PMLD LINK
sharing ideas and information

Therapies

Winter 2011

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

GUEST EDITORIAL

Therapies

As Peter Limbrick and his colleagues point out, defining “therapy” is not always straightforward and they explore critically what is ‘therapy’ and what it really means to be a ‘therapist’. Helpfully, they offer guidelines for the uninitiated about how to make appropriate selections from the growing number of therapies that are on offer.

It is good to have a family’s view of therapy. Rebecca Ormian and her family share their experience of postural care, a twenty-four hour therapy using systems of support, while Jenny Whinnett and Anna Waugh hail the new Postural Care Campaign, following Jenny’s son’s experience when postural care systems were not available.

The significance of modern equipment, a well designed environment and staff training, feature in the articles by physiotherapists. Jenny McLaughlin working in a school, Gemma Smith, in a residential transition service, and the physiotherapy team in Newham’s community health team, working with adults with learning disabilities in the community, value their resources and explain their work in enhancing joint mobility, relaxation, communication, independence and access to active activities.

Dorian Thomas describes the impact of therapists working together as a multi-disciplinary team to provide day services staff with training that empowers all staff to improve their practice and achieve important outcomes for the people they support, both in the context of their normal routines and their activities.

Communication is a focus of several articles. Lisa Margetts tells us about Music Therapy and how, using piano and percussion, she has engaged a young man’s interest by listening and responding, enabling him to become aware that he has a means of communicating with another person. Janet Dowling tells us that she aims to communicate with children with acquired brain injury through traditional and made up stories using multi-sensory objects and materials. Coryn Memory powerfully illustrates the need to truly listen to what children and young people might be needing to say and to mitigate the potentially overwhelming sensory impact of commonly occurring events and activities. In an example from adult services, Thomas Chalk and his colleagues describe a genuine attempt at consultation in Leeds using three communicative approaches to ensure that the voices of people with PMLD have been ‘heard’ and translated as accurately as possible, when developing services.

Paula Hellal explains the key principles for developing a personalised and meaningful communication system using objects of reference and describes Helen who has been given a new opportunity to make decisions using this system. Clare Caughey describes “interaction therapy” and, building on her research into Intensive Interaction, provides yet more evidence that it pays to devote time to fulfilling the basic human need of people with PMLD to socialise and to find common ground, a pleasure shared on equal terms.

We thank all our contributors for helping to make this issue of PMLD LINK such an interesting package and we are sure that all readers will enjoy and appreciate the contents.

Chris Fuller and Rob Ashdown

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Professor Chris Kiernan An Appreciation

We would like to take the opportunity to comment further on some important points raised in Chris Kiernan's obituary by Professor Hogg (PMLD LINK, Summer 2011, Issue 69, p.39). Chris Kiernan produced several publications in the 1970s and 1980s which had great influence on many teachers, classroom assistants, nurses and others working with children and young people with severe learning difficulties. His work was invaluable in offering a principled and systematic approach to addressing the needs of these learners, particularly those with profound learning difficulties and with minimal understanding of spoken language. Regrettably, it seems that many of these important publications are now out of print even though they have not yet been bettered in many respects.

For instance, Chris Kiernan and Barbara Reid produced the Pre-verbal Communication Schedule (Kiernan and Reid,1987) at a time when there were no other British assessment procedures that asked questions about the abilities of this group of learners or how they used their communicative skills to affect the world around them. The PVCS gathers information that helps to identify targets for teaching and also allows decisions to be made about selecting appropriate alternative or augmentative communication systems (e.g. sign language or pictorial systems).

There was considerable interest among speech therapists and teachers in teaching communication using signs and symbols to those with no spoken language, but that systems varied from service to service as shown by surveys (Kiernan, Reid and Jones, 1982). Kiernan and his colleagues made proposals for a consistent approach to using signs and symbols and other augmentative communication systems which were later incorporated into a training package (Kiernan, Reid and Goldbart, 1987).

Other popular publications included the *Analysis of Programmes for Teaching* (Kiernan, 1981), which presented task analyses and explanations of programmes for teaching a range of skills, and *Starting Off* (Kiernan, Jordan and Saunders, 1978), which was a cogent attempt to present to the lay person a description of a structured, behaviour modification approach to teaching. Another influential assessment tool was the *Behaviour Assessment Battery* (Kiernan and Jones, 1982). There are many more papers and articles and books that could be cited.

For all sorts of reasons, many grass roots professionals working in the field of profound and multiple learning difficulties today, if not the majority, will be unaware of Chris Kiernan's huge contribution. People whose own work was profoundly influenced by him have either retired from the field or are likely do so in the coming decade. For the rest, energies have been diverted over two decades by the introduction of national curricula in schools and the push for inclusion. Research in the United Kingdom diminished as a result of economic pressures over the same period. In the obituary Professor Hogg suggests that professionals are beginning to refocus on supporting skills development and that Chris Kiernan's work could again become influential. We agree that new generations of teachers, nurses and carers would all benefit from a full appraisal of his publications.

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Obituary for Professor Chris Kiernan (1936-2011)

In the Summer 2011 issue of PMLD-Link (Issue 69) we printed an obituary and photograph of Chris Kiernan but failed to indicate their source. The obituary was derived from one written by Professor James Hogg and the original obituary and the picture actually appeared first in June in the Guardian newspaper.

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What do the terms ‘therapy’ and ‘therapist’ really mean in early childhood intervention for children who need on-going multiple interventions?

Peter Limbrick with Lynne Boulter, Liz Wassall and Suzanne Rimmer

There are moves in service provision in early childhood intervention (ECI) for children with disabilities and special needs in the UK and some other countries that will erode the primacy of statutory public services and increasingly embrace the voluntary and private sectors and, at the same time, empower some parents as budget holders. We are already seeing at such UK exhibitions as *Naidex* and *Kidz up North* that therapy has an important place in this rapidly expanding market so it seems a good time to put ‘therapy’ under the microscope to see what the word means.

In my teaching career I have worked alongside physiotherapists (PTs), speech and language therapists (SALTs) and occupational therapists (OTs) since the 1980s with children and young people for whom, to be effective, I needed to be in collaborative teacher-therapist partnerships – ideally including parents. These working relationships gave me a sense of security in my work, a growing whole-child competence and a richer knowledge and skill base.

Until I became a keyworker/interventionist with neurologically impaired infants and their families in the charity One Hundred Hours (Limbrick-Spencer, 2001) I had assumed ECI could be neatly divided into treatment, therapy and education offered by medics, therapists and teachers respectively. Working closely with therapists in One Hundred Hours I began to see that much therapy work shared the same approaches and goals as education (e.g. in alternative communication) or nursing – chest drainage, for example. I am also aware that some paediatric therapists are now taking on particular functions that have traditionally belonged to paediatricians.

I began to wonder what would be left in the therapy basket if we took out those things that seem to overlap with education or with medicine. This exercise should help to define the term *therapy* and point to the exclusive domain of therapists, and offer increased clarity to new parents trying to make informed choices about what they want for their child and family – choices made much harder now because of the bewildering array of therapies that might be sold to eager parents at a very vulnerable time.

In the book *Blue Sky July* Nia Wyn wrote about her battles to ‘heal’ her son Joe who was born blind with cerebral palsy (Wyn, 2007). In my review of the book (Limbrick, 2007) I tallied up the first interventions offered to Joe. These included physiotherapist, speech therapist, medication for epilepsy, doctor at the eye clinic, sensory rooms, oxygen tanks, patterning, Reiki, cranial osteopath, muscle tapping (all in Joe’s first year), and then a private Peto-trained conductor, music therapy, Steiner nursery, massage, rocking therapy, a second skin, Botox, and faith healing.

Since Joe was born the therapy world has moved on. My quick internet search for infant therapies for this article came up with (in addition to the ones in Joe’s list above), rebound therapy, aroma therapy, infant craniosacral therapy, infant therapeutic touch therapy, infant yoga therapy, parent-infant therapy, infant therapy, dance therapy (for mothers and infants), mirror therapy and baby sleep therapy. This brings us a very long way from paediatric physiotherapy, speech & language therapy and occupational therapy!

It also brings me a very long way from my comfort zone. I do not claim to know anything about most of these approaches so I am in much the same position as new parents as they try to decide what they want from this market place. With this confusion and anxiety in mind, I turned to three experienced paediatric therapists, Lynne Boulter, Liz Wassall and Suzanne Rimmer with the following questions:

So, what is exclusive to 'traditional' paediatric therapy?

It is a fair question. There is often confusion about this, partly because our good practice means that we work closely with others around the same child or children and we do not always explain explicitly to parents and fellow practitioners what our core skill areas are. For the sake of clarity here, each therapist has a particular key role: OTs focus on upper limb function, perception, self-help skills, accessibility to education and everyday activity at home; SLTs are concerned with speech, language and communication to optimise an individual's ability to participate in the world around them; PTs are concerned with optimising gross motor function, postural stability and integrated movement, and mobility.

But none of us stick rigidly to just one approach. We look at needs as they are presented and open our 'tool box' to find ways of helping the child and family find positive solutions. We help prioritise needs and any one of us might step back for a while if other interventions are more important at that time. This same professional flexibility means we will abandon our plan for a particular session if the family's immediate need is for support and guidance in a particular issue or just to have someone to talk to. Often, we become signposts to other services because we know the child and family well and can match needs to what is available in our locality.

Paediatric therapists, traditional for the sake of this interview, are specialists providing high quality, effective interventions designed to impact on the overall development of the child – be it physical, medical, cognitive, social, emotional, etc. As therapists we must focus on delivering our particular specialism whilst at the same time facilitating a holistic approach – quite a juggling act at times!
We have a major training role too, training the other people around the children with whom we work (including fellow therapists) and training parents so that they have the knowledge and skills they need to help their child. We can never be territorial in our work: sharing skills with others is part of an essential blurring of roles in pursuit of seamless support for each child and family no matter which other people are also providing interventions.

In Walsall, the Multi-disciplinary Dysphagia Team can take on referrals and the management of children with feeding problems without having a paediatrician in an overseeing management role and we are developing a pathway for children with cerebral palsy (hemiplegia in particular) that is co-ordinated by therapists – referring to a paediatrician only when necessary. Both of these initiatives expand the role of therapists and take pressure off our paediatricians.

It sounds to me as though this defining and delimiting of the term therapy is an important issue for you.

Yes, it is extremely important for us to let parents and other practitioners know what is unique to therapy because this clarity all too easily gets hidden when we join our interventions to others' in integrated working. But we are getting better at marketing ourselves, for example by putting out good written information, attending local parent support events and using the internet. As part of our professionalism we must keep ourselves and everyone else aware of the added value we bring to ECI. As more and more therapies appear, we have to keep the profile of our traditional paediatric therapies as high as possible so that parents understand our real value.

Do you share my concern about all the other therapies that are out there?

We do! There is a potential dangerous trap here for those parents who are seeking a cure for their child's disability and for those, probably a greater number, who are driven to try anything and everything – either because they perceive their child as a sort of empty bucket to be continuously filled up 24/7 or to assuage their feelings of guilt about their child's condition. The private therapy trap is also aided by a common belief that services you pay for are likely to be better than those that come 'free'.

But parental choice is a good thing and we see it as part of our role to support it. After all, many paediatric practitioners, like many of the rest of us, have benefited from various therapies in their own lives. Part of our role is to help families explore what is available and to think through whether it might benefit their child. Rather than withdraw our intervention when parents opt for a non-traditional therapy, we might integrate the two – for instance a SALT working with a private autism programme. It is reassuring that many parents return to NHS therapy after exploring other options.

The persistent problem for us though, is not knowing enough about the other therapies to help parents come to an informed choice. We can be as bewildered and confused as they are in this expanding and unregulated market place.

So what criteria can we use to distinguish between therapy that is thoroughly professional and that which is not?

This is an important question for everyone working in ECI, partly because some therapies might do more harm than good – the last thing any of us want for disabled infants and vulnerable families. It comes down to what is known about the therapy, how the therapist is trained and supported and how he or she operates.

The first question must be about the clinical evidence base for the particular therapy as applied to a particular category of need whether in skill development, improved wellbeing or enhanced environments. If there is no valid information then we should not support it. Training is critical and we must never equate professional training over a number of years, perhaps at graduate level, with skills learned over a few weekends or at a summer school! In the UK, all NHS therapists are registered with the Health Professionals Council and must make a declaration every two years that they are up to date with innovations in professional practice.

A professional therapist will begin with an appropriate assessment, discuss the results with the parent to agree a course of action, integrate her work with any other interventions being offered and measure outcomes. She is accountable to the child, the parent and the agency that employs her. When she has uncertainties, these are acknowledged and dealt with in supervision.

After this exchange of views, we all agreed some recommendations to improve clarity and to support parents in the difficult decisions they have to make. They are as follows:

1. To help protect children and families, the paediatric world should promote awareness of two categories of therapy:
   a. Professional therapy with an evidence base, properly qualified therapists and accountable and responsible delivery.
   b. Other therapies which do not meet these criteria.
2. This distinction does not necessarily conform to statutory and non-statutory (whether 3rd sector, i.e. charities and voluntary organisations, or private agencies).
3. Paediatric NHS therapists should support parents in learning about and making judgements on any additional therapy interventions and be willing to work with, when appropriate, additional professional therapists.
4. Therapists, other paediatric practitioners and parents would be greatly helped in the above by an official register of professional therapy and therapists or the promotion of existing registers.
5. Authorities that allocate budgets to parents should restrict their use to professional therapies on the register.
6. Local councils and NHS trusts should strive to agree contracts with local registered therapists, whether 3rd sector or private, to ensure they will, as appropriate, work in partnership with others around the same child in pursuit of an integrated whole-child and whole-family support system. Turning for additional support to the 3rd sector or private agencies should not automatically lead to fragmented and disjointed support

Conclusion

There is much room for confusion about what therapy is and what therapists do and this can worsen as new therapies appear on the scene. There is a strong argument here for traditional paediatric therapists to be explicit in describing their work and its value. As parents have a wider array of therapies to choose between, with the added strains for some of purchasing what they think will be helpful, there is a second strong argument for traditional paediatric therapists to offer them informed support with access to a register of professional therapies and therapists.

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Time to Listen: Music Therapy with a Young Man with Profound Multiple Learning Disability

Lisa Margetts

It may be said that music itself lies in a relationship between sounds and silence. Music therapist Sandra Wilson suggested that: “Music can reach us when often nothing else can, and a relationship precipitated by music has tremendous power” (Wilson, 1991, p. 14). Music therapists agree on the particular effectiveness of musical interplay to “forge an affective relationship” (Sobey and Woodcock, 1999, p136), arguing that musical improvisation “reflects the dynamics of emotional relating” (Streeter, 1999, p12) and is the basis for communication and understanding in music therapy. Fundamental to this is the capacity to listen, and to attune to an other.

Music therapists seek to integrate elements shown here in the Chinese symbol for “to listen” in listening and attuning to each aspect of the client’s musical and non-verbal communication. Pamela Steele said;

> ‘Perhaps the most primary service which we offer our patients (clients) within the space and time of the therapeutic environment is our willingness and ability to listen, - more broadly, to take in from them in every aspect the nature and quality of their presence with us in the room. The ability to stand on ‘perceptive tip-toe’ is one worth striving for. We are often limited in our capacity for it. There is a difficulty in being really open to hearing the often disturbing qualities of a (client’s) sounds and silences. We seem to have a natural tendency to close down our ‘receivers’ in the face of what is aggressive, acutely painful, fearfully paralysed or terrifyingly unending, without variation, without shape or character’ (Steele, 1988, p3).

It is the capacity to “attend, witness, wait” (Steele, 1988, p2) which enables the beginnings of connection with a person with profound disabilities for whom a verbally saturated, fast moving world can be so confusing and isolating (Bunt, 1994). It is often this sense of isolation and confusion which gives rise to the anxiety and incipient responses for which people with profound learning disabilities are frequently referred to music therapy. “Containment is an essential prerequisite for any therapeutic change, and is especially crucial for this....client group” (Sinason, 1992). The following short case study illustrates these principles.

Sean’s Story

Sean suffers from severe epilepsy in addition to his profound learning disability. On our initial meeting, I was struck by the intensity of the anxious energy he radiated, exacerbated by constant, frantic movement that seemed to allow no time for grasping and processing the world around him, nor for connecting meaningfully with others. His very caring staff explained that anxiety and frustration often seemed to spiral into huge “outbursts” of screaming and uncontrolled, violent arm waving which seemed frightening and potentially hazardous to himself, as well as to staff and fellow residents in his group home. Initially, it was to explore ways of expressing these overwhelming emotions that

Sean was referred to music therapy.

I arranged the music therapy room for Sean with plenty of space to accommodate his energy and constant movement, enabling him to use the space safely and to access instruments at will. A number of robust instruments were placed around the room, offering a variety of sound qualities, shapes, colours and surfaces. From the first session, Sean showed great curiosity and enthusiasm for the musical instruments, beginning excitedly to explore as soon as he entered the room; often while his carers were still trying to help him take off his coat!

The challenges which Sean experienced in trying to make sense of his environment were evident in his use of the therapy space. Sean would often charge energetically and randomly around the room, briefly picking up, using, and dropping the instruments he encountered. This combination of excitement in the instruments as objects and sound sources, with a generalised sense of being overwhelmed, leading progressively to anxiety and then frustration was the same as had been described by staff at home.

Accordingly, an immediate aim for Sean's music therapy was to try to provide some containment for this maelstrom of emotional energy. Firstly, I aimed to be a physical point of stability and continuity by remaining at the piano throughout each session. I sought both to offer an improvised musical grounding, using a deliberately slower, consistent pulse and rhythmic pattern, and to communicate that I had heard Sean's rapidly changing choices of instrumental sounds by matching the pitch, volume, duration and rhythm of his short bursts of playing.

