PMLD LINK
sharing ideas and information

Celebrating 25 years of PMLD Link

Spring 2013

Vol 25 No 1. Issue 74
ISSN 2042-5619

PMLD LINK
sharing ideas and information

Vol. 25 No. 1 Issue 74

SPRING 2013 contents

10 Multisensory Environment

16 Theatre company

20 Bag Books

www.pmldlink.org.uk

PMLD Link is a journal for everyone supporting people with Profound and Multiple Learning Difficulties

PMLD LINK
sharing ideas and information

Vol. 25 No. 1 Issue 74

PMLD Link Journal: Celebrating 25 Years

You are invited to join us for a celebration conference on

Friday 28 June 2013
10:30am – 3:00pm

Room G39 - School of Education
Chair: Dr Penny Lacey, Senior Lecturer in Education, DISN

The University of Birmingham, Department of Disability, Inclusion and Special Needs (DISN) is hosting the conference and we are very grateful for their kind support. DISN has been associated with 'PMLD Link' for many years and currently Dr Penny Lacey is on the editorial team.

Many members of the PMLD Link Editorial Board will be at the event to discuss a wide range of topics. Speakers include:

Dave Hewett on Intensive Interaction | Jo Fitzgerald on Personal Budgets

To reserve a place please contact Karen Turner-Brown **k.turner-brown@bham.ac.uk**

Refreshments and Lunch included

This event is free to subscribers

To subscribe to PMLD Link, please visit the website at http://www.pmldlink.org.uk/subscribe/

www.birmingham.ac.uk/

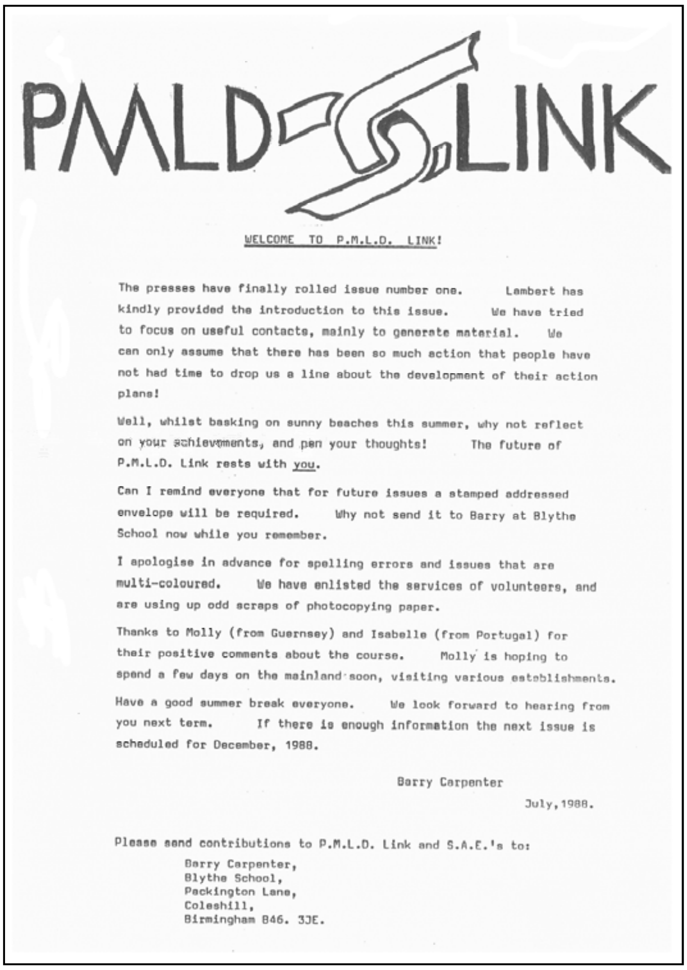
UNIVERSITY OF
BIRMINGHAM

@DISN_UoB

GUEST EDITORIAL

Celebrating 25 years of PMLD Link

This issue is the first in the year in which PMLD Link celebrates 25 years of publication. These images of the front covers show that PMLD Link has not only survived, but developed over the years from a few simple, photocopied sheets to the fully fledged journal it now is.



PMLD LINK

WELCOME TO P.M.L.D. LINK!

The presses have finally rolled issue number one. Lambert has kindly provided the introduction to this issue. We have tried to focus on useful contacts, mainly to generate material. We can only assume that there has been so much action that people have not had time to drop us a line about the development of their action plans!

Well, whilst basking on sunny beaches this summer, why not reflect on your achievements, and pen your thoughts! The future of P.M.L.D. Link rests with you.

Can I remind everyone that for future issues a stamped addressed envelope will be required. Why not send it to Barry at Blythe School now while you remember.

I apologise in advance for spelling errors and issues that are multi-coloured. We have enlisted the services of volunteers, and are using up odd scraps of photocopying paper.

Thanks to Molly (from Guernsey) and Isabelle (from Portugal) for their positive comments about the course. Molly is hoping to spend a few days on the mainland soon, visiting various establishments.

Have a good summer break everyone. We look forward to hearing from you next term. If there is enough information the next issue is scheduled for December, 1988.

Barry Carpenter

July, 1988.

Please send contributions to P.M.L.D. Link and S.A.E.'s to:

Barry Carpenter,
Blythe School,
Packington Lane,
Coleshill,
Birmingham B46. 3JE.

Many of the major issues of 25 years ago relating to 'PMLD' continue to be debated and we have reprinted a few items from those early days – see the poem by Christina Ross from Issue 1 in 1988 and an article on multisensory environments by Nick Howard - with accompanying articles on present practice. Other perennial themes are represented by the articles on the arts (in this issue theatre and storytelling), accessibility and inclusion, research, the National Curriculum and this continuing debate is surely healthy in challenging, informing and improving practice.

What began as a very informal newsletter sent to participants of a course for teachers [so that they could keep in touch and share ideas and good practice] has grown into a journal, now sent out to parents, carers and practitioners in all services across the UK and indeed, with readers across the world.

The first few issues were sent out by Blythe School, and we have to thank Barry Carpenter, then head of the school, for starting the ball rolling. Before long more and more people wanted copies of PMLD Link and subscriptions had to be introduced. At this point Carol Ouvry took over as 'chief cook and bottle washer' collating articles and items sent in, getting it printed and sending it out to the subscribers. You will see from the images that in the early days, it was a literal 'cut and paste' to begin with, later articles were retyped to create a house style; still a very informal Newsletter, although attracting articles from some of the people who were well known in the developing field as well as from the readers themselves.

As it grew, it was evident that a more formal organisation was needed. An Editorial Board was created to help generate articles and broaden the focus of our topics and to generally support all aspects of the production process. Further developments have included professional management of the production, becoming a Charity and most recently, the creation of a website on which nearly all back issues are available to subscribers. This latest development also enabled us to modernise the 'look' of PMLD Link by having a colourful cover and including photographs to ensure people with PMLD were at the centre of what we were doing and bring the articles to life.

Through all these changes, the priorities have remained the same: to support and disseminate good practice; to share information and experiences and to provide a forum for subscribers to contact other people in similar situations.

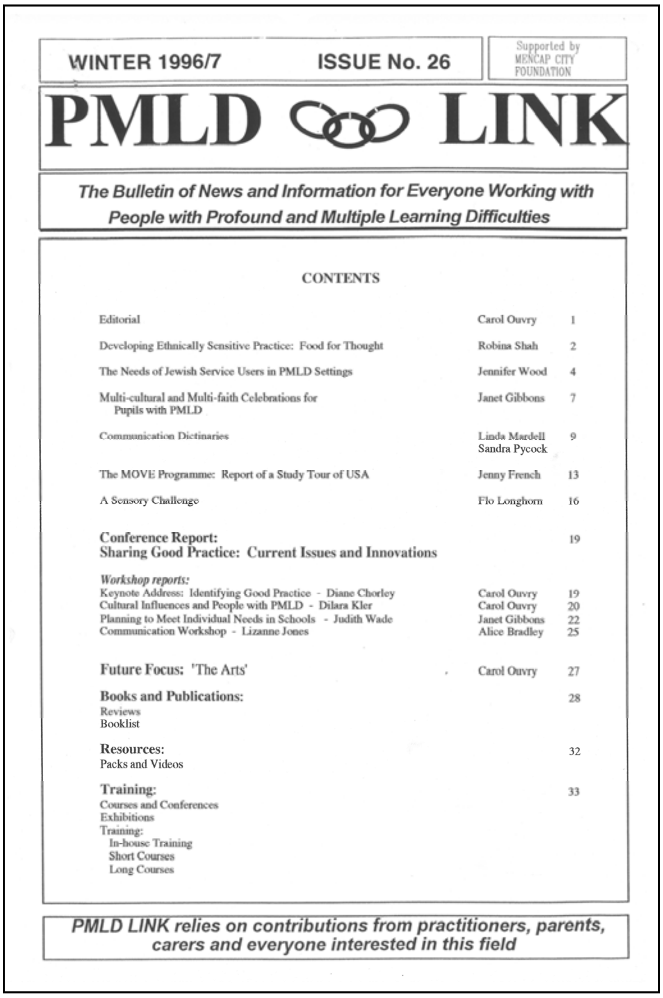
All the work necessary to keep PMLD Link going is done voluntarily by the Trustees and members of the editorial board (listed on the back cover) who encourage authors to write, compile all the other sections and, in turn, edit each edition. The preparation for printing and the mailing is managed professionally by Paul

Bramble who has made a huge contribution to the development of PMLD Link into the current format, as well as the development and management of the website.

PMLD Link has always prided itself on being editorially independent of any other organisation but it has benefited from a number of grants which has allowed it to develop and also to keep the subscription cost as low as possible, so as to reach as many people as possible, whatever their role. We feel sure that this has helped to ensure that the articles cover such diverse topics and are relevant to people's daily lives and work, whilst alerting readers to important updates and innovative research.

Twenty five years is a very long time in the life of any venture and our editorial group membership has understandably changed and evolved in that period. We have been very lucky over the years to attract enthusiastic volunteers to represent families and the many disciplines involved in this field. Carol has been the driving force for all of those 25 years! Very sadly for us, she is 'retiring' this summer. However, her huge efforts over the years have helped establish the journal on a firm foundation that will enable it to continue to develop and flourish.

While celebrating 25 years of publication, we are now hoping that PMLD Link will go from strength to strength and reach even more people who strive in the interests of people with profound and multiple learning disabilities. Hopefully too, you as subscribers will share more of your stories, your research and your ideas – to enable us all to feel more informed and less isolated in facing challenges that are part of the territory of profound and multiple learning disabilities.



WINTER 1996/7 ISSUE No. 26

Supported by
MENCAP CITY
FOUNDATION

PMLD LINK

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

CONTENTS

PMLD LINK relies on contributions from practitioners, parents, carers and everyone interested in this field

With very special thanks to Carol - Happy retirement!

But great thanks must go to you - our many readers and contributors for an exciting 25 years – here's to the next twenty five!

Annie & Carol

Contact Us

Subscriptions and advertising enquiries
Rob Ashdown
15 Cliff Gardens,
Scunthorpe,
North Lincolnshire,
DN15 7PH
rob.ashdown@ntlworld.com
tel: 01724 852818

Reviews
Penny Lacey
Email: p.j.lacey@bham.ac.uk

Production
Paul Bramble
The University of Northampton
Boughton Green Road
Northampton, NN2 7AL
Email: pmldink@northampton.ac.uk

Website: www.pmldlink.org.uk

ISSN 2042-5619

Looking back yet moving forward

Roy McConkey

Perhaps it is feature of growing old but I am more conscious than ever of the need to assess future priorities. There is so much we would want to do but when time is shortening it is crucial we put our talents and energies into those matters that are likely to make all the difference. Fortunately the elderly have the advantage of their lived experience in making these appraisals. The lessons of the past should surely guide our future. So with that in mind, here's my assessment of the three major achievements of the past 25 years in the international world of disability and my predictions of the three foremost challenges in the coming years. Of course if you like competitions you might pause here to draw up your own list of nominations. Such personal reflection will perhaps give you a deeper insight into your values and aspirations. Indeed that would be the real winner from reading this article!

Major achievements

Top of my list of achievements has to be the 2007 UN Convention on the Rights of Persons with Disabilities. Article 1 summarises its purpose:

> *to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.*

Note the word all: these articles apply to everyone, no matter the origin or severity of their disability. Yet the convention is worthy of top billing not just for its content – important as that is – but also for the manner in which it was created. It resulted from widespread consultation, negotiation and compromise among disabled persons and their advocates across the globe. After previous decades of bickering amongst organisations for people with disabilities, this was no mean feat and it gives us an inheritance on which to build. As national governments ratify the Convention - which the United Kingdom did in 2009 – it provides the framework to strengthen and extend state legislation to enforce the rights of persons with disabilities. The pressure for change needs to be maintained nationally and as Peter Mittler (2011) among others have argued, if we don't use the Convention we risk losing it.

My second award goes to another UN agency: the World Health Organisation (2001) for their International Classification of Functioning, Disability and Health (abbreviated to ICF). This marked a major shift from the so-called medical or disease model of disability with its sole focus on impairment. Rather the ICF views a person's level of functioning as a dynamic interaction between health conditions and contextual factors both personal and environmental. In this way of thinking about disabilities, the focus of interest in both assessment and treatment is placed on the barriers that prevent people with disabilities from participating fully in society and the supports and adaptations that would enable this to happen. ICF does not classify people into discrete groups but rather aims to describe the situation of each person within an array of health-related domains (including bodily impairments and illnesses) and in the context of environmental and personal factors that are known to influence their levels of functioning with society. Each person is given an array of codes – usually between 3 and 18 to describe their particular characteristics. I live with the hope that the ICF will be the catalyst for teams of professionals to integrate their work with the growing child or teenager with PMLD and to see them as not apart from society but as people who are striving to become part of society.

I had many other possibilities for my third international achievement but in the end I opted for the one with the longest word – deinstitutionalisation! My hesitation centred on this being aspirational because in many countries of the world – including the richest – institutional care is still prevalent. However while it might exist - as does smoking and drink driving – it too is no longer considered socially acceptable. The research evidence is overwhelming that institutions are bad for your health and should be closed down (Mansell and Ericson, 1996)! People with even the most severe disabilities live fuller, happier lives in family and community settings and often at little extra cost. But including the closure of institutions among my achievements is a salutary reminder that although it follows on logically from my previous two nominations, the force of history and dare I say the collusion of professionals, can still maintain service systems that are malign and cost ineffective.

Continuing failures

If as they say, we can learn as much from our **failures** as much as from our successes than it is in that spirit that I have identified three glaring **failures** that have proved resistant to change internationally. No doubt you could add to this listing but irrespective of how long it becomes, we need to reflect on why we have failed.
The abuse of the people with disabilities continues. As the recent Winterbourne case in the UK demonstrated, physical abuse happened even when all the so-called safeguards of police vetting, registration and independent inspections were in place. More worrying still are the levels of undetected, unreported abuse in all its forms that take place daily in every country around the world.

The social isolation of people with disabilities continues. Even in the best resourced and most enlightened service systems, a common failing is the dearth of friendships and social connections reported for teenagers and adults. Many lead lonely, empty lives with higher levels of mental health difficulties than their able-bodied peers.
The lack of support for families continues. Family care is the bedrock of modern, community-based service systems. Although the supports for families have improved markedly in the past 25 years, progress has been uneven nationally and supports often fall away when the children becomes adults. In times of austerity it is likely too that families will be expected to do more with less support.

A myriad of interconnected reasons can be given for this unhappy state of affairs. But of one thing we can be certain: they are NOT due to a lack of resources. These **failures** are arguably just as prevalent in the richest countries of the world. So what then accounts for them? One possible root cause is the continuing stigma associated with disability in human society and the devalued status of these persons (Scior, 2012). Overt discrimination has been replaced by more subtle arguments: competing **priorities**, value for money, the common good. None of us can easily escape from the societal and cultural attitudes that unconsciously shape our thinking and responses. In my experience, families do this better than most whereas among professionals, civil servants and politicians, stigmatizing attitudes are often alive and well. The rhetoric may have changed but old practices linger. The solution then is to focus on changed practice as a means of reducing stigma.

Moving forward

So what then should our **priorities** be for the next 25 years? In the interests of symmetry, I identify three but wouldn't it be intriguing if you too came to the same conclusion despite having noted different achievements and **failures**?

A focus on relationships. As we have argued elsewhere, the key to a better life for anyone with a disability is the relationships they have with others in their family and community (McConkey et al., 2009). These need to be built for each person at a time and carefully nurtured through all of life's stages. The promise offered by befriending schemes as an alternative to day centres; or host families as a means of providing short breaks still have to fully exploited but for now, they provide a vision of what might be possible in forging relationships beyond the family for people with PMID.

A focus on community. Building relationships does not just mean forming one-to-one bonds with one other person. Generally these relationships develop and are lived out within a network of relationships that link us as a group in a mutually supportive and committed manner. That is community in a nutshell! Families are a good example but as we grow up, we become part of other communities - of friends, of students or of workers. This is the not the case for many people with disabilities. For them, the concept of circles of support has emerged as a promising way forward (Neill and Sanderson, Undated). A starting point is getting people connected into existing groups within their local community.

A focus on supportive leadership. Leaders have a crucial role to play in nurturing, guiding and sustaining supporters in their work (Hartley and Benington, 2010). Yet many traditional services have a culture of authoritarian leadership with their hierarchies of managers and directors. In building future support services, a different culture and a style of leadership is needed which is better described in terms such as 'team leader, facilitator or co-ordinator'. Their style of leadership has to be consultative and based around personal, open communication. They have four key roles: promoting the vision, empowering and motivating their team; reviewing progress and sharing knowledge. They may well come from disciplines such as community development or further education rather than the therapies.

