sup>th</sup> years: beginning to accept more touch outside sessions**

Around this time it was observed that Simon was making little steps forward in his all-round acceptance of touch, as well as in his Tacpac sessions. At home he was a lot less agitated to touch, for instance when having his hair brushed. At school we were able to successfully make small changes. We were able to move onto the second Tacpac level. Even from the start Simon was quite at ease with the experiences and he didn't show the distress that he showed those years before. This led him to become more tolerant of objects placed on his tray and of hand over hand exploration during everyday lessons.

#### **This year's revelation: Simon offers touch, makes eye contact, seeks objects, shows feeling**

We have now entered the sixth academic year that Simon and I have used Tacpac together. He has only just started to work through unit three. This has been a long term approach to meet his individual needs. I have continued to use Tacpac for this length of time because when he experiences a prolonged time without the sessions he shows signs of regression.

Simon is now making some good eye contact, accepting certain levels of touch and has been known to deliberately reach for objects and even rest his hand on a member of staff's arm. This has been truly delightful to see as Simon now displays his emotions, makes it clearer when he is happy and when he is sad. This ability to show his emotions and acceptance of touch is generalised beyond not only his class life but also to his home life.

#### **Communication and relationship: Simon now** (written by Wendy)

I had the pleasure to go into a Tacpac session with Simon and his assistant. It was, I truly believe, a special time for Simon.

The clear structure appeared to cue Simon into the session and his reactions began to change. Whereas initially he held his hands up tight to his body and moved his head from side to side, as soon as the music started and the tactile experience began he started to react. He showed a preference to the variety of touches he was experiencing. It was obvious that his hands were more hypersensitive than other parts of his body and that he preferred the rhythmic tapping rather than things rolling across his hand. The teaching assistant responded to Simon's non-verbal communication with respect, altering where the touch was experienced when Simon indicated displeasure. Simon was communicating! Simon was empowered to change an aspect throughout the session - he was the leader. The change in rhythm, pace, pitch and dynamics of the music appeared to give Simon an auditory clue to which touch he was about to experience. The music was an integral part of the whole experience as it also organised the teaching assistant.

#### **The miracle of trust**

The final part spoke volumes in the way that Tacpac has affected Simon's life. During this part he was wrapped in a blanket, the teaching assistant's face was just inches away from his. Simon began to actively seek eye contact from his teaching assistant bending his head so he could look into her eyes. He repeated this eye contact; his arms relaxed in his lap, his vocalizing stopped and eventually he closed his eyes and fell asleep. Not only had he tolerated closeness with his teaching assistant, he was so at ease that he slept.

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## Inclusive Libraries Research Project

Penny Lacey, Senior Lecturer at the University of Birmingham

The University of Birmingham is working with the British Institute of Learning Disabilities to design a project to increase the ability of public libraries to meet the needs of children and adults with severe and profound learning disabilities.

The intention is:

1. to seek out examples of current successful inclusive practice in libraries around the Midlands area
2. to set up small-scale projects in libraries in or close to Birmingham, based on this successful inclusive practice
3. to monitor and evaluate progress
4. to disseminate what works to other libraries through a booklet and a DVD showing inclusive practice

From research carried out by Lacey, Layton and Miller (2002) and Layton, Lacey, Miller, Goldbart and Lawson (2006), it is clear that there are a significant number of children, young people and adults with severe and profound learning disabilities who will not learn to read and write in the conventional way. More able people, in this group, will manage to learn a few words and the sounds of letters by the end of their formal education, but the majority will make little use of letters, words and text. This, however, does not mean that literacy is not open to people with severe and profound learning disabilities. What the researchers argue is that literacy needs to be regarded as a more inclusive activity, which is not only about reading and writing text.

As part of the above research studies, examples of inclusive practice in the teaching of literacy were collected and arguments put forward for encouraging teachers to use them in literacy lessons. These included sensory stories & multimedia stories, photo albums and scrap books, reading icons and symbols, simple conventional and picture books, television and films, navigating or creating websites, using digital media. It is not the intention at this stage to explain all of these activities and how they are relevant to teaching literacy (see Lacey, 2006 for an explanation) but it is important to consider how some of these activities may be suitable for public libraries to include to enable children, young people and adults with severe and profound learning disabilities to participate in literacy in their community.

During childhood, schools are usually the hub for inclusive literacy activities and, in some areas, this is transferred to colleges for young adults. For adults, however, there is often nowhere other than

the public library to access books and computers. With the demise of day centres and the rise of day opportunities in the community, it has become very important for public libraries to meet the needs of those who would like inclusive literacy resources and activities.

Inclusive literacy requires more than for libraries to stock plenty of picture books or copies of specialist resources such as Story Sacks or Bag Books (story resources for children and adults with severe and profound learning disabilities) or Books Beyond Words (a series of books with no or few words for adults with learning disabilities). There is a need for staff to be able to support people with severe learning disabilities in a range of activities within which they can participate. For example, searching the web for pictures of favourite animals or helping them to create their own website of pictures, sort their family photographs or facilitate personal storytelling.

From a brief search of the literature on public libraries and disability, there appears still much to be done to improve inclusiveness. For example five years ago, McCaskill and Goulding (2001)'s study found that there was considerable variation around the country in the response of libraries to the Disability Discrimination Act 1995 and that progress was very slow. More recently, Ineson and Morris (2006) reiterate this and suggest that advertising examples of best practice and forming support networks might encourage further developments.

As a concrete example, Epp (2006) suggests that only 5% of the world's publications are accessible to people who do not use print, by which they mean people with disabilities of sight, or with physical, neurological or perceptual difficulties.

Other studies have added detail to this overall view of lack of response to special needs. For example, Ryder (2004) looked at how library services meet the needs of housebound people. The focus of her study was on quality issues and good practice and her conclusion were that many authorities were still providing tokenistic services and were reluctant to publicise them in case they could not meet the demand. Despite that she found examples of good practice where a full range of services were provided to a high standard.

There are a range of groups who require resources and support over and above that given to the general population in libraries. Depending on definitions, it has been estimated that 20% of the population have print disabilities, mainly due to sensory impairments and that their needs are often unmet (AFB, 2005). In addition, Black (2004) suggests that people who have literacy difficulties such as dyslexia are often excluded from services or are subjected to a lower priority of service. Epp (2006) enumerates other groups, but because she is writing about university libraries, she does not include the group for whom reading and writing conventional text is not possible, those with severe and profound learning difficulties.

However, some of what Epp (2006) explores is as relevant to providing services for people with learning disabilities as for people with physical or sensory disabilities. For example, she explores staff and public attitude, suggesting that it is the single most important factor in creating an accessible environment. Special needs are seen as the province of specialists such as charities, rather than public libraries, with the consequence that the needs of people with disabilities are often just not considered. Epp (2006) also discusses partnerships between libraries and commercial providers. She is writing about audio and e-books for people with sight difficulties, whereas people with severe and profound learning disabilities may need resources such as simplified books (published by Axis, for example), objects to accompany stories (such as Bag Books), multi-media stories (such as produced by Pete Wells on the web) or websites that use symbols (such as Symbol World). The issue of collaboration between publishers and libraries is similar though and something important to pursue.

Not only do libraries require inclusive resources for lending but staff also require sufficient training to be able to meet the needs of borrowers with severe and profound learning disabilities. They need training not only in locating and identifying resources but also in approaching and supporting individuals. McAuley's (2005) study of disabled students in a university library showed the

importance of the staff-user interface as well as that of specific assistive technology. Staff need to be able to communicate with their users and help them to find the resources they are seeking. Disability-awareness training can upgrade the quality of front-line services delivered to disabled users (Charles, 2005) and this will be useful for helping to meet the needs of people with severe learning difficulties. However, more in-depth training is likely also to be required if librarians are going to be able to support users who cannot read and write.

From the literature it is clear that there is a group of children and adults with severe and profound learning disabilities who are not able to learn to read and write and most public libraries do not cater for their literacy needs. There are non-conventional (or 'inclusive') literacy activities that meet the needs of the most disabled children and adults and some of these may be suitable for the involvement of public libraries. Generally public libraries are being slow to meet the needs of disabled people and maybe the gathering together and sharing of good practice will contribute to speeding this up?

Research questions derived from previous research and practice are:

1. What is current and future good practice in public libraries for meeting the literacy needs of children and adults with severe and profound learning difficulties?
2. Which 'inclusive literacy' activities are suitable for development in public libraries and how can they best be used?
3. What training would be useful for library staff so that they can meet the needs of people with SLD/PMLD in respect of the staff-user interface, resources and technology?
4. How can good practice be disseminated across the country?

A project has been designed by the University of Birmingham within which the above research questions will be investigated. There will be two main stages to this project: the first stage will mainly comprise a survey of local authority library services in the Midlands area in search of good examples of current practice. This will be carried out through telephone interviews followed by a visit to some services to interview librarians face-to-face and look at some of the resources and technology available in the library or for lending.