Sean seemed very responsive to this way of being together in musical improvisation, and he appeared to feel increasingly held within the continuity, regularity and responsiveness of the piano music. As De Backer stated;

"Music offers the advantage that the patient need not be alone in his chaotic expression and experience. The music therapist has the means of being with him without having to exclude him…This means that the patient (client) can….feel that someone accepts his experience, accompanies him without being swept along, and does not become alarmed."

De Backer (1991)

Sean's previously frenetic movements around the room very gradually slowed, and he began to seem less overwhelmed. He was now able to be more consciously aware that I was listening very closely to his musical and non-verbal contributions. In turn, he became able to listen to my idiomatic responses. The potential for dialogue emerged.

Extract from a session after one year of music therapy

At the piano, I improvise a slow, regular, rhythmic pattern in the left hand, and reflect Sean's use of resonant bells in the right hand. Sean moves energetically and randomly around the room, but with a little more control. My piano improvisation, in a style reminiscent of tango, seeks to reflect something of this energy, while providing a sustained, grounding musical framework. Sean picks up a beater and moves to the window. With his back to the piano, he taps rather chaotically on the glass. Sustaining the piano pattern, I quickly take a beater and respond with a firm rhythm on the piano lid. Sean immediately turns, and joins me, this time also tapping on the piano lid while looking at me, and we share our very first brief musical dialogue. As Sean moves away, I echo the rhythm of this exchange in the ongoing piano improvisation. Sean vocalises in a warmly open "Heyyyy!" and as I respond with a vocal phrase matching his pitch and duration, he begins to explore the sounds of surrounding instruments with an apparently new, more focused curiosity. Sean then briefly taps his beaters gently against my back. For the first time, it is as if he feels able to be curious about me too. What sound will I make if he taps me?

The piano music continues. Sean moves right away from me to the back of the room, turns, and comes back towards me, vocalising in long rising phrases and flapping his arms excitedly. His vocalisation now resembles the word "Hello!" It is as if he is delighted to recognise me again, and able to hear this delight mirrored in the quality of my improvised vocal responses as he comes close to me at the piano.

As if to communicate that this is as much connection as he can manage at this point, Sean then moves away to the window, puts his beater into his mouth, and covers both ears with his hands. He is continuing to vocalise, but this vocalisation has taken on a strained, repetitive quality. We pause.

Here, Sean seemed to begin to demonstrate a need for space to process our musical "conversation" by covering his ears and moving away. As sessions progressed, and I responded to this behaviour each time by ceasing to play, Sean seemed to gain in awareness both of this need for himself, and of my capacity as the therapist to listen and respond accordingly.

Sean then began increasingly to focus on using beaters. As I responded to his tapping on the window and other surfaces, our rhythmic play began to assume greater importance in sessions. Sean seemed to be seeking a sense of order. Each of our gestures became of a similar duration, as Sean appeared increasingly able to listen, to process what he received, and to respond appropriately, in a musical "conversation". From this point, Sean began to develop clear patterns in his consecutive use of a small number of instruments. We improvised together in an increasingly organised way, which Sean acknowledged in eye contact and vocalisations. Sean also continued to indicate a need for space between our improvisations by remaining silent by the window, keeping one hand over his ear until he was sure that I would wait silently until he was ready.

Extract from a session in the third year of music therapy

On the piano lid this time are the container of beaters, a wooden slit drum, and a small gong. I again improvise a sustained, regular musical framework at the piano. Beside the window Sean is holding two small finger cymbals by their connecting string in his mouth. This inventive solution enables him to knock one cymbal against the other with one hand, leaving the other free to play a different instrument simultaneously. Maintaining the consistent rhythm in the left hand, I respond to these bright, ringing sounds at the upper end of the piano, echoing with accents the moments where the cymbals strike each other. I notice the greater detail that is now possible in our musical interaction.

The cymbals still held securely in his mouth, Sean moves to a set of wooden chimes suspended from a stand and shakes them gently, sustaining the contrastingly drier percussive sound. Over piano chords, I respond by playing rapidly all over the wooden gato drum to mirror the quality of Sean's playing. He turns his head towards me, listening intently. Our dialogue continues as Sean once again plays the cymbals, more loudly this time. As I respond with piano phrases which aim to match his pitch and sound quality, Sean moves slowly back to the window and becomes still. There is a calm silence for several minutes. I attend, listen and wait at the piano.

When he is ready, Sean turns from the window, the cymbals still in his mouth, and looks towards me as he returns to the wooden hanging chimes. I improvise gently with the leisurely pace of his walking. As he begins to repeat the previous pattern, Sean turns towards me this time before I play the gato drum, appearing to anticipate my response within this now familiar repeated structure. We play together for a few minutes. This time Sean leaves significant spaces in his shaking of the wooden chimes, listening carefully to my idiomatic response to the music he has initiated. The mood is relaxed, but attentive. This time when Sean turns back towards the window, he smiles at me gently and vocalises warmly, acknowledging the musical dialogue we have shared.

Summary

As Sean gradually discovered, the predictability and sequencing, rhythm and structure of music can provide a "secure framework for the risky business of reaching out into the far from predictable world of other people" (Ockelford, 2008, pp. 142–3). While the music we improvised together may be said to have facilitated this process for Sean, it was our growing capacity to listen and attune to each other, to find our own pace and timing which enabled trust in our therapeutic relationship to develop, and growth and change to take place.

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Function and Fun at Orchard Manor

Gemma Smith

Physiotherapy doesn't have to be all about pain, repetitive tasks and intense exercise. At Orchard Manor we create a fun, functional and action packed environment for our young people to enjoy, whilst continuing to promote physical health and wellbeing. The young adults at Orchard Manor have profound and multiple learning difficulties and disabilities with a wide range of coexisting physical and health requirements. It takes all of my physiotherapy knowledge to ensure person-centred, individual therapy for each resident through a range of exciting and challenging activities.

Orchard Manor is a residential transition service run by the disability charity Scope for 31 young people with severe physical, sensory and learning difficulties and disabilities. Our overall aim is to promote skills and put in place programmes to enable these individuals to live as independently as possible in later adult life. Placements last 3 years and within this time we provide a vibrant, supportive and challenging timetable of development and therapy sessions. This encourages people to develop existing and new skills that they can retain and continue to use when they move on in the future.

Physiotherapy is a key area in the lives of these young people and my role is to ensure each individual has the vital equipment, individual programmes and input to enable our high level of physiotherapy care to continue within the wider community when they move on. Orchard Manor practices a multidisciplinary method of working and therefore I work within an extensive team of professionals, sharing knowledge and expertise to ensure that each young person is supported to maintain and extend their abilities. We have an onsite Skills Development Centre which delivers sessions in art, drama, music, media, ICT, cookery, occupational therapy, speech and language therapy and physiotherapy and aim to ensure that an individual's time is full of functional experiences as well as fun and satisfaction.

I take a 'hands on' approach to my role and see each person between 2-4 times per week depending on their level of physical disability and need, and provide physiotherapy intervention within a group setting or on an individual basis depending on the task or activity being provided. Each of our groups is carefully created to combine residents with similar cognitive and communicative skills in order for us to customise activities to suit their level of understanding and ability. I work in many different environments to ensure that physiotherapy is a functional and daily aspect of our people's lives and, for example, spend a lot of time within the residential flats making certain that the equipment and physical management programmes are being correctly carried out by support staff. Individuals in the community are also supported in their activities and this includes support in the local public swimming pool and gym and at the local horse riding facilities. My plan is to combine social integration and physical wellbeing into the day to day lives of the young people.

Physiotherapy sessions are always full of laughter, games and opportunity. Four mornings a week I work on the trampoline providing Rebound Therapy. This acts as an ideal platform to carry out alternative positioning, stretching programmes and functional tasks such as bridging and rolling. Each individual completes a specific programme working on their level of mobility and physical aims. Some people are able to bounce with support. However some require adaptive equipment to support their physical position and trained staff to assist them with passively moving their limbs, in order to achieve stretches and activities such as throwing and catching.

Everybody works towards personal goals appropriate to their level of cognition and physical ability. This may be through a sensory experience, increased body awareness, independent sitting or rolling, standing or bouncing. Any physical activity on the trampoline during Rebound Therapy also enhances the respiratory system, circulatory systems and bladder and bowel function.

We also have a hydrotherapy pool and I run hydrotherapy sessions four afternoons a week for people who are unable to access the local community swimming pools due to inaccessibility or the cold. Our pool is specially adapted with excellent changing facilities and a hoisting system straight into the water. Working with individuals who have complex physical and health support needs in the water is particularly enjoyable as they are able to achieve so much more mobility and function in this weightlessness this environment provides. We are able to effectively support them to achieve certain positions which would not be possible on land. For example, some young people use wheelchairs at all times throughout the day, but they are able to stand and take steps in the water with suitable support from myself and adaptive hydrotherapy equipment. The 34-36 degrees c. temperature in our hydrotherapy pool also allows muscle relaxation and hence further stretching potential for those with contracted limbs. The young people may help actively with their stretching programmes or we may support them passively to achieve as much additional range of movement as possible. Within this controlled, relaxing and sensory water environment, they perceive physiotherapy as pleasurable, comfortable and safe.

Another very important aspect of the physiotherapy intervention focuses on mobility and physical activity through active exercise. We have a range of adaptive pieces of equipment to support individuals to achieve this. Our focus is to ensure that everyone has their own equipment for long term future use. We help individuals and their families to proceed with the funding for these pieces of highly specialised equipment via private funding or applications through the health or social authorities. I also work closely with the Occupational Therapist to ensure the equipment is individually assessed so that it is both suitable and physically beneficial for the person who will use it. We also have close links to representatives from large equipment companies who regularly demonstrate new equipment and maintain and reassess our existing equipment. This means that people remain safe, supported and comfortable and benefit from advances as they become available.

Our young people have an array of standing frames, walking frames, side lying boards, tricycles, comfortable seating and sleeping systems all individually adapted for their use. The extensive grounds include a private road that orbits the entire site and can safely be used for tricycle riding and walking. This provides a change of scenery and a stimulating environment in which to complete these activities.   Mobility comes in a range of different forms depending on the physical needs of each person's body. We use the most adaptable walking frames to achieve walking/stepping with the most unlikely to mobilise young people. As you can imagine, this creates a rewarding personal achievement along with the health and physical benefits gained from moving and being in an upright position.

Postural care is a major aspect of each individual's physiotherapy regime. Our staff ensure that positive postural positioning, for each young person, is applied 24 hours a day and individual photographic and written programmes are composed for the young people, their support staff and families to follow. Alternative positions are implemented within the day, whether that is in a music session, whilst watching a film, when eating or drinking, or in an individual's free time. I work with each person and liaise with our care and skills development staff to identify the most beneficial and appropriate positions using adaptive equipment. Every young person also completes weekly small group physiotherapy sessions that focus on positioning. During this time individuals are supported 1:1 by a member of staff and achieve a suitable position, whether that be in standing, sitting, lying on their back, front or side. When each person is positioned correctly and comfortably we can do a range of activities such as bowling, puzzles, sensory object manipulation, exercise tape recordings, drawing, looking at books or using table-top games. This again incorporates function, fun and positive positioning for the young people.

Staff training has great benefits and I lead formal training on Postural Care & Passive Movements, indicating the aims, benefits and safety precautions within these topics. This includes a practical demonstration of full body passive stretches and a sleep system demonstration. Support staff use sleep systems with individuals on a nightly basis, without immediate physiotherapist assistance and so this training is vital to ensure that they are used effectively and safely. This has helped staff to further their knowledge and understanding of these important aspects of care. Staff are also trained to assist in the hydrotherapy pool so that the young people can make the most of this facility in the evenings and at weekends.

These are just some of the physiotherapy-led activities at Orchard Manor but every day is different and we adapt, change and explore alternative ideas all the time to achieve exciting and beneficial results. Orchard Manor Transition Service is a fantastic place to work and the attitudes of the staff combined with the facilities and high standard of care, ensure that each person's needs are met and that they are happy, motivated and ready for the challenges the future is sure to bring.

Contact details

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For further information or to arrange a visit please contact the Registered Manager on 01763 268 030 or write to us at the address below.
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Scope
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NEXT ISSUE

The focus in the Spring issue is on **Life is for Living**

Do you have any knowledge or experiences to share on this theme?

If so, contact the editor:
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Postural Care – a Vital Therapy A family's story

I am Ruth and I am the sister of Rebecca, a woman of 42 who has profound and multiple learning disabilities.

Picking up my notebook and pen I first considered where to sit in order to start scribbling down my thoughts regarding Postural Care as a Therapy. Would I sit on the wooden dining room chair or on the sofa in the lounge? The decision was easy; I put comfort first and opted for the sofa. If I was relaxed and comfortable maybe my ideas would flow more easily. In fact on a daily basis I make choices about where I might sit, in a cafe, pub, restaurant, office or at home and I think that my personal comfort is the overriding focus for my decisions.

However, my sister cannot make such choices for herself and relies totally on her wheelchair and bed for her seating and lying needs. Have we, over the years spared enough thought to her personal comfort as she sits and lies in one position for prolonged periods of time? What if those positions lead to pain and discomfort and she cannot alter her position to relieve the pain? About four years ago we as a family discovered the concept of 'postural care' and as a result have learnt a whole new way of thinking regarding body positioning over a 24 hour period.

How would you feel if you had to lie like this for 12 hours?

How long could you sit like this?

The approach is simple and incredibly logical:

Lie straight ⟹ ***Sit straight*** ⟹ ***Grow straight!***

There seems to be an acceptance that the positions that children and adults with PMLD lie and sit in are an inevitable part of their disability and so, are unavoidable. 24 hour postural care encourages people of all ages with movement difficulties to lie and sit straight with the gentle support of sleep systems, cushions, rolls and supportive wheelchairs and seating. When positioning somebody you are aiming for a supported, balanced, neutral position that minimises the twisting of joints, physical tension, pressure and distortion.

Why should postural care be seen as therapeutic?

For anyone with PMLD we should not just consider how comfortable they look when lying or sitting, but we also need to think about what is happening to them internally. Our skeletons are designed to protect all our internal organs and give them the room they need to function effectively. If we do not protect this internal space, then some organs may struggle to work, leading to health complications that may result in the need for medication, hospitilization or surgery.

By taking simple steps to protect and support an individual's posture you are helping to relieve pain and discomfort and thus contribute to the effective functioning of the internal organs, promoting good health and well being. Postural care can not only improve the quality of life for people with PMLD but also for their families and carers. It is such a simple way of improving the lives of others.

My sister has over the years received and benefitted from many therapies, including speech therapy, physiotherapy, occupational therapy and music therapy. I think that as a family, had we been aware of postural care 42 years ago it would have been of huge benefit to us all and would have greatly complemented her other therapies.

Hello, this is me – Rebecca! My Mum and Dad are helping me tell my 'postural care' story.

I have never been able to move about very well and by the time I was 14 years old I had developed spinal scoliosis and kyphosis, which made it very difficult for me to lift my head. The problems with my spine also caused a distortion to my chest making my sternum and rib cage bulge out to one side. I was also unable to straighten my legs due to the fixed flexion of my knee and hip joints. My GP referred me to an orthopaedic consultant who reassured my parents and me that the deformities *'will not be a problem'* and there *'isn't anything active to be done'*.

As I got older and heavier it became increasingly difficult for me to move about and I became totally reliant on my wheelchair. My lack of mobility contributed to the general decline in my body shape and abnormalities in my pelvic bones and the partial dislocation of my left hip were also identified. My legs were in a fixed 'windswept' position, which made sitting in my wheelchair difficult and uncomfortable. I only had limited movement in my arms, which I tended to hold tightly to my chest.

My parents expressed their concerns to our local learning disabilities physiotherapist who, on observing me lying in a fixed, twisted, windswept position in bed said, *'She looks very comfortable doesn't she?'* Although I was spending all night, every night, unable to move from this position, and also many hours during the day if I was sleeping after a seizure, no advice or guidance was offered. In fact we were given the impression there was really nothing at all to be concerned about.

Fortunately, and purely by chance, my parents were invited to attend a conference where, for the first time, they heard about postural care. This was a complete revelation to them and they knew straight away it was exactly what I needed. They decided to find out more and attended a number of postural care 'awareness' presentations before again approaching our local learning disabilities physiotherapist. Fortunately for me a new physiotherapist, who had some knowledge of the importance of postural care and the benefits of night positioning, had been appointed and following an assessment, I eventually received a sleep system.

As I have severe, uncontrolled epilepsy and chronic acid reflux everyone was very concerned about me choking because using a sleep system for night positioning entailed me lying on my back. I also don't like new things very much so it was decided to introduce my sleep system very slowly. To start with I used my sleep system for about half an hour during the day when I was having a rest on my bed. I got used to it really quickly and didn't mind it a bit so gradually I started to use it when I was sleeping after a daytime seizure. Introducing my sleep system during the day meant there was always someone about to keep a check on me and make sure I was safe. I also have a bed with a special tilting mechanism, which we used to minimise the risk of choking. After a while I began to use my sleep system when I went to bed at night. To start with I just used it for about an hour and spent the rest of the night without it. However this caused a problem as I like my sleep and don't react well if I'm disturbed. I'm afraid I let everyone know I didn't appreciate the sleep system being taken out just when I was comfortably drifting off! After that I kept my sleep system in all night.

I have now been using my sleep system for a few years with absolutely no problems; in fact lots of things have improved enormously. My chest shape is now virtually normal (symmetrical) allowing my lungs room to work effectively, my scoliosis is less pronounced, I can lie straight unaided, my legs are far less windswept reducing the strain on my hip joints, I have regained functional movement in my arms and as you can see I am able to sit straighter and more comfortably in my wheelchair.

Unfortunately the spinal kyphosis is taking longer to improve but on a good day I have the strength and ability to hold myself in a good, upright sitting position enabling me to eat and drink more easily, which reduces the likelihood of reflux. However when I'm not feeling well, usually after seizures, I find it difficult to sit up straight and lift my head. This poor daytime posture is obviously not good for me and is counteracting the benefits provided by good night time positioning. So the next step is to exchange my current wheelchair for a more suitable, posturally supportive wheelchair and to complement it with a posturally supportive 'comfy' chair.