It would be easy to dismiss these aspirations as day dreams were it not for the fact that they have become a reality for at least some people with PMLD. I suspect that as regular readers of PMLD Link you have done more than most to change the expectations, cultures and practices that were prevalent 25 years ago. Human creativity allied with a spirit of solidarity can still make these new dreams come true.

References

Hartley, J., and Benington, J. (2010) *Leadership for Healthcare*. Bristol: The Policy Press.

McConkey, R., Dunne, J. and Blitz, N. (2009) *Shared Lives: Building relationships and community with people who have intellectual disabilities*. Amsterdam: Sense Publishers.

Mansell, J. and Ericsson, K|. (1996) *Deinstitutionalization and community living: Intellectual disability services in Britain, Scandinavia and the USA*. London: Chapman & Hall.

Mittler, P. (2012) *It's our convention – use or or lose it. Disability*, CBR and Inclusive Development, 23 (2), 7-21.

Neill, M. and Sanderson, H. (undated) *Circles of support and personalisation*. Available at: http://www.helensandersonassociates.co.uk/media/75948/circlesofsupportandpersonalisation.pdf

Scior K. (2012) Public awareness, attitudes and beliefs regarding intellectual *disability: A systematic review.* Research in Developmental Disabilities, 32, 2164–2182.

United Nations (2006). *Convention on the Rights of Persons with Disabilities*. New York and Geneva: United Nations.

World Health Organisation (2001) *International Classification of Functioning, Disability and Health*. http://www.who.int/classifications/icf/en/.

Contact Details

Roy McConkey
Professor of Developmental Disabilities,
University of Ulster
r.mcconkey@ulster.ac.uk

Vol. 25 No. 1 Issue 74

Multisensory Environments

Rob Ashdown

A recurrent theme in PMLD-Link issues throughout the past twenty-five years right up to the present has been the design and use of 'multisensory environments'. The multisensory environment (MSE) is a room or space with a collection of devices that offer sensory stimulation – some are designed especially for people with PMLD but others have been borrowed from the leisure industry, notably discos.

By the early 1990s, MSEs had become big business with special schools and other organisations installing costly equipment in dedicated spaces. These developments raised a number of questions about the purpose, design and use of MSEs that are explored in various article in PMLD-Link. Particularly telling questions are:

Questions to ask:

- Could the money be better spent on enhancing other learning and leisure opportunities?
- How should staff be trained to use the MSE to best support people with PMLD?
- What influences the choice of equipment? Is it purchased because of its availability, the hard-sell activities of the commercial companies, and its glamour, or is it chosen because it truly met the needs of the people with PMLD?
- Could everyday learning and leisure experiences be used instead to develop the same cognition and communication skills and to give the same degree of pleasure and amusement?
- How is progress in learning assessed and measured and can this data be used as evidence of the worth of the MSE?

Early articles in PMLD Link showed that improvisations may be no less effective than expensive equipment. Howard (1990) described how his school's MSE was built in a storage room adjoining a classroom for young people with PMLD. With the aid of £800 from the Children in Need Fund, a variety of lighting equipment from a local disco supplier was purchased. The room was painted black, so that lights could be seen against a contrasting background. However, so that coloured images and patterns could be projected onto the walls, white fabric was hung on washing line around the room and was furled or unfurled as need be. Similar developments were occurring in schools up and down the country. We can tell from articles and letters in PMLD-Link that typical equipment at that time would have been coloured lights, lava lamps, projector with special effects wheels, pin spotlight focused on a rotating mirror ball; coloured filters for spotlights, bubble tubes, fibre optics, and bubble machines. Scrap stores and shops were good sources of netting, chiffon, tinsel, fabrics with different textures, cellophane, textured papers, foil wrapping, etc. A separate room was seen as desirable but various contributors showed that it was possible to create special corners in classrooms or even use large cardboard boxes to create mini-MSEs. Wall displays with various textures, fur, brushes, coconut matting, or visually interesting materials (e.g. mirrors, foil survival blankets, holograms) all helped to stimulate interest and learning. Massage and aromatherapy techniques were also used to induce relaxation and provide pleasurable stimulation.

MSEs should not provide essentially passive experiences where the person with PMLD has little control over what they experienced. For instance, Howard (1990) described simple ways in which physical interaction with the environment and vocalisation could be encouraged. He said that:

It cannot be over-emphasised that the purpose of the room is to encourage interaction and exploration on the part of our pupils, not to provide so-called "stimulation"………… Although we also use the room as a recreational facility for our pupils, this was not a reason for its construction. Its purpose is educational.

Interactive approaches

Advances in technology have improved MSEs for people with PMLD, although Pagliano (2003) cautioned that technology is not a 'cure-all' and lack of adequate preparation and failure to keep abreast of technological advances can undermine its use. Howard (2003) described the use of a laptop and projector to project moving and still images as part of curriculum delivery. Orr (2000) commented that the biggest change in the equipment since the early days of MSEs had been the introduction of myriad switches. Today a range of specialist switches, activated by deliberate touch, simple movement or vocalisation can be used to switch on and off a range of equipment to which they are connected by wires or, commonly now, wirelessly. This specialist hardware helps greatly to develop awareness of cause-effect relationships and notions of contingency awareness and contingency responding.

Strict adherence to a guiding philosophy of normalisation might suggest that MSEs are not compatible with ordinary life styles. There has to be some debate about whether people with PMLD have a right to an environment which meets their needs even though it may not prepare them for an ordinary life style. Howard (1990) suggested that to allow a person to spend an inordinate amount of time in the artificial and enhanced MSE is to encourage them to opt out of the real world. He preferred to see the MSE as a ‘gateway’ to a more typical environment. In other words, the MSE enables the development of skills in a tightly controlled environment that could not easily be acquired otherwise. This requires careful assessment of progress and planning to ensure that learned skills generalise to a more natural environment. Normalisation also suggests that there should be a deliberate focus on the multisensory experiences which are enjoyed by the general public – sensory gardens, aromatherapy, massage, discos, cookery, interactive tablets (iPads and android technologies), desktops and laptops with touch screens, musical activities (including CD players, iPods and MP3 players), and so on – all with the advantage of being connected to more ordinary lifestyles and all with definite potential for enhancing learning as well as leisure.

There has been some debate about the merits of black rooms and white rooms. Orr (2000) noted that white rooms do not suit all visually impaired learners. The white rooms may be associated more with leisure and relaxation whereas the principal use of the dark room or black-painted room is more for visual stimulation. In fact, Pagliano (2000) identified a dozen design prototypes each with particular resources and purposes plus hybrids of varying complexity.

Purposeful MSEs

Orr (2000) expressed his reservations about some uses of MSEs, although he recognised it as a valued tool for the teachers who are determined to empower their students. He complained that in the early days it was not uncommon to find rooms where ‘trigger-happy’ staff would switch on every gadget and ‘pile the whole class in for a rumpus’. For Orr, MSEs in schools are only as good as the staff who use them and he suggested the following, among others, as good practice:

- Arrange for calmness and clarity in the journeys towards the specialist room so that the learner can anticipate their journey's goal - with judicious use of objects of reference or symbols if necessary.
- Allow periods of interpersonal, face to face conversation so that the learner knows who they are with as well as where they are and not just what is required of them.
- Let the learner attend to the objects and switches without invasive outbursts intended as social "reinforcers". Cries of "good reaching" etc. turn the process into a more complicated social and language event which may be more than the learner can manage while still engaging in the task.
- Observe whether the learner has registered the fact that it is they who have brought about the change of events out there. Allow plenty of time for the penny to drop and repetition until you are sure that the cause and effect are established in the mind of the learner.
- Have a spotlight directed at the attractive and relevant object that is rewarding to the sense of touch as well as vision and that fits into class activities.
- Any speech should be aimed at what the worker thinks the learner is experiencing and sessions with no speech at all can be very effective.

Porter and Miller (2000) reported the outcomes of a small-scale research project into MSEs in several schools. They found that MSEs were used to provide carefully targeted stimulation of a particular sense, often vision but not exclusively, and to promote exploration. They were also used enhance story telling and other aspects of curriculum delivery. They suggested that the starting point for any school policy on the use of the MSE must be a shared understanding of its purpose and clear identification of a person with responsibility for the MSE in terms of its initial development, monitoring and evaluating its use, and dealing with health and safety matters. Byers (1998) reported similar views from a working group of teachers convened to share practice. This group also highlighted the role of the sensory coordinator and the importance of training for staff so that they are aware of the purposes of their MSEs and effective ways of using them. It was noted that a range of portable small scale items and the development of multi-functional spaces and resources had the potential of bringing sensory experiences to a wider range of pupils. Again, there was mention of promoting emerging skills in specialist environments, then generalising them in a wider range of locations. Other issues identified included ensuring that activities are age-appropriate and avoiding undifferentiated sensory bombardment. Above all, staff should see themselves as the most important and most sophisticated resources in any sensory environment and should not allow themselves to become disempowered by the technology.

Need for Research

Byers stressed the need for more research starting with a full audit of current practice – something that has not really happened although there are some good books and websites providing useful information and guidance. We know from the papers in PMLD-Link (the ones cited here and others besides) that there have been a range of uses of MSEs – not just for leisure or relaxation but also for access to the curriculum, opportunities for pupil-led exploration, investigation and problem-solving, simulations, and as a means for developing sensory awareness, cause effect and environmental control skills. The thrust of the various articles in PMLD-Link is that the choice of MSE equipment should be primarily determined by the capabilities and interests of the users or, as Pagliano (2003) put it, that the MSE should be 'built from the user out'. But the most important, most flexible and most responsive pieces of equipment in the MSE are still the people who are supporting the users.

Contact Details

Rob Ashdown
Retired Special School Teacher of Children with Moderate, Severe, Profound and Multiple Learning Difficulties
rob.ashdown@ntlworld.com

References

Byers, R. (1998) Sensory environments for pupils with profound and multiple learning difficulties: innovations in design and practice *PMLD-Link, Issue 32, 28 - 31*

Howard, N. (1990) The Hillside School multisensory environment. *PMLD-Link, Issue 36, 6 - 8*

Howard, N. (1993) Using a laptop computer and projector in a multisensory room. *PMLD-Link, Issue 46, 13 - 14*

Orr, R. (2000) Using sensory environments *PMLD-Link, Issue 8, 7 - 9*

Pagliano, P. (2000) Designing the multisensory environment *PMLD-Link, Issue 36, 2 - 5*

Pagliano, P. (2003) Multisensory environments and high technology: a macro-perspective *PMLD-Link, Issue 46, 20 – 24*

Porter, J. and Miller, O. (2000) Developing the use of multisensory environments *PMLD-Link, Issue 36, 8 - 11*

Further Reading

Fowler, S. (2008) *Multisensory Rooms and Environments: Controlled Sensory Experiences for People with Profound and Multiple Disabilities* London: Jessica Kingsley

Pagliano, P. (2001) *Using a Multisensory Environment: A Practical Guide for Teachers* London:David Fulton Publishers

SUBSCRIPTIONS AND PASSWORDS

Thank you to all readers who have already renewed their subscription for 2013. If you have not yet done so, please act soon as this will be the last issue you will receive if your subscription is not up to date before the Summer issue is mailed.

Carol Ouvry (charity treasurer and subscriptions secretary) is stepping down at the beginning of May so all enquiries about subscriptions and passwords, and renewals should be made to:

Rob Ashdown at 15 Cliff Gardens, Scunthorpe, North Lincolnshire, DN15 7PH
rob.ashdown@ntlworld.co.uk

PMLD LINK
sharing ideas and information

Vol. 25 No. 1 Issue 74

Reprinted from PMLD Link Issue No.08 Autumn 1990

The Hillside School Multisensory Environment

Nick Howard

The multisensory environment was built in a storage room adjoining the 14 to 19 years class of the PMLD unit at Hillside School. The room measures approximately 10ft x 10ft.

We have a large number of PMLD pupils at Hillside School, several of whom have severe visual disabilities. The storage room that eventually became the multisensory environment was already being used as a darkroom for a variety of visual activities, but we felt we could do much more with this space to meet our pupils' needs.

With the aid of £800 from Children in Need, we purchased a variety of lighting equipment from a local Disco supplier, which I will list later.

The first step was to paint the room black, so that lights could be seen against a contrasting background. However, we also wished to project images and patterns onto the walls. In order to do this, we suspended washing line around three walls of the room, and on this, using shower curtain hooks, hung white fabric that could be furled or unfurled at will.

This meant that we effectively had two kinds of multisensory environment at once, as most of the examples we were aware of had either light or dark walls. We are able to change the colour of the walls to suit the activity.

The Equipment

This consists of the following. 1 x Optikinetics Solar 250 effects projector. 2 x pin spotlights (These items mounted by means of adjustable brackets to a rail suspended from the ceiling across the back of the room). 1 x mirror ball (suspended in the middle of the ceiling). 1 x 30 ft light rope (attached to the top of three walls) and controller. 2 x scanners (motorised pinspotlights).

To this, we later added a Coomber Multisound Hi—fi unit and an Aroma Disc player. We also built a "Sputnik", which is a large beach—ball covered with diffraction foil, and suspended it from the ceiling on elastic. Small chimes are attached to the elastic.

The pinspotlights and scanners can have different colour gels inserted to change their lighting effect, and can either be directed at the mirror ball to create hundreds of coloured blobs moving around the walls, or positioned to illuminate other objects within the room, including the Sputnik.

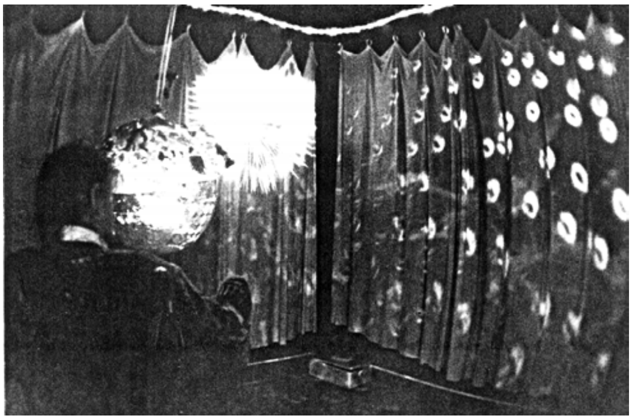
The Lightrope can be attached, via its controller, to the Hi—fi. So that it flashes in time to music.

The Activities

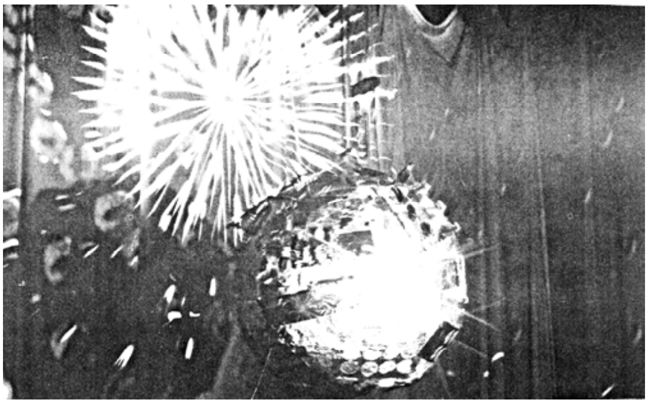
These are numerous, and we are constantly devising new ones, but some of the most frequently used are outlined below.

a) **Visual Attention and Tracking.** This can be done in a variety of ways, either using the room as a normal darkroom and using penlights etc, or by using the spotlights to illuminate objects placed on the child's tray or held or suspended in front of him or her. We have a variety of effects cassettes for the projector, and the images can be projected anywhere in the room that is suitable for the pupil. The light rope can be set so that the lights in it are stationary, or can be made to slowly (or quickly) move from left to right or vice—versa.

b) **Encouraging physical interaction with the environment.**
   i) The Sputnik is suspended in front of the pupil and illuminated by a spotlight (This is excellent for pupils with impaired vision) Any contact made by the pupil causes the Sputnik to bounce around and the chimes to tinkle. This activity provides strong visual, auditory and tactile feedback to a pupil's exploration.
   ii) The pupil is placed in a giant box full of shredded survival blanket, and the box illuminated by a spotlight. This again provides visual, auditory and tactile feedback to any movement made by the pupil It encourages gross bodily movements as well as manual exploration of the material.
   iii) A microphone is connected to the Hi—fl and then placed either on the pupil's tray or on a drum (preferably a snare drum) on a table in front of the pupil. Even if the pupil is unable to lift his or her hand and drop it on the tray or drum to make a noise, lateral movements on the surface of the drum or tray produce loud swooshing sounds through the Hi—fi. This activity encourages exploration of a surface.



c) **Encouraging vocalisation.**
By connecting a microphone to the Hi-fi and switching on the Light—rope, any vocalisation made into the microphone causes the sound to be greatly amplified through the Hi—fl and also makes the lights race round the light—rope. This activity has proved extremely successful with a number of pupils with different handicaps It has encouraged purposeful vocalization in a number of pupils who had previously not exhibited it. The enhanced auditory feedback appeals to pupils with even severe hearing loss and the visual feedback appeals to pupils with visual loss.



By sharing a microphone with a pupil, or using two microphones so a member of staff can vocalise alongside the pupil, we have been able to encourage vocal turn—taking with a number of pupils. This activity has also provided many pupils with their first experience of control over the environment, by allowing them to use their voices to make the lights move.

d) **Drama.** We use the room to stage "Galaxies" (a Multisensory Drama package produced by The Consortium at Jack Tizard School). We have been able to greatly enhance this already excellent activity by making use of the lighting, sound and smell effects available in the room to emphasis sections of the story.

In Conclusion

Although a project on this scale may be beyond the scope (and financial means) of many teachers of PMLD pupils, perhaps elements of the work we have done could be adapted to make use of existing equipment (for example, using a projector instead of spotlights).

