PMLD LINK

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

Spring 2006

Working Together

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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.

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

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Articles

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GUEST EDITORIAL
Spring 2006

Working Together

This issue has the focus on 'Working Together'. This theme has been interpreted in a variety of ways and we have nine very different articles for you to read, ranging from collaboration in the classroom to partnership between professionals and families and two articles on working together using Intensive Interaction, one from Nottinghamshire and the other from Australia.

I have personally been involved in and anxious to promote ways of working together for the 35 years of my working life. My first job in special education was with children with physical and learning difficulties and I remember how surprised the physiotherapists were that I wanted to know what they were doing so I could help the children practice in the classroom. I don't think they had experienced that kind of interest from a teacher! Since then, I have been lucky enough to work in several really good multidisciplinary teams and have conducted research in many more. When two or more people work together well, the results can be really great, not only for the child or adult with profound and multiple learning difficulties at the centre of the partnership, but also for the partners themselves. Not only does it feel good to be supported, but how true it is to say 'the whole is greater than the sum of the parts'. Pooling ideas undoubtedly helps to produce more that none of the partners would have come up with on their own.

Amongst several other pieces of information, we have included a definition of PMLD that we hope you will read and consider. Is it useful for you to have a definition? Can it inform your work in any way? Do let us know.

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Guest Editor
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Future Focus: Early Years

By Julia Dixon

Recent years have witnessed a commitment from the government to give children the best possible start in life. This is commitment is underpinned by the national service framework “Every Child Matters” 2004. The development of the Birth to Three Framework (2003) was a very significant milestone in recognising and valuing our youngest children and the contribution made to their growth and development by the practitioners who work with them.

When our youngest children have multiple disabilities, it is now widely recognised that they should be identified at the earliest possible stage so that effective early intervention and practical support for them and their families can be put in place. The theme of early intervention is central to the SEN strategy, “ Removing Barriers to Achievement ” first published in 2004. It is also central to other initiatives including the Sure Start Projects .

In the “Together from the Start ” (2003) publication we have for the first time guidance for professionals working with very young children and their families. Many service providers have long used key worker systems for when working with families but now, The Early Support Programme for parents and carers recommends a key worker system as part of its approach to integrating services and supporting families.

So where are we now?

At PMLD link by focusing on Early Years we have the opportunity to take a view of the current practice and issues for those caring, teaching and working with our youngest children with PMLD.

What is the latest research telling us?

What has been the impact of the some of the developments and changes ?

Have services for families improved ?

Is the key worker system working for you?

How easy is it to access support in the early years?

If you are a parent ,carer, practitioner, and have a story to tell which you would like to share , we would love to hear from you.
Some of the contributions may be about

- Sure Start Early Support Programme and materials
- Breaking the news
- Parent support groups and projects
- Early intervention strategies
- Inclusion of children with PMLD in mainstream settings
- Children’s centre development/integrated services
- The team around the child & key worker systems
- Therapies for example baby massage
- Specialist equipment
- The Early Years Foundation Stage
- European/international perspectives for PMLD

We look forward to hearing from you.

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Working together: Making it work

By Heather Murdoch
Teacher at the MSI Unit, Victoria School, Birmingham

Not so long ago, specialist Units for children with particular needs were largely self-contained and self-sufficient. Staff expertise, specialist resources and pupils often remained largely detached from the host setting, in it but not of it. Visiting specialists (therapists, for example) worked within the Units but not with their staff. The boundaries of specialism stood firm and strong.

Although I'm exaggerating for effect, the picture wasn't that far removed from truth. In a few short decades, everything has changed. Our definitions of special needs, our notions of appropriate education, our ideas about the nature, purpose and scope of specialist expertise - all are immensely different. Firm boundaries are no longer an option. Those working in specialist fields must work together to meet needs, and the more complex those needs are, the greater the need for collaboration.

So how do specialist Units operate now? The common factor is that generally they act as a hub of collaboration - a focal point for the exchange of information and expertise between children, parents and professionals from a range of disciplines. This can work superbly well, or less well, or disastrously. Often, small factors (like passing on phone messages to the right people) have a huge impact on the process as a whole. In the rest of this article, I want to look at how 'working together' happens in practice in one specialist Unit, and especially at the factors which help it to work well.

The Birmingham MSI Unit

Victoria School is a large day special school in Birmingham, catering for pupils with physical disabilities and a range of other needs. It hosts the regional MSI Unit for pupils with multi-sensory impairments. The MSI Unit serves five LEAs and provides outreach support for children with MSI in other schools within this area. It is one of a handful of specialist MSI facilities in the UK, and a centre of excellence.

MSI is a very rare disability which creates very complex needs. The fifteen children attending the Unit all have both hearing and visual impairments and a range of other physical, medical and/or learning difficulties. Paradoxically, complexity makes a good starting point for collaboration: one of the first things professionals learn in working with children with MSI is that they'll never know it all. The need for other expertise, new perspectives to help interpret children's responses, will always be there.

Within the Unit, pupils are split into classes, each with a teacher, teaching assistants and lunchtime supervisor. These staff form a core group, with teaching staff acting as keyworkers for individual children and the first point of contact for their parents. Class boundaries are fluid, however, with some pupils moving between classes for specific activities. Staff, too, may move around the Unit, to offer specialist support, help with assessment or provide emergency cover.

There is considerable traffic between the MSI Unit and the main school. Pupils from the Unit use specialist teaching areas within the school – the hydrotherapy pool, the science lab and HE room, the library, music room and PE hall. Some subject specialists teach groups of MSI pupils, with support from pupils' Unit keyworkers. Most pupils spend weekly sessions with other classes in the main school, again with keyworker support. Main school staff and pupils, in turn, benefit from the expertise of Unit staff, who offer assessment and support for children with sensory impairments.

Contact with parents is through the usual means of daily home-school diaries, phone calls and visits. In addition, the school has a family liaison specialist and family support system. Bus and taxi guides provide another point of contact between the Unit and the child's family.

The school has nurses, physiotherapists and speech therapists on site, with the doctor, dentist and dietician visiting regularly. The nurses, especially, are in regular contact with Unit staff, visiting the Unit daily. The audiologist and orthoptist also visit, working with Unit staff to assess and evaluate pupils' auditory and visual function.

Victoria School shares a campus with two other special schools, one of them for children with hearing impairments. MSI Unit staff liaise with staff from this school and offer occasional support for specific children, and a couple of MSI Unit pupils spend regular sessions there with their keyworkers. There are links, too, with many other professionals

– social services staff; local LEA staff for out-county children; paediatricians, ophthalmologists and other medical professionals. In addition, the Unit's outreach role entails regular contact with staff in a range of other schools serving children with MSI.

Working together well

Unit staff and other professionals who work with them were asked to identify what helps them to work together; the factors below are taken from those discussions. There was considerable agreement about how to work well together; what matters, and what doesn't. Many of the points are obvious - passing on messages, for example – but that still doesn't mean that they'll happen without effort.

*** the use of keyworkers***

Unit teaching staff act as key workers for individual pupils. The critical elements of this role include an understanding of MSI and a very detailed knowledge of the individual child. Keyworkers can help others apply their expertise in the light of MSI-specific and child-specific needs – knowing, for example, how best to present information to the pupil, or the right pace of working.

*** sharing information***

This ranges from the very basic (returning phone calls, passing on messages) to the more complex: not making assumptions; maintaining discussion; being clear about who will take what action; understanding different perspectives. The MSI Unit classrooms serve as the physical centre for communication - a place where messages can be re-routed if they can't be delivered directly. The daily home-school diary system helps parents easily to access other staff on site via classroom staff.

*** giving relevant information***

Not all information needs to be shared, however. It is important to tell people what they need or want to know – taxi guides, for example, need quite specific information about their particular child. Speech- and physiotherapists may want more general information on the impact of MSI on communication or mobility. Parents need to be the ones to decide how much information is passed onto them on a daily basis, and in what form.

*** approachability***

Everyone involved with the pupils needs to see it as a partnership – no one person has all the answers, or even sole ownership of the question. Staff need to avoid disappearing behind their own professional defences – for example, using jargon, or blinding people with unnecessary science. This becomes easier once professionals get to know each other, and especially once they get to know the pupils as individuals.

*** respecting each other's expertise.***

Because MSI creates such complex needs, expertise from different disciplines needs to be integrated – for example, MSI affects children's motivation to move in space. Staff need to be willing to share and if need be relinquish some of their own expertise in order to decide and meet priorities. Two sources of expertise are particularly important and sometimes overlooked: parents are the overall experts on their children, and within the school environment keyworkers are usually the best placed to interpret pupil's responses.

*** formal and informal training***

It is easier to respect other people's expertise if you're sure what their expertise is. Staff from different disciplines need to know what the others do, and what their priorities are. Whole-school training in MSI helps Unit pupils to be better integrated within the school, by taking away the mystique of MSI without belittling the complexity. Professionals need to encourage parents to train them, in what the child is like outside the specific environment of school, and in what the parents think is important for the child.

*** accessibility***

The MSI Unit gains enormously from the wide range of school facilities. It is very much easier to work together with others on the same site, or who visit regularly and are easily accessed. Having educational and health service staff on the same site, in particular, allows for regular and informal contact, and for sudden serendipitous advances in joint thinking.

*** a flexible approach to planning and teaching***

Children with MSI often have particular problems with generalisation because they get so little information about experiences. For this reason, teaching activities tend to be cross-curricular so that skills and concepts are not taught in isolation. In addition, pupils in the MSI Unit follow largely individual programmes, and staffing levels are high. In this context, it is relatively easy to incorporate, for example, therapy needs, into other activities.

Finally: being committed to the idea of working together isn't enough. It needs to be built into the everyday structures of practice, to the extent that you can't envisage any other way of doing things.

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A Collaborative Approach to Education and Care

By Julia Prince
Curriculum Leader, Enhancing Quality of Life

A definition of collaboration is given by NNEV:

> "A mutually beneficial well-defined relationship entered into by two or more organizations to achieve common goals. Collaboration is the process of various individuals, groups, or systems working together but at a significantly higher degree than through coordination or cooperation. Collaboration typically involves joint planning, shared resources, and joint resource management…" (2005)

I would like to consider this in relation to our work with learners with profound or severe and complex difficulties. We are part of the Division of Student Entitlement in a large further education college and our provision was set up in 2002 as a response to the Enhancing Quality of Life – EQOL - project. This project involved University of Cambridge (2001), Skill and the Further Education Development Agency working together to establish available opportunities for people over school leaving age, with profound barriers to their learning. When this was established the next stage was to facilitate and support additional organisations to provide further opportunities.

From the outset the focus was on working together with other service providers. The initial bid to run a pilot EQOL course was dependent upon 'partnership' and the pre start up training required 'partners' attending joint sessions to idea generate and plan.

However it is not the early stages I wish to share but rather the current situation that could be summed up well by Disability Services Queensland's statement:

> "A partnership approach that relies on an open exchange of information. It is dependent on mutual respect, and is aimed at supporting service users to gain some control in decision making." (2005)

The organisations working together include private care and nursing homes, charitable run homes, social services, a National Health brain injury unit based at the local hospital and the college. With such diverse management structures, mission statements and staff time tabling there have been and probably always will be real challenges to overcome in order to share time and space, planning and training.

We believe it is vital for our learners that barriers to collaboration are overcome. Lifelong Learning (2005) inform us:

"… teaching … is rarely integrated with the rest of people's lives. For example, a person may be taught by conflicting methods, uncoordinated inputs from day, residential and education staff. The lack of integration is compounded by a lack of clear learning outcomes, poor recording mechanisms, and gaps in inter-agency collaboration. Staff often teach new skills with little or no attention to the maintenance of skills already acquired" (Page 1)

We believe the only way to 'integrate' teaching is for the teachers to work closely with carers and significant others. From initial referral from a care organisation we aim for team working. The potential learner is assessed either at their home or at college and the carer is invited in to the learning situation with the learner until it is jointly felt (through observation of the learner in the new situation) that it is appropriate for them to withdraw.

We share our recording procedures and once a term we invite carers and other professionals and family members to take part in a joint training morning. Following this session we all meet and identify further training requirements. In turn college staff have taken part in training at residential homes, the hospital and the social service day centre. This not only broadens knowledge base but also gives some insight into the work commitments of carers and professionals who are working for and with us and our learners.

There are difficulties involved with this practice, including greatly varying salary scales of collaborating staff, different regulations in organisations affecting how and if staff are paid to attend training and the intricacies of staff time tabling. However over the duration of our provision I think we all agree that a multi disciplinary approach provides more information and therefore greater opportunity for meaningful interactions with a learner who is profoundly challenged. Brown, McLinden and Porter in Lacey and Ouvry (2003) state:

> "It is likely … that staff will need to build up a picture over time of the learner's abilities and disabilities and to do this they will need to call on the experiences and skills of others..." (Page 35)

An example of this in practice is recent collaboration with carers for curriculum action research. A learner with acquired severe and complex needs attended college from a local nursing home. During the first few months it became apparent that communication was inconsistent. Sometimes the learner moved a finger to communicate or closed their eyes briefly. At college we began to focus on the use of sign and symbol and the learner started to use some signs, initially copying hand shapes we made and then starting to use signs to initiate interactions. The activity organiser at the home discussed this with us, observed a lesson and undertook the Induction level training in Somerset Total Communication (2005). Subsequently in completing a questionnaire relating to the learners communication the Activity Organiser was able to record the signs the learner was using and more importantly able to use sign with the learner.

As well as sharing training we have experienced real benefits from sharing mini busses and drivers. The generosity of our partners in providing transport for educational trips has enabled us to benefit from more outings than our budget alone would have funded.

Tilstone and Barry in Lacey and Ouvry (2003) celebrate the power of working together and emphasise the dynamism of "shared ownership" (Page 183). It is exciting, empowering and hard work and if anyone would like to comment about our experiences or pose questions please email me:

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Integrated Programmes in Schools

By Penny Lacey
The University of Birmingham

With the encouragement from the Early Support programme, many pre-school services are addressing how to integrate the work of teachers, therapists, nurses, Portage workers and medics who work together with a particular family and profoundly disabled child. It is by no means universal across the country but the most effective services are working closely together, closely enough to combine their individual programmes into one document which belongs to the family. Sometimes there is a very large group of people who provide services for families and children with PMLD and the integration between them is only partial. So, for example, the speech and language therapist, physiotherapist and occupational therapist work closely together; combining their assessments and jointly writing therapy programmes. In addition there may be other programmes relating to cognition and sensory development.

