PMLD LINK

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

Summer 2009

Sharing Perspectives

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PMLD Link relies on contributions from practitioners, parents, carers and everyone interested in the field.

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GUEST EDITORIAL
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Sharing Perspectives

This is our second general issue – a chance to air and share ideas and points of view on many different topics and from many different perspectives and it has certainly provided a varied and, I hope, informative and enjoyable read.

The first two articles provide a link with the last issue on the arts; Antonio describes the value and enjoyment he gets from volunteering; there is a thought provoking account of some of the issues which may arise when a young person leaves school and moves into adult services; followed by a personal view of the nature and value of Intensive Interaction.

A discernable underlying theme in the following articles is understanding the processes involved in developing thought and learning and Penny Lacey provides a clear and informative introduction to this topic. Many of the issues she raises are explored in the following articles and although many of them are written with the school curriculum in mind, it is clear from Penny's discussion that learning is lifelong, and the underlying strategies and techniques needed to help children with PMLD to learn in school are just as relevant in the lives of young people and adults. The final article relating to the school curriculum is Rob Ashdown's review of the newly published Primary Curriculum Review. Although he is less than enthusiastic about its helpfulness to teachers in special education, he nevertheless manages to pull out some useful pointers for curriculum development.

There is up to date information on the Inclusive Libraries Project and there are all the usual sections on News, Books, Resources, Courses and other sources of information. I hope all our readers find things which interest, excite, and help them in their day to day practice.

Future Focus introduces the topic for the next issue – health – and all the details for sending articles are given there.

Finally, thank you to all the writers of articles for their contributions to this issue.

Carol Ouvry

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Future Issues

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Health Issue

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The Wisteria Lodge Steam Train

Bernard Tagliavini - *The Uckfield Festival Association*

As a professional storyteller and member of the Uckfield Festival Association, it struck me last year whilst working with the PMLD residents at *Wisteria Lodge* in Nutley, East Sussex, that they would greatly benefit by participating in our annual Festival procession.

With sponsorship from *News International* and *The Persula Foundation*, and assistance from *Same Sky Community Arts Group*, based in Brighton, I began to think. How could a group of wheelchair-bound young people participate in the loud and colourful 45 minute procession through the steep streets of our mostly sleepy town? The theme for the 2008 Festival had been decided as 'Ticket to ride: the railway', with Uckfield being at the end of a picturesque (if slow) rail link up to London. I decided that we might as well make the most of lots of wheels on lots of wheelchairs, and construct some sort of train, with the Wisteria folk processing in a line with the wheelchairs dressed as railway carriages.

The more I thought about it, the more I had this image of a steam train chugging up and down the streets in the procession. I set about building an engine which could 'smoke' as we walked, with all the other wheelchairs behind as a tender and carriages. Two designers from *Same Sky* – Sarah Parsons and Angela Carter – set about designing the construction for each of the wheelchairs, whilst I began work on a steam engine, using a shopping trolley on loan from Tesco, lots of chicken wire, bacofoil, flower pots, bamboo poles, and a dustbin lid. The smoke was eventually provided by a disposable BBQ hidden under the funnel, with dried leaves and grass cuttings being added periodically to the hot coals, enhanced with 'plumbers smoke pellets'.

At the first of three construction workshops at Wisteria Lodge, we brought in all the materials to begin work. Seeing the WL residents' faces as we all assembled was quite amusing! They really did seem puzzled yet intrigued as to what Sarah, Angela and I were doing.

However, they quickly got stuck in - quite literally – and hands from every direction began to help disperse glue, paint and glitter over the surfaces of the soon-to-take-shape train, as well as on clothes, faces and hair! Luckily, all non-toxic and washable!

Then, at last, after several long hours work, we had our train – including the front engine which belched real smoke!.....

The day of the procession arrived, and two very excited minibus-loads of wriggling, chattering and laughing young people arrived at the assembly point at Uckfield Technical & Community College. The threat of rain seemed to pass as a baking sun exposed itself between clouds, and waterproof covers and clothing was stowed away. Together with hundreds of others in fancy dress and themed costumes, a group of Brazilian-styled drummers and the town's scout and guide marching band, we set off. Lots of noise, music, dancing and colour trickled through the heart of the town, with the pavements spilling over with spectators, smiling, waving and taking photos. The Wisteria train weaved and smoked its way down and then up the steep High Street, its wide-eyed passengers peering in every direction from their wheelchairs.

Luxford Field, most unusually, sits in the centre of the town, and was our final destination. This is the focus of *The Big Day Out,* the day so named with the procession.

It was a colourful and noisy affair, with drummers and dancers.

It's here that all manner of entertainment, displays, stalls and competitions take place. Again, the Wisteria Lodge young people were treated to a feast of sensory delights, and indeed, after 'disembarking' from the train, I noticed that both staff and parents/guardians decided to stay on with the residents well into the afternoon, and it was only as stall holders began to pack away 3 hours later, that I spotted the trail of wheelchairs heading back to the minibus.

.....with some proud and delighted parents and the end of the ride.

As for the 2009 Festival procession…….well, we've decided to convert the WL residents and their wheelchairs into…..Roman Charioteers and Chariots, complete with charging horses!

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Holistic Music For Children

Len Baldwin
Teaching Assistant at St. Luke's Primary School, Scunthorpe

I have been a musician since childhood and have been working in a special school in Scunthorpe, North Lincolnshire, for 21 years as a teaching assistant. Prior to this, my involvement in the area of special needs began at about 14 years of age and took the form of various voluntary exploits and positions, totalling 30 years plus experience.

Along the way I have had input to many music sessions at all levels of disability and have said many times that I must produce my own music for children, as most of the resources in our area are either too 'busy,' 'complicated,' 'too fast,' 'not aimed at the correct level,' 'old,' or just not available.

Also, as the years have progressed, my recording equipment and experience in this field have both improved, so the only natural progression was to amalgamate my skills, take the bull by the horns and create Holistic Music For Children (HMC) a company with the primary focus of producing good quality music and songs suitable for pre-school children and children with additional needs.

The other driving force is my dear lady, Vicki Baldwin, who works in early years and like me has vast experience in special education, with expertise in child development with a particular interest in speech and language.

Along with the music we also wanted to produce a product that was informative and easy to use, with both of us having worked in classroom situations and knowing the obstacles people face. Vicki used her excellent design skills and with everything taken into consideration, produced the planning sheets which accompany the CD's, aimed at reducing staff planning and preparation time.

The name of the company was decided upon because the songs and music can be used for a wide range of children, from babies and toddlers, through to children with profound and multiple learning difficulties and because the packs are designed to be used as a 'tool box'. A holistic approach can be utilised taking exactly what you wish for a particular child or group of children.