Although the project probably cost us close to £1000, this was a fraction of what it would have cost us if we had had the room constructed for us. The project was carried out under the supervision of the County Electrician, who fitted Earth Leakage Circuit Breakers for us to plug the equipment into. This is an essential safety precaution when using mains electrical equipment with pupils, as the current is shut off instantly if anything should malfunction.

The room has proved to be a valuable resource to the whole school, and has been of immeasurable benefit to many pupils.

It cannot be over—emphasised that the purpose of the room is *to encourage interaction and exploration on the part of our pupils, not to provide so—called "stimulation' (*thank you for that bit of advice, Carol).

Although we also use the room as a recreational facility for our pupils, this was not a reason for its construction. Its purpose is educational.

Similar facilities have been built on a much larger scale on the continent and are being used as an alternative to structured teaching programmes for people with profound learning difficulties. If a client (these facilities are being used with adults as well as children) chooses to spend much of the day looking at a light rope or other piece of equipment, they are allowed to do so. There are difficult ethical issues to be addressed here about how much we allow people in our care to remain in situations they find pleasurable, and how much we place them in situations which may be slightly stressful, but ultimately encourage them to develop new skills. I personally feel that to allow a person to spend an inordinate amount of time in what is, after all, an artificial and enhanced environment is to encourage them to opt out of the real world.

I prefer to see our facility as a gateway to a more “normal” environment, by allowing our pupils to develop skills in a tightly controlled environment that they would have difficulty learning in any other way. However, it is very much hoped that these skills will then be transferred to a more natural environment, and great emphasis is placed on this. This approach has in fact proved successful with many of our pupils.

I feel very strongly that to decide that our pupils or clients can only function in, and benefit from, an artificial environment is doing them an enormous injustice, by depriving them of a wealth of “normal” experience. There are times I would love to remain in bed in the morning or in the bath—tub of an evening. However I do not do so (admittedly for mainly financial reasons). I may well find the alternatives to staying in bed (or the bath) stressful, and at times distressing, but those alternative experiences allow me to grow and develop as a person in a way that would never occur if I were to remain where I felt comfortable.

Surely the same applies for people with profound learning difficulties. The problem is that these people are unable to take the same long—term view of their situation. How right is it for us to say “I know what is best for you”? This happens every day in education, but the situation is very different in adult placements (and rightly so). I think the bed analogy can be stretched a little further. If a person in our care looked happy in bed first thing in the morning, would we allow them to remain there? If not, then why allow them to remain for much of the day in a multi—sensory environment, particularly if it is not being used for educational purposes, but for entertainment? How much would our perception of the situation change if we, were to substitute the word “containment”?

All this discussion evolved out of an article discussing the use of a learning environment which I helped create. I don’t think there are any easy answers but feel there are much wider implications for our work with PMLD pupils which need addressing. Of all the population, our client group has the most limited opportunity for self—advocacy. We have almost total control over what happens to our pupils on a day to day basis. Often their signals are going to indicate wishes which are contrary to our judgement as professionals. We have all had pupils or clients who have objected to physiotherapy. We “know” it is in their best interests that we continue with it. But would we continue if our pupils or clients were physically but not mentally handicapped, and were able to say “Stop! It s hurting. I don t want it any more “We might then be able to discuss with them the long term benefits of what we were doing. I feel then that we would reach some sort of compromise.

Unfortunately, with our pupils or clients, our wishes or judgements remain paramount. We retain almost total power over the people we are working with. If I were to become overnight totally dependent on others, I would not wish to remain in bed all day, nor to be wheeled from one passive activity to another that I found distressing and to be physically manipulated in a way I found acutely painful, but unable to stop. These may be extreme examples, but are not so far from actual practice.

These issues, I feel, are never going to be resolved in our field of work. What we need to do is to be constantly aware of the power we hold over our pupils and clients, and question what we are doing, and why. We need to be able to put ourselves in the shoes of the people we are working with and to be as far as is possible empathic with them, whilst retaining a more objective overview of what we are doing However, we are still going to have to make some extremely hard decisions, when our personal feelings and professional judgement are at variance.

Reflections on my 1990 article

Nick Howard

Receiving a copy of PMLD Link from Autumn 1990, and reading my article on the development of a Multisensory Environment, provoked some serious reflection on my part how much, and how little, myself, my practice and the education of people with PMLD have changed over the interceding 23 years. Back then, I had only recently qualified as a teacher and had been working with pupils with PMLD for about 3 years, initially working with Nursery aged pupils in the Inner London Education Authority, under the guidance of Carol Ouvry, and at the time of writing the article had been teaching older, teenage students with PMLD for one year at Hillside School.

I have helped develop multisensory environments (MSEs) in 2 subsequent schools, but have gradually had less and less hands-on experience of their use as I became first a Deputy Head and more recently a Headteacher, although I retain an interest in their use.

Although the article started as an account of the setting up of the room, the equipment chosen and the uses to which it was put, I spiralled off in the conclusion to reflections on personal autonomy for people with PMLD and the use of the environment as a resource for learning transferable skills rather than just sensory stimulation or relaxation. This, dear reader, is why I never made serious progress into the realm of the academic, unlike many of the other contributors to the issue- I could never stick to a brief when writing, or the approved structure for writing a paper!

With regards to the selection of equipment, I remain utterly convinced that if a Multisensory Environment is to be effectively used, then the equipment must be chosen on the basis of what one hopes to achieve for the pupils using it. Back then, I had very clear goals in terms of encouraging my pupils to

- attend to and track visual or auditory items,
- physically interact with the environment, and to
- encourage vocalisation

and the equipment was chosen, or made by myself, to those ends. Often, the home made items achieved these as well as, if not better than, commercially available equipment, which at that stage I still purchased directly from local disco equipment suppliers.

"Up close" sensory experiences

In fact, much of the work in the room was rooted in the work of Lilli Nielsen, in particular her "Little Rooms". I was trying to find ways to bridge broken sensory feedback loops - if our pupils had difficulty seeing, then they would not so readily realise the impact that they could have on the environment. Therefore, the results of their movements needed to be tactile and auditory as well as visual. Similarly, if they had difficulty moving, then it would be hard for them to make significant things happen in the environment. Therefore, everything was brought close to the learner, to places where they would be likely to make direct, initially accidental, contact with sensory items, resulting in sound and colour and movement, which would make it more likely that they would repeat the action.

Less often means more

I did, soon after writing the article, fit a mains switching system, allowing pupils to turn on devices like music players and fans, but the room remained rooted in what we wanted our pupils to achieve and in the hope that skills developed in it, would be able to be transferred into a more "real" setting. Many of the companies that supply and fit this equipment were only just coming into the market at this point. I have seen some increasingly sophisticated environments over the years, driven by a variety of switching and control systems, but, much as I love the technology, remain convinced that, in this area, "less often means more". Schools, including my own, have all-singing, all-dancing multi-sensory environments that can, if staff are not clear about what they want their pupils to achieve, become solutions in search of an issue and, all too often, if not well used, result in sensory overload rather than sensory learning.

Skilled practitioners in this field, such as Richard Hirstwood, constantly remind us of the joys of smaller, cheaper, carefully chosen sensory items that engage our pupils and encourage them to look, to follow to reach out, to touch. All too often, however, in a modern MSE , the temptation just to turn everything on at once can be hard to resist. What people all too often forget is that learning the skills of looking and listening is more easily achieved in the absence rather than the presence of other sensory stimuli, especially if the pupil has a cortical sensory impairment. Trying to pick out a particular sensory source, and then following it or reaching towards it is massively harder if there is a bewildering barrage of other stimuli competing for attention. To me, the sensory room is like a blank canvas, into which can place carefully chosen sensory sources, that make it easier for the pupil to learn to use their senses and develop their hand-eye co-ordination, by removing visual and auditory clutter. Also, by introducing only one sensory source at a time, one can be sure exactly what the pupil is responding to.

I always thought of it as like learning a language. Listening at home, with headphones on, one can isolate and comprehend familiar words. Compare that to trying to make out the same words when spoken by an impatient waiter in a crowded and noisy restaurant.

Meaningful involvement

Towards the end of the article, I ponder some issues that seem very reminiscent of discussions we are currently holding in the area of Mental Capacity. Rightly we now have to start with an assumption of Mental Capacity and, if necessary, make Best Interest Decisions on behalf of people with Learning Disability. We are now much more person centred than we were when I wrote the article, taking care to consider the views, hopes and dreams of people with learning disability and giving these a high priority when making decisions. Planning *with*, rather than planning *for* the people we work with. Rightly this may mean, allowing a person with learning disabilities to make decisions with which we disagree, and may even be harmful, provided they are aware of the consequences of their decision. This means that people with Learning Disabilities can be much more in control of their own lives than they have been unlike the not so distant past, when the assumption was that the people working with them knew what was best for them.

However, for people with Profound and Multiple Learning Difficulties, best interest decisions will still be made for them in many areas of their lives and it is crucial that those of us who work in this field allow as much opportunity for choice and control as possible, noting and respecting preferences likes and dislikes, however these are communicated, in order that the people we work with realise that they are able to exercise influence over the environment and the people in it and over what happens to them. Learning to communicate "NO" is one of the most powerful skills we can teach the people we work with however inconvenient that may prove to us at times.

Contact Details
Nick Howard (Head Teacher)
The Forelands School, Broadstairs, Kent.
Email - foreland@foreland.kent.sch.uk

Reprinted from PMLD Link Issue No.01 July 1988

Every time my bum gets warm

Christina Kirkman Ross

Every time my bum gets warm
They expose it to the cold;
And when I'm slipping into sleep,
They throw me in a mould.
Sometimes my head is in the air,
Sometimes it's on the floor;
And where they put my hands and feet,
I'm really not quite sure.
I love the one who picks me up
And whispers in my ear;
But all the others seem to think I'm deaf,
Or just not here.
They blot me out with blackness,
And stun me with bright white.
They stick my hands in soothing slime,
Then stab them so I fight.
When my body shakes and shivers,
I giggle till I cry;
But I don't know how it happens,
As no one tells me —
Why?

Christina Kirkman Ross contributed the enclosed poem, "Every time my bum get warm", at the end of a HMI. course on Children with Profound and Multiple Learning Difficulties in April 1988 atWesthill College.

Theatre for Young People with Profound and Multiple Learning Disabilities

Lucy Garland and Amber Onat Gregory

In 2012 Seeing Beyond and Tell Me A Tale were given an Arts Council England grant to create a theatre production specifically for 13-25 year olds with PMLD.

Seeing Beyond is a theatre company run by myself (Lucy Garland) that is based in Norwich. For the past six years Seeing Beyond has been creating small scale multi-sensory storytelling shows for children and young people with PMLD. These shows have toured to special schools throughout East Anglia.

Tell Me A Tale, run by Amber Onat Gregory, is a London based theatre company that, alongside its other work, also creates multi-sensory storytelling shows. Amber has been creating this work for six years and during this time has travelled extensively with her work. She has taken multi-sensory theatre to Turkey, Dubai and Australia. In Australia, Amber was part of a collective of artists who started Sensorium, Australia's first multi-sensory theatre company for children with complex disabilities. Although Amber is now back in the UK Sensorium is still going strong in Western Australia www.sensoriumtheatre.com).

In 2012 we decided to work collaboratively to extend our practice and create a large scale theatre production specifically for teenagers and young people with PMLD. Both of us had become aware that when we performed in schools the shows were being performed to groups of children from as young as three, all the way up to 19 year olds. We felt that although the audiences seemed to enjoy the shows we wanted to work together with the aim of creating an age appropriate piece of theatre for 13 -25 year olds.

There are currently more arts experiences created for younger children and we felt it important that young people with PMLD be given the same opportunities. The UN Convention on Children's Rights, Article 31 states that 'State Parties recognise the right of the child… to engage in play and recreational activities appropriate to the age of the child and to participate freely in cultural life and the arts'. We thought it important to create a piece of theatre that was appropriate for both the individual needs of our audience as well as their ages. We felt passionately about creating a piece of high quality theatre that could tour theatre venues nationally. Previously we had primarily worked in special schools and felt that although providing theatre in a school is incredibly important, especially due to accessibility, we also wanted to give young people the opportunity of an accessible production in a theatre venue. We wanted to create theatre that could stand up next to the highest quality mainstream theatre with the only difference being that it was accessible to a specific audience.

Multisensory theatre

To make this project a reality we needed funding to ensure the quality of the work. Multi-sensory theatre is extremely prop and design heavy due to the sensory aspect and it would have been impossible to achieve the high quality theatrical experience we were aiming for without funding. Due to the small numbers in our audiences (we perform to groups of six audience members + their carers/parents/teachers) we are unable to fund the work through ticket sales. The small audience numbers are crucial for the needs of our audience and to ensure that they receive the best experience possible. We received our main grant from The Arts Council England and were also kindly funded by The Boshier Hinton Foundation, Norfolk Community Foundation, The Islington Council, The Helen Foundations and The Co-Op Customer Donation Fund. In September 2012 we began to develop our new show: Tunnels.

Our main aim was to look at how to make the show suitable for 13-25 years olds without making the story too complex. Part of the beauty of multi-sensory work is its simplicity. Both companies have always worked with stories, be that traditional or original work. We take a story and then adapt it using sensory elements to enhance the audiences experience and enjoyment of the show. Each part of the story/performance is accompanied by a sensory experience, a smell, something to touch, sounds or lighting change.

A fantastic adventure

We decided to create a production that was an underground adventure- something out of this world. We looked at teenage fantasy films such as Lord of the Rings and Harry Potter for inspiration. We brought on a talented musician, Al Watts, who created an original score for the show and became a fantastic actor along the way. The music is integral to the piece and helped keep the show age appropriate. During the development of the production we spent a day working at The Unicorn theatre in London with Tim Webb from Oily Cart who helped shape the show.

Tunnels is based around the main character, Lana, who lives in a cold, dark city. Lana is enticed down a Tunnel by Cardini, the master of the underground. Once underground, Cardini and her underground companion, Manu, take Lana on a journey through many different tunnels. Each tunnel corresponds with a different light, sensory and sound experience. Tunnels is set in the round making it a collective experience for the audience. The audience enter and leave the space through a tunnel that is large enough for wheelchairs and care beds. Some audience members have even chosen to watch the entire production from inside the tunnel! We take care when creating the production to create a safe space that the audience have the flexibility to move around in if that is what they choose to do.

After the initial development we took Tunnels on the road and toured it to nine special schools in Norfolk, Suffolk, London and Devon. The aim of the school tour was to see how audiences responded to the show and to see how it could develop it further. The tour was a success and feedback from the schools and audience members really helped in the further development. We looked at incorporating more collaborative sensory aspects, really defining the moments of individual 1:1 attention and collective sensory and theatrical experience. We explored how to make the show more theatrical whilst still keeping the simplicity and sensory experience of the performance and how to define the different sections of the piece to make it clearer for the audience.

Performances at The Garage

After the re-development we took the show to The Garage in Norwich. The production was a part of their 'Curtain Up' season- as theatre season for young audiences. It was important to us that Tunnels was programmed alongside mainstream productions. The theatre space is a black box in a venue that specifically focuses on the arts for young people. The space was stripped of the stage and raked seating and we installed our set in the round. As soon as the show was in a theatre, the sensory elements seemed to become clearer, bigger and better. Surrounded by professional theatre lighting, surround sound and a blacked out area it enhanced the space and made it more magical. As supportive as the schools had been on the tour it is difficult to find a clear and quiet space to perform in at a school. We had grappled with the fact that the audience might be anxious with entering a strange space and was there really a need to take the young people out of a comfortable school environment where the show could also happen; their own school hall for example? Ultimately we decided that the pros outweighed the cons.

Part of our motivation in this project had been to provide young people with PMLD with experiences outside of school. We met teachers during the tour stating that they wanted to take their students on school excursions but that there was nothing accessible for them. We wanted to create accessible theatre that young people could have the choice to attend that was programmed alongside mainstream theatre shows and to bring issues of accessibility into the mainstream venues consciousness, to make people question why people with PMLD are excluded from theatre due to complex access needs. To reduce the audience's anxieties each person that attended was supplied with a Social Story with photos of the venue, the actors and an explanation of what would happen on the day and in the show.

The theatre was briefed about the needs of the audience and front of house staff were made aware that any audience member could leave or enter whenever they wanted throughout the production. We asked the theatre to keep any background noise to a minimum, no music in the foyer, tannoy etc. so that if an audience member needed to have some time out of the performance then the foyer area was a calm space. The performers also met the audience in the foyer and accompanied them into the space, therefore making the transition into the theatre space a smooth journey. All of this helped the audience and they seemed calmer and more responsive than they were in an often cluttered, cramped school environment.

We did three shows on the day at The Garage. The first two groups came from special schools in the region. The third show was at 5pm and was a public performance. This was very exciting for us as the young people came with their families and friends. As all of our previous performances had been in school venues we had never had the chance to perform to families. One of the reasons we had wanted to perform in a theatre venue was that we think it is important for young people with PMLD to be able to come to theatre with their friends and their family just as mainstream theatre goers do.

Accessible theatre

Performing Tunnels at The Garage reiterated to us the need for accessible theatre for audiences with PMLD in a theatre venue. Currently theatres across the UK are trying to improve their accessibility and the post of an Access Manager is becoming more common. Theatres are making their venues more accessible with ramps, toilets, hearing loops, sign interpretation, and even programming relaxed performances for audiences with autism. All of this is absolutely fantastic but there is still minimal work being programmed specifically for audiences with PMLD. People with PMLD often find it difficult to access mainstream theatre shows for many reasons: the stage is too far away; the text is complicated; the only senses that are really used are sight and sound (very difficult for blind or deaf people with PMLD) and you are expected to sit in one spot and stay silent. All of this on top of large audiences and mobility needs makes mainstream theatre almost unapproachable. One mother of a teenage audience member told us that her daughter loves live music and the theatre but the only shows she can go to are with young children because her daughter can be quite noisy.