Integrating programmes is just as important in school settings, and it is to that context that we now turn. Once a child with PMLD starts school, the focus for intervention shifts from the home to the classroom (although of course both are important). Most of the visiting professionals such as therapists and specialist teachers work in the school, certainly during the term time, and often the teacher becomes a co-ordinator of the different aspects of the intervention. Sometimes the teacher takes on a formal co-ordinating role but at others co-ordination seems to occur by default. Visiting professionals each provide a separate programme to be carried out in the classroom and the teacher needs to bring these together somehow or the targets and activities will be unwieldy. In classrooms where co-ordination is not well-planned, the teacher can find it very difficult to integrate advice which at worst can be contradictory and at best disparate.

Let us spend a few moments on a familiar scenario in the school setting. Edward is 8 years old and has complex needs. He has spastic cerebral palsy involving all 4 limbs and is a wheelchair user. He has had a gastrostomy and takes medication for epilepsy which is mainly well controlled. He has a visual impairment but the extent of his useful sight is not fully known. Edward’s communication is mainly unintentional, although he can quite clearly show his likes and dislikes.

Edward attends a mainstream school where the teachers are very keen to meet his needs. Various peripatetic professionals come to the school to work with him but that means that sometimes in the course of a week, he will have been seen by:

his teacher
his teaching assistant
3 specialist teachers for Science, Music and ICT
speech and language therapist
physiotherapist or her assistant
community nurse
specialist teacher for the visually impaired

In addition, there are intermittent visits to various clinics at the hospital for checks on his physical condition, his epilepsy, his gastrostomy, his boots and his wheelchair. Edwards also goes to a local children's home for respite care once a month. Altogether there are more than 20 people involved, all of whom contribute to his well-being.

So what would be an effective way for all the people to work with Edward and his family? At the moment the community nurse has a keyworker function in that she liaises as best she can between most of the different people involved and the family. She helps to organise the many appointments and provides a listening ear. The teacher co-ordinates what happens in the classroom, often through the classroom assistant, who is assigned to Edward full-time. The speech and language programme was written by the therapist and checked with the teacher and it informs Edward's classroom work as far as possible. The same is so with the work on his vision.

There seem to be some effective ways of working at the moment. For example, the keyworker role taken on by the community nurse makes all the hospital appointments much more manageable. Edward’s mother usually takes Edward to appointments and as she works part-time, she likes to see more than one specialist each time she goes to the hospital, to minimize the number of days she has to get time off work. The co-ordination in the classroom seems to be working well on one level. The teacher and the teaching assistant meet together frequently and work together on suitable activities for him in subject lessons. Where more could be done is in integrating the intervention programmes from the therapists and visiting teacher of the visually impaired (VI).

Unfortunately little can be done to improve the integration of programmes without time being set aside for teachers and therapists to talk and work together. It is rarely satisfactory for therapists or visiting teachers either to withdraw the child and work with him separately or to write programmes and expect classroom staff to carry them out. The first scenario means that whatever happens in therapy does not influence Edward's daily life and the second scenario means having to find extra time for therapy programmes on top of an already full curriculum. Neither is effective.

Integrating the different programmes seems to be the most effective way of working. Not only does it mean Edward is treated as a whole person and not a sum of limbs, mind, eyes and mouth but it also means that the most important things happen constantly. Everyone communicates with Edward in the same way, everyone can use the same range of positions, everyone knows how to help him use his vision effectively and everyone can help him practice stretching out his arms and learn about simple cause and effect. When the speech and language therapist is able to work with Edward she can work in the classroom alongside everyone else, supporting Edward to contribute to lessons, enjoy lunchtimes or play with his peers. She would know exactly what his physiotherapy targets are, how to encourage him to use his vision and how to enable him to progress cognitively.

Integrating programmes means that schools and visiting services need to work in different ways from those that are traditional. Therapists and visiting teachers should not only be seen as working directly with individual children, but also with classroom staff. This will mean arranging to meet outside lesson times, using preparation time or time after school. It could mean paying teaching assistants for an extra hour each week so they are available at a time when teachers are. Therapists may need to vary their times so they can see children in class *and* talk to staff when they are free. It could mean therapists and visiting teachers clustering their time for a particular school, so they can spend a whole day or several days in one place whilst they are conducting assessments with classroom staff, writing programmes together and talking about the holistic needs of individual children. Visiting professional would need to co-ordinate their school visits so they could all meet together as a team. My motto is 'You can't be a team if you haven't got time to talk' and if the needs of children like Edward are going to be met holistically on a daily basis then time needs to be managed in a way that enables people to talk together and work together. Many special schools have achieved integrated working but it is undeniably harder in mainstream schools because fewer members of the team are on site. It is relatively easy to talk to people you pass in the corridor (although not always achieved) but more difficult when team members have to travel halfway across the county to meet. It is not impossible though, especially if schools and visiting services are prepared to change their working practices. Change can be painful but oh so rewarding!

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Working Together – A Review of the Intensive Interaction Program at Bayside Special Developmental School (Melbourne, Australia)

By Rosemary Gallagher, Principal
Bayside Special Developmental School

It's been nearly two years since the term *Intensive Interaction* was first introduced to the staff at Bayside SDS. Since then, the approach has become part of the culture of the school and used regularly by a range of staff members for the benefit of those students at the school who have profound and multiple learning disabilities.

Under the inspiration and tutelage of Dr Mark Barber (Consultant in Profound Intellectual Disability and Severe Communication Impairment), it became clear that *Intensive Interaction* offered us a means by which we could 'tune in' to our students in new and meaningful ways, in contrast to the traditional forms of communication.

To my knowledge, Bayside SDS was the first school in Australia to adopt the approach. All staff members attended the initial six training sessions, but not everyone felt confident to embark on the program. Indeed, *Intensive Interaction* was only deemed to be appropriate for approximately 20% of our students.

Early success fired us all with enthusiasm, and the 'I.I. Club' evolved as a consequence. Now 10 –12 staff members meet with Mark and myself every three weeks where we 'work together' to review progress and reflect on and improve our practice. Achievements are shared and celebrated. A sense of humour is mandatory, as failures and problems are also tabled. To monitor progress, we are using a variety of recording methods including a framework based on Graham Firth's Hierarchy of Attainment. Our newly acquired video camera, data projector and large screen television have become invaluable items of equipment.

Recently, the teachers involved in the pilot program shared their personal journey and reflections with the full staff at a specially convened meeting. I have included some of their thoughts in this article. Each acknowledged how the support and enthusiasm of their colleagues was fundamental to their successes and achievements. Their stories were received with enthusiasm and encouragement. We all agree that the changes have been many, and we now have a successful way of communicating with the 'difficult to reach' students. There is more fun in the classrooms, and less stressful environments have been created. There is also a greater sharing of roles between the teachers and their support staff. The following reflections indicate that there has been a paradigm shift in thinking.

From Karryn Bowen – an experienced classroom teacher:
"*Walking into a different classroom at the start of a new year has always been a daunting and overwhelming experience for me. Coming into a classroom of high needs, pre-intentional, non-verbal students with challenging behaviours even more so! It's relatively easy to work with students who 'give something back' when you approach – a brief look, a touch, a sound. It encourages you to persevere and spend time with them. The student who is so self-involved with his own activity that he seldom registers your presence does not. In this situation, I found my self guilty of gravitating back to those students who responded in ways I understood, and only spending short periods of time with those with whom I was unable to engage. That was until I was introduced to the approach of Intensive Interaction. Working in this way has enabled me to establish a deeper sense of trust and rapport with all of my students, an increased feeling of 'togetherness' when the solitary and isolated activities become more social, and it gives me great pleasure and joy in just being with them, helping me to look beyond the disability and to see the person beneath. Sometimes I fall into the trap of focussing on myself – concerned only with the future and what still needs to be achieved. When this happens, I put pressure on myself to move things along at a more rapid pace to 'get things done', becoming more anxious and stressed. When I stay focussed on the student, I am able to relax in the 'here and now' and take great pleasure in how far we have all come!*

Working together with the other staff using this approach, and validating my interpretations and assessments has prevented me from feeling isolated, and maintains enthusiasm for the program. As a teacher, Intensive Interaction has had an enormous impact, changing forever my teaching style; it has given me confidence to meet *the needs of all my students and to see things from their viewpoint.*

From Karen Coltman- Art Craft specialist and team teacher;
The Intensive Interaction program has had a lasting impact on me. The journey that has taken the last two years has been so rewarding. I can see how the relationships that I have developed with the children have greatly influenced the way I teach in the art room. I enjoy the one-on-one time in the classrooms, and I am constantly amazed at how much the children are changing from week to week. I feel as though I have learnt to listen while they teach me, as opposed to the teacher oriented 'I teach while the children listen'. In the art sessions, I now have a new understanding and connection with the pre-intentional children with whom I have worked, enabling me to communicate and participate on their terms. There is an ever-growing level of comfort, a mutual trust that now allows students to feel comfortable enough to try new skills in the art session. I now no longer think about what needs to be done, but rather how shall we do it.

And finally from Mark Holland, mature-aged graduate teacher:
I came to the Intensive Interaction method this year, as I did to teaching more generally, a novice. When I began I had one question in my mind (actually it was three questions that all sort of joined into one rather terrifying sentence): How does one begin, from scratch, to run a class for a group of 5 – 7 year old boys?...with special needs? …for a year!

As I'm sure is the case with many (if not most) beginning teachers, whether working in special education or the more mainstream fields, when panic began to subside, my initial concerns centred on what to teach. Content instantly became my watchword.

I re-read "The Beginning Teacher's Handbook". I waded through goals and reports of the boys from previous years. I talked to people at school, asked advice…and (again, as I'm sure most beginning teachers do) I focussed on and laboured with preparation.

As I began to know the kids it became very quickly apparent however, that in addition to content (what to teach), I was going to have to figure out how to teach…and how to teach in a way that was going to be meaningful, useful, practical, but most of ***accessible*** *to these kids. This was important and a little scary at the time. I was unsure of myself, inexperienced and at the same time knew that something special was needed. Content – even great content and lots of it – wasn't going to be enough. It wasn't just that. Intuition was telling me that content and a conventional teaching approach – however patient and well-meaning – wouldn't work. "Content" ground suddenly to a halt as my watchword.*

Around the same time I was sent off to do a PD (professional development day) about a"new"communication method intended specifically to enable greater and (hopefully) deeper and more meaningful transactions between people with severe intellectual disabilities and those who work with them. Dr. Mark Barber, who also worked at my new school, was running the seminar. It was the first time we met and the first time I heard the words Intensive Interaction used together. These two events changed everything.

As the day progressed, I saw kids (kids just like mine) communicating and interacting in ways I'd not seen before. I saw people (teachers like me) doing things – using techniques and methods – that made me laugh and cry at the same time. It was clear, vividly so, that I was seeing what was to become the cornerstone of the curriculum for my group. I was witnessing the resource I needed… access…me to them and them to me. Enthusiasm began replacing fear. Here was the "something special" I needed. I left the seminar that day already bubbling with ideas and possibilities about how to begin using these methods in my classroom.

Very soon after the seminar I spoke with Mark about my ideas. I wanted to bring the Intensive Interaction method into the classroom, for the whole class, to schedule it as a regular part of our timetable. My only reservations were that we had very little (read: none) experience and would also need to be able to staff these sessions.

Mark responded enthusiastically. Up until then I don't think he had considered the possibility of Intensive Interaction as a "whole-class" activity (I *could be wrong though)…and one that would be scheduled as a regular part of the weekly class timetable. He assured me that he would make himself available for some sessions each week and would attempt to organize the additional staff needed as well.*

Our "I-I-sessions" (as they eventually became known) began and things developed quickly. Perhaps the biggest surprise of all initially, was how much the kids seemed to like the sessions. We set up a style of session I came to refer to as "free-form" ("free-fall" more affectionately). By this I mean that we put all the ingredients into the classroom for these sessions and let the kids decide how they were going to develop. Surprisingly for both Mark and myself, at least, they developed quickly into a routine. The kids are free to decide who they interact with, how they interact and for how long. Staff present in our I-I-sessions, are there simply to be "available" for interaction. We do not "direct" any activity.

To convey some form of evaluation of this approach is both difficult and easy at the same time. It's difficult – and I tread carefully here, with due awareness of my comparative inexperience – because I'm unsure, as yet, about whether the intensive Interaction method is an end in itself, or perhaps a means (I think I mean a vehicle) to other ends. Actually, I think it might be both. Whatever the case may be, whether it's a means, an end, or both, I do know, unequivocally, that it's been a tremendous success in our classroom this year… and that's the easy part to explain…

As our sessions began to develop, they started to "overflow" into our class curriculum more generally. This just seems to have happened, a perfectly nature progression. This is why, for me at least, as I conclude my first year of teaching, Intensive Interaction is not strictly an end in itself. I see it rather as a ***resource****. Over the course of this year my kids have extended their average interaction time from an initial 1 – 3 minutes to routinely seeking and maintaining interactions for 20 – 30 minutes. This is the key: they seek and they maintain the interaction. This increased capacity, I've found, is transferable to everything else in the curriculum. It means that we can now do PECS (Picture Exchange Communication System) sessions for 20 minutes instead of 1 – 3. Some students are now self-managing for 20 – 30 minute music sessions, art classes…and so on across our curriculum. It's* ***access****. Best of all however, is the relationship, the two-way exchange that develops along the way. It's a genuine understanding and friendship. It's* ***contact****.*

In Conclusion;
We are eagerly awaiting the documented outcomes from the pilot project, as we are supremely confident that it will confirm what we have observed – that *Intensive Interaction* provides an important way for students who have PMLD to better understand the world, to learn to enjoy the company of others and be able to express themselves. At Bayside, we intend to play our part in making the approach available to others within our Special Education fraternity.

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The editor of the **Winter edition** of PMLD LINK is

Alice Bradley
A General Issue

The copy date for all articles, information and news for the Winter issue is the 1st November 2006 and the focus is a 'General Issue'.

Please send contributions to: Alice Bradley, 2 Chestnut Way, Cadzow View, Quarter, Hamilton, S. Lanarks ML3 7FD

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).

