

PMILD LINK

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

Winter 2006

Changing Perspectives

PMILD Link

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

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

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

PMLD-Link also includes:

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

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

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GUEST EDITORIAL

Winter 2006

Changing Perspectives

A warm welcome to the Winter 2006 edition of PMLD Link. As you will recall, this issue is without a particular theme – our first ‘general’ issue. When we decided on the title, ‘Changing Perspectives’, we felt it would provide scope for exploration and imagination. We wanted to highlight the importance of the ways in which our own perspectives change through learning and experience but also our role in changing other people’s perceptions – and the effects this has on the lives of people with profound and multiple learning disabilities and those who care for and about them.

I think you’ll agree that the articles featured do all of this and more. They both cross and push back boundaries of all sorts – professional, geographical, theoretical and practical. They inform us, ask us to reflect and challenge our own perceptions. They cover all ages and different areas of life. They relate to school, adult services, family and community. In short, they reflect the variety and creativity for which this journal has become known.

As a Scot who has lived and worked in Scotland, England and Wales – and has strong links with Northern Ireland – I’m especially pleased to see that our contributors represent all four nations of the UK. One of my frequent complaints is that we often look abroad – to America, Australia or New Zealand for example – for new influences and developments, but ignore our nearest neighbours. Overstated, I know but I do feel strongly that we and those we work with and for will benefit greatly from closer working relationships within the UK and being better informed about what is happening in one another’s schools, adult services and communities.

At the same time, I don’t underestimate the importance of sharing across international boundaries. I’m delighted therefore that we also have a thought provoking contribution from an Indian colleague whom I’ve had the pleasure of working with. There’s nothing quite like being lifted out of your own context with its reassuring frames of reference to make you start questioning your own assumptions, beliefs and ideals.

So a big ‘thank you’ to all our contributors both for their articles and for their patience with me as I’ve put this issue together. In addition, I’m extremely grateful to colleagues on the editorial board for their help and support in my first venture in editing PMLD Link. Enjoy your reading – and remember we welcome your feedback.



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Articles, News, Reports, Letters **Spring Vol. 19.1 Issue 56** **Copy date 1st March 2007** **Adult Years**

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Articles, News, Reports, Letters **Summer Vol. 19.2 Issue 57** **Copy date 1st June 2007**

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The Development of a Culture of Engagement in a Service supporting Adults with Profound & Multiple Learning Disabilities

John Ockenden, Practice Development Advisor, United Response

It can be argued that People with Profound and Multiple Learning Disabilities [PMLD] are amongst the most marginalised and ignored members of our society. In the days of the big Victorian institutions they were those most likely to be found in the “back-wards” and then in general they moved [or were moved] into community settings later than less disabled people. Research examining quality of life outcomes in all forms of residential settings has consistently shown a relationship between the degree of disability and the quality of life experienced [i.e. the more disabled you are the lower your quality of life is likely to be].

In recent years this phenomenon has been increasingly recognised and explored [not least as evidenced by the publication of this bulletin]. However for those supporting Adults with PMLD it frequently seems that there is a wealth of information and support focusing on Children with PMLD and Education and precious little that is of use in the minute by minute support of adults to live rich and fulfilling lives.

Apple Grove

Apple Grove¹ opened in 1988 as a service for five people in a small semi-industrial town in the North of England. The five people who initially lived at Apple Grove had all moved from a local long term hospital, would all be described as having PMLD and specifically experienced significant physical disabilities. The service was transferred to United Response² from another provider in the mid-90s. Staffing levels allow for three to four team members on duty at any one time. Typically, considerable staff attention needs to be addressed to health issues and physical care.

Although two of the original five people died during the 90s, those who moved in needed the levels of physical and medical assistance that the service was accustomed to providing.

Engagement & Active Support

Engagement in everyday activities has been demonstrated to be an important measure of service quality and can be shown to be a strong indicator of quality of life. Active Support is a package of approaches designed to enable staff to promote engagement. It has a track record of proven success and has recently been

comprehensively described [as Person Centred Active Support] by Mansell et al [2005].

In 1998 United Response began to focus particularly on the issue of engagement and the implementation of Active Support as a means of enabling better life outcomes for the people it supported [Tindall, 1999], after earlier work showing the value of such an approach [Ashman, 1997]. A baseline assessment in 1999/2000 included the gathering of information about engagement levels for people being supported and the extent to which staff were using Active Support [using a tool which gives a % figure] in each service. Across the organisation the mean level of engagement [scored on a 0-3 scale, where 0 = largely disengaged and 3 = engaged over 75% of the time] was 0.78; mean active support implementation was measured at 52%³. At Apple Grove although the Active Support score was 37% the level of engagement was found to be zero.

This result was not untypical of similar settings and supports the contentions that:

- levels of support that might be sufficient to enable engagement for less disabled people may not be successful for people with PMLD; and that
- more disabled people tend to get less support to be engaged despite needing more.

From 2000 to 2005 a number of factors influenced the development of service delivery at Apple Grove. Steady improvements in the quality of support and increases in the extent to which people are engaged⁴ have been seen so that now

¹To protect the privacy of some people living at Apple Grove, its name and location and the names of the people living there have been changed

²United Response is a large national voluntary organisation providing a wide range of supports for people with a learning disability and mental health needs [www.unitedresponse.org.uk]

³Published results [Mansell et al 2003] were not represented in this way but data were retained for future comparisons.

Apple Grove is an exemplar of good practice in United Response.

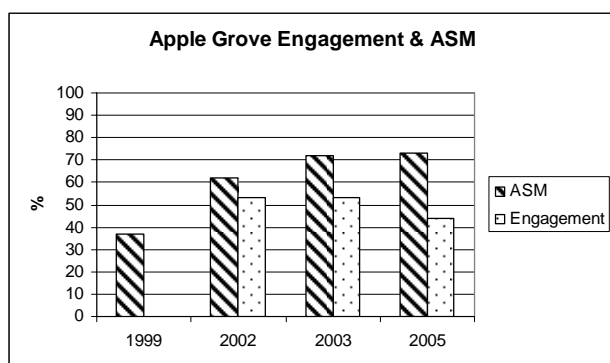


Fig 1 – showing changes in Engagement and Active Support Measure over time

Given the agreed difficulty in supporting people with PMLD to be engaged in everyday activities, the factors that facilitated this development are detailed below in the hope that they may help others to similarly transform the experience of the “Silent Minority”⁵.

Background Factors

1. Facing the Reality

Not least amongst the influential factors was the stark reality that a measure generally considered to be a good indicator of quality of life had produced a zero figure for the five people living at Apple Grove. It was recognised that people were very well cared for, that they lived in clean and comfortable surroundings and were taken out for meals, drives and to shopping centres, that their physical needs were met and that staff and others in their lives regarded them very positively. But it is also true that when staff were busy doing the things that are part of daily life they didn't find ways to involve people in them. Typical was the lead up to a meal in which staff would do all the food preparation with the people they supported physically present, but dozing or engaged in self stimulatory behaviours.

More importantly still, staff had some misgivings about the relevance of engagement for the people they were supporting. For example they understandably viewed engagement as meaningful only if the activity itself was meaningful to the person⁶. This would probably be the view of the average person in the street and would be appropriate to supporting people with more independent living skills. But engagement in daily living activities has long been promoted not for the

sake of the activity itself but as an opportunity for activity per se, for interaction and the development of predictability, personalised routines and a meaningful environment [eg Toogood, 1989] as well as a platform for any other engagement with the wider world.

Piecemeal attempts to involve people were reported as having been unsuccessful – ie. the person concerned had rejected the opportunity – and, in the absence of a coherent counter argument, this was understood in the staff team as confirmation that engagement was inappropriate.

Equally the considerable medical and physical needs of the people concerned tended to lower the priority of promoting engagement, as well as causing immediate difficulties, for example in holding objects or getting close enough to activities.

So when engagement has a low priority, is seen as being of low relevance, apparently inappropriate and is difficult to achieve, it tends not to happen.

Therefore for the five people who lived at Apple Grove it was important that those in a position to influence positive change had a clear grasp of the reality of life they experienced and the prevailing ethos and culture of the staff team.

2. Management Approach

Up to 2000 the on-site manager's approach was consistent with the staff ethos described above. When he left, the locality manager appointed a replacement who was committed to a culture of support for engagement over and above high standards of care. Over the next four years the on-site manager, in addition to all the other demands on this critical role, managed the balance between responding to people's significant health needs and developing a culture of engagement and the implementation of Active Support. Her replacement [from 2004 to date] has continued this work. All of the specific interventions detailed below were led and monitored by the on-site management.

3. Practice Development Team [PDT] and Inclusion Team involvement

In 1999 United Response established an internal resource, part of whose responsibility was to support locality and on-site managers in implementing good practice in supporting people. This small team works nationally, with one member

⁴The engagement level has dropped between 2003 & 2005 but this is accounted for by the departure of the most able person living at Apple Grove [the effect of his arrival in 2000 is discussed in point 4 below] – however the engagement measure for others can still be seen to be substantially higher than in 1999.

⁵As described by Samuel & Pritchard [2001]

⁶So why would we engage Bryan in making the tea when he doesn't understand the relationship between cooking and eating?

of the team working with each group of locality and on-site managers. Members of the team have experience

- a. as support workers, on-site and locality managers
- b. of implementing change in learning disability services
- c. of working with many people with learning disabilities;

and expertise in

- d. Active Support
- e. Person Centred Approaches
- f. Challenging Behaviour

At about the same time United Response created a national Inclusion Team [of five individuals]. Inclusion Team members have similar experience and expertise to members of the PDT but with a particular interest and knowledge in developing communication, advocacy and empowerment. The relevant Inclusion Team member for Apple Grove had a particular interest and expertise in these issues for people with PMLD.

Over a period of two years, from 2001 to 2003, the PDT and Inclusion Team workers supported the Apple Grove team in developing improving practice through a series of meetings identifying issues and agreeing strategies and approaches. The actual changes were, of course, effected by local managers and staff, not by external experts visiting periodically – but these meetings did enable attention to be focused on good practice when it might otherwise be directed to the wealth of other pressing concerns.

4. Colin

In 2000 a new person moved in to Apple Grove. Colin experienced some physical difficulties and a degenerative disorder but crucially was [at least at the outset] less intellectually disabled than his new co-habitees. Staff soon discovered that Colin was not only able to do more than others they were supporting but also was clearly indicating a wish to do so and they readily found ways in which he could be involved in everyday activities. Most staff had limited experience of working with people with a learning disability [often only having worked at Apple Grove] so they were struck by the discrepancy between their work with Colin and with others. For some this created a sense of dissatisfaction with their support for more disabled people and a desire to do the same with them as they were doing with Colin.

Specific Interventions

5. Training

An early approach to changing the service culture was the provision of training. Training in active support had been delivered to most staff as part of the broader organisational implementation but had clearly failed to have any effect, so the new on-site manager delivered specific training focussing on issues at Apple Grove in team meetings and in ½ day sessions. However she and staff still in employment report that this training also had little effect on practice and that it was probably only useful in providing a helpful background to other more potent factors.

Training and mentoring in communication [provided by the Inclusion Team] had also been accessed by some staff. This tended to have the effect of raising awareness for those staff, but their attempts to change the ethos of the whole team were not successful, and positive effects [even arising from the Inclusion Team demonstrating, in situ, approaches that encouraged communication] tended to fade.

6. On-the-job Coaching

Jones et al [2001] describe the powerful effect of on-the-job coaching in implementing active support and contrast this with the poor impact of training on its own. At Apple Grove this approach was adopted by the on-site manager – in doing so she created circumstances in which a number of related approaches could be pursued:

- a. Direct coaching
 - i. demonstrating in real life situations how to enable people to be engaged,
 - ii. encouraging staff to try the same approaches,
 - iii. observing practice
 - iv. providing feedback on performance
 - v. repeating the process as appropriate
- b. Addressing misconceptions about active support and engagement & ongoing difficulties

By demonstrating active support in practice, the on-site manager was able to deal with a number of misconceptions that had grown up, more directly and meaningfully than in the traditional training situation. In particular the staff team had come to view active support as a way to get people [and/or support staff] to clean their rooms thereby justifying the removal of cleaning staff. There was also a sense that it had been imposed on them without explanation, and little or no sense that it was about

improvement in people's quality of life. In demonstrating increased engagement, and the opportunities this provides for interaction, choice making, skills acquisition and well-being, the on-site manager was able to address these issues.

In addition the new management approach opened up possibilities for more productive feedback in general, in that staff were happier to accept constructive criticism from someone who had demonstrated that they knew what they were talking about.

c. Identifying champions

Inevitably team members differed in their willingness to change. When planning and delivering coaching and encouragement, the on-site manager focused on staff who she judged were most likely to adopt the approaches concerned. By infecting them with her enthusiasm she was able to create islands of good practice that could grow across parts of the team and across shift patterns. In fact she found that team members were competitive and wanted to outdo each other in their work practice and in the outcomes they were able to promote.

Staff still in employment are in no doubt that encouragement and support to try ways of getting people involved pushed the culture change more than anything else. As one team member said: "It was doing it, not training, that really made the difference".

Understanding Rejection

As reported in point 1 above, one of the key experiences of the Apple Grove staff team was the rejection of involvement in activity by the people they supported. There are two ways of looking at this frequently encountered situation:

- a. Rejection is the person saying they don't like or want to be involved in this, or [if repeated in enough situations] any activity; or
- b. Rejection is the expected reaction of people who:
 - i. have limited experience of enjoyable activity
 - ii. have difficulties in understanding what activities might be about
 - iii. are supported by people who will do the same thing differently
 - iv. may not understand time sequences
 - v. are used to doing nothing
 - vi. have limited [or no] experiences of controlling what happens
 - vii. experience things coming out of the blue at them.

It became important to support the team to appreciate the virtue and benefits of the second approach and they were introduced to a model developed by McInnes & Treffry over 20 years ago [McInnes & Treffry, 1982]. Derived from work on babies of mothers suffering from Rubella, McInnes & Treffry's model suggests that rejection is merely the first and expected stage in a sequence of responses to opportunity – by continuing to offer opportunities despite that initial rejection [and doing so with care, sensitivity & predictability] people can be supported to move through other stages [Tolerance, Passive co-operation, Enjoyment, Responding co-operatively, Leading, Imitating & Initiating].

The crucial concept that staff grasped was that a rejection was not necessarily a choice of "No" as opposed to a "Yes", but might very well be a "No, not yet" – a necessary stage on the way to positive choice making.

8. Clarifying Senior Support Staff Roles

The on-site manager also set about convincing senior members of the team of the merits of increasing engagement and that a key part of their role was to plan shifts [to promote opportunities for engagement] and to monitor staff support and engagement. In due course the on-site manager's deputy became more important to the overall process and strong shift leaders became key drivers in the delivery of high quality support on a minute by minute, hour by hour basis.

9. Communication, Consultation & Speed of Change

As well as the day-to-day interventions described above the on-site manager changed the agendas for team meeting and supervisions to reflect the significance being placed on active support and engagement. This allowed more formal and recorded discussions of the debate as it, and the change in culture, proceeded. However the rate of change was deliberately not rapid and the on-site manager took a step-by-step approach to transforming the way the staff team worked. This was due to:

- a. A desire to ensure staff were always on board
- b. The range of other matters requiring attention
- c. The size of the challenge
- d. The nature of the support provide by the PDT and the Inclusion Team [ie agreeing specific actions at each meeting].

10. Opportunities arising from Staff Turnover

As and when staff left [although turnover was not high], the on-site manager and her senior team ensured that new staff got appropriate messages about Active Support and engagement, and support to work in the ways described above, very early in their induction so that they would be protected from any vestiges of the old culture, and would contribute to the momentum towards a culture of engagement.

11. Increasing Support Flexibility

The departure of staff also provided opportunities to employ new employees on part-time contracts. This enabled support to be rostered more flexibly and meant that people were more likely to be supported when they needed to be, rather than when a more rigid shift pattern allowed it.

12. Rewards and recognition.

It can seem to managers that there are precious few things that will motivate staff, and even fewer over which they have any sort of control. Indeed the most potent available motivator may be their own attention to staff activity and what they choose to notice, encourage and praise. However there are often means in organisations like United Response to grant one-off payments. The on-line manager very deliberately arranged one such payment to a team member in recognition of work she had done around improving practice, thus giving an important message [at not much financial cost] about what is considered important.