Our packs are designed to encourage children's language and social skills and can be differentiated to encompass science, music and movement, maths and body awareness.

The response we have had so far has been very encouraging, especially seeing the music being used at St Luke's Primary School by the staff who have different levels of music ability and experience.

We have more ideas of projects we would like to produce and I am at the moment working on a dedicated music and movement CD for children with PMLD, with the tracks written individually for a specific part of the session.

We believe this is a much needed resource for special education, children and staff, giving access to modern, simple, quality music.

Contact details
Our website www.holisticmusicforchildren.co.uk has examples of our music and packs along with reviews from professionals.

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Being a Volunteer

Antonio Douglas with Dannie Keevens

As we all know, volunteers play a crucial part in many of our service and often comment on the great returns they get from the experience. Here Antonio Douglas talks about his voluntary work with Making Tracks, a day facility for people with profound and multiple learning disabilities.

Antonio Douglas is a member of Building Bridges Training, a social enterprise, consisting of people with learning disabilities and their facilitator, which aims to make a difference to people's lives through delivering training. The group are experienced trainers who live in Sandwell in the West Midlands, and provide training on a range of topics that are important to people with learning disabilities. They use a variety of training methods including telling their personal stories and experiences, PowerPoint presentations, interactive activities, group work, quizzes and games. They aim to demonstrate how everyone can contribute towards providing better support and improved services and true inclusion for all. They say on their website: 'As our name says we want to help build bridges so that people with learning disabilities can be more included in their communities.'

As well as being a trainer, Antonio also attends Options for Life, a facility which provides a range of day opportunities, leisure, work experience and support services for people with learning disabilities who live in and around Sandwell. The focus of this article, however, is Antonio's work as a volunteer at Making Tracks, a small day service for people with profound and multiple learning disabilities, which is run by Options for Life and based in Oldbury. High supportive ratios from staff and volunteers are important if people are to gain maximum independence and develop their self-esteem, communication skills and their ability to make choices. The service also encourages personal and social independent living skills, and promotes health care by enabling people to access appropriate services, such as physiotherapy, podiatry and speech and language therapy. Participants get support for community leisure activities, such as swimming, aromatherapy and walks, as well as trips to places of interest, personal projects, art sessions and a weekly 'STEPs' evening social group. Making Tracks has recently introduced evening GAP groups offering 1:1 support so that participants can enjoy social activities together that they may not otherwise get to do, such as cinema, shopping, meals out or bowling. They describe this development as 'A great hit!'

Deputy Coordinator Dannie Keevins at Making Tracks interviewed Antonio about his voluntary work and here's what he said, using Makaton to help him put his points across.

'My name is Antonio Douglas, I'm 30 and live with mum, me dad, my sister. I've got a bird and a cat. I came to Options for Life when I left school. I go to Smethwick leisure, Afro Caribbean - I walk to Oak Green in the morning and go on the run with Liam before going Afro Caribbean with Julia for music and Making Tracks. I also go to college and walk with teacher Mark, play cricket with Tatiana. I taste food - have to make it as well.

I've been a volunteer at Making Tracks since it started (about three years ago), on Wednesdays. I wash people's hands to make them clean. I learnt I have to have clean hands because of germs. I wash my hands lots of times when at Making Tracks'. I make drinks for participants when they get off the bus. I help take Lottie's, Dayles, and Melvyns, Jason's and Simon with the helmet coats off and Gamma's. We say good morning and offer the button (big mac switch) to the participants to touch to say good morning. I help Dayle and Lottie have a drink. I get the tables out, put aprons on participants and lay the tables, I help feed Lottie and Dayle. After dinner I clean tables with the spray and a clean cloth'.

In the afternoon I check the lights are working and the oil on the mini buses with Wicky. I hoover the mini bus tracking so the things (clamps) stay in. I help them (participants) with cookery, going in to the dark room (sensory room) and to play skittles. Walk in the park and shopping. I sit with them to watch films - dirty dancing is my favourite film. At the end of the day I help put coats on, open up the buses, put their (participants) bags on the buses. I push the wheel chairs out to the bus. When they have gone I help Ken clean. I hoover the carpet and take rubbish out.

I like coming to Making Tracks because it makes me happy working with you (Dannie) Claire and Wicky to help the participants. I talk to participants and staff. I use Makaton and my folder (P.E.C.S book) to help be understood. My favourite thing is washing the buses with Ken.'

Staff comments indicate how much Antonio is appreciated at Making Tracks:

'Antonio has boundless enthusiasm and always tries exceptionally hard to help the participants at Making Tracks in every way. He is an asset to the group especially with his keen interest in mini buses and trips out.'(Norma, Coordinator of Making Tracks)

'Antonio attends every week without fail. Come rain or shine he is waiting at the gates in his trademark fluorescent jacket after walking from home. He is very loyal to the group and the one time he became poorly whilst at Making Tracks and had to go home he was devastated he couldn't stay for the remainder of the day to help do the mini bus checks. Wednesdays wouldn't be the same without him, he is a great help. (Dannie, Assistant Coordinator)

'Antonio is always very cheerful and pleasant.'(Julia, Support Worker)

'Antonio is a fantastic volunteer whom the participants benefit from spending time with.'(Emma, Support Worker)

Undoubtedly, Antonio gets as much out of the experience as he contributes. He is sure that his own use of augmentative communication helps him empathise, and communicate more effectively with, the people he works with at Making Tracks.

Contact details
Antonio can be contacted through Options for Life at http://www.optionsforlife.info/ or at Building Bridges Training at http://www.cerebusnet.com/building_bridges_training

Moving into Adult Services

Amy Drewnicki

Transition can be a stressful time for all involved, particularly the young person. Barron and Hassiotis (2008) found that good experiences at transition positively correlated with health and reduced morbidity for young people with physical disorders. This article focuses on a young woman currently in the early stages of transition from the children's to adult services. I work alongside her as her keyworker within her respite services, and in the time I have known her, have begun to identify her preferences. She has various health issues that may impact on her access of services and her treatment by others. Following investigation and discussion of possibilities, she may be offered a more individualised package of care.

Emily's medical map

Emily (pseudonym) is 19 years old and lives at home with her family. Emily's mother works as a foster carer with Social Services and there are two foster children with the family too. Following a meeting in which we discussed Emily's physical and social needs, I compiled a "medical map". From this can be identified issues the family has experienced and what services they are happy with. Due to the severity of Emily's intellectual disability, her mother makes the majority of decisions regarding physical health interventions, in her best interests.