The second stage would be driven by action research which would cover four distinct strands. There would be cyclical trial and evaluation of:

1. the selection, management and lending of inclusive resources

2. inclusive literacy activities within a library context
3. training for library staff
4. dissemination materials, such as a DVD and booklet

Funding has been sought for this project and so far (Summer 2008), nearly half the money has been raised. Hopefully in a later issue of PMLD Link we will be able to report on what we found in the project.

#### Contact Details

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#### Resources

Axis - [www.skillbuild.co.uk/template1/home.asp?](http://www.skillbuild.co.uk/template1/home.asp?)

Story Sacks - [www.storysack.com/sacks/list](http://www.storysack.com/sacks/list)

Bag Books - [www.bagbooks.org](http://www.bagbooks.org)

Symbol World stories - [www.symbolworld.org/stories](http://www.symbolworld.org/stories)

Books Beyond Words - [www.rcpsych.ac.uk/publications/booksbeyondwords.aspx](http://www.rcpsych.ac.uk/publications/booksbeyondwords.aspx)

Pete Wells' stories - [www.petewells.co.uk](http://www.petewells.co.uk)

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## Changing Lives through Community Partnerships

Alice Bradley, member of the PMLD-Link editorial group

For millions of disabled people who live in the developing world, including those with profound and multiple learning disabilities, it isn't a question of *where* they go to school or which kind of service is best, but *whether* they have any support at all. Community Based Rehabilitation (CBR) developed in an effort to respond to this situation. It was promoted by the World Health Organisation (WHO), and drew upon the model of Primary Health Care (PHC). The idea was relatively straightforward. Family members and volunteers from the community would receive basic training in disability and rehabilitation and train disabled people and families in their own homes. Emphasis was on developing a strategy which provided wide coverage and was affordable to governments (Thomas & Thomas, 2002). In 1989 WHO published the CBR manual. '*Training in the Community for People with Disabilities*' which ran to three editions and was translated into over fifty languages. It is still used extensively. Seldom has a development initiative attracted so much interest.

That doesn't mean it has escaped criticism. One issue was the use of the word 'rehabilitation' with its narrow medical focus. This failed to take account of the social aspects of disability, i.e., the social construction of society which disables people through exclusion, low expectations, negative attitudes and lack of accessibility both in the built environment and socially. To deal with this, ILO (International Labour Organisation), UNESCO (United Nations Educational, Science and Cultural Organisation) and WHO issued a Joint Position Paper in 2004 and re-defined CBR as '... a strategy within general community development for rehabilitation, equalisation of opportunities and social inclusion of all children and adults with disabilities'.

The idea that CBR should rely on volunteers and originate from and be owned by the community has also been problematic. All this presupposes a community that is ready, willing and able to support its disabled members. However, for most people in poor communities it is a struggle merely to survive and provide for their own families. They have neither the time nor the resources for volunteering. Similarly, the families of people with severe and profound disabilities, especially mothers, are fully occupied caring for their disabled child and the others in the family. As Hartley (2002) points out, poverty is a major barrier to participation, given other pressing needs. There is also the suspicion that community participation is a ploy by governments to evade their responsibilities.

There has been considerable debate around the question of what constitutes 'community' given the considerable diversity that exists within a single community, let alone the vast differences in communities nationally and globally. What suits a community in rural Uganda, for example, will be very different from what is needed in a slum area in

Pakistan, so is it possible for one strategy such as CBR to meet such diverse needs and conditions? An additional difficulty was that every new project came to be called CBR, whether it truly was a community based initiative or one that promoted a more institutionalised approach.

Despite these challenges, CBR programmes have multiplied rapidly on an international level and diversity has proved to be a strength rather than an obstacle. For instance, the KASAMAKA programmes in the Philippines which include children and adults with profound and multiple learning disabilities is based on a Portage model and many of the CBR workers are mothers of disabled children. They have established active partnerships schools, hospitals and rehabilitation centres in order to access specialist and technical expertise. In Mexico, the families of children with physical, intellectual and multiple disabilities have established support groups, rehabilitation facilities and a special school. The Janakpuri project, in India, helps the families of children with profound and multiple learning disabilities by giving them loans to start small businesses, which improves the position of the whole family and means better care for the child (Bradley, A. 1998).

So how effective has CBR been in meeting the needs of children and adults with profound and multiple learning disabilities? Not surprisingly, the answer is that we don't really have enough information to get a comprehensive picture. Because programmes had to show results fairly rapidly, they tended to focus on people with mild or moderate disabilities, who could respond more easily to support. However, my own experience across several countries is that, although there are still enormous challenges ahead, CBR has made a difference to a considerable number of people with

profound and multiple learning disabilities and their families and will continue to do so.

CBR has been particularly successful in raising awareness of disability, in combating isolation and in empowering people. Families that were hitherto isolated have received some form of support for the very first time. Children and adults with profound and multiple learning disabilities who were hidden away are now more visible within their own communities. Parents have formed self help groups to support one another, find creative solutions to their problems, make demands on professionals and put pressure on authorities. For example, a group of Zimbabwean mothers of children with severe and profound learning disabilities who first met one another through a local CBR programme have campaigned successfully to get their children into a local special school. They have also formed a cooperative which makes school uniforms and thus generates additional incomes for their families.

The natural resources and traditional skills within communities have been harnessed for technical purposes, such as making equipment. One father in a rural area in Thailand started by making his daughter a 'floor seat' so that she could sit up, see the world from a different angle and play with her brothers and sisters as they sat on a mat. He now designs and produces low-cost aids and equipment for other families and runs design and production workshops for parents. Sustainability is ensured as materials are local and there is no dependence on expensive equipment from overseas which will probably be culturally inappropriate and difficult to maintain.

One of the obstacles identified in evaluation reports is 'rehabilitation professionals' becoming hidebound by their own roles. Partnerships between professionals and families at community level can help to demystify professionalism, facilitate the exchange of skills and enable all partners to arrive at creative solutions together. Community partnerships, whether in the industrialised or developing world, can enable us as family members, professionals, policy makers and providers to cross traditional boundaries, challenge our own thinking and find more productive ways of working together.

Research studies have identified the need for additional training for CBR workers if they are to provide more specialised support for people with profound and multiple learning disabilities (Narayan & Reddy, 2008; Rajendra 2001; ILO, UNESCO, WHO, 2004) The expertise exists within special schools and centres, most of which are beyond the reach of poor families because of cost. But partnerships between schools or centres and

communities can spread skills and knowledge more widely. The Indian Institute of Cerebral Palsy in Calcutta is just one organisation amongst many which has for years had programmes of training for CBR workers and parents groups from both remote rural and slum areas.

Contributors to an African CBR conference (Hartley, 2002) stressed that CBR programmes should be part of community development, since to provide them in isolation is to separate disabled people further from mainstream society and services. CBR is a development process (Thomas and Thomas, 2001). As such it requires active participation from all partners, but ownership by the community. And development takes time. Community partnerships are powerful forces for change but if life is to change for people with profound and multiple learning disabilities and their families in low income countries, partnership needs to extend beyond the geographical community (or school, leisure centre, day service or family home). Grass roots developments at community level and top-down initiatives must meet and interact if we are to influence policy at local, national and global levels. Partnerships between CBR programmes and health, education and other groups can help to develop appropriate services where there are none, and to encourage existing services to include people with profound and multiple learning disabilities. To date, all CBR research has been mainly descriptive, with little in the way of evidence which can inform policy or practice. This presents obstacles in the 'scaling up' of CBR, planning and decision making.

CBR programmes need to be integrated with other development goals, such as poverty alleviation. One of the themes which emerged most strongly across a number of evaluations (Kuipers, P., Wirz, S. and Hartley, S. 2008)) was the need for greater collaboration between CBR programmes, local organisations and government departments, and better links with social and political agendas. Planners and government officials need to be made aware that CBR is not just for disabled people and their families, but that it strengthens the whole community.

Over the last few years WHO has been reviewing CBR and has held a number of meetings involving representatives from all stakeholders groups. The purpose is to make a link between policy and practice by developing new CBR guidelines, encompassing health, education, livelihood, empowerment, and social components. The guidelines are due to be launched in December 2008.

Many of the issues raised above are reflected in

the debates and controversies we encounter in the UK and other 'western' societies, so there is substantial opportunity for the exchange of ideas and practice. As Ojwang and Hartley (2002) remind us, 'It is by sharing experiences and perceptions across countries and continents that new initiatives are born' (p.68). And partnerships strengthened. Sustainable change takes time, but with CBR we have at least made a start.

#### Contact details

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## **PMLD Link: Future Focus**

### **Money Matters**

Kim Scarborough

The Winter edition of PMLD-Link will be exploring 'Money Matters'.