Intensive Interaction in Nottingham – Creative Partnerships

By Sue Thurman

Head of Speech and Language Therapy for Adults with Learning Disabilities, Nottinghamshire

> All persons, regardless of the extent or severities of their disabilities have a basic human right to affect, through communication, the conditions of their own existence ……. the right to be communicated with in ways that are meaningful, understandable and culturally and linguistically appropriate. (ASHA 1992)

The PMLD Network was formed in 2000 in response to the White Paper, Valuing People. There was a concern amongst many people supporting adults with profound and multiple learning disabilities that the White Paper failed to fully address the needs of this most vulnerable group of adults. The resulting document (PMLD Network, 2001) made a series of recommendations – some of which were related to communication issues – including:

- Further funding should be given to citizen advocacy schemes to ensure access to an advocate.
- Agencies should be required to have communication plans which focus on meeting individual needs.
- People with profound and multiple learning disabilities should be given priority for person centred planning.
- Staff working directly with people with profound and multiple learning disabilities should have access to high quality training, in particular, communication skills training.

The PMLD network followed this up with a survey in 2004 which revealed that people with high support needs were still being left out of the developments taking place across the country. The Valuing People Support Team subsequently issued guidance to Partnership Boards on 'including everyone' which concluded that the key barriers to good services were:

- people not understanding what people want because of communication difficulties.
- other people not expecting much for them.
- buildings in the community not having the things they need such as accessible toilets.

They also issued a checklist for Partnership Boards by which to check that all their plans included those with 'high support needs', asking them to

- Find a 'champion' - someone who will make sure that everything the Board does thinks about people with high support needs.
- Understand more - find out more about what it is like to live the life of a person with high support needs or for their family.
- Check work - look at all the plans they have written and work they have done and check that they work for people with high support needs.
- Work out what to do next and keep on talking and doing things to improve the lives of people with high support needs.

As a speech and language therapist working with adults with learning disabilities for over twenty years I have seen at first hand many improvements in services for the people I serve. However I have also become increasingly aware of the concerns of many parents and carers, well expressed in a letter from the parent of a 52 year old with profound learning disabilities cited in a recent newspaper article by Dominic Lawson.

'With the wider adoption of the euphemism 'learning disability', my wife and I, in common with many other parents, have noticed a decline in recognition of those people with the more severe and profound mental handicaps. This seems to be because officials and service providers too readily allow organised groups of able and articulate people with disabilities (albeit susceptible to manipulation) the authority to speak also for such as my son and his peers'
(Independent January 27th 2006.)

Whilst I would disagree with some of the arguments Lawson uses in his article to defend his use of the term 'mentally handicapped,' I share the concern expressed that not enough attention is being paid to the needs of people with profound and multiple learning disabilities in the current service culture (Samuel and Pritchard 2001, Gray and Chasey 2005). For several years, the Speech and Language Therapy team for adults in learning disabilities in Nottingham have attempted to promote the communication rights of individuals who face the most severe communication challenges. This has included the use of communication passports, multi-sensory referencing, meaningful ways of passing on information (Thurman et al 2005), simple communication technology and sensory and interactive approaches to communication. For many years the idea of Intensive Interaction had been promoted in both children and adults services by therapists but there had been only patchy take up of the idea. Few staff members knew about the approach and many young people left school without the approach being either fully explored or explained to their parents or being integrated into future care packages. We have therefore been excited by one of the most successful initiatives we have undertaken over the last few years which is the Intensive Interaction Special Interest Group. This is a group of people living and working in Nottingham who are interested in the use of Intensive interaction with adults with learning disabilities. The group has been established for over four years, following concerns from the speech and language therapy team that the communication needs of adults with the most significant communication difficulties in Nottingham were not being fully addressed. More information about the establishment of this group can be found in the article 'History of Intensive Interaction in Nottingham' on the Intensive Interaction website www.intensiveinteraction.co.uk.

The group meets quarterly and has become a much valued support for many different people including social workers, residential staff, day service staff, advocates, therapists and family members. Since the group was formed there have been changes in both the size and make-up of the membership and a number of achievements of which we are proud. The group has produced guidelines for the use of Intensive Interaction in Nottinghamshire. We have shared successes and frustrations in maintaining Intensive interaction in the different settings in which the members work. We had explored how Intensive Interaction can be sustained in the face of constantly changing services for adults with learning disabilities. A group of us, including speech and language therapy staff, day services officer, community care officer and a parent, did a presentation of our work at a regional Valuing People communication conference which was extremely well received. We have organized training sessions with outside speakers such as Cath Irvine and Phoebe Caldwell and also run our own in-house training sessions to give staff and others an awareness of what Intensive Interaction is all about. We have plans to develop our work further with the secondment of a member of social services staff to work with the speech and language therapy department to promote the approach further. We are also developing links with groups in neighbouring areas and learning from national developments such as those shared at the Intensive Interaction conference due to be held in Leeds in June 2006.

We have found Intensive Interaction to be one of the most useful approaches to the communication needs of adults with profound and multiple learning disabilities. One of the encouraging aspects of the group has been the way in which professionals and family carers have learnt from each other in supporting the communication needs of people with profound and multiple learning disabilities. The exchange of ideas between independent advocates, paid staff and family members has been central to each group understanding different points of view and has created a richness of shared experience and knowledge that continues to benefit the individuals we all support. The following case studies (based on real life examples, but with details changed to protect confidentiality) illustrate some of the positive outcomes of our work.

Case study one: One of the earliest people to join our group was the mother of a young woman with profound and multiple learning disabilities. Following a referral to speech and language therapy, the therapist quickly realized that this mum was already an expert in using Intensive interaction principles with her daughter but didn't know anything about the approach! Her story, which is not uncommon, was one whereby she felt unable to share openly with professionals the way she interacted with her daughter in case people felt she was not being 'age appropriate.' She told how she would stop using her usual ways of interacting in the light of comments from visiting professionals (including one who seemed more concerned that her daughter's 'communication rights' were being met by ensuring that her mum read out loud any mail that was sent to her daughter, even when it was clear she would be unable to understand their content!) This mum was thrilled to learn about Intensive Interaction although as professionals we felt there was little we could add to her current methods of communicating with her daughter. She was grateful for being given a label for describing what she did as she felt this gave her confidence in explaining to others who did not understand how to communicate with her daughter her rationale for doing what she did.

Case study two: Gina had attended the same unit at a local day centre for over ten years. Staff struggled to feel that they ever made real contact with her and Gina spent much of her day self-engaged in repetitive behaviours that blocked staff from engaging her successfully in activities. After coming on one of our training sessions, staff at the unit began to use Intensive Interaction utilizing finger moments and later vocalizations and returned to the next session with great excitement saying that they felt they knew Gina better after three weeks than they had done over the last ten years. Her parents had contacted them to ask them what they were doing with her at the unit because they had noticed how more interactive she was at home. When staff explained her parents remarked 'Oh that's what it is called – we do that all the time with her!'

Case study three: Leroy lived in a local nursing home. He has multiple learning disabilities and staff found his communicative signals very difficult to read. Whilst reviewing his care package, his community care officer, who had previous experience with Intensive Interaction, recognized that this approach would significantly improve his quality of life. She encouraged Leroy's key worker to attend some training and supported him to use this approach in conjunction with the speech and language therapist. The community care officer ensured that this Intensive Interaction was recorded as an essential component of Leroy's care package to increase the likelihood of its use being maintained in the future.

We hope to find further ways to involve and learn from more carers and family members in the year ahead. We have produced some simple leaflets explaining Intensive Interaction and also hope to put on some training sessions especially for families. There remain ongoing issues for service development that paid professionals have failed to resolve alone. These include:

- Ensuring that communication is seen as a vital right of all, irrespective of their disabilities.
- Understanding how to promote the sustainability of approaches such as Intensive interaction in overstretched services.
- How to learn effectively from families in ensuring the future needs of their relatives are successfully met by their future carers.
- Creating responsive environments for people with profound and multiple learning disabilities in the context of service modernization that seems to focus its priorities on the more able and independent people with learning disabilities.

We have found that listening and sharing ideas with family carers has allowed us to think outside our professional boxes and look for creative solutions to these and other longstanding issues. The dialogues that occur within the Intensive Interaction Special Interest group has reinforced our view that in order to develop truly person centred services for people with profound and multiple learning disabilities, it is important for professionals to, as Herb Lovett exhorted, 'learn to listen' to both our service users and their families and carers (Lovett 1996).

Further information

The Special Interest Group is open to anyone in the Nottingham area who spends time with an adult with learning disability for whom Intensive Interaction is a valuable way of communicating. For more information contact:

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Reading and resources

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Children Away from Home: Psychology's Role in the Dissemination of Information to Families

By Jo Graham and Sarah Weaver, Psychology Assistants, Sunfield

Sunfield residential special school is a school for children with severe and complex learning needs. As Psychology Assistants at Sunfield, our role is not only to assist in the positive management of behaviour and the teaching of skills, but also to liaise between all parties involved with our students. This is in line with our practice of providing a consistent approach in all aspects of our students' lives. As a fifty two week residential placement, Sunfield has many departments that work for our children, including care, education, health, psychology and therapies, however the most influential 'department' is inevitably the parents.

If any of the children are experiencing a difficult period of their life, a referral is made to the psychology department. As Psychology Assistants we are each responsible for a specific group of students and will take the lead on any cases referred regarding these students. Once a referral has been made we begin to gather information in many forms. These can be observations, functional analyses of recorded incidents and assessments involving interviews with parents and staff. Casework meetings are frequently held between all facets of the psychology and therapies department to generate ideas and strategies from varying therapeutic perspectives which all departments are consulted upon to ensure agreement.

Once ideas have been formulated a variety of methods are used to outline proactive strategies to be implemented. Consistency is essential for Sunfield students, as often their difficulties prevent them from generalising their behaviour in different settings. For example, behaviour practices which have been learned in one setting such as putting toys away at home, will often not be generalised to the school environment or vice versa. To ensure that the strategies are applied consistently, the recommendations are collated and disseminated to all involved, in a range of formats. The success of strategies and the relationship between all parties is dependent on proficient communication and explanation of recommendations. This is especially important for families as they are not immediately accessible within the residential setting but are the most influential in the child's life. Psychology uses a range of mediums with which to pass on information to families. These include reports, behaviour development plans and guidelines, presentations and workshops, meetings and reviews, video footage and phone calls:

- **Reports**- Whenever a report is written by the psychology department a copy is sent to families. This may be part of the annual review package or a report written to evaluate and monitor behaviour. Reports are written for a wide variety of recipients and avoid psychological jargon which may alienate readers. Frequently reports will conclude with recommendations to help reduce challenging behaviours and increase positive skills.
- **Video Footage**- Video footage is regularly used, both as a record of changing behaviour and as a tool for families. It also allows parents to see their child's capabilities with a specialist, such as speech and language therapists or therapeutic play workers. At regular intervals, therapeutic sessions are recorded for family groups to observe interventions. This then allows families the option of following the same methods when at home, to extend the child's use of their new skills. For example a therapeutic play session may provide families with further ideas of games to play at home, which is especially beneficial to siblings. Video footage is also valuable to every parent to monitor and recapture growth and development.
- **Personal Contact**- Personal contact can take place through informal and formal meetings and telephone calls. Informal meetings can take place during families' visits to Sunfield or via telephone, whereas formal meetings tend to take place at reviews. Personal, direct contact provides an introduction between the psychology department and members of the family. Families may then feel more comfortable in initiating contact, for clarification on issues and support. A meeting may involve discussion of the function of behaviours, recommendations and updates on progress. In addition to this a meeting may be called to gather information from the families in light of a referral. This could be a general discussion or structured interview for assessment purposes. In a formal review meeting families can gain an overall update on their child's progress from all areas of Sunfield. This is an ideal time to evaluate the effectiveness of strategies and recommendations when applied in the care, education and home environments. Personal contact can also involve seeking

permission from families for students to be involved in wider interventions, including research initiatives and counselling.

- **Workshops-** Workshops may be held to assist families and staff in the application of interventions. A workshop for example, can help to clarify and apply the proactive strategies included in behaviour development plans. It is also a positive method of enhancing staff and family contact as well as ensuring a consistent approach.

In a large residential setting such as Sunfield, consistency and co operation between all departments, but especially families, is of paramount importance to the child's well being. As Psychology Assistants it is our role to co ordinate positive behaviour management strategies to achieve collaboration. The use of sound communication methods is essential to facilitate a reciprocal channel to pass information between families and psychology. We also aim to offer guidance, support and reassurance to families and children when going through difficult times or periods of stability. It is always rewarding to find that we have made a difference to not only the child's life, but to their families too.

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Are any people with profound and multiple learning disabilities involved in 'user involvement initiatives'?

I would like to know if anyone has any examples of people with PMLD being involved in any of the many initiatives that are aimed at enabling people with learning difficulties to speak up about what is important to them.

I am interested in personal experiences or observations as well as any reports or research. Examples could be on a small scale such as one person who has got what they wanted from a service because they were included in something like a consultation or service evaluation. Or, it could be on a larger scale like two or three people with people with PMLD speaking up at a Partnership Board.

You may be thinking: well how would they do that? And that is exactly why I am asking this question. How *would they do that*? I know there are lots of ideas about how participation for this group could happen in theory e.g. building relationships, spending time, providing skilled advocacy, ensuring appropriate communication technology etc. But where is it happening in practice?

What I have found so far mostly focuses on how people with PMLD participate in decisions at the **individual** level. Some research reports on involvement of people with learning difficulties (without always stating anything about relative abilities) in decision making about policy and strategic issues. But I have not found yet many examples of research on the involvement of people with PMLD in policy and strategy; except to note their exclusion.

I would be very interested to hear your examples and your views on this issue.

I plan to feedback my findings to you and wider audiences in the future. Thanks.

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Building Pathways of Hope: Services and Families

> Hope is like a road in the country; there was never a road,
> but when many people walk on it, the road comes into existence.
> Lin Yutang (1895–1976)

By Chris Nield, *Head of Service and Educational Psychologist*, Juliette Brooke and Mark Conway, *Outreach Workers*, and Jo Egerton, *Administrator*, Sunfield Assessment & Outreach Service (SAOS)

Background

SAOS is a specialist service which offers relatively intensive support to children and young people with profound autistic spectrum disorder in many different settings within their communities. The service aims to complement and work alongside existing local authority services. The SAOS's multidisciplinary team consists of specialists in Education, Speech and Language Therapy, Psychology, Occupational Therapy and Social Care: staff who have all gained their experience through working in the challenging and highly specialised, 52-week, residential environment of Sunfield School for children with severe and complex learning needs.