Emily has Lennox-Gastaut syndrome, which results in her having a severe intellectual disability and epilepsy, with a prevalence of 1-2 seizures a week. Her seizures are predominantly tonic-clonic, but she also experiences absence and atonic seizures, also known as "drop seizures" caused by brief loss of muscle tone. Lennox-Gastaut Syndrome may also lead to an increased risk of chest infections, which can impact on lifespan (British Epilepsy Association, 2008).

Emily is prescribed Topiramate tablets and Sodium Valproate (Epilim) liquid to control the frequency of her seizures. Topiramate is linked with acute myopia and closed-angle glaucoma, (adequate hydration must be taken whilst taking this drug to ensure the drug is excreted and to prevent a build up in the body), whilst Sodium Valproate requires a liver function test be performed regulary during the first six months of use. She is also prescribed Buccal Midazolam to be given in the event of a prolonged seizure lasting 10 minutes. However Emily's mother says she has never experienced Status Epilepticus, but she is prone to clusters of seizures over a 24 hour period. Luckily Emily has not experienced any side-effects from her anti-epileptic medication.

Standard visual and hearing tests have been carried out and she presents with hypermetropia (long-sightedness) - she attends an optician regularly for check-ups and is prescribed glasses which she chooses to wear at all times. Tests have not indicated any raised intraocular pressure due to use of Topiramate. Her hearing in within the normal range.

Emily is registered with an easy-access GP practice near her home where her mother attends all appointments with her, and feels she is offered a good service overall. She is also registered with Dr White (pseudonym), whose surgery is near the respite centre and all healthcare professionals' correspondence is forwarded to Dr White, to ensure Emily's medical records are complete. Dr White has assisted with organising appointments at hospital, and introduced Emily to other professionals, such as a continence nurse.

Emily was born with a scoliosis of the spine, which has impacted on her lung capacity. Unfortunatley she has suffered from frequent chest infections, and has been hospitalised with pneumonia more than once. This is due in part to the fact that she cannot adequately expel phlegm and it settles on her chest; and she is also at risk of aspiration.

She underwent an operation in February 2005, where a rod was inserted into her spine to correct the scoliosis. Scoliosis surgery is considered to have most effect on ventilation, exemplified by oxygen consumption, and patients often display decrease in the energy required during respiration (Lenke, 2003). However, a literature review by Weiss and Goodall (2008) identifies a "varying but high rate of complications" following scoliosis surgeries. Two days later, Emily was admitted back to Mid West due to respiratory failure, and her lungs collapsed. This "trauma" also resulted in sudden loss of muscle tone, causing severe impairment to Emily's swallow reflex. In her best interests with regard to maintaining weight and ensuring adequate nutritional and fluid intake, a percutaneous endoscopic gastrostomy (PEG) was inserted, however after some time her mother was keen for Emily to begin eating again. She has four Fresubin Energy 200ml (1.5kcal/1ml) feeds a day, given as a bolus via the PEG tube, and her medication is also given this way. She also eats some finely mashed food orally, and is encouraged to drink to maintain and build up the swallow reflex. At college and respite, her mother is happy for Emily to eat, but requests that if she begins coughing she stops eating to minimise the risk of aspiration.

She is prone to infection around the PEG site, and the site can weep if it is pulled or knocked. Her mother gets antibiotics from her GP, and maintains the cleanliness of the site. Her mother does physiotherapy with Emily on a daily basis, moving her legs and arms to maintain muscle tone, and also uses percussion methods of physiotherapy on Emily's back to help loosen phlegm and stop it settling on her chest or transferring onto her lungs. Emily produces a lot of saliva, and is prescribed a Hyoscine Bromide patch to wear on her neck to control the level of secretions.

Emily uses a wheelchair and sleeps in a profiling bed with the head raised to a 30-40 degree angle to reduce the risk of aspiration (Metheny 2002) both at home and the respite service.

Respite Services

At Tall Trees respite unit (pseudonym) near her home Emily is allocated 95 nights a year by Social Services on a regular pattern of a stay through the week every four weeks and one weekend each month.

Tall Trees provide nursing care, and a qualified nurse is on duty 24 hours a day. Staff turnover is quite low, which is beneficial for Emily in forming relationships with staff - she has begun to develop some positive relationships with staff since she began using the service when she turned 18. Emily is also able to maintain relationships with her peers, as Tall Trees provides respite for other young service users that she attended school with, and a number of other guests of a similiar age with similiar interests.

Staff who spend a lot of time with Emily have all received training in dealing with epilepsy and administering feeds via PEG. Care plans are updated twice a year but it may be more frequent than this if the care needs have changed. Emily and her mother are both pleased with the service provided, and feel communication is good between the centre and home - a ‘communication book’ is used between home and the respite service.

Education

She has recently started at College, but her mother has concerns regarding the care the college provide for her during the day. The main issue that has been raised is that of non-compliance, in that Emily will refuse the feeds she is required to have during the day - she should have two 200ml bolus feeds during the day. She also refuses to allow staff to assist her with personal care. The latter is of great concern as Emily is doubly incontinent and often has loose stools due to the high fibre levels in her feeds and her mainly liquid diet; therefore she is at a high risk of her skin breaking down due to caustic properties of faeces.

Emily's mother sees this response to staff at college as a way of gaining a level of independence, but due to her intellectual disability, Emily does not fully understand the implications of these choices, such as the risk of skin breakdown and dehydration. Emily’s mother approached the staff at the college and raised her concerns that they may inadvertently be neglecting Emily's needs, but was met with a very hostile response and staff claimed that as an adult, Emily is allowed to make her own choices in these matters. The British Medical Association released a "Consent Tool Kit" in 2003, prior to the introduction of the Mental Capacity Act (2005). It provides information on determining "best interests" and states that a level of clinical judgement should be implemented when allowing an individual to make decisions regarding interventions. Where the individual is a child, the BMA also advise discussion with parents - this would also apply in Emily's case due to her mother being her primary carer. Although it is admirable that the college are allowing Emily personal freedom of choice, they do not appear to be taking into consideration the effects that these decisions will have.

At Tall Trees, staff incorporate feeds into mealtimes or when clients are having a drink, and do not isolate Emily at these times. This is greatly beneficial as Emily remains involved in the social aspects of meal times and social gathering and is not ostracised. Tall Trees staff have offered this advice to staff at College, as they were attempting to remove Emily and carry out feeds in a secluded room, which is not necessary and upsets Emily. Having sought advice from a dietician who has been involved with Emily since she had her PEG fitted, the college were advised to implement use of a ‘pump feed’ - a 500ml feed is fed through a machine directly into the PEG tube at a rate of 75ml/hour, meaning that Emily does not miss out on the calorific content of the feeds she was refusing. Emily’s mother and the college are still in discussion regarding how Emily may overcome her refusal to be changed during the day at college.