We welcome articles from anyone who supports a child or adult with PMLD including families, health, social care and education staff and managers, researchers, academics and students. The range of contributors helps us produce a journal which a wide range of people read so please do think about sending us an article.

People have lots of views and experiences of Money Matters that we would like to hear about. As this is my first attempt at editing I am really looking forward to receiving your articles about topics related to finance and resources, and hoping there will be lots of them. Possibilities are

- Maybe you manage a family trust for someone with PMLD and could write about the financial management, review or monitoring systems
- Do you know of local agreements for obtaining specialist resources or equipment such as communication devices or specialist seating equipment?
- Have you accessed funding from a source you would like to tell us about and what was the process you followed?
- Have you read a recent report that you could give us a brief outline of?
- Have you experience of an Individual Personal Budget?
- Maybe you have an example of the Carer's Grant or Learning Disability Development Fund being used to support new initiatives for people with PMLD or their family carers?
- Have you had to fight for resources and feel able to share your story with us?
- Maybe you are campaigning for improvements in resources.
- Are you conducting research into budgets, finances or accessing resources that you can share in PMLD Link?

With so many possible topics for an article we are hoping for a thought provoking and informative Winter Edition. Articles should be no more than 2000 words. We are happy to receive shorter articles and stories that are only a few hundred words. Your contributions to PMLD Link are essential in ensuring it is current and reflects the real issues and successes impacting of people with PMLD and their families.

Please send your articles or ideas for articles to me by 6<sup>th</sup> October 2008 at

[KimLScarborough@aol.com](mailto:KimLScarborough@aol.com) or [Kim.Scarborough@uwe.ac.uk](mailto:Kim.Scarborough@uwe.ac.uk)

Kim Scarborough

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**PMLD Network Email Forum  
A Digest of Discussions  
March 07 - May 08**



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

**1. Housing options for people with PMLD**

Someone asked for information on resources to use with parents to show the range of housing options available for people with PMLD. Suggestions included:

- MySafeHome Ltd [www.mysafehome.info](http://www.mysafehome.info) and the Housing Options website [www.housingoptions.org.uk](http://www.housingoptions.org.uk).
- Someone said that his son who has PMLD is buying his own flat with some other young adults who have similar care needs. He suggested people look at [www.sharedownershiphomes.org](http://www.sharedownershiphomes.org) as a starting point. He said that funding is complicated but the basic principle is that the benefits an individual is entitled to can fund the accommodation and care that the individual needs. He suggested people learn from others that have done this already so they are not re-inventing the wheel.
- The Martha Trust run three CSCI registered nursing homes for people with PMLD and demand for places at their homes has always been high. They said there are few existing supported living schemes for people with multiple disabilities and complex needs and wanted to know people's views about whether supported living is a viable option for people who require 24/7 support and nursing care.
- Someone replied that they think it is a viable option and pointed people towards information from the Joseph Rowntree Foundation about the early years of supported living in the UK: [www.jrf.org.uk/knowledge/findings/socialcare/SC94.asp](http://www.jrf.org.uk/knowledge/findings/socialcare/SC94.asp)

**2. Respite provision for PMLD younger adults**

Someone said they were having problems finding respite provision with appropriate nursing care for adults with PMLD who are over 18. They said they were based in London but were prepared to travel. Some comments and suggestions were:

- They could try Caretech Nursing Home in Arkley, Barnet
- The Martha Trust is a charity which offers respite for adults with PMLD and nursing care.
- Someone said that Credo care - a private foster agency for people with special needs including high medical needs - provide respite care. Although they may stop at 18.
- 'There really is a gap in service provision'.

**3. PMLD and bank accounts**

Someone asked if anyone had experience of opening/ managing a bank account for someone with PMLD in the context of the Mental Capacity Act (MCA). They said that even where a parent has authority to manage benefits on their adult daughter's behalf, they do not have authority to manage other monies. They said that having looked at the British Bankers' Association guide for 'people who lack capacity to make decisions' it seems that the only way is to become a court appointed deputy – which costs. Responses from the forum was as follows:

- Someone said they had to apply to the courts for a 'court of protection order' to run their daughters accounts. They said it was quite straight forward but involved a lot of form-filling.
- Someone who cares for their adult daughter at home said they receive direct payments combined with Independent Living Fund (ILF) package. This is paid into a trust that she set up for her daughter. There are no cards for the account but she is able to write cheques out to personal care assistants as long as they are countersigned by one of the other trustees of the account. She accounts back to social services and ILF when necessary.
- Someone said there is no cost effective way for their son to have a bank account to put in small sums such as birthday money. They have decided it is not worth becoming a

deputy for the sums involved.

- Someone clarified that the Act does not allow someone to make decisions about the money of a person who lacks capacity unless that person has made a lasting power of attorney appointing someone to do this or if someone is appointed by the court as a deputy. They said it is possible to open a bank account without going in person to a bank, provided correct proof of ID is supplied but it would be counted as fraud if someone did this on behalf of a person who lacked the capacity to consent. They suggested that the person who posted the original query contact the Office of the Public Guardian to ask for their advice on this as well.
- Resources: Banking and change [www.choiceforum.org/bankon.pdf](http://www.choiceforum.org/bankon.pdf) Banking for people who lack capacity to make decisions [www.choiceforum.org/banking.pdf](http://www.choiceforum.org/banking.pdf)

#### 4. Barriers to learning for adults with PMLD

Someone involved in delivering innovative training for adults with learning disabilities bordering on PMLD asked what people saw as the most important feature of a barrier-free adult learning landscape. Comments included:

- Teaching approaches need to include an appreciation of hearing and vision problems and understand the implications of them so that appropriate support can be given. See [www.lookupinfo.org](http://www.lookupinfo.org) for information about eye and hearing care for people with learning disabilities.
- Regular checks of hearing and vision are needed so that hearing and sight problems are identified. People also need to have health action plans or person centred plans which show what support they need.
- 'LSC funding that recognises the need for continuing education for PMLD students'.
- 'If PMLD learners were recognised as valid within the NQF and funding streams, life after 19 would be a lot easier'.
- There needs to be greater understanding about the needs of people with PMLD so that the approach is suitable.
- A barrier free adult learning landscape would involve the individual being able to communicate and express themselves.
- An interactive environment with information presented in pictorial and audio form.
- Support - including appropriate transport/escort - to enable individuals to access the course of their choice.

- Someone who teaches adults with PMLD in their own environment (rather than at college) said that that she has to fight to get funding. She said the biggest barrier is to show other professionals that learning has taken place. She has to do this by photographing and documenting each tiny show of learning in each session.

#### 5. Quality assurance

A manager of a supported living network sends out questionnaires to service users and their relatives to find out how satisfied they are with the service they receive. She said that questionnaires are not appropriate for people who have PMLD and wanted to know what other services use. Comments included:

- Someone said they address the questionnaire to the carers who work regularly with the clients.
- Someone else said they had put on some events for their local supporting people team which gave people the opportunity to express their views through activities.
- Clear for All are developing 'sensory asking' as a planning tool to find out the views of people with PMLD. 'Sensory asking' uses a variety of sensory experiences and a structured way of recording what and how people tell you what they think of them. It aims to knit this information into planning in a practical way. Practical applications include informing communication passports and transition planning. 'Sensory asking' is included on Clear for All's 'More than Words' training course: [http://www.clearforall.co.uk/training\\_words.htm](http://www.clearforall.co.uk/training_words.htm)

#### 6. How many people with PMLD?

A PMLD champion at a partnership board wanted population data about the number of people with PMLD. He said his county had little understanding of the needs and numbers of people with PMLD. He wanted to 'guesstimate' how many people had PMLD in the county. Some of the responses were as follows:

- Someone said he had used the PMLD Network incidence number of 40,000 people with PMLD to work out the approximate number of people with PMLD in his borough.
- [www.intellectualdisability.info/mental\\_phys\\_health/epidemiology\\_vp.html](http://www.intellectualdisability.info/mental_phys_health/epidemiology_vp.html) has information about numbers of people with learning disabilities. The site states that

‘severe and profound levels (of intellectual disability) combined account for 0.1% of the whole population’.

- Valuing People 2001 has the 1999 prevalence at 210,000 people with severe and profound learning disabilities with a 1% per annum growth prediction until 2015 (both groups together).
- The Hatton study (1998) has the number of people with severe and profound (combined) at 3 to 4 people per 1000.
- Someone said it might be worth getting in touch with their Community Learning Disabilities Team and doctors surgeries to see how many people with PMLD they have on their registers.
- Someone said that every LA has to maintain a disabled children’s register with information about various categories of needs so, if asked, they might collect information on numbers of children with PMLD or share information they have already.
- The PMLD Network said there is a serious lack of understanding about the numbers and needs of people with PMLD. It is lobbying the government to collect national data about numbers and needs. It is also encouraging people to do local audits of the numbers and needs of people with PMLD so that there can be proper planning to meet these needs: [www.pmlidnetwork.org/get\\_involved/index.htm](http://www.pmlidnetwork.org/get_involved/index.htm).
- The PMLD Network said the figure of 40,000 people with PMLD in the UK is an estimate that they have used for some time and it is now likely to be higher.