Theatre venues need to realise that they are unintentionally excluding people with PMLD from their venues by not programming multi-sensory accessible theatre. It is not easy to program this work because it is unprofitable due to the small audience numbers in a climate where the arts are struggling financially. Theatres however have a moral duty to program this work and if not, examine why they don't already.

Now, is the perfect time for theatres to be approaching this issue with the publicity surrounding the Paralympics and the push on access in venues. Our goal is to get our work to as many theatre venues across the country and to give people with PMLD the opportunity to access an entertaining, imaginative and fun, theatrical experience.

Tunnels at The Garage brought us to the end of the funding we had to create the production. We are now hoping to secure funding to take Tunnels on a national theatre tour in early 2014.

Contact details

Lucy Garland, Artistic Director of Seeing Beyond
Photography by Andi Sapey

seeing-beyond@hotmail.co.uk
info@tellmeatale.org

For more information about our work please visit:

www.seeingbeyondtheatre.blogspot.co.uk
www.facebook.com/seeingbeyondtheatre
www.tellmeatale.org
www.facebook.com/tellmeatale

Small Beginnings: Bag Books

Chris Fuller

The celebration of twenty five years of PMLD LNK coincides with some of the very first multi-sensory stories which were designed for pupils with PMLD in my special school, and subsequently produced in their thousands by Bag Books. Writing a brief article on that journey provides a moment to reflect on small beginnings that managed to flourish!

A Do-it-Yourself manual on how to make six multi-sensory stories (Fuller, 1990) was apparently well received, but on discovering later that only two per cent of buyers had had the time to assemble them, it became clear that a good idea - and I'm sure that many other teaching staff had produced similar resources - would need to be available, ready to use. The stories, told in short sentences, consist of separate sheets of A3 cards with objects or materials attached which people with PMLD can be helped to handle, to hear, feel, smell or see, in order to gain inviting sensory feedback. Clearly the making of such hand manufactured articles in fairly small numbers was not going to be economically viable, the project would have to be subsidised and so began the process of establishing Bag Books as a company with charitable status.

Now the door was open for applying to charitable trusts for funding and our very first application – an application form twenty three pages long! - was to the National Lottery and was successful. Their two-year grant of £72,000 gave us the core costs of twenty hours admin. and one day for the director post per week, a full-time craft artist and workshop rent.

A very run down shop with a large basement was secured in south London, with the first two months rent free while we dealt with damp, electrics and decor, and production began in November 1997. A year later a charitable trust underwrote a full-time post for myself for a year so that I had time to write and design new stories and fundraise for the company's expansion and it turned out to be just in time for in 1998 the National Literacy Strategy was introduced and we were inundated with orders.

To support our full-time craft artist, we now needed a pool of craft artists who had skills in metalwork, woodwork, plastics, rubber/latex and sewing, and who were familiar with all the necessary health and safety issues regarding power and hand tools, spray paints, glues and solvents and the industrial sewing machine. Luckily we were close to a number of art schools and their undergraduates proved to be a brilliant source of professional skills. They produced impeccable and beautiful story-packs as they became known, and often stayed for the duration of their college course. They loved all the work – except for wrapping the orders, a task which went on all day in the basement with everyone taking turns and the only plus being that they could choose the radio station playing their choice of music!

Raising funds for stories for teenagers and adults was the next focus and we also wanted to encourage new authors and included a request for stories at the end of the monitoring questionnaire which went out with each delivery. Generally the response to this was along the lines of 'write a story about going to the hospital, the park, the shops, people who help us…etc.' but just a few actual storylines were submitted. We always met with the authors and discussed the objects and materials that would be attached to the page cards so that they would be comfortable with what was going out under their name and we could be certain that the listeners would indeed find them interesting and, most crucially, be able to physically access them to get the sensory feedback.

Many of the titles that are still very popular are the work of outside authors; "The Haircut" by Kristina Fuchs and Tricia Johnson relates the story of a disastrous visit to the hairdresser and includes a bald wig! "The Uninvited Guests" by Richard Burbage tells how an unimaginable mess is created when Mum is out and ends with a pillow fight! Whereas "C J the Library Cat" by Carole Wolstenholme, about a cat who finds a loving home in his local library and "Kofi and the Magic Shaker" by Chris Cobson, an African story, are calm and charming, even though the latter includes a large and very hairy spider and some lively African music composed by the author.

New Territory—Libraries

With new stories for all ages beginning to multiply, we wanted to edge further towards our aim that multi-sensory stories should be available where all children and adults would expect to find stories, and began a project running multi-sensory storytelling sessions in libraries and training librarians. It sounds crazy to suggest that librarians of all people would benefit from storytelling training but, for a start, the physical interaction required to deliver the stories, was totally against their usual practice of not touching any child. Then there's the handling of a large card with something attached that they had to take a listener's hand to make 'work', whilst being aware of and responding to the tiniest sound, movement or change in gaze from some children, and coping with challenging behaviour and hyperactivity from others, keeping the whole group attentive, and feeling rather embarrassed at delivering a storyline in exaggerated voice tones!

Initially just a small number of libraries were interested, which meant that sessions were booked at libraries all over the UK and usually nowhere near each other! Not cost effective for the charity but we did encounter some brilliant librarians who were genuinely keen to take multi-sensory storytelling on board and be proactive in inviting children with special needs into the library for regular sessions.

Training Story Tellers

Our next project was far more manageable. We divided the UK into regions and trained two new storytellers so that over a period of three years there was a timetable of storytelling and training in a central library in each area and three free stories to give them a start. This worked very well and enthusiasm grew but in many cases the staff still did not feel sufficiently confident to provide story sessions themselves.

So, a whole new project began which would provide every region with a trained multi-sensory storyteller covering a small number of libraries, to mentor and support two library staff in each, for six months. They would invite the same special school class or group on a regular basis, and just practice and practice their storytelling and gain confidence in interacting with the children.

Running alongside these projects was - and continues to be - the core work of providing training in special schools, mainstream schools with special units, schools for children with sensory impairment, nurseries, playschools, children's centres, adult day services and residential care and for childminders, wherever it was requested. Creating awareness was helped by the big Special Education shows in Glasgow, Cardiff, Bolton, Manchester and London and enabled us to sample the delights of 'reasonably priced' bed and breakfast accommodation - *that would make a story in itself!*

More Collaborative ventures

We aimed to write, design and produce a stock of a minimum of four new stories a year but there were also commissions to produce stories for a particular purpose and collaborating with other organisations was always inspiring and rewarding. Working with PAMIS on the first titles for their Sensitive Stories project (Watson, Lambe & Hogg, 2002; Fenwick, 2005, 2007; Young et al., 2011) was a joy, and the later research into their effectiveness proved invaluable for Bag Books, giving credence to our work too. Three stories were produced for Disabled Living in Manchester to address continence issues and the education department at the Tower of London asked for a story for young people with severe and profound learning difficulties, which would introduce them to what they would find on a visit.

The team were in their element! A sheet of brass came into the workshop and left as two perfect replicas of the coronation crown complete with jewels and ermine. The metal gauntlet in the White Tower was loaned for two days and numbered templates made of each section so that the Bag Books versions worked perfectly and I was allowed special entry at six in the morning to accompany the Raven Master and record the ravens in their early morning exchanges! The story took the listeners on the wheelchair route through the Jewel House, the White Tower and around the green, and when it was launched with a group of secondary pupils with PMLD in the Sword Room and the sound of the Last Post brought it to a close, all the visitors stood to attention! Another fun occasion was our being the chosen charity to benefit from the Annual Charity Dinner of a large city bank and instead of after dinner speeches we had *after dinner stories* told by trained bank employees at each of the sixteen tables! As the story was 'Desmond' which includes a plant spray, you can imagine the laughter. The warmth generated for children with profound difficulties that evening resulted in donations amounting to £30,000 for story-pack production.

Work experience for adults with PMLD

Weekly work experience for adults with PMLD took place every Friday in the Bag Books workshop with myself and the workshop manager partnering a local resident for six months and hand over hand, using all the tools to make their own multi-sensory story. Six people attended over eighteen months and then returned for a further six months in rotation, so that the experience would not just be a one-off stimulating activity but would allow for progress. The stories they made were specially designed to include the maximum amount of hammering, drilling, sanding, sawing etc. so that the sensory feedback was seriously interesting! The sessions were recorded and it was amazing how people with the most profound needs did indeed develop skills, became aware of the result of their actions, could anticipate the routine of how each tool was held and used, and in some cases could locate and work the switches. At the end of the six months they took their stories home to share with other residents.

It has been an amazing journey and most importantly, Bag Books has continued to thrive under new leadership, and is reaching out and including more and more children and adults in the fun and the learning to be had from interacting with multi-sensory stories.

Contact

Chris Fuller
Editorial Group PMLD LINK
www.pmldlink.org.uk
fuller.chris@hotmail.com

Websites
Bag Books: www.bagbooks.org
PAMIS: www.pamis.org.uk

References:

Fuller C. (1990) *Tactile Stories: A do-it-yourself manual:* London: Bag Books

Fenwick M. (2005) *Multisensory sensitive stories. Eye Contact:* RNIB, 42 12-14

Fenwick M. (2007) *Sensitive stories*. Insight: RNIB, 10, 30-32

Young, H. B., Fenwick, M., Lambe, L. & Hogg, J. (2011) Multi-sensory storytelling as an aid to assist people with profound intellectual disabilities to cope with sensitive issues: a multiple research methods analysis of engagement and outcomes. *European Journal of Special Needs Education*, 26,127-142

Inclusive research: where does it leave people with PMLD?

Melanie Nind

With the support of my colleague, Hilra Vinha, and about 60 other researchers who participated, I recently completed study that shows what happens when research communities become inclusive of people with learning disabilities. This research was funded by the Economic and Social Research Council and it was essentially about research designs and research methods. In this paper I reflect on the implications of developments in inclusive research for people with learning disabilities - particularly those with more profound and complex impairment.

Why research matters

Research concerning people with learning disabilities has been undergoing considerable change in the last two decades. It used to be the case that research was done with a professional or medical gaze and many people with learning disabilities and their families and allies have found this uncomfortable or unhelpful. Valuing People (DoH 2001), with its emphasis on people with learning disabilities as active citizens enjoying rights, independence, choice and inclusion, marked a change; in research terms it suggested that there were alternatives to people with learning disabilities being the passive objects of other people's research. This reflected, as much as directed, changes becoming apparent at the grassroots.

Research produces knowledge, but it also tells us what is worth knowing and who is worthy of doing the prestigious work of doing the finding out. Ultimately research is about whose knowledge counts. So, when the research community becomes inclusive of people with learning disabilities things begin to shift. New roles open with people with learning disabilities becoming researchers, advisors, writers, and even reviewers, editors and commissioners of research. Any reader of British Journal of Learning Disabilities would see evidence of this shift in the accessible abstracts and balance of topics and authors. (Readers of other journals might not have any indication that the world of research production was any different from the 1960s or 70s!) It takes time for the ripples of change to spread outwards and while there is certainly plenty to celebrate, there are also questions to ask, including how much the inclusion of some people with learning disabilities in research communities changes things for all people with learning disabilities and what this means for people with PMLD.

Taking stock of where we are

I have been researching in the field of learning disability for three decades and the majority of this research has been about how we might communicate and relate better with people whose disability circumstance mean they seem most remote to us. This research has involved a lot of imaginative listening to, and observing and attuning to, young people without verbal or formal communication and those who are part of their social worlds. It has only been more recently that I have been reading papers (co-)authored by people with learning disabilities, enjoying their presentations at conferences, and seeking to work with them on projects in new ways. All this has helped to alert me to the way that policy supporting inclusive research has run ahead of our ability to evaluate it. There is a celebratory narrative and a new orthodoxy emerging, but there are also people (such as Walmsley and Johnson, 2003) calling for pause for thought so that we do not gloss over the real challenges.

The aim of my recently completed research, 'Doing Research Inclusively, Doing Research Well?' (Nind and Vinha, 2012), was to better understand inclusive research and to build capacity for it among individuals and systems. It involved a range of us, each knowers and learners, in dialogue together. We used focus groups to pool knowledge leading to guidance on working through the issues and challenges faced by people, with and without learning disabilities researching together and separately.

So what does all this mean for people with profound and multiple learning disabilities

This was a hugely productive process in which many of the people leading the way in grappling with breaking new ground in learning disability research were candid in openly sharing their perspectives and struggles. They reflected on things like how theory is made accessible, how people with learning disabilities engage in data analysis, and how people with profound impairments are enabled. For this anniversary issue of PMLD Link it is the later issue that matters most.

The nature of the study was that the people with learning disabilities who were invited to take part were competent researchers or able to contribute to research with support. This did not mean that they were all literate, or eloquent, or without additional impairments. It did mean though, that the population was skewed towards those who have already found their voice and a way to use it in research, and away from those with profound intellectual impairment. This is the reality of the population of inclusive researchers in the learning disability field. The decision to include a group of academic researchers who do research in which they seek to maximise the participation of people with learning disabilities was in part about anticipating this and ensuring that research with people with profound impairment was represented. In the focus groups I asked:

- Can everyone be a researcher?
- Can everyone give research data?
- What do you need to be a researcher?
- Has anyone done research involving people with profound and multiple disabilities?
- What were you trying to find out?
- How did you go about it?

The question of who can do research led to answers that were grounded more in politics than experience. People with learning disabilities involved in collaborative research partnerships spoke a little of the ways in which they reached out to people with high support needs (for example, someone who was losing their abilities to dementia). Academics spoke of methods they used to enhance engagement, such as working responsively in the co-design of bespoke musical instruments and using (life) story methods and mobile interviews. There was a real reluctance, though, for people to speak about the boundaries to what was possible. This may relate to the ‘stifling of debate’ that Walmsley and Johnson (2003) have highlighted, or to a genuine desire not to close down possibilities. There was a touching faith in what might be achieved given the right training or support. For example one researcher with learning disabilities reflected:

The way I see it, because you can't verbally communicate, there is always a way that you can find [to] communicate with people. I think there is an assumption we often make that just because the person can't verbally communicate like talk that they don't understand and that is so [.] I mean they can. Just because they can't [talk] doesn't mean they can't understand.

This fails to confront the realities about over-interpreting voice and opinion among people with PMLD that Ware (2004) alerts us to. It does, however, reflect the commitment to recognising the humanity – and human rights – of those with PMLD.

There were explicit references to working to extend the understanding of steering committees and ethics committees so that they might have greater confidence in seeing people with PMLD as more than just vulnerable. One academic argued ‘good research is also research that is not frightened to go near people with high support needs’. She describes,

trying to involve people with very high support need alongside people who were more articulate and documenting that experience. I was thinking I can't say that I involved everyone in the analysis. But now, towards the end I can see my ideas of analysis completely changed ... the idea of analysis being quite complex can inhibit us and it can work against people with high support needs.

In this context, by prompting reflection, people with PMLD were contributing to knowledge.

When it came to the skills or qualities needed to do research participants avoided the things that they saw could be aided by better accessibility and focused instead on curiosity: ‘Perhaps what we do require to be a researcher is agency or to be able to demonstrate a willingness to want to find something out and to ask questions’. This for some raised the question of how we know whether someone is expressing agency in terms of research. They looked for ways round this, including life story work; one participant asserted: ‘we have to have their inclusion in research. There are ways of doing it’. Such ways included dynamic, flexible and respectful approaches to consent issues, and tackling people’s fears of getting the ethics wrong.

The research exposed the continuing attitudinal, social and material barriers that make inclusive research challenging; it offered less clarity on the intellectual barriers that may also be relevant. Here I think we may need to look not just to the advocates of inclusive research, but to the advocates of new ways of thinking about impairment and disability. I see real promise in the way Goodley (2001) describes distributed competence –

the real importance being in increasing what we can do together rather than alone. Similarly, Simmons (2011) challenges us to re-think our current conceptual frameworks surrounding people with PMLD as 'pre-' many of the developmental stages of infancy. Using a case study of one child, involving interviews with his significant others and extended observation, Simmons was able to engage in deep data analysis and show different readings of that child's social interactions and abilities. If I were to argue that this research was inclusive I may need to stretch the concept, but in identifying it as research in the interests of people with PMLD I feel that I am on safer ground.

Conclusion

There was, and is, a great deal of talk about research done with people with learning disabilities when collaborations and partnership are involved, and more radically about research done by them. These are the completely welcome alternatives to research done to them. Occasionally our focus group talk turned to research for people with learning disabilities. It is this, I think, that is in danger of being lost in the clamour for, and celebration of, research with and by. Research for can reflect all the very best of citizen advocacy and of people working as allies of people who face the biggest obstacles in speaking for themselves.

Some self-advocate researchers will remember those with PMLD and assert their rights; they may capture the attention of users of research in ways that academic researchers cannot. Whether or not they are more able than other allies/carers to speak for the experiences of people with profound impairment, though, is debatable. In this respect creating a new breed of experts – so-called experts by experience - brings with it new problems as people with learning disabilities are diverse and their life experiences equally so. My own view is that we are all learners rather than experts. We have travelled massively important territory when it comes to both advances in inclusive research and advances in recognising the humanity of people with the most profound impairments. We are, however, only at the very beginnings of bringing the two together.

Contact details

Melanie Nind
University of Southampton
M.A.Nind@soton.ac.uk

Acknowledgements
I am grateful to the participant-researchers in this study and to the ESRC for funding the research.

Further information
Information about the Doing Research Inclusively, Doing Research Well? Study is available at www.doingresearchinclusively.org

References

DoH (2001) *Valuing people: a new strategy for learning disability for the 21st century.* London, The Stationery Office.