I will then have really good 24 hour postural support that will enable me not only to sit and lie comfortably, but also fully protect my body shape, enabling all my internal organs to work properly.

Mum and Dad's final words….

When Rebecca's sleep system was first introduced we were lucky enough to have access to professional support and guidance in its use. However, contact with other families suggests this is seldom their experience. Many families provided with sleep systems are left without any follow-up advice or monitoring, resulting in the equipment being left unused in a cupboard. In our experience having access to on-going support, particularly in the early stages, is vital to the successful introduction and use of a sleep system.

What has become abundantly clear to us over the years is that postural care is not just about a sleep system, a wheelchair, or a comfy chair. It is about taking a professional, holistic approach to an individual's specific needs and providing appropriate equipment, on-going support and training to those who are in a supporting role.

We should not let the most vulnerable in our society suffer because we cannot provide a forward-thinking, joined-up service for them. We have come across some brilliant professionals who have helped Rebecca enormously, but all too often they are beaten by the system, bureaucracy and chronic lack of funds. It's surely time for a change.

The nature of Rebecca's disabilities prevents her from speaking up for herself. Her parents and close family have to be her voice – we just need people to listen!

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Extra information that you might find useful.
We first heard about postural care at a health conference. An organisation called Postural Care Skills made the presentation. They do parent awareness days sometimes.
Contact: www.posturalcareskills.com
Telephone: 01827 304 938
Rebecca first used a sleep system from Symmetrikit
www.symmetrikit.com
Tel: 01531 635 388
Rebecca now has a sleep system from Simple Stuff Works www.simplestuffworks.co.uk
Telephone: 01827 307 870
Ruth is now a trained postural care tutor and offers awareness training in Lincolnshire.

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- Life is for Living -

The copy date for all articles, information and news for the
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Please send contributions to:

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Summer Vol. 24 No. 2 Issue 72

- Families -

The copy date for all articles, information and news for the
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Please send contributions to:

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hd.castor@btinternet.com

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

Craig's Experience and the Postural Care Campaign

Jenny Whinnett and Anna Waugh

People who find it hard to move are most at risk of developing body shape distortions and failure to protect body shape can have serious consequences for a person's health and quality of life. It can even cause premature death.

A Family's Perspective

Twenty one years ago, my life changed forever. Most parents say this on the birth of their first child, but my life changed again when my fourth son joined our family.

Craig touched us all from the start. He met every challenge with his beautiful smile, and over the years of his life there were so many challenges. He underwent major surgery for a fundiplication and then for it to be repaired, a gastrostomy to be fitted, and then in his teens a Baclofen Implant was inserted into his abdomen to help his muscle tone. In between the surgeries, he endured a number of serious bouts of pneumonia, unsettled seizure control, and a period of poor mental wellbeing. He fought his way back from each illness with his unshakable love of life, and people.

The family were exhausted, but Craig revived us every time with his smile and obvious enjoyment in everything he participated in. He loved his Kindergarten, sharing time with the children in his village, his wonderful school days, interspersed with visits to Badaguish a special holiday/ respite centre for children with disabilities up in the Cairngorms, and then his family time with many outings to the cinema, ten pin bowling and family parties. His trip to the States to participate in his brother's wedding was particularly special, saying his vows along with his brother - Amy had two husbands for a while!

But there was a deepening cloud on Craig's horizon that crept up, and prevented him from continuing the life he so enjoyed. It was as a result of his deteriorating body shape, rotated hips and severe scoliosis. During his early life great emphasis was put into Craig being correctly seated and supported in standing frames by his therapists, and I duly followed all the instructions for his therapies and positioning as guided, but nothing was advised for his sleeping position. A third of his life was quite appropriately spent in bed, sleeping. I requested and was given a hospital style bed while he was still young, and then this was replaced with a special care bed in his teens, but there was little advice given about his sleeping, resting position. Funding for sleep systems was not available, and in his early life I was not aware of any to examine. I became conscious of Craig's deteriorating scoliosis over his childhood, but apart from a serious effort being put into his seating, nothing was discussed around his resting position. A consultant intimated during his early teens that his poor body shape would shorten his life, but there was no advice from him to improve this prognosis!

A Life with Value; a Life worth Living

A senior orthopaedic consultant did examine Craig with a view to spinal surgery to correct his scoliosis, but sadly by the time this consultation took place, Craig's body shape was too poor for surgery to go ahead. This was devastating news to us as a family, so we concentrated on giving Craig as full a life as possible.

Five years ago, I discovered information on the Sleep System and on protecting body shape. We purchased a sleep system ourselves, as there was still no funding available, and then booked a training workshop for Craig's carers and myself to be given skills to support his posture. Craig really enjoyed all the attention and joined in the workshop with great interest and amusement. The training given by Postural Care Skills really opened our eyes as it all made such sense! We were given the information to work with Craig in positioning him safely and comfortably at night to prevent further postural deterioration, and to work towards improvement in body shape. However, we sadly did not know then how little time we still had with Craig.

Over the last two years of his life, he had the support of a respiratory consultant, who informed us that Craig's respiratory function had become serverely impaired due to his poor body shape and the compression of his internal organs, but he gave Craig all the support he could. He had developed serious respiratory failure so he received oxygen therapy in the home, and latterly was supported by a non invasive ventilator at night to aid his breathing.

Sadly during the summer of 2008, Craig became seriously ill, suffering great pain, and it became evident that the only support that could now be given was palliative care. We were able to take him home, and he was cared for to the end by his family and those that loved him, passing away in the arms of his mum.

The sleep system and the training given to us on Postural Care by Postural Care Skills helped him to enjoy added time, with a good quality of life, coupled with the effort of all the other professionals in his life, and the love of his family.

But Craig should not have had to live with such a poor body shape that impacted on his quality of life and expectancy to such a degree. He would want a person's body shape to be far better protected from the time of diagnosis, and continuing support throughout their lives by the professionals involved with them, so that they would enjoy a healthier life than he did, due to his severe scoliosis.

Contact details

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The launch of the Postural Care Campaign

In 2008 Jenny and a number of other individuals and organisations – including, Postural Care Skills, the Chartered Society of Physiotherapy, the Royal College of Nursing, the College of Occupational Therapy, Mencap, PAMIS and Simple Stuff Works - came together and established the Postural Care Action Group. The purpose of the group is to raise awareness about the importance of protecting body shape for people with complex healthcare needs and movement difficulties.

The group has had articles published in a number of journals and we have now launched our Postural Care awareness raising campaign. The campaign is aimed at all those who support people with multiple disabilities or who commission services for them.

We want:

- -to challenge the assumption that distortion of body shape is inevitable for people with multiple disabilities
- all people with multiple disabilities to get the support they need to protect their body
- shape, 24 hours a day.

A booklet and 6 short film clips are now vailable explaining why postural care is important and what you can do to take action and to ensure that appropriate postural care services are developed in your local area. We have also developed a PowerPoint presentation you can use to tell other people about the importance of postural care.

The booklet, film clips and presentation can be viewed at www.mencap.org.uk/posturalcare. Free copies of the booklet and film can be ordered at publications@mencap.org.uk or Tel: 020 7696 6900.

Aquatic Therapy

Jenny McLaughlin

At St. Roses School in Stroud we are lucky to have a beautiful new Aquatic therapy pool, courtesy of an incredibly successful fundraising campaign and the generosity of our community. There is a splendid range of lights and sounds which change the colour and acoustic environment with simple floating switches, the water is heated to 34 degrees centigrade and we have overhead tracking to hoist children comfortably between changing room and water. We even have a raised bench area, as part of the pool, from which a bubbling Jacuzzi can be conjured at the flick of a switch….. envious now?!

Some of the range of skills we might include into our SMART targets in aquatic therapy are increased swimming or floatation skills, increased joint range of movement, improved attention, responsiveness, muscle strength, balance, tolerance of touch and altered postures, three dimensional movement, spinal symmetry, initiating/maintaining eye contact, vocalisation and cardiovascular fitness. We hope also to be improving that elusive thing, the child's overall wellbeing.

A planned sensory experience

Personalised aquatic therapy delivery, here at St Rose's, tries to offer a uniquely tailored sensory experience to our pupils. The environment can be adapted in terms of switch access, music, lights and water turbulence so that acceptance of tactile and sensory input can be graded. We try to be thoughtful and plan which children share sessions so that the sensory environment is as good a match as possible to the child's needs. The pool can provide either a stimulating or a calm sensory space. I have witnessed children showing improved concentration, responsiveness and alertness in the pool. I have also observed extremely relaxed children who, during a session, shut down into a quiet mental space. Both of these can be desirable goals for a session depending on whether you want sensory excitation or relaxation. Many children benefit from a "bit of both" approach. Some children here literally "awaken or come alive" in the water in a way that we do not see often in the classroom. One parent remarked recently, "He is truly happy and at his best when he is in the water".

The facilitation of movement through tactile input is a corner stone of physiotherapy and the water provides an ideal medium to grade the sensory stimulation that the child's skin and joints receive. Activating sensory neurological pathways can magnify a motor response as you will have observed.

A focus for communication and collaboration

Being in the water affects the motivation to communicate for both the pupil and staff. Some children and facilitators become quieter and others become more engaged. The water allows communication and intensive interaction to happen using the whole body of the pupil and the facilitator. Eye contact, observation and connection during sessions can be intense in the water because of proximity and intimacy. There is a sense of calm and trust that is hard to reproduce on dry land. The potential opportunity for collaborative working and shared goal setting between speech and language therapists, teachers, occupational therapists and physiotherapists in the pool is significant and is something we are keen to try to take further as the use of our new pool develops.

A relaxing, pain relieving space

Immersion in water heated to just 3 or 4 degrees below our own body temperature has been shown to slow the conduction of some nerves. The benefits of this are that spasticity or high muscle tone can be reduced and pain messages can be damped down. One particular child arrives for aquatic therapy contracted and tight in all her muscle groups, possibly also a little chilly after her shower. After a few gentle techniques in the pool she is floating, swaying in the water and starting to feel her flexed limbs relax.

Total body support and a rest from gravity

Water has a density similar to our own since we ourselves are three quarters composed of it. This gives us "buoyancy" which is perhaps the greatest benefit that water offers our children, time to feel weightless and temporarily free from the constant downward pull of gravity. For many of our children, affected by contracture, deformity, muscle weakness and reflex spasms, this constant gravitational pull is a moment by moment battle. The pressure and forces, on every part of the body, that gravity exerts is immediately eased and replaced by the buoyancy of the water.

Increased motor control

Muscles which may be too weak to produce movement of a joint on "dry land" can sometimes in water, even with the smallest flicker of contraction, produce small movements in a normally immobile joint. For some children, immersion in water is the only time that their joints feel, even mildly, under their own motor control. However minimally this change is perceived by us observing the child, (because changes in joint movement can be very minimal indeed,) we can be sure it is experienced at a very basic sensory level, in neurological terms within the child's body. Hundreds of deep pressure receptors in the joints register the movement and send sensory stimulation along neurological pathways to the brain. Even 2 or 3 degrees of increase in active movement at a joint has sensory and physical benefits.

Three dimensional movement

For children who cannot move three dimensionally through space on dry land, learning to tolerate facilitation into a full roll from their back to their front and over on to their back again in the water, provides a unique motor experience. The vestibular system of the body, which relates to balance and movement, is stimulated and it has been one of the most useful techniques I have used for increasing awareness and arousal level in the pool. Providing motor opportunities in the water are essential for some children, enabling them to experience sensory events that their peers access as a part of their childhood and normal development. (The comparison here is children seeking out strong vestibular challenge such as rolling themselves down a hill.)

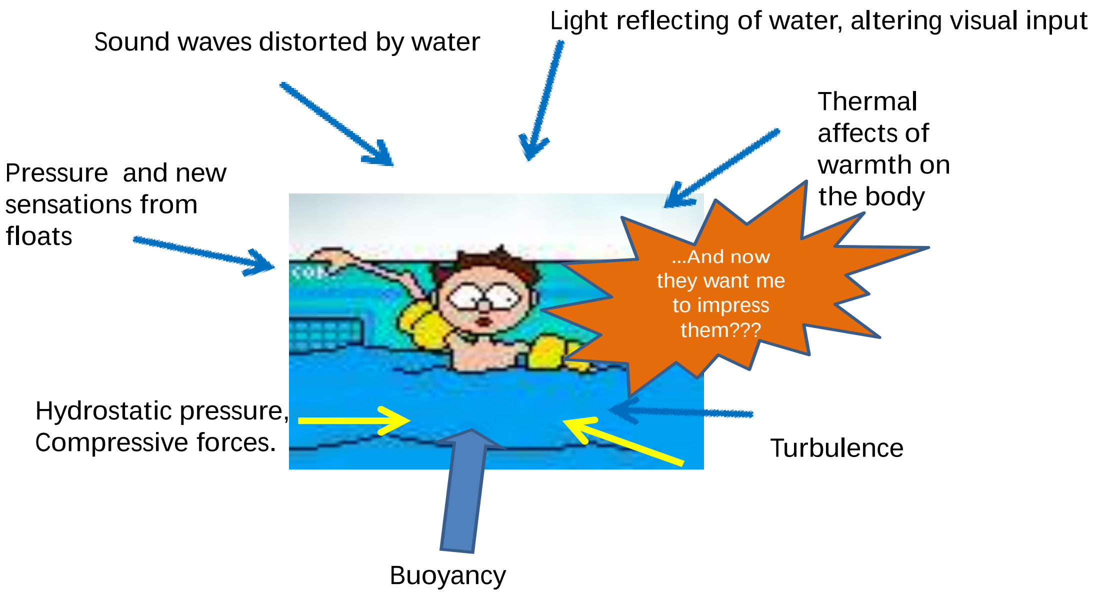
Some pitfalls to be explored

It is a complex transition for these children to go from the classroom into the water as the cartoon tries to represent!

As in any setting, a "one size fits all" approach never works in aquatic therapy. Things that have worked with other children in the past, even with very similar difficulties, may not translate well for another child. Not only that, but each session may need to be modulated or adapted for the needs of the individual child on that day and things that have worked for them in the past may not help on another occasion. Emerging gross motor skills can be inconsistent and performance and achievements may not be translated into consolidated skills. The practitioner has to constantly reassess, respond appropriately and remain objective.

A consequence of aquatic therapy is that the relaxation and reduced blood pressure it causes can lead to intense fatigue. A pupil that has been engaged, participating and communicating in the pool can then sleep through the rest of the day's meticulously planned sessions in the classroom. Also it is possible to overheat in the pool and the physiological consequences of this can be severe.

As with everything we do there is a "risk versus benefit" analysis to be considered. Aquatic therapy is contraindicated for a small number of children and all children need to be assessed by someone qualified to understand the factors involved in contraindications.



The following table summarises the potential benefits and possible risks.

PROPERTY OF WATER	BENEFITS	POSSIBLE RISKS
At 34 degrees water provides warmth and insulates the body from heat loss.	Slowed nerve conduction, therefore reduced muscle tone and damped pain messages to the brain causing relaxation. Can reduce high blood pressure which may be beneficial to some.	Extreme vasodilatation causes reduced blood pressure and dizziness. Some children/people can over heat, causing vomiting or other more severe side effects. A cooling down period is needed after each session. Fatigue can be overwhelming following sessions, leading to sleep.
Density close to ours provides Buoyancy.	Relief of pressure areas so improved skin viability, support to aching or painful joints, the damping down of muscle spasms and relief from the distraction that gravitational forces cause. Children feel lighter and easier to handle for the facilitator. Three dimensional movement through water is possible.	Buoyancy can be disorientating for a child. This can be mitigated by skilful handling and choice of posture in the water. For example some children feel more relaxed when held in side lying in the water, as compared to being held supine.
Mass, causing more hydrostatic pressure the deeper you go.	The weight of water pushing against the body is called hydrostatic pressure. The forces involved are considerable. This increases the venous circulation back to the heart and effectively gives the heart a work out. This is good news in terms of cardiovascular fitness, even before the exercise has started.	Increases in circulation mean that the organs of the body work harder. Metabolism goes up. The kidneys work more and the bladder fills. This is all good unless there are underlying vulnerabilities. The risks can be reduced by making sure that fluid is replaced and a snack is given.
Mobile molecules, offering turbulence.	This increases or decreases forces on the body. You can move into turbulence using it to provide resistance, strengthening a muscle. Or you can move with the direction of the turbulence assisting a weak muscle to move a joint. The turbulence also stimulates and massages the skin.	The sensory input from turbulence needs to be moderated for each child. It can be hard to predict what the child is experiencing below the surface if there are lots of others in the pool.
Unique visual appearance, sound and feel.	Sensory integration techniques can be used and incorporated into a motor program. The facilitator is in direct contact with the pupil at all times. It may be the only medium where a child can safely experience the movement of another person's body at such close quarters.	There may be some fears involved with these sensory experiences, such as the sounds of splashing, or the feel of water close to the ears and eyes.

Being clear about the benefits

Thinking about all of the positive benefits of aquatic therapy I could bravely state that "The medium of water offers benefits to the life experience and learning for most children with profound learning and physical difficulties, many of whom also have concurrent severe medical difficulties". It would be tempting to accept this as being fundamentally true and proven. Empirically you know that is not yet true. It is hard to say how aquatic therapy can affect the educational and clinical outcomes for individual children. The impairments, movement issues, and participation limitations seen in children with profound disabilities are wide-ranging as we all know. Quantifying outcomes are going to keep us all busy, and frustrated, for years to come. It is difficult to extrapolate between children. Each child is a "study of one".

The best advice I could give anyone working with children with PMLD in a pool is, try to experience it yourself soon. There is nothing more likely to increase your skills and enjoyment of this opportunity than to experience it yourself!