**7. Who represents those with PMLD or severe learning disabilities?**

Someone said that it is only those with mild learning disabilities who get included on Partnership Boards. They said ‘who represents those with PMLD or severe learning disabilities?’. Responses included:

- Someone said they applied for membership of a forum in order to represent their sibling who has PMLD, but was turned down as they themselves don’t have a disability. They said that many groups who ‘purport to represent the needs of disabled people’ are ‘dominated by those with physical impairments and those with mild disabilities’.
- Someone else said that they agree about representation from family being sidelined. They are concerned that the voices of the

most vulnerable are not getting heard.

- Someone said he is a parent champion for people with PMLD on the local Partnership Board and takes every opportunity to ensure the needs of the most disadvantaged in society are highlighted.
- Someone who is part of a group of parents who advocate for their children suggested people contacting Partners in Policymaking: <http://www.partnersinpolicymaking.co.uk/>. He said their training and support has helped him to be an effective advocate for his children and helped the group secure some important objectives as policy partner with the local authority and NHS primary care trust.
- Someone said that Valuing People started off with money to be allocated to citizen advocacy but that has been redirected to self advocacy groups. And although IMCAs have been brought in, they can only be used in certain situations. They are concerned as there are many people who cannot self advocate and who have no family to represent them.
- Someone said that the only solution they have found is a good circle of support which must be sustainable.

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

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

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

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



## NEWS

## AWARDS GALORE AT ST MARGARET'S SCHOOL

St Margaret's School, part of national charity The Children's Trust, celebrated the achievements of 14 of its students today (11 July) as they were given their qualifications as part of the Accreditation for Life and Living (ALL) scheme certified by Oxford, Cambridge and RSA Examinations (OCR).

The students, all of whom have profound and multiple learning difficulties, gained qualifications for modules covering a variety of areas including The Community, Creative Arts, Leisure and the World of Work. All students in St Margaret's Further Education classes have gained at least one qualification each this year.

The modules allow each student

to build an evidence-based profile of their own achievements which reflects their own needs and skills. The school selects ALL modules which will fit within its own developed and published specialist 24-hour curriculum that emphasises sensory awareness and promotes the inclusion of therapy procedures within the classroom.

In addition to the achievements of St Margaret's students being celebrated, six students from a Sussex Health Care residential home which the school provides post-19 educational outreach service to were also given their awards. Combined, over 62 qualifications were celebrated, an amazing achievement.

Jan Cunningham, St Margaret's School's Head Teacher, said: "I am very proud of all the students' achievements and am especially impressed with the effort that they have put in to gaining their awards this year. Well done everyone."



From left to right the students are: Kate (from Rapkyns – a Sussex Health Care residential home); Francies and Laura from St Margaret's School; and Jodie again from Rapkyns. The people in the back row are: Pauline from Rapkyns; Susan Drake, ALL Co-ordinator for St Margaret's School; Laura's Foster Dad Kevin; and Jan Cunningham Head Teacher at St Margaret's School.

### Petition to ask that VAT be abolished on all Disabled Facilities Grant works

Petitions have long been sent to the Prime Minister by post or delivered to the Number 10 door in person. Did you know that you can now both create and sign petitions on a government website too? This gives you the opportunity to reach a potentially wider audience and to deliver your petition directly to Downing Street. Who knows, you may get a phone call from the PM! The e-petitions system was launched in November 2006.

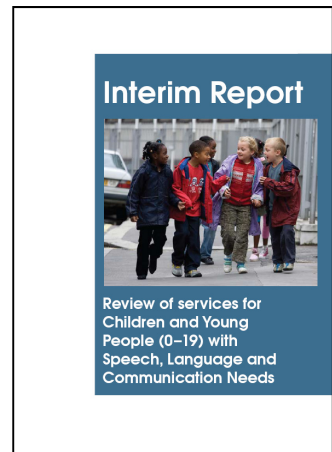
A recently lodged petition relates to concerns that the Government charges VAT on works funded by the Disabled Facilities Grants they give out. If you would like to join the others who have signed the petition, you will find it at <http://petitions.pm.gov.uk/DFG-VAT/>

The petition reads as follows:

VAT should be abolished on all Disabled Facilities Grant works. Working out VAT on Disabled Facilities Grant works is a minefield, with some items such as ramps and bathrooms being exempt, while other essential items such as accessible kitchens and bedrooms are not exempt. Charging VAT on these works can reduce the available grant by up to 17.5% (reducing the current maximum grant of £30,000.00 to £24,750.00).

## Bercow Review of Services for Children and Young people (0-19) with Speech, Language and Communication Needs

The review group chaired by John Bercow, MP, produced an interim report in March 2008 which sets out evidence received for the review. The interim report explained that the review would now focus on specific issues identified for further consideration, including, among other things, how best to improve families' overall experience of "the system", the need for guidance for commissioners of universal, targeted and specialist services, cost-effective investment in services for children and young people, and the availability and quality of speech and language therapists and other professionals. A final report, including firm recommendations, is due to be made to the Government in July.



On its website, Mencap has published its response to the Review's call for evidence and this has a particular focus on the speech, language and communication needs of children and young people with PMLD. (Visit [www.mencap.org.uk](http://www.mencap.org.uk)). The response makes a number of key points:

- Children and young people with PMLD have very specific communication needs but current support does not always meet these needs
- There is a national shortage of speech and language therapists
- There is a poor data about numbers of children and young people with PMLD which means it is difficult to plan effective services
- Speech and language therapists, school staff, staff in children's services and parents need to be trained in the informal communication methods that are required and they must be given the support, including specialised equipment, to use these methods
- There is a lack of joint working; communication support needs to be co-ordinated across all agencies.

Mencap's response stressed the right of children and young people with PMLD to communicate. The fact that they do not use formal communication (e.g. symbols, signs or speech), means that their communication needs are not easily addressed. Indeed, the focus of many services tends to be on their complex health needs to the exclusion of developing communication skills.

The response also points out that the number of children with PMLD continues to increase. This is due to improved diagnosis and better survival rates of pre-term infants with complex disabilities. This means it is more important than ever that the specific communication needs of people with PMLD are planned for and met.

For further information please contact: [bella.travis@mencap.org.uk](mailto:bella.travis@mencap.org.uk) [sarah.mepham@mencap.org.uk](mailto:sarah.mepham@mencap.org.uk)

### A Special Needs Handbook

The forum on the PMLD network contains news of a forthcoming publication being compiled by Deborah Gundle. It is intended to be an easy to use guide book containing good ideas that parents and therapists have tried and tested over the years. Carers of a disabled child who are having a difficult time over any aspect of their care can look it up in the Special Needs Handbook and find tips from other carers that have been in the same boat.

Deborah would welcome any contributions of solutions to problems you have overcome.

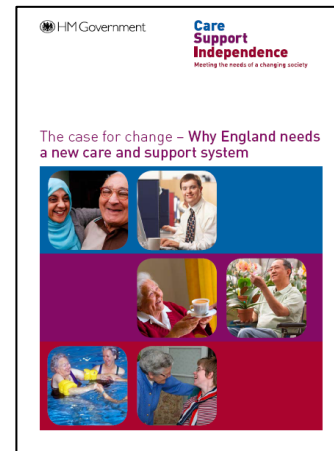
e-mail: [Deborah@specialneedshandbook.com](mailto:Deborah@specialneedshandbook.com) Tel: 020 7183 2277

## Government Launches National Debate On The Future Of Care And Support

There is currently an opportunity to be involved in a debate about the future shape of care and support services. The debate was launched in May by the Government in response to concerns that the growth in the number of people with care and support needs will put tremendous pressure both on services and on the financial support that they receive through benefits and other funding streams.

The government is seeking the views of stakeholders with the intent to create a new and affordable system. Radical change appears to be envisaged. In 20 years from now, a £6 billion 'funding gap' for social care is anticipated although the Government is keen to stress that its initiative is not just about money. It is also about providing for individual choice and enabling people to live as independently as possible for as long as possible.

The public are invited to contribute to the debate through a new national website [www.careandsupport.direct.gov.uk](http://www.careandsupport.direct.gov.uk). There is a downloadable publication called '*The case for change – Why England needs a new care and support system*'. If you require further copies of this title visit [www.orderline.dh.gov.uk](http://www.orderline.dh.gov.uk) and quote: 286897 giving the title or write to DH Publications Orderline, PO Box 777, London SE1 6XH or e-mail: [dh@prolog.uk.com](mailto:dh@prolog.uk.com).