Goodley, D. (2001) '*Learning Difficulties', the social model of disability and impairment: Challenging epistemologies*. Disability & Society 16(2): 207-31.

Simmons, B. (2011) *The "PMLD ambiguity": articulating the lifeworlds of children with profound and multiple learning difficulties*. Paper presented at the Nordic Network on Disability Research (NNDR) 11th Annual Conference, Reykjavík, Iceland, 28.05.2011.

Walmsley, J. & Johnson, K. (2003) *Inclusive research with people with learning disabilities: Past, present and futures*. London, Jessica Kingsley.

Ware, J. (2004) Ascertaining the Views of People with Profound and Multiple Learning Disabilities, *British Journal of Learning Disabilities*, 32: 175-179

The multifaceted condition and collective competence

Peter Limbrick

In promoting the idea of the ‘multifaceted condition’ in this essay, I am going to argue against the traditional idea that an infant can have ‘multiple disabilities’ that must be treated by ‘multiple practitioners’. The phenomena ‘pantry’ and ‘pastry’ might help me get my point across. As words they differ in only one letter but, as elements in the kitchen, are very different in how they are composed. A pantry might store, amongst other things, sugar, fat and flour. They do not interact with each other on the shelf, you can remove any of them at will, and, if you go on a health spree, you can replace the lard with vegetable fat, the white sugar with brown and the white flour with wholemeal. They are three elements among the multiple items in the pantry.

Not so with pastry. Now the fat, flour and sugar have merged together in the mixing process and have interacted with each other in the oven. They are no longer separate entities and cannot be taken out should you change your mind about the sort of flour or sugar or fat you used. In the cooking process they have interacted with each other to produce a new entity – pastry, that has taste, texture and nutritional value that the separate ingredients did not. It is no longer meaningful to look for the flour in the pastry or even to think in terms of the flour from the pantry being inside the pastry. It is not. It has become part of something else and is no longer flour.

Before I get to the ‘pastry’ of the multifaceted condition, it needs to be acknowledged that a grown man or woman can have multiple disabilities just as a pantry shelf can have multiple food items. Suppose I emerge from a car accident with a damaged eye, burns, a ruptured stomach and shattered knees. I would not object to being described as having multiple disabilities and I would expect multiple medics to tend to my needs. I would not expect that the damage to my retina would have much impact on my knees and I would not demand that the burns specialist goes into conference with the gastric surgeon. I would be content for these multiple practitioners to get on with their tasks more or less separately over the coming months and years on my multiple problems.

After my imagined car accident my injuries and disabilities remain more or less separate from each other like groceries in the pantry because I completed my child development processes some time ago. But what about the infant who is deeply and perpetually involved in the process of developing and learning, and in establishing the necessary new neurological connections and pathways that allow new behaviours now and yet more new learning tomorrow? Though the relevant specialists and parents might identify such separate entities as cerebral palsy, visual impairment, hearing impairment, autism, learning difficulty, etc, we should consider these items to be much more like ingredients in pastry in an oven than like separate grocery items on a pantry shelf.

Separate conditions?

My argument is that an infant’s separate conditions become ‘cooked together’ into a new and unique entity in the development and learning process at the neurological level. Imagine an infant who has dual diagnoses of cerebral palsy and significant visual impairment. Her learning will be in the context of the two conditions interacting with each other, and the resulting neurological structures will be the product of those interactions. Hand/eye co-ordination, for example, will develop very differently in a child with this dual diagnosis to a child with just one of them. While a baby with visual impairment might reach for a bauble – with increasing accuracy and reliability as neurological connections develop in response to the behaviour, the child who also has cerebral palsy has to reach out using body posture and arm and hand movement that are making her task more difficult and success harder to achieve.

We can also look at the bauble-reaching task from the point of view of the physical impairment. The child, who already has a much harder task than a typically developing infant as she attempts to get her hand to the bauble, has to struggle with imperfect vision that makes it harder to locate the bauble in space.

So it is my contention that the emerging neurological pathways for hand/eye co-ordination in this infant are the product of both conditions (and of course of such other factors as personality, motivation, attention, etc) and that the product is like pastry in that the separate ingredients can no longer be found. They have inter-acted with each other – or fused together – and brought into being a new entity which we could label 'blind cerebral palsy' or 'cerebral palsy blindness'.

We can envisage another dual disability to help promote the idea of the multifaceted condition in preference to that of multiple disability. This toddler, who has significant hearing impairment and is on the autism spectrum, is establishing new neurological pathways and connections in response to, amongst other influences, his encounters with other people. In these interactions and relationships he has to endure, enjoy, accommodate to and celebrate much the same things that other children of his age on the spectrum are also subject to – but he has to manage without hearing. The corollary is that while he faces the challenge of learning an alternative non-hearing communication system, the outcome, in both behavioural and neurological terms, will be significantly altered by his autistic features. In his multifaceted condition of 'deaf autism' or 'autistic deafness', there is no pure deafness or pure autism to be found – there is only the fusion of the two.

We could continue the theme and look at children with three or four or more labels – and this would certainly help emphasise the uniqueness of each child with a multifaceted condition, but the space in this essay might be better used to consider how the concept of the multifaceted condition could impact on early childhood intervention, or early support, for these children and their families.

Intervention models

In my experience in the UK, our most common approach borrows much more from the pantry than the pastry. We model our interventions on the treatment of the car accident victim envisaged above as though, in the developing child, the various conditions and disabilities are somehow not interacting with each other in the child's development and learning – as though the physiotherapist can promote reaching without considering the visual issues, and as though the hearing-impairment teacher can promote communication without considering the autistic features. Our knee-jerk response to the child and family's need, perhaps bowing to traditional thinking, perhaps bowing to parental pressure, perhaps bowing to managerial demands, is to treat multiple disability with multiple practitioners and separate programmes.

There is a general and growing awareness about all young children that we should treat each one as a whole child – but if this is seeping into the training of early interventionist teachers, therapists and play workers, it is doing so remarkably slowly. With our fragmented health and education interventions it can appear that we expect the infant to do posture and motor work on Mondays, language and communication on Tuesdays, play and hand/eye co-ordination on Wednesdays, seeing and hearing on Thursdays, cognition on Fridays and then learning about bathing, dressing and mealtimes over the weekend. We know that typically-developing infants would demolish such an ill-advised approach in minutes but we expect disabled children, including those with a learning disability, to learn in self-contained segments and then (as their homework perhaps) to try to fit it all together into something which helps them function in the world as whole beings.

A more responsive approach

Following and developing a whole-child approach to development and learning, we should explore in early childhood intervention, or early support, how to meet each multifaceted condition with a multifaceted intervention system. This means acknowledging the inevitable fusion of conditions in new neural pathways and anticipating and promoting the process by fusing together our interventions.

When I talk on this subject, this is the point where some practitioners and parents anticipate my preferred approach to be either the Peto Conductor or some dumbed-down Jack-of-all-trades. Though I am a great admirer of Conductive Education I do not see UK services going in that direction. I dismiss the Jack-of-all-trades because infants with multifaceted conditions have a right to support from all the highly trained expertise we can focus on them – and this includes specialist practitioners trained in separate disciplines. I want ever more expertise available to these children and their families.

The challenge these children bring to us (and we should thank them for the wonderful development and learning opportunity) is to find ways to put our separate strands of expertise and experience together before they are delivered to the child and parent. This requires more skills and more professionalism than do separate programmes and it requires all of us to find ways of collaborating with each other – even in the absence of effective training in multi-disciplinary teamwork. The forum for this can be the small collaborative TAC (Team Around the Child) which comprises just two or three key practitioners and parent, and the process they can employ is collective competence.

Collective competence

Achieving collective competence means, taking as an example the infant with blind cerebral palsy, mother, physiotherapist and visual impairment teacher coming together in regular TAC meetings to share observations, ideas and aspirations, to learn from each other and to find creative whole-child approaches to such development and learning tasks as moving around the home, playing with toys, communication and socialisation, managing clothes, etc. The reader will recognise that none of these activities are the province of any single practitioner. It can be helpful, when planning development and learning strategies, to move away from thinking about which practitioner a child might need to which interventions the child might need – to move from, 'The child needs to see a Physiotherapist.' to 'The child needs help now in playing with toys on the floor.' This can help us keep our thinking open and multifaceted and to remember that any solution is likely to come from collective competence.

I would like to finish by looking at the same issue from another angle. When we apply the old principle of sending in a new practitioner for each need that arises, do we ever ask ourselves if this vulnerable infant is socially, emotionally and psychologically ready for a new relationship with yet another adult, to be manipulated by yet another pair of hands? If the infant is still a babe in arms, if there is a sensory deficit, if the mother and child have not yet bonded with each other, if the child has a learning difficulty, then the answer might well be 'No'. In which case the multiple practitioners might be doing more harm than good.

These infants with their multifaceted conditions invite us politely to be more creative and to find solutions that are more child-friendly for delivering our skills and experience to mother and child. TAC's multifaceted collective competence achieves that and also provides the parent with a small and trusted team for helping her think through all the difficult decisions and dilemmas that arise in families.

Contact details

Peter Limbrick
Director of Team Around the Child (TAC)
Interconnections consultancy service
peter.limbrick@teamaroundthechild.com

SUBSCRIPTIONS AND PASSWORDS

Thank you to all readers who have already renewed their subscription for 2013. If you have not yet done so, please act soon as this will be the last issue you will receive if your subscription is not up to date before the Summer issue is mailed.

Carol Ouvry (charity treasurer and subscriptions secretary) is stepping down at the beginning of May so all enquiries about subscriptions and passwords, and renewals should be made to:
Rob Ashdown at 15 Cliff Gardens, Scunthorpe, North Lincolnshire, DN15 7PH
rob.ashdown@ntlworld.co.uk

Vol. 25 No. 1 Issue 74

The Revised National Curriculum in England: A Consultation

Rob Ashdown

The Department for Education (DfE) has organised a public consultation for a revised Framework for the National Curriculum in England. Revised programmes of study have been published too at www.education.gov.uk/nationalcurriculum. The April deadline for responses will have already passed by the time you read this. The intention is that the final version of the Framework will be published in the Autumn term 2013 and that the revised National Curriculum will be fully in effect from September 2014.

So, the question is what does this new National Curriculum offer for children with PMLD? Yet again, the answer must be that these documents offer nothing of any obvious relevance. There are glimmers - the Framework document does state that 'the National Curriculum is just one element in the education of every child. There is time and space in the school day and in each week, term and year to range beyond the National Curriculum specifications.' (DfE, 2013, p.6). Also, it makes plain that schools are free to choose how they organise their school day, as long as the content of the National Curriculum programmes of study is taught to all pupils.

There are just a few brief lines about enabling access to the National Curriculum. The Framework document is clear that 'Lessons should be planned to ensure that there are no barriers to every pupil achieving. In many cases, such planning will mean that these pupils will be able to study the full National Curriculum. A minority of pupils [my emphasis] will require access to specialist equipment and different approaches.' (DfE, 2013, p.9)

There are significant changes to the programmes of study – some are very brief. Subject to the consultation outcomes, 'information and communication technology' will be called 'computing' targeted more specifically at teaching the principles of computer science and applying new and unfamiliar technologies to analysing and solving problems. 'Foreign languages' have to be taught in the last four years of primary education. The subject 'content' is ambitious and challenging for average learners; for instance, in 'computing' at Key Stage 1 pupils are to be taught what 'algorithms' are and in history 'the concept of a nation and of a nation's history'. For those of us working with pupils with PMLD and pupils with severe learning difficulties there is not much of interest in these programmes of study. 'Citizenship' features at Key Stages 3 and 4 within the new National Curriculum but personal, social and health education (PSHE) does not feature as a subject in its own right. PSHE is key to the holistic development of pupils, but the new Framework says only that all schools should make provision for PSHE drawing on good practice. So, is PSHE to be relegated again to the back divisions?

People who have been in the special education field for long enough cannot help but hark back to the debate about the National Curriculum as reflected in early issues of PMLD-Link. For instance, the staff of Tye Green School in Essex voiced the criticism at that time that:

> *'The National Curriculum is subject-based and bound by bodies of knowledge and as such is just not relevant to the educational needs of our pupils. Of course it is every child's right to have access to a broad and balanced curriculum - but just as important is that the curriculum is relevant to the child's needs. It is educationally dishonest to maintain that the National Curriculum - as it stands - is relevant to our pupils' needs.*
>
> (Staff of Tye Green School, 1990 p.23)

Not much change then. Of course, these same early issues of PMLD-Link contain articles that show how some teachers rose to the challenge and tried to show how their innovations in teaching might ensure that these pupils would gain their entitlement to the statutory curriculum. These articles reflected a vast literature on enabling access to the National Curriculum that has burgeoned during the past twenty years. The aims and teaching approaches set out in this body of books and articles have not suddenly become obsolete because the DfE has chosen to issue a new National Curriculum.

The handbooks for both primary and secondary schools for the 2000 version of the National Curriculum (DfEE/ QCA 1999a, 1999b) began with a clear and detailed statement of values, aims and purposes. Disappointingly, in the new Framework there are just a few lines to the effect that the school curriculum comprises a range of valid learning and other experiences and that the National Curriculum is not the whole curriculum.

The Framework document has implications for some fundamental documents that have tried to demonstrate how the current version of the National Curriculum can be made relevant. For the first 10 years of existence of the National Curriculum, schools struggled to come to grips with it without any clear directions for their schemes of work or short-term planning and then along came the excellent Planning, Teaching and Assessing the Curriculum for Pupils with Learning Difficulties – a rainbow-hued pack of booklets covering each National curriculum subject and PSHE and religious education as well as ‘key skills’ and appropriate approaches to planning the whole curriculum and assessment (DfEE/ QCA 2001). The previous Government showed some commitment to the ideas in these booklets by reissuing them in 2009. Will the DfE show the same commitment by rewriting them to reflect the new National Curriculum and new thinking or will they sit forgotten in the National Archives along with so many other excellent publications?

The specific guidance in the pack on curriculum planning (DfEE/QCA 2009a) suggested appropriate aims for the school curriculum that do not stand out in the new programmes of study. Another booklet covers planning the curriculum in order to develop a range key skills (DfEE/QCA 2009b) whereas the new Framework talks mainly about the importance of developing spoken language, literacy and numeracy across the curriculum. The current handbooks for the National Curriculum have a section on Promoting Skills across the National Curriculum (DfEE/QCA 1999a, p. 20, 1999b, p. 22) which gives a clear acknowledgement of the importance of promoting the development of thinking skills and ‘learning how to learn’.

What seems certain is that the DfE and Ofsted will be keen still to measure the rates of progress of pupils for whom the statutory content of the new programmes of study will be largely irrelevant. Therefore, it seems highly likely that the P-Scales will survive, perhaps only for English and Mathematics, and the DfE’s SEN Progression Guidance will remain as a point of reference for Ofsted’s inspection teams. Now the inadequacies of these systems, and of the various commercially published schemes for measuring and rating progress in relation to the P-scales, have been much debated but schools would do well to keep in mind the advice to schools on using the SEN Progression Guidance (DfE, 2010) and the latest published advice from Ofsted to inspectors.

As ever, much work remains to be done to achieve a national consensus about what should be taught, when it should be taught, how it should be taught, how much time should be spent teaching it and how the achievements of pupils with PMLD and pupils with severe learning difficulties should be measured. Schools and others must somehow widen the debate beyond the narrow concentration on a tightly circumscribed set of pupil competencies in the new programmes of study and take the lead in offering a vision of what makes for inclusive schools and classrooms.

Contact details

Rob Ashdown

Rob Ashdown

15 Cliff Gardens, Scunthorpe,
North Lincolnshire, DN15 7PH

References

DfE (2010) *Progression 2010–11: Advice on improving data to raise attainment and maximise the progress of learners with special educational needs*. London:DfE.

DfEE/QCA (1999a) *The National Curriculum: Handbook for primary teachers in England*, London: DfEE /QCA.

DfEE/QCA (1999b) *The National Curriculum: Handbook for secondary teachers in England,* London: DfEE/QCA.

DfEE/QCA (2001) *Planning, Teaching and Assessing the Curriculum for Pupils with Learning Difficulties*, London: DfEE/QCA.

DfEE/QCA (2009a) *Planning, Teaching and Assessing the Curriculum for Pupils with Learning Difficulties: Guidance*, London: DfEE/QCA.

DfEE/QCA (2009b) *Planning, Teaching and Assessing the Curriculum for Pupils with Learning Difficulties: Developing Skills*, London: DfEE/QCA.

Staff of Tye Green School (1990*) Untitled statement on the whole school curriculum and the relevance of the National Curriculum*, PMLD-Link, Issue No.8, 21-23

the accessible planet.com
the complete guide to everything accessible

The Accessible Planet.com

www.theaccessibleplanet.com

Why Anything and Everything Wheelchair Accessible?

How often have you been frustrated, by simply not being able to find the information you need to meet your wheelchair access requirements or daily living issues that you face as a wheelchair user, or person with mobility issues, or parent or carer seeking the support or equipment you need.

The Accessible Planet.com was borne out of that frustration. When the angst of two full time wheelchair users brought like minded thinking together, and the concept of a single port of entry on the internet, to find what you need, what you want and things that you would like to do, and that meets your wheelchairs or mobility access requirements, The Accessible Planet.com was conceived.

Great Oaks from little acorns are grown. This is how we consider the development of the web site. Of course it would be ridiculous to suggest that we will ever have ‘absolutely everything’ listed, as new products and services are being created all the time, however we aim to become the definitive website for everyone searching for information, products, activities, services, etc… that are either wheelchair accessible or meet the needs of wheelchair users and those with mobility issues.