Contact Details

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Hello, Can Anybody Hear Me? : How Intensive Interaction Is Being Developed at St Rose's School, Stroud

Coryn Memory

" If a man does not keep pace with his companions, perhaps it is because he hears a different drummer. Let him step to the music which he hears, however measured or far away" – David Henry Thoreau (1854)

Imagine for a moment that when you wake up tomorrow you emerge from your slumber into a very different world. You find yourself in a world where very little makes sense to you. Perhaps you are restricted to a wheelchair, here one moment, pushed to somewhere else a moment later. Someone is telling you where they are taking you but all you hear is noise coming from their face. You are taken to a large hall where the piano, singing and talking, are all invading your senses simultaneously and the distant noise of the telephone and printer are like nails running down a blackboard to you. You try to call for help, but everyone around you is talking a strange language. The more you call out the more complicated the noise coming from their faces becomes. You rock and close your eyes, fingers pressed into your ears. Later in the day your sensory overload has eased and you are feeling happier. There is a toy just out of reach that you would like to explore, so you ask for it. Someone comes to you and pats your arm. The corners of their mouth turn upwards but you don't understand what this means. You ask again for the toy but no one understands your language, you just hear the noise from their faces.

Eventually you learn that when your surroundings are causing you sensory pain you can distract yourself by rocking, flicking your fingers and talking to yourself - "Ahh, ahh, ung. Ahh, ahh, ung". When you are bored you can amuse yourself –"Ahh, ahh, ung. Ahh, ahh, ung". You still try to talk to the people around you – "Ahh, ahh, ung. Ahh, ahh, ung", but you just hear the noise from their faces. Then one day your world changes. A pair of hands appear next to you, the fingers flicking your rhythm and you hear "Ahh, ahh, ung. Ahh, ahh, ung". A feeling of warm relief floods through you as this familiar rhythm and noise breaks into your solitary world. The corners of your mouth turn upwards as you turn to see who has thrown you this lifeline.

The above is my interpretation of some of the behaviours I have seen in people with PMLD and/or Autism. The smiles of recognition when I am involved in Intensive Interaction, however, need little interpretation. My launch into the world of Intensive Interaction came in January 2010 when I started working with a three year old little boy with significant Global Developmental Delay. I was, at the time, embarking on writing my dissertation for a BPhil in Severe, Profound and Complex Learning Disabilities. I had read Intensive Interaction books and was very drawn to it, so I decided this would be the focus of my dissertation. I discussed the idea with Sam's (pseudonym) mother and she was very enthusiastic. Sam was in a world of his own when he started in the Early Years Department, showing little interest in the people around him and spending most of his time occupied with self-stimulating behaviour. After first establishing a baseline observation when no intervention was being used, I started using Intensive Interaction with Sam. By the summer Sam's solitary self-stimulating behaviour had reduced dramatically and he was happily learning to interact with the people around him, especially through Intensive Interaction. Even though I was the instigator of the Intensive Interaction with Sam and it was myself who spent time specifically with him using the techniques, his family and other team members watched some of our sessions and started using the techniques with him. He became a much happier child and his family found that, at last, they were receiving something back from their little boy.

In July 2010 the school's speech and language therapist and myself attended a Mark Barber workshop at Penhurst School and were inspired to raise the profile of Intensive Interaction at St Rose's and make it a more integral part of the timetable. Dave Hewett suggests, "The best work has a judicious blend of natural responding and reflective judgement." Our aims are to help staff become more aware of the principles behind Intensive Interaction and the wide range of techniques used (contingent - not directive, burst/pause, drama, sabotage etc). This could develop the staff's interactions and steer them towards a more reflective and documented practice. We are hoping to develop staff training and already have a number of staff who are keen and are trying out some of the techniques during group sessions. We have also recently organised family information sessions to encourage families to use Intensive Interaction at home, building on and legitimising what many naturally do with their children anyway and encouraging those who struggle to reach their children.

I have been fortunate to be able to devote two and a half days a week to working with the pupils with PMLD in the school, and after the first six months am seeing some extremely promising developments, even in our students who are hardest to reach. One of these students is a very solitary, tactile defensive young woman who showed little awareness of people around her and was almost constantly engaged in hand chewing and making repetitive noises, to the exclusion of all else. This student now laughs and gives fleeting eye contact when she sees me, smiles when I respond to her sounds and often puts her head in my lap, smiling while I give her a back rub. A boy I started working with initially was only interested in using me as a plaything, fiddling with my fingers and flicking zips and buttons on my clothing. Six months on he now focuses for long periods during our times together. He constantly introduces new patterns of noises and waits with bated breath, laughing if I copy his sequence correctly. He also grabs me to turn back to him if we get disturbed and my attention is taken from him.

I share these success stories here not to blow my own trumpet, rather to shine a light on how Intensive Interaction can improve life for the more profoundly disabled people in our lives. I would urge anyone who knows someone with PMLD to investigate Intensive Interaction as a means of communicating with that person. If we know someone who hears the beat of a different drummer, let us take the time to listen and join them in their dance.

Some recommended websites with further information

http://drmarkbarber.co.uk/

http://www.intensiveinteraction.co.uk/

http://www.phoebecaldwell.co.uk/

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Interaction therapy

Clare Caughey

I am among the many people in our population who has at some point in their lives experienced emotional and mental health difficulties. For this I have tried a variety of "therapeutic" approaches. I should also say at this point that I work as an educational and child psychologist and so have spent many an hour poring over journals and texts for the magic bullet which will suddenly make me (and the young people I work with) feel instantly better, listened to, relaxed and understood. I've tried anti-depressant drugs, hypnosis, Cognitive Behaviour Therapy, Psychotherapy; and indeed I've also tried a few weird and wonderful alternative therapies (Acupuncture, Cranio-Sacral therapy, Kinesiology, Reflexology- you name it, I've had a go!). But over the last ten years of working with very special learners I've come to wonder if the answer (or at least part of it) lies in something much more simple; something basic, primal and innate to most of us - human interaction.

In 2006 I began my training as an educational psychologist. I had previously studied psychology at university, followed by training as a teacher. I worked as a teacher for children who have PMLD (or "very special learners" as I would prefer to describe this eclectic group of unique individuals), and since I was a teenager I have volunteered and worked in many capacities within local special schools. It was natural to me that as my career progressed into psychology to look in greater depth at the social and emotional lives of very special people. How do we understand those whose voices are harder to hear; and perhaps more importantly how do we tailor our actions in order to ensure those people's needs are met therapeutically? As part of my doctoral training I began a research project which aimed to explore the social and emotional experience of having PMLD. I recruited two participants from local special schools who were willing to have me visit them weekly for one year. During my visits I would film portions of their average day, and I would also film some 1:1 interaction with them (and me), using the well documented "Intensive Interaction" approach (Hewett and Nind, 1994). A brief descriptor of this approach would be that it is a child/client-led style of interaction which is based on infant-caregiver behaviours; and is typified by frequent playful interchanges which aim to promote social experience through turn-taking, and reflecting back the "language" of the individual with profound needs. This approach has been evaluated by several research papers (usually on a small scale, for example: Kellett (2000), Samuel, Nind, Volans and Scriven (2008), Firth, Elford, Leaning and Crabbe (2006), and Watson and Fisher (1997)), and has in many cases shown improvement in dimensions of social interaction.

The boys who were chosen from a list of potential participants were aged 9 and 18, and attended two different special schools. Each had very unique needs (and personalities as I would later discover). I could talk at length about these individuals, their families, their "stories", and what they have taught me in their own very personal way. As the constrictions of space limit me, an all too brief outline of each boy is given below (although one participant was aged 18 his parents are more comfortable with the term child/boy as opposed to young person/adult; as such their preferred terminology has been favoured here):

"Noah" (aged 18) was nominated to participate by his mum and dad. Noah was nearing the end of his school career as the research began. He was born with "Ohtahara Syndrome"; he had some movement of all of his limbs although he sat in a wheelchair for weight bearing and transport. Noah was believed to be visually impaired, and he communicated via facial expression, quiet vocalisations and hand gestures.

"Aaron" (aged 9) was a lively little boy born at 23 weeks gestation. As a result he experienced Cerebral Palsy and visual impairment. Aaron also used a wheelchair for transport and weight bearing, and he used vocalisation, facial expression and limb movement and muscle tone to communicate with the caring adults around him.

Both of these boys (and their teachers and parents) kindly allowed me the privilege of being part of their lives for one year. During this time I filmed our intensive interactions, let the camera run as I pottered about their classes, chatting to teachers and classroom assistants and observing "a day in the life" of a person with very special needs. I became (I hope) a friend to the boys, and to some of the teachers and parents involved. When it came to analysing the footage I looked at a range of indicators of their social and emotional experience; and interviewed the parents and teachers regarding their opinions of what it feels like to live as one of these beautiful individuals. I also asked a number of colleagues (including Dave Hewett) to look at snippets of Noah and Aaron's lives and comment on what they felt were the qualities of the social and emotional experiences they were privy to.

As one might expect there were highs and lows throughout the year: moments of elation, of sickness, of low mood, of irritation and possibly fear or anxiety. The moments which were characterised by more communication, more engagement and more moments in which we might describe the boys as "lighting up", were however dominated by meaningful 1:1 human interaction. In the main this appeared to be provided via the intensive interaction approach - time specifically dedicated to the observation of the individual, careful watching and waiting to respond in a way that seemed comfortable and appropriate; mirroring the child's own personality, and providing appropriate physical touch to facilitate emotional communication and to enhance reciprocity of communication. In addition, however, these glimmers of intense happiness, understanding and reciprocal interaction were noted in 1:1 encounters with a caring adult who is using their own instinct to nurture and care for the individual (essentially the tenets of intensive interaction as an approach). Brief moments during circle time, helping an individual to eat their snack, or in facilitating interaction in a school assembly or music therapy session were also noted to be examples where Noah and Aaron seemed to be in an "emotionally well" state; where they could communicate their own preferences, be understood, and share in their enjoyment with another person. In this sense these interactions could be deemed to be therapeutic. What else does a person hope to gain from a therapeutic alliance, only effective communication of our own story or experience; being understood or validated; and sharing with another person the information which can help us to feel well?

When looking in further detail at what made these interactions more "therapeutic" than any other daily encounter, there appeared to be four essential components: 1:1 interaction (even if this took place as part of a wider group context), use of physical touch, mirroring of the child's own personality style and the responsiveness of the interaction partner. We need the time and patience to work on an individual basis (even within contexts which demand sharing our attention between many individuals). We need to observe for the cues of communication and use physical touch to respond appropriately (and in particular to demonstrate our very human understanding of another person's experience). We need to look at the individual's personality and tailor our responses (for example the quiet and serene child should not be met with over exuberant hair ruffling or loud joviality; but rather with a gentle, soft and non-threatening approach). We need to be the ones who change in order to facilitate therapeutic alliances for these individuals - we observe, we adapt and we build upon interactions and we provide the bridge to further interaction. Finally we need to think carefully about our responses, use multi-sensory tools to demonstrate that we *have* heard, we care and we will act to help the individual to feel well.

Perhaps *therapy*, for all its bells and whistles, really comes down to this: interacting effectively with another being. Allowing oneself to be understood, engaging in reciprocal communication, and being both comfortable and comforted by the presence of another person. Intensive Interaction, I believe, provides us with the tools for guiding this therapeutic process. For those of us who are lucky enough, this is an instinctive process: to have a natural gift for "hearing" other people, whatever their language, simple and natural interaction with people should (I believe) be viewed as therapy. Interaction therapy. Regardless of the pressures of curriculum, of policy or of our demands for ever complicated methods of creating the miracle cure for emotional wellness; I feel we all need to bear in mind and make time (both for ourselves and for our clients/pupils) for the importance of interaction as our own very human means of therapy. Perhaps rather than my medications, behaviourist principles and weird and wacky needles and tinctures what really benefits me most in providing a bridge to emotional wellbeing is interacting with a person who observes, understands, mirrors and enjoys being with me. Similarly for our very special learners this in itself is therapeutic; and should be given credence in our busy timetables, lives and schedules. As Aaron's mum succinctly stated *"I've often said to people when they ask is there a toy or anything he'd like for Christmas I say 'what he'd really like better than any flashing light or fancy toy is an hour of your time'. But people don't really know how to do that with children like Aaron".* We need to learn how to do this. It is our therapy for boys like Aaron and Noah, and it is our therapy as human beings. When I am low or anxious my instinct may be to hide away and wallow in my own negative emotions; but what actually helps is to spend some time with a caring person who will listen, hug, reflect and care.

Since carrying out my research sadly Noah has passed away. He was 20 years old when he died, and I can honestly say I have never met another 20 year old who has the wisdom and life experience which he taught without any words at all. I will forever be glad to have spent time engaged in interaction with him; as I believe it was not just therapeutic for him, but also for me.

So, what's next? I continue to encourage, to empower and to implore education providers to look at Intensive Interaction as a therapeutic process; and to use educational psychology time to provide this therapy if staff feel unable to pursue it individually. In addition I have begun to look at how the company of animals can provide therapeutic interaction for children and young people who find humans more challenging or intimidating to engage with. I am currently exploring the use of assistance dogs as a therapeutic tool particularly with those children whose complex needs include Autistic Spectrum Disorders; and I hope to bring interaction to the fore of the curriculum and of therapeutic approaches to emotional health and well-being with very special learners.

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PMLD LINK
sharing ideas and information

Not just sitting in the corner: Intensive Interaction and service user consultation

Thomas Chalk, John Burley and Nick Guthrie

As more and more people are included in consultation work, it is important to consider those who face the greatest barriers to communication. Creative work has been done to engage with people in the ways that best suit them. The danger is that people with the most profound learning disabilities might still be left out. This article suggests the use of Intensive Interaction as a way of bringing people into consultation events. If one of the therapeutic purposes of Intensive Interaction is increased opportunity to make connections and engage socially, this is strong justification for using it in a public arena such as a consultation event.

Inclusion and involvement have become key issues in supporting people with learning disabilities. Inclusion is one of the four guiding principles of *Valuing People* (Department of Health, 2001) and *Valuing People Now* (Department of Health, 2009). The involvement agenda is seeing people with learning disabilities gain more meaningful opportunities to comment on and shape the work of services that affect them (see inset boxes *Inclusive Consultation*, which uses Intensive Interaction practitioners as facilitators for one group, and *The All Means All Event*). It is vital that people with the greatest barriers to communication and understanding are not left behind in this work.

Overcoming communication barriers has been key to including more and more people in meaningful consultation work

The PMLD Network (Mencap, 2008a, 2008b), noting the lack of progress for people with profound and multiple learning disabilities in gaining involvement with local Partnership Boards, offers examples of ways to improve this: peer advocacy by other people with learning disabilities; and supported self-advocacy through multimedia work, objects of reference, and storytelling.

> People's views may not be directly available, as often the concepts we want views on may be difficult to grasp. […] However you can find out whether someone's experiences have been positive or negative and how someone has responded to an experience *by being sensitive to the communication of individuals*. (Mencap, 2008b, p.1, emphasis added)

Inclusive Consultation

A short film or slideshow tells people what the meeting is about. People then join the group that best suits them:

A discussion group
people talk about the things they think are important, supported by Advocates.

A signs and symbols group
people have their say using symbols, pictures, signing and gestures, supported by Speech & Language Therapists

A supported group
people have someone who knows them well to speak up for them, supported by Intensive Interaction practitioners

The All Means All Event

The All Means All Project was the result of a two day Partners In Policymaking course, in which people with high support needs explored their lives in terms of past and present with a view to improving the future.

The project organised an event giving people the chance to find out about health, communication and access, where a campaign for fully accessible Changing Places toilets in Leeds was launched .

An information market had stands made as interactive as possible – activities ranged from food tasting to craft work. People viewed presentations and videos throughout the day from a central seating area. A second room housed workshops in Postural Care and Intensive Interaction, with scope for people to dip in and out of the sessions. A multisensory relaxation area allowed time out from the event.

The All Means All event sent a clear message that excluding people with high support needs is a choice that is actively made and not simply a difficult problem to tackle.

Naturally, there is strong focus on knowing people and finding ways to intuit how they might be feeling; and while Intensive Interaction is not about the exchange of information, there is clear crossover in the techniques of Intensive Interaction and those suggested for consulting with people with profound and multiple learning disabilities. However, to advocate the use of Intensive Interaction solely as a stepping stone to more ‘meaningful’ consultation would be to miss an important point: inclusion is driven by valuing people for who they are, regardless of ‘how well’ they can contribute.

The use of Intensive Interaction proposed here is as a way of valuing the presence of people whom we are still unable to directly include in other ways despite all of the alternative communication techniques that can be employed. Work on service development and planning, for example, can be very abstract, and understanding the preferences and views of people who will be affected is only the start; further work must be informed by this but is likely to be tied up in verbal communication and intangible concepts such as ‘the future’. Having Intensive Interaction practitioners engaging with people will demonstrate that their presence is valued. Clearly, there is a danger of straying into tokenism, of mistaking ‘being in the room’ with ‘being part of the process’. If Intensive Interaction is the only provision for people to take part, it will be dishonest to suggest that their views are represented; it must happen in parallel with other work ensuring their preferences and needs are represented as fully as possible.

Using Intensive Interaction at consultation events will allow people to be brought into events rather than left sitting in the corner or not present at all. Social inclusion means more than just being a visible part of the local learning disabilities community, but if people are excluded from activity specifically designed to promote inclusion then arguments for wider community profile ring very hollow indeed.

What is Intensive Interaction?

Nick and A

Intensive Interaction is an approach to facilitating two-way communication with children and adults with severe or profound learning disabilities and/or autism, who are still at an early stage of communication development. (DoH, 2009, p.38)

Intensive Interaction provides opportunities for people to spend mutually enjoyable task-less times together exploring conversational exchanges and building on repertoires that are familiar and personal.

Intensive Interaction was originated by Melanie Nind and Dave Hewett in the mid 1980s. Influenced by clinical psychologist Geraint Ephraim’s ideas on ‘Augmented Mothering’ (1979), the approach is based on caregiver-infant interactions, and celebrates ‘The Fundamentals of Communication’ (Nind and Hewett, 2005) – emergent human abilities such as sharing space and eye contact, giving and receiving attention, and turn-taking. It allows people to express themselves, to be accepted for who they are, and to be socially included.