In addition staff were helped to represent the amount of engagement they were enabling in graph form [using a simple adding up of existing records and a collation into a spreadsheet]. They liked this visual picture of their work as it enabled them to quickly see a product of their efforts.

Conclusion

Too many adults with PMLD are sitting around with nothing to do, because it's not immediately obvious either that they do want to be engaged, or how to enable them to be. The Apple Grove experience shows that there is no single fix for this situation, but that a combination of approaches can radically change the approach of those supporting people with PMLD and the life experience of those people. The evidence suggests a substantial improvement in these two issues and current indications are that staff and others view people as being twice as able as they did before and they relate to people more as individuals than previously.

Crucial to this change has been the influence of the

on-site manager and subsequently the senior members in the team. Their approach has focused on in-situ work directly with staff and those they are supporting. Organisational policy, staff training and other resources [though good in themselves] made no difference to day to day reality without practice leaders in line management positions interpreting them in ways that made sense to staff, demonstrating and encouraging implementation and providing feedback, correction, support and reward, and driving step by step development. Structural change designed to increase flexibility, monitoring and accountability enabled an entrenching of the change such that support is now described as being flowing and natural. As one team member reported: "Now, I don't know how we could ever have worked the way we used to"

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Realising the Potential of Play for ALL Children

Professor Roy McConkey, Institute of Nursing Research, University of Ulster.

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In every country of the world, children and families play and this has gone on for generations. Why? Many explanations have been given. It's fun, it's a way of using up excess energy – be it mental or physical – or it simply passes the time!

As always there is some truth in each but none can provide the whole story. You need only to recall the seriousness with which children get absorbed in their play and the upsets which can arise, to realise that play can be serious business. The excess energy theory is equally incomplete. Play is often most therapeutic when we are tired and care-worn. And play must be more than a way of passing time. How else do you explain the terrific diversity, not to say the complexity of the many play activities which humans have invented?

Confusing play with toys

Play is such an enduring part of our humanity; that these superficial explanations will not do. We have to begin by freeing our minds from the concept of play as an activity done with toys or equipment. This myth leads to various mistaken beliefs. For example, the more toys children have, the more opportunities they have for play. A moment's reflection quickly identifies the naivety of this assumption. How often have we heard parents exclaiming that their child can't possibly be bored because of all the toys they have!

The converse view is possibly more pernicious. One of the most depressing statements to my ears, is the assertion that a child is too disabled to play. Here the focus is on the child's inability to manipulate toys when alone or in the company of other children. However this incapacity is just as true of babies and yet we would not dream of saying they can't play. Indeed adults make strenuous efforts to get babies playing and their reward at first is simple – the baby's smile.

When a child has severe impairments our thoughts tend to turn to therapies, care packages and teaching programmes rather than to playing with them. The unintentional consequence is that we fail to engender a spirit of playfulness in our interactions with them and in so doing, I believe we make the person less human. Let me explain further.

The essence of play

Philosophers and child development experts have struggled to provide an adequate definition of what play is. No trite phrase can capture the richness and diversity of play; rather we need to take a three-dimensional view of the qualities of play.

Play is dynamic

Play is better thought of as a process rather than a product; as actions rather than an activity; as a verb rather than a noun. The value of play lies within its dynamics; just as the value of the football match is in the play of the two teams rather than the final score.

Viewed in this way then, we can see how it is possible for parents to play with new-born babies even though their only contribution may be a stare, a gurgle or a yawn. Of course as their repertoire of behaviours grows, babies are able to contribute more to the interchange; with smiles, body movements and noises. Then a really important change occurs – the baby starts to lead in the play and the adult responds! In time other people can also get incorporated into the play as will toys and books even if it is simply a focus of attention or interest.

All of the foregoing is just as true for children with PMLD. They depend on other people to instigate the play dynamic but when it happens most will be able to join in as long as we are patient and observant of their reactions. Perhaps 'play' is too small a word for these human games. Others have invented terms like 'intensive interaction' or 'reciprocal communication' to describe these play activities. But call it what you will, the really important thing is to ensure that *every day*, the child with PMLD has the chance to experience the dynamics of play.

Thankfully the advent of modern technology and easily operated switches gives lots of opportunities

for even the most profoundly disabled child to initiate play – be it with objects, lights, music or people.

Play is creative

All play experiences are essentially a creative act even when the same activities feature again and again! Play springs from the person or people involved; they have total control over its expression and development, and they are free to vary it as they wish. In this respect it's like a musical performance.

No one can doubt the creativity of preschoolers in their imaginative play but we may struggle to observe it among children with marked visual or motor impairments. Perhaps a better way of approaching this play theme is through our creativity as adults and the variations we incorporate into our play with the children. For example, by varying the setting of our play – on the floor; in the bath or swimming pool; out of doors; on table-tops and so on. Or we can vary the sensual experiences we offer our play partners – from vision to touch to smell to hearing and so on. In a sense we become like a conductor trying to elicit a creative response among the players of the orchestra. The question is: have we the time and will to persevere in being creative?

Play is feeling.

Play touches us emotionally. Often it makes us happy and proud but it can just as easily be frustrating; or it can make us angry or sad. The drama of play lies in resolving emotions that otherwise could be harmful to ourselves and others. A theatrical performance is another analogy for play.

Although we experience our own emotions, we can only guess at how another person feels. Indeed we may be selfish enough to be unconcerned or too preoccupied with our work to think about their feelings. Playing together with others forces us to tune into their feelings in ways that may not happen at other times. Parents are often adept at both tuning into their child's moods and encouraging them out of 'bad' ones. This emotional intelligence as it's sometimes called, is an invaluable tool in dealing with people who are unable to express their feelings but who nonetheless can experience a range of emotions. Can you read the feelings of your playmates and attune your interactions to them?

Play makes us human

Viewed in these three dimensions, we can begin to

glimpse the value of play to humanity. The dynamic of play encourages communication and co-operation with others. The creativity of play develops our capacity to solve problems and to invent novel solutions. The emotions of play prepare children for living within a society that can be isolating and hurtful as well as companionable and enriching.

Humankind is unique among the animal species in the richness of our play throughout adulthood as well as in our growing years. We don't play because we are human; we are human because we play. That's a thought worth holding on to. The evidence to support it is plentiful. For instance the dehumanising aspects of institutional care lay not in the buildings but in the attitudes of the staff working there. They thought it was not worth playing with orphaned, abandoned or disabled children simply because they considered them to be less than human!

Promoting play

So how often do teachers and therapists really play with children who have PMLD? Although it can be very difficult to adequately define play in words, what is remarkable is that we know when we are playing and when we are not! I suspect children can detect a play spirit as well; perhaps from a very young age. Ultimately then the question of play is one that only an individual can answer but perhaps it would be salutary for teachers and therapists to audit their daily practice so that they could accurately defend the amount of time spent playing.

Then again, maybe professionals are not the best play-mates for children? So who else is there? Parents, siblings and other children all spring to mind but do we try hard enough to mobilise their play talents? For example, they may need to be shown lots of examples of what it means to play with a child who has PMLD. Other children and young people need opportunities to be in their company especially if the persons with PMLD attend special schools and centres. And what access do all these potential playmates have to specialised play environments such as pools, sensory rooms or soft play areas. Do they lie unused when the clinic or school closes?

A focus on play gives non-specialists a means of engaging with the child or adult that is culture free and can even be age appropriate. It has other benefits too. Unlike therapy, play can take place anywhere and at any time. Indeed the fun often comes from being in new settings and having new experiences. A play focus may encourage families and friends to take their relative on more outings.

In less well-off localities or countries, the promotion of play overcomes the dearth of specialists and specialist equipment by emphasising what can be done with whatever and whoever is available. Admittedly this requires great ingenuity and creativity on the part of professional staff but I have been humbled in my travels in the so-called 'developing world' to see what can be achieved at little or no expense.

A challenge for all

I don't doubt there are many challenges in realising the potential of play with children who have PMLD just as there are when we try to meet their physical care or health needs. What concerns me is that we expend a great deal of effort and money on the latter which is not matched by our response to their need for play. I hope readers of this article will prove me wrong either by putting pen to paper and sharing their play experiences with a wider readership or better still, by renewing their efforts to ensure that in their professional and personal lives, they make more time for play.

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Further reading

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www.intensiveinteraction.co.uk/

www.dundee.ac.uk/pamis/

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

Inclusive Literacy

Penny Lacey, Senior Lecturer in Education, The University of Birmingham.

Researchers from the Universities of Birmingham, Manchester Metropolitan and Plymouth studied the way schools approach teaching literacy to children with severe learning difficulties. The research was carried out by Lyn Layton, Penny Lacey, Carol Miller, Juliet Goldbart and Hazel Lawson. Although not the main focus of the study, pupils with profound learning disabilities featured in the information we collected. This article is an attempt to share some of what we found.

The study took about 18 months to complete and during that time we carried out five different activities:

1. desk-based research using books, journals, magazines and web-sites
2. observations in classrooms, in both literacy lessons and other lessons where literacy skills might be being used
3. interviews of the teachers who taught those lessons
4. focus groups of teachers to discuss our results
5. interviews of 'expert witnesses' (people who are well-known for developing aspects of literacy with children with SLD/ PMLD).

Conventional Literacy

Most definitions of the word 'literacy' contain reference to reading and writing text and the reality in schools (special or mainstream) is that Literacy on the timetable is about learning to read and write or to engage in activities that are eventually meant to lead to reading printed or written text as well as generating written text and writing. The original National Literacy Strategy material (DfEE, 1998) answers its own question of 'what is literacy?' with 'Literacy unites the important skills of reading and writing'. It does go on to include speaking and listening as important, but the rest of the materials are about reading and writing: speaking and listening are hardly mentioned again.

This position has changed with the new Primary National Strategy (DfES, 2006), where speaking and listening are much more prominent under the literacy heading, with four of the twelve strands relating to 1. speaking, 2. listening and responding, 3. group discussion and interaction and 4. drama. The other eight all relate specifically to reading and writing, with the emphasis at an early stage on learning through 'synthetic phonics', where children need sophisticated knowledge about the segmental nature of spoken language and to be able to match speech-sounds and letters.

I have dwelt on conventional views of literacy because when we went to schools for pupils with SLD/ PMLD, we found that most of them were taking a conventional approach to teaching literacy, at least to pupils with SLD. Children were being taught words and phonics, how to get information from books and other kinds of text, and lessons we observed looked very similar to those that can be seen in mainstream classrooms all round the country. There was a greater variation for pupils with profound learning disabilities, but even so, many lessons looked, in essence similar to the prescription for the Literacy Hour.

Observations

Typically, a class of children with severe and profound learning disabilities were seen sitting in a semi-circle around a teacher holding a big book. The book was read or a story told using the pictures and staff engaged the pupils in the story through pictures and objects. Following the story, again typically, the class divided into smaller groups for work related in some way to the book but pitched at a level that was right for the individuals in that group. Usually, the whole class met again for a plenary session at the close of the lesson where pupils' work was recalled and celebrated.

The work we observed that was specifically designed for pupils with profound learning disabilities was often sensory in nature. It was usually centred around a story or a book, but access to the activity was often through objects to touch and activate or odours to smell, things to look at and listen to or even food to taste. We saw stories being told through a range of sensory experiences, such as the Bag Book 'Gran's Visit'.

There were also examples of what might be called 'pure communication', rather than anything specifically related to conventional literacy or pre-literacy skills. These were variations on Intensive

Interaction (Nind and Hewett, 2000) and usually began from the child him or herself, rather than from a book or a story. The intention appeared to be to engage the child and achieve even minimal social interaction using little games associated with typically developing infants and caregivers. One game observed involved the adult having a conversation of 'ahs', following the lead of the child's vocalisations. It is not known whether the adult thought that what was happening was part of literacy but it was happening in a Literacy lesson.

Inclusive Literacy

One of the central concepts that developed through the study was the idea of 'inclusive literacy'. Conventional literacy is clearly not open to children (or adults) with profound learning disabilities as they are not going to learn to read and write. However, if we conceive of literacy as 'inclusive', there may be ways in which even the most profoundly disabled can take part. So what did we mean by 'inclusive literacy'? We identified a range of activities for learners with SLD that we want to argue could legitimately be identified as 'inclusive literacy' even if there was no use of text at all, and many of these can include those with profound learning disabilities. We identified:

- Objects of reference
- Life quilts and life history boxes
- Personal storytelling
- Sensory stories & multimedia stories
- Cause and effect software
- Photo albums and scrap books
- Picture books & stories
- Graphic facilitation
- Reading icons and symbols
- Talking books
- Early conventional reading skills
- Simple conventional books
- Drama and role play
- Simple software for computer
- Television and films
- Navigating websites (eg: Eastenders)
- Creating websites
- Still photography to create books
- Film-making

The list includes some activities that definitely do not fit into conventional literacy relating to letters, words and text. Some can be seen as 'new literacies' belonging to the media age of television, ipods and computers (Lankshear and Knobel, 2003) and others are seen as, perhaps

simplifications of, or substitutions for, the whole business of traditional text-based literacy, such as objects of reference, life quilts and sensory stories.

Objects of Reference

The first few in the list seem to have the greatest potential for learners with profound learning disabilities. Objects of reference (Ockelford, 2002), for example could be seen as the first real step into learning about symbols, which in conventional literacy might lead to more and more abstract symbols and eventually into letters, words and text. In the absence of this kind of progression, learning to use objects of reference can be seen as an early and important form of literacy in its own right for those learners who are unable to progress further down the conventional literacy or even the new literacies route.

Life Quilts and Life Boxes

Life quilts (Grove, 1996) or life history boxes can be seen as akin to books about a person. A life quilt is literally a quilt made from sewing together pieces of material from the clothes, curtains, cushions, duvet covers that have meaning for that person from early childhood through to adulthood. There can also be objects sewn into the quilt: anything that might spark familiarity. If this is started at an early age and continually added to and enjoyed, it can become an important 'book'. Alternatively or in addition, a box can be used to collect important objects such as slippers, a personal cup, a toy or birthday candles. These can be used regularly to 'tell the story' of the person's life.

Sensory Stories and Multimedia Activities

There are many examples of sensory stories in schools and colleges: published and home-made, although perhaps fewer multimedia stories. If you haven't already found Pete Well's disgusting stories, you might try them especially with teenagers or young adults. Go to www.portland-school.co.uk/Petes-stuff/PetesStuff.htm. Two other special school websites that offers interesting activities for learners with profound learning disabilities are Priory Woods School www.priorywoods.middlesbrough.sch.uk/ and Meldreth Manor School <http://atschool.eduweb.co.uk/meldreth/textandinfo/Powerp/Media2.html>.

Pictures and Moving Pictures

The activities on our list that are related to pictures (still or moving) may or may not be meaningful to an individual with profound learning disabilities.

Learning to understand and 'read' pictures is an important skill for learners with SLD and the first rungs of that ladder may be relevant to someone with profound disabilities, especially recognising themselves, their family and friends on video. For some people, attaching the camera to the television and watching themselves in real time can be motivating and interesting.

Film-making and Drama

There are some other activities on our list above within which learners with profound disabilities could be included; for example film making or drama. Nicola Grove and Keith Park have many suggestions for how this can be achieved and if you haven't come across their work, you might start with their book 'Odyssey Now' (Grove and Park, 1996) or 'Macbeth in Mind' (Grove and Park, 2001) or find Keith's many articles published in *SLD Experience*, *BILD*. Keith's work can also be seen on Teacher's TV online in a programme called 'Special Schools: Access the Curriculum' www.teachers.tv/video/1403.

Conclusions

From our research we were able to see examples of activities that we called 'inclusive literacy'. We recognise, as did the teachers in the study, that literacy for learners who don't learn to read and write is not conventional. It includes a wider view of communication than might typically be seen as literacy, as well as some of the new literacies that are more often associated with creative, performance or media studies or information and communications technology. For the most profoundly disabled learners, to be inclusive, literacy must also embrace the use of objects as a kind of text and perhaps even see someone learning to anticipate a favourite activity as learning to 'read' what is happening. I don't want to stretch literacy to a ridiculous degree but there is definitely more to it than the conventional reading and writing of text.