Communication
Emily has a good understanding of spoken word, and responds appropriately. She will hold conversations with staff and her peers at Tall Trees, but tends to respond with "babbling", facial expression and gestures rather than speaking. She has a speech impediment, so she can be difficult to understand, however when she speaks she is patient and will repeat words if others do not understand what she is saying. Emily's mother says she has a very good vocabulary and speaks appropriately at home; she feels that Emily's choosing not to speak to people at college and the respite centre is due to her still building relationships and not having fully placed her trust and confidence in them yet. Emily is slowly beginning to speak more to staff at Tall Trees, but due to the problems she has encountered at college, she will not speak to staff there and relies on her "babbling" instead. Emily will use objects of reference and symbols or pictures appropriately and can use some basic Makaton; these may be appropriate options to augement her communication whilst she is at respite or college, as it would enable her to make her needs and desires fully known and enable her to communicate better with her peers who may use similar methods of communication.

Training Issues
Emily's parents could benefit from some 'moving and handling' training and input from an Occupational Therapist in order to ensure they are safe and not putting themselves at risk of injury when assisting Emily. They would also benefit from contact with their local community learning disabilities team who could keep them informed of any new changes and offer them the opportunity to shape local services and provision. Research by Saloviita et al (2003) has linked parental stress when caring for disabled children to their negative perception of their situation; in fathers this is most commonly related to their experience of the child's social acceptance. This is also an issue for the primary caregiver; Hastings et al (2002) found that a mother's perception of the child is associated with perceived value of support; therefore the mother's wellbeing will directly link to her ability to maintain her role as carer.

The provision of respite through Tall Trees is a vital aspects of Emily's care package, it is important the staff there have the appropriate training and support to provide optimum care for Emily that closely follows the routine at home. Barr and Gates (2008) identify effective education as a key factor, and all Tall Trees support staff have undergone a LDAF induction course (Learning Disability Award Framework). Although this provides an introduction into basic care of people with intellectual disability, it is by no means individualised. Emily has complex needs, and does not currently have any physiotherapy input during her respite, due to lack of training. Middleton and Kitchen (2008) identify lack of staff confidence and minimal attendance from physiotherapists as primary reasons for physiotherapy not being carried out in day centres. Tall Trees and college staff need to seek input and training from Emily's physiotherapist, so they may continue to carry out her physiotherapy programme. Tall Trees already have training updates and contact numbers for advice from the company who provide the feeds and equipment for Emily's PEG tube. College staff would benefit from something similar, so they understand the implications a PEG involves - Doyle (2006) provides an easy-read summary of the needs of an individual who requires PEG feeding.

It is not just education of staff that determines the quality of services. Barr and Gates also indicate that the attitudes of staff should also be taken into account when considering how effective a service is. Research suggests that people often have a low expectation for people with intellectual disabilities, or feel that the resources available do not allow for much to be achieved (Routledge and Gitsham, 2004). This could be an issue that has contributed to the difficulties that Emily has experienced at college. College staff accepted Emily without visiting her at school or making contact with staff who had worked with her there. Heslop et al (2002) identify continuity of staff and communication between agencies as fundamentals aspects of a successful transition.

Planning for Independence
Improvements could be made in all aspects of Emily's care package, relating to her capacity to consent. Emily already displays some autonomy of thought in choosing her clothes and activities. The Mental Capacity Act (2005) states that every adult has the right to make their own decisions regarding health care. It must be assumed that a person has mental capacity - understanding and considering given information, and communicating a decision - unless it is proved otherwise. Although no person is legally entitled to make a decision on Emily's behalf, she may require support in this field. The Mental Capacity Act states that a decision must be made in a person's 'best interests' and the action that least restricts their rights. Services should liaise with Emily and her mother to discuss plans, and seek additional professional advice where necessary; certain interventions may require approval through a multi-disciplinary 'best interests' meeting.

Education and attitudes have already been shown to have a fundamental effect on the quality of services, and this remains true in the case of Person-Centred Planning (PCP). A plan that focuses specifically on Emily's personal needs and wishes is fundamental to her achieving the most from her services. At Tall Trees, care plans are drawn up according to the Roper-Logan-Tierney Model (2000) below.

Emily would also benefit from having an Essential Lifestyle Plan (ELP). Sanderson et al (1999) described ELPs as a method for identifying important people and items and how to follow a chosen lifestyle. Needs are covered in an ELP under terms such as "What is essential to me" and "What others need to know/do". Sanderson et al (1999) would also advise it is important for those involved in helping Emily formulate her ELP that the plan is 'alive'; therefore needs monitoring and updating as necessary. Emily would benefit from an ELP whilst at college, as this could identify meaningful activities for her, and help her form relationships with her peers and the staff.

Conclusion

Identification of the training needs of staff, and following this up with appropriate training and refreshers is essential to Emily achieving all she can through her services. This should include informing staff about the Mental Capacity Act (2005) and local and national policies and guidelines that will assist staff in carrying out the highest standard of care. This will in turn provide a support network to her parents, which will improve their coping abilities and promote a healthy and happy family environment. Formation of an Essential Lifestyle Plan, and a person-centred approach to care and services will ensure Emily receives individualised care and her parents receive appropriate support in all aspects of her life.