For Intensive Interaction to work, an individual’s communication partners need to be observant, interested and empathic. Intensive Interaction is not a wand-waving miracle ‘cure’ for overcoming barriers to communication; rather, it is an application of the natural human instinct towards communication and inclusion.

Perhaps most powerfully, Intensive Interaction can allow people to represent themselves through their very presence. Some visitors to consultation events have little contact with people with learning disabilities, and meeting people with the highest need of support can be very powerful (see *Changing Places: A's story*, inset box).

Changing Places: A's Story

A is a very outgoing and sociable man who has profound and multiple learning disabilities. He doesn't use words or speech, but enjoys interacting with people, and has a knack for getting their attention and making friends. Intensive Interaction has been used with A, with great success.

A was a member of the All Means All Project. The presence of A and others with profound and multiple learning disabilities at the All Means All event ensured it was impossible to forget or overlook their needs.

A key All Means All campaign was for Changing Places to be built in Leeds. It was not possible to convey the meaning of this work to A, but his support staff confidently advocated the importance of the campaign to him. His consent to participate was inferred from his enjoyment of being out in public and meeting people, and the clear benefit to him of any success of the campaign. A was part of the team collecting signatures for a petition, and of the deputation delivering it to Leeds City Council. It was here that he really came into his own as a self-advocate: his presence said more about the people who need Changing Places than would have been possible if they were merely represented with words in their absence.

Intensive Interaction does more than just fill time with people while they are in the room: it can show people with profound and multiple learning disabilities at their best, and can show the support they are given at its best. More than highlighting disability, Intensive Interaction is a powerful demonstration of *ability*: the ability to engage, the ability to be involved, the ability to simply be with others if the opportunity is given.

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Therapeutic Storytelling

Janet Dowling

Stories are the oldest form of communication and I believe that stories and oral storytelling are a very effective way of supporting the development of children and adults with PMLD. It does not matter whether they can cognitively follow the narrative line, there is always a sensory narrative that the listener can follow and it is the responsibility of the storyteller to maximise both.

I was once a psychiatric social worker and whilst training met a psychologist who taught me how to use stories and storytelling to help people change their view of the world. With the support of my supervisor in the workplace, I used storytelling as part of my therapeutic work with adult mental health clients, and mental health groups.

When I took a step back from social work, I worked as a storyteller in performance, but found I was also drawn to therapeutic storytelling in hospitals and hospices in the UK. For three years I was the Therapeutic Storyteller at The Children's Trust, in Tadworth, Surrey, which provides care, education, therapy and rehabilitation to children with multiple disabilities, complex health needs and acquired brain injury.

As a storyteller, when I am working with children and adults who have PMLD or acquired brain injury, I look for ways to intensify the cognitive and sensory narrative experience to enable them to develop a cognitive and sensory emotional literacy and to better interpret the world around them.

I feel it is important to "punctuate" the session at the beginning and end with a brief song, so that the child associates that time with a separate activity and using the song voice differentiates the voice from the talking/ telling voice. The session song 'bookends' vary in tone and rhythm, with the last "story ends" fading out.

I use fictional, traditional and personal stories, and with children with acquired brain injury, I make up a story about the child as a metaphor for their own issues. If I had the opportunity to meet one of their parents or primary carers, I would ask if their child had any particular favourite stories prior to the incident. Sometimes it was fairy tales - Red Riding Hood seemed to be popular, sometimes a book - Harry Potter was a favourite, or sometimes a TV show - Sponge Bob Square Pants or Tracy Beaker.

By basing the work on the stories that the child was already familiar with, we didn't have to establish an emotional connection with a character as that was already in place. The focus was then on using existing characters, and creating new stories that put the characters into situations where they might be experiencing the same emotions as the child.

For children recovering from traumatic brain injury, part of the process was enabling them to create a vocabulary and emotional literacy to deal with and understand what had happened to them and how they felt about it. The trauma of injury may well leave them in a mental and emotional state where they have no words to describe or convey how they are feeling. This was especially relevant for children who could not demonstrate any regular cognitive functioning, although they might be locked in mentally.

I used props to include the three modalities, visual, aural and kinesthetic, at appropriate points in the story. Sensory objects such as scouring pads, silky materials, rough tea clothes, knotted string, red stretchy material – good for anger - evoked a sensory metaphor for the emotions that the child may be experiencing, and then words were introduced to describe them and to develop their emotional vocabulary and literacy. For children with PMLD this gave them an opportunity to experience the emotions in the story.

If a child was unable to speak, but had some way of communicating - a gesture, head turn, eye spotting, hand movement - or sound, then the story would be simply told together with objects, and simple options offered for them to indicate their preference. Sometimes the child would need to be assisted to feel the object, and I also used the button communicator - a Big Mac - to record up to 20 seconds of a story. A repeating refrain e.g. "Fee Fi Fo Fum, I smell the blood of a human man!" can be recorded and the child helped to press the button at the appropriate moment in the story. This increases their sense of participation as they begin to recognise, remember and then anticipate the pressing of the button and the ***blood curdling*** refrain.

When there was no obvious physical movement or cognitive functioning, then the storytelling focused on repeating sequences of sensory storytelling with the same three stories told every week for six weeks and then another three stories. This would allow for the development of a pattern of sensory experiences using voice and body, and words and multi sensory objects.

Working with Tommy

Tommy had been an active 10 year old boy, with a lively interest in football, and a great passion for Harry Potter when an accident and the resulting brain injury left him unable to have any control of his limbs or to show consistent signs of cognitive functioning. He would experience limb spasms and his eyes would be open for part of the day, and then close.

His father had read and taped the Harry Potter books for him, and the nurses would occasionally sit by his bedside and read aloud to him from one of the Harry Potter stories. Being a Harry Potter fan myself, I was very familiar with the stories and could have retold them, but I only had half an hour a week, and he was getting Harry Potter in different snippets from both the carers reading aloud and the tapes.

I felt that Tommy needed an experience of being told a story that had a beginning, middle and end all in one session. If Tommy was able to cognitively follow the story, this would be more satisfactory than having snippets told to him that he may not be able to hold in his memory. If he was not able to understand the story, he would at least have the pattern of familiar sensory experiences from the props, the way I used my voice and tone, and the patterning of the words.

Harry Potter has great potential for exploring traumatic injury and developing emotional literacy. He falls from his broom in the Quidditch match and lays in the sick wing unable to move. The bones grow back but very slowly, there is no sudden magic response. “Harry Potter and the Prisoner of Azkaban” is particularly relevant as the background story for enacting, and telling new stories that address metaphors for physical and mental trauma. The “dementors” suck all the good experiences out, leaving the person with just the negative emotions- i.e. depression.

I had a series of small puppets of different colours and textures that would also feature in the story - spiders, cats, dogs, a gryphon and a phoenix - and transparent cloths of different colours that could be draped over Tommy’s hand and face to create a sensory and light change.

Tommy would be lying on his bed in his room with cushions and pillows to give him support, and each week after the song I would tell a short Aesop’s fable, followed by a made up story about Harry Potter or one of the other key characters. He was not able to communicate in any consistent way but staff fed back that they thought he enjoyed the storytelling because he was less restless after our sessions.

On one occasion, I was feeling tired and not up to creating a Harry Potter story, so I told a number of short stories and then sang the “end of story “rhyme. Tommy’s eyes filled and a tear slid down his face. My feeling in that moment was that he was upset because I had not told him a Harry Potter story, and the only way he could communicate this was through the tear. This may have been a fanciful response on my part, but none the less it reinforced my ethic that every child is an individual and that my storytelling was focused on giving the child the best sensory experience possible. I apologised to Tommy, and promised I would always tell him a Harry Potter story. I saw him every week for 18 months until he returned home, and I never saw another tear.

Working In groups

I also ran story clubs at The Children’s Trust for children with acquired brain injury. The focus of the group story was multisensory and interaction, with everyone taking part - children, parents and carers, and I modeled how to engage the children through storytelling. Taking a theme over a six week period, I would tell stories related to that theme - King Arthur, Robin Hood, and Star Wars etc. That allowed us to establish characters and develop the story.

A line of the story (maximum of 5 syllables) would be told directly to each child, and they would be invited to repeat it. Those with no voice used the Big Mac. I had puppets and sensory materials and somewhere in the story there would be a sword fight. I had a range of plastic swords and the sword fight became a metaphor for fighting their own battle with their injury. The children with severe physical disabilities were supported to hold their swords. Mayhem reigned and much laughter, with one father crying as he had a sword fight with his son with paraplegia. Afterwards the father said how the story group was the highlight of his week, and that he would be using stories in the same way when his son returned home, as he felt that it was one way that he could connect with him.

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PMLD LINK
sharing ideas and information

Vol. 23 No. 3 Issue 70

Using Objects of Reference as an individualised communication aid in a social care setting

Paula Hellal

Objects of Reference (OOR) have been used as a means of communication since the mid 1960s when van Dijk first used them in his work with the congenitally deafblind. In the late 1990s McLarty found that the methodology had been taken up somewhat piecemeal by colleagues in the wider area of special education leading to an emphasis on practicalities: How to use OOR, rather than How does OOR work? The lack of any supporting theoretical framework and of evaluative studies was highlighted as a cause for concern. Park (1995, 1997) also called for research into OOR putting forward a model of his own. More than a decade later, while there is a small body of "how to do" literature on the subject, considerable work still needs to be done to provide the "thorough evaluation of how and why they work" (McLarty 1997). In a recent review of communication aids used with people with complex needs Goldbart and Caton (2010) made the same point. They also found that while 70% of the practitioners in their survey made use of OOR, only one parent and two researchers (experts in communication and disability) reported using the method.

The Function of Objects of Reference

The literature on OOR focuses on its practical application typically in a classroom setting. There is general agreement as to the purpose of using OOR and how OOR can be put into practice. Using OOR may enable someone to:

- Communicate wishes and needs
- Develop an understanding of the environment through the haptic sense and enable the anticipation of familiar activities
- Make choices
- Develop an understanding of sequencing and organisation
- Develop a receptive and expressive means of communication
- Develop language concepts

OOR can be used on a basic level e.g., to indicate the commencement of a particular activity and at a higher level e.g., to sequence the activities of the day through the use of calendars and storyboards that act as a memory aid for the individual, with the added bonus of enabling his or her day to be "read" back by someone.

Hierarchy of OOR used to represent a person, activity, location etc and the development of symbolism

- Real object
- Part of an object or miniature version of an object
- Photograph
- Color drawing
- Black and white drawing
- Symbol

Advantages to method

- Relatively low demands made on cognitive processing; as the objects are continuously present, unlike speech, they need only be recognised, rather than recalled from memory
- Depending on the type of object selected (and bearing in mind limitations due to individual

sensory impairment) OOR may be touched, seen, smelt, tasted or even heard
- Readily handled and manipulated by simple motor response i.e., eye gaze, pointing, touching and picking up
- Hierarchical system from iconic (close relationship to the referent) to abstract representations may facilitate language development
- Can be used in combination to compose a message

Disadvantages to method

- Unconventional communication method that may not be used consistently or understood by all communication partners
- Objects may be introduced before the person has mastered concepts essential to their understand
- Objects may not be easily understood or associated with the intended referent
- The use of whole objects may not be portable

Pre-requisites to the introduction of an OOR system

The fundamentals of communication stem from the early interaction between infant and care giver: shared attention, shared gaze and pointing. Research suggests that joint attention to objects and others, cause-effect, discrimination skills, turn taking and imitation facilitate the development of symbolism or abstract representation necessary for language. Before offering OOR as a communicative method we need to support the development of these fundamentals of communication.

The tricky question of meaning

The repetition of simple routines is likely to encourage memorisation and anticipation. When a particular object is always involved in a task it may come to characterise that task. The object becomes an "object cue" (Aitken, 2000) e.g., putting on an apron before a meal. The cue becomes an OOR when it is separated from the task by time or by using a different object than that being referred to. Understanding the referential function of an object, that is that something "stands for" or "represents" something else, is crucial to the use of OOR as a communication aid. Much of the practitioner and online resource literature is dedicated to ways of making the link. Suggestions include when first introducing OOR the object/s selected should be iconic to facilitate understanding and frequently reinforced (use OOR for frequently occurring events).

But how do we know that the meaning we intend to convey has been acquired? Why, for example, as Park (1999) points out, should a purse represent shopping? How do we know what an object may or may not represent for someone else? There are reported instances of OOR users learning a completely different association from the one intended. Explanations have been proposed ("over-learning", "over-generalisation") and suggestions put forward to try and reduce the risk. The need for research into OOR and the acquisition of meaning in people with severe cognitive impairment is long overdue.

Types of OOR schemes: shared, differentiated and individualised

- Shared- everyone uses the same object to refer to the same thing - spoon to refer to dinner
- Differentiated - everyone uses a spoon to refer to dinner but the spoon itself differs
- Individualised - one person uses a spoon to refer to dinner, another a photo of a plate etc

Advantages of shared scheme

- Easier to maintain and manage in large settings such as schools, large residential homes
- Communication between student/ service users would not be possible with individualised symbols
- According to recent research a shared scheme makes less demands on, and instructs and motivates, staff (Jones et al., 2002)
- It "provides a means by which the use of objects of reference by individual clients may be assessed and planning for the development of their communication may be informed" (Jones et al., 2002)

Disadvantages of shared scheme

- The communication of those with PMLD may be pre-intentional, idiosyncratic and context dependent necessitating the use of individualized OOR
- Different objects may mean different things to different people
- When the person moves to another setting (i.e., from school to school or school to adult care) a different scheme may be in place leading to confusion and a breakdown in communication

Despite the advantages Jones and colleagues highlight in their study of 13 adults with PMLD using a standard set of objects, they recommend the use of objects specific to individuals where practicable (Jones et al., 2002). Likewise, in deafblind research, much emphasis is typically placed on the importance of individualised selection.

Case study example: Helen

Helen is in her late 30s and is one of eight residents with PMLD in a Mencap adult social care home. She is severely cognitively impaired, severely hearing impaired and non-verbal. Helen communicates through pointing, crying, facial expression and body language, and by self harming. She has cerebral palsy, poor motor control, including poor oro-motor control, is non-weight bearing and uses a wheelchair.

Helen was introduced to the Paget Gorman signing system while at school but any progress she made (receptive and/or expressive) is no longer known. An individualised OOR system has been in place for a number of years in her care home. For some considerable time she was making use of only a few OOR (to refer to basic needs). Recently, her OOR set has been increased to enable more choice and now includes the categories: person, place, activity as well as basic needs. The OOR system is used with Helen in two main ways: to indicate what is about to happen and to enable choice. Helen's understanding of her environment is to a large degree dependent on routine. Unexpected changes provoke distress and may lead to self-harming episodes. It is hoped that the development of the OOR method of communication will enable Helen to gain a greater awareness and understanding of her environment and, by informing her of any alteration to her routine, reduce anxiety and stress and lead to a decline in her self-harming.

Helen is able to look at, point to, grasp and hold the OOR. Her ability to make a choice between two offered objects has been established and reinforced through regular (and tested) choosing of clothes. Using OOR expressively to make choices is a late stage in the acquisition process: "It can only be achieved once a firm association is established and the student is used to being expected to initiate" (CALL Centre, 2004). Her OOR set varies from iconic items used to refer to basic needs (i.e., a cup for a drink) to abstract objects. The use of photographs (life-size and colour) has been introduced gradually and Helen is demonstrating an ability (hitherto unsuspected as anecdotally she was held to be cognitively incapable of understanding two dimensional representation) to make her choice using this method. That her choice is intentional and not random has been tested.

To facilitate her learning, her OOR set is used consistently and on a routine basis. The OOR set is meaningful and motivating for Helen. Helen does not initiate the use of her OOR set as she is physically unable to access the set (kept in a bag at the back of her wheelchair) and needs to wait until the selected objects are placed before her and she is encouraged to make a choice. To use OOR expressively she needs firstly to be encouraged to hand the objects to staff as a communicative act and to have the means of getting hold of the objects for herself. Using miniature versions will aid access. We are currently working on increasing her set of OOR, extending the choice offered from 2 objects to 3 and developing her understanding of more complex forms.

Acknowledgements: I would like to thank Helen's mother for permission to describe her daughter's experience of using OOR.

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An outcome focussed approach to day services

Dorian Thomas

I was invited by the managers of day services to support them in introducing an outcome focussed approach to day services. The services were for people with profound and multiple learning disabilities (PMLD). The request for support arose from a strategic led directive for all PMLD day services to become more accountable for the service they offered. All too often day services have been criticised for having no particular aim, being ill defined, and serving only as an alternative to home (Mencap, 2002).

The social services budget pressures did not pass by these day services; as with all other departments they had to show that the budget was well spent and gave maximum return on its investment. The response to this requirement was to develop service outcomes which best described the client group's aims and objectives. For the services I was supporting, these outcomes were set as *maintenance* and *improvement* outcomes and I realised that the main focus of support should be not on the activity offered but the framework on which it was delivered.

Challenges faced

The challenges which faced me concerned the nature of the service user's disabilities, in particular their limited level of function, and the barriers this presented for them in performing activities

As a starting point, in understanding this particular client group, I researched cognitive development theory, exploring Piaget's six sub-stages in the sensory motor period, (Lacey and Ouvry, 2003). This helped me to develop a better understanding of how to approach activity participation for the people I was supporting.

Outcomes

Outcome measures are becoming an increasing focus of our intervention. The need to evaluate effectiveness of intervention is not a new phenomenon. Florence Nightingale was one of the first to look critically at the need for effective outcome, when she recognised the relationship between soldier mortality and distance from the hospital. Outcome in a clinical sense can be seen as a measure of change between the start of a study period through to its end, (Pynsent et.al., 1993). In a similar sense, my approach to the implementation of outcomes aimed to measure the effectiveness of intervention from two fixed points, albeit not according to strictly scientific criteria. The outcomes set were therefore related to attainment of goals, which were based on the person's functional ability and also gave purpose for the programme of daytime occupation.