Case study

[K.] is a young man, aged 17 years, who has a diagnosis of profound autism and significant additional learning needs. He was referred to Sunfield Assessment & Outreach Service for support by his local education authority because his specialised day placement had closed, supplementary respite had broken down due to the challenges of his behaviour, and his family were managing him at home. This situation had continued for almost three years. The family had sought help from the local authority only because [K.]'s behaviour was becoming more and more severe. The majority of the care had fallen on his father's shoulders. He managed [K.] on a daily basis, protecting the other members of his family and keeping [K.] safe and occupied. However, as with many teenagers as they enter their middle teens, [K.] had become less responsive to adult direction. At the time SAOS were asked to support, his community activities were extremely limited in terms of access due to his behaviour and size, which had contributed to a gradual narrowing of experience and opportunity for [K.] and his family.

Meeting [K.]'s family

When we met [K.]'s family, we were able to learn from them effective ways of interacting with [K.], and which strategies we could use to encourage him or to calm him when he became upset. [K.]'s parents welcomed our involvement, but were understandably anxious both about whether [K.] would be safe with us – and whether the SAOS staff would be safe with [K.]. They were very open and honest about what we could expect – from his cooperation educationally ('He might not sit down'; 'He might just rip paper'), to the challenges he could present ('He might push and hit'). This helped us to develop realistic expectations of [K.], and set achievable targets for him. [K.]'s family are deeply committed to him. Without denying the challenges [K.] faces and can present, they were also very concerned that he would be seen in a positive light; that SAOS staff would treat him as a person and accept him for who he is.

Stage 1: to ensure that SAOS could manage [K.]

[K.]'s family had supported him for three years without respite. Placements at interim non-specialist services had broken down because of [K.]'s behaviour, and the family needed reassurance that SAOS could manage [K.]. Initially, we spent time building up relationships, not only with [K.], but with his family as well. During early visits one Outreach Worker would spend time engaging with [K.], while the other would spend time talking with his father and mother, answering questions and finding out more about [K.]. To establish familiarity was important for all of us – SAOS, [K.] and [K.]'s family – as the basis for trust, predictability and good communication.

Over the course of initial support visits spent with [K.] and his family at their home, his parents sought to reassure themselves that SAOS staff were competent – by direct questioning, posing 'worst case' scenarios, and watching the outreach workers interacting with [K.]. The outreach workers were able to demonstrate their in-depth specialist knowledge and experience of profound autism, and reassure the family by using anonymous examples from their own experience of working at Sunfield School with young people who have a similar profile to [K.]. The outreach workers were also working towards a point where they could predict how [K.] would react in most day-to-day situations, and be confident that [K.] trusted them enough to rely on them if he was in difficulty.

Stage 2: to enable [K.] to attend Sunfield

Once it became clear to [K.]'s family that we would be able to manage him, we began to work towards the next stage – enabling [K.] to attend Sunfield. As [K.] had been out of school for so long, it was unclear what his tolerance of a school environment would be. We put together a stepped programme of support for [K.] with the goal of him being able to spend initially half-days, but eventually whole days, at Sunfield, away from his family home.

An essential feature of enabling [K.] to accept coming to Sunfield was to make Sunfield a predictable environment for him so he could manage his anxieties around change and unfamiliarity. There were two stages in this. The first involved creating a visually structured teaching environment (advocated by the TEACCH organisation; cf. Mesibov and Howley, 2003; Shea and Schopler, 2005) in order that [K.] would be able to focus and learn. [K.]'s classroom structure allows him to see, in the form of visual, concrete tasks, what he has to do, how much he has to do, when he has to do it, and what will happen afterwards. When he understood this, he was happy to sit down to work, and we could begin to build in intermediate steps between his current skills – e.g. sorting and matching shapes – and his goals for long-term independence and purposeful occupation – e.g. using his sorting and matching skills to put away cutlery in a drawer at home. Continuing the use of the TEACCH structured teaching approach supported him in gaining success.

The second stage involved establishing a reliable, formal means of communication between us and [K.] to extend his own family's well-established and informal methods. From assessment, we knew that [K.]'s understanding was very visual and concrete. By introducing a communication system based on 'objects of reference', we could help [K.] predict what he was going to be doing within the next few minutes. This lowered his anxieties. Even if he became distracted on the way to a destination, for example, and forgot where he was supposed to be going, he still had the object of reference grasped in his hand to refer to. The system also provided a means by which [K.] himself could accept or reject activities, or request alternative activities! The speed with which [K.] learned the associations taught, and began to use the system to his own advantage, suggested that he felt the need for it and benefited from it. The system allowed him to self-advocate and make his wishes known to us. [K.]'s family, too, began to use an object of reference to show [K.] when he would be going to Sunfield for the day.

Currently, [K.] has built up his attendance at Sunfield to three days per week. This has been possible because he understands the structure in which he is expected to operate, knows what is expected of him, and, through the communication system, has the capability to make his own requests for activities if they are available. If they are not, the related objects are removed from his object bag. Having learned from [K.]'s family about effective ways to work with him, we are now able to begin to feed back alternative strategies that we find useful at Sunfield and which might (or might not) be useful for them in their family environment.

Stage 3: extending [K.]'s skills

Once the foundation of an individually tailored learning environment and communication system had been put into place, we began to build on the hope that [K.] would learn skills which could be transferred, with structured learning, to a real-life environment, e.g. his family home or a respite placement. However, for this to happen, [K.]'s family needed to see how he was working at Sunfield using structured teaching and the objects of reference communication system.

[K.]'s father has been able to visit Sunfield, and see, at first hand, [K.]'s success within an educational environment using these methods. He was able to see how [K.] managed his own anxiety through the use of the objects of reference and used them to anticipate what he would be doing next. The outreach workers had the opportunity to explain how [K.]'s work system operated. Mr A. saw that [K.] was able to remain seated while doing tasks, to undertake a simple puzzle, and to perform simple activities which would be the basis of household and independence tasks. He saw him dining in a social setting, and saw him interacting with the outreach workers. SAOS also benefited from Mr A.'s visit to Sunfield, as he was able to offer the outreach workers his advice and perspective on [K.]'s responses and behaviour.

This has not been a partnership just between SAOS and [K.]'s family. Another vital part of the link has been [K.]'s social worker from Children's Services and two of the adult team involved in planning for [K.]'s transition who were enthusiastic and committed enough to visit [K.] at Sunfield. Having seen the structure in which [K.] works at Sunfield, they appreciated its importance for [K.]'s future achievements.

Hope for the future

Although [K.]'s behaviours, when he is anxious, upset or agitated, are still challenging, he has achieved much over the past six months, and the skills he has learnt will form a foundation for future achievements in many situations. The key to maintaining [K.]'s level of formal communication – using objects of reference – and his use of visual structure is to develop and adapt these approaches consistently and appropriately across all of the environments he accesses. It may be that, while his family have an effective, in-depth understanding of his informal communication in his home environment, they might see a place for a formal communication system (i.e. objects of reference) in building new activities and skills which [K.] could contribute in the home or community. [K.]'s family, SAOS and Social Services together have been able to begin to construct a pathway of hope for [K.]'s future.

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DY9 9PB

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Website of organisations Mentioned in this Issue	
Disability Services Queensland 2005	http://www.disability.qld.gov.au/quality/index.cfm
Mencap	http://www.mencap.org.uk/html/campaigns/PMLD/index.htm
PCSP (UK) Ltd	www.posturalcareskills.com
Options holidays	www.optionsholidays.co.uk
Somerset Total Communication (2005) *Information for the public: Somerset Total Communication (STC)* Somerset County Council	http://www.somerset.gov.uk/somerset/socialservices/pi/stc/
Intensive Interaction	www.intensiveinteraction.co.uk

Postural Care Skills Programme: Empowering Parents and Carers

By Liz and John Goldsmith, Helping Hand Company Ledbury
(http://www.helpinghand.co.uk/)

24-hour Postural Care enables individuals with movement difficulties to grow and/or stay as straight, independent and comfortable as possible. Good physical care is fundamental to wellbeing and has a profound beneficial effect on quality of life for the individual and all those who care for them. A course called the Postural Care Skills Programme has been devised to provide a qualification for families and carers, to give them the knowledge and skills to successfully self manage this condition.

Current Provision, Culture and Value Base: The Medical Model
In 1976 a seminal article was published (Fulford and Brown) which identified position as a cause of what was then termed "deformity" and called for physiotherapeutic intervention and yet in 2005 there are no relevant National Standards and services to provide this care are still inadequate. Services routinely fail to provide either structured training or a reliable source of equipment and label the family's difficulties with making changes in care routines as "non–compliance". The difficulties involved in producing scientific evidence in relation to these multi-factorial physical, behavioural and social issues are used as an excuse to discredit common sense solutions to obvious problems. Individuals are left to lie and sit in easily avoidable destructive postures which result in permanent damage to body structures.

A specialty known as "Postural Management" has been seen as the province of therapists, with core standards of the physiotherapy profession reflecting a medical model of care. The terminology employed by therapists subscribing to this concept reveals a culture in which families are expected to do as they are told and includes the terms "Assessment" and "Prescription" with lack of "Compliance" being cited as a major difficulty. Adherence to the medical model has paralysed progress in this field with numerous therapists adopting an inappropriate stance as "The Expert" expecting "Compliance" from families who in fact have encyclopedic knowledge and experience of living with chronic complex needs. This lack of respect for carers, both family and professional, results in unacceptable attitudes within the profession which need to be challenged if the present value base is to change. Whilst progressive therapists welcome the opportunity to transfer power from transient professionals to those who live with the challenge, some openly ridicule carers and their efforts to do their best:-

"Too often I feel the choice of equipment is viewed more as a "shopping expedition" for parents to choose an item of equipment rather than guided by the expert as to which best meets a child's needs" This comment was published in 2003 in the Association of Paediatric Chartered Physiotherapists Journal.

"The problem with the Postural Care Skills Programme is that it will encourage them to "fiddle" with things I have set up".

"A little knowledge is a dangerous thing".

"Don't get me wrong, how can I put this? The carers we are talking about are paid carers, they are low quality and they don't care, can't understand and won't benefit from training".

Some are confused about who services are set up to help - "As a qualified physiotherapist I fail to see what I get out of the Postural Care Skills Programme. Do I get an MSc or a Doctorate?" The answer to this query is that the physiotherapist may be reassured that her intrusion into other people's lives is likely to result in long lasting benefit.

Cultural Change: The Social Model
When searching for solutions to these problems the option of employing enough therapists to provide 24 hour care for all those in need is clearly impractical and it is suggested that a social model of empowerment to raise widespread knowledge and skill must be considered. (Carpenter 2000. Samuel, J. Pritchard, M. 2001) When considering the timings involved it is clear that Postural Care has to be applied by families and carers on an ongoing basis:-

There are 8,760 hours in the year
Typically an individual will spend approximately:-
1,140 hours at school or 1,440 at day care

7,620 hours with their family
3,600 hours in bed

The key to providing successful postural care is to empower families and carers. Valuing people with PMLD recommends that family and professional carers should have access to high quality specialised training to provide the best possible care. At present many individuals are responsible for providing complex care, but are left without the understanding, training and equipment required. By empowering and valuing carers through quality assured training, we value people with movement problems.

The terminology of those subscribing to the concept of Postural "Care" includes "Empowerment through Education" "Collaboration" and "Support". The Postural Care Skills Programme acknowledges, enhances and formalizes the already existing, vast skill of families and professional carers. They are taught therapeutic principles, carry out their own risk/benefit analyses and make their own plans as to how theory can be applied to the complexities and reality of their situation. Within the social model the Tutor may come from many different backgrounds but demonstrating genuine respect for both family and professional carers, and the rewarding but demanding work they do, will be a fundamental requirement. Given the highly structured nature of the course they will easily acquire the necessary clinical skills. Tutors will provide high quality training, collaborate to access appropriate equipment and then give ongoing support

The Need

The vast range of existing skills of both family and professional carers needs to be enhanced and formalised so that the following principles become common knowledge:-

1) Identification of need

This section covers how and why the body distorts with identification of destructive postures and conversely the supportive symmetrical postures which protect body shape.

(Symmetrikit Postural Care Pathway 2002)

2) Pain and Consent

This section contains analysis of pain and non-pain related behaviours leading to the development of a baseline score so that pain can be monitored and managed. This also allows the individual's level of consent to be identified and respected.

3) Achieving Thermal Comfort

The concepts in this section cover understanding of the complexity of achieving thermal comfort when both the reflex and behavioural components of thermal regulation may be compromised. Learners apply routine monitoring of core temperature and application of appropriate thermal care.

4) Therapeutic Positioning at Night

The topics covered introduce an understanding of the behavioural complexities, physical dangers and disturbances of sleep behaviour in those with neurological impairment. Students learn about application of therapeutic positioning at night in a safe, humane manner (Night positioning has been found to be effective in preventing/reducing distortion of body shape as it typically accounts for approx 4000 hours per year at a time when the body tends to be relaxed and susceptible to gentle supportive forces).

5) Use of Equipment

This covers use of postural care equipment effectively, safely and humanely.

The Programme

A highly structured course to provide this training has been developed, the course is a nationally recognised qualification, quality assured through the Open College Network at Warwick University, and an independent education provider, PCSP (UK) Ltd. www.posturalcareskills.com

Implementation of the course consists of investment in existing personnel by training Postural Care Tutor/Managers to deliver the General Skills course to family and professional carers. In this way postural care skills can be introduced over a wide variety of services including residential and family homes, day services and schools.

The process takes 1 year for the Tutor/Manager and 6 months for the General Skills Learners. The General Skills course is carried out over six x 4 hour long tutorials with project work to be completed in between.