Our aim is to deliver a comprehensive information service that is both easy to use for those seeking good reliable resources and an effective marketing tool for those supplying wheelchair accessible goods and services and many of the other assistive products that we need that make daily living, and enjoying life so much easier.

If you would like to recommend a product or service to The Accessible Planet.com you can do so by using the ‘Tell Us’ button at the top of the page. We want to make the world a better place by making living in it more accessible. Nothing is too small or too local to be listed on The Accessible Planet.com, so if you have a favourite wheelchair accessible curry house, a great wheelchair accessible taxi company, a wonderful wheelchair accessible holiday or hotel story, a brilliant wheelchair accessible vehicle converter, and the list goes on……. Then we want to know about them and get them listed at The Accessible Planet.com

Information is the key, help us unlock the world!

Annie and Carol’s top 10

Some useful websites

Some Interesting Websites for Commercial Companies and Consultants

Please note that there are many other companies and the following list is intended only to indicate the range of equipment that is now available for MSEs. No particular endorsement of a company or consultant is implied by inclusion on the list. Potential buyers of equipment must make their own judgements carefully after shopping around.

http://www.inclusive.co.uk

Specialises in software and hardware for learners with a physical disability, sensory impairment or learning difficulty. They sell some resources for sensory work as well.

http://www.multi-sensory-room.co.uk

Richard Hirstwood is a consultant who provides training in a range of areas including MSEs, as well as selling some digital products.

http://www.mikeayresdesign.co.uk

Mike Ayres Design offers services in designing and creating MSEs and providing long-term servicing and training. The company sells a range of equipment.

http://www.thesensorycompany.co.uk

Provides a range of products, including original ‘DST causes’ (wireless switches) and ‘DST effects’ (equipment that responds) and professional advice to create the MSE.

http://www.experia-innovations.co.uk

Provides a range of products, including its own wireless talkers (various types of switches) and listeners (equipment that responds) and professional advice to create the MSE.

http://www.spacekraft.co.uk

Claims to have designed and installed over 4000 MSEs during their 20 years. Sells a whole range of equipment and resources.

http://www.senteq.co.uk

This is the website for Sensory Technology which offers design, manufacture, sales, installation and after care services for MSEs, including sensory gardens.

www.pmldnetwork.org
pmld network Is a collection of people and organisations who champion improving lives for people with pmld. The site links to: good resources from many organisations, the PMLD Network forum see below. It responds to consultations. The organisations of the Network Lobby Government and politicians.

www.pamis.org.uk/
PAMIS is an organisation in Scotland working with people with PMLD, their family carers and professionals who support them

and don’t forget…PMLD Link **www.pmldlink.org.uk**

FUTURE FOCUS:
Celebrating 25 Years of PMLD Link

2013 continues to be a year of celebration of the 25th anniversary of PMLD Link. After our retrospective spring issue and celebration event in Birmingham on 28th June, we continue to celebrate by focussing on the human rights of people with profound and multiple learning disabilities in our summer edition.

In the academic world there has been debate on the 'moral status' and 'personhood' of those with severe cognitive disabilities, sometimes with disturbing conclusions. The prejudice, discrimination and low expectations faced by people with profound and multiple learning disabilities and their families and carers was clearly highlighted by Jim Mansell in Raising our Sights. He concluded " ... the underlying prejudice that people with profound intellectual and multiple disabilities are not fully human is wrong. The daily experience of their families and others who care for them, together with a large body of research, demonstrates this. The protection of the law, including the Human Rights Act and the Disability Discrimination Act, extends to them too."

In the summer issue we continue to celebrate by reflecting our belief that the human rights of people with profound and multiple learning disabilities must be protected at all costs and their value as individual human beings affirmed. As always, we really welcome contributions from you, our readers – whatever your 'role' in this area. Have you got stories to share of how the human rights of people with profound and multiple learning disabilities has been recognised and celebrated?

Please send your contributions or requests for the celebratory issue to:

Bev Dawkins Beverley.Dawkins@mencap.org.uk

or

Sue Thurman s.thurman@ntlworld.com

Date for articles is Friday 21st June

GIFT AID

Is your subscription your own personal one and do you pay tax?
If so, by signing the gift aid form we can get an extra 25p in every £1 you pay to us in tax refund from the government. This makes a significant contribution to our finances at no cost to you.

If you subscribe through PayPal you can download and print off the Gift Aid form from the website or use the one on the subscription form on the back page, and send it to Rob Ashdown, 15 Cliff Gardens, Scunthorpe, North Lincolnshire, DN15 7PH

If you can't remember if you have already signed the Gift Aid form, just sign it again – We can check whether you are on the gift aid record.

Thank you to all personal subscribers who have already done this.

Vol. 25 No. 1 Issue 74

PMLD Network Forum
A Digest of Discussions
January—March 2013

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.

Anything to reduce behaviours

A teacher said that a boy in their class who has autism and is non-verbal enjoys all sorts of water play, including sitting on a chair and playing with his own urine. They said he does not wear pads and can ask go to the toilet using a sign or a symbol. They said they don't think he has a urine infection but are looking into that. They said that at home and at respite he also plays with faeces. They asked for any advice.

Responses included:

- 'I would advise that you seek an OT sensory assessment, as the behaviours you are describing could suggest that he is seeking sensory stimulation (tactile/ olfactory). Obviously it is not appropriate that he should continually be wet or play with faeces, so strategies advised by an OT would include activities that would provide him with sensory stimulation that is more appropriate.'
- Someone said 'Re playing with faeces - he could be encouraged in playing with similar type substances via cooking /baking - dough rolling, shaping, or using playdough… maybe replacing an appropriate activity as quickly as possible after discouraging the inappropriate one.'
- 'Have you had advice about his level of fluid intake too, as he can produce vast amounts of urine it seems?'
- 'Does he do this when out in the community too or just indoors as there may be an element of not being kept busy enough/ stimulated environmentally?'
- 'I think the first thing you have to ascertain is what it is about this "activity" that he enjoys so much. If it's just a case of him liking water play, than I would immediately direct him to a water play activity every time he starts and encourage him to request that instead of playing with his urine.'
- 'Maybe even just having a tray with some water in it to hand would be a good idea. Urine on a chair would be very shallow compared to say a sink or bowl of water, so that's probably the sort of experience you need to re-create. I'd suggest trying as many different suggestions as you get until you find something that works. I just hope it is not the smell of the urine that he enjoys, as that would make things much more difficult.'
- 'I'm wondering what this boy's cognitive skills are like. If he's got strong cognitive skills I wonder what the affect of rules would be, either expressed by words or social story? You know "wee goes in the toilet" sort of stuff. You'd probably need to complement it with alternative activities too.'

Measuring engagement in students with PMLD following sensory integration

Someone said that they are trying to find a suitable means of measuring the impact of sensory integration work on students with PMLD before a work and learning session – to see if it increases engagement. She said that she has read about the limitations of measurable SMART targets, but needs to develop something. She said that her school is developing engagement targets for every student. She said she thinks that the measurement tool will have to be bespoke to individuals. She said that similar to the Affective Communication Assessment, she thinks she could use knowledge of individual responses to sensory stimulation eg. a stilling to sound, and record the frequency of these over a short-time frame, before and after the intervention. She asked for any advice, comments or suggestions of a better tool she could use to collect data.

Responses included:

- A number of people said to look at the 'Engagement Profile and Scale' produced by the Complex Learning Difficulties and Disabilities (CLDD) research project. See http://complexld.ssatrust.org.uk/project-resources/engagement-profile-scale.html
- 'We trialled the use of the Engagement Profile and Scale and found it useful for pointing less experienced staff towards what engagement looks like for pupils with complex and multiple learning needs. We have also used the Building Blocks pre-verbal sensory development observation forms from the SALT team in Rotherham which we are finding useful to build up a profile or students responses to activities offered to them.'

- ‘Don’t forget you can also ‘show’ progress through videos’.
- ‘We developed Video Profiling to help us to monitor the sometimes miniscule (yet vitally important) developments in communication. See www.VideoProfiling.co.uk’
- ‘I use the Goal Attainment Scale (GAS) with people with PMLD as it allows you to measure the person against themselves and set individual personalised goals. The challenge is being clear about what you want to measure and then breaking this up into expected outcome/better than expected outcome/ worse than expected outcome…there is research that has used GAS with people with a learning disability and monitoring effects of sensory integration intervention (British Journal of Occupational Therapy, Green et al 2003).’
- Someone else referred to the GAS: ‘Goal Attainment Scales (GAS) can be a very useful method of doing this and can reflect individual goals and attainment levels.’

Direct payments to Continuing Healthcare

A parent said that their son’s social services department are trying to have him re-assessed so that he is moved from Direct Payments to Continuing Healthcare. They said ‘Do they have a right to do this? I have been told he would lose his respite and it looks as if he would lose all his social care as well. All advice gratefully received.’

Responses included:

- Some people shared concerns:
    - ‘We as parents in Cardiff are fighting a similar battle at the moment! You are welcome to follow our Facebook group to see what we are doing. The group is called ‘the cwtch network’ short for carers working towards change.’
    - ‘Under CHC the NHS will probably agree to keep on his current care package at the start – don’t just fall for this. They could then decide, without involving you/him, say a year down the line that it’s too expensive and move him to somewhere they think is better/cheaper against your wishes’
- Others were more positive:
    - ‘My friend’s son is now funded entirely by continuing health care where previously it was a combination of LA funding and ILF. He still has the same support team as before and it has never been a problem. My son is partly funded by CHC and his team is also the same so it can and does work.’
    - ‘As a parent I am in the process of going through this with my daughter. You should in theory not lose any services - it is just a matter of who pays.’
- ‘Under CHC you can still be assessed as needing respite - and you can have a personal health budget - there are more restrictions on how the budget is administered - but if the needs haven't changed it shouldn't make a difference to the package. There is a point at which managing health becomes the overwhelming need and at this point the local authority is not allowed to fund the package. You may have a lot of negotiating to do - and personal health budgets are fairly new so you have a lot of teaching to do - you will be the expert.’
- ‘Health will be able to offer personal health budgets from April 2014 - unless your area was a pilot site for health budgets and then they should be able to offer them now. They work the same way as direct payments but the money comes from health.’ He should not lose any social care services - all it means is health will pay to provide those same services.’
- ‘There is a very good guide written for families by Alison Giraud-Saunders: What do I need to know about Continuing Healthcare? http://www.learningdisabilities.org.uk/publications/continuing-healthcare/’
- ‘You can read the Government guidance on continuing health care—revised in November last year called National Framework for NHS Continuing Healthcare and NHS funded Nursing Care: https://www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care
- ‘Your trust should give you a shorter leaflet to read - NHS continuing healthcare and NHS funded nursing care. You can download it from www.dh.gov.uk/publications’
- ‘A UK Continuing Care network exists. It’s a free resource. To join, log onto www.jan-net.co.uk’

Any good suggestions for a holiday?

Someone asked for good suggestions for a holiday for a man with PMLD in his 50s who is a wheelchair user.

Responses included:

- ‘See the Home Farm Trust (HFT) holiday guide http://www.hft.org.uk/Supporting-people/family-carers/Resources/Holiday-guide/’
- Various places, companies and directories were suggested

  www.bondhotel.co.uk
  www.thenewmayfair.co.uk
  http://www.calvert-trust.org.uk/kielder/kielder
  www.centerparcs.co.uk/
  http://www.optionsholidays.co.uk/
  http://www.yellowsubmarine.org.uk/index.php

http://www.naturalbreaks.co.uk/
http://www.disabledaccessholidays.com/
http://www.disabilityholidaysguide.com/
http://www.disabilitytravel.co.uk/
www.disabledholidaydirectory.co.uk

- 'Sense run holidays (people who have a visual or hearing impairment as well as another severe or profound impairment are also eligible for Sense holidays, not just people who are deafblind). See http://www.sense.org.uk/content/holidays-and-short-breaks'
- Someone asked some questions: 'What does he enjoy doing? How much can he afford? What support will he be taking? Will he need support at his destination? Does he need a hoist? How far is he able and willing to travel?'
- Someone else said 'It really depends what sort of thing he likes!...I'd go nuts if someone decided on a holiday for me based on the fact I'm in my late 20s and have a severe physical impairment without thinking about anything else!'

Help wanted re: flights for people with a learning disability

Someone asked how parents manage on flights with their children that have physical disabilities and are full time wheelchairs users. She said that her daughter has a molded seating unit on her wheelchair and as her physical shape has deteriorated they would now struggle to sit her on a standard plane seat. They said she is too tall now for the "flight seat" that can be provided so they couldn't use that. She said they don't want to stop going on holiday abroad but can't see how they could seat her comfortably for the 2.5 hour flight.

Responses included:

- A number of people suggested using the Burnett body support (a full length one) – which is a bead cushion where the air is evacuated and the cushion moulds to the person's shape. Someone said that some of the airlines have one available to borrow.
- Someone said that years ago they managed to negotiate using the seat component of the wheel chair as an insert on the plane seat.
- If you are using one of the established carriers, call the airline direct – they normally will go out of their way to help you
- Some people mentioned their experiences with specific airlines:
    - ◊ 'I believe Virgin are one of the companies that have the Burnett available, I'm sure there are others too.
    - ◊ 'I have found Monarch Airlines very helpful, they have a disabilities department that arranges for loading, they also have seat adaptations and harnesses I find it useful to give them a call
    - ◊ 'Air New Zealand also has a hoist for getting from wheelchair to airline seat'
    - ◊ 'We booked with BA and ended up having a pre flight trip to the airport a couple of weeks before the flight. They had a plane at a stand waiting for us, the same as the one we would be flying on, and we rehearsed the whole process of boarding and seating. It reassured us and made the whole thing much less stressful.
- Some people suggested alternatives to flying: trains, using a cross channel ferry and drive, going on a cruise
- Someone from Postural Care Skills asked what support the young woman was getting in terms of protecting her body shape. They said if they would be happy to be contacted at http://www.posturalcareskills.com. They also said there are videos and a booklet about postural care at www.mencap.org.ok/posturalcare

Engaging people

Someone said that they and their colleagues are interested in meaningfully engaging people with complex disabilities in improving their health and our services. They asked if anyone had done any work in this area or knows of anything that may help them.

Responses included:

- 'If you look at www.changingourlives.org it may give you ideas from a Dudley perspective, focusing on health needs of individuals with complex needs.'
- Someone said that Person Centred Active Support a method of supporting a person to be more engaged and take part more in their own lives. They gave the link to the Association for Real Change website with further information and resources on Active Support http://arcuk.org.uk/activesupport/'
- 'People with the most severe disabilities can benefit from Multi Me in terms of the circle of support having access to a multimedia facility that allows a positive, intimate and knowledgeable profile to be built up, using video, pictures and sound on behalf of even the most profoundly disabled individuals. See www.multime.com'
- 'Intensive Interaction is what you need http://www.intensiveinteraction.co.uk/'
- 'In Leicestershire the Valuing People Team, speech and language therapists and the local Mencap worked on a project with the aim of involving the choices of people with PMLD. We wrote communication guidelines and made a short film to support the guidelines. The film is called 'If you listen you will hear us'. You can view the film on You

Tube': http://www.youtube.com/watch?v=Hp4PW17U_h8

- Someone who had watched the film said 'Wow this video is definitely worth looking at! It would be worth using in training for people new to working with people with PMLD.'

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

Visit the PMLD Network website at www.pmldnetwork.org

NEXT ISSUE

Summer Vol. 25 No. 2 Issue 75

- Celebrating 25 Years of PMLD Link -

PMLD LINK

SUPPORTED BY the MENCAP City Foundation

Carol Ouvry
March 1992

Do you have any memories of PMLD Link to share?

If so, contact the editors:
Bev Dawkins
Beverley.Dawkins@mencap.org.uk
or
Sue Thurman
s.thurman@ntlworld.com

The copy date for all articles, information and news for the
Summer 2013 issue is the
21st June 2013

IN THE NEWS

From a Greek-themed Taverna night in Margate to the dazzling metropolis of Monte Carlo, Lynne Hadley has been there and done it - and all for a really good cause.

I've taken part in some crazy car challenges over the past four years.

Along with my husband, John, we've driven through some of Europe's most beautiful countryside to Frankfurt, Geneva, Paris, Monte Carlo and Barcelona. We've dressed as convicts, Noddy and big Ears, Beryl the Peril and Desperate Dan, and we've done it all in cars costing no more than £200. The aim, of course, is to raise money and the charity is Martha Trust.

I first came across Martha Trust as a student nurse on a work placement. Martha provides residential, respite and day care for people with profound physical and multiple learning disabilities. Their homes in Deal and Hastings are wonderful, inspiring places to live and work and it's become very special to me, which is why we take on their annual car challenge.

The car challenge itself is an incredible experience and a real adventure. Each team has to pledge to raise £1,500 for Martha Trust and in return, they organise your ferry crossings, overnight stays and flights home. You get to meet some fantastic people and there's a terrific camaraderie among the teams along with some healthy competitiveness and some not-so-healthy minor sabotage!

There's plenty of opportunity to enjoy the journey and once you reach your destination, the cars are scrapped and the teams can relax with a celebratory meal before flying home. You can even extend your stay to soak up the atmosphere of Rome, Monte Carlo or Barcelona – wherever the challenge has taken you.

Over the years we've raised thousands of pounds for Martha, ensuring that people like Peter have the very best chance to flourish and grow. Peter has lived at Martha Trust for just over two years now and his larger-than-life personality has made a huge impression.

Energetic, boisterous and enormously affectionate, Peter was brought up on a farm so he naturally loves animals and being outdoors. His room at Mary House in Hastings has floor to ceiling windows that look directly out onto the gardens and he's a huge fan of the regular visits from Pat the Dog.