Training

In order for the staff at the day service to work in an outcome focussed way, it was necessary for them to receive training in the key concept of outcomes and how it applies to clients. This was then developed and delivered by the therapy team supporting the service. This team was comprised of occupational therapy, speech and language therapy, and physiotherapy personnel; the focus being on a multidisciplinary approach to achieving outcomes. The training involved each discipline outlining their uni-professional focus on developing function through activities; however with a view that all activity was understood in terms of its multidisciplinary value. This approach to activity analysis can be illustrated through the example of a music group; here the physiotherapist may be concerned with an improvement in seating control, whilst the speech and language therapist's concern would be the person making choice, and the occupational therapist would be concentrating on bilateral coordination, grip and concentration.

The multidisciplinary opportunities for daytime occupation were not exclusive to structured activity - it was also relevant to all other experiences, such as hanging up one's coat, loading the washing machine, or wiping the table after lunch. These experiences hold equal value, when appreciated for the opportunities they offer for maintaining or developing function. As a means of capturing the potential importance that every opportunity offered, one of the team coined the phrase, 'the whole day experience.' The emphasis here was very much on analysing each encounter in one's day and picking apart its functional components. The person therefore was viewed in terms of a world of opportunity which existed around them and no individuals, regardless of ability, should be excluded. It is important therefore to provide a responsive environment in which services users can receive responses to their actions, get the opportunity to reciprocate the actions of others, and furthermore have the opportunity to take lead in interaction (Ware 2003).

Implementation / working towards achieving outcomes

Post training then involved consolidation of the training, and how this translated into practice. I initially needed to have time to meet with each key worker to discuss specific outcomes that could be set for the people they support. Each outcome was then based on the person's needs and functional ability. Once we had set specific outcomes the next stage involved designing each individual's participation plan. This was a combination of group activities and one to one sessions, as well as every day experiences. In accordance with occupational therapy focus, these activities were categorised according to self care, productivity and leisure.

The activities offered were diverse and involved every aspect of the day service operation. This also included clients supporting staff with their operational duties, such as cleaning tasks, in addition to engagement in the standard activities on offer. Participation in whole day activities also involved the service user in assisting in their own self- care, e.g. handling items required for changing continence pads. Through these real working examples I was eager to outline to staff that a person can expand their opportunities as possible to achieve their outcomes beyond traditional structured activities, i.e. supporting the person to engage in as many meaningful opportunities throughout the day.

This change of practice was nonetheless a challenge, not only due to having to implement new concepts to working, but also having to attend to the complex health needs of the service users. A sizable proportion of the services users, for example would have a combination of having to be fed by nasal gastric tube, require daily tracheotomy suctioning, be hoisted for all transfers, as well as be on a cocktail of medication due to the fragile state of their health. When also considering their early developmental level, it was evident that a small steps approach would be necessary in this setting. Henley (2005) illustrates the importance and right to develop function in outlining that, irrespective of the service user's level of function and the degree of complexity and disadvantages this poses, they should not be discriminated or deprived of access to a continuum of opportunities.

Although the outcome aim for the service was within the domain of maintenance and improvement outcomes. In practice, one of the service user's quality of life outcomes was to reduce their level of anxiety; which was then focussed upon ensuring that all activities were planned according to the levels of sensory input they were likely to experience. Another example involved a service user who was registered blind and would accompany one of the staff to open the curtains each day. The functional benefit of this activity was to experience the change of light when he pulled the curtain cord. The outcome that this was working towards was empowerment: recognition of cause and effect.

Within the day service there were also some individuals for whom a higher level of developmental outcomes could be set. For example, one person's outcome was to become more effective in communicating their needs. One of the sub goals in reaching this outcome was to then develop more successful execution of arm and hand control. The activity programme was then designed around offering opportunities for the person to exercise arm and hand control. Examples of such activity would include switching devices to operate the computer, or pointing to key words or symbols to make choices. In developing more effective execution of arm and hand control, painting was used as a developmental exercise.

The way forward

I continue to support the day service in question, and have since carried out continued project work to develop aspects of the daily performance of the service. This has included running a workshop for writing daily notes on the services users. The next step will now involve expanding this project into other day services for people with PMLD in Swansea.

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Physiotherapy Opportunities for People with Profound and Multiple Learning Disabilities in Newham, and the Olympics Legacy

by the physiotherapy team at Newham's community health team for adults with learning disabilities

We are part of Newham's community health team for adults with learning disabilities, a multi disciplinary team which consists of physiotherapy, occupational therapy, speech and language therapy, psychology, psychiatry, nursing and art therapy.

One of the therapeutic treatments we offer people with PMLD is 'trampoline therapy' (also known as rebound therapy)

This has positive effects on the:

- Cardio respiratory system
- Muscle Tone
- Posture and Balance Mechanism
- Kinaesthetic awareness
- Digestive and excretory systems
- Communication and motivation
- Weight Management
- Exercise Tolerance
- Behavioural difficulties

This is also an opportunity for service users with profound and multiple learning disabilities in Newham to engage in a social and physical activity that supports freedom of movement outside of their wheelchairs, whilst enabling our physiotherapy team to carry out programmes to maximise function and minimise secondary complications.

This treatment modality is currently taking place in various community settings across Newham; through Physiotherapy at Newham Leisure Centre,
Special Needs Trampoline sessions offered by coaches at the local leisure centre, and coaches employed by local day opportunities services. The qualified special needs trampoline coaches are mentored by the Physiotherapy Team.

Aquatic Therapy (also known as hydrotherapy) is another treatment modality used within our team. The properties of water such as buoyancy and turbulence, offers freedom of movement to those with a physical disability, especially service users with PMLD.

Depending on the individual's programme, the therapeutic effects of exercises in warm water may include:

- Improving circulation
- Improving cardiovascular fitness
- Improving self-esteem
- Promoting freedom of movement
- Relief of muscle spasm and pain
- Maintenance or improvement of the range of movement at joints
- Strengthening muscles
- Improving core stability
- Improving coordination
- Encouraging mobilisation
- Relaxation
- Fun!

Our service users with PMLD attend weekly 1:1/group physiotherapy rehabilitation at their local leisure centre swimming pool and our service user case load is forever increasing. People with PMLD are rarely discharged from our services because of the complexity of their health and physical needs and we also encourage use of the leisure centre swimming pool at different times of the week, in addition to attending the physiotherapy led sessions.

We have found that support workers and carers are often worried about going swimming with the person they support outside of the physiotherapy sessions, and so we provide training to build their confidence around this, and work with leisure centre staff to ensure that the pool is accessible and people feel welcome if they attend at other times. Newham's Leisure Forum (part of our Learning Disability Partnership Board), has worked with the leisure centre operator, Greenwich Leisure Limited (GLL) to ensure that the leisure centres are accessible for people with PMLD to use. It has not been possible to overcome all the obstacles (such as ensuring the water temperature remains high), but by working together many of the barriers around accessing the leisure centre have been overcome. Leisure centre workers are aware of the importance of issues that would prevent people from being able to use the centre, such as broken hoists, lack of changing facilities or timetabling issues which result in the pool being crowded, and they try to minimise these.

The local leisure centres now host various disability swimming sessions during the week where our service users have access to the hoist for a safe transfer into the pool, swimming aids are always available, and the pool area quieter than during a general needs swim, but they are also able to attend the swimming pool during open swimming times.

These activities are opportunities for service users with PMLD across Newham to access local community leisure and resource centres. Our physiotherapy team are continually linking up with GLL and local day service opportunities to ensure that there are physical activity opportunities for people with PMLD that are therapeutic, fun and engaging. GLL, and other sports and leisure providers, have also recognised that people with PMLD are a valuable customer group, and have taken on the challenge of providing accessible sport and leisure activities for adults and children with PMLD, including multisport sessions, yoga, and gym sessions advertised for people with disabilities and with additional staff available. They have also hosted events aimed at people with PMLD to advertise the opportunities available within the leisure centres.

Many of the Olympic sports venues are located in or near Newham, and the Olympics offers a great opportunity to ensure that our local sports and leisure facilities are accessible for people with PMLD. With the support of Mencap and the Changing Places Campaign, we have secured a number of changing places toilets around the Olympic park, and at the Westfield Shopping Centre next to the Olympic park. The construction of new sporting venues, and the inclusive philosophy of the Olympics, has also provided an opportunity to overcome some of the barriers to inclusion that we have found at our other leisure centres that are housed in older buildings. For example the aquatic centre will have a larger number of changing rooms with hoists, and a system that will allow people with physical disabilities to get in and out of the pool more easily. We are still working together with the large number of people who are involved in deciding what is going to be included in the Olympic legacy, but are hopeful that the Olympic park will offer a full range of sporting and leisure activities for people with PMLD, as well as facilities for therapeutic work. These will provide therapeutic and health benefits to local people and people with PMLD who travel to visit the park, and a model of inclusion and equal access to community resources for people with PMLD.

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FUTURE FOCUS

Life is for Living!

The next issue of PMLD-Link has the title 'Life is for Living!' and we are looking for articles that celebrate the fun that can be had with children and adults with PMLD. Of course fun can be had whatever is happening, even if someone is in hospital or stuck at home on an ordinary dark winter afternoon so articles can be inspired by almost anything.

We would particularly like to hear about holidays. What kind of holidays have you been on? What sort of activities are suitable by the seaside, in the country, abroad, close by? Days out would be interesting, especially if you have been able to use a Changing Places toilet!

What about some of the fun things that are included in the school curriculum? At our school children go horse riding, swimming and are facilitated to play in the woods. They ride their bikes and enjoy specially adapted play equipment. We have a Summer Play Scheme which is filled with fun things to do – some of them very messy! Can someone write about play with children (or adults) with PMLD?

The 'Involve Me' project, written about by Louisa Wait in the Summer 2011 issues of PMLD-Link was partly about having 'fun, interest and engagement'. The story about Tanya in the article (on page 19) shows how important it is to keep an open mind and how interpreting behaviour accurately can lead to a change in the activities offered to someone with PMLD. Understanding Tanya's like, dislike and boredom signs has encouraged staff to bring new interesting experiences into her life. Have you got stories about changes such as this?

The arts, of course, are positively made for inducing enjoyment! There is nothing more catching than the joy of being enveloped in musical sounds or vibrant coloured paints. There are some delightful interactive drama games around and lots of ways to dance both in and out of a wheelchair. I'm sure you have stories galore about arts activities that have inspired and engaged people with PMLD?

My final suggested area that might provide fruitful ideas for an article for the next issue of PMLD-Link is one that comes up over and over again: Intensive Interaction. Some people seem only to have been existing, rather than really living, before they have been reached through Intensive Interaction. Tell us their stories and send us photos of them showing us that 'Life is for Living!'.
I look forward to receiving your articles and those of your friends and acquaintances. Remember they can be long or a short. I could weave together several little stories if you can write 150 words on a successful holiday, a visit to a local place of interest, an arts activity, interactive games or a multi-sensory fun time. Sharing your enthusiasm can inspire others.

The deadline for the 2012 Spring edition of PMLD-Link is 13th February. I look forward to a flood of articles by that date!

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Do you pay your subscription by Standing Order?

Thank you to all subscribers who pay by standing order. Have you checked that the right amount has been paid? Subscriptions have increased slightly this year so there may be a small amount outstanding.

The subscription for 2012 will be £18.00 so could you please make sure that your bank is notified of this – you have all year to do it, but now is the best time! At the same time could you change the payment date to 4th March each year as this will give time to alert you to any increase in subscription in the future.

If your details have changed please let me know as I only have your name from the bank.

Beryl Smith (November 1932 – May 2011)

Some readers of PMLD Link may not be familiar with the name of our friend and colleague Beryl Smith, who has died of cancer of the pancreas, but her influence in the field of learning difficulties and disabilities is far reaching.

Beryl trained as a psychologist and her doctoral thesis, undertaken when she was a principal researcher at the Centre for Child Study at the University of Birmingham, formed part of a major longitudinal study on the abilities of some 200 children with learning difficulties in special schools in Birmingham in the late 1970s. The assessments undertaken in the study and her own perceptive observations of these children gave her an insatiable interest in developmental psychology and a deep understanding of the work of Piaget. Consequently, using Piagetian principles she was able to explore in great depth the cognitive processes of children with severe and profound difficulties in learning. At a time when behavioural methods of teaching were at their height, Beryl was instrumental in encouraging teachers to foster their pupils' ability to understand the world around them through interactions with others and to develop models of learning that facilitated mental growth.

When she later became a lecturer on the B.Ed course for teachers of pupils with learning difficulties at Westhill College, Birmingham, she organised conferences on what she called 'Interactive Approaches'. Contributors to the conferences (Dave Hewett, Melanie Nind, Roy McConkey and Rob Ashdown to name but a few) and the subsequent books based on the papers given will be familiar to readers of *PMLD Link*. Beryl's fundamental tenet that the pupil must be considered as an active modifier of information rather than a passive recipient inspired the work of these 'giants' in the field as it did her own students on the B.Ed course. Her own teaching was based on such principles and her skills in using the students' own experiences to enhance discussions led to the development of innovative but measured and carefully considered educational practices that enabled them to reach an understanding of the relationship between their teaching and the learning of their pupils.

Thanks to Beryl's tutoring, encouragement and support many of her students obtained first class honours degrees and she often persuaded them and colleagues (including us) to write for journals in the field. She was instrumental in getting extensive press coverage when the government misguidedly closed all courses designed for teachers of children with severe learning difficulties. Thanks to Beryl's efforts, and the reputation of the course she helped to build, the Westhill B.Ed for these teachers was one of the few in the country to be given a reprieve of an extra year before it finally closed, and the staff transferred to various departments of the University of Birmingham.

At that point Beryl went to teach in the Medical School where she was instrumental in developing a course on learning disabilities which covered a range of topics and themes including aspects of PMLD. As Editor of the BILD publication *SLD Experience* (a post which she held for many years) she continued to encourage all in the field to write about their experiences and she was particularly keen to receive articles focusing on children and young people with PMLD.

Her academic career focused on the promotion of a child-centred approach to teaching and learning, which aimed to develop our understanding, through effective interaction of the experiences offered and the social environment, of those with a range of difficulties in learning. We are all the richer for her work.

Christina Tilstone and Penny Lacey

PMLD LINK
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Vol. 23 No. 3 Issue 70

PMLD Network Forum
A Digest of Discussions
June 2011 to November 2011

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

Assessment and progress tools

Someone said that they work at a school and currently use Routes for Learning as an assessment tool and for ideas as to how to progress students with PMLD.

They said that it seems a really useful tool but that they have also been asked to look at using the SSAT's CLDD Engagement profile. They said this looks interesting but the guidance seems a bit sparse. They asked if anyone was using the Engagement profile and if, or how, it fits in with Routes or Quest for Learning.

Responses included:

- 'My understanding is the engagement tool gives a structure to begin exploring why students (at what ever level of ability) are not engaged in their learning and looks at ways you can make changes to teaching/environment/activities to get this to happen so its not an assessment tool in the same way that Routes for Learning is.'
- 'I think more training will come on line around the tool as the work develops.'
- 'Routes for Learning is the only tool we have ever come across that really does meaningfully apply to those students with the profoundest level of learning disability.'
- 'We were part of the trial for the SSAT Engagement profiles and have found it very valuable with our complex learners. It does serve as an assessment tool for us in terms of engagement but only really measures progress in engagement in a specific task. We use this alongside other assessment tools as an additional measure looking at engagement and then create a profile looking at the whole child.'
- Someone said that alongside the Engagement profile is the Inquiry Framework for Learning which provides ideas of where to move forward with complex learners. They said it is a valuable resource but they are not sure it would serve as a comprehensive assessment tool on its own. They don't use it in that way http://complexld.ssatrust.org.uk/project-resources/inquiry-framework-for-learning.html
- 'engagement profiles give a full picture of a child and has helped us particularly in transition when new staff are working with a child.'

Communicating and interacting with people who have PMLD

Someone said that on behalf of their local partnership board, they are putting together a two hour workshop/training package on communicating and interacting with people who have PMLD. This is to be aimed at support staff and members of the public. They asked if anyone had any resources (other than those listed on the PMLD Network website) that could help with this.

Responses included:

- Someone said that Mencap and BILD's Involve Me project explored some different communication approaches and there is lots of information on communication and communication tools. For more info see www.mencap.org.uk/involveme or Email: Louisa.Whait@mencap.org.uk
- Storysharing™ was one of the approaches featured in Involve Me and is designed to support people with profound and complex needs to recall and share experiences, using techniques drawn from research and observation of anecdotal conversations. More info at www.openstorytellers.org.uk
- A couple of people suggested they look at the Intensive Interaction approach.
- Someone said that they run regular training sessions on communication and interaction. They said 'as a school for people with profound and multiple learning disabilities this is regular bread and butter!' They said they would be happy to help jennyboyd@roseroad.org.uk

Sensory activity classes

Someone said that they work as an educational psychologist and special needs teacher and are thinking of setting up their own business - a sort of recreational activity club which provides multi sensory stimulation specifically for children with special needs. They said the idea would be to run weekend/birthday parties/early years or baby group classes which parents can attend with their children and which each have a theme eg. seaside, underwater, festivals, spring, Christmas. It would also give parents a chance to share experiences and teach how to use sensory stimulation to improve attention, concentration and engagement and to be a fun recreational activity which children and young people can engage in at a level appropriate to their needs. They wanted to know if people would be interested in this type of facility.