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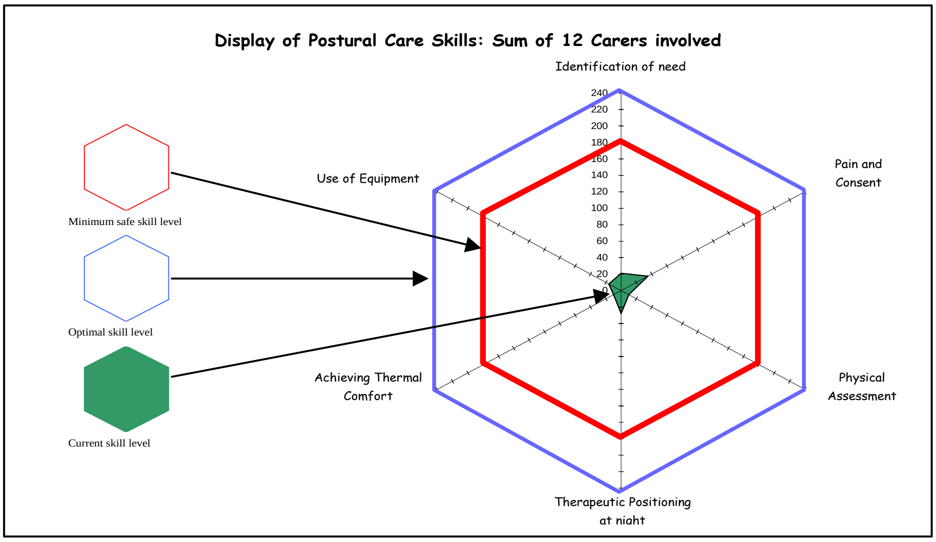
Samuel, J Pritchard, M (2001) "The Ignored Minority: Meeting the Needs of People with Profound Learning Disability" *Tizard Learning Disability Review, Vol 6 Issue 2, 34-44*
Symmetrikit Postural Care Pathway (2002) Helping Hand (Ledbury) Ltd, Ledbury, Herefordshire
Valuing People with PMLD (2000) *PMLD Network*

Outcome Measures

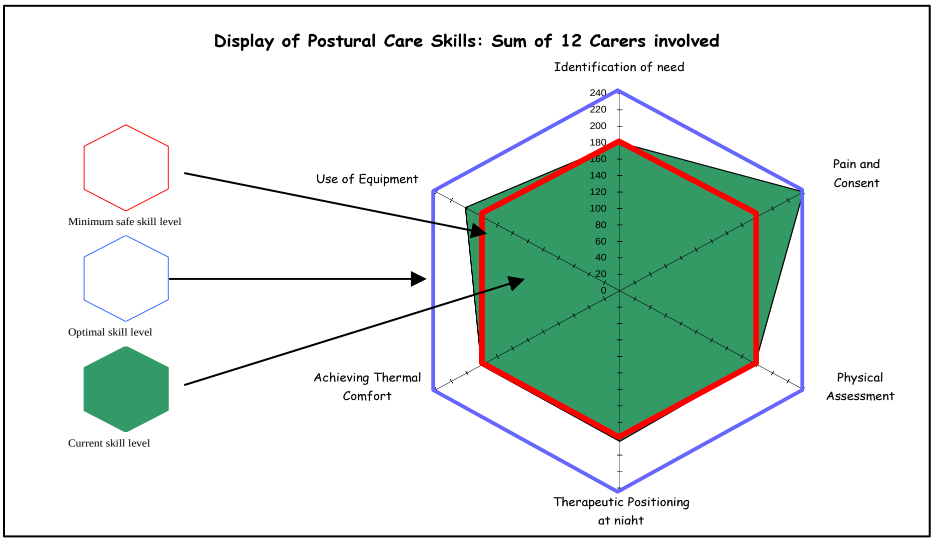
Learner Skills profiles (see example below) can be completed prior to the course and on completion to illustrate either individual skills or consolidated team profiles and manage progress.

The Helping Hand Company
Bromyard Road
Ledbury
Herefordshire
United Kingdom. HR8 1NS

Consolidated Pre- Course Skills Profile



Post course Skills Profile



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Grow Your Own Specialist

Michael Thompson, Former Headteacher : Emily Fortey School, Leicester (1999-2004)

It is difficult to conceive that anything positive could have come out of the Soham murders. However, in the curious way in which seemingly unconnected events become linked, those dreadful events of 2001 could be said to have led, indirectly, to a raising of the professional skills of staff working with pupils with profound and multiple learning difficulties at Emily Fortey School Leicester. Strange, but true.

In Summer Term 2001, when I was headteacher at Emily Fortey School, we appointed a teacher coming to us from mainstream, a teacher trainee on the Graduate Teacher Programme and five new teaching assistants – all to start with us the following September. The previous career profile of these potentially very effective new staff will be familiar to any special school when trying to recruit – very little, if any, experience of working with pupils with severe learning difficulties and no experience whatsoever of working with pupils with profound and multiple learning difficulties. Since specialist initial teacher training courses for teaching pupils with SLD/PMLD disappeared in the early 1980s, we have grown to expect that any teachers coming through our doors will need to be trained up to be specialists – on the job, and often from scratch. In fact, it is more common for new teaching assistants to have some experience in the field, as these posts in special schools often attract applicants from associated agencies – social services, health, voluntary sector etc.

Prior to 2001 we had followed what (we thought) was the only route open to us regarding induction training for staff with little knowledge and skill in working with pupils with profound and multiple learning difficulties – one, possibly two, introductory training days at the very start of the autumn term (before the pupils start) then "on the job" support and advice using physiotherapists, advisory teachers, twilight training – very much a "learning as you go" model of professional development. In practice, the initial training days could only cover generic aspects of working in the school and very seldom, if ever, managed to touch upon the specifics of working with pupils with PMLD. A typical "first day of training" for a new member of staff at Emily Fortey School looked like this (See Table One).

This (with the follow-up support and "hands-on" training) was what we had planned for our new intake of staff in September 2001. In fact, they had already received this training the previous Friday when, at 7.30am on the first day of term, I received an urgent fax from Human Resources at the LEA telling me that government advice was that new members of staff could not begin working with the pupils until they had been cleared by a Criminal Records Bureau check. (This was the knee-jerk reaction to the public outcry around fact that Ian Huntley, the Soham murder suspect, had worked in a school but seemed to ignore the point that he had, in fact, had CRB clearance).

School Aims	School Development Plan
Behaviour policy	Child Protection
Our curriculum	Absence procedures and timekeeping
Tour of the premises and finding resources	Health and safety fire procedures • **manual handling** • **swimming pool safety drill** • **tidiness** • **hazardous substances and procedures** • **epilepsy**
Summary : A typical school day	

Table One

Our qualified teacher was fine – she had CRB and list 99 clearance – so she could begin teaching straightaway. This still left me with six members of staff drinking coffee in my office while I spent the first part of the morning hastily arranging cover. By lunchtime they had tidied the PE cupboard but we were an orderly school and I was not sure I had enough for them to tidy for the rest of the week! One of our senior teachers (our qualified Makaton trainer) had non-contact time on a Monday afternoon and came to the rescue with some Makaton training to keep them gainfully employed until the end of the day. Realising that, if this was going to go on for a week (it was estimated there was at least a week's backlog in CRB checks) the best thing I could do was offer more training, I began to work the phone.

By the Tuesday morning, owing to the great goodwill and flexibility of colleagues from Leicester City LEA Special Needs Teaching Service and the school nursing service, we had set up a full week of training including gastrostomy feeding, moving and handling, an introduction to visual impairment, and an introduction to hearing impairment. I canvassed the opinion of our new recruits and they all felt that they were much less apprehensive of working with our pupils with the most extreme difficulties having had this whole week of induction. In other words, they felt much more confident on the second Monday morning (by which time the government had back-tracked and allowed them into the classroom) than they had felt on the first Monday morning – even though they had not had contact with the pupils for the whole of that first week. (When I suggested to them that they would be feeling even more confident by now if they had actually been in class for the first week, their reply was that this was true, but they could still gain that "hands-on" confidence with the added benefit of a full week of very relevant induction training). Their enthusiasm was a tribute to the quality and relevance of the hastily-arranged training and the knowledge and professionalism of the multi-professional team.

This gave us food for thought over the following year. In adversity, we had chanced upon a very effective way of giving quality induction training, but at what cost. Had we actually created an unsettling "false start" to the term for the pupils? Which was best - for new staff and classes to begin to get to know each other straightaway, or for this process to begin in week two, with staff feeling more professionally confident? As a senior leadership team, we felt these questions were answered for us as the "hands-on" training proceeded across the year. Comments from staff along the lines of "this is much easier to grasp having had that first week of training" were complemented by those of the trainers "this year's new staff are much easier to work with having had that first week with them".

We decided to "go for it" the following year and make that first induction training week part of our practice. Having had more time to organise and structure it second time around, our induction training week in 2002 (which again followed that first more "general" training day) ran as follows (See Table Two).

MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY
Moving and handling training Led by : School's own qualified trainer	Working with pupils with visual impairment Led by : LEA (Advisory teacher for visual impairment)	Makaton Sign Language Led by school's own Makaton trainer	Gastrostomy training Led by School Nurse Feeding techniques Led by Speech and Language Therapist	Managing challenging behaviour Led by School's "team Teach trainer"
ICT facilities for pupils with PMLD Led by : School's ICT technician	Using the sensory room to develop cognitive skills Led by : LEA Advisory teacher for visual impairment	Working with pupils with hearing impairment Led by LEA Advisory teacher for hearing impairment	Afternoon reading Policies + procedures. Discussion of interaction policy. Location : staff room	Food hygiene training (External trainer : City catering)

Table Two

For all staff, this initial training week was just the start of a two-year cycle of training which ran at the school every Friday afternoon. A cross-section of one third of the staff attended each week, and sessions were repeated three weeks in a row.

This “Friday training”, as we called it, happened during assembly time, for one hour. Identifying this time as a weekly slot for training ensured that we were not “too busy sawing to sharpen the saw”.

The Friday training had a strong “health and safety” emphasis and, wherever possible, training was accredited and added to the online professional development portfolio we maintained for all staff. Across a two year cycle, it looked like this :

Course	Provider
Feeding and Tube Feeding	School Nurse + SALT team
City Pool Test	City Council trainer
Epilepsy and Rectal Valium	School Nurse
Hygiene in toilets and bathrooms	School Nurse
Food hygiene	City Catering
First Aid Awareness	St John’s Ambulance
Physical restraint (Team Teach Refresher)	LEA Behaviour Support Team
Child Protection	LEA Child Protection Officer
Hoist Training (Teams of 12)	Red Cross trainers

+ Renewal of full first aid qualifications (9 staff), City Pool Tests and Minibus Tests : as appropriate

Course	Provider
Feeding and Tube Feeding + Hygiene in Toilets and Bathrooms – Refresher	School Nurse
Fire Training	(LEA Health and Safety Officer)
Safety in the pool area	PE Coordinator
Drugs Education	Drugs Adviser : LEA
Epilepsy and Behaviour	(School Nurse) + PSHE Coordinator
Moving + Handling Training	School’s fully trained Moving + Handling trainers
Reporting accidents and incidents (S02, SO1, Accident Book, First Aid book)	Headteacher
Team Teach refresher.	LEA Behaviour Support Team
Health + Safety relating to school minibus.	School transport officer

Course	Provider
Physical Restraint (Team Teach – full course)	LEA Behaviour Support Team
Feeding and Tube Feeding	Nicola Bellis (SALT Team) + School Nurse
First Aid Awareness Training	St. John’s Ambulance
Food hygiene	City Catering
Hygiene in toilets and bathrooms	School Nurse
Stress Awareness (Teaching Team + Nursery Nurses Team)	Browns Health and Safety Consultants
Stress Awareness (LSAs)	Health and Safety Consultants
Hoist Training	Moving Solutions
Safety in the Pool Area	PE Coordinator
Child Protection	Michael Thompson, Susan Pesic-Smith
Risk Assessment	Michael Thompson, Ian Dennies.

This “Friday training”, as we called it, happened during assembly time, for one hour. Identifying this time as a weekly slot for training ensured that we were not “too busy sawing to sharpen the saw”.

As stated to the Investors in People Assessor at the end of the second year of organising our “basic needs” training in this way “its not just a skills thing, it’s a confidence thing”. Our interview procedures at Emily Fortey School ensured that we employed people with the right attitude – we recognised that the obligation to give them the knowledge and skills was ours and this article, hopefully, is a snapshot of how we went about it.

Impact on standards? On teaching and learning? On pupil performance? Well, surely you have a more smooth running classroom – therefore more efficient curriculum delivery - if you have a teacher who knows how to use a hoist, how to set up a switch programme, how to create a non-glare environment, how to use a loop system etc, than one who doesn’t? Ours was a decision to “get in quick” with the training and therefore take away the fear of the unusual and the unknown.

Michael Thompson
(Headteacher : Emily Fortey School, Leicester 1999-2004)

Definition: people with profound and multiple learning disabilities

Drawn together by Beverley Dawkins, PMLD Officer, Mencap

We are publishing the latest version of the PMLD definition which has been drawn together and editied by Beverley Dawkins from people who contribute to the PMLD-Forum.

Why are we describing people with 'profound and multiple learning disabilities'?

Children and adults with profound and multiple learning disabilities are, like everyone else, unique individuals. But sometimes it is helpful to talk about groups of people who have common concerns. This can help us as a society to make sure that people's human rights are upheld. A good example of this is people who come from minority ethnic groups. Another example is people with profound and multiple learning disabilities. At the moment the needs and rights of people with profound and multiple learning disabilities are frequently neglected.

It is vital that we understand the distinctive needs of people who are often excluded from society. That's because, in doing so, we are respecting their right to be included. It is only by focusing on their needs and rights and working to remove the barriers that they face that people with profound and multiple learning disabilities will achieve their rightful place in society. This approach supports the social model of disability. But it also acknowledges that while many barriers can be challenged and even removed, ultimately we cannot change the nature of people's disabilities. In doing so we are not being discriminatory, rather we are respecting people's differences and valuing them for who they are. At the same time we can continue to fight for equal rights.

Who has profound and multiple learning disabilities?

Children and adults with profound and multiple learning disabilities have more than one disability, the most significant of which is a profound learning disability. All people who have profound and multiple learning disabilities will have great difficulty communicating. Many people will have additional sensory or physical disabilities, complex health needs or mental health difficulties. The combination of these needs and/or the lack of the right support may also affect behaviour. Some other people, such as those with Autism and Downs Syndrome may also have profound and multiple learning disabilities. All children and adults with profound and multiple learning disabilities will need high levels of support with most aspects of daily life.

Learning needs. Like all of us, people with profound learning disability will continue to learn throughout their lives if offered appropriate opportunities. To do so it is important to understand that most people are likely to be learning skills that generally appear at a very early stage of development. For example cause and effect, such as pressing a switch to make something happen or turn-taking, such as rolling a ball between two people. Learning is also most likely to take place very slowly. For example, some people may have a very small short- term memory and will need the opportunity to encounter events many times before they become familiar. Constant repetition and a great deal of support will be needed to generalise learning into new situations. Supporting the learning needs of a child or adult with profound and multiple learning disabilities will also need to take account of any additional needs, such as sensory needs (see below) so that the best approach to learning can be established.