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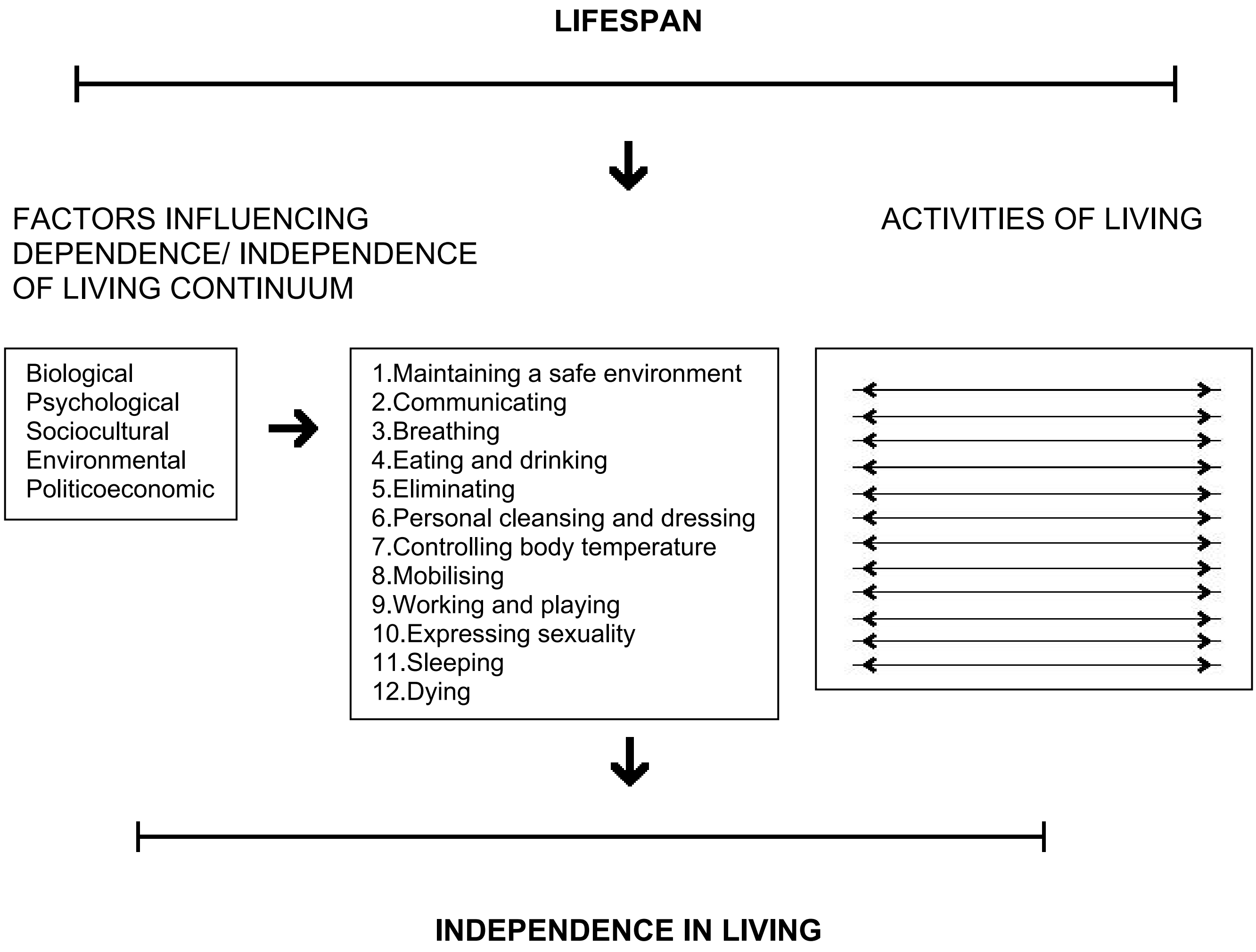
The Model of Living



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Intensive Interaction: Find yourself and be yourself

Kieron Hubrick

I am a special education teacher who works with pre-verbal/pre-intentional students at Carlson School for Cerebral Palsy (in Auckland, New Zealand) using intensive interaction as the basis for my pedagogical focus.

The Dawn of Communication and Social Education

I think of paintings I shall do.
Last night I thought of one, it was a sort of butter-yellow (farm-butter-yellow) field rising to a white luminous sky and the sun just rising. A strange rose-pink, I knew it exactly, full of hushed stillness, the beginning of things, lark-song without larks.

(Miranda from) The Collector – John Fowles.

Let me 'unpack' intensive interaction, and what I feel it is and how it should work in a classroom. On the face of things it is a one to one encounter, a pre-intentional student with a communication partner, trying to build a common communicative bond between each other; but of course it is more than this. It is a way to find PMLD students lost in themselves, and a way for us to be better educated about our special students.

I like to think of the 'dawn of communication' when I think about intensive interaction. I like to think of it as a method/approach that is essential and fundamental to human connection and happiness. I believe that instead of up-skilling myself I have de-skilled - in one sense - so that I can be ego-less, socially unsophisticated and open to any encounter with a student. In another sense I see myself as highly analytical before, during and after the interaction, intuitive, a charismatic play partner and a professional operating effectively in a specialised field. Indeed, with intensive interaction, a teacher or intensive interaction practitioner will on the surface appear more unstructured and uncontained. Underneath this playful exterior however – the opposite is true: he is deftly interpretative, insightful and open to exploring his partner's hidden communication. Hewett (2007) describes intensive interaction as a teaching style that is quite artistic in that the progression of a teaching session is not planned or prescribed, the teacher and student working to develop a communication flow which will gradually expand in duration, complexity and sophistication.

With this in mind – a community has been built with the students as core members, so that the classroom has become less like a classroom and more like a common-room; a common-room whose curriculum subtext is based around intensive interaction and the confirmation of self-identity. I prefer the term common-room where the staff and students can meet on a level appropriate for the daily interactions, where the common ground is ironically uncommon and personally unique. This is the environment that best facilitates our intensive interaction work. We need to become less role specific in the face of the student in order to promote a microcosmic social world in the classroom (or common-room). And we must let the students teach us, and allow ourselves to become willing students so that they have the opportunity to inform us about themselves and their world. This is essential in understanding how we may be able to help facilitate their unique growth. Recently I made notes on one of my students and a surreal interaction we had whereby my student enlightened me, intentionally or otherwise, that she (who I will call Brittany) was also schooling me:
I think that sometimes Brittany is testing me – as if we had suddenly swapped roles (I the 'pre-verbal' student with Brittany as teacher). This is the amazing power of pure connected communication. Her attention to my contributions is becoming more precise and timed – as I say as if very suddenly the roles had swapped.

That is the emphasis – that within context they can teach us as equally as we can teach them. And that the educational social model we should keep in mind is one that accepts as much as it attempts to 'school'. Nind and Kellet (2002) remind us of the (British) Royal National Institute for the Blind's caution:

Staff need to think why they want someone to change, abandon or modify their behaviour. They need to consider what they are doing and how, before they try to change another human being. What right have staff to make these demands? Have they anything better to offer?

We need therefore to remain open to progress and change without asserting this aim as the necessary ultimatum. It is simple enough that during the intensive interaction session unfettered togetherness and mutual fun is enjoyed and purposeful. Whilst keeping in mind the guiding principals of intensive interaction, and analysing what is actually happening as you let it happen.

Finding Michael

Beyond a certain point there is no return. This point has to be reached.

The Collected Aphorisms – Franz Kafka.

In recent talks with a professional intensive interaction colleague I have noticed rather incidentally how much of an impact intensive interaction may have made on my students. For instance, Melinda (SLT) might mention an characteristic trait that a certain student has exhibited during their time at Carlson School. Quite often I have found myself saying: *well actually Michael (not his real name) doesn't self-stimulate himself so much with his full hand in his mouth anymore – in fact I can't remember the last time he did that, at least not to the extent he was – maybe it was last term, I'm not sure?* And there it is, a certain revelation occurs, could this be because of intensive interaction? Is he now more in tune and interested in a world that before now had not catered for him in enough of a way for him to make some sort of change in himself. And what is my or our personal/professional responsibility in this 'change'?