Hopefully, the inclusive literacy activities that have been briefly discussed in this article will inspire you to be as creative as you can in providing experiences for learners with profound learning disabilities. Although joining in a conventional literacy hour with more able peers is one activity,

there are lots more that appear to us as legitimate responses to teaching literacy to learners who are not going to learn to read and write. Have fun in Literacy!

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Using Multi-Sensory Stories to Develop Literacy Skills and to Teach Sensitive Topics

Julie Taylor Library & Information Officer, PAMIS

(PAMIS is a voluntary organisation and a registered charity working in Scotland with families and carers of people with profound and multiple learning difficulties (PMLD)).

In 2000 'Real Lives: Real Stories' was set up by PAMIS to develop literacy skills in children and adults with PMLD, in order to fulfil specific needs within the PMLD community. Through a personalised multi-sensory story, based on Chris Fuller's Bag Books model, students with PMLD could begin to access books and develop early literacy skills such as understanding sequences and anticipation. 50 personalised multi sensory stories were developed in collaboration with parents, carers and staff from schools and day centres across Scotland. Duplicates of all these stories were then produced to create a multi-sensory story library available for borrowing across Scotland, through the PAMIS library.

The principles underlying the development of the multi-sensory stories are based on those devised by Chris Fuller of Bag Books, adapted and further developed to meet the needs of students with PMLD and the project's remit. The stories are short, familiar, and repetitive. Each storybook includes several "pages" which the storyteller presents in sequence to the student. The materials in the stories are chosen and fitted to suit the student's abilities, for example their vision and dexterity are taken into account and the language is at an age appropriate and cognitively comprehensible level.

The book cover is a cardboard box, with a label at the side with the title of the story and a tactile symbol relevant to the theme of the story, which the student can recognise over time. If the student uses a signing system, the storyteller signs the story's title. Inside the book cover are 6-8 pages, of neutral coloured A3 board with usually a single stimulus attached. Each large neutral page creates a frame in which the individual can focus upon the presented stimulus. Each stimulus is attached to the board usually by velcro and appropriate to the individual. For example, if the student is visually impaired the stimuli are large and brightly coloured. The story line is written on a separate story card, with one or two short rounded sentences per page, the total length of the story being 4-6 minutes so as to remain within the student's visual and auditory attention span. The language is clear and the sentences relate directly to the stimuli on each page. On the back of the story card are clear instructions explaining to the storyteller how to read the story and present the stimuli.

In the PAMIS *Real Lives: Real Stories* project there were built in agreed learning targets in all the stories; for example, maintaining attention for the



'Itch the Pony'

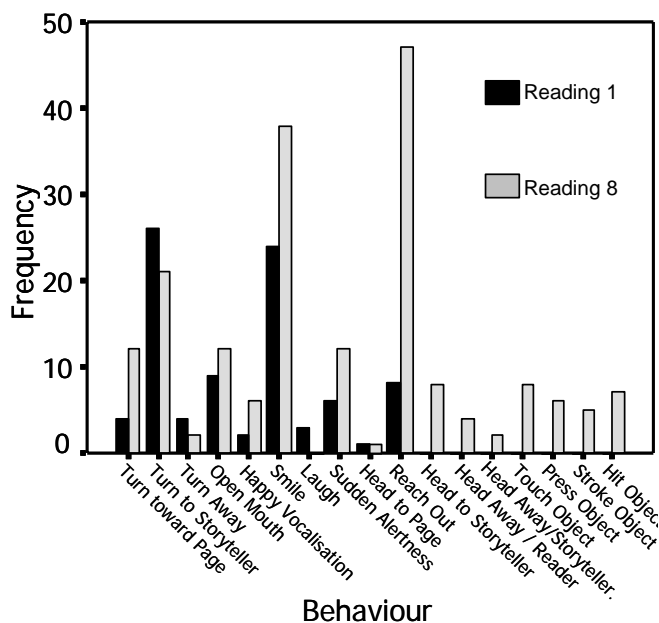


**A page from 'Itch the Pony'
– coconut shells to mimic horses' hooves.**

duration of the story, eye and finger pointing, choosing between two objects or manipulating an object. The learning targets were learnt through repetition of the story and exploration of the objects. In addition although the stories were developed for an individual student, they were designed to be equally interesting and enjoyable to other young people with PMLD.

As part of the project, we videotaped a series of readings by parent or teacher of an individual story over a period of several months. The individual student's behavioural responses were then analysed. The results showed an increase in the frequency and range of behaviours in response to the presentation of stimuli from the first to later readings, with the greatest increase in smiling and reaching out. The results not only clearly demonstrate that multi sensory stories are very effective in teaching literacy skills, but also increase positive behavioural responses e.g. communication and cognitive and motor skills. Figure 1. below clearly illustrates this learning.

An example of the changes of response by a 9 year old blind student to the stimuli after reading a multi-sensory story (adapted from Watson, 2002)



The feedback on the *Real Lives: Real Stories* project from both parents and teachers was extremely positive. Below are some of their comments:

“The story was an activity to share with the family”

“My son has an entertaining and educational story that gives him pleasure, and informs him too”

“Her responses are much better than I had expected, it is difficult for me to get things she responds to, but with her story she responds to the stimuli most times”

“She watches other’s reactions when it is ‘read’ to them and laughs appropriately and tries hard to be as actively involved as possible.”

These stories do not need to be used solely as originally developed, using a one-to-one technique. They have been very successfully used in a number of innovative ways. For example, in several schools the storyline has been recorded onto a switch, so that a student can read their own story to the class and other students can take turns reading the story. The student concerned is in control of the switch and at the appropriate time presses the switch to ‘turn the page’ and listen to the next part of the storyline. Meanwhile the teacher can pass the relevant page to all the other students in the class to interact with the stimuli on that page.

A parent whose daughter with PMLD has a ‘Circle of Support’, takes along a different story to each meeting. The ‘Circle of Support’ starts with a story, with each member reading a different page from the story. The young woman can then take an active part in the meetings and the use of the stories helps build up a relationship between the members and the student.

The feedback from this project showed that there was a need to extend the scope of the stories and go on to develop stories on ‘difficult topics’, such as menstruation, sexuality, epilepsy, going to the dentist and transition. This new Sensitive Story project began in 2004 at PAMIS and is still ongoing. It is receiving a very positive response from parents/carers, schools, day centres and child assessment centres throughout Scotland, to the extent that the demand for the sensitive stories far surpasses the rate at which they can be produced.

As with the previous Multi-Sensory Stories Project, the Sensitive Stories Project will include extensive behavioural analysis research to show the effectiveness of using this method to teach difficult topics

Ultimately our hope is to duplicate a number of stories based on sensitive topics that will be made available to borrow along with the other collection of multi-sensory stories, from the PAMIS library. The *Real Lives: Real Stories* are proving to be in great demand from our library and are borrowed across Scotland by schools, day centres, families, carers and summer play-schemes. There are presently almost no accessible materials for people

with PMLD to borrow from libraries, apart from the limited materials we are able to offer. The PAMIS library also has a number of Fuller's Bag Books stories available for loan.

For further information on the Sensitive Stories Project please contact Maggi Fenwick at PAMIS
Tel: 01382 385154

or email:

m.fenwick@dundee.ac.uk

www.dundee.ac.uk/pamis/projects/sensitivestories.htm

To borrow stories from the PAMIS library (Scotland only) – contact Julie Taylor
Tel: 0382 385154 or email j.t.taylor@dundee.ac.uk

Bag Books
60 Walham Grove,

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

Touch Trust

Dilys Price & Charlotte Aubrey

The Touch Trust is an arts organisation funded by the Arts Council of Wales. Touch Trust provides a new and innovative art of movement programme which is unlike any programme offered by other art organisations. In 2004 the Touch Trust was invited to be one of the seven flagship art residents of the Wales Millennium Centre, Cardiff (WMC). This was a tremendous privilege as Touch Trust is the only arts organisation working with people with such profound disabilities. The opportunity to be in partnership with organisations such as Welsh National Opera and Diversions Dance Company in such a cultural centre for Wales is a dream come true.

The Touch Trust is a pioneering charity that works creatively with people with profound and multiple disabilities, challenging behaviour and autism. Touch Trust aims to act as advocates for the development of an inclusive community through the provision of creative movement opportunities for those often denied access to the arts.

The Touch Trust provides creative, touch-based art of movement and dance programmes for individuals with autism, challenging behaviour and profound and multiple disabilities. Touch Trust art of movement and dance sessions are inclusive to all. We have several sessions daily in the Touch Trust suite with qualified creative movement session leaders. We provide group sessions for schools, community centres / day centres and adults post eighteen in the community. We also offer one to one sessions for adults and children and specially designed programmes for babies and toddlers.

The programme is adaptable to suit each individual's needs and capitalises on positive outcomes achieved through a creative approach. The programme allows Touch Trust guests to move at their own level and provides the opportunity to explore authentic sound and movement in a positive and nurturing environment. Through the exploration of movement and sound guests begin to build up a positive body image, enhanced self-esteem and well being. Some key aspects of the session include; enjoyment, enlivenment, self worth and group / partnership sense.

The initial success of Touch Trust programme has been achieved through a simple structure. This set format provides security and safety; as a result it can be taught well by a non professional who is committed and passionate. We are pleased to find that many of the ideas used in the sessions are also taken by support workers and integrated into day to day life in the community.

To our delight schools and community services

have been beginning to form partnerships with the Touch Trust. Teachers and care workers have been so inspired by the unique programme and as a result have trained with the Touch Trust to become creative movement session leaders. Several schools and centres have now adapted a room in which the Touch Trust programme is provided on a daily basis and is taught by the staff. To ensure quality the partnership organisations attend sessions at the Touch Trust suite monthly and a senior session leader goes out to provide support and monitor the quality of sessions.

Being one of the seven flag ship arts organisations at WMC, the Touch Trust often runs successful four day projects in partnership with some of the other residents. The most recent project was in August 2006 and was a project led by the Welsh National Opera and several independent artists. The projects allow the guests to explore the main principles of a Touch Trust session in more detail.

At Touch Trust we believe in the importance of each of our guests feeling safe, secure and above all happy working creatively within their own personal limitations. Touch Trust praise constantly the guest for all achievements made with the belief that "where they are is right".

A Touch Trust Story

Choreographer and Musician

'When Jane first started coming to Touch Trust she was extremely introverted and appeared to be unaware of the world around her. In the early days she would often lie curled up with her head in her hands for the whole session. She was extremely frustrated and unhappy and would self harm as a way of dealing with her frustration. To begin with Jane didn't use her voice except for the sound she would shout as she hit herself; passers by would comment on the disturbing nature of the sound. Jane also did not tolerate touch at all and particularly disliked the percussion instruments and

loud sounds.

One day after several months Jane began to move her fingers gently in time to the music. I began to mirror these gentle movements; Jane then offered me her hands and we did a very delicate finger dance together. As we danced together with our fingers Jane gradually began to uncurl her body and she lifted her head. The expression on her face was one of pure innocence and awe of the space around her, like a new born baby opening her eyes for the first time.'

Jane has made huge progress over the last year, and has developed this gentle finger dance in to a whole body dance; she has become the choreographer. Jane is now able to listen to a piece of music and choreograph movement phrases and motifs with appropriate dynamic qualities to compliment or contrast the musical accompaniment. She is now also able to recognise the phrasing in the music. If the melody is repeated several times in the accompaniment Jane is aware of this and uses repetition of movement phrases and motifs each time the melody recurs. If there is a slight musical variation she repeats her motif or phrase of movement and develops it in relation to the music variation.

Jane is the leader in the session. As she choreographs the movement her support staff and I follow her lead and she is the composer of a group composition selecting and refining movements. Jane has really enjoyed choreographing for a group and gets a huge amount of satisfaction when we mirror her movements back to her. She now fills the room with laughter and beautiful sounds with her voice.

When Jane first started with touch Trust she found it difficult to tolerate loud sounds, especially the percussive sounds. She is now beginning to explore these sounds with confidence. As part of her choreography she is beginning to introduce sound. As she is dancing, if the dynamics become quicker and more powerful she uses the drum and beats it strongly and also uses her voice and sings low strong alto tones. The group mirror these sounds back in a question and answer response and Jane often gets louder and more powerful as the musical accompaniment builds to a crescendo and climax.

In August 2006 Jane attended the Touch Trust summer school which was a project that was led by Welsh National Opera and several independent artists. The project was based on the Greek myth The Odyssey and the central themes were explored through the art of movement. During this week Jane was able to work with several professional musicians and this enabled her to grow in confidence. She really explored sounds she could make with her voice: beautiful low alto sounds which she sustained until they trailed off in to the distance and sweet soft melodic sounds.

During the project Jane sang as the violinist played. It became apparent that Jane was able to change the tone of her voice to complement the tones of the violin. Jane is building in confidence and becoming so aware of movement and sound, selecting and refining to create beautiful compositions and choreographies.

At Touch Trust Jane has been given the opportunity to explore sound and movement in a positive environment. With encouragement, praise and a feeling of self worth Jane has blossomed. This is reflected in her personality she is now more comfortable with herself and able to interact positively in a social environment. Jane's smile lights up the room and her beautiful sounds enliven us all.

Touch Trust

Touch Trust is a pioneering charity that was established by its Founder, Dilys Price in August 1997 in response to the need for touch-based, creative and educational movement opportunities for people with profound and multiple disabilities.

You can find out more by logging on to www.touchtrust.co.uk/

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Challenging Perceptions

Brinda Crishna

(Brinda is a social development consultant who has worked with people with multiple disabilities in centre based and rural settings in India and internationally. She has a particular interest in the wider issues of development of marginalised communities. Currently she is the director of the International Deaf Children's Society, India (IDCS-India) working in partnership with existing non-government organisations (NGOs) to develop programmes for the empowerment of families of deaf children through providing information and encouraging the development of parent groups. In this article she shares some very personal reflections of the ways in which her own perceptions have changed over the years as a result of her experiences.)

Only the brave dare to think upon the grey –
Upon the things which cannot be explained easily,
Upon the things which often engender mistakes,
Upon the things whose cause cannot be understood

Upon the things we must accept and live with.
And therefore only the brave dare to look upon
difference without flinching

(Richard. H. Hungerford)

On a visit to a village in India, where we were shooting a film on the attitudes of communities in rural areas to people with learning disabilities, we were told by the disability NGO community worker that there was a widow we needed to meet, who had three adult 'mentally retarded' sons. While walking to the widow's home my colleagues and I discussed how difficult it must be to have three sons with learning disabilities, how we were sure we would have to treat the mother with a great deal of gentleness and not show how sorry we felt for her, how we shouldn't show any negative behaviour as we were sure the home would be unkempt and the widow sorry and sad.

We arrived at a semi pukka home, with a well tended garden, the cow shed clean and cow pats (which are used for fuel) drying in the sun, fire wood stored neatly in piles and a well with a hand pump to draw water. 'Are you sure this is the house?' we asked our community worker. He assured us it was and called the mother. A neatly dressed woman, smiling, came out to greet us. She was dressed in pale yellow sari and seemed very pleased to see us. With traditional Indian hospitality she gave us tea and was then ready to talk to us.

'I believe you have three boys', I said. 'Yes', she said, 'grown up now and the eldest will be ready to marry soon'. 'What do they do?' I asked, 'Like everyone else here they work on the land. Since my husband's death they have been the ones who have looked after all the heavy work on the farm. I am greatly blessed as they work hard and I only have to take care of the cooking and seeing about how the money needs to be managed'. We asked

to meet her sons, feeling quite sure that we had come to the wrong home. Her three sons came in with two of them supporting the third and helping him to walk. They must have been in their twenties, the one being supported obviously the youngest. They obviously had learning disabilities, the youngest having the most severe and the eldest the mildest. Before we could say anything she got up and helped her sons to seat their youngest brother in a chair which had wooden wheels attached to it and two arms.

'We are a very blessed family', she said. 'My sons are a little simple, in the way they understand things, but this is a real blessing for me. Many of the other mothers envy me because I have all three sons with me. No one is running away to the city because they think farming is beneath them. My boys are very happy to work in our fields and have been very well trained by their father. The youngest one has weak legs, so he is not able to go into the field, but sits in his chair and makes cow pats all day. He never complains!' On a visit some years later, I met the same mother who now had a daughter-in-law; the eldest son had been married, and since the daughter in law was literate, she had taken over the managing of the accounts.