Communication needs. Many people with profound and multiple learning disabilities rely on facial expressions, vocal sounds, body language and behaviour to communicate. Some people may use a small range of formal communication such as speech, symbols or signs. However there are some people with profound and multiple learning disabilities who may not have reached the stage of using intentional communication so they may rely on others to interpret their reactions to events and people. Most people are also likely to find it difficult to understand the verbal communication of others. Some people will rely heavily on the context in which the communication takes place, such as the clues given by a routine event. It is important for those who support people with profound and multiple learning disabilities to spend time getting to know their means of communication and find effective ways of interacting successfully.

Physical needs. Some people described as having profound and multiple learning disabilities are fully mobile. Many people may use a wheelchair. Others have difficulty with movement and are unable to control or vary their posture efficiently. These individuals will need specialised equipment to aid their mobility, to support their posture and to protect and restore their body shape, muscle tone and quality of life. It is vital that people with physical needs have access to physiotherapy, occupational therapy and hydrotherapy, and that those who care for them are trained to enable them to confidently manage their physical needs on a day to day basis.

Complex health needs: There are a wide range of conditions that children and adults with profound and multiple learning disabilities may have, such as complex epilepsy. There are an increasing number of people who are described as being ‘technology dependent’, such as needing oxygen, tube feeding or suctioning equipment. Some people have conditions that are described as ‘life-limiting’. Others have fragile health and may be susceptible to conditions like chest infections and gastro-intestinal conditions. Skilled support may be needed for feeding and swallowing as good nutrition is a vital part of achieving good health. Many people may experience a combination of medical needs and access to specialised health support will be needed to ensure the holistic management of these conditions.

People with profound and multiple learning disabilities experience the same health conditions as the rest of the population. The challenge is about how these are identified in people who may not be able to communicate their symptoms easily. For example, it is very important that effective ways of recognising and managing pain are developed. It is crucial that a proactive approach is taken to ensure that each person is able to achieve the best possible health they can, for example by arranging annual health checks and support to access general health care.

Sensory needs. Special attention needs to be given to the sensory needs of people with profound and multiple learning disabilities. Many people have some degree of visual and or hearing disability or a combination of both. Some people may have their sense of taste or smell effected by the drugs they may be taking. Other people may be hypersensitive to touch. It is essential to know as much as possible about a person’s vision, hearing and other senses so that the most effective way of approaching their learning and communication needs can be developed.

Understanding behaviour. Some behaviour that is seen as challenging may arise because little attention has been given to other needs. It should never be assumed that certain behaviours are just part and parcel of having profound and multiple learning disabilities. For example a behaviour that services may see as challenging, such as pushing people, may be an attempt to communicate a need. Other changes in behaviour may be due to undetected health needs such as scratching the face because of a toothache. However, some behaviour will be because people are simply doing things that they enjoy, for example putting a hand under the tap to enjoy the feeling of running water. The important thing is to understand what the behaviour may mean and to respond accordingly, such as checking out any possible health causes or making changes in the environment.

Mental health needs. The mental health needs of individuals with profound and multiple learning disabilities are often not considered. For example, someone who becomes very quiet and passive may be seen as having improved their behaviour when in fact they are depressed. Research suggests that people with profound and multiple learning disabilities may be more susceptible to mental health conditions than the rest of the population so it is important that careful attention is given to these needs and the right treatment and support found to meet them.

Profound and multiple learning disabilities and other syndromes or conditions. There are many other conditions and syndromes used to describe people, some of who could also be described as having profound and multiple learning disabilities. Some examples of those more usually associated are Retts Sydrome, Tuberous Sclerosis, Batten’s Disease and some other rare disorders. However, some people who are described as having Autism and Downs Syndrome may also have the combination of profound learning disability and one or more of the needs we have discussed and therefore could be equally described as having profound and multiple learning disabilities.

Support needs. All children and adults with profound and multiple learning disabilities will need high levels of support from families, carers and paid supporters. This will include help with all aspects of personal care such as washing, dressing and eating, as well as ensuring that each individual has access to high quality and meaningful activity through out their lives. Those who offer this support will need access to good quality and appropriate training, especially around particular skills. For example, on particular feeding needs and communication approaches. Good support will be person-centred, flexible and creative to enable the person with profound and multiple learning disabilities to learn and to achieve their full potential.

Why not use the term 'high support needs' or 'complex needs'?

It is true that people with profound and multiple learning disabilities have high support needs. It is most likely that they will need 24-hour- a-day support with all aspects of their lives. Their needs are also complex, for example the range of medical conditions that they often experience. However, these terms alone do not help others to understand the specific issues that affect their lives. This is because there are many other people who could be described by these terms who do not have a profound learning disability.

For example someone with a physical disability and communication impairment may be described as having complex needs or high support needs. The famous scientist and author Stephen Hawking is an example of this. The provision of a wheelchair, good personal support and an effective communication device enables him to demonstrate his high level intellectual ability.

Attitudes

One of the greatest barriers that people who have profound and multiple learning disabilities face is the negative attitudes of others. Judgements are made about the meaning and quality of people's lives. This can stop people being offered some of the more innovative forms of support, such as individual funding, because some people do not think that they will benefit or think that the costs involved are too high. But these negative attitudes can also be life-threatening, for example, if they result in the denial of medical treatment. These judgements are only ever subjective. Most people do not know what it is like to have a profound learning disability and perhaps experience the world by touch and smell. Neither do they reflect an understanding of the contribution that each individual will make to the lives of the people around them.

It is important that everyone understands that people with profound and multiple learning disabilities have the same rights as every other citizen. We must enable each individual to engage with their world and to achieve their potential so that their lives go beyond being 'cared for' to being valued for who they are as people.

Training for students to become registered nurses for people with learning disabilities (RNLD).

The University of the West of England provides training for students to become registered nurses for people with learning disabilities (RNLD). Many of these nurses go on to become unit managers and learning disability community nurses.

Over the past year we have worked with families and people with learning disabilities to review the way we prepare students to work as qualified nurses in learning disabilities. This has resulted in us developing a learning opportunity for students to work within a family for 7.5 hours a week over the second year of their training.

We are therefore looking for families who care for a person with learning disabilities to work with us and become actively involved with our students. We recognise that families may be diverse and support children, adults and older people, or may be parents themselves with a learning disability. Whatever your family situation we feel your involvement with our students is vital in their development of knowledge and skills gained from working within a family.

If you live with the areas of Gloucestershire, Bristol, Somerset, Bath or Swindon and would like to find out more please contact

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PMLD Network Forum Digest November 05 - March 06

pmld network

Personal Held Records

Discussion on personal held records for children and young people with profound and multiple learning disabilities. Request for a model that includes details on communication and aspects of healthcare. For joint use by parents and all professionals. Suggestions included the Early Support family pack available from their website, (www.earlysupport.org.uk), multimedia profiling, personal communication passports and person centred plans.

Epilepsy monitor

Ideas for getting an epilepsy monitor that can detect if someone if having a seizure even if they are still moving after a fall, were requested. A company called Easy Links, (www.easylinks.co.uk), were recommended several times.

Establishing Communication

Ideas were swapped around establishing communication with someone who is non verbal and does not use signs. Among the suggestions were using: pictures, objects of reference, intensive interaction, communication passports, photos, establishing relationships and building trust. Several resources were suggested, *Everyday Lives, Everyday Choices* and *Choice Discovered* available from the Foundation for people with Learning Disabilities as well as websites on multimedia profiling and intensive interaction, www.acting-up.org.uk and www.intensiveinteraction.co.uk respectively.

Funding for CA

Suggestions for getting Citizen Advocacy for young people with complex needs schemes funded were requested. Ideas included social services/local authority, www.carers.org, PRTC, local council for voluntary services, directory of social change, (www.dsc.org.uk), www.trustfunding.org.uk and "funderfinder".

Learning Disability Nursing

It is apparently sometimes difficult to find jobs in this area. There was encouragement and support in pursuing them though and several suggestions including moving regions, applying straight to local trusts and private providers.

Young People with Learning Disabilities Dying

Questions were asked around palliative care and arrangements regarding choice. It was suggested that it is important to include the young person's wishes and not just those of the parents.

Intimate Care

Advice on intimate care for those at an all age special school was requested. Several sets of guidelines were offered. Useful resources can be found on,
www.choiceforum.org/intimate.netdoc.doc and
www.choiceforum.org/scottishcentre.doc

Youth Matters: Next Steps

After their consultation on the youth green paper the government announced their next steps. They want to offer more funding which will go into children's trusts and have said information, advice and guidance should be more flexible and easier to access. They also plan to have better targeted support co-ordinated by a lead professional for young people experiencing difficulties.

PMLD dementia assessment tool

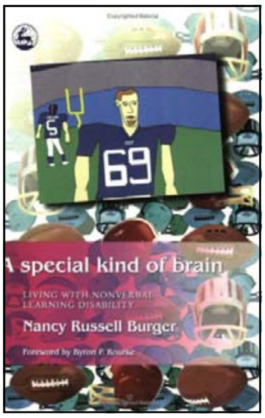
Request for an assessment tool for recognising early onset dementia in people with profound and multiple learning disabilities. One was suggested that has been devised based on a Wheland and Speake assessment. (See forum for details).

Protective clothing

A request for a supplier of "bibs" that are both attractive and absorbant for adults with PMLD. Suggestions included www.seenin.co.uk www.dribble-bandanas.co.uk or Disability Resource Centre, Lancaster Road, Harlescott, Shrewsbury, SY1 3NJ, Tel: 01743 444 051.

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 7802 0316. Fax. +44(0) 20 78020301. Email: nmorris@fpld.org.uk Website www.learningdisabilities.org.uk Registered charity No: 801130 Company Registartion No: 2350846

Reviews



Title:
A Special Kind of Brain - Living with Nonverbal Learning Disability

Author:
Nancy Russell Burger

Publisher:
Jessica Kingsley Publishers

ISBN 1843107627

Pub Date: 2004

Nancy Russell Burger's book is about a family's experiences when one of them has Nonverbal Learning Disability (NLD). This is a condition that has profound effects on all of them, and is caused by a dysfunction of the brain's right hemisphere effecting both boys and girls.

She describes NLD as presenting like Asperger's Syndrome but it is not on the autistic spectrum.

Ms. Russell Burger gives a moving account of her own and her husband's shock and pain when their eldest child is first diagnosed with NLD, their feelings of ignorance about the condition and search for information. She writes about having to sift through the avalanche of material available on the Internet, and the importance of not becoming overwhelmed by it.

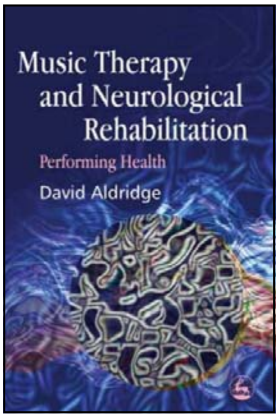
This book is important for its accessibility, and the descriptions of situations and problems that arise when living with a child with NLD. The book shares some practical, flexible solutions, which the author found worked in her family, and most importantly for her child.

There are helpful chapters on diagnosis, parenting, school and social skills, - each with a very useful summary at the end. Ms. Russell Burger describes her son's development and behaviour throughout, and how she and her family adjusted to his needs in order to maintain his, and their own quality of life.

Whilst Jimmy is not described as having profound learning disabilities, this book is more about the love and closeness of a family's support for this young man and how they have coped together with life events, diagnosis and the official processes so far to date.

I was so impressed with this book that I intend to now go out and buy a copy to give to a friend whose daughter has just been told her son has been diagnosed with NLD. I think it will give her a useful insight for the future, and how best to support her daughter and much loved grandson.

Frances Bain
Residential Care Worker
Penhurst School



Title:
Music Therapy and Neurological Rehabilitation: Performing Health

Author:
D. Aldridge, Ed.,

Publisher:
Jessica Kingsley Publishers

ISBN 1843103028

Pub Date: 2005

This book is a clear, concise and often lyrical exploration of communication during and through rehabilitation. The Editor orchestrates a collection of dialogues that provide the reader with an insight in to the use of music as therapy with people experiencing profound or severe neurological difficulties.

In addition to the descriptions of a range of music therapy interventions the contributors outline the effects of a range of neuro degenerative conditions including dementia, multiple sclerosis and traumatic brain injury. There is also discussion about possible consciousness of those who are diagnosed as being in the persistent vegetative state. This is handled with sensitivity and with reference to spirituality and ethics. It illustrates perceived instances of communicative intent where the person in coma 'encounters' the therapist and is able to react, through minute adjustments of position, alteration to rhythm of their breathing and eye movements.

Whilst this book doesn't incorporate in depth studies relating to people with congenital profound and complex needs it clearly encompasses studies of responses to music from those with acquired profound or severe and complex needs and one can see potential for wider application. It should appeal both to the professional therapist, carers and staff working with people with neurological deficits and those involved with people with congenital profound/severe complex needs.

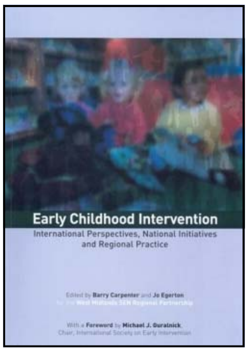
Examples of relevance to the above groups are the descriptions of taped music used during activities of daily living, which describe reduced agitation during meal times and bathing for those who have dementia. The use of taped music immediately proposes the advantage of being accessible and affordable for all staff and carers and those who they work with, requiring no specific training or expensive materials.

Another activity that could be incorporated into daily life without excessive expense or training is the taping of auditory aspects of an activity such as cooking and the replaying of this tape to clue people in to the activity at a future time. The use of such tapes, with people with dementia, coupled with olfactory cues, is described on page 57 and 58 and concludes that using more than one sense increases the recall potential.

Of interest to staff and carers working with people with profound and complex needs will be G. Tucek's example (Page 221) of the use of an instrument as a sound experimentation opportunity for a woman with acquired profound disability. Throughout the book the reader is reminded of the importance of dialogue and communication and of the desolation experienced when this breaks down. For people who have literally 'no voice' with which to engage in the turn taking of conversation music can allow them to be heard, to break the silence and begin to interact with others.