### Whose decision?

This is the first of two reports from the Mental Health Foundation and the Foundation for People with Learning Disabilities on the implementation of the Mental Capacity Act 2005, which came into full effect on 1 October 2007.

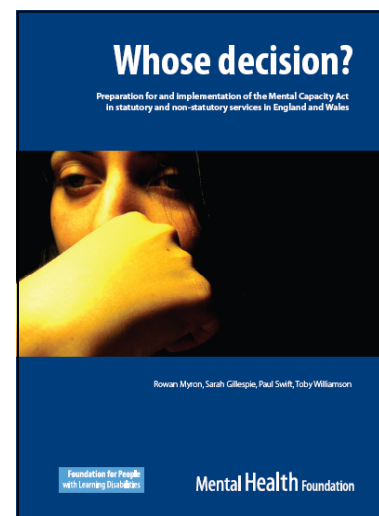
This report's authors found that many health and social care staff felt confused about mental capacity issues. 98% of staff interviewed said they needed more training on mental capacity and making capacity assessments. The authors' recommendations for the health and social care sectors include:

- ensuring coherent strategies are in place to communicate guidance and training about how to apply the Act to frontline staff
- an audit of current knowledge and training to identify and plug gaps that need to be filled
- more resources to be employed to support service users and their carers in playing as full a role as possible in decisions about their care

The researchers spoke to professionals working with vulnerable adults throughout the social care and health sectors, as well as to service users themselves and their carers. While they found some good practice, the overall picture was one of confusion about what mental capacity means and the criteria needed for assessments of capacity to be made.

The next stage of the Foundations' work will look at how people's attitudes and knowledge about mental capacity have changed since the Act came into force.

The report is available to download at: [www.learningdisabilities.org.uk/](http://www.learningdisabilities.org.uk/)



## The Mental Health of Children and Adolescents with Learning Disabilities in Britain

by Eric Emerson & Chris Hatton  
Institute for Health Research  
Lancaster University

The authors of this paper analysed combined data from the 1999 and 2004 Office for National Statistics Surveys of the mental health of children and adolescents in Britain. Their findings were published in 2007 by the Foundation for People with Learning Disabilities. Their report makes for disturbing reading.

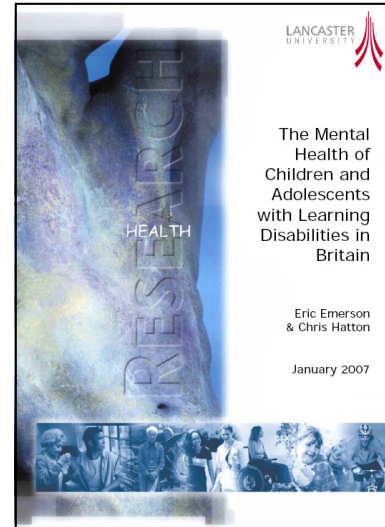
Over one in three children and adolescents with a learning disability in Britain (36%) have a diagnosable psychiatric disorder. Children and adolescents with learning disabilities are over six times more likely to have a diagnosable psychiatric disorder than their peers who do not have learning disabilities. The increased risk of having a mental health problem cuts across all types of psychiatric disorders. Children with learning disabilities are also significantly more likely to have multiple disorders.

However, the authors show that mental health problems are not necessarily caused simply by having learning disabilities. Children with learning disabilities have increased exposure to poverty and social exclusion. These children live in more challenging family circumstances and have fewer friends; all of which are factors known to be associated with an increased risk of mental health problems.

The authors stress that addressing the mental health needs of children with learning disabilities is important for three inter-related reasons.

- First, mental health problems can have a major negative impact on the well-being, social inclusion and life opportunities of children.
- Second, mental health problems in children with learning disabilities have a negative impact on the well-being of their families (and especially their mothers).
- Third, mental health problems in children are likely to lead to out-of-home placements, especially the use of high-cost residential educational placements.

The analysis in the report shows that addressing the mental health needs of children with learning disabilities requires that we address the social circumstances under which the children and their families are living. Responding to these challenges is not just a question of developing better services.



### Special Needs Play Session in Worcester

Every Tuesday. Started January 2008. The Deep Sea Den, The Raven, Droitwich Road, Worcester. 6 - 8pm. (Term time & holidays). £2.50 for the first child & £1 each for siblings. Free hot drink for adults/squash & biscuits for children. No age/height restrictions for children/siblings. Parents/siblings are able to help & support in the play area. Exclusive use for special needs only. Parental supervision is required at all times. Booking is not necessary. For further information phone June Urosevic on 01905 457857

Do you know of other opportunities for families that are worth publicising?



## Joseph Rowntree Foundation Overview of Housing for Disabled Children



Recently the issue of housing and disabled children has moved up the government's policy agenda, and there are currently opportunities for change at both the national and local policy level. The Joseph Rowntree Foundation posted on its website in May a round-up of what is known about the housing circumstances of disabled children and their families. This overview provides links to a range of relevant documents produced over the past.

Families with a disabled child are more likely to be renting their homes than families with non-disabled children. Families with a disabled child are 50 per cent more likely than other families to live in overcrowded accommodation, to rate their home as being in a poor state of repair, and to report problems with wiring, draughts and damp in the child's bedroom. The sorts of problems with housing most frequently reported by families include lack of family space, and lack of space for storing and using therapeutic equipment. Other common problems are difficulties with location and unsuitable or inaccessible kitchens, toilets and bathrooms.

Disabled children and young people spend more time at home than non-disabled children, but there is evidence to suggest that their homes are the most restrictive environments in which they spend their time. Families can experience significant difficulties accessing support and services to help them address the problems with their housing. Living in unsuitable housing has been found to be associated with increased levels of parental stress.

[www.jrf.org.uk/knowledge/findings/housing/2208.asp](http://www.jrf.org.uk/knowledge/findings/housing/2208.asp)

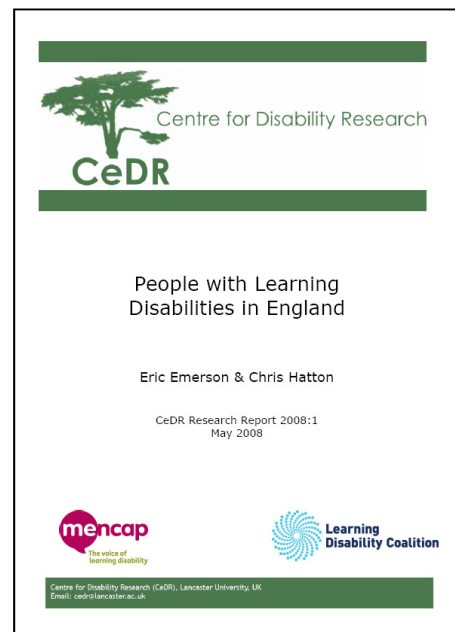
### Report highlights lack of essential learning disability data

'*People with Learning Disabilities in England*' is a report that tries to document the life experiences of adults with learning disabilities and provide robust estimates about the number of people with learning disabilities. The report by the Centre for Disability Research was published in May; it was commissioned by Mencap.

The astounding finding is that there is no reliable information on these matters held by central government departments or derivable from population surveys. This raises concerns about how the government can effectively plan the development of services when crucial information about learning disability is not available. More research needs to be done into the number of family members and friends providing unpaid care, especially older carers. Not only do these carers need support now, but the social care system will have to support many people with a learning disability when their family members are no longer around to care for them.

The report also identifies factors that could lead to a change in the number of people with a learning disability, including increased survival rates among young people with severe and complex disabilities, who often require life-long complex packages of care, and reduced mortality among older adults with learning disability.

The report follows the government's announcement of a six-month debate on the future of care services in England. The report can be accessed at [www.mencap.org.uk/publications](http://www.mencap.org.uk/publications)



## Lamb Inquiry: increasing parental confidence in the SEN assessment process

The Lamb Inquiry was set up as part of the Government’s response to the House of Commons Education and Skills Committee Report *Special Educational Needs: Assessment and Funding*. The Inquiry is being led by Brian Lamb, the Chair of the Special Educational Consortium, and will advise on the most effective ways of increasing parental confidence in the SEN assessment process. Brian Lamb has brought together a group of experts to advise him and he will report in September 2009.

The Inquiry is seeking evidence of positive developments that have improved parental confidence and had other benefits. In addition, the Inquiry has commissioned innovative projects in order to examine a range of ways in which parental confidence in the SEN assessment process might be increased.