Smith (2001) asserts that, "the heaviest responsibility falls upon the facilitator of the communicative behaviour (advocate, carer, support worker) to make it possible for that individual to experience a positive outcome in terms of what follows upon that behaviour. Once that happens, the power of communication can begin to be experienced."

In other words to build a positive communication setting is my major responsibility, whatever change may occur will occur through consistent positive relationships and a fine tuning of their intimacy, fun and connectedness. Jill Bradshaw (2001) cites McLarty in saying that "it should be stressed that relationships are the key in the development of communication skills, as it is through the development of these relationships that the individual will be motivated to communicate."

Furthermore, in the context of all professional responsibilities, I believe the biggest responsibility of all is <u>not</u> to give up on a student. To believe that individuals want to connect with others regardless of how removed to this they may be at the time. When Michael started in my class at the start of 2008 I was very worried. He would arrive at school and promptly begin sleeping; a simple but effective technique that would shut the world out (and it really was impossible to wake him). Downs, Morgan, Ouvry and Porter (2001) mentioned in their case study of 'Peter' (a pre-verbal PMLD individual) that several people felt that one way Peter chose not to join in an activity was to go to sleep. And so it was with Michael. The professional concerns for me were many: Is that 'healthy' for him? How will I 'educate' him? If he sleeps through mealtimes how will he receive the correct nourishment he needs? And, petty enough as it seems, what will I say to his parents when they turn up to discuss Michael's progress in a few months? In many ways Michael is an inspiration, over time he did start to change – as sessions progressed he seemed to anticipate this unique involvement, he would be awake and ready his head turning this way and that – as if searching the room for the social moment to occur - a chance to make contact. Furthermore, instead of maintaining his tactile defensive front he would search for and maintain hand contact throughout the session. Over time more and more progress developed including a reduction of 'self-stimming' as stated above; but as I say - *over time* – sometimes pushing through personal and professional desperation. After all, intensive interaction is *intense* and can be personally draining for people in these important interactions, and time can seem to change once one is in the interaction.

At the same time in the apparent history of Michael's school life - change was relatively quick; halfway through the school year evident changes in Michael had occurred. Caldwell (2007) notes that those that have been using intensive interaction for many years know that as an approach it is extremely successful, and the time it takes to effect behavioural change can be very quick. So although we hit a wall with Michael very early on using intensive interaction, at some point this 'wall' was broken, and strong human connection was made and maintained. This 'wall' can be very robust and difficult to break down; after all it has had years of internal reinforcement, from within the student, and incidental (or accidental) reinforcement from the student's regular environment (especially in the more detached wider world including the child's school life). In fact they are bed partners - the internal and external - as some sort of symbiotic duplicity that defines an individual's isolated state. In a class of six students I noticed that at least three others had a very entrenched wall that eventually broke (or cracked). And this is perhaps why change suddenly happens - when this internalised obstruction is suddenly broken or at least cracked, allowing the possibility of human connection and bonding to occur.

Therefore, the journey with each student is to build a sense of useful and fun togetherness, an empathetic togetherness and then to expand the student's interactive and communicative spectrum beyond there – using the principles of intensive interaction (and its subsequent goals of communication learning). And this, to me, means being brave enough to shed your previous skin as a mainstream adapted curriculum and activity heavy pedagogue so that you are actually not just another situation-dependent figure that the student meets in their life, but more like an intimate friend and confidante with the acceptance, understanding and empathy that this would naturally entail. We need to focus on what the most essential things are that students need to learn – it is not knowledge about the outside world as such, but rather knowledge about themselves and who they are to us, and we to them. Beyond there - the bigger outside world can wait… *for now.*

Teaching Connected Humanity

Look beneath the surface: never let a things intrinsic quality or worth escape you.

Meditations - Marcus Aurellius.

I believe that in order to teach what is essentially connected humanity, one must have some sense of equality as the basis for our… *now what's that term again?...* common room. Teachers and teacher aides should mesh in front of the students' eyes – along with other 'professionals' involved (Speech Language Therapists etc). Perhaps I do not necessarily believe in 'community' in a wider social sense (there are too many variables), but we can provide something close to a real community in the 'common room'. The ownership of the students' education should be spread, keeping in mind – of course - a teacher's professional commitment to purposeful education and the students' families. This also means maintaining that important school-home link; the common room door is always open. Also, we can – through this approach – give some sense of ownership regarding the students' education to our diligent and sometimes under-appreciated teacher aides. They are just as valuable as anyone with a long-buried professional degree, let's make their time in the common room as purposeful and as valuable as possible – as I say this will naturally benefit the students, the teacher aides themselves, and *ultimately* teachers… so yes we then can call it a community of learning. Or even, if I may be so bold, a community of purposeful learning.

The final statement: in education, we must be ourselves – or as close as we can be - in the context of our work. If we are brave enough to be ourselves – combining forces as community equals - hopefully the students will be too. And intensive interaction in its socially responsive way promotes this. *Find yourself and be yourself* – students and staff, for in reality this is, in my mind, the only true way to effect positive human change.

This is a heavily abridged version of my paper – which is available from me in its entirety via e-mail (my e-mail address is available at the end of this paper, alongside a brief glossary of special education terms).

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Developing The Thinking of Learners With PMLD

Penny Lacey

In the Winter edition of PMLD Link, I wrote briefly about a literature review I was undertaking on developing a curriculum for teaching learners with SLD and PMLD to think more effectively. Now I am in a position to share with you what I found. Most of the literature that I reviewed relates to typical children or to children and adults with mild, moderate and severe learning difficulties. There is very little that is specifically about people with PMLD learning to think. However, I think it is possible to understand the kinds of difficulties faced by learners with PMLD from the body of literature consulted, extrapolating the essence and applying that to learners who have the most difficulties in thinking.

Difficulties in Thinking

Learners with PMLD by definition have enormous difficulties in the area of cognition (thinking and learning). They struggle with even the most rudimentary logical thinking, understanding cause and effect, solving simple problems and using what they have learned in one context in another. Even those who have acquired basic understanding of cause and effect, appear to be very limited in how they can apply this understanding. For example, Susie could search for and find pens, her favourite objects, but did not use the same strategy to find other things. She could spot an open door and was through it immediately running down the corridor clearly watching for someone following her but yet did not anticipate other events. Why could she do a few seemingly thoughtful things but not others? It seems that many people with profound learning disabilities have learned certain behaviours that are very successful in their effect but because of their limited understanding of the world, these learned behaviours do not lead to real comprehension.