As a professional who has worked in the disability sector in many parts of the developing world my greatest challenge has been in constantly having to challenge my own levels of understanding and accept, as a reality, truths which I cannot even comprehend as my baseline of understanding has not experienced them. As I have grown older and my years of 'experience' of gaining 'knowledge and expertise' have increased, the more convinced I am of how little I really do know, how quickly the professional in me jumps to conclusions and makes value judgements of good and bad practice, how easily one falls prey to feelings of superiority because one feels that we have so many answers.

Definitions of who 'people with learning disabilities' are, of what they can do or should do, of assessment schedules that define whether a

person has mild or moderate or profound learning difficulties, of what a person must learn and not learn, abound in my country. We have special programmes in special schools, in integrated setups with support teaching, in vocational training set-ups; the list is endless. Much has been imbibed and copied from western cultures, from the developed world, where many of our professionals are trained and training models and curriculum have been shaped.

A time has come, however, that we who practise in our own developing countries, we need to look at strategies for making a qualitative difference in the lives of people who have learning disabilities by recognising that many of the solutions are within our own cultures. Solutions to learning need to be culturally appropriate and in context with where the person lives. As an example, take a village in India where the majority of people live as traditional farmers, where levels of literacy are low, where many children don't go to school because they work in the fields with their families who teach them traditional agricultural practices. Why should the child with learning disabilities be any different; is the child really disabled, or do we make the child disabled because of our knowledge that tells us that the child needs to learn functional academics to survive, and really do we need to set up a special school ?

I visited a young boy of about 14, in Bhaktapur in Nepal, who was profoundly multiply disabled and lived in a one room apartment with his parents and two siblings. He had no sitting balance so when at home lay on his bed. Bhaktapur has maintained its traditional homes, which are tiny rooms one on top of the other and narrow stairs that lead through these rooms. Each room often houses an entire family of five to six people. These dwellings are ancient and cannot be modernised as Bhaktapur is being preserved as a world heritage site.

The family in question were very poor and the parents worked as daily labourers. The two non disabled children went to a local free school and were away for most of the day. Who would then care for the disabled child? The community had come up with a solution. They had erected a pulley outside the window with a seat made of old canvas and cloth. The boy was lowered down to the street using this pulley and placed in an old wheelchair and tied to it with an old sari (since the cloth was soft it would not cut him). He was then wheeled to a nearby tea shop and placed on one side of the open shack. The tea stall owner and local people kept a watch over him. Since the family belonged to the community and everyone knew each other anyway, someone would constantly be chatting with him, or feeding him something. The tea stall owner said he loved to 'talk' to people and would

smile and make sounds. The siblings normally returned from school before the parents and the brother would take him for a walk while the sister went ahead to make the evening meal. Once the parents returned the boy would be put back into the pulley and taken up to his home, when the mother would clean and feed him and put him to bed. 'What about when it rains or gets really cold?', I asked. 'We keep the wheelchair near the fire so he stays warm and dry. He's a good watchman. He makes a big noise when he sees the cat coming to steal the milk, or if it's going to rain!' they replied.

How many rules of 'special education', 'child care', 'child protection' and 'good practice' as we understand it, has this solution broken?

A review study was conducted of Community Based Rehabilitation (CBR) services which had been initiated by a well established NGO to cover all the districts of West Bengal. Many aspects of the results were unexpected and challenged many set ideas. Many of the professionals in the organisation believed that children with profound multiple disabilities were isolated and left very much to themselves. However the review showed that out of the 438 families who were interviewed, the majority took their children with them wherever they went and some even sounded surprised that we should have asked such a question. Many families did not consider going to school a priority for their child with a disability, not because the children had disabilities, but because the other children in the families did not go to school either.

How does one conclude an article of this nature? Probably by reflecting on the need to redefine our roles as professionals and look on ourselves as facilitators who have an inherent belief within ourselves that 'beneficiaries of projects' have the ability to analyse their own lives and make decisions about it themselves (Crishna 99).

'The process will succeed if the persons facilitating that process have a genuine faith in the capacity of the people they are serving to bring about change in their own condition. Such a belief is infectious and inspires people to achieve more than they thought they were capable of doing', (O'Toole, 1996).

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For the references please see page 41.

Engaging People with Profound and Multiple Learning Disabilities in Sporting Activities, SOMA – Sporting Opportunities for Motor Activities

Eileen Ramsay

Eileen is an OT Technical Instructor 1, Leisure Officer with NHS Tayside. She is currently on secondment to PAMIS, working two days a week as a Leisure Officer on the Healthy Lifestyles Project.

PAMIS is a voluntary organisation and a registered charity based in Scotland working in partnership with people with profound and multiple learning disabilities, their families and professionals.

There is wide agreement that leisure has the potential to improve a person’s health and wellbeing, as well as providing enjoyment. For people with learning disabilities participation in community leisure can lead not only to social inclusion but also improve fitness and overall physical well-being (Hogg, 1995; Lacioni & O’Reilly, 1998; Lambe & Hogg, 2000). This is certainly the case for people with profound and multiple learning disabilities (PMLD), for whom involvement in suitably designed sports activities can have a huge impact on their quality of life.

PAMIS has secured funding from the ‘Big Lottery Fund’, together with matched funding from a number of local authorities across Scotland to run a Healthy Lifestyles Project over the next three years for families and carers of people with PMLD. This will be achieved through holding training workshops on health-related issues and the development of leisure opportunities in the community aimed at encouraging activity and exercise. SOMA, which is the focus of this article, is an integral part of this Healthy Lifestyles Project.

The article describes the development of SOMA by *PAMIS* in conjunction with Special Olympics International & Great Britain in the Tayside area. It includes the health benefits derived from

participation in the SOMA project along with an illustrated case study.

What is SOMA?

Sporting Opportunities for Motor Activities

The word SOMA comes from the Greek meaning ‘body’. This is a very apt description for this new Motor Activities Programme that has been especially devised for people with PMLD

What are Motor Activities?

Special Olympics International set up a Motor Activity Training Programme (MATP) in 1997 to allow individuals with severe learning disabilities to acquire the necessary skills to participate in Official Special Olympic Sports.

A set of activities were devised to simulate different Special Olympic sporting events. Within these activities there is a motor skill teaching sequence as well as fun activities (see Figure 1 below). Each participant is given an individualised programme that is age appropriate, tailored to develop their skills and to help them reach their full potential. Adapted equipment is used to facilitate participation in the motor activities.

Required Skills	Leading to	Sporting Event
Mobility	→	Gymnastics
Dexterity	→	Athletics
Striking	→	Softball
Kicking	→	Football
Manual & Electric Wheelchair	→	Athletics

SOMA Training Activities

PAMIS has adapted, from the MATP programme, a selection of activities that are appropriate to the needs of individuals whom we work with and that can be carried out within the constraints of equipment and facilities. This has resulted in a smaller focused programme of activities but one that is showing remarkable results since its implementation. The main activities of this programme are described below:

Mobility

- Log Roll
Roll from stomach to back and return
- **Wide Beam & Bench**
Rise to standing position from gym bench with or without support and return back to sitting position.
Move along the bench in a seated – sliding motion with support.

● **Dexterity & Fine Motor Skills**

- **Bean Bag Lift**
grasp, move and release bean bag into a target
- **Ball Lift**
grasp, move and release a ball
- **Ball Push**
- Touch, move and push a ball towards a target



Ten Pin Bowling

- **Ten Pin Bowling**
- Push a bowling ball down a ramp and knock down skittles

Striking & Kicking

- Ball Strike
Swing arm and strike ball off a tee using hand or bat
- **Ball Kick**
Touch, push or kick a ball forward with foot

Wheelchair Control – Manual & Powered

- Wheelchair Slalom
Self propel the wheelchair forward without assistance for 1 metre.
Self propel the wheelchair forward without assistance for 5 metres.
Negotiate the wheelchair through cones

Each activity is offered at three levels of achievement. The levels refer to the type of assistance required by an athlete to allow him/her to participate in their chosen event(s) to the best of

their ability.

- Level 1** – prompts, physical, verbal and or other assistance is required
- Level 2** – verbal assistance only is required
- Level 3** – the athlete participates independently

Benefits for the Athletes

There are potentially a number of benefits for the athletes who engage in these actions and some of them are listed below:

- Promotes improvement in co-ordination and body control
- Increases sensory awareness
- Develops physical fitness
- Increases muscle usage
- Body weight development
- Vitamin D production (outdoor activities)
- Improves mental & emotional well-being
- Enhances self awareness and being part of a group
- Provides opportunities for integration of people with PMLD in community based facilities

SOMA Club

PAMIS, working in partnership with Dundee City Council Disability Sports Team set up The SOMA Club in Dundee, which meets on a monthly basis. This club has now been running for over a year and has been growing in popularity. At present 15-20 athletes participate in each session with families travelling across Scotland to attend. All developments by the athletes are very closely monitored and a record is kept from each training session charting these improvements. The club is organised and run by the author Eileen Ramsay, and Joyce Carle a woman with physical disabilities who is a volunteer at PAMIS.

Athlete Case Study - Graeme

Graeme is a 26 year old man with PMLD who lives at home with his mother in Dundee. He attends a day resource centre five days a week. From the outset Graeme enjoyed the monthly SOMA training sessions at the Club which were supplemented by twice a week practice sessions at his day resource centre.

Over the year Graeme has been training there has been a steady improvement of his fine motor skills. At the beginning of his training programme Graeme attended the Special Olympic Great Britain Summer Games in Glasgow, competing in the following events: Bean Bag Lift, Wheelchair Propel, Ball Kick all at Level 1. At the Scottish Championships a year later, Graeme competed in the same events but at Level 3.

Bean Bag Lift

A year ago Graeme was unable to grasp and pick up the bean bag with his right hand, needing hand over hand help from his coach to achieve the grasping and lifting motion. Graeme can now grasp and lift the bean bag without assistance, only a verbal command. He can place the bean bag in a basket using either hand, and can even pass the bean bag from one hand to another. We are now working on developing the same skill level in his left hand.



Striking & Kicking

Graeme was able to kick the ball a very short distance when the training sessions started, with assistance from the coaching staff. He now has the ability to kick the ball 5 metres. Graeme has developed his ball skills using either a giant football or a small ball mounted on a pedestal and has developed his skills such that he can play a goal game with other more able bodied athletes.



Wheel Chair Propel

Graeme had been encouraged to propel his wheelchair round the resource centre he attends. Coaches and staff have been working with Graeme on a hand over hand wheelchair propel development. This skill is built up slowly, with the athlete starting to move the wheelchair over short distances. After six months' training Graeme was able to compete at the Summer Special Olympic Games in Glasgow. Today Graeme's skills have developed to Level 3 – Wheelchair slalom 5 metre propel.



Graeme is now able to propel himself round his home and resource centre. His seated posture, speech and health and wellbeing are all much improved. Graeme's improvement in developing other skills due to the motor activity training sessions is very apparent and he is now taking a more active role in all aspects of his life.

Future Plans

Due to lots of encouragement and practice all the athletes who have been attending the SOMA Club have been able to develop other new skills through the medium of sport. Many of these athletes have developed new skills far beyond the expectations of parents, carers, coaches and staff.

The SOMA Club has had a tremendous effect on all the athletes who come along on a monthly basis to the training sessions, with improvements in their motor skills becoming apparent with every training session they attend. The local resource centres and schools are now eager to reinforce this training within their daytime routine.

The SOMA Club in Dundee was a pilot and due to its unqualified success we are making plans to set up similar clubs across Scotland where we are implementing the Healthy Lifestyles Project. Development Workers involved in this project are just finishing their training and new clubs are expected to open in the very near future.

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Lambe, L. and Hogg, H. (2000) Creative Arts and People with profound and multiple Learning Disabilities: Education, therapy and leisure. London: Pavilion.

Special Olympics (1997) Motor activities Training Program: Special Olympic Sports Skills Program. Washington: Special Olympics International.

Direct Payments

Linda Campbell

(Linda's article is based on her experience as a Development Worker for Learning Disability with Direct Payments Scotland on an 18 month pilot project in Stirling and South Lanarkshire, giving information and practical help for people with learning disabilities about accessing direct payments. She also coordinates 'Hear Here' a self advocacy and community involvement group and 'Voice Glasgow', a group which looks at the services of Enable Scotland in Glasgow.)

On 1 June 2003, it became a duty for local authorities in Scotland to offer Direct Payments to disabled people who had been assessed as requiring community care services including people with learning disabilities, parents of disabled children, attorneys and guardians (Community Care (Direct Payments) (Scotland) Regulations 2003).

Direct Payments are made by the social work department following a Community Care Assessment (or Children's Assessment for a disabled child). The payment is made so that the person can organise and pay for their own services, instead of the local authority providing services.

If done properly, Direct Payments provide an individual with flexibility, choice and control over how their services are provided. If the authority is prepared to give an individual the freedom to make decisions about the use of the direct payment without imposing too many rules, the benefits can be huge. The attitude of the local authority is crucial as, potentially, they can limit how much a direct payment recipient can adapt and tailor services.

Direct Payments allow people to manage their own support needs. Individuals can choose to have a direct payment for all their needs or have one as part of their package along with directly provided services. If an individual has a fluctuating condition and requires a greater amount of support at short notice, Direct Payments may allow them the flexibility to meet this need.

Direct Payments can support independent living and can enable people to lead fuller lives in the community. For example, Direct Payments could be used to pay for support to go out during evenings or weekends when mainstream services are usually more difficult to get. They can also be used to help support people back into work or education, or to pursue their own interests.

Support to manage direct payments

People may need different sorts of support to manage their direct payment at different times, and

there is no set model. Support can come from one, or a combination, of family members, friends, independent advocates, user-led support organisations, circles of support or independent living trusts.

They can ask third parties to undertake some, or indeed all, of the management of their direct payment. The two main things to manage in a direct payment are looking after money from the Social Work Department and making sure it is spent on support that meets a person's assessed needs.

It is crucial that people are supported to choose if a direct payment is the best option to meet their assessed community care needs and that they are given the right support on how to manage their direct payments.

Consent Issues

People with learning difficulties have had difficulty accessing Direct Payments because they have been judged as unable to consent to them. Changes to legislation in Scotland have clarified the issue around consent to direct payments:

- The Adults with Incapacity (Scotland) Act 2000, allows greater autonomy in the decision making process for people with learning difficulties and mental health problems.
- The Community Care and Health (Scotland) Act 2002 makes it a duty for local authorities to offer Direct Payments to all eligible people who can manage the payments either alone or with assistance.

Supported decision making plays a major role in helping people with learning difficulties and mental health problems both to consent to and manage direct payments.

Values Into Action (VIA), has done a lot of work in this area and has produced numerous publications detailing case studies which practitioners can use

to explore issues in more depth. The evidence clearly shows that with the right level of support in place the benefits for people of accessing individualised support packages are significant.

“All people with learning difficulties have preferences, no matter what their level of disability. Questions about an individual’s capacity to consent to a course of action should not be confused with their capacity to make choices about their life, who supports them, the people they like to be with and the things they like to do.”

Safeguarding is important so that people who might be regarded as being vulnerable are not exposed to risk from abuse and control does not slip to third parties.”

Andrew’s story

Andrew began having epileptic seizures when he was four and by the time he was nine years old, he was diagnosed as having complex uncontrolled epilepsy and severe learning difficulties. A range of anti-convulsant medications were explored, most of which showed little improvement. In fact many had numerous ugly side effects.

When Andrew was 17 years old he needed more independence as a young adult and what about his parents? They heard about Direct Payments. This meant you could choose your own staff (or agency) and have them work for you when it suited best. You controlled the budget.....this seemed a good arrangement!

They started off with a smallish Direct Payment and sourced staff who were already working in the local play project as Andrew knew all of them. It worked well.

When Andrew was due to leave special school his parents decided to apply for Direct Payments which would incorporate a full week service. It was a big undertaking, getting it all set up in the initial stage – designing a programme of activities which Andrew would do each day and thinking about evenings out, occasional week-ends, holiday cover and, of course, socialising with his peers.