Small amounts of funding have been made available to provide opportunities for local authorities, working with partners, to explore ways of increasing parental confidence in the SEN assessment process. The Inquiry has expressed interest in the following areas at least:

- making the provision of educational psychology advice “arm’s length” from a local authority;
- sharing best practice in developing good relationships between the authority and parents, through effective parent partnership services and other local mechanisms;
- developing the ‘team around the child’ approach.

At the time of going to print, it is not known which bids by local authorities have been successful.

**Individual Subscribers - To enhance our funds, we would be grateful if you agree to Gift Aid**

### Gift Aid Declaration for subscribers

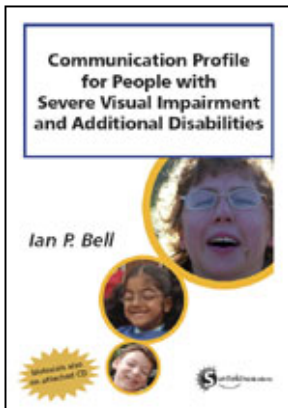
<b>Name of Charity:</b>	<i>PMLD-Link</i>
<b>Details of donor:</b>	
Title .....	Forename(s).....Surname.....
Home Address: .....	
.....	
..... Post Code:.....	
<p><b>I want the charity to treat</b> all donations that I make from the date of this declaration until I notify you otherwise as Gift Aid donations.</p> <p>You must pay an amount of Income Tax and/or Capital Gains Tax at least equal to the tax that the charity reclaims on your donations in the appropriate tax year (i.e. 28p for each £1 you give up to 5 April 2008 &amp; then 25p for each £1 you give on or after 6 April 2008)</p>	
<b>Date</b> .....	...../...../.....

**NOTES**

1. You can cancel this Declaration at any time by notifying the charity
2. If in the future your circumstances change and you no longer pay tax on your income and capital gains equal to the tax that the charity reclaims, you can cancel your declaration
3. If you pay tax at the higher rate you can claim further tax relief in your Self Assessment tax return.
4. If you are unsure whether your donations qualify for Gift Aid tax relief, ask the charity. Or, refer to help sheet IR65 on the HMRC web site ([www.hmrc.gov.uk](http://www.hmrc.gov.uk))
5. Please notify the charity if you change your name or address

**Please return this form to PMLD-Link, 31 Birdwell Road, Long Ashton, Bristol, BS41 9BD**

## RESOURCES



### Communication Profile for People with Severe Visual Impairment and Additional Disabilities *Includes supporting CD*

This Profile is designed to overcome many of the difficulties encountered when presenting information to professionals about levels of communication in a developmentally young child with severe visual impairment and additional disabilities. It provides a comprehensive description of the individual's communication skills, and can be used with adults as well as children. Its uniqueness lies in the specific focus upon people with visual impairment and additional disabilities, rather than being an adaptation of instruments primarily designed to target other disability groups.



This is for a project which was undertaken by HFT on TATE (Through Assistive Technology to Employment). Although the technology on this project is aimed at people who are more able than those with PMLD, it is clear that assistive technology is progressing all the time and already we can see applications with those with PMLD.

Contact Ann Aspinall, The Home Farm Trust Ltd (HFT), [ann.aspinall@hft.org.uk](mailto:ann.aspinall@hft.org.uk) to get a free DVD



The MOVE Programme is unique. We combine the knowledge of therapists, teachers and family to teach severely disabled children and young people independent movement skills - sitting, standing and walking. They're basic movements that we might take for granted, but can be key to freedom of choice, improved health and a world of possibilities.

A registered charity, we're the only organisation to offer this kind of training, advice and support. And our aim is to give all 110,000 severely disabled children and young people in the UK access to the programme - because everyone deserves the chance to MOVE.

If you want to see what MOVE is about go to <http://www.move-europe.org.uk/index.htm>



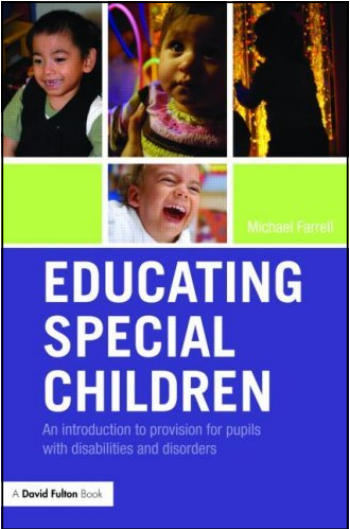
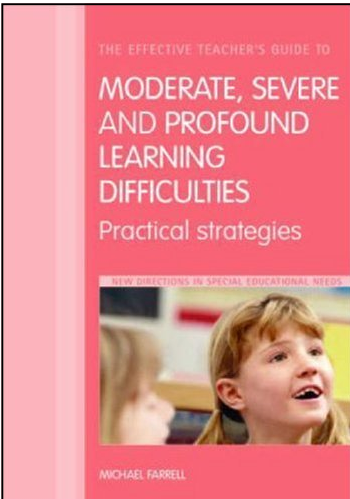
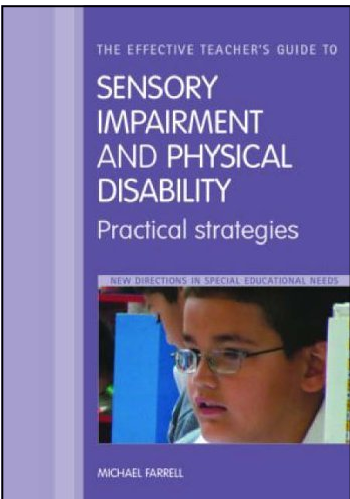
### Irish Curriculum Guidelines for Severe and Profound Learning Difficulties

Go to the web address <http://www.ncca.ie/eng/index.asp?docID=293> now scroll down to find the pdfs of the different subject guidelines. You may find these to be a set of helpful ideas when planning to personalise the curriculum for the pupils you teach.

### Sunfield Student Risk Assessment

The Sunfield Student Risk Assessment (SSRA) is a pioneering and innovative risk assessment for use in the care and education of children and young people with special educational needs. The concept of a comprehensive risk assessment format began to be developed at Sunfield in 2004, the year which saw the introduction of the Children Act (England and Wales). However, what makes the SSRA stand out from others of its kind is that it incorporates within its framework the five outcomes for children from the *Every Child Matters* (Department for Education and Skills, 2004) initiative: 'Be healthy', 'Stay safe', 'Enjoy and achieve', 'Make a positive contribution' and 'Achieve economic wellbeing'.

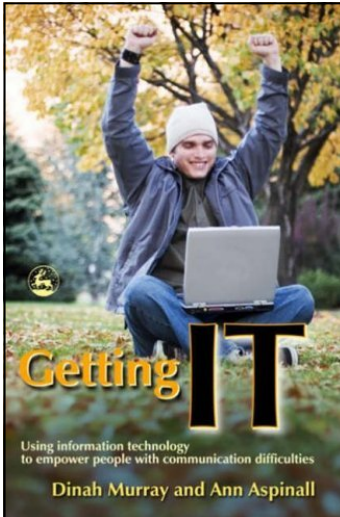
## PUBLICATIONS

	<p><b>Author:</b> Michael Farrell</p> <p><b>Publisher:</b> Routledge</p> <p><b>ISBN:</b> 978-0-415-46315-7</p> <p><b>Pub Date:</b> 2008</p> <p><b>Price:</b> £18.99</p>	<p><b>Educating Special Children: An Introduction to Provision for Pupils with Disabilities and Disorders</b></p> <p>Several of the twenty chapters in the book may be of interest to readers of PMLD-Link – on moderate to severe and profound cognitive impairments (note the use of American definitions), hearing and visual impairments, deafblindness, ‘orthopaedic impairment’ and motor disorders, health problems, traumatic brain injury and communication disorders. Educating Special Children provides an overview of appropriate provision for children with a wide range of learning disorders and disabilities. As well as descriptions of special education appropriate to each category of need, the book describes prevalence, causal factors and assessments. Key texts for further reading are recommended, though most are American ensuring the book’s appeal outside the UK.</p>
	<p><b>Author(s):</b> Michael Farrell</p> <p><b>Publisher:</b> Routledge</p> <p><b>ISBN:</b> 978-0-415-36041-8</p> <p><b>Pub Date:</b> 2006</p> <p><b>Price:</b> £20.99</p>	<p><b>The Effective Teacher's Guide to Moderate, Severe and Profound Learning Difficulties: Practical Strategies</b></p> <p>The book is written with teachers in mind but may be appropriate for other practitioners. It is one of a series by the same author. With appropriate emphasis upon inclusion, the book examines and explains the terminology and definitions of learning difficulties. Typical provision for each category of pupil is explained and aspects of teaching and learning are examined, including ways of assessing and raising achievement and classroom organisation strategies. The book provides an overview only and key texts for further reading are suggested.</p>
	<p><b>Author(s):</b> Michael Farrell</p> <p><b>Publisher:</b> Routledge</p> <p><b>ISBN:</b> 978-0-415-36042-5</p> <p><b>Pub Date:</b> 2006</p> <p><b>Price:</b> £20.99</p>	<p><b>The Effective Teacher's Guide to Sensory Impairment and Physical Disability: Practical Strategies</b></p> <p>A brief guide to sensory impairments, physical disabilities, and some medical conditions that may require SEN provision, including epilepsy, asthma, diabetes, and cystic fibrosis. There is a discussion of the provision for deaf-blind children. Writing in an accessible style, the author provides an overview of the main conditions and describes appropriate education and health care provision. The book is written with teachers in mind and key texts for further reading are suggested. There is a good bibliography and addresses for contacts.</p>