Sometimes the presence of learned behaviour, such as using individual words, manipulating objects or laughing appropriately can persuade us that the person has more understanding of the world than s/he really has. If we observe carefully, the behaviour can only be used in certain circumstances and is a product of constant repetition rather than really thoughtful behaviour. The most striking example of this is when John opens his mouth in anticipation of a spoonful of food and yet cannot anticipate anything else that happens to him, even when it is an activity that has been used with him many times. Just think about how many times John will have experienced the spoon held to his mouth even if he is only 5 years old (maybe 100,000!). Gradually after so much repetition, John can anticipate one event but still cannot transfer that learning to enable him to anticipate other events.

Developing Thinking

So what do we know about the development of thinking in typical children and how it can be applied to people with PMLD? Firstly, the theory that all children go through the same development sequence is reasonably well established in relation to children with learning difficulties, although not to those with multiple impairments or particular syndromes and conditions. For example, children on the autistic spectrum do seem to develop differently, especially in the areas of communication and language (Jordan, 2001). Many learners with PMLD do not progress very far along the developmental route set out by the biologist, Jean Piaget. Piaget describes the first stage of development in young infants as ‘the sensory-motor stage’ (0- 2 years) within which typical babies learn to use their senses and connect those with moving their bodies to start the journey of understanding the world around them (Goswami, 2008). Most people with PMLD remain within this stage throughout their lives, depending highly on personal sensory-motor experiences which they find hard to generalise. Some people with PMLD seem to get stuck on a particular developmental step, for example, mouthing objects. Perhaps this is an example of a learned behaviour getting in the way of developing new behaviours that enable more effective exploration of objects?

Glenn (1987) suggests that typically developing babies have been shown to be more able than Piaget thought but because they cannot show easily what they understand, it is assumed they do not understand. She cites the research that shows that typical infants can recognise their mother’s voice at only 3 days old and newborns can imitate their mother’s facial gestures and then wonders if this is also true for babies and older people with PMLD. She reports on her own experiments where children with PMLD functioning at a six month level showed preferences for the same stimuli as typical infants at the same developmental age. Given a tone and voice, they preferred the voice; given a nursery rhyme sung or played on instruments they preferred the sung version and given an adult speaking ‘motherese’ (baby talk) to them than two adults talking together they preferred the motherese. She used switch access to obtain these results.

From her work, Glenn (1987) suggests that if learners with PMLD are not given opportunities to act on their environment, because of their multiple difficulties, they will be severely restricted in their cognitive development. She cites other work that shows learners with multiple disabilities functioning at a three-month level who could learn to break a beam to set a go-cart in motion. Motivation and opportunity are both important and technology can help with accessing the opportunities, though generalisation of such skills is likely to be a challenge.

Problem Solving

Generalisation and problem solving are know to be difficult for all learners with learning difficulties. There is research evidence to suggest that people with Down syndrome and Fragile X syndrome have specific difficulties in this area (Fidler et al, 2005; Mazzocco et al 2005) even if they have a good grasp of cause and effect. Few people with PMLD will reach the developmental stage where they can solve problems, except at a very rudimentary level where they might repeat an action where the first attempt is unsuccessful. They might be able to modify their actions when repeating it does not work or trying a new strategy when the old one fails (Welsh Assembly, 2006). Of course there are always exceptions, like Samuel who can solve problems with more than one step. He can open boxes and lift covers for favoured objects; find the right doors and remember routes to find these objects and persist until he is successful. However there are predictable limits to his problem solving. His highly developed search strategies are only related to what he wants, and remain strictly within that context. He will not search for something in which he has no interest.

Neuroscience

If we turn to a different set of theories on cognitive development, we can apply what is known about what is happening in the brains of typical infants to help explain the difficulties faced by those who have brain damage or a different brain structure. Neuro-imaging has shown that typical infants have most of their brain cells (neurons) at birth and the connections between them (synapses) are rapidly developed in response to use. Neural pathways are made and lost throughout our lives, depending upon our experiences but the greatest number are made in the first few years of life (Ward, 2006). The effect of brain damage or lack of parts of the brain, by definition will restrict the number of neurons present from the outset and, of course, also restrict the numbers of synapses that can develop. However, if we remember that synapses are formed throughout our lives (brain plasticity) there are always possibilities that people with PMLD can make new connections and learn new things just like typically developing people. Sensory stimulation, experiences with objects and new activities are just as important whatever the age of the learner.

Memory

The development of memory is vital for all learning and in typically developing infants, this seems to be present from birth. Experiments have shown that babies as young as 3 weeks can remember simple objects because they look longer at new objects than those they have seen many times (Bushnell et al, 1984). There have been a number of experiments on memory, particularly with people with Down syndrome showing their difficulties with memory when it is reliant on verbal input. Their memory for visual-spatial information is better and this points to the importance of providing plenty of visual aids such as objects, pictures and symbols during learning (Wishart, 1998). The work of Hulme and Mckenzie (1992) suggests that difficulties with memory are experienced, not just by people with Down syndrome but by others with severe learning difficulties and this can help explain why people with PMLD seem to have huge difficulties in remembering even much repeated activities. Maybe some people with PMLD constantly experience, even much repeated, activities as if for the first time? Maybe even people they meet on a daily basis are strangers to them every time?

So if people with PMLD have such difficulties with memory, how can they learn? As was suggested earlier in this article, sheer repetition is likely to be the answer. If John can learn to open his mouth to anticipate food on the spoon, then he can learn to anticipate other things, but not without a tremendous amount of repetition. In my experience we do not repeat activities sufficiently. We want to give learners with PMLD an interesting life with lots of different sensory experiences, where perhaps we should be concentrating on a few that are repeated many times. If we are going to be driven by repetition, then understanding the exact level of each person’s learning is vitally important. It would be of little use to be offering experiences that are either below or above the level of cognition. The first is boring and the second impossible.

Routes for Learning
The development of a simple assessment tool, 'Routes for Learning' (Welsh Assembly, 2006) has made the task of pinpointing the cognitive level of people with PMLD much easier. The assessment covers both communication and cognition that are usually developed in the first year of life. This first year is divided into 43 different behaviours and learners with PMLD could take many different routes through those behaviours. It is very important to see the Routemap as a guide and not as steps to be completed from 1-43.

About halfway down the Routemap is 'contingency awareness' which refers to 'cause and effect'. If the person is able to connect what s/he is doing with the effect this has, then we can say s/he has grasped basic cause and effect. This skill is of vital importance in developing, for example, the capacity to communicate 'more' and 'no more' and to go onto making choices between objects and activities. Before that time, it is very unlikely that people will be able to make choices. They may be able to show that they like or dislike activities/ objects as they occur but they are not yet able to make a specific choice even between two. In my experience, many people offer choices to learners who are not yet at that developmental stage and declare that the object the person has looked at is their 'choice'. This assumption can be very misleading and can encourage teachers and supporters to attribute greater understanding than individuals actually have.