Unfortunately, Peter's first steps into adult care weren't so successful and by the time he joined Martha Trust he'd become slightly nervous and had lost weight. But with round-the-clock nursing care, tailored therapies, regular activities and the occasional double-breakfast, Peter has blossomed.

His mum and dad are thrilled with his progress: "We're so happy to have found Martha. Peter now has a home for life where he's well looked after, not just physically but mentally. And because we no longer have to worry about his care, it makes the time we spend with him even more special."

This is the reason why, each year, John and I dress up in silly outfits and set out on our adventures across Europe in cars fit for the scrapheap. It's why we throw fundraising dinners and pester friends, family and local companies for sponsorship. We do it so that people like Peter can face challenges of their own and realise their true potential in a safe and loving environment.

This year's car challenge will take us across France to Italy's ancient capital – Rome. So register a team and join us for Rome or Bust and do something remarkable in 2013. Sense of humour essential! Find out more at www.marthatrust.org.uk/romeorbust.

Extract from The Guardian, 19 February 2013

Charity bond will give people with learning disabilities homes of their own

A housing group is launching a £30m bond to help move people out of long-stay care. Mark Hogg is all too familiar with the indignities many people with learning disabilities have endured while confined to institutions.

Hogg spent the best part of 20 years as a resident at Budock hospital in Cornwall, his final stretch being in its Lamorna wing – a unit shut down soon after he left in 2006 when a series of abuses including physical harm to residents and withholding food came to light.

Hogg, now 51, has complex needs. As well as a serious learning disability, he has a number of physical health problems. While at Budock he was subject to restraint and tranquillised on a number of occasions. According to his support worker, Jim Gray, who has known him since his early days at Budock, there is no doubt that moving from an institution to a place he can call his own in the community has had a transformative effect on Hogg's wellbeing…

Source and full article at

http://www.guardian.co.uk/society/2013/feb/19/charity-bond-housing-learning-difficulties Alternatively try: http://sn.im/26hbi3i

Antonia receives a Bexley Volunteers Award

In our 2012 Summer issue *Family and Friends* Antonia Martinez wrote an article with help from her Mum, about her friends in Roy Kinnear House, a residential home for people with PMLD. Antonia has since received a Student Achievement Award from Bexley Council for volunteering at Marlborough School, her old school, and at Roy Kinnear House.

I was fortunate to catch up with her at Christmas and she kindly agreed to an interview. Antonia was nominated by the Headteacher of Marlborough School, Linda Lee and the award was presented at a grand occasion with the Deputy Director of School and Education and the Mayor of Bexley both present. Antonia said that she chose a new dress for the occasion, had her hair done and was treated to a massage but when the time came, she was very nervous! Luckily she spotted someone she knew, and her Mum, Dad and Nan, and that made her calm.

I asked her what inspired her to volunteer at Roy Kinnear House and she said that it makes her feel good and she really likes helping her friends Donna and Kelly. Apparently they smiled when she told them about the award.

Chris Fuller
Editorial Group *PMLD LINK*

Lambeth Mencap - Carousel Project

Carousel is a new project at Lambeth Mencap, focusing on the health needs of adults with PMLD in Lambeth. The project was initiated by family carers of people with PMLD and followed the ground-breaking ‘Lambeth PMLD Report’, (Mencap 2009), which acknowledged and mapped the gaps in services for people with PMLD within the borough.

Carousel has successfully been awarded funding for two years from Guys and St Thomas’s Charity, which will enable Lambeth Mencap to develop new activities for people with PMLD in the London Borough of Lambeth. There will be a focus developing inclusive, high-quality and meaningful activities, enabling people with PMLD to build up good quality support plans and develop ways to use their personal budgets.

The project is a collaborative piece of work, with full involvement from family carers, and partnership working with Lambeth Council Day Services, Care Managers and Commissioners, and the community learning disability health team from Guys and St Thomas’s NHS Trust. This project aims to tackle some of the many barriers around access, good practice and inclusion, to open up community opportunities in Lambeth, and to build a network for communication, information and advice for people with PMLD, their families and professionals.

We plan to share progress with PMLD Link readers, as this exciting project develops over the next two years.

For further information about the Carousel Project please contact
Becky Loney, Service Manager.
E-mail: becky@lambethmencap.org.uk
Telephone: 0208 655 7737

PAMIS Future Choices Project: Training Courses and Support for Family Carers

PAMIS is delighted to announce that it has secured nearly £400,000 from the Big Lottery Fund to provide a 3 year transition project to family carers who have a relative between the age of 15 – 18 years old with a profound and multiple learning disability (*PMLD*). The *Future Choices Project*, which will provide training and support for family carers of young people with profound and multiple learning disabilities (PMLD) commenced in April 2013 and is in the early development stages. It is envisaged direct work with family carers will commence in May 2013.

The project will initially provide direct support to family carers within Glasgow City in year one. In year two the project will be rolled out in all *PAMIS* geographical areas, covering Greater Glasgow & Clyde, South Lanarkshire, Fife, Tayside and Grampian, the project will continue to provide support in the above areas in year three.

Independence advice, support and practical assistance will be offered to family carers who often find transition a very difficult, stressful and anxious time, where they can be left feeling isolated, misinformed and unsupported.

Each participant will be provided with a *PAMIS* Personal Communication Passport and a *PAMIS* Transition Planner. These will be individualised to the young person with PMLD and Project staff will work closely with family carers, education, social work (social services) and social care providers who are currently involved with the young person. These documents will provide detailed information on all aspects of the young person’s support needs and will assist in the planning and facilitation of their transition from education to adult services.

In conjunction with the above practical support, the project will also offer family carers the opportunity to access informal peer support through meeting other family carers at training events. The training events aim to reduce family carers stress and enable them to make informed decisions by providing them with the necessary information on transitional issues such as:

- Welfare and Financial Guardianship – under the Adults with Incapacity, (Scotland) Act[1]
- Self Directed Support – the processes and implications
- Welfare Reform and how this will affect family’s finances

PAMIS will monitor closely the effects of recent and forthcoming changes under the Welfare Reform Bill[2] how also how each local authority is implementing The Social Care (Self Directed Support) (Scotland) Bill[3] which is currently going through parliament. All aspects of the project will be evaluated and a final report will be produced of its findings.

Elizabeth McBride
Manager, PAMIS Futures Choice Project
elizabeth.pamis@btconnect.com

References:

[1] Scottish Government (2000) *Adults with Incapacity (Scotland) Act 2000.* Edinburgh: The Stationary Office.
[2] Great Britain (2012). *Welfare Reform Act 2012. London:* The Stationary Office
[3] Scottish Government (2013) *Social Care (Self-directed Support) (Scotland) Act 2013.*
Edinburgh: The Stationary Office.

LOTTERY FUNDED

Thinking Ahead survey launch: Do you have an adult son or daughter with a learning disability?

The Foundation for People with Learning Disabilities is launching a survey to help us understand how parents can be helped to plan for the long-term support of their adult son or daughter.

The survey, to be filled in by parents, forms part of our Thinking Ahead project which aims to help people with learning disabilities and their families to prepare and plan for the future so that the death of a parent does not lead to unexpected and potentially traumatic changes in their son or daughter's life. Having a plan in place would also help to reduce the anxiety families have about the future.

Christine Towers, Research and Service Development Manager at the Foundation for People with Learning Disabilities, says:
"We want to build up a picture of the issues that parents of people with learning disabilities are worried about when it comes to planning for the future – not just when they are not around, but when they are no longer in a position to give support. This will really help us to campaign for better support for families to plan for the future and to ensure the resources we are developing meet the needs of families".

"If you have a son or daughter with a learning disability aged 18 or over, and you have 15 minutes to spare, please take part in our survey. The information you give will be anonymous and confidential. We would greatly appreciate your time. At the end of the survey you can tell us if you would like to receive an alert when the planning resources are available". You can take part in our survey here. http://www.surveymonkey.com/s/thinkingaheadfpld

Competition for schools with a chance to win £5,000

Resilience and Results competition for schools is now open for entries
With three children in every class suffering from a diagnosable mental health disorder, schools' and teachers' support for their pupil's emotional wellbeing and mental health is increasingly imperative. Schools play a hugely important role in providing their pupils with the support they need to flourish, at a time when they need it.

To celebrate and recognise all schools' hard work and commitment to supporting your pupils, the Children & Young People's Mental Health Coalition's Resilience and Results competition is giving all schools in England an exciting chance to win a financial prize, provided by Zurich Community Trust. The winning school will receive £5,000, with two runners-up getting £2,500 and additionally there are nine 'Highly-Commended' awards, one per England region, to be won.

By entering the competition schools will also have to opportunity to appear in a digital showcase of innovation and best practice, which will be shared with all schools to increase awareness and raise standards of effective mental health programmes.

To be in with a chance of winning, all schools need to do it complete an Application Pack, which asks you to outline your effective approaches to supporting and improving the emotional wellbeing and mental health of pupils.
The application asks schools to demonstrate how you have approached:
- Promoting mental and emotional wellbeing,
- Tackling behavioural and emotional difficulties,
- Demonstrating pupil and parent involvement
- Implementing innovative commissioning and delivery of services.

The judging panel, led by Katherine Weare, Emeritus Professor of Education and Honorary Member Faculty of Public Health, is made up of esteemed professionals spanning the education and social care sectors, as well as young people themselves.

It’s never too late to make it personal: Decision making at the End of life for people with profound and multiple learning disabilities (PMLD).

Hello,

I am a third year student at Bristol University and I am currently working towards the completion of a dissertation for an MSc in Inclusive Theory and Practice

The working title of my dissertation is - It’s never too late to make it personal: Decision making at the End of life for people with profound and multiple learning disabilities (PMLD).

This is a wider appeal for grey literature as my dissertation will be a desk based study. By grey literature I am referring to information already made informally public. Examples of grey literature in this case may include; working papers from research groups or committees, white papers, preprints, DVD’s, websites, tools that are used in local settings, local projects and presentations from events.

I need examples that highlight–

Practices, approaches, projects and tools currently used to include people with all/any learning disabilities in End of Life decisions.

Practices, approaches, projects and tools that exist for involving people with PMLD generally in any decision making or topic.

If you are replying to this request via a forum - as a forum user you will be aware that any reply you send may be seen by other people on the forum and adhere to the usual forum good practice of not using the names of other people in your replies, unless previous informed consent has been sought.

Please also forward this request to people who you feel may be able to help and let me know if there are any other forums or if you have any suggestions of where I could post this request.

If you wish to send a reply directly to me, my University email is kb9255@my.bristol.ac.uk

I am not asking for your own personal stories about supporting someone at the End of Life. As this is a desk based study, I have not sought ethical approval for collecting primary personal accounts. Unless personal stories have already been made public as part of the grey literature, they will not be able to be included in my dissertation.

If you do you need some support regarding a personal issue you can -
Call Mencap's Learning Disability Helpline on 0808 808 1111.

Contact your local Community Learning Disabilities Team. You can find out the contact details for your local team from your council or Primary Care Trust.
Visit www.dyingmatters.org/overview/need-support

I will post my finished dissertation to the forums I have used for your information, once I have approval from the University to do so.

I will be collecting information until May 2013.

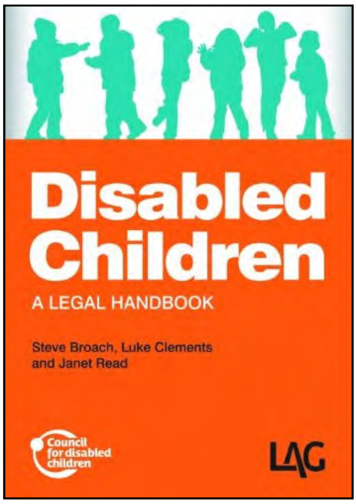
Thank you in advance for your help,

Kate Burns.

RESOURCES

Council for Disabled Children

Disabled Children: A Legal Handbook



Disabled children: a legal handbook is an authoritative yet accessible guide to the legal rights of disabled children and their families in England and Wales. The authors expertly navigate the many, often overlapping, sources of law, explaining the difference between what public bodies must do to support disabled children and that which they may do.

The handbook aims to empower disabled children and their families through a greater understanding of their rights and entitlements. It is essential reading for the families of disabled children, their advocates and lawyers, voluntary and statutory sector advisers, commissioners, managers and lawyers working for public authorities, education, social and health care professionals, students and academics.

How to order

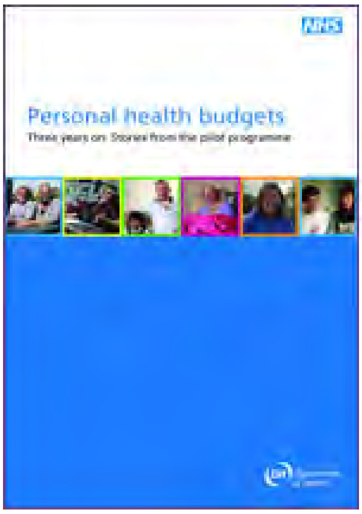
Copies of this handbook can be ordered from the Legal Action Group website (http://sn.im/26fxbs5)

Online version

For online PDF copies of each chapter please see

http://www.councilfordisabledchildren.org.uk/resources/cdcs-resources/disabled-children-a-legal-handbook

Personal health budgets DVD now available to professionals



“Three years on: Stories from the pilot programme”, a DVD of patient and clinician experiences with personal health budgets, is now available to health and social care professionals.

Seven patients, in the final year of the personal health budgets pilot programme, share their experiences, what the process is like, what they spend their money on and how they decided on this. The films include the perspectives of their family, carers and health care professionals, as well as a film specifically for health care professionals – interviews with GPs, nurses and a range of practitioners.

The DVD includes an introduction by Minister of State for Care Services Norman Lamb who launched the DVD, part of a good practice toolkit for healthcare professionals, when the government announced the national rollout of personal health budgets.

The films aim to illustrate the kind of choices people can make if they have a personal health budget, and the positive impact it can have on their health and lives. The DVD could be used in professional education and training in the NHS and social care, or to give to patients who are considering a personal health budget.

To order the DVD please see http://www.personalhealthbudgets.dh.gov.uk/About/Stories/

New information resources provide early support for disabled children and young people

Early Support have produced a range of new, updated, extended and refreshed information resources. Early Support is a Government funded approach to improving services for disabled children and young people, based at the National Children's Bureau.

The Early Support information resources describe, discuss and explore specific conditions, disabilities and difficulties and more general information that parent carers and young people have said they would find useful to know.

The resources were produced in response to requests from families, professional agencies and voluntary organisations for better standard information about particular conditions or disabilities and more general and reliable background knowledge resources. Kim Bevan, Director of Early Support, said: 'Parents, carers, young people and practitioners have told us how much they value having reliable and accurate sources of information - this is what the Early Support information resources provide. We hope these resources will open the door to increased knowledge about conditions, disabilities, additional needs and the support that could be available for all, from birth to adulthood. We would like to thank all of our voluntary sector partners for so generously sharing their knowledge and expertise in helping us to produce these resources - the sector have stepped up and provided high quality resources for all'

'Over the coming months, we will be providing additional versions of all of these resources in web-based versions, with photographs, diagrams and film footage to ensure they are engaging and interactive when accessed online.'

Early Support resources can be accessed at: www.ncb.org.uk/earlysupport and are also available in the partners resources section of our website

http://www.councilfordisabledchildren.org.uk/resources/our-partners-resources/early-support-information-resources

Alternatively try: To keep up to date with Early Support, like them on Facebook at: www.facebook.com/earlysupport, follow them on Twitter at: www.twitter.com/earlysupport or email: earlysupport@ncb.org.uk

multi me

Multi Me

People with the most severe disabilities can benefit from Multi Me in terms of the circle of support having access to a multimedia facility that allows a positive, intimate and knowledgeable profile to be built up using video, pictures and sound on behalf of even the most profoundly disabled individuals.

Form more information please visit http://www.multime.com

http://vimeo.com/49957264

Sibs
for brothers and sisters
of disabled children & adults

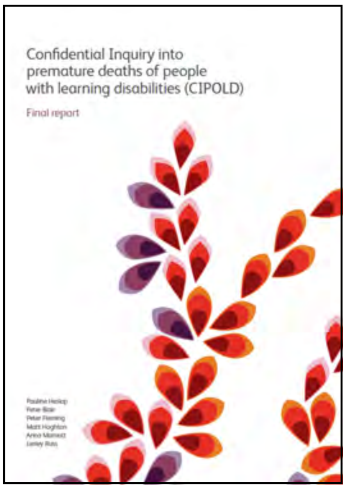
Sibs - for brothers and sisters

Young siblings can help their brothers and sisters behave well.

Many young siblings find it hard if their disabled brother or sister has difficult behaviour. They can feel that they have no control over it and they are likely to react in ways that reinforce the undesirable behaviour. We recognise that changing difficult behaviour in children and young people with learning disability or with complex needs is not a simple process. However we know that there are some small things siblings can do that help. Share our tips and short DVD with young siblings on how they can promote positive behaviour in their disabled brother or sister.

http://www.youngsibs.org.uk/info/helping-your-brother-or-sister-to-behave-well/

Improving Health and Lives Learning Disabilities


Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD)
Final report
Pauline Heslop
Peter Blair
Peter Fleming
Matt Hoghton
Anna Marriott
Lesley Russ

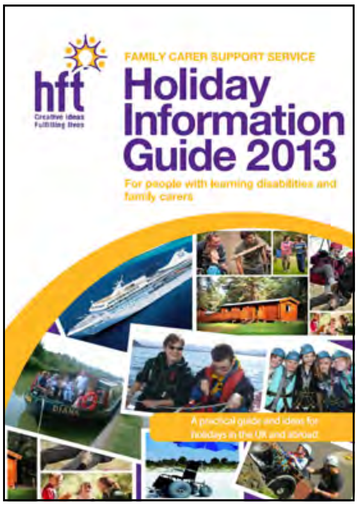
The final report of the confidential inquiry into the premature deaths of people with learning disabilities has been published.