## REVIEWS

**Title:** Getting IT: using information technology to empower people with communication difficulties



**Authors:** Dinah Murray and Ann Aspinall

**P u b l i s h e r s :** Jessica Kingsley Publishers

**Pub date:** 2006

**Price:** £13.99

I enjoyed reading this book. It is not your usual mind boggling IT book but tells the stories

of three people with learning disabilities who, with help, have used multi media to learn, participate in activities with others, make their own record of their interests and life events and improve their communication and decision making skills. The stories are of Kumar who is on the autistic spectrum, Marie who has dementia and Irene who has very limited verbal communication skills. Along the way it gives practical tips for using information technology in ways that help people with learning disabilities release their potential through a variety of IT medias. It also has tips, help sheets and resources to help improve your use of information technology such as PowerPoint and make it exciting and fun to use.

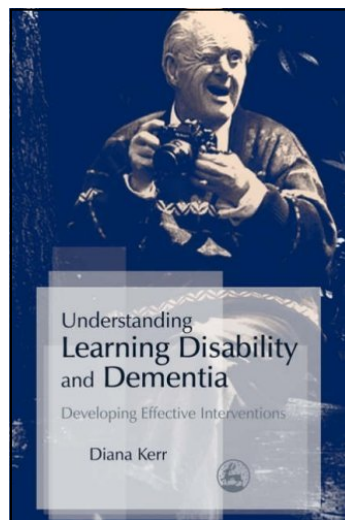
The book does not have specific stories about using multi media with people with PMLD, however, it can still offer ideas and tips to those who want to start do this. I have worked with people with PMLD who have loved seeing themselves on video and having read this book the potential for using IT on large computer screens with a mix of pictures, moving images, easy navigation buttons and touch screens is something I would explore with more confidence and imagination.

For those serious about exploring how they might start using IT with people with learning disabilities this book would be inspiring and helpful. For the creative amongst you the lack of direct reference to people with PMLD will not hold you back. However if you are looking for a book with stories, tips and problem solving ideas specifically about using

information technology with people with PMLD you will not find that here. People who have been using multi-media might find this interesting but it might not teach you much. If you would benefit from descriptions of how to do things and resource lists this would be value for money.

*Kim Scarborough - Senior Lecturer, University of the West of England*

**Title:** Understanding Learning Disability and Dementia



**Author:** Diana Kerr

**Pub date:** 2007

**P u b l i s h e r :** Jessica Kingsley Publishers, London

**ISBN:** 978 1 84310 442 1

**Price:** £18.99

People with learning disability are four times more likely to develop one of the dementia disorders than people in the general population. Those with Down's Syndrome are at a greatly increased risk of developing Alzheimer's type dementia. For these reasons it is important that staff working with people who have a learning disability and those who work with dementia services should be aware of the needs of this client group.

In this book Diana Kerr, a renowned expert on the subject, aims to inform both groups as well as the family and friends of people with dementia. Her book is easy to read but has a strong evidence base aided by meticulous and wide-ranging referencing for the reader who wishes to go further into a particular subject. Twenty-six short case studies are used to illustrate the points made. The chapters build on each other to provide an overall picture of the subject but the book can also be used to dip into to provide information about specific problems as each chapter covers a separate need.

I found the sections on therapeutic interventions, supporting people to eat well and creating supportive physical environments particularly useful. The section on the role of technology was also inspiring but there was no information about how to obtain the equipment described. I also felt that it would have been useful to include a glossary of terms and a contact list for further information and support.

Overall this book provides a good introduction to learning disabilities and dementia and will be of use to those working in dementia care as well as in learning disability services. The reader with some previous knowledge may find some of the information is already known to them but will be able to use the numerous references to further their knowledge.

Alison Barsby, Senior Occupational Therapist,  
Worcestershire Mental Health Partnership Trust

## **INTERCONNECTIONS ELECTRONIC BULLETIN**

**About Children and Young  
People (0 - 25) with  
Disabilities / SEN**

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

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

## **Useful Websites**

### **Launch of [easyhealth.org.uk](http://easyhealth.org.uk) website**

This website was created by Generate – a charity that works with people with mild or moderate learning disabilities – with funding from the Department of Health (see the article by Jo Giles in the Winter 2007 issue of PMLD-Link).

The aim of the website is to make it easier for people with learning disabilities to find useful health information that is easy to understand. It does this by bringing together good quality accessible health information from across the country, and putting it on to one website. Over 40 organisations from across the country have put their information on to this website so it can be downloaded for free. There is a facility that allows organisations to contact the website managers to include useful information of their own. It also has the potential to help carers and to help professionals to give a better service.

The website is designed to be eye-catching and uses simple words supported by photos, symbols and pictures. People with profound and multiple learning disabilities have many health needs and there is some really useful information on the site for people who support them. For example there are resources on person-centred planning and direct payments as well as leaflets on an A-Z of health issues.

Visit [www.easyhealth.org.uk](http://www.easyhealth.org.uk) to find out more.

### **[www.move-europe.org.uk](http://www.move-europe.org.uk)**

MOVE stands for Mobility Opportunities via Education. The website provides more details about the MOVE programme. This aims to combine therapy and education to most effectively teach functional activities and, therefore, MOVE gives people with physical disabilities the opportunity to take greater control of their lives. MOVE uses a top down approach that focuses on activities that people are motivated to achieve. In an initial assessment with the individual's family and therapists and teachers, involving the person with physical disabilities as much as possible, goals are determined and a time frame to achieve these goals is set. These goals are then broken down into activities within which manageable and achievable targets are set. Some specialised equipment is used on the programme as a tool for learning new skills.

The use of the MOVE programme has been shown to improve greatly the life chances and the education of people who have significant physical disabilities. It gives people the opportunity to sit, stand and walk and to explore actively their environment. These activities stimulate their physical development since they help improve breathing, circulation and muscles and promote bone density and good posture.

MOVE offers courses for beginners that cover the MOVE framework including the establishment of the team, assessing the person's current abilities, the setting of goals, teaching mobility skills including prompt reduction, and maintaining skills for the future. MOVE also offers courses for experienced people to become in-house instructors for their service or setting.

## The P Scales Focus Area

[http://www.standards.dcsf.gov.uk/primary/features/inclusion/sen/p\\_scales](http://www.standards.dcsf.gov.uk/primary/features/inclusion/sen/p_scales)

The P Scales Focus Area provides guidance to support the effective use of P scales in order to improve outcomes for pupils with special educational needs (SEN) who are working below level 1 of the National Curriculum. It is well worth exploring.

All schools **must** now use P scales to provide data for pupils with SEN who are working below level 1 of the National Curriculum. As mainstream schools become more inclusive there will be an increasing need for them to use the P scales in assessment and planning.

The use of P scales is central to the Government's commitment to recognise the attainment and progress of pupils with SEN, aged 5-16, who are working below level 1 of the National Curriculum.

It is the DCSF's stated intention that this P-Scales Focus Area should include links and references to existing materials, processes and initiatives to support the use of P scales in both special and mainstream schools.

The source of much of the resource material on this site originates from a three year research project with The University of Northampton and the East Midlands Regional Partnership working in collaboration. There are a range of free downloadable materials that will be useful for school-based training and moderation activities.

## Early Support Programme

The Government's Early Support website has had a makeover - visit [www.earlysupport.org.uk](http://www.earlysupport.org.uk).

The website reflects the fact that the programme is focused on young children with disabilities and their families, with colourful photographs and short videos of people talking about their experience of using Early Support. Several new areas have been added to the website.

The website provides information for lead professionals and key workers about implementing service change. The section for families explains what the Early Support programme offers parents and carers and helps those visiting the site for the first time to find their way around.

The website provides downloadable materials for using with parents and carers including information about particular categories of special needs such as cerebral palsy, multisensory impairment and autism. New materials include developmental profiles that can be built by parents as regards their children with Down Syndrome or hearing impairment.

The revamped website is well worth exploring and holds out the promise that even more useful materials will be available in future.