Music Therapy and Neurological Rehabilitation is a book that will be appreciated by those with a professional or personal interest in enhancing the quality of life of people who experience profound barriers to communication. It will also hold interest for anyone working in areas requiring research as the requirements for valid and reliable studies are explored in some detail. It is artistically written and gives the reader the feeling they have encountered the authors and been enriched by this experience.

Julia Prince
Curriculum Leader for ***Enhancing Quality of Life (EQOL)***
Provision for adults with brain injury and/or severe/ profound and complex needs
Somerset college of Arts and Technology, Taunton



Title:
Talking to Families - Listening to Families.

Author:
Barry Carpenter

Publisher:
Sunfield

Pub Date: 2005

This is a collection of articles illustrating the development of Family Services and family focussed models of practice. The papers (11 in total) date from 1998 - 2004 and the pack contains an up - to - date forward by Philippa Russell.

Although the papers have been published elsewhere, the beauty of this pack is that it brings together a wealth of information from a family perspective. This would make it particularly useful for students, professionals and carers and save much leg-work in sourcing the information.

The main themes of the papers cover partnership working between professionals and the family starting with the family first. The papers also look at the roles and needs of different family members and the quality of the all the articles is extremely high – though no peer review is offered with any article.

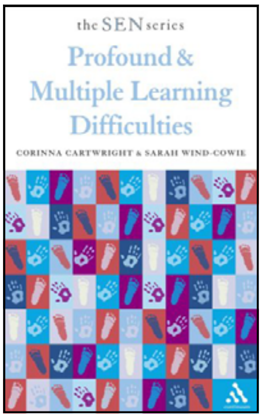
Much of what is written is about the family that includes a disabled child, and as such is highly relevant to all families who have a child with profound and multiple disabilities. The pack may be less useful for those families with adult children – although probably an interesting read and proactive families and professionals in adult services may wish to follow the family centred method of working.

Most of the papers are either written by, or co-written by the editor who is also parent of a child with learning difficulties.

This pack of papers is available from Sunfield School only and costs £8.50 (tel. 01562 882253 or TraceyD@sunfield.worcs.sch.uk).

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

Title:
Profound and Multiple Learning Difficulties (Special Educational Needs Series)



Author:
Corinna Cartright and Sarah Wind-Courie

Publisher:
Continuum London

ISBN 0826478360

Pub Date: 2005

This small, very readable book is packed with information regarding current best practice in the education of pupils with PMLD. The running theme throughout the book reflects huge respect for the needs and rights of these pupils with clear insight into the components of appropriate educational provision.

With a wealth of practical ideas and suggestions, this book is invaluable for any classroom staff to read and essential reading as part of induction for anyone new to this field of work. Other professionals within the school, students and volunteers will all find it accessible and digestible as a description of, and rationale for, quality educational provision for pupils with PMLD.

Debbie Wilson
Head teacher School for Children with Special Needs

http://www.everychildmatters.gov.uk/

This government web site is all about children's services from the governments perspective. It is quite an exciting time at the moment with lots of policy and legislation driving the children's agenda forward.

On this web site you can access key documents and see how the health, social services, education and voluntary sectors are been driven to work together in providing one seamless service. The links and build up on this site are happening at a great speed and there are several areas that are interactive, which would be a good avenue for parents to feed into.

Children with profound and complex needs are included here and it is important to keep the profile raised by interacting on this site. However as the wealth of information on this site grows it is becoming harder to find specific information on services and reports that are primarily addressing this group. I'm afraid much is about reading and searching for relevant clauses within more general focussed child information

The site includes sections on such areas as schools and youth so that you can find specific information here, and includes a newsletter – the first being about Professor Al Aynsley-Green appointment as England's first Children's Commissioner. This appointment happened 1st year at the beginning of March 2005. There is also information about the latest proposed changes to the school system and also information on the Vulnerable People Bill currently before parliament.

The site is easy to use and navigate your way around although there is a danger of it becoming too overcrowded. There is also link ups to your area of the country where you can read about good practice schemes. At the moment it lacks feed-in on the discussion boards from service users but since its inclusive approach is highly visible I'm sure this will change.

Di Foxwell
Coordinator of Clinical Education and Practice Development – BHCT NHS Trust and Distance Tutor with Birmingham University.

Report Back ....

The Intensive Interaction Sustainability Conference: June 7th 2005

Conference report:
The 2005 Intensive Interaction sustainability conference in Leeds addressed the issue of the sustainable adoption of the approach as a method of developing fundamental communication and sociability with clients who have severe or profound learning disabilities. Over 70 delegates attended from all over the United Kingdom, with one special school principal attending from Melbourne, Australia! The delegates included care workers, speech & language therapists, psychologists, teachers, learning disability nurses, and a number of service managers and directors.

The informal feedback from the delegates and speakers alike was very encouraging, with the overall opinion being that the conference was enjoyable, informative and enthusing in equal proportions. As well as the four presentations given by Mark Barber, Theresa Moyes, Graham Firth and Dave Hewett, four delegate workshops provided many practical suggestions for effective and sustainable Intensive Interaction service innovations. We report on the discussions in these workshops.

The afternoon workshops split the delegates into four groups to discuss the 'sustainability' of Intensive Interaction from different perspectives, or service levels. The groups were asked to identify a long-term vision for Intensive Interaction adoption, and also to identify the practical steps required to turn such a vision into a sustainable reality. The chairs from each group then reported back to the whole conference, and their reports are summarised below.

The Practitioner Level Workshop: this group identified issues that were important for sustained Intensive Interaction adoption from a practitioner's perspective. These included:

- The need for an ethos change for any involved organisation
- Intensive Interaction should have equal status with other approaches
- Intensive Interaction practitioners need supportive managers, who should also have Intensive Interaction training
- Intensive Interaction practitioners need 'on-going support' after initial training
- Intensive Interaction should be part of a client's Person Centred Planning (PCP)
- Services and staff need to share information on a client's interactive successes
- Induction training in Intensive Interaction for teaching and nursing staff should be compulsory

The Unit Managerial Level Workshop: this workshop identified a more strategic picture of the issues involved. Some issues were identified that could make sustained Intensive Interaction adoption problematic, including that Intensive Interaction is labour and resource intensive, it therefore needs long term investment in both these areas. The goal-directed ethos of organisations is potentially problematic for Intensive Interaction with its more intangible social outcomes. There is also the potential for conflict between approaches e.g. behavioural interventions. Finally, there was also a lack of inspirational leaders. However, the group did identify a range of measures to support sustainable Intensive Interaction adoption. These included:

- Creating mechanisms to maintain change e.g. creating Intensive Interaction coordinators or steering groups
- Creating a unit or organisational policy embedding the philosophy of Intensive Interaction
- Promoting the use of video – the most powerful tool in demonstrating the practical use and potential outcomes of the approach

The Organisational Strategic Level Workshop: this workshop identified issues that were important from an organisational perspective. They clearly identified a 'passionate individual' or champion as central to the process of practice change and Intensive Interaction adoption. They also recommended:

- Possible NOCN (National Open College Network) accreditation of Intensive Interaction courses to strengthen the perceived validity of the educational provision
- National support is required to 'push the right buttons' for Intensive Interaction adoption, possibly using the Valuing People white paper (DOH, 2001), ECM (Every Child Matters) and the Children's Bill to guide

future practice change in this area

- Reporting on areas of good organisational practice e.g. in Somerset
- Including Intensive Interaction in the PCP process
- Families and carers should have an important role as advocates
- Greater publicity was required e.g. articles in mainstream journals, perhaps even a T.V. programme.

The National Strategic Level Workshop: this workshop had a wide ranging discussion about national or 'strategic' issues. There was some discussion around the formation of an official institute, although there were concerns raised about what level of formality would best serve those who practice the approach. The issue of 'quality control' for Intensive Interaction training was raised, however, there were concerns expressed about making Intensive Interaction appear too 'expert' or centrally sanctioned. Information dissemination was also discussed, and greater use of currently available means was advocated (including more active use of the official website at *intensiveinteraction.co.uk*). Further conferences, both national and regional were also recommended, as was the development of regional Intensive Interaction Special Interest Groups.

2006 Conference:
The official feedback by the conference delegates was very pleasing and because of the success of the day, the 2006 Intensive Interaction Multidisciplinary Conference is currently being organised. The provisional date for your diaries is Tuesday 13th June 2006, in Leeds (email graham.firth@leedsmh.nhs.uk for further details).

Graham Firth
Intensive Interaction Project Leader and
Conference Chair

INTERCONNECTIONS ELECTRONIC BULLETIN ABOUT CHILDREN WITH DISABILITIES / SEN

About the Interconnections Electronic Bulletin

It comes from Peter Limbrick who set up Interconnections in 1995 to offer independent consultancy to statutory services in the field of babies and children who have disabilities / SEN. Peter is also Chair of the Handsel Trust (visit www.handseltrust.org)

The Interconnections Electronic Bulletin goes free to over 6000 people (and growing) in all parts of the UK and Ireland and then finds it way into many other networks and countries. The Interconnections electronic address list includes people from health, education and social services, the voluntary and private sectors, parent organisations, research organisations, campaign offices, etc. People who receive the bulletin are welcome to forward it to their own colleagues and networks and to use the information in newsletters and bulletins as long as the '**Interconnections Electronic Bulletin'** is acknowledged.

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

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

NEWS, PUBLICATIONS AND RESOURCES

David Fulton: 'Retired', but still working for those with PMLD

By Christina Tilstone,
Regional Tutor in Special Education,
The University of Birmingham

David Fulton officially retired in 2005 from the publishing company he founded in 1987, and David Fulton Publishers is now part of the Granada Learning Group. His contribution to the special needs field has been outstanding. Not only has he systematically and relentlessly encouraged teachers and other professionals working in the sector to write about their practice, but he has had the courage and conviction to explore, what others may regard as, the 'Cinderella' areas of special education. His publishing house, along with Jessica Kinglsey Publishers and BILD, provided (and still provides) one of the few sources of information and resources on aspects of the teaching and learning of children and adults with PMLD. His interest in the PMLD field comes from the fact that he values people – all people, and regards everyone as 'special' and worthy of recognition.

Such a principle of recognition has meant that he has really 'listened' to teachers and other professionals, and encouraged them to articulate their views on what they required in order improve their practice. His talent for paying attention to the needs of others has meant that not only has he persuaded the academics in the PMLD field to share their opinions and expertise, but he has successfully persuaded practitioners to contribute their skills and ideas to the development of knowledge. Such a combination has, on the one hand, enabled theory to influence practice and on the other, practice to influence theory. Not a bad legacy in an area little written about before he can on the scene!

David's retirement does not mean that he will not continue to work for all those with special educational needs including those with PMLD. He has recently become the Chair of Finance and General Purposes Sub-Committee of NASEN (National Association for Special Educational Needs), and has already used his influence to encourage the Granada Group to work collaboratively with the organisation to publish jointly high quality publications on SEN. The venture is now established and readers of PMLD Link can be assured that their interests will be well looked after by a proven advocate and a good friend. Thank you David!

New materials aim to support parents from minority ethnic communities raising a child with a learning disability

Many parents from minority ethnic communities raising a child with a learning disability do not get the support they need, according to research by the Foundation for People with Learning Disabilities. Language and cultural barriers can make it difficult for parents to communicate with services. The charity has produced a range of free materials for parents.

· First Impressions: Emotional and Practical Support for Families is a booklet written in Urdu for parents raising a small child with a learning disability, which aims to provide emotional and practical support.

· Meeting the emotional needs of young people with learning disabilities from minority ethnic communities is an audio CD available in Urdu, Punjabi and Sylheti for parents raising a teenager with a learning disability.

Alison Giraud-Saunders, Co-Director of the Foundation for People with Learning Disabilities says; "We know that parents raising a child with a learning disability do not always receive enough support and it can be especially difficult for those whose first language is not English. It is important that all parents are supported and we hope that these resources are useful."

The booklet and the audio CD are both available now from the Foundation for People with Learning Disabilities. To order free copies call 020 7803 1100 or visit www.learningdisabilities.org.

Health and Social Care White Paper shows good intentions, says Foundation for People with Learning Disabilities

The Foundation for People with Learning Disabilities welcomes the intentions of the Government's white paper, Your Health, Your Care, Your Say. However, the charity believes that measures still do not fully ensure that people with learning disabilities are supported to access mainstream health services and engage in their communities.

The Health Secretary, Patricia Hewitt, has outlined proposals for the future of health and social care, including extending Direct Payments and piloting Individual Budgets. The Foundation believes this will give people with learning disabilities more control over their lives and encourage services to become more responsive to their needs. However, the charity believes that other proposals should be developed in more detail.

Hazel Morgan, Co-Director of the Foundation for Learning Disabilities, said: "The Department of Health must expand upon other measures if people with learning disabilities are to receive the support they need. We welcome a closer integration of health and social care but joined up working should include looking at all aspect of a person's life, including education, employment and leisure. Also, the Foundation has been calling for annual health checks for the last ten years and hopes that the commitment to regular checks will be speedily implemented.

"A major neglected area is support for family carers. Many need regular short term breaks that are flexible and can be accessed when the family experiences an emergency. Also, older family carers need trusted workers to help them and their relative with a learning disability plan for the future. We have a major concern that support for those in a caring role cannot be delivered without additional funding. The Government must seriously consider how to meet these additional needs."

Swindon Parent Partnership Service (SPPS)

SPPS offers parents and carers independent information and support about all aspects of their children's special educational needs, particularly during Statutory Assessment. Information is given to parents via the telephone, by letter, a home visit or by parents just dropping into the service base. Parents may have as little or as much help as they want. This may involve support at meetings, helping with paper work and reports, or just as a listening ear. Support is provided Parent Partnership staff or by trained, volunteer Independent Parental Supporters (IPS).

We are always looking for parents who are interested in supporting new parents through the SEN maze. If that might be you, then ring Jill for details of how to train to become an IPS.

SPPS runs a bi-annual SEN Forum. This gives parent and volunteer representatives an opportunity to highlight any concerns they may have and discuss SEN issues with LEA Officers. It gives LEA Officers a chance to hear directly from parents and carers and to build their views into policy development. For the first time Social Service Managers joined the Forum this May and will be attending all future meetings. We are always looking for wider representation from parent support groups. If your group would be interested in participating please contact Susan to discuss.