It’s now a year since Andrew left special school and he is happy. He has six part time staff who work with him and they are male and female, different ages and have a variety of hobbies and interests. His lifestyle has changed significantlythanks to Direct Payments.

Case Study 2

Joanna is a young girl who has a learning disability, a degree of physical impairment and also

has epilepsy. Her mother used to be her only carer. However Joanna had no social interaction with other people and the fear was that she would become socially isolated. She enjoys solitary pursuits such as jigsaws, working on the computer and watching TV. Having her mother as her only carer meant that she did not get out very often.

The local learning disability team told Joanna and her mother about Direct Payments. They were initially anxious about the paperwork involved, but with help from local support organizations, Joanna has received a Direct Payment for two years now and it has worked out well. Her mother oversees most of the paperwork, payments and keeps the rotas under control.

Joanna’s direct payment is used to employ four Personal Assistants (Pas) privately, which has allowed her to be more independent and mobile. She no longer relies on her mother for transport into town and being able to go out without her has made Joanna more self-reliant and helped her to overcome problems associating with strangers. With help from PAs she is able to pursue hobbies even when her mother is busy, and she enjoys having the company of different people. Her mother also feels the pressure on them both has been relieved.

Case Study 3

Matthew is a 7 year old boy who has profound classic autism. He has associated learning difficulties due to hyper-sensitivities, poor communication skills, poor concentration level, etc. He requires constant supervision and support to ensure his personal safety.

His parents accessed a direct payment for him. Matthew has three PAs. His mother also buys short breaks from a local council-subsidised provider, and occasionally purchases support from Matthew’s after school club bank staff when Matthew’s staff are unavailable.

PA disclosures have been processed through the Scottish Personal Assistant Employers Network (SPAEN) as there is no local support organisation in place to undertake this. Assistance with staff payroll is provided by a local accountancy agency.

Matthew’s mother received informal support from other people who manage direct payments and found this to be very helpful. Matthew’s direct payment is working well without further support.

Matthew could not attend his local after school club and school holiday play scheme without support. He previously attended a special play scheme, but it was not suited to his needs. He now thrives in

the local mainstream club, attending twice weekly and in school holidays and he enjoys a wide range of activities with his peers. He is supported by a 16 year old PA. Because of her age she fits in well (just like another kid!) and does not spoil the group dynamic and especially the way that the other children behave towards Matthew.

Matthew has a male PA who visits once a week in the evening and once a month at the weekend. Sometimes they go to a sports club or swimming, but often they stay at home and play. They enjoy art activities and playing computer games. In the summer they go rambling in the woods or go on bike rides. Every fourth weekend they go to Saturday Club together.

Matthew also has a "granny PA". His own grandparents are not able to spend time with him and having someone of the older generation working with him has helped him see a different side of life. He enjoys baking cakes, reading stories and watching cartoons. In the summer they go for gentle walks or go to the park.

Matthew has a well-balanced, interesting life with some extra friends around him now that he did not have before. He enjoys activities without his parents always having to be in the background.

Before Direct Payments Matthew's parents did everything for him, or relied on family to help when they needed support for Matthew. As he got older it became increasingly hard to keep asking his aunts and uncles who all have their own children and even grandchildren. His parents felt this was not normal or indeed healthy for a 7 year old boy and also not beneficial for them to maintain a healthy parent-child relationship.

Matthew's mother had no anxieties about Direct Payments because she knew that if it didn't work she had at least tried it. Prior to Direct Payments they were not receiving any social work support services and so there was nothing to lose from trying it out. As Matthew gets older he will require an increase in support so his assessment has this longer term vision.

Matthew's mother commented, "I am glad that I have started small with Direct Payments as I now know that I can manage it. It has had a very positive impact on Matthew's life and on ours."

She hopes that, as Matthew gets older, and moves into adulthood, they will be able to expand his

Direct Payments and combine it with Independent Living Fund (ILF) to facilitate a stimulating and active adult life with all the support he may require.

Care Managers, social workers and support staff should have a positive attitude towards the benefits of Direct Payments and actively identify people with learning disabilities who should have greater choice in the services they receive.

Local authorities should be sure that they promote, and put into operation, their duty to provide Direct Payments by identifying, ring-fencing and advertising budgets, promoting success stories and reassuring family carers that support and funding will be on-going.

Further information

'An Easy Guide to Direct Payments in Scotland' produced by the Scottish Consortium for Learning Disability.

www.dpscotland.org.uk

www.ncil.org.uk

The Community Care, Services for Carers and Children's Services (Direct Payments) (England) Regulations 2003

www.dh.gov.uk/PolicyAndGuidance/OrganisationPolicy/FinanceAndPlanning/DirectPayments/fs/en

The Carers (Services) and Direct Payments Regulations (Northern Ireland) 2003

www.uk-legislation.hmso.gov.uk/sr/sr2003/20030226.htm

The Community Care (Direct Payments) (Scotland) Amendment Regulations 2005 www.opsi.gov.uk/legislation/scotland/ssi2005/ssi_20050114_en.pdf

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www.wales.nhs.uk/documents/direct-payment-policy-e-merge.pdf

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SMILE: a new service development for people with Profound and Multiple Learning Disabilities

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Background

People with profound and multiple learning disabilities (PMLD) constitute a diverse group of individuals, who have many varied and complex needs. Debate continues about terminology and definitions so, in order for readers to be clear who this new service is for, it is necessary to define briefly what is meant by the term PMLD. PMLD has been defined in a variety of ways. It has been referred to in relation to normative development in adults as those with a 'mental age of below three years' (ICD 10). Others have defined it as a 'degree of learning difficulty so severe that they are functioning at a developmental level of two years or less, in practice often well under a year' (Ware, 2003). Whilst the widest definition of PMLD (ie, those functioning below 3 years) was used when setting up the service, in practice the majority of individuals functioned well below one year with regard to their social and cognitive skills.

Historically people with profound learning disabilities have tended to receive fewer services than those with severe learning disabilities (Raynes, 1980). Regrettably, even more recent studies show that this is still true for people with PMLD: they are less engaged (Rose et al, 1993) and experience a lower quality of life (Perry & Felce, 1994). In studies within schools, Ware (2003) reported that students with PMLD had fewer opportunities for interaction generally, and even fewer chances to participate in those interactions.

There has also been a view that people with such difficulties are incapable of learning (ie, ineducable) and developing. Therefore people were often not given appropriate opportunities to learn and develop their skills. There have been tendencies to both under (O'Brien & Tyne, 1981) and over estimate (Bartlett & Bunning, 1997) the abilities of this group of people. As a result inappropriate opportunities were frequently offered to them. However, recent studies show that people with profound learning disabilities can learn, as long as they receive the right support and in the right environment.

A responsive environment is a key factor in a child's development. Ware (2003) discusses several studies that demonstrate that children with PMLD tended to receive fewer responses to their communication attempts and were less likely to be active participants in communication. It seems almost too obvious to state, but the need for a responsive environment for people with PMLD

(namely getting a response to your communications, being given time to respond, being given an opportunity to lead and take turns; Ware, 2003) cannot be underestimated.

Local context

Following a period of significant change within North Cherwell day services, a review was undertaken in 2001 to look at what impact these changes had made on service users and their families. One of the key areas identified as requiring further development was to improve support for people with profound and multiple learning disabilities. As a result, in 2002 a small group of day service staff in conjunction with a clinical psychologist set up a working group to consider how people with the most profound disabilities were currently being supported, how their needs were being met and how this might be improved. The level of funding that individuals received was also considered, as this would be an indicator of how much one to one time was available for each person. Visits to other day services helped the group to gain experience from what others had done and provided a basis upon which to develop our own service.

A small staff survey was completed that looked at staff's understanding of PMLD. It aimed to identify training needs within the team that would be supporting these individuals. Considerable work had been done within the service advocating a developmental perspective in understanding individuals' functional abilities. Probably as a result

of this work, staff had more realistic ideas about people with PMLD abilities than a previous group of staff working in residential settings (Pratt, 2000), where there was a consistent over-estimation of individuals' abilities.

Intensive interaction (Nind & Hewitt, 2000) as an approach had already been successfully implemented within the day service for a small number of service users. As a result there was more enthusiasm for how to further support these individuals and others in a developmentally appropriate way.

SMILE

As a result of this work, SMILE (Sensory, Musical, Interactive Learning Experience) was set up in June 2003 as a pilot project. One of the first questions to answer was - Who should be included in the new service? To answer this, we used developmental assessments that the clinical psychologist had already carried out, and day service staff's knowledge of service users to ensure that only people with profound learning disabilities (using the broadest definition) were included. Clearly it would have been inappropriate to include individuals with profound physical difficulties but whose intellectual functioning was not within this range. Obviously, even within the broadest definition of PMLD, there is a wide range of abilities. In reality the majority of people who attended were functioning well below a 1-year level. In total 29 different individuals attended a SMILE session, a few people attending more than once.

Based on this information people were loosely divided into groups. For example, one of the groups comprised individuals who were able to sign and who had some limited spoken language. Consideration was also given to the sort of environment that individuals might prefer, eg, noisier vs quiet groups, and also if there were any known acquaintances or adversaries. As the groups have developed, the configurations have been reviewed regularly and altered as necessary.

SMILE is based within the day service. It has its own room with all its equipment available there. A project leader (with knowledge and expertise in working with this group of people) was allocated ring-fenced time to set up and develop the group. Some limited finances (a few hundred pounds) were made available in order to purchase necessary equipment.

Whilst SMILE is based within a day centre, it was set up to be a resource for all people with PMLD who live in the local area. Not all of these people would have routinely come to the day centre, as their daytime occupation was provided from home.

We made an agreement with the provider of these services that those individuals could access SMILE, with support from a member of their own staff team. Each group is a mixture of people, some who use the day services generally, and some who do not. Where possible the same staff members support people at SMILE in an attempt to ensure consistency. All service users attending come with their own member of support staff. This was a pre-requisite as appropriate one to one support is such a necessary part of developing basic communication skills with this group of people.

Aims of SMILE

Put very simply SMILE aims to provide:

A venue for interaction / communication through the use of sensory stimulation using smell, touch, taste, sound and sight. This will involve intensive interaction, taking turns, sharing, waiting, listening, and making choices.

Its objectives include:

- To develop sociability and fundamental communication abilities
- To develop emotional well-being
- To develop cognitive abilities eg, cause and effect
- To teach ways of spending time other than in self-involvement / ritualistic behaviour
- To have fun!

The sessions initially occurred every morning (five sessions per week). However, we have now included two afternoon sessions. A different scent represents each day of the week - orange, mint, lemon, lavender and vanilla. Each session is about 2 hours long. The groups vary in size between 4-6 service users. There is a worker who takes responsibility for leading the group, although they are also supporting an individual. Historically this has been a member of staff from within the day service. Over time the skills of a wide range of day service staff have developed and other staff members now take the lead.

In some of the sessions, other people with learning difficulties who use the service assist the groups. This helps to build links with the rest of the centre and promotes more of a sense of being included in the whole service.

Content of sessions

Having a dedicated room within the day service in effect acts as a cue for people: they associate the SMILE activities with that area of the building and know what is about to happen. Just before the group starts the same song is played, again to help cue people into what is about to happen.

Each session follows a similar structure:

Good morning song

Everyone is welcomed to the group with a 'good morning' song that is sung and signed to each person in turn. This aims to increase eye contact, vocalisations and signing. Each time the song is sung it starts with a 'thumbs up' which is the Makaton sign for 'good' or 'good morning'.

Sensory boxes

Next, individual sensory work occurs based upon the aroma of the day. SMILE has a large range of sensory objects that are used as a medium for interacting. These include bowls of bubbles, aroma boxes of different shapes, massage creams, bubble machines and fruit of the day, textured objects etc. Principles of Intensive Interaction are incorporated. Staff are encouraged to pause and await a response that may indicate that the person wants 'more'. Making basic choices is encouraged.

Music and singing

Music and singing happens for the next 10 minutes. This encourages vocalisations and group involvement. A parachute, large velvet elastic ring or instruments are used to facilitate this part of the group. Some of these sessions include techniques from Soundabout (soundabout@freeserve.co.uk), which encourages communication through patterns of sounds and silence. Rhythmical songs are used, the rhythm and repetition often being more important than the words.

Tea and coffee

This provides a break from the activities. During this time different flavoured foods (eg, flavoured jellies and mousses, lavender cakes) and drink that correspond to the aroma of the day are offered. Individuals who have difficulty with eating / drinking are indicated on a planner on the wall in order to ensure health and safety.

Bag books

This is the final part of the session. SMILE has eight bag books altogether. These are age appropriate multisensory stories that have tactile boards that listeners can manipulate throughout the story. These boards are passed around the group as the Story is read. This encourages turn taking, sharing, waiting and anticipation, usually as the story reaches its climax.

Goodbye

Each session finishes with a goodbye song, which acts as an indicator that the session is ending.

There is one group whose communication skills are further developed. Instead of the sensory time this group has worked on various themed projects eg,

animals, colours, mosaics, cooking. In addition these activities have been extended to community trips that correspond with the relevant theme. For example, this group had a favourite song that involved a crocodile; they went on to make a paper mache crocodile and then had a trip to the wildlife park to see a real crocodile.

Progress

Group progress is difficult to evaluate. Progress is measured for each individual, depending on the particular skills that they have developed. At the end of each session support staff are asked to complete a form on the person's participation that day. New skills are noted. Reports are written annually, based upon the recording charts, and sent to people's homes and other settings. For many people progress has been a succession of very small steps indeed. For some it is responding to their name being called; for others it has been an increasing awareness of other people, putting out a hand to initiate staff contact; others may have learnt a new word or sign, or learnt to wait their turn. Making simple choices has been one of the most common progressions.

It has been vital to complete baseline assessments against which progress can be judged. Staff turnover is a frequent problem within services and, without baseline information, it is easy for new staff not to realise that the skills someone now has may not have already been there. Seeing progress has been a large motivator for staff to continue with this work. Each tiny step of progress is celebrated.

SMILE has recently been nominated for a 'project of excellence' award by Oxfordshire learning Disability NHS Trust. However our most important achievement is the progress of everyone who attends and the fun and laughter that our sessions provide.

Professional Involvement

The clinical psychologist who worked with the original working party has continued to be involved. Many developmental assessments (Vineland Adaptive Behaviour Scale) had already been completed as part of routine clinical practice; hence there was already baseline information about a person's abilities.

A speech and language therapist has also become a key support to the SMILE team. The support from both professionals has included consultancy regarding progress or difficulties that may have arisen about individual people, as well as support regarding how to 'move groups on' or what the next developmental stage might be.

A lot of teaching and training had taken place in the

service in previous years regarding a developmental model and appropriate ways to support people with PMLD. It is the first author's view that the skill level, experience and motivation of the day service staff running SMILE on a day-to-day basis has resulted in probably less input from professionals than might be required in less favourable settings.

Tackling issues

As is often the case with new services, a few issues arose during its early stages that needed to be addressed. For example, one of the effects of increasing people's communication skills can be that individuals who once requested very little from staff start to 'demand' more attention. Whilst for most people this is something to celebrate, some do see such changes negatively. Another issue is that some support staff found the repetition difficult to tolerate. Clearly the structure and repetition has been a vital part in providing an optimum learning environment for the people who attend. Support from the project leader, flexible rotas and consultations have been key in addressing this and ensuring that the needs of clients are prioritised.

The future

Staff running the group and those who support service users have continued to be inspired by the progress that people have made by being given the right support in order to learn. Many achievements are very small developmental steps; however, for the group of people that SMILE supports, they are huge achievements. The SMILE team are now looking to spread this good practice to other settings. For some people it is the first time that their individual preferences and ways of responding have been mapped out.

SMILE has become a model of good practice for how people with profound learning disabilities should be supported within day services. It is continuing to be developed throughout the county at other day services and at one college. Some service users who attend several services have begun to have SMILE-type sessions in other places, which is excellent news. Demand for consultation on how to set up such a service continues and SMILE has had a large number of visitors from services in other areas. Having had this opportunity of considering how the very complex and multiple needs of this group of people need to be met, many have subsequently expressed a wish to develop such a service. Visitors are always very welcome, but be warned, active participation is expected!