Responses included:

- Someone said that they have been running a project for people with PMLD who live in Yorkshire. It has included training for parents/ carers in the various activities & therapies that help people with PMLD eg, Rebound Therapy, floatsation, dance. It has also included a trial of a Kitemark for schools/ centres that have offered good provision in sport/ activity for PMLD. They said they are still developing this, but the results have been very encouraging. They said they think there is definitely a market for this sort of facility and would be happy to talk to them about it – email fhall@fdso.so.uk.
- A couple of people said that they would be more likely to use this as an in-house service. They said that because of their daughters' health needs, having people come to them is the most likely way they have of accessing anything like this.
- Someone said they run their own business called The Willows Sensory Service. They plan and deliver sensory dramas for individuals, do sensory play, aromatherapy, reflexology, run courses from their home for special school staff, or hire out their sensory room. They said they put many hours into the planning and preparation of sessions and they greatly enjoy doing it, however it is not presently economically viable. They suggested the person limits their themes for planning, preparation, cost and storage reasons. They also suggested looking to hire a sensory room in a special school. She said to email her for more information at sarah.hall73@virgin.net
- Someone said that there are 2 good magazines that can help with practical ideas that are specifically related to PMLD: PMLD Link (paper and online) www.pmldlink.org.uk and Information Exchange (online only) www.multi-sensory-room.co.uk/page25/page25.html. They said that the latter website has got lots of sensory ideas as has www.hirstwood.com/page18/page21/page21.html
- Someone said another good website is: www.whiteboardroom.org.uk/LearningSystem/PortalHome/Start.asp?Institution=au&Campus=
- Someone said they keep hearing terms such as "rebound therapy" and "soundboards" but that they still have no idea what they mean and no-one seems to provide training to parents.
- Someone replied that Rebound Therapy is the use of a trampoline to let people experience movement. They said it is very valuable for people with PMLD as it helps with circulation, sensory stimulation, and above all, it's fun! More information at www.reboundtherapy.org
- Regarding Rebound Therapy, someone else added that advice must be obtained from the person's physio and assessments carried out.
- Someone said that soundboards are simple wooden platforms slightly raised so that when you lie on them and they are tapped or drummed, your whole body resonates. They are sometimes called resonance boards. They said they are easy to make and great for people who enjoy music and vibration.
- Someone said there are also various other suitable activities used in schools/ physio centres, including Floatsation (where people are able to enjoy water based activities, fully supported on a bed of balls. The mesh bed lets water through, (unlike a lilo for example), which allows the person to feel the water around them, whilst being safely supported) www.floatsation.com
- Someone said that sound beams/ sound trolleys multi sensory rooms are another option for interaction. These are lights/ sounds/ lasers/ etc set up to stimulate, usually in a comfortable environment. The better ones "reward" movement by switching on/ making a noise/ changing colour, etc upon the stimulus of movement. They said that special schools often have this equipment installed, and in some areas leisure centres have them.
- As a carer for a child, I and my little boy would definitely benefit from this service, and the opportunity to do it as a group rather than an expert doing it on a one to one basis with a child is even better as we can advise each other and relate to each others experiences!
- Someone said to check out this website: www.soundabout.org.uk/Schools_02.html. It explains the uses of resonance boards and offers training. They said they use them in their classroom on a regular basis and the pupils respond really well.
- Someone gave a link to a film about rebound therapy: www.youtube.com/watch?v=0Kkfr9Rc000
- Someone said they think it is a fantastic idea and think it would be great to extend the idea into young adult groups, with carers instead of parents.
- Someone said that they are a parent of a young woman with sensory needs, they would like more drop-in centres to which they could send her with her PAs employed through an individual budget. They said 'we are a growing group of people who need somebody to organise a social club for us. It is our PAs that need teaching how to engage with our children.'
- 'This is something I have been asking for from schools, playscheme providers and others, but haven't had much luck. I'd like to be able to work with my child, and would love to know what can help, and how can I use the few skills my child has in order to help him progress no matter how little, but I want to stretch him as much as possible. I'd also love to know what I can do at home and how to arrange bedrooms or living rooms to make them more sensory, without it all taking over our lives completely. I'd also love to have a book, with some simple things to do, sensory exercises, how to use percussion instruments or other toys, knowing how might children learn if they have a disability, and how do we use that child's ability to help them progress and enjoy life' We are losing too many day care centres and respite centres, but they are not being replaced or not being added to either.
- Staff need training in working with disabilities. Where staff are employed through direct payments, parents have to train the staff. Training staff as a group would be more productive, and it would enable them to share their issues and concerns as well as ideas.

- ‘Drop in centres are a great idea, as it would enable our children and young people to socialise more, not be isolated as seems to be encouraged by all these closures and the limited criteria of direct payments as well as the limited mind set of some service providers.’
- Someone said it might be a good idea also to raise the issues and opportunities with our local Parent Carer Forums (part of the National Network of Parent Carer Forums) to show that we are not alone, that there are many more parents and disabled children/young people out there with the same needs. For contact details of local Parent Carer Forums see www.nnpcf.org.uk

Pain Assessment

A third year learning disability nursing student said they were writing their dissertation on pain assessment in people with a profound learning disability and communication difficulties. They wanted to know how people found the pain assessment tools currently available and where the deficits lie in implementing them within different settings.

Responses included:

- I am a physio within a Community learning Disabilities Team in Sheffield. The main pain assessment we use within day services etc is DISDAT. We have found this to be good baseline indicator of an individual’s behaviour when experiencing different types of pain. What we have attempted to do is empower carers to become familiar with certain indicators and then to act accordingly rather than simply observing and not intervening.
- ‘People may be interested in chapters 11-13 or the whole book 'Handbook of Pain Assessment' 3rd edition. Eds Turk and Melzack. 2011 Guildford Press’
- Someone recommended 2 papers by Karen Dodd and a colleague. One is on an audit of communication skills and pain measures and the other is on a training programme for staff to improve their use of AAC to enable their clients to communicate pain. They are both in British Journal of Learning Disabilities, 2010 and 2011 respectively. You should be able to access these through Birmingham Uni library. See this website for contact details and a bit more on Karen Dodd’s work: www.surreypb.org.uk/archive/2010/Feb%2010%20bulletin%20for%20web.pdf
- At a more generic level - someone emailed a link to free e-learning of a pilot module entitled ‘Pain assessment and management for children: A training module linked to the new WHO guidelines for persisting pain’. They said that in exchange for feedback you can access the training at no cost:
- http://tinyurl.com/6gv7uxl
- ‘I too have had an interest in this area. Personally I've used two different pain assessment tools, DisDAT and Paediatric Pain Profile, but increasingly have found them wanting. I've abandoned the use of DisDAT totally because although it was a useful tool for collating and recording pain information, it was unable to offer any measurement of changes. I also was not overly impressed by some of the literature which I didn't think offered too much credible objective evidence as to its efficacy. The Paediatric Pain profile can be used as more of an indicator of changes although it does depend on the respondents’ ability to be accurate, objective and consistent. Where you have a big staff team you can find results vary considerably. You also have to bear in mind that it was not designed for adults and for me personally this has a huge bearing on its validity with this group of people.’
- Someone suggested other tools which could be looked at:
  - ◊ The Non-Communicating Children's Pain Checklist (NCCPC) – they said they believe there is a lot of work being done on this at present so it may be worth consideration, but it is not specifically designed for adults.
  - ◊ Pain and Discomfort Scale (PADS) – they said that although research implies that this is unable to discriminate between pain, anxiety and discomfort, it appears to be a reasonable observational checklist.
  - ◊ Tools such as Facial Action Coding system (FACS) and Coloured Visual Analogue for Pain (CAS) – they said these may be interesting but require training to use so are not really practical for use within a generic LD setting.
- A mother of a son who is non verbal and who has a high pain threshold said that he tends to generalise any pain discomfort he experiences. She said that interestingly reflexology has actually identified areas of concern which he didn't/ couldn't tell them about but which they were then able to address.
- ‘I am a teacher in a unit for children with PMLD and find it really frustrating that at times the team and I can not truly understand their communication/signs when in pain/distress. If detection was earlier it would enhance the quality of their experiences, meet their individual needs more effectively and ensure emotional well being.’
- ‘One of the issues I have is that staff will often struggle to differentiate a client being stressed by environmental factors or seeking automatic stimulation, from specific pain reactions. As challenging behaviours can be under the control of different functions at different times.’
- ‘I have a copy of a useful resource developed by a residential home manager and a speech and language therapist. It was originally created as a way of enabling people with PMLD/limited communication to have a say or ‘complain’ when things weren’t right, including when in pain or discomfort. It’s not a medical focused tool but more about looking holistically at what has changed in a person - from what would be ‘typical’ behaviour in someone to non-typical responses and behaviour and when these responses occur etc. Ideally it involves those who know the individual best. I was involved in using it when I was convinced a person had a back problem and some others suspected it was more likely to be ‘challenging behaviour’ (it was the former & pain related). It was a valuable focus to get people from a range of settings involved in interpreting what was happening so

we could then look at finding a solution. She wrote about it in PMLD Link a couple of years ago (Winter 2007 issue) – and this is available to download from the journal website www.pmldlink.org.uk .You might also be interested in a later health-related edition of the journal [Winter 2009 issue] which is also downloadable.

- During assessments I tend to use the DisDat but it is not used to assess whether someone is in pain but to highlight the behavioural cues so that they can be shared with the wider team, once we are clear that the function is pain.
- The person who posted the original query explained more about their work:
- 'My main interest is whether subjectivities means the same signs could be interpreted differently by different people, leading to inconsistency in the recognition of pain. Once I have investigated this I intended to review whether this problem is a consequence of the tools themselves, a lack of training, people knowing the individual to different degrees, people's perceptions of why the person may be in pain or not (e.g. physio, OT, nursing, carers) and so on. I am them going to look at how assessment results can be made more portable so acute care, people new to the individual can refer straight away to a guide rather than potentially exposing the person to pain due to a lack of knowledge (knowledge which is already available and documented elsewhere).'

Winterbourne

Following the Panorama programme about abuse at the learning disability hospital, Winterbourne View, there was much discussion on the forum including links to press statements and other documents.

Discussion and links to documents included:

- The Challenging Behaviour National Strategy Group press statement
- http://www.thecbf.org.uk/planning-future/CB-NSG.htm. You can also view their charter for people with learning disabilities who are labelled as challenging, which aims to highlight and protect their human rights and to encourage all sectors of health and social care to provide individualised, high quality, reliable and safe care and support to them and their families, at www.thecbf.org.uk/pdf/CompletedCharter.pdf
- BILD's response:
- http://www.thecbf.org.uk/planning-future/BILD.htm
- National Valuing Families Forum response: http://www.choiceforum.org/docs/nvff.pdf
- A group of learning disability organisations and individuals wrote to the Prime Minister to demand action following Winterbourne. The letter can be viewed here: www.choiceforum.org/docs/nr.pdf
- 'I have worked at a home for adults with learning disabilities that did not have an inspection from August 08 until now, almost 3 years!'
- 'Regular unannounced inspections will ensure that homes and services are run with an awareness that an inspector will turn up at any time and not as now, knowing if the inspector has visited you, you are free for at least a year.'
- 'I am a home manager for people with moderate to severe learning disabilities. I have fought for the past 15 years to ensure that the care we provide comes from the heart together with legal requirements. I will not take just any staff and, because of this, the home provides a stable and loving environment, a home from home.' To those parents whose son or daughter is moving to a residential home, she said 'Check out the length of time staff have been there, turnover, what you feel as you walk into the home. In my opinion, a good home is a happy home for both service users and staff. Speak to other parents and find out what they feel about the provision. Look at the services users, do they look content?'
- 'A lot of the time this profession seems to take on people on the lower pay scale, which does not attract the correct type of carers.'
- 'All residential homes are not bad, there are still some good ones and they should not suffer because of the bad ones.'
- 'All we can do as parents is the best we can at the time and the doubts over the future remain. We have little confidence in Government and the agencies involved to protect the interests of our son when we are not able to do so.'
- 'My brother is considered to be 'challenging' in as much as he self harms but he has his own bungalow, is sole occupier with 24hr support and has a good quality of life and has changed dramatically for the better since his move.'
- The National Family Carers Network said that places in assessment and treatment units are bought by NHS commissioners. They have written some questions for family carers to ask NHS commissioners. They said that people could ask these at their local LD partnership board: www.choiceforum.org/docs/pbq.doc
- The Association for Supported Living (ASL)'s report, 'There Is An Alternative' report, includes 10 case studies of people who moved from institutional services to supported living services. In each case quality of life improved, while costs fell. The report calls for the government to act to put an end to institutional services. The report can be read at: www.choiceforum.org/docs/alt.pdf

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

Visit the PMLD Network website at www.pmldnetwork.org

IN THE NEWS

A double celebration!

Young people from The Children's Trust had the opportunity to create their own works of art based on Jan van Huysum's, *Flowers in a Terracotta Vase* as part of bespoke multi-sensory art workshops provided by the National Gallery. The project was organised and funded by Credit Suisse, who partner with the National Gallery, and support The Children's Trust through the Bank's UK Charity of the Year 2011 programme.

Taking inspiration from the brightly coloured petals, leaves, summer fruit and fluttering butterflies featured in the painting, the young people created vibrant art. They worked in a range of media including plaster casting, printmaking and sculpting in wire and paper, and also experienced soundscape recordings of birdsong, insects, trickling water and rustling leaves to assist their appreciation of the painting.

Guy Portelli, sculptor and Vice President of The Children's Trust and James Leigh-Pemberton, Chief Executive of Credit Suisse in the UK applauded the National Gallery for facilitating the programme and for their staff enthusiasm in providing such practical creative workshops and a fulfilling opportunity for the young people to engage with art.

The National Gallery in Trafalgar Square houses the national collection of Western European painting from the 13th to the early 20th century and is open 361 days a year, free of charge. Sense It! is the Gallery's programme for pupils with PMLD and their staff. The programme, the outcome of consultation and a pilot project with specialist PMLD practitioners, includes tailor-made Gallery sessions and exclusive use of the Gallery's Education Centre which is equipped with special personal care facilities. www.nationalgallery.org.uk

From left to right: Samantha Moy from The Children's Trust; Catherine a young person from The Children's Trust; Guy Portelli, Vice-President of The Children's Trust; and Marc Woodhead, National Gallery educator

Picture (left to right): Pupil Development Assistant Charlotte Stacy congratulates college learner Joshua as he receives his certificates from Dr Mary Greenaway, Chair of Governors at The School for Profound Education

Learners aged 19+ in the College classes at The School for Profound Education (formerly St Margaret's School), celebrated their achievements and hard work at a special awards ceremony in July. The learners, all of whom have profound and multiple learning difficulties (PMLD) as well as complex health needs, have gained modules in the nationally recognised Accreditation for Life and Living (ALL) scheme.

Subject areas studied included Creative Arts; ICT; Home Management; Communication; and Personal Skills and each learners gained at least one certificate. The modules enabled them to build an evidence-based profile of their achievements which reflected their own needs and skills. The ALL scheme is assessed and awarded by the Oxford, Cambridge and RSA Examinations (OCR) boards.

Jan Cunningham, Headteacher, said: "They have worked so hard and are a real credit to the school. It is wonderful that we have been joined by so many parents, family members and friends to share in our celebrations."
The Children's Trust, Tadworth Surrey. www.thechildrenstrust.org.uk

One year to go to the London Paralympics

Athletes, volunteers and spectators with a learning disability gear up for the Olympics and Paralympics.

The UK is preparing to host the Olympic and Paralympic Games for the first time since 1948. The Olympics will take place in London from 27 July to 12 August 2012, and the Paralympics from 29 August to 9 September 2012. For athletes with a learning disability, the Paralympics will have the added significance of offering their first opportunity to compete since 2000.

A ban on people with a learning disability competing was imposed after the Sydney Paralympic Games, when it emerged that ten players in the gold-medal-winning Spanish basketball team did not have a learning disability. In November 2009, the International Paralympic Committee voted to reverse it. People with a learning disability will also take part in the Olympics and Paralympics as volunteers. Olympics tickets were allocated this summer and applications for two million Paralympics tickets were accepted in September.

The organisers of the Games plan to install Changing Places toilets in the Olympic and Paralympic venues, and have announced additional services for disabled people, including free blue badge parking spaces at all venues, accessible shuttle buses, spectator information in accessible formats, and free loans of manual wheelchairs and scooters.

Seb Coe, chair of LOCOG, said: “We want to ensure that disabled spectators have as great a Games experience as anyone else and we are committed to providing services and facilities that meet all accessibility requirements.”

Postural care for people with PMLD

In October, the Postural Care Action Group launched a campaign to raise awareness of the importance of good postural care for people with multiple disabilities, including people with profound and multiple learning disabilities (PMLD).

The Postural Care Action Group is made up of organisations including Mencap, PAMIS, Postural Care Skills, the Chartered Society of Physiotherapy, the College of Occupational Therapists and the Royal College of Nursing.

Beverley Dawkins OBE, national officer for PMLD at Mencap, said: “People often assume that body shape distortion is inevitable for people with multiple disabilities, but that is not actually the case.

“With correct positioning, body shape distortion is preventable and can even be corrected later in life. Failure to protect body shape can have serious health consequences – it can even result in premature death.”

The group is calling for effective support for people with multiple disabilities to protect their body shape. A booklet and a film have been launched to support the campaign. They use case studies to explore how training, information and funding for equipment can be used to ensure good postural care.

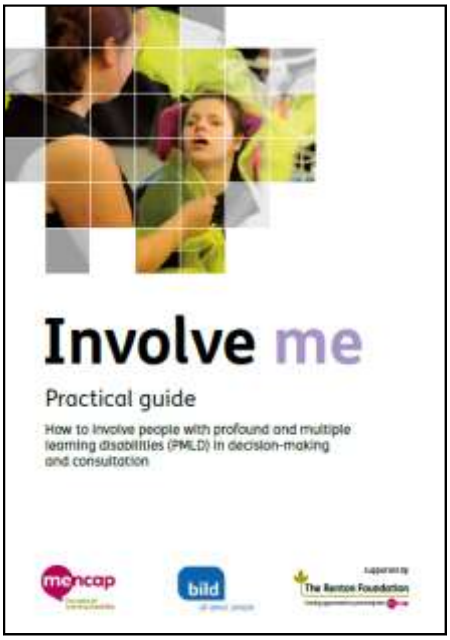
View the booklet and films at: www.mencap.org.uk/posturalcare

Working together

Working together for best practice in PMLD education, a conference in October hosted by The School for Profound Education and chaired by Keith Park, brought together over 60 special educational needs professionals to share best practice for young people with PMLD. Topics included intensive interaction, implementing research, and focusing on learners not budgets when looking at transition to adult placements. Jan Cunningham, Head Teacher of the school, said: “The conference had a wonderful vibrant atmosphere and the willingness to share best practice was evident from the minute delegates arrived. [....].”