"Supporting Parents Information Network" (SPIN) meets six times a year. We try to cover a wide range of issues that may be of interest to as many parents of children with SEN and/or disabilities as possible. This is the agenda for the rest of the year. We are very happy to have suggestions from parents on topics they would like covered.

SPPS also supports schools by helping them develop and extend partnership working with parents in a variety of ways. This may include helping to run SEN information sessions, setting up parent support groups or direct training on partnership working.

For more information about how SPPS can support parents contact:
Susan Bennett,
SPPS Co-ordinator,
01793 466494, or
email sbennett@swindon.gov.uk
Jill Wells, SPPS Assistant,
01793 466515, or
email jillwells@swindon.gov.uk

Options holidays

Option Holidays Ltd, are a registered, not for profit, company. We can organise holidays on request and have access to experienced qualified carers, as well as, when necessary, medically qualified personnel who can accompany families. We can normally find appropriate accommodation, however it must be noted that we do not generally use nursing homes as a venue, but ordinary hotels or villas that have some facilities for the disabled. So the amount and type of equipment rather depends on what we, or the family would be able to take to this place, or what we can hire at the venue.

We would see our service as working alongside the family to provide the support needed to enable the whole family to have a holiday together. This may mean that for part of the time the child/adult who has PMLD may with the support of our carers, access one type of leisure activity whilst parents access another activity with brother or sister. When the person concerned also requires to stay in the accommodation due to maybe being too tired then one of our carers would stay back to enabling the rest of the family to continue their planned activities.

Sometimes we also take groups (of teenagers for instance) of people who have learning disabilities on holidays, and with good fore planning this could include someone who has profound and multiple learning disabilities

We generally make all the travel arrangements, unless the holiday is in the UK, and the family can get to the holiday destination unaided. This is because we have the experience and contacts to do this more easily than many individuals would have, and also we are aware of some of the pitfalls and problems that can occur.

We would normally provide 2 staff for the holiday, and they would eat, sleep and take part in all the activities as far as possible. They are aware that they are there to work, and not to have a holiday at someone else's expense.

As far as costs are concerned, we cannot really quote until we have some idea of what the individual requirements are. Obviously a large proportion of the costs are in staffing the holiday, but the other variables like do the family prefer full board or self catering, where they wish to go on holiday, are they prepared to travel at inconvenient times, would they like to get together with another family and perhaps share some of the costs, have to be taken into account. We would quote for the total package, except for insurances for the family members and of course personal expenses of the family.

As far as we are concerned there is really no reason why a family with a disabled member should not go on holiday wherever they wish - within reason (Iraq would at present be considered unreasonable - for example), and we would do our best to come up with a package that suits. However, organising a package and getting the appropriate staff can take a little time, and we do require a reasonable amount of notice. Last minute bookings are rarely satisfactory, and no cheaper in the long run - despite what some travel programmes and the man down the pub might say.

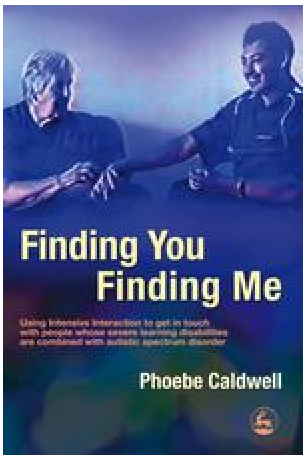
Some of our popular overseas holidays are to:- the USA, Canada, Northern Portugal, Turkey and Tunisia – as well as cruise holidays (ideal for those in wheelchairs).

We also do themed holidays both abroad and in this country, for music lovers, theme parks, Elvis fans, Star Trek conventions, gourmet foods, crafts, outdoor pursuits and train fans. The above sounds like it might be widely expensive; however you may be quite surprised at some of the packages we can put together.

For further information about us and the holidays we do in this country, plus prices, visit our web site www.optionsholidays.co.uk
As specialists in organising holidays for people with disabilities we have been operating for over twenty years, and over recent times we can include some Mencap home residents and local authorities, as well as families amongst our clientele.

If you have any further queries please contact us either by email (opthols@hotmail.com) or telephone 07000790348

Geraint Williams
Options Holidays Ltd



Author (s): Phoebe Caldwell

Publisher: Jessica Kingsley Publishers

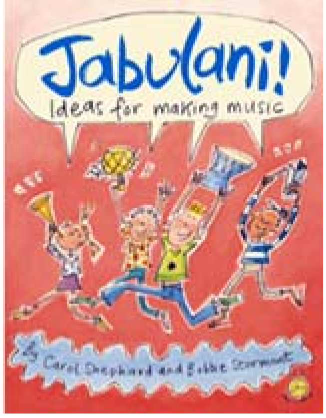
ISBN: 1843103990

Pub Date: 2005

Price: £13.99

Finding You Finding Me

This new book makes accessible for the first time the complex, intricate inner and sensory worlds of people whose learning disabilities are combined with autistic spectrum disorder and, often, difficult-to-manage behaviour. Based on many years of working with such people, many of whom have withdrawn into a world of their own, she explores the different sensory reality they experience, showing it to be infinitely more complex and varied than is widely understood.



Author: Carol Shephard and Bobbie Stormont

Publisher: Hawthorn Press

ISBN: 190345851

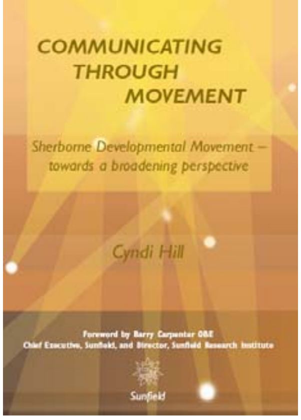
Pub Date: 2005

Price: £14.99

Jabulani!

Ideas for making music

Jabulani! has all the tools you need to enjoy creating music - without having to read music or follow a song-sheet. Find your voice with chants and raps, write your own songs, and celebrate rhythm with marching, finger clicks, clapping and rumble games. The activities are suitable for all ages and abilities, including those with special needs.



Author: Cyndi Hill

Publisher: Sunfield Publications

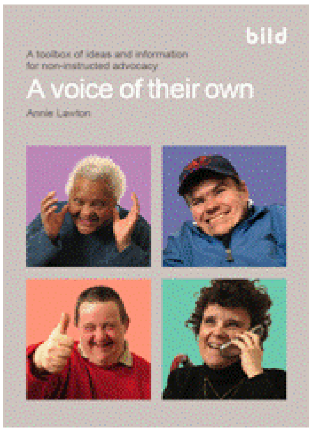
ISBN: 0955056802

Pub Date: 2005

Price: £14.99

Communicating Through Movement: Sherborne Developmental Movement - Towards a Broadening Perspective

In seeking to engage children and young people with severe learning difficulties in interactive learning, Veronica Sherborne developed a unique way of working with them which became known as Sherborne Developmental Movement. In its conception, she drew on her knowledge of child development and her intense interest in human movement and its psychological implications. Whilst her ideas are well-documented in her films and videos, and in her own book, this book by Cyndi Hill addresses the many requirements, issues and aspects surrounding her work.



Author: Annie Lawton

Publisher: BILD

ISBN: 190408298

Pub Date: 2006

Price: £16.00

A Voice of Their Own

A toolbox of ideas and information for non-instructed advocacy

This toolbox is a place to come for ideas, suggestions and contact details to help you ensure your advocacy partner has a voice, is listened to and is taken seriously by others who can bring about change.

It is particularly useful for anyone advocating for a person with high support needs by which we mean anyone who does not communicate using words, has significant barriers to communication and/or complex physical, health or emotional needs and requires lots of extra support as a result.

ADVERT

Short Courses and Conferences *2006*

CONTACT 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

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

Concept Training

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

EQUALS

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

Catalyst Education Resources Ltd

1A Potters Cross
Wootton, Bedfordshire MK43 9JG, U.K.
Tel. 01234 764 108
E-mail: FloCatalyst@aol.com
Web: www.cerl.net

Consent

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

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

April

28th
Catalyst
The Sensory Brain <- -> The Thinking Brain
28th April London

May

4th
TEAM AROUND THE CHILD (TAC)
Thistle Hotel, Piccadilly Gardens, Manchester
interconnections
Peter Limbrick, 9 Pitt Avenue, Worcester, WR4 0PL
Tel/fax: 01905 23255,
E-mail: p.limbrick@virgin.net
www.icwhatsnew.com

5th
Every Child Matters Outcomes: what do they mean for disabled children?
University of York
This is a multi-disciplinary conference.
Teresa Frank
t: 01904 321950
e: tjf3@york.ac.uk

10th
PowerPoint for PMLD (a hands on course)
Sunfield PDC
At the end of this course those participating will have:
- A knowledge of the many different uses and applications that PowerPoint can be used for when devising educational activities for all learners, but especially those experiencing PMLD.
- The skills to produce activities with Text, pictures sounds and videos.
- A knowledge of where to find further resources to use in their PowerPoints

Martyn Maltby - Deputy Managing Director, Liberator Ltd

19th May
Concept
Using Intensive Interaction
Reflect on your experiences and change the way you work to build more fulfilling relationships with people who have profound learning disabilities and complex needs
Trainer – Janet Gurney
EXETER, Matford Centre

19, 20 & 21
Sunfield PDC
Sherborne Developmental Movement - Advanced Level III
This is a 3 day residential course which is open to all participants who have attended a SDM level 2 course prior to June 2005 and have been using SDM in a work situation for at least 1 year following the course.
(a 3 day residential course)

19th
Catalyst
The Sensory Brain <- -> The Thinking Brain
19th May Leeds

24th May
Concept
Using Intensive Interaction
Reflect on your experiences and change the way you work to build more fulfilling relationships with people who have profound learning disabilities and complex needs
Trainer – Janet Gurney
COLCHESTER, Ramada Hotel

25th
The Child Bereavement Trust
Additional Training Workshop
"Communicating with Families when Children have a life Limiting Condition and Complex Needs"
Venue: The Child Bereavement Trust, Aston House, High Street, West Wycombe, Bucks. Hp14 3AG
Tel: 01494 479749
website www.childbereavement.org.uk
or Emai:l training@childbereavement.org.uk

25th May
Concept
Using Intensive Interaction
Reflect on your experiences and change the way you work to build more fulfilling relationships with people who have profound learning disabilities and complex needs
Trainer – Janet Gurney
MAIDSTONE, Grangemoor Hotel

26th
The Liver-pool ASD pathway is providing training on Understanding ASD and the affect on the child and behaviour (2 sessions)
Session 1 Friday 26th May
Session 2 Friday 9th June
Venue: Lace Conference centre
The Training team on 0151 225 4969

June

9th
Creative Communication:
How to listen to people who do not use traditional communication methods
This interactive communication training is beneficial for anyone working with, for, or on behalf of people with learning disabilities and/or high support needs.
Kate Duncalfe – Sole Trainer – CAN Communicate

12th
'Speak Up, I Cannot See': The Impact of Hearing on Vision, Integrating the Senses.
A one day conference for professionals supporting children with vision impairment and multiple difficulties run by the Vital Group with Leicester City Council.
Contact Becca Palmer on 0116 225 4800 or email
Rebecca.palmer@leicester.gov.uk

14th
Sunfield PDC
Intensive Interaction
This course will be of interest to staff of all disciplines who work with adults and children with severe learning difficulties. Intensive Interaction is an approach where the member of staff is seen as the main teaching resource, using personal qualities of face, voice and body language to involve the learner in progressive sequences of interactive activities.

14th
BILD
Advocacy
The role of a self advocacy supporter
Event code RSAS3
The day will look at strategies for supporters to develop their skills and those of people with a learning disability, to run effective self-advocacy groups.

15th
Risk management in challenging behaviour and physical interventions
Kidderminster
This one day event is designed for staff working with people whose behaviour may pose a risk to themselves or others. They will have some previous experience of problem behaviours from being in practice, and may have attended related training.

19th
Creating a communicative and interactive environment for learners with PMLD
Mark Barber
The University of Northampton
CPDE office: 01604 892695
cpde@northampton.ac.uk

29th
RNIB – Sounds of Intent: Music for Children and Young People with Complex Needs
Bristol tel 0117 953 7750

July

6th
Interactive Storytelling
Keith Park
The University of Northampton
CPDE office: 01604 892695
cpde@northampton.ac.uk

November

29TH
Sunfield PDC
A Conference Celebrating 35 Years of Education for Children with SLD

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

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 a 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

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.
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 Disaibilities: Life Long Learning
6. Either: Special Studies in Special Education or Practtioner Inquiry in Education

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

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

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

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

Students working on BPhil or Postgraduate Diploma programmes with some additional activities can, on successful completion, be recognised as meeting the requirements of the DfES for the mandatory qualification for teachers of children with multisensory impairments.
For further details please contact: 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 please contact: 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 please contact: Dr Stuart Cumella, Division of Neuroscience on 0121 414 4507 or email: S.Cumella@bham.ac.uk

Postgraduate taught MSc 24-36 months
Profound Learning Disability and Multi-Sensory Impairment MSc— *Distance Learning*

The course is aimed at students who personally and professionally come into contact with individuals with complex learning needs and sensory impairments, or who have a desire to gain the specialized knowledge related to this area of interest.

- To provide a unique opportunity for a wide range of people to acquire knowledge and skills to empower them to enable individuals with very complex needs to reach their full potential.
- To provide an increased knowledge and understanding of children and adults who have complex learning needs and sensory impairments.
- To enable those directly concerned with this group to advocate for the rights of the individuals concerned and work towards improving their quality of life and community presence.
- To enable this to happen by providing current information relating to cognitive, emotional, physical, sensory and social needs.

For further details please contact: Email pg-education@manchester.ac.uk or telephone 0161 275 3337

Postgraduate taught PG Diploma
Profound Learning Disability and Multi-Sensory Impairment PG Diploma - *Distance Learning*

The course is aimed at students who personally and professionally come into contact with individuals with complex learning needs and sensory impairments, or who have a desire to gain the specialized knowledge related to this area of interest.

- To provide a unique opportunity for a wide range of people to acquire knowledge and skills to empower them to enable individuals with very complex needs to reach their full potential.
- To provide an increased knowledge and understanding of children and adults who have complex learning needs and sensory impairments.
- To enable those directly concerned with this group to advocate for the rights of the individuals concerned and work towards improving their quality of life and community presence.
- To enable this to happen by providing current information relating to cognitive, emotional, physical, sensory and social needs.

For further details please contact: Email pg-education@manchester.ac.uk or telephone 0161 275 3337