The report found that the NHS was failing to properly investigate, diagnose and treat people with learning disabilities to the same extent as other people. People with learning disabilities were found to die on average 16 years earlier than other people.

A link to the confidential inquiry reports including an easy read version can be found at http://www.bris.ac.uk/cipold/

2013 Holiday Information guide

The annual Holiday Information Guides are packed with information to help people with learning disabilities and those closest to them choose a holiday.


hft
Creative ideas
Fulfilling lives
FAMILY CARER SUPPORT SERVICE
Holiday Information Guide 2013
For people with learning disabilities and family carers
A practical guide and ideas for holidays in the UK and abroad

The guides include:

- Pre-booking information
- Information on guides provided by other organisations
- Tour Operators
- Places to stay in the UK and abroad
- Meeting specialist health needs
- Specific Interest Holidays
- Insurance
- Available benefits and help

http://www.hft.org.uk/holidayinformationguide

SHORT COURSES & CONFERENCES

Providers Details

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

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

Hirstwood Training
Tel. 01524 42 63 95
Email: richardhirstwood@gmail.com
Website: www.multi-sensory-room.co.uk

April	
Title:	**Personalising learning for children with complex needs**
Date:	April 24th East Midlands, June 19th North West
Provider:	Specialist Schools and Academies Trust (SSAT)
Contact	www.ssatuk.co.uk Email: sen@ssatuk.co.uk
Title:	**Practical & Effective Ways of using Multi-Sensory Equipment**
Date:	April 24th Dublin, 25th Belfast, May 9th Birmingham, 10th Liverpool, 13th Middlesborough June 26th London, 27th Taunton
Provider:	Concept Training

Title: Date: Location: Provider:	**P Scale Moderation Workshop** 25th Manchester EQUALS
Title: Date: Provider:	**PMLD: Profound and Multiple Learning Disability – engaging children in learning** April 25th Brighton, May 3rd Glasgow, 16th Doncaster, June 13th Middlesbrough Concept Training
Title: Date: Provider:	**Communication and people with learning disabilities** April 26th Birmingham, June 14th Sheffield BILD www.bild.org.uk/events
Title: Date: Provider:	**iPad and iPod** April 26th Sheffield, June 10th Chester Hirstwood Training
Title: Date: Location: Provider: Contact:	**Managing Incidents of Challenging Behaviour** 26th Birmingham Dave Hewitt www.intensiveinteraction.co.uk/
Title: Date: Provider:	**Developing Special Needs Practice in Early Years Foundation Stage** April 26th Birmingham, May 14th Manchester, June 4th Chorley, 19th Taunton, July 2nd Doncaster Concept Training
Title: Date: Provider:	**Communication through Music and Sound** April 29th London, May 1st Birmingham, 3rd Manchester Hirstwood Training
Title: Date: Provider:	**Great Goal Setting System** April 29th Manchester, June 7th London, 12th Bristol Hirstwood Training

May	
Title: Date: Location: Provider: Contact	**Understanding learning disability** 2nd London BILD www.bild.org.uk/events
Title: Date: Provider:	**Make my Multi Sensory Room fantastic** 4th Birmingham,17th London Hirstwood Training
Title: Date: Location: Provider: Contact	**Promoting evidence based approaches.** Positive Behaviour Support International Research and Practice Conference 2013 8, 9,10th Brighton BILD www.bild.org.uk/events
Title: Date: Location: Provider:	**Literacy for Today in Special Schools** 9th London EQUALS
Title: Date: Location: Provider:	**Conference: iPads in special education** May 10th Manchester, 20th Birmingham, June 27th London Hirstwood Training
Title: Date: Location: Provider: Contact:	**Intensive Interaction** May 10th Birmingham, June 21st Watford Dave Hewitt www.intensiveinteraction.co.uk/
Title: Date: Location: Provider: Contact:	**Conference: Celebrating Sensory Development** 11th Northampton Guild of Sensory Development Web: www.gofsd.org.uk

Title:	**Inclusive Play**
Date:	May 13th Brighton, October 14th London
Provider:	Concept Training
Title:	**Communication through Sensory Interaction**
Date:	May 14th London, June 14th Birmingham, July 5th Sheffield
Provider:	Hirstwood Training
Title:	**Interactive and Multi-Sensory Storytelling**
Date:	May 14th Chorley, 16th Manchester, 21st Birmingham, June 4th Middlesborough, 6th Glasgow, July 2nd London
Provider:	Concept Training
Title:	**Conference: Best Practice and Essential Techniques in Moving and Handling Children**
Date:	14th
Location:	Manchester
Provider:	Disabled Living
Contact:	Christine. Tel: 0161 6078200
Title:	**Supporting a person with learning disabilities to access healthcare**
Date:	May 15th Birmingham, July 15th London
Provider:	BILD
Contact:	www.bild.org.uk/events
Title:	**Creating Low Tech Multi Sensory Sessions**
Date:	May 15th London, June 14th Middlesbrough, 19th Birmingham, July 11th Manchester
Provider:	Concept Training
Title:	**Exploring communication through touch**
Date:	17th
Location:	London
Provider:	VITAL - network for professionals with an interest in complex needs
Contact:	Email: vital@rnib.org.uk Tel: Sara Holton 0121 665 4235

Title:	**Personal, Social, Health Education and Citizenship for SEN**
Date:	17th
Location:	London
Provider:	EQUALS
Title:	**Sensory Approaches for Autism**
Date:	May 22nd Birmingham, June 24th Manchester
Provider:	Hirstwood Training
June	
Title:	**Understanding and applying Mental Capacity Act and Deprivation of Liberty Standards**
Date:	5th
Location:	Birmingham
Provider:	BILD
Contact	www.bild.org.uk/events
Title:	**Health inequalities and health improvements**
Date:	6th
Location:	Belfast
Provider:	The Royal Society of medicine
Contact:	Chanel Roachford. Email: intellectual.disability@rsm.ac.uk
Title:	**PMLD curriculum**
Date:	7 th
Location:	Leicester
Provider:	VITAL with E. Midlands Multi-sensory impairment network
Contact	Email: vital@rnib.org.uk Tel: Sara Holton 0121 665 4235
Title:	**iPads and Autism**
Date:	June 14th Liverpool, 17th Sheffield,
Provider:	Hirstwood Training
Title:	**P. E. – An Introduction to Sherborne Developmental Movement – Level 1**
Date:	14th
Location:	Northampton
Provider:	EQUALS

Title: Date: Location: Provider: Contact	**Communication and autism** 17th Birmingham BILD www.bild.org.uk/events
Title: Date: Location: Provider: Contact	**Handling people with Special Needs.** 'Training for Trainers' 17-21st Peterlee, County Durham Centaur Training & Development Lee Hodgson Tel: 0191 375 3746 Email: lee@centaurtd.co.uk www.centaurtd.co.uk/
Title: Date: Location: Provider: Contact	**Safeguarding and protection of people with learning disabilities and/or autism** 24th Birmingham BILD www.bild.org.uk/events
Title: Date: Location: Provider:	**iPad Conference** 27th London Hirstwood Training
Title: Date: Location: Provider: Contact:	**Family Education and Awareness Conference: 'This is the Place for Hope'** 27-29th Midway, Utah International Rett Syndrome Foundation Web: www.rettsyndrome.org/
Title: Date: Location: Provider: Contact:	**PMLD LINK Journal: Celebrating 25 Years** 28th Birmingham University Department of Disability, Inclusion and Special Needs (DISN) Karen Turner-Brown k.turner-brown@bham.ac.uk
Title: Date: Location: Provider:	**Support and Aspiration – the Future of Special Education** 28th London EQUALS

July	
Title: Date: Location: Provider: Contact:	**Supporting a person with learning disabilities in a person centred way** 1st Sheffield BILD www.bild.org.uk/events
Title: Date: Location: Provider: Contact:	**Supporting young people with transition** 10th Birmingham BILD www.bild.org.uk/events
Title: Date: Location: Provider: Contact:	**Developing positive behaviour support for individual people** 19th Sheffield BILD www.bild.org.uk/events
Title: Date: Location: Provider: Contact:	**Brain Development and Learning Conference** 24 - 28th Vancouver, Canada University of British Columbia, Dept. of Psychiatry Email: devcogneuro.com
Title: Date: Location: Contact:	**International Summer School: Water, Dreams & Attachment** 30 July -13 August Transylvania, Romania Register through: creativecare.office@gmail.com; information from drsuejennings@hotmail.com

LONGER COURSES (with accreditation)

MA Education
Pupils with Severe and Profound and Multiple Learning Difficulties (P1: Contexts & Understanding P2: Curriculum & Teaching)
The modules address the requirements of the Teacher Development Agency (TDA) National Special Educational Needs Standards
The course 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.
For further Details: The University of Northampton. Tel: 08003582232 Email: study@northampton.ac.uk

MA Education Physical Disabilities (P1: Contexts & Interventions P2: Curriculum Issues)
The first module (P1) provides opportunities for those with QTS and professional qualifications and 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 second module (P2) provides students with opportunities to investigate, critique and evaluate a range of curriculum approaches in the field of physical disabilities. It engages students in debates concerning the relevance and practical efficacy of recent guidance and legislation in physical disability-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 physical disabilities.
For further Details: The University of Northampton. Tel: 0800 358 2232 Email: study@northampton.ac.uk

MA 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.
For further Details: The University of Northampton. Tel: 0800 358 2232 Email: study@northampton.ac.uk

Certificate in Higher Education (CHESL): Supporting Learners with SLD/PMLD
This course aimed at Teaching Assistants will look in detail at the needs of learners who are known to have severe or profound and multiple learning difficulties. These learners 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: 0800 358 2232 Email: study@northampton.ac.uk

BPhil, PGDip and MEd Inclusion and SEN
Year 1 Learning Difficulties and Disabilities (Severe, Profound and Complex) Year 2
Autism (Children) or Autism (Adults)
Distance Education
This two/ three year course contains 6 modules and students study the required number from this list for their chosen award plus a dissertation.
1. Understanding Learning Difficulties and Disabilities
2. Interventions for People with Learning Difficulties and Disabilities
3. Learning Difficulties and Disabilities: Communication and Behaviour
4. Special Educational Needs of Children with Autism *or* Autism (Adults) Understanding and Working with the Continuum of Need
5. Curriculum and Treatment for Children with Autism *or* Autism (Adults) Intervention, Care and Education
6. PGDip includes a practical project based on your work

MEd includes a research methods module and a dissertation
For further details: The University of Birmingham, Penny Lacey p.j.lacey@bham.ac.uk or Helen Bradley h.bradley.2@bham.ac.uk

BSc in Professional Practice
BSc in Professional Practice - includes forensic, mental health/learning disability, challenging behaviour, older person with LD and epilepsy modules. Students will be provided with an educational experience, tailored to their particular requirements, so as to gain professional experience. This will enable them to work collaboratively and flexibly within health and social care systems.
For further details: University of Chester Tel: 01244 511000 Email: enquiries@chester.ac.uk

MSc in Advanced Practice
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). This course is suitable for health and social care professionals who would like to develop higher levels of professional knowledge and expertise in their sphere of practice.
For further details: University of Chester Tel: 01244 511 000 Email: enquiries@chester.ac.uk

Postgraduate Courses in Profound and Complex Learning Disability
The course is studied by distance learning plus attendance at an Autumn Study School at the University of Manchester.
The course accent is on moving towards increasing choice; developing community presence and participation; and increasing respect for individuals with complex needs. This approach underpins all aspects of course delivery. The course has three aims:
· To support the professional development of people working with children and adults with complex disabilities.
· To empower course participants to advocate for people with profound and complex learning disabilities.
· To enable course participants to develop knowledge and understanding of key issues in the field.
For further details: The University of Manchester, Lesley Jenkins Phone: 0161 275 33337 Email: pld.distance@manchester.ac.uk

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

AdCert, BPhil, PGCert, PGDip, MEd.
Multisensory Impairment (Deafblindness) - *Distance Learning*
This programme enables teachers and others working in education related fields to work more effectively with learners who are deafblind (multisensory impaired). Some students are teachers working with children or adults, but others are from social services, medical, or residential work. A one-year programme can lead to the awards of Advanced Certificate or Postgraduate Certificate.
· A two-year programme can lead to the award of BPhil, or Postgraduate Diploma.
· A two-year programme with a dissertation can lead to the award of an MEd.
Students working on BPhil or Postgraduate Diploma programmes with some additional activities can, on successful completion, be recognised as meeting the requirements of the DfES for the mandatory qualification for teachers of children with multisensory impairments.
For further details: University of Birmingham Dr Liz Hodges on 0121-414 4873 or email: e.m.hodges@bham.ac.uk

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

· Challenging behaviour
· Mental health
· Offenders with learning disabilities
· Older people with learning disabilities
· Profound and multiple disabilities
· Vulnerability, victimisation and abuse
The programme leads to further qualifications at Diploma and Masters level.
For further details: University of St. Andrews http://psy.st-andrews.ac.uk/people/personal/mc1/ Dr Martin Campbell email: mc1@st-andrews.ac.uk

PMLD LINK
sharing ideas and information

Subscription Year 2013

Subscription prices for 3 issues are: **UK:** Personal £18.00 Organisation:£25.00
Non UK: Personal £25.00 Organisation:£35.00

Name of Subscriber: …………………………………………………………………………………………………….

Address: …………………………………………………………………………………………………….....

…………………………………………………………………………………………………….

Telephone No. ……………………………… **e-mail:** …………………………………………………………………….

Place of work (if applicable)……………………………………………………………………………………..

Contact name within organisation (if applicable) …………………………………………………………….....

This is a new subscription / renewal subscription

I/we enclose a cheque for £ *(made out to PMLD Link*)

I/we have set up a standing order for £ with our bank starting on ……………………………………………….

How did you hear of PMLD-Link? …………………………………………… Date: ……………………………………….

Please send this form with payment to: Rob Ashdown, 15 Cliff Gardens, Scunthorpe, North Lincolnshire, DN15 7PH

If you require a receipt please enclose a stamped addressed envelope marked Receipt.

Gift Aid Declaration

Name of Charity: **PMLD LINK**

Details of donor:

Title …………..Forename(s)……………………………………Surname……………………………………………………

Home Address:……

………

……………………………………………………………………………………Post Code:…………………………..…

I want all subscriptions and donations that I make from the date of this declaration to be treated as Gift Aid until further notice
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 25p for each £1 you give on or after 6 April 2008)

Date …………/……………../……………..

STANDING ORDER MANDATE (Send to *your* bank)

Please pay:	HSBC Bank plc., Ross-on-Wye branch
For the Credit of:	PMLD-Link
Account No:	81156284
Sort Code:	40-39-06

The sum of: £………………

Commencing: …………………………………….. and thereafter on 1st January annually until further notice

Account to be debited: ……………………………………………………………………………………….

Account No. ……………………………………….

Signature(s): ……………………………………………………………………………………………….

Date: ………………………………………….

PMLD LINK
sharing ideas and information

Vol. 25 No. 1 Issue 74

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 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 covers issues pertaining to all groups, including occasional articles by practitioners and parents from overseas. It enables readers to create networks, and provides a forum for contact with others involved in the field. The contributions may be:

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

About Us

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

Rob Ashdown	Former teacher and special school head teacher specialising in the needs of pupils with severe and profound and multiple learning difficulties
Alice Bradley	Has worked in schools, universities, health and social care settings in the UK, Canada, Thailand and various countries in Africa and Asia. Currently working in international development and as a volunteer with some UK charities.
Jeanne Carlin	Disability Consultant (freelance) and a parent of a young woman with PMLD.
Helen Daly	Mum to a young Adult with PMLD, previous career in Further Education for 20 years - including Curriculum Team Manager for Inclusive Learning and Developing an Improving Choice Programme for people with Complex Needs. Currently involved in carers groups in the Eastern Region, Learning Disability Partnership Board and associated projects.
Beverley Dawkins	Policy manager - profound and multiple learning disabilities, Mencap
Ann Fergusson	Researcher and tutor for severe learning difficulties and PMLD courses at The University of Northampton. Trustee of National Family Carers Network. Ann also has a family member with a learning disability
Chris Fuller	Founder and former Director of Bag Books: multi-sensory stories for people with PMLD, and previously special education teacher
Rachel Parry Hughes	Lecturer in Social Work, Goldsmiths, University of London, researcher in the field of profound and multiple learning disabilities
Penny Lacey	Coordinator of the University of Birmingham course in severe, profound and multiple learning difficulties; freelance consultant; Penny has a family member with severe learning difficulties
Loretto Lambe	Director of PAMIS an organisation in Scotland working with people with PMLD, their family carers and professionals who support them
Wendy Newby	Teacher and curriculum coordinator St. Rose's School, Stroud, a school for children with physical disabilities and complex health needs
Sue Thurman	Former NHS Speech and Language Therapist for adults with learning disabilities with a particular interest in PMLD. Now writes and trains about communication and is a Registered Intermediary assisting vulnerable witnesses to communicate at police stations and courts.

Subscribe

PMLD Link publishes 3 issues per year. Your subscription will start on the latest printed issue.
Subscription prices for 3 issues are:

Annual Subscription	**United Kingdom**	**Non United Kingdom**
Personal	£18	£25
Organisation	£25	£35

If you wish to subscribe to **PMLD Link** please contact: Rob Ashdown rob.ashdown@ntlworld.co.uk or tel: 01724 852818

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

PMLD LINK

sharing ideas and information

PMLD Link is a journal for everyone supporting people with profound and multiple learning disabilities. Visit **www.pmldlink.org.uk**

Vol 25 No 1. Issue 74

ISSN 2042-5619

2013.443_04.13