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Good Moves: A Report into Movement and Leisure Provision in Gloucestershire for Adults with Profound and Multiple Learning Disabilities

Good Moves is a leisure and movement project in Gloucestershire, started by a group of family, friends and carers whose vision is to provide physical and movement opportunities for people with profound and multiple learning disabilities. Their philosophy is based on the belief that disability should not create the exclusion of any individual and that we should try to respond to the special needs of all.

In August 2006 Good Moves launched the report of a research study into Movement and Leisure Provision for Adults with Profound and Multiple Learning Disabilities in Gloucestershire, with the support of their local MP and Mencap.

Connie Williams, mother of a 25 year old daughter with PMLD and a founding member of the group, sent a copy of the report to PMLD Link. Here we present a brief summary of the research. Details of how you can access the full report are provided at the end of the article.

Good Moves was registered as a charity in November 2003 and in December of that year was awarded a small grant from the UK National Lottery 'Awards for All' scheme to commission a piece of research that would further their aim 'to support people with profound and multiple disabilities and their carers'. They appointed Concord, consultants based in Cirencester to carry out the research on their behalf.

Prior to receiving their grant, Good Moves had recognised that there is a specific need in Gloucestershire which is not covered by existing services. Responses received following the distribution of over 700 leaflets suggested that they had indeed correctly identified this need as well as a potential user group.

It also became apparent that day services are not available throughout the entire working day. People are often home from a day centre or other service provider by 3.30pm. This can put additional pressure on working families. In many cases



day services are not available every day and rarely include evening or weekend activities. There are many people with profound and multiple learning disabilities who are not able to access day services

as there are none that can meet their individual needs. Even when such services can be accessed, they may only be available for part of the week. Leisure and movement opportunities need to be available more extensively including afternoons, evenings and possibly weekends.

The research was carried out between May and November 2004 and concentrated on ascertaining the level of provision of leisure opportunities for people with PMLD.

Methodology included:

- questionnaires to care homes in the county followed by a number of telephone interviews,
- face-to-face and telephone interviews to collect family stories
- desktop research to identify publicly held information.

Responses from Care Homes

Key findings from the survey of local care homes indicated that:

- There is a general lack of understanding even within the care industry about PMLD – its definition and the kind of care people require
- There are good recreational facilities within Gloucestershire for some disabled users and some care homes use their local facilities very well
- There is general lack of publicity and knowledge about 'hidden' facilities
- The physical presence of some facilities does not in itself mean that those who need them can easily access them. Difficulties associated with travel, cost, staffing, waiting lists and availability can be prohibitive.
- Within care homes that provide for people with profound disabilities the researchers found strong evidence of a real lack of suitable recreational facilities within the area. The number of care homes and individuals eager to hear more about Good Moves and the possibility of increased facilities confirms this view.

Interviews with families

Interviews with families identified a number of key issues, including the following:

- Services that are available may be neither accessible nor suitable
- The limited provision beyond 19 years of age is a major concern for families. Whilst residential services are being developed, day services are less of a priority. Of great importance to families is the need for skilled staff to support people to access activities on an individual, flexible basis.
- Anecdotal evidence suggests that finding some respite is a problem for many families
- The provision of accessible toilet facilities often makes the difference between going out or not. Staffing, transport, cost, opening times and equipment are relevant issues but none is worth discussing if the toilet facilities deny access
- The amount of time and financial commitments that family members make to support people with learning disabilities to enjoy a varied life is invaluable. However, the need for fully staffed activities was a common issue for families with local opportunities for physical activity being difficult to find. It was felt that there is a need for family carers to get together whilst their family member was having fun in a safe environment.

In his foreword to the report, David Drew, MP for Stroud writes:

'There remains a stark shortage of appropriate facilities for those adults with profound and multiple learning disabilities in the county and further afield. I congratulate Good Moves on taking the initiative to start to try and bridge that gap.'

This report demonstrates the depth of those needs and explains how the provision of leisure and movement facilities can open up opportunities for those with disabilities and their carers alike.

I congratulate all those who, by their hard work, have driven this campaign forward, compiling this report with its crucial data. This has been driven out of necessity. There is a cry for action.

I am pleased to be associated with this and I hope that others will get behind it and start to help those who are amongst the most vulnerable in our society and deserving of all that Good Moves want to provide.'

The launch of the report was followed by an afternoon of fun and activities attended by over 160 visitors, some of whom had come from as far afield as Weston Super Mare, Bath and Hereford.

In her description of the afternoon's events, Connie Williams tells us:



'Thanks to our activity groups the atmosphere swung into gear in no time at all. Photographs were taken as well as some film and we plan to create some DVDs that will show just how positive an experience it can be to see people of such a wide range of abilities having a great time together, exactly what we were aiming for – and just what Good Moves would like to develop on a permanent basis. The feedback we have received, both on the day and since, is almost 100% encouraging and positive.'

'...We need your support in raising awareness of the needs of these most vulnerable adults in our society and we need to acknowledge the burden that is carried by all those who give care to them.'

During the afternoon participants were invited to place their comments and wishes on a wish tree and did so with great enthusiasm. Here is a flavour of what they said:

'Brilliant – do it again'

'I wish aeroplanes had changing facilities'

'Can there be a place for people who don't like noise - and no balloons?'

'Love to access one hour of Soundbeam. If there are several other people we could make it work for all'

'I really enjoyed it and I had a nice cup of tea'

'Freedom through music'

'Really lovely launch – I liked serious fun and cup of tea'

Contact details

You can access the full report at the Good Moves website www.good-moves.org.uk/

email: admin@good-moves.org.uk

Future Focus: Adult Years

By
Di Foxwell

This is now my second opportunity as a guest editor for **PMLD Link** and I am really looking forward to putting together the material for this next edition due out in Spring 2007. We hear quite a lot about children – yet the adult years span many, many more decades, and cover a wider range of life events. These life events may be the results of life pathways, or events in some-one else's life close to us. How have you helped adults cope with these events at both an individual level and a service level – please write in if you have a good example you would like to share with others.

I currently work for the NHS and have witnessed at first hand some of the current financial problems occurring across the country. As trusts try to save money this has led to some hard decisions needing to be taken. Sometimes, decisions made can actually be to the benefits of some individuals – such as authorities looking at providing their own services for some people who have high support needs rather than continuing to fund out of area remote placements that are both isolating, difficult for families to visit, and difficult for care managers to monitor. A further benefit is also the transfer of homes from the health service to a more societal normative pattern of living. However the picture of benefit for many who have PMLD can be difficult to discern as various authorities battle to reduce expenditure. Questions are asked such as where the line is drawn between social care and health care needs, are people with PMLD able to benefit from psychotherapy? Many therapies available to you and I need staff with additional skills in order to ensure accessibility for people with PMLD - particularly in assessment and communication. Perhaps you work for such a service and have developed, or experienced a good example of such a service, in which case please write and share it with others here.

Many children who have more severe physical health problems have now begun to reach adulthood. This is challenging the adult services which are having to skill up their staff in order to cope with these additional health needs. A recent discussion on the internet showed the diverse views and needs in this area around adults who were fed by a tube as discussion ensued around experienced tastes by mouth. Of course this group of people may be able to tolerate some mouth tasting whilst for others this would be dangerous. Maybe your service has skilled up to meet these additional needs; if so we would love to hear more of your service.

Are you a dentist/dental nurse or practice nurse? We would love to hear from you about your work in helping deliver health and dental care - or perhaps you are a parent who has helped to train their local nurse/dentist/doctor in order for your son or daughter to receive a better service.

Much of the above has focused on health care for adults, yet for many of us a greater time is spent in pursuing leisure activities and friendships. Sometimes this is aided by specialist equipment and specialist groups, whilst for others it is possible to access ordinary groups/facilities with the aid of a friend or assistant. Let us know your thoughts, or activities and your service philosophies. You may be a teacher offering specialist classes or indeed a mainstream teacher who has included someone with PMLD in your class – in which case we would love to hear from you.

PMLD Link is a journal that aims to share ideas of good practice, so if you are considering writing for the first time, we are a friendly journal to 'test the water with.' If this is you, and you are feeling a bit shaky but itching to have a go, then please get in touch for additional editorial support.

I am eager to here from you.



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**PMLD Network Email Forum
(A Digest of Discussions)
August 06 - October 06**

This is an open email discussion group who focus on issues relating to PMLD.

PEG Feeding in public

A parent complained that teaching staff at her child's school had been told that children are not to be peg fed in class, as it is 'demeaning' for them. She was concerned that this is excluding her child. One suggestion from a member of the forum was that the school nurse was enlisted to make sure children were not being discriminated against. There was also the suggestion of support from PINNT, (patients on intravenous and naso-gastric nutrition therapy), a national group. www.pinnt.com The general consensus on the forum was that people should be included in the social aspects of eating and drinking and that other children should be encouraged to understand and accept their needs.

Health and social care inspectorate/ Cornwall abuse investigation

The health and social care inspectorates have serious concerns about services for people with learning disabilities. Anna Walker, (Chief executive of the health care commission), and David Behran, (Chief inspector of the commission for social care inspection), released a joint statement saying that the Cornwall investigation has highlighted unacceptable standards of care. The investigation into learning disability services in Cornwall found widespread institutional abuse of people with learning disabilities.

The foundation for people with learning disabilities said that the NHS must be held accountable for this.

The department of health gave a statement saying it was "appalled".

Simple computer software

A parent asked for suggestions of simple computer programmes for her daughter who has PMLD.

Suggestions included:

Switchit! Maker

Chooseit! Maker

Switchit! Jigsaw Maker.

These are apparently good programmes at a very basic level. They are available at Inclusive Technology, 01457 819790

Also simple one touch programmes are available free on this website:

www.priorywoods.middlesbrough.sch.uk

Changing Places

The Changing Places campaign has been launched to get fully accessible toilets, (with hoists, changing beds etc) installed in major public venues so that people with diverse needs can access their community.

To find out more and how you can help go to: www.changing-places.org

Rough Terrain Wheelchair

A parent asked if the above exists as her family lives on a farm and they want their child to be fully included in life there.

There was a suggestion of the Axiom 2 wheelchair. Further details can be found on www.foam-karve.demon.co.uk or alternatively on Amazon.

Equality 2005

This new scheme is apparently an opportunity for people with disabilities to get their views across to the government in order to further move towards equal opportunities.

It was argued on the forum however that people with PMLD are being discriminated against here. One contributor pointed out that people with PMLD do not appear to fit into the criteria for people with disabilities and also that there is no mention of advocacy support.

A parent and IT expert adds to the questions being asked about how people with PMLD can be consulted on their views, how can people be engaged in contributing to policy decisions that effect them? he asks, then suggests that we may need communication experts who can apply themselves to each individual case.

The discussion moved towards communication in general and the need for people to understand communication as flexibly as possible rather than always looking at formal systems of communication and how technology can assist.

There were suggestion of peer advocates, (more verbal people with learning disabilities), being involved as well as the inclusion of parent carer reps.

Ice breaking

A query was raised about how to “break the ice” when meeting someone with PMLD for the first time. It was emphasised that just being with someone, spending time with them without feeling you have to ‘do’ anything, is really important. If some people find that difficult another way might be to look at the person’s communication passport, (a document with lots of photos that lets you know about the person likes/dislikes, their communication and what’s important to them), with them. This doesn’t have to be on paper, it might even be in the form of a shoe box, with objects in it that you could go through with the person which represent what is important to them.

Short break services

Advice was requested on how to purpose build a new short break service. Parents whose daughter attends a service called, “Short Break House” in Sunderland, (0191 553 2214), feel that it has learnt from past mistakes and become an excellent provision, particularly in terms of its physicality. Recommendations contributed to the forum included that the service should have, room coverage hoist systems, plenty of space for wheelchairs and equipment, (though not in a way that makes it seem institutionalised and un-homely), no tight corners and low windows, light switches etc that people in wheelchairs can use.

Tac Pac boxes

There was a query as to whether Tac Pac boxes were still available and being used. It was explained that these boxes are a pack with objects and a music tape included that are relevant to a theme. For example, (a contributor gave this example of one he’s made himself), there might be a Tac Pac on the theme of pets. It would then include sensory items such as a cold metal dog chain and a music tape with different tracks on at different speeds and rhythms so that the objects can be interacted with in creative rhythms etc. It is designed to develop pre-communication skills. Apparently they can now be ordered through www.drum-talk.co.uk/tacpac.htm or on www.tacpac.co.uk

As the person above did you can make up activities with music, rhythm and song to go with the pack.

Cooking with people who are nil by mouth

There was a query from a teacher as to how to include those who are tube fed, ‘nil by mouth’ in food technology sessions. One contributor said that meaningful involvement is different for every individual. Smell, texture, observing and being included can all be really important. Friends and family should be involved in passing on knowledge about how a person enjoys experiencing things. Someone else suggested that the session could be about learning that some people do eat and some people don’t/can’t. It was also pointed out that some people may not enjoy food technology at all if they are part of the cookery and then not allowed to eat it. Another suggestion was that, (subject to clearance by the relevant health professionals), the group has taste experiences. This would be with food that melts in the mouth and doesn’t have to be swallowed, (eg: icing sugar, runny honey, ice, candy floss, mouth freshener). Then each person could have a fuller experience of food. Or the teacher could take a small piece of rice paper and put a drop of something, (like orange, oxo, coffee), on to it then insert it, (being careful of the person’s reaction and observed choice), into the inside of their cheek or under their tongue. However a parent of a child with severe aspiration problems was alarmed by the above suggestion. She points out that for her son the production of saliva is distressing as it can be aspirated. Taste may not therefore be appropriate for all. Perhaps the social aspects of eating are just as important.

The PMLD network discussion forum, (www.pmldnetwork.org), is run and maintained by the Foundation for People with Learning Disabilities 7th Floor, 83 Victoria Street, London SW1H OHW. Tel. =44(0) 20 78020301. Email: nmorris@fpd.org.uk Website www.learningdisabilities.org.uk Registered charity No: 801130 Company Registration Number: 235 0846

Reviews

Title: Early Childhood Intervention: International Perspectives, National Initiatives and Regional Practice

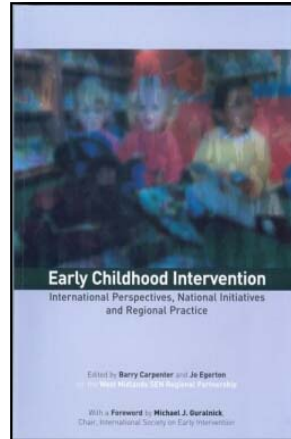
Authors: edited by Barry Carpenter and Jo Egerton

Publisher: West Midlands SEN Regional Partnership

ISBN 0-9551804-0-6

Pub Date: November 2005

Price: £15



This book is based on a series of seminars on early childhood intervention that were organised on behalf of the West Midlands Regional Special Educational Needs (SEN) Partnership by the Sunfield Professional Development Centre. The SEN Regional Partnerships in England have been charged by the Government with encouraging local authorities and other local agencies work more closely together to support children and young people with SEN. Early childhood intervention is a key theme and the message from the Government is that the needs of young children with disabilities are changing and that the old methods of meeting their needs will not achieve the best possible outcomes for them and their families. Government initiatives are forcing the creation of a new culture for inter-agency working that entails much changing of attitudes and training.

This book contains contributions by different authors based upon their presentations at the seminars which were convened by Professor Barry Carpenter. His opening chapter sets the scene quite clearly as regards important international research and national developments which are then elaborated in the succeeding chapters. A stark picture of changing family and social patterns is painted along with information about the factors that underlie an increase in the numbers of 'at risk' children; for instance, there is disturbing research about the high percentage of low-birth-weight infants surviving who have severe disabilities. The book contains several important descriptions of initiatives in England such as 'Team Around the Child' and 'Early Support'. This book does not focus upon the needs of any particular group of children but on all vulnerable children. Nevertheless, it still has great relevance to the

readership of this journal. It is a scholarly book, densely packed with research information, but the knowledge and passion of the contributors is evident.