The School for Profound Education: www.thechildrenstrust.org.uk/profoundeducation

Involving people with PMLD



Involve me

Practical guide

How to involve people with profound and multiple learning disabilities (PMLD) in decision-making and consultation

A major new resource for all those working with people with profound and multiple learning disabilities (PMLD) was launched in September at City Hall, London.

Since 2009, Mencap and the British Institute of Learning Disabilities (Bild) have been working on Involve Me, a three-year project on increasing the involvement of people with profound and multiple learning disabilities (PMLD) in decision making.

“Often, when we have convinced people to involve people with PMLD in decision making, they’ve asked how to do this meaningfully. So we hope Involve Me offers strategies for involving people as fully as possible,” explains Beverley Dawkins OBE, Mencap’s national officer for PMLD and chair of the Involve Me steering group.

Funded by the Renton Foundation, Involve Me used four practice sites to explore creative ways to communicate with people with PMLD.

These included creative communication – using methods, such as art, music, dance and film to enhance communication -– and peer advocacy, through which someone with a learning disability acts as an advocate for the person with PMLD.

Practical resource

Now, the findings of the project have been used to shape a major new resource. The resource consists of a short booklet, which summarises the project, and a practical guide with accompanying films.

In addition, an independent evaluation of Involve Me, carried out by the Foundation for People with Learning Disabilities, includes 16 recommendations for all those involved with PMLD services, from support workers to the government.

Changing Places in Stormont

A Changing Places toilet has been installed at Parliament Buildings, Stormont, in Northern Ireland.

The toilet was officially launched on 5 October. Children from Glenveagh Special School took a tour of Parliament Buildings, before visiting the new facility with Mencap in Northern Ireland’s director Maureen Piggot, Mencap’s chief executive Mark Goldring, and Northern Ireland Assembly chief executive Trevor Reaney.

Standard accessible toilets do not meet the needs of thousands of people, including people with profound and multiple learning disabilities. Changing Places toilets include a height-adjustable changing bench, a hoist and plenty of space.

Rebecca Shea, campaigns manager for Mencap in Northern Ireland, commented: “This is a fantastic step forward for the campaign. So many people choose to limit family outings or are unable to go out at all as the appropriate facilities for their loved ones are not available.

“The introduction of a Changing Places facility within Parliament Buildings, a popular tourist attraction, will provide a fully accessible experience for so many people living in and visiting Northern Ireland.”

There are now more than 300 registered Changing Places toilets in the UK. In Northern Ireland, locations for the facilities include George Best Belfast City Airport, Divis and the Black Mountain and Lisburn Civic Centre.

Find out more about the campaign at www.changing-places.org

Funding for short breaks pays off - but children with complex needs still miss out

A report published in October has highlighted an increase in regular, reliable and appropriate short breaks for families of disabled children in England. ‘Raised Expectations: parental experiences of short breaks’ is a report from Every Disabled Child Matters (EDCM). It addresses short breaks between 2007 and 2011, and says that funding for and a government focus on short breaks has ‘transformed’ the services on offer.

However, the report also warns that ‘it is clear that there is still progress to be made’. In particular, children with complex health needs continue to face barriers in accessing short breaks. Parents also expressed their concern about the future of short breaks, now that funding for them will no longer be ringfenced.

EDCM is urging the government to monitor short break services and ensure local authorities fulfil their legal requirement to publish a short break service statement, setting out details of services and eligibility criteria. Families can use the EDCM website to email their local authority to ask for details of their statement. See www.edcm.org.uk

Christine Lenehan, EDCM Board Member said: “In order to make sure services continue to improve, and to tackle remaining barriers for children with complex needs, EDCM urges the government to track local authority short breaks statements and to provide a transparent national picture for families with disabled children.”

Postural Care Action Group
working to protect body shape

New information sheet from the CBF

The Challenging Behaviour Foundation has published a new information sheet for family carers to help ensure good support and services for adults with severe learning disabilities whose behaviour is described as challenging.

Written by Professor Luke Clements, an expert in Community Care Law, 'Ten top tips' provides basic legal information including getting an assessment of needs and a care plan, and the role of allocation panels.

'Ten top tips' provides practical information and advice to families concerned about cuts in funding for support and services. It will also be useful to families concerned that their relative is receiving poor quality support.

The information sheet has been written for family carers whose relative is aged 18 years or above and has severe learning disabilities and behaviour described as challenging. Each 'top tip' is accompanied by action points which family carers can take to ensure their relative receives good support and services.

To download a copy of the new information sheet visit: www.challengingbehaviour.org.uk

Behaviour

Behaviour was the theme of the 2011 East Sussex Consortium Conference in April which was attended by 300 staff from five special schools in the East Sussex, Brighton and Hove vicinity. Workshop topics included, creating a proactive and functional environment to support behavioural change, managing stressful situations, managing anxiety and developing relaxation as part of a daily class routine and managing behaviour through creative sessions. Sessions on the impact of sensory perception difficulties in children with Autism, play, playfulness, positive relationships, social stories, sexual and personal relationships and Intensive Interaction were also available.

The event was run by Concept Training who liaised with the Special Schools Consortium. Delegate feedback was very positive and included “So enjoyable, I feel really inspired to go back and start again!”

Concept Training: www.concept-training.co.uk

REVIEWS

Title: Mouth & Tongue Let's Have Some Fun
Author: Karina Hopper
Illustrator: Lisa MacDonald
Published by: Jessica Kingsley Publishers
Price: £4.99
ISBN: 978 1 84905 161 3

This little picture book has been written to encourage children with delayed speech to do exercises which will strengthen their facial muscles and help their speech development. The real appeal is that this is a fun book, making the exercises a fun thing to do every day.

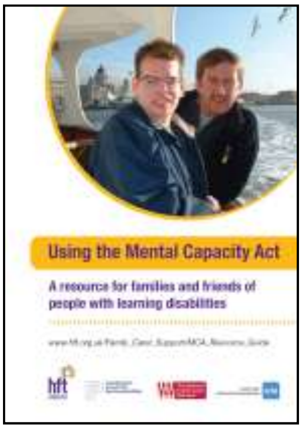
It features Sam who loves making silly faces in the mirror and they all involve stretching his mouth and his tongue called Timmy. Each double page has a single simple sentence in bold, good sized clear script telling the child what to do – "Timmy Tongue points down to the ground", "Timmy Tongue wiggles from side to side" - and a black and white line drawing of Sam doing the action in a mirror.

When trialled with a mainstream five year old, the bright yellow and red cover immediately caught her attention. She took it to the table and made all the first ten faces, keenly turning each page to find out what the next one was going to be and I think that most children will enjoy copying Sam and Timmy Tongue's funny faces and will stretch and strengthen their facial muscles in the process. Karina Hopper wrote this book after being unable to find a similar resource to use with her own two children who had delayed speech and so it is based on practical experience, with just twenty inviting exercises for children to repeat over and over again. The pages are completely clear of visual clutter, no page numbers and a standard format for the figure and the mirror frame, allowing the child's attention to focus on the mouth shape.

Whilst not at the developmental level of children with profound and multiple learning difficulties, this book would certainly appeal to children with mild learning difficulties and young mainstream children. It is a good resource for both parents and professionals wishing to improve a child's speech production.

Review by
Chris Fuller
PMLD LINK

Title: Using the Mental Capacity Act - A resource for families and friends of people with learning disabilities
Authors: Partnership between Family Carer Support Service, Foundation for People with a Learning Disability and National Family Carers Network
Funded by: Social Care Institute for Excellence
Price: free download of written guide and DVD or £1.50 for a posted copy.
Website www.hft.org.uk/Family_Carer_Support/MCA_Resource_Guide



This is an excellent resource. It comprises of a written information pack and supporting DVD. The two parts to the resource work well together. It is focused on family, friends, and those who know a person best, but would be an excellent reference document for paid support/practitioners and other students/trainers who work with people with learning disabilities. It directly and succinctly addresses the issues specific to family and friends and others who know a person the best. The information is designed to support people to understand how the Act affects them and those they care about when:

- They want to support their family member to make a decision
- The family carer needs to make a decision or act on a relative's behalf
- Someone else makes a decision on behalf of their relative

Significantly research was carried out with families prior to producing the resource giving the authors an unmatched understanding of what families and individuals were looking for from such a resource. The DVD includes people, family and professionals as expert partners.

The Pack guides the reader easily through the technical details of the Act, i.e. the legal principles, code of practice, the rights of families to be involved, assessment of capacity and best interest decisions. Having established the legal framework it then moves to the practical application of the Act - and considers particular decisions. These written sections are particularly well supported by the DVD including: transitions into adulthood, moving home, getting authority to make decisions, managing finances (welfare benefits appointee, applying to be a deputy, lasting power of attorney), complex decisions about health. The final three sections are challenging decisions, safeguarding and deprivation of liberty.

At a family forum where a number of resources were available for people to look at this definitely received the most attention and praise from families.

Review by
Helen Daly
PMLD LINK

SHORT COURSES & CONFERENCES

Providers Details

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

Concept Training
15 Beach Street,
Morecambe,
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

Florich Productions
Tel. 01524 42 63 95
Email: flocatalyst@aol.com
Website: www.multi-sensory-room.co.uk

RNIB Children's Services
58-72 John Bright Street
BirminghamB1 1BN
Tel: 0121 665 4235
Email children@rnib.org.uk
Website: www.rnib.org.uk/shortcourseschildren

Sunfield PDC
Clent Grove, Clent,
Nr. Stourbridge,
West Midlands DY9 9PB
Tel. 01562 883183
E-mail: pdc@sunfield.org.uk
Website: www.sunfield-school.org.uk/courses.htm

January 2012

Date: Jan 12th Longfield, Kent, 18th Lowestoft, Suffolk, Feb 28th Newcastle Upon Tyne
Title: SEN Children with complex needs – The 21st century challenge
Provider: The Schools Network
Contact: Tel: 01733 405 771
Web: www.ssatrust.org.uk/specialschools

Date: 20th Nottingham, 27th London
Title: Back to the Sensory Classroom
Provider: Richard Hirstwood
Contact: Tel: 01524 426395
Web: www.multi-sensory-room.co.uk

Date: Jan 23rd Middlesborough, Feb 8th Liverpool, Mar 6th Glasgow, 12th London, 20th Gateshead, 26th Taunton, 27th Birmingham, Apr 30th Ipswich, May 1st Doncaster, 21st Belfast, 22nd Dublin
Title: Practical & Effective Ways of Using Multi-Sensory Equipment
Provider: Concept Training
Contact: See provider details

Date: 25th
Title: Creative Technology in EYFS for Inclusive Learning
Location: Leeds
Provider: EQUALS
Contact: See provider details

Date: 26th
Title: Dementia in people with intellectual disabilities: getting it right
Location: London
Provider: The Royal Society of Medicine
Contact: Ruth Threadgold. Tel: 020 7290 3942
Email: intellectual.disability@rsm.ac.uk

Date: Jan 27th Glasgow, Mar 5th London, 12th Middlesbrough, 14th Birmingham, May 14th Brighton
Title: Intensive Interaction: Connecting with People who are Difficult to reach
Provider: Concept Training
Contact: See provider details

February

Date: 1st – 5th
Title: Early Intervention from Interdisciplinary Perspectives
Location: Kemer, Antalya, Turkey
Provider: TAC Interconnections
Contact: Peter Limbrick
Email: peter.limbrick@teamaroundthechild.com

Date: 8th
Title: Understanding the Autistic Spectrum
Provider: Sunfield PDC Contact: See provider details

Date: 8th
Title: Inquiry for learning workshop: Developing school-based approaches for children with special educational needs
Location: West Midlands
Provider: The Schools Network
Contact: Tel: 01733 405 771
Web: www.ssatrust.org.uk/specialschools

Date: 9th
Title: Confident Parenting
Location: Manchester
Provider: EQUALS
Contact: See provider details

Date: 10th
Title: Conference: National Forum for Neuroscience & Special Education ‘Myths, methods and making a difference’
Location: London
Provider: The Schools Network
Contact: Natalie Eccles
Email: natalie.eccles@theschoolsnetwork.org.uk
Tel: 01902 796067

Date: 28-29th
Title: Conference: Working Together for Better Outcomes
Location: Manchester
Provider: The National Autistic Society
Web: www.autism.org.uk/conferences/professional2012

March

Date: Mar 1st Chorley,12th London, 28th Gateshead, May 16th Birmingham
Title: Effective Partnerships with Families
Provider: Concept Training
Contact: See provider details

Date: 2nd
Title: Musical Activities to Support Key Skills Across the Special School Curriculum
Location: Chorley/Leyland
Provider: Concept Training
Contact: See provider details

Date: Mar 2nd Glasgow, April 27th Bristol, May 18th Liverpool, June 22nd London
Title: Sensory Approaches for Autism
Provider: Richard Hirstwood
Contact: Tel: 01524 426395
Web: www.multi-sensory-room.co.uk

Date: 8th
Title: Developing Stories to Support Social Understanding in Children with ASDs
Provider: Sunfield PDC
Contact: See provider details

Date: Mar 12th Birmingham, May 14th Middlesbrough
Title: Profound and Multiple Learning Disability – engaging children in learning
Provider: Concept Training
Contact: See provider details

Date: 13th
Title: Intensive Interaction
Provider: Sunfield PDC
Contact: See provider details

Date: 20th
Title: Intensive Interaction – Dave Hewett
Location: London
Provider: EQUALS
Contact: See provider details

April

Date: 5th
Title: Strategies to Promote Sensory Well-Being: How to Make Sensory Integration Work at Home and School
Provider: Sunfield PDC
Contact: See provider details

May

Date: 16th-19th
Title: Annual Conference: Bridging from Research to Practice
Location: Istanbul, Turkey
Provider: European Academy of Childhood Disability
Web: www.eacd2012.org

LONGER COURSES (with accreditation)

MA Education
Pupils with Severe and Profound and Multiple Learning Difficulties (P1: Contexts & Understanding P2: Curriculum & Teaching)
The modules address the requirements of the Teacher Development Agency (TDA) National Special Educational Needs Standards
The course provides students with an opportunity to gain an understanding of those influences which impact upon the learning, development and management of pupils with severe and profound and multiple learning difficulties.
For further Details: The University of Northampton. Tel: 08003582232 Email: study@northampton.ac.uk

MA Education Physical Disabilities (P1: Contexts & Interventions P2: Curriculum Issues)
The first module (P1) provides opportunities for those with QTS and professional qualifications and experience in services for children, to engage in structured critical reflection, exploration of key substantive issues and overarching policy determinants in respect of children and young people with physical disabilities. The second module (P2) provides students with opportunities to investigate, critique and evaluate a range of curriculum approaches in the field of physical disabilities. It engages students in debates concerning the relevance and practical efficacy of recent guidance and legislation in physical disability-related issues, and offers an in-depth series of curriculum-focused activity which is intended to enhance both the understanding and the practice of those working with children and young people with physical disabilities.
For further Details: The University of Northampton. Tel: 0800 358 2232 Email: study@northampton.ac.uk

MA Education Understanding Multi-Sensory Impairment
This module addresses the requirements of the Teacher Development Agency (TDA) National Special Educational Needs Standards (Extension 2.i – 2iv.). It is directly related to Pupils with Multi Sensory Impairment (MSI) The module provides students with an opportunity to gain an understanding of those influences which impact upon the learning, development and management of pupils with multi sensory impairment. It provides professional development for teachers and other professional colleagues working in an area of low incidence need and addresses priorities established by Local Authorities, individual teachers and others working with children and young people who experience MSI.
For further Details: The University of Northampton. Tel: 0800 358 2232 Email: study@northampton.ac.uk

Certificate in Higher Education (CHESL): Supporting Learners with SLD/PMLD
This course aimed at Teaching Assistants will look in detail at the needs of learners who are known to have severe or profound and multiple learning difficulties. These learners may also have other additional or associated disabilities, such as physical or sensory impairments. The course will examine topics of both a theoretical and practical nature to provide students with a greater understanding about this group of learners, together with a broad range of strategies and approaches that can be applied to practice. The sessions will include lectures, workshop activities, discussion and some visiting speakers.
For further Details: The University of Northampton. Tel: 0800 358 2232 Email: study@northampton.ac.uk

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

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

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

MSc in Advanced Practice
The School of Health & Social Care, University of Chester, MSc in Advanced Practice (Learning Disabilities) - includes generic modules in research and inter-professional working plus 3 LD specialist modules (socio- political themes in LD; developmental perspectives on LD; profound & complex needs). This course is suitable for health and social care professionals who would like to develop higher levels of professional knowledge and expertise in their sphere of practice.
For further details: University of Chester Tel: 01244 511 000 Email: enquiries@chester.ac.uk

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

AdCert, BPhil, PGCert, PGDip, MEd.
Learning Difficulties and Disabilities (Severe, Profound and Complex)
Distance Education
This distance education programme has been developed for the range of staff who work with people with severe, profound and complex learning difficulties, for example teachers and lecturers, nurses, therapists, psychologists and support staff. It is primarily about the learning and development of children and adults with severe, profound and complex learning difficulties, particularly in the areas of cognition and communication. Education, in its broadest sense, is seen as a key topic but other areas covered include health, therapy and social care. An important central theme is multi-agency collaboration and course participants will be expected to develop and reflect on their collaborative work as part of course. All the course assignments are grounded in reflective and evidence-based practice and are driven by the individual professional development needs of participants.
For further details: University of Birmingham Dr Penny Lacey, phone: 0121 414 4878 or email: p.j.lacey@bham.ac.uk

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

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

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

PMLD LINK
sharing ideas and information

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