## Short Courses and Conferences

### August

**Date:** 22nd-27th

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

**Provider:** Sense Scotland

**Location:** Glasgow

**Contact:** Sense Scotland

Tel: 041 429 0294 Fax: 0141 429 0295

Text: 0141 418 7170

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

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

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

**Provider:** Concept Training

**Locations:** Edinburgh, Glasgow.

**Contact:** See providers' details

### September

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

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

**Provider:** University of Northampton

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

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

**Date:** Various workshop dates

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

**Provider:** Concept Training

**Locations:** Taunton, Birmingham, London

**Contact:** See providers' details

**Date:** 15<sup>th</sup>

**Title:** promoting inclusion and the sensory approach in the learning environment

Course tutors: Flo Longhorn and Richard Hirstwood

**Location:** Stone

**Provider:** Florcih Productions

**Contact:** See providers' details

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

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

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

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

Paul Hart – SENSE Scotland

Melanie Nind – Professor of Education

University of Southampton

Gail Deuce – SENSE Consultant Teacher

David Brown - Education Specialist

California Deaf-Blind Services

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

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

### Providers Details

#### BILD

**British Institute of Learning Disabilities**

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

Tel. 01562 723025

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

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

#### Concept Training

15 Beach Street,

Morecambe,

Lancashire LA4 6BT

Tel. 01524 832 828

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

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



**Date:** 16th**Title:** Very special mathematics**Provider:** Concept Training**Locations:** Glasgow**Contact:** See providers' details**Date:** 17th**Title:** Aromatherapy and massage for children with complex needs: developing good practice**Location:** Leeds**Provider:** RNIB Children's Services**Contact:** See providers' details**Date:** 26th**Title:** promoting inclusion and the sensory approach in the learning environment

Course tutors: Flo Longhorn and Richard Hirstwood

**Location:** W5 Belfast**Provider:** Florich Productions**Contact:** See providers' details**Date:** 30th**Title:** promoting inclusion and the sensory approach in the learning environment

Course tutors: Flo Longhorn and Richard Hirstwood

**Location:** Guilford Cathedral**Provider:** Florich Productions**Contact:** See providers' details

## October

**Date:** 8th**Title:** Aromatherapy and massage for children with complex needs: an introduction**Location:** London**Provider:** RNIB Children's Services**Contact:** See providers' details**Date:** 9th/10th**Title:** promoting inclusion and the sensory approach in the learning environment –Science Focus

Course tutors: Flo Longhorn and Richard Hirstwood

**Location:** Eureka! Halifax**Provider:** Florich Productions**Contact:** See providers' details

## Providers Details

### EQUALS

PO Box 107, North Shields,

Tyne &amp; Wear, NE30 2YG

Tel. 0191 272 8600

Email: [admin@equals.co.uk](mailto:admin@equals.co.uk)Website: [www.equals.co.uk](http://www.equals.co.uk)

### Sunfield PDC

Clent Grove, Clent,

Nr. Stourbridge,

West Midlands DY9 9PB

Tel. 01562 883183

E-mail: [pdcsunfield.org.uk](mailto:pdcsunfield.org.uk)Website: [www.sunfield-school.org.uk/courses.htm](http://www.sunfield-school.org.uk/courses.htm)

### Learning in the multisensory environment-helping the special learners brain compensate in positive ways

Tuesday 7th and Wednesday 8th  
October London, MIC at Euston**Dr Paul Pagliano**, Australia, Author of 'Multisensory Environments', one of the academic innovators from the world wide Sensory Movement, presenting a two day workshopFurther details at Florich Productions or [www.sensology.org](http://www.sensology.org) call 0845 127 5281 or email [flocatalyst@aol.com](mailto:flocatalyst@aol.com)**Date:** 15th**Title:** Music gets us going: musical ways of prompting visual development in children with visual impairment and complex needs**Location:** Leeds**Provider:** RNIB Children's Services**Contact:** See providers' details**Date:** 13<sup>th</sup>, 21<sup>st</sup>**Title:** Sensory play and leisure in the multi-sensory environment**Locations:** London, Birmingham**Provider:** Concept Training**Contact:** See providers' details

## November

**Date:** 7th**Title:** Multisensory environments: big and Small: How to do it!**Location:** MIC London-Euston**Provider:** Florich Productions**Contact:** See providers' details

**Date:** 11th  
**Title:** Sensory differences and the role of positive touch  
**Provider:** Concept Training  
**Location:** London  
**Contact:** See providers' details

**Date:** 13th  
**Title:** Assessment and development of functional vision: children with complex needs  
**Location:** Birmingham  
**Provider:** RNIB Children's Services  
**Contact:** See providers' details

**Safeguarding Across the Generations**

**Wednesday 19th November**

The Ann Craft Trust will be holding its annual conference in Nottingham at the National College for School Leadership (NCSL).

Presentations will include the safeguarding of disabled children and vulnerable adults, the implementation of the Safeguarding Vulnerable Groups Act and the Independent Safeguarding Authority, the adult protection legislation debate and lessons learned from child protection. For more information please download booking form.

Further details are available by contacting Charlie Heywood, Marketing & Development Officer on 0115 951 5400 or by e-mailing [charlie.heywood@nottingham.ac.uk](mailto:charlie.heywood@nottingham.ac.uk)

**Date:** Various dates  
**Title:** Very special mathematics  
**Provider:** Concept Training  
**Locations:** St. Helen's, Enfield, Wolverhampton  
**Contact:** See providers' details

**Date:** 19th  
**Title:** promoting inclusion and the sensory approach in the learning environment  
 Course tutors: Flo Longhorn and Richard Hirstwood  
**Location:** Newcastle Centre for Life  
**Provider:** Florich Productions  
**Contact:** See providers' details

**Date:** 21st  
**Title:** Multisensory environments: big and Small: How to do it!  
**Location:** Manchester University  
**Provider:** Florich Productions  
**Contact:** See providers' details

**Date:** 26th  
**Title:** Switches. Who needs them? Technology for Pupils with Complex needs  
**Location:** Leeds  
**Provider:** RNIB Children's Services  
**Contact:** See providers' details

## December

**Date:** 9th  
**Title:** Learning through touch: identifying and reducing barriers for learning for children with multiple disabilities  
**Location:** Leeds  
**Provider:** RNIB Children's Services  
**Contact:** See providers' details

## February 2009

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

### Providers Details

#### Florich Productions

Tel. 0845 127 5281  
 Email: [flocatalyst@aol.com](mailto:flocatalyst@aol.com)  
 Website: [www.sensology.org](http://www.sensology.org)

#### RNIB Children's Services

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

## LONGER COURSES (with accreditation)

Updated April 2008

### MA in Education

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

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

**Module: EDUM081**

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

### MA in Education

#### Physical Disabilities: Contexts & Interventions

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

**Module: EDUM058**

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

### MA in Education

#### Physical Disabilities: Curriculum Issues

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

**Module: EDUM059**

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

### MA in Education

#### Understanding Multi-Sensory Impairment

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

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

**Module: EDUM054**

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

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

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

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

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

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

**For further details:** University of Chester

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

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

### PGCert, AdCert.

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

*Distance education.*

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

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

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

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

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

The modules are as follows:

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

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

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

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

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

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

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

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

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

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

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

**Adults with learning disabilities who have significant and complex needs**

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

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

The next intake is October 2006.

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

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

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

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

**Programme Structure**

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

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

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

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

**For further details:** University of Chester

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

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

**BPhil, PGDip and MEd**

**Inclusion and SEN**

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

Year 2 Autism (Children) or Autism (Adults)

*Distance Education*

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

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

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

**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](mailto:emma.hardy@manchester.ac.uk)

**PMLD-Link  
Subscription Year 2008**

Volume 20 Nos. 1,2 and 3

<b>Subscription Rates:</b>	Individual:	<b>UK</b> £12.00	<b>Overseas (sterling)</b> £17.00
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**PMLD-Link** is an informal journal for practitioners and carers working with people with profound and multiple learning disabilities (PMLD), of all ages and in all situations. It is published three times a year and covers a wide range of issues of interest and practical use in the day-to-day work of practitioners, parents and carers in schools, colleges, adult provision, in the home, and many other settings. In recent years the scope of the articles has been widened to include all professions and services, and to cover issues pertaining to all groups, including occasional articles by practitioners and parents from overseas.

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

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

**PMLD-Link** also includes:

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

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

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

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

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

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

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

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

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

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

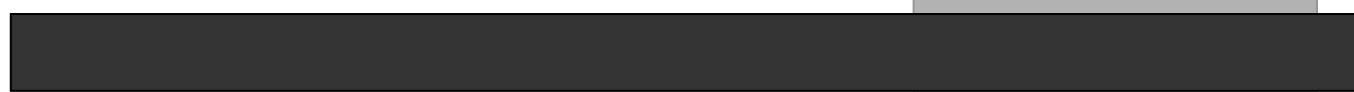
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# PMLD Link

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