Title: Good Practice in Physical Interventions: A Guide for Staff and Managers

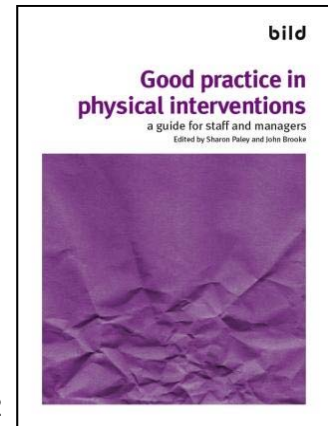
Authors: edited by Sharon Paley and John Brooke

Publisher: British Institute of Learning Disabilities

ISBN – 1-904082-74-2

Pub Date: 2006

Price: £20



The British Institute for Learning Disabilities has long been a leading body in the promotion of good practice in interventions for effective development of behavioural interventions, including physical interventions, to manage violent and aggressive behaviour. Sharon Paley, the lead editor, notes that research suggests that 50 per cent of people with challenging behaviour and learning disabilities are subject to physical interventions and that physical interventions are not without risk to both service users and staff. This book contains chapters by various professionals who provide well-informed coverage of ethical and legal matters as well as advice about good practice in relation to risk assessment and planning and recording interventions. The book also contains an insightful contribution from Ros Blackburn, an adult with autism, who had some dreadful experiences of being physically restrained by people who did not seek to understand why she was harming herself and others.

This book does not focus specifically upon physical interventions with people with PMLD. However, many of these people are subject to behaviour management strategies and, inevitably, this book is entirely relevant to professionals working with them. It is a scholarly book providing comprehensive coverage of the topic, providing references to further reading, resources and contacts, as well as much practical guidance. Given the lack of authoritative guidance from the Government, it may be regarded as an essential read for managers and practitioners in all settings.

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

Title: Children with Seizures: a guide for Parents, Teachers and other Professionals

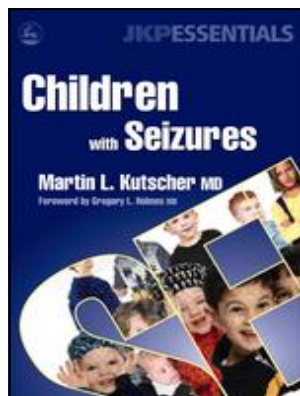
Authors: Martin L Kutscher MD
Foreword by Gregory L Holmes MD

Publisher: Jessica Kingsley Publishers

ISBN 1-84310-823-2

Pub Date: 2006

Price: £12.00



Children with Seizures is an accessible and concise introduction to epilepsy. The book provides an informative and straightforward account of epilepsy – Part 1 of the book looks at presentation, causes, diagnosis, treatments, and the management of the condition. The author addresses some of the emotional and social issues that can arise, and there are chapters designed to be read by young people themselves, or together with their parents. Part 2 looks in detail at some of the most common syndromes, using a number of short case studies, each designed to highlight different causes and presentations of epilepsy in children, and subsequent prognoses as children move towards adulthood.

Although targeted at parents, teachers and other professionals, the book would appeal to a wider readership and I would also recommend it to care workers and students of health and social care. Whilst the book would appeal to anybody interested in epilepsy, it focuses on the unique features of epilepsy in children and the practical issues associated with epilepsy in childhood.

The tone of the book is reassuring, encouraging the reader to adopt a pragmatic approach to the subject. Whilst recognising the distress that often arises for parents, epilepsy is presented as a regular occurrence for many people, similar to asthma or other conditions that may require management and possible medical intervention.

In the foreword to the book, Holmes describes and reflects upon his experience as a child where the epilepsy of a fellow pupil was managed in such a way as to imply a general air of ignorance on the part of the teacher, together with a level of secrecy, as if there was something to be ashamed of. This is not dissimilar to the experience of many of us when we first came across a person with epilepsy – thankfully, times have changed and I am hopeful that this book will go some way to dispelling the myths, and improving understanding in this area.

Maria Dowling - FE teacher, Kingston

Report Back ...

Launch of Mencap's 'Meet the People' CD at TATE Modern, London

This was a great event - not just the launch of a very valuable resource, but a celebration of the six 'stars' of the 'Meet the People' CD who, through their involvement, gave us an insight into their world.



The CD explains what it means to have profound and multiple learning disabilities (pmlD) through six short, personal stories - 'a day in the life' of Miranda, Karen, Frances, Mohammed, Francis and Jessie. We met these individuals on centre stage and shared in their pride as we watched their stories on the big screen with interest and admiration. As any other premiere, the event had a real 'showbiz' air to it with Donal MacIntyre presenting gifts to them all. Donal, an ambassador for Mencap, provides the voice over on the CD.

Keeping these people at the heart of the event, interactive storytellers Nicola Grove and Jem Dick from *The Unlimited Company* facilitated a fun story about 'Victoria's birthday', with Victoria leading the entertaining sequence of events and the rest of the audience (inclusively) joining in. Next, Keith Park 'guided us' all through some more interactive and evocative activities, that were very apt for the occasion – particularly the one about eating too much party food!

Not to lose sight of why we were there, this interactive CD, 'Meet the People' focuses on the very challenges people with pmlD face being included in society, illustrating in particular the key issues of communication and advocacy. This very valuable *free* resource has been designed to help health care, education and social work professionals among others, explain pmlD further, as it is one of the least understood forms of disability in the UK today.

For more information on 'Meet the People' and to order your free copy—call Mencap on 020 7696 6019 or visit www.mencap.org.uk

For more about Nicola or Keith's work go to www.storytracks.com/intro.html

Annie Fergusson, University of Northampton

NEWS, PUBLICATIONS AND RESOURCES

Snap!

A winning partnership

Snap! Is a Mencap photography competition based on stories by and of people with learning disabilities. The photographs are showcased at the V&A museum, (9th June-14th August, 2006, Cromwell Rd, London, SW 2RL), and winners are judged by a panel that includes high profile professional photographers as well as Mencap representatives.

There are eight categories of photos with one winner, (and several runners up), in each. Winners were recognised at a prize giving ceremony on 14th June.

This year Terry Gorczynska and Frances Clarke were winners of the 'Changing Minds' category with their entry, (taken by Terry, of Frances and her friend's baby), "Baby and me". Frances has Profound and Multiple Learning Disabilities.

The photograph was taken when Frances' advocate had been away on maternity leave and been very much missed. Frances was delightedly meeting her advocate's baby for the first time. According to Terry who took the winning photo, "Frances is a friend of mine and makes me laugh, she's such fun to be with". Terry works for the same charity as the advocate did and is a volunteer at the Gateway club Frances attends. On her reasons for taking the photo and entering it in the competition Terry comments, "I knew how important meeting her advocate's baby was to Frances and I know her well enough to know when she is looking her best and that she loves having her photo taken".

Frances seems to have communicated clearly that winning this prize and attending the prize giving has meant a great deal to her personally. Terry notes that Frances loved being the centre of attention at the ceremony, (people came up to her in recognition, there were postcards of her picture everywhere and the photograph was shown to everyone on a big screen). It also meant a lot that she could buy a new dress and bring her friend Dennis with her to the occasion.

The only downside to the event seems to be that her prize of a camera was not a digital, a shame as she cannot make her multimedia profile with an instant one.



Frances Clarke, Terry Gorczynska and Lisa Scott Lee middle

In terms of the impact of the photo and its enthusiastic recognition Terry feels the judges were affected by Frances' sheer joy in the photo. She hopes that people will learn from it that someone with PMLD can express happiness without the need for words and that people of all abilities can form close, mutually rewarding bonds with others. It is vital that people see this so more of those with PMLD are offered meaningful experiences. Terry says,

"I think Frances would want everyone to understand how important these experiences are to her and other people with profound and multiple learning disabilities, so that people would buck up their ideas and enable her to have many, many more such fun experiences, so that she can laugh like that even more!"

All about us!

Mencap's President, Lord Rix will publish his latest book - 'All about us!' on 14 November 2006. The book contains a number of moving personal stories from people with a learning disability, their families and carers as well as contributions from leading academics in the field and some of Mencap's celebrity ambassadors.



For more information on the articles above please go to www.mencap.org.uk

People With Learning Disabilities To Have Their Own Homes

Avenues, the social care provider for people with learning disabilities and mental health problems, will today launch its report, "Avenues to Challenge" which sets out the work of the Avenues to Challenge project. This was set up to look at alternatives to residential group homes for people with learning disabilities and challenging behaviour in Kent, including the opportunity to rent homes of their own with the option to buy through shared ownership.

The Avenues to Challenge project began in August 2004, funded by the Kent Learning Disability Development Fund, to look at two key areas: alternative housing options for people with a learning disability and challenging behaviour in West Kent, and supporting two people living in a residential home in West Kent to move into flats of their own. The project has worked with agencies across Kent, including social services, health and housing associations.

Caroline Fleming, Avenues' project manager, explains: "Having a home of your own is something that most of us aspire to, and many of us take for granted. But for people with a learning disability, this would have been unthinkable 20 years ago.

Thankfully, we've come a long way since then. Having a disability should not mean you can't have a home of your own; shared ownership schemes for people on low incomes make this a real possibility. This not only gives people with a disability the same rights as everyone else, it also gives them control and stability; it really puts them in the driving seat."

The completed model of support has been presented to Kent Learning Disability Strategy team; identifying 39 people who might currently benefit from the service, 200 people living outside of Kent who might be entitled to and benefit from the service and a further 200 children and young people who might benefit from the service in the future. It found that there would be no additional cost overall to agencies already providing support in a group home setting. Building is scheduled to start early 2007

Mobile Changing Suite

This Mobile Changing Suite has been developed in conjunction with IDEAS (Independent Disability Equipment Advisory Services) and 'Andy Loos'.

Here is a revolutionary new product that will dramatically alter the lives of many, enabling them "to get out and about in the community" – a term so often used, but difficult for many to do because the facilities they need do not exist.

It is a trailer that can be towed and sited virtually anywhere, only requiring an electricity supply and firm level ground. It has an overhead hoist, changing bed and toilet, with room for carers and wheelchairs. It can be bought or hired and comes with a variety of options.

Now it is available, it becomes "reasonable" under D.D.A. to provide such facilities for a whole range of people who cannot access the commonly-provided disabled toilets. Users could be the elderly infirm, adults and older children with profound disabilities, people suffering from conditions such as M.S, Motor Neurones and severe Arthritis and those with temporary disabilities due to accidents or operations. Don't forget the families, friends and carers that these folk need as well; they accompany them when "out and about".

There will be a great many people who will want to access such facilities.

The unit has been enthusiastically received at both Naidex and the Disabled Living Show in 2006. Mencap are also using it in their "changing-places" campaign to raise awareness of the current lack of provision.

This is a wonderful opportunity for a whole range of sites; shows, sporting venues, local councils, educational establishments, shopping and art centres to become genuinely accessible to all.

Andy Loos Limited

Head Office:

Brickbarns Farm

Evesham Road, Egdon

Worcestershire WR7 4QR

T: +44 (0)1905 345821

F: +44 (0)1905 345849

www.andyloos.com

www.changing-places.org

Bill launched to give families a right to a break

At the **Every Disabled Child Matters** parliamentary launch on 21 November, over 50 MPs are expected to back a new bill designed to give disabled children and their families the legal right to short break care. The **Disabled Children's Short Breaks Bill**, if it became law, would ensure a specific duty is placed on Local Authorities and the NHS to provide appropriate short break care for 100,000 families with disabled children who provide a substantial level of ongoing care.

Every Disabled Child Matters c/o Council for Disabled Children
National Children's Bureau
8 Wakley Street
London EC1V 7QE
tel +44 (0)20 7843 6448
fax +44 (0)20 7843 6313
info@edcm.org.uk

Every Disabled Child Matters launched September 2006

A three year campaign was recently launched striving for rights and justice for every disabled child. The campaign needs 10,000 supporters by the end of the year, so that the needs of disabled children and their families are no longer ignored.

Some of the issues;

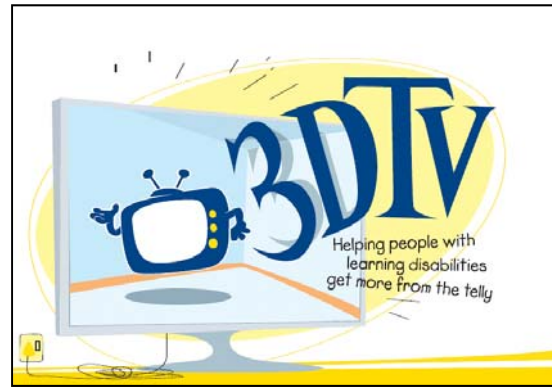
The government says that Every Child Matters – so why aren't disabled children getting their rights?

- Only 1 in 13 families get support from social services
- Disabled children are 13 times more likely to be excluded from school
- 8 out of 10 families with disabled children say that they are at breaking point

"Services for disabled children and their families are a national scandal" - Sir Al Aynsley-Green, Children's Commissioner for England.

For more information or to add your support to the campaign:

<http://www.edcm.org.uk/Page.asp>



Most people with learning difficulties watch a lot of TV. So it's particularly important that TV viewing can offer the chance to be a lively and stimulating experience. It can, for example, be a powerful way of building relationships, rather than a substitute for them. TV can be a catalyst for connections between people who are watching together or who have watched the same things separately. It can help bridge physical and emotional distances between family members and friends who don't live together, but who can watch and then discuss the same programmes.

What is 3DTV?

3DTV is a way of making TV watching dynamic, interactive and multisensory. It's 3D because it goes beyond the TV screen and helps people experience programmes in a very physical and multi-sensory way. This resource for staff suggests dozens of ways (some elaborate, most very simple), that we can enhance the many hours that people with learning difficulties spend watching TV each week. Many of the ideas are particularly suitable for people with profound and multiple disabilities. There is one main, and very simple, way of improving what people get from TV, and that's for us to ditch the belief, or habit, that TV is watched in silence. By asking questions about or commenting on what is happening in the programme or advert, this immediately makes the experience more enriched. This chatty way of watching TV could, however, be distracting or annoying for other TV viewers in the room, so this will need to be taken into account. TV can be a wonderful source of interesting, funny, important things to talk about, while the programmes are going on. And you can build on ideas stimulated by what's on, to enjoy activities before, during and after the programmes.

For more information please visit:

<http://www.ldmedia.org.uk/3DTV.html>

Life In The Community

As reported on the Foundation for People with Learning Disabilities (FPLD) website.

FPLD are providing funding to four voluntary organisations, so they can explore:

- ways for people who need a lot of support to be more included in their communities
- ways to improve day services
- changes that need to be carried out in the design of the organization to improve opportunities for people with high support needs

Four organisations have been selected because of their aims, their innovative ideas on how they will work with their local authorities and ways in which they will support young people and adults who have learning disabilities and high support needs to become inclusive members of their communities.

An evaluation and support team will ensure that things are progressing well at each of the project sites. The teams are representative of people with learning disabilities, family carers and practitioners. They anticipate the people involved in the project will be able to enjoy greater involvement in community life and exercise their rights and responsibilities as contributing citizens. The community will also gain greater awareness of how people who have high support needs can engage and contribute to mainstream activities.

They aim to find out how to

- influence national and local policy makers, commissioners of services and the practice of support for people who have high support needs in contributing to their successful inclusion into the community
- support local authorities to have a greater understanding of what is meant by real community inclusion and how to commit to the continuation and development of inclusive community support services

The research and practical 'good practice models' will contribute to the implementation of the '*Our health, our care, our say*' white paper objectives and will complement the SCIE knowledge review,

ensuring that the needs of people who need more support are not overlooked.

There will also be workshops for representatives from all of the project sites to share and learn. Feedback from these workshops, and the evaluation and support team will help to inform the development of services. Reports, articles and seminars will identify good practice and seek to influence policy in this area.

For more information go to

www.fpld.org.uk/page.cfm?pagecode=OWCILC

Or contact:

Barbara McIntosh bmcintosh@fpld.org.uk or Molly Mattingly mmattingly@fpld.org.uk
Foundation for People with Learning Disabilities, Sea Containers House, 20 Upper Ground, London, SE1 9QB. Tel: 020 7803 1100.

Challenging Perceptions

Brinda Crishna
(From page 20)

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Crishna, B. (1999) What is community-based rehabilitation – a view from experience. *Child: care, health and development*, **25**, 27-35

Hungerford, R. H. (1950). 'On locusts' *American Journal of Mental Deficiency*, 54, 415–418.

O'Toole (1996) Community-based rehabilitation: the Guyana evaluation project. In: *Practical Approaches to Childhood Disability in Developing Countries: Insights from Experience and Research* (eds M.J. Thorburn & K. Marfo), Project Seredec, St. John's (Canada) & 3D Projects, Jamaica.

Unpublished Report 'Interim Participatory Evaluation conducted by Spastics Society of Eastern India and the District Partner Organisations of West Bengal' (1998), India

New Report on Provision for Children with Special Educational Needs

The House of Commons Education and Skills Committee has produced a report called 'Special Educational Needs: Third Report of Session 2005–06 (HC 478-I)' which was published in June 2006. This is available in three parts either as a priced publication or in downloadable format from the House of Commons website



(www.parliament.uk/publications).

During the course of its inquiry the Committee took evidence from around 50 witnesses including Baroness Warnock, Rt Hon Ruth Kelly MP (the then Secretary of State for Education and Skills); Lord Adonis (Parliamentary Under-Secretary of State for Schools), and representatives of teachers' unions and other organisations such as Mencap. This evidence has been included in full in the report. Over 230 written memoranda were received but have not been printed for reasons of privacy. *You and Yours* and BBC Radio 4 held a phone-in discussion about special educational needs (SEN) and provided a summary of responses to the Committee which allowed ordinary voices to appear in the report. *You and Yours* receiving over 700 emails, telephone calls and letters from parents, children, teachers and other interested parties. The Committee had its own specialist advisers: Professor Ann Lewis (University of Birmingham), Professor Alan Dyson, (University of Manchester) and Mark Rogers (Director of Education and Children's Services, Solihull Metropolitan Borough Council).

This report looks at policy relating to children with SEN and disabilities. It does not give comprehensive and detailed consideration to specific issues facing children with PMLD and their families. However, it does provide much useful information and recommendations that are relevant to this particular group of children because they have relevance for all.

In 2005 around 18% of all pupils in school in England were categorised as having some sort of special educational need (SEN) – that is 1.5 million children. Around 3% of all children (250,000) had a statement of SEN. Around 1% of all children

(90,000) were in special schools which were where the vast majority of children with PMLD received their education. There were geographical variations in terms of the percentages of pupils with statements and placement in special schools. The number of maintained special schools, specifically, has reduced slightly from 1,171 in 1997 to 1,049 in 2005. The Committee noted evidence that there is a certain amount of "re-structuring" going on as some types of special schools close and others open.

The Committee recognised that many children are receiving the education they need in an appropriate setting. However, their report highlighted the difficulties faced by a large number of parents for whom the system is failing to meet the needs of their children. This report gives many recommendations about how SEN provision might be improved to the benefit of all children with SEN.

The Committee noted a range of opinions about how much change is required. Baroness Warnock said that a radical review of Government SEN policy is needed. The DfES did not favour a major review of policy on SEN but recognised the need for change 'on the ground'. There seemed to be some recognition from the DfES and Ofsted that it is not simply a question of tweaking the system. However, they had a view that any new review would simply delay progress in addressing well-known challenges and changing what does not work.

The Committee noted that the Treasury is undertaking a "root and branch" review of funding for children with complex needs and that the DfES has identified this area as the one in which it would most like funding to be increased in the next spending review - an area that includes looked-after children, children with special educational needs and those with severe disabilities. The Committee saw their report as timely and hoped for a significant increase in the level of funding directed towards children with complex needs.

The Committee noted anomalies in various Government pronouncements on the future of special schools. In the 2004 SEN Strategy, *Removing Barriers to Achievement*, guidance to local authorities unmistakably says that "the proportion of children educated in special schools should fall over time". Yet, Lord Adonis claimed in his evidence that the Government has no policy whatever of encouraging local authorities to close special schools. The Government plays no role in relation to local authority reorganisations or in respect of decisions to close schools at present but the Committee viewed this as an abdication of responsibility. Of course local authorities must

continue to have the capacity to plan and reorganise provision to meet local needs but the Government must provide a much clearer National Strategy linked to minimum standards and a statutory requirement for local authorities to provide a broad continuum of flexible provision—including high quality special schools.

The Committee recommended that the Government needs to develop a child-centred approach with regard to each stage of the statementing process: assessment of needs; allocation of resources; and placement. It should develop a system based on early identification and intervention, where schools are fully resourced and staff are fully equipped to meet those needs. There needs to be a radical increase of investment in training so that all staff are fully equipped and resourced to improve outcomes for all children with SEN and disabilities.

The Committee urged the Government to consider a completely fresh look at SEN provision and ensure that it becomes integral to the *Every Child Matters* agenda. There should be a seamless service in place with multi-agency involvement across key transition phases and through adulthood. The evidence to the Committee demonstrated how far the country is from achieving such a vision. For this reason, the Committee found the DfES response to the perceived shortcomings unacceptable and urged that SEN provision should be prioritised, brought into the mainstream education policy agenda, and radically improved.

This is a voluminous report that contains much of interest to people working with children with PMLD and their families. It is too early to know whether it will have a significant impact on Government policy but is well worth reading the analyses and the evidence, if only because it is the nearest thing to a review of SEN provision that we are likely to see for some years.

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

INTERCONNECTIONS ELECTRONIC BULLETIN ABOUT CHILDREN WITH DISABILITIES / SEN

NOVEMBER 2006. NUMBER 35.

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If you would like a copy of Interconnections Electronic Bulletin please contact:

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9 Pitt Avenue
Worcester WR4 0PL
Tel/fax: 01905 23255
E-mail: interconnections.services@virgin.net



Author(s): Alice Bradley, Mary Buchanan, John Dawson and Agnes Forsyth

Publisher: BILD

ISBN: 1904082831

Pub Date: 2006

Price: £8.00

Everybody Needs Toilets: an easy guide for people with a learning disability

This illustrated easy-to-read booklet is for people with a learning disability who find it difficult to talk about any problems they have with going to the toilet. It describes how people can keep healthy by looking after their bladder and bowels. It also deals with the problems they sometimes have with going to the toilet and the people who can help.

The book is designed to be used by people with a learning disability with, where necessary, the support of family carers or support workers who are expected to customise the book to suit their own circumstances.



Author(s): Alice Bradley with Loretto Lambe

Publisher: BILD

ISBN: 1904082823

Pub Date: 2006

Price: £12.00

Helping people with learning disabilities manage continence: a workbook for support workers and carers

Continence is one of those things we seldom think about if we don't have a problem, but which assumes massive proportions if we do. Incontinence is very much a taboo subject and relatively little has been written about it in relation to people with learning disabilities. This workbook has been produced in partnership with people with learning disabilities to rectify the situation.



Author(s): Alice Bradley with Loretto Lambe

Publisher: BILD

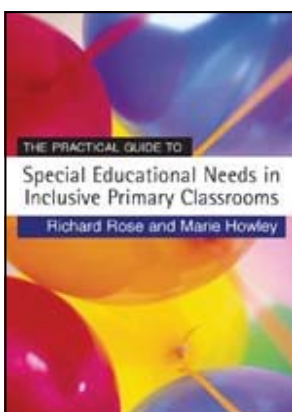
ISBN: 190408284X

Pub Date: 2006

Price: £20.00

Supporting continence management: a reader for managers

This reader can be used by managers to support staff members studying for the LDAF Certificate in Working with People who have Learning Disabilities but is also intended as a stand-alone guide for line managers, senior practitioners, carers and professionals with a specific interest in the topic of continence.



Author(s): Richard Rose and Marie Howley

Publisher: Paul Chapman

ISBN: 1412923271

Pub Date: 2006

Price: £14.99

The Practical Guide to Special Educational Needs in Inclusive Primary Classrooms

Written for newly-qualified teachers and students approaching the end of their training courses, this practical and accessible text is an introduction to working with children of a range of abilities in inclusive primary classrooms. The book draws on recent research and innovation in the education of pupils with special educational needs to provide practical examples and advice on how to meet the challenges of developing effective teaching and learning in inclusive settings.

Short Courses and Conferences 2006

Providers Details

BILD

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

Catalyst Education Resources Ltd

1A Potters Cross
Wootton, Bedfordshire MK43 9JG, U.K.
Tel. 0845 127 5281
E-mail: patcerl@aol.com
Web: www.cerl.net

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/

Consent

Woodside Road
Abbots Langley
Herts WD5 0HT
Tel: 01923 670796
E-mail: consent.ESU@HPT.nhs.uk

EQUALS

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

Sunfield PDC

Clent Grove, Clent,
Nr. Stourbridge,
West Midlands DY9 9PB
Tel. 01562 883183
E-mail: Sunfield@sunfield.worcs.sch.uk
Website: <http://www.sunfield-school.org.uk/Training/Summer2006.htm>

Some of next years short courses & conferences were not available at the time of print. Please visit their websites for updated information.

January

Date: 10th January
Title: Young People And Adults With Learning Disabilities And Complex Health Needs - Conference
Location: Wolverhampton University
Contact: For more information and a booking form, please contact: Inclusion Distribution 29 Heron Drive Poynton STOCKPORT SK12 1QR Tel: 01625 269243 Fax: 01625 269243

Date: 23rd January
Title: Rock & Role Play
Provider: Sunfield PDC
Contact: (See Providers Details)

Date: 30th January
Title: Risk Assessments
Provider: Sunfield PDC
Contact: (See Providers Details)

Date: 31 January
Title: Every Child Matters
Provider: Sunfield PDC
Contact: (See Providers Details)

Date: 31 January
Title: Protection of vulnerable adults
Provider: BILD
Location: Manchester
Contact: (See Providers Details)

February

Date: 1st February
Title: Assessing the Mental Health Problems
Provider: Sunfield PDC
Contact: (See Providers Details)

Date: 2nd February
Title: Literacy Activities for People with Severe and Profound Learning Difficulties
Provider: Sunfield PDC
Contact: (See Providers Details)

Date: 5th February
Title: Science and SEN
Provider: Sunfield PDC
Contact: (See Providers Details)

February

Date: 7th February
Title: Young People And Adults With Learning Disabilities And Complex Health Needs - Conference
Location: Kingston University and St George's University of London
Contact: For more information and a booking form, please contact: Inclusion Distribution Tel: 01625 269243 Fax: 01625 269243

Date: 8th February
Title: Life story work
Provider: BILD
Location: London
Contact: (See Providers Details)

Date: 20th February
Title: Managing continence
Provider: BILD
Location: Kidderminster
Contact: (See Providers Details)

Date: 23rd February
Title: Sensory Play and Learning
Provider: Sunfield PDC
Contact: (See Providers Details)

March

Date: 2nd March
Title: Announcing a Multisensory Master Class with Flo Longhorn
Provider: Catalyst Education Resources Ltd
Location: London
Contact: (See Providers Details)

Date: 2nd March
Title: Sherborne Development Movement Level 2
Provider: Sunfield PDC
Contact: (See Providers Details)

Date: 6th March
Title: Announcing a Multisensory Master Class with Flo Longhorn
Provider: Catalyst Education Resources Ltd
Location: Manchester
Contact: (See Providers Details)

Date: 9th March
Title: 'Care, Learning and Neuroscience – integrating the latest brain research into your daily professional practice' (Conference)
Provider: Catalyst Education Resources Ltd
Location: The Wyboston Lakes Business and Knowledge village Wyboston Bedfordshire
Contact: (See Providers Details)

Date: 7th March
Title: Making Sense of P Scales
Provider: Sunfield PDC
Contact: (See Providers Details)

Date: 12th March
Title: Announcing a Multisensory Master Class with Flo Longhorn
Provider: Catalyst Education Resources Ltd
Location: Birmingham
Contact: (See Providers Details)

Date: 16th March
Title: Meeting the needs of people with profound learning disabilities
Provider: BILD
Location: Manchester
Contact: (See Providers Details)

Date: 20th March
Title: Intensive Interaction
Provider: Sunfield PDC
Contact: (See Providers Details)

Date: 22nd March
Title: Autistic Spectrum Disorder and People with Learning Disabilities (Conference)
Location: The TechnoCentre, Coventry
Contact: Mr. David Martin, Learning Disabilities Services
 Tel 024 76 246 323

Date: 27 March
Title: Protection of vulnerable adults
Provider: BILD
Location: Kidderminster
Contact: (See Providers Details)

April

Date: 20th April
Title: Intensive interaction
Provider: BILD
Location: London
Contact: (See Providers Details)

Date: 27th April
Title: Valuing Teams: working together for children and adults with learning difficulties and disabilities (Conference)
Provider: BILD
Location: University of Birmingham
Contact: (See Providers Details)

June

Date: 8th June
Title: Achieving the Every Child Matters: outcomes for all children and families (Conference)
Provider: BILD
Location: Holiday Inn, Solihull
Contact: (See Providers Details)

LONGER COURSES (with accreditation)

Updated April 2006

Master of Arts in Education

Understanding Severe and Profound and Multiple Learning Difficulties (EDUM028)

This module addresses the requirements of the Teacher Training Agency (TTA) National Special Educational Needs Specialist Standards. This accreditation is awarded to students completing the requirements for the three modules EDUM028, EDUM029 and EDUM040. This module is directly related to developing the competencies, knowledge, understanding and critical reflection of students who are, or planning to be Special Education Needs Teachers. The module adheres to the national TTA SEN Specialist Standards (Core and Extension Standards) and students are given opportunities and support to collate evidence to meet the standards.

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

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

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

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

AdCert, BPhil, PGCert, PGDip, MEd.

Learning Difficulties and Disabilities (Severe, Profound and Complex)

Distance Education

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

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

The modules are as follows:

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

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

Postgraduate Professional Development *Multi-Sensory Impairment (MSI)*

The module aims:

To enable teachers to support the learning needs of pupils who have Multi Sensory Impairment (MSI in this context refers to pupils who have multi-sensory impairment and complex needs).

Opportunities will be provided for students:

1. To develop an understanding of definitions of MSI and how typical child development may be affected by multi-sensory impairment
2. To have an overview of relevant modes of communication for pupils who have multi-sensory impairment
3. To understand how specific theory and practice may be used as a basis for working with pupils who have multi-sensory impairment
4. To understand what needs to be assessed and why, when working with a child with MSI
5. To understand the roles of the other individuals involved with the child who has MSI including different models of collaborative working
6. These modules can count towards a post graduate award (Certificate, Diploma or Masters Degree)

The module will involve seven taught days, four school based training days (supported by a mentor) and school/institution based research. **Applicants must have QTS**

This is a reduced fee - subsidised by the TDA grant funding, plus a top up £100 subsidy from EMSEN, reduces the cost to schools, services or individuals.

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

PGCert, AdCert.**Early Years: Sensory and Multiple Needs—This programme begins in January**

Distance education.

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

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

MSc and Graduate Diploma in Learning Disability Studies - Distance Learning

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

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

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

**Postgraduate Certificate/Diploma Profound Learning Disability and Multi-Sensory Impairment Programme
MSc Learning Disability and Multi-Sensory Impairment Programme**

Programmes available by Distance Learning at The University of Manchester, School of Education

Programme Aims

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

Programme Structure

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

For further details: University of Manchester Janet Grimshaw, Phone: 0161 275 3463, Email: janet.grimshaw@manchester.ac.uk

BSc in Professional Practice (Learning Disability Pathway)

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

For further details: University of Chester

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

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

MSc in Advanced Practice (Learning Disabilities)

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

For further details: University of Chester

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

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

Adults with learning disabilities who have significant and complex needs

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

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

The next intake is October 2006.

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

For further details: University of St. Andrews <http://psy.st-andrews.ac.uk/people/personal/mc1/>

Dr Martin Campbell email: mc1@st-andrews.ac.uk

Websites mentioned in this issue	
United Response (UR) website	www.unitedresponse.org.uk
Intensive Interaction website	www.intensiveinteraction.co.uk/
Teachers TV website	www.teachers.tv
Bag Books website	www.bagbooks.org/index.html
DfES (2006) <i>The Primary National Strategy</i> website	www.standards.dfes.gov.uk/primaryframeworks/
PAMIS website	www.dundee.ac.uk/pamis/
Touch Trust website	www.touchtrust.co.uk/
Every Child Matters website	www.everychildmatters.gov.uk/
Good Moves website	www.good-moves.org.uk/
PINNT website	www.pinnt.com
Mencap website	www.mencap.org.uk

PMMLD Link

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