So how do we make use of the results of assessment using Routes for Learning? If we have discovered the learner with PMLD is beginning to learn about 'contingency awareness' then that should become central to all their learning. School children may be working on a range of curriculum activities and adult learners are likely to be involved in a range of community activities but what is required for all at this stage is for teachers and supporters to provide as many opportunities as possible to practice contingency awareness. This should be done throughout the day, preferably with a range of different resources so the person can learn to generalise his/her understanding in many different situations. Technology is particularly good for practising contingency awareness (eg: pressing a switch to hear music) but reactions from people can sometimes be even better, especially as people can make decisions about how to respond in relation to the input from the person with PMLD.

Intensive Interaction (Nind and Hewett, 2005) can be extremely useful in teaching contingency awareness as a central intention is to react to the actions and sounds by echoing these back to the person. The learner claps her/his hands and the interaction partner joins in or maybe offers a slightly different action known to be within the repertoire of that person. The cause is the learner's actions or sounds and the effect is the reply from the partner. Many people with PMLD understand they can control the 'conversation' and much enjoy the effects.

'Routes for Learning' is not just an assessment tool but it also contains teaching strategies to move learners to the numbered behaviours. An example relates to an earliest behaviour on the Routemap, 'notices stimuli' where there is advice to try a range of actions and sensory experiences in a pattern of 'on-off' so the learner has a greater opportunity to notice something happening and then not happening. There are suggestions about making the stimuli very obvious and looking for any changes in behaviour to indicate the stimuli are being noticed, such as stilling, turning or a change in breathing. As the learner becomes more skilled at noticing stimuli then supporters can start to look for stronger reactions eg: vocalising, open mouth or finger movement and later responding differently to different stimuli eg: smiling, eye contact or touching each as appropriate. Once the reactions are secure, during the on-off sequence it might be possible to see the learner anticipating a repeated stimulus. 'Notices stimuli' is the first step and 'anticipates repetitively presented stimulus' is number 14, which indicates the tiny steps of learning at this stage. Typical infants can anticipate which visual image will appear next in a sequence by the age of 3 months (Wentworth, Marshall and Karrer, 2001) but it can take learners with PMLD many years to reach this point, and there are some who may never learn to anticipate. Learners who are so restricted in their understanding of the world are likely to need a small repertoire of stimuli that are repeated very often if they are going to have a chance of moving on in their thinking.

Multiple Disabilities
It is important not just to consider the development of typical infants when considering how to teach thinking to people with PMLD but we must also recognise the limitations placed on those with multiple disabilities. Lack of vision, hearing, and the ability to move are just three of many possible impairments that severely limit the path of cognitive development. Typical infants learn from being able to see, hear and act upon their environment in the sensory-motor stage and if any or all of these are difficult or even impossible, it is very hard for that learning to take place. Cognitive development for those who have a sensory or physical impairments but no learning difficulties is usually delayed but the combination of impairments often seen in learners with PMLD has devastating effects.

Whatever the combination of difficulties, it seems to be most important to build on strengths rather than weaknesses. Hodnapp and Dykens' (2004) research shows that different syndromes and conditions have different strengths and weaknesses in cognitive functioning but that generally areas of strength develop well over the years but areas of weakness develop slowly or not at all. That seems to be important when considering how to teach children with SLD/PMLD to think and learn more effectively. Building on strengths maybe much more fruitful than trying to remediate weaknesses.

Sometimes it is hard to find strengths, especially if the learner is at the very early stages of cognitive development. It can be very helpful to conduct an Affective Communication Assessment (Coupe et al, 1985) as from this it is possible to find a range of stimuli to which the person reacts. The purpose of the assessment is to gather information about precisely how the person reacts to these stimuli. For example, Michael smiles and moves his legs and arms when he likes a stimulus and gives a 'pained look' when he doesn't. If he really does not like something he will cry and if he really likes something then he will smile broadly. From these small beginnings it will be important to build on these reactions, gradually increasing the different kinds of stimuli that provoke the strongest reactions to form a repertoire of motivating activities. Once motivating activities have been established, opportunities are given for Michael to learn to anticipate the favoured events (and the unfavoured) and from that learn to indicate when he wants 'more' of an activity. This course of events is much more likely to occur if the following is true:

- activities are motivating and build on the smallest of strengths
- they occur in the same order each time (until anticipation is established)
- they are repeated many times every day
- supporters are responsive to even the smallest of reactions
- expectations are realistically related to the level of cognitive development reached by the learner with PMLD

When I'm working with people with PMLD, I always remind myself of the adage:

'start where the learners are and not where you think they should be…..but you can't leave them there'.

I know I must expect people with PMLD to learn how to think but I must also be realistic and build on what I can see is happening. I can't just give sensory experiences and hope that learning will take place. I need to know how many times to repeat the stimulus, what the likely reaction will be, how long it takes for that reaction to occur, where the best reactions take place, who gets the best reactions. It has to be very precise or I may not be 'where the learner is'. Typical learners can learn as long as the input/activity is roughly in the right cognitive area. Learners with PMLD need more precision or they may sink into helplessness or resort to learned rather than thinking behaviour.

Conclusions

From the literature, it can be seen:

1. Learners with PMLD have enormous difficulties in learning to think.
2. They are likely to develop thinking in broadly the same way as typical infants, with allowances for their multiple disabilities which may mask their abilities.
3. Cognitive development may be prevented not only because people with PMLD do not have sufficient opportunities to learn to connect cause with effects but also because successful learned behaviour might prevent new learning.
4. Learning to think is possible throughout childhood and adulthood through creating new neural pathways (brain plasticity).
5. Learners with PMLD are likely to have great difficulty with memory, with perhaps some having virtually no memory at all, meaning every person and activity they experience is as if for the first time, every time.
6. Thus learners with PMLD require an enormous amount of repetition to learn.
7. 'Routes for Learning' and the Affective Communication Assessment' are very valuable tools in understanding the level of cognitive development of individuals with PMLD
8. Once the level is established and motivating activities are found then new learning can be encouraged through building on the person's strengths

So, despite the profound difficulties faced by learners with PMLD, it is possible to teach them how to think more effectively. Even if the tiniest progress is made, it can be celebrated, though perhaps not always through the officially recognised tools for recording. Recording of progress is another topic and I won't get into that now!

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Using switch-technology to facilitate the development of contingency-awareness in people with PMLD

Rosie Hogg

People with PMLD are commonly misconceived as “passive recipients of care”: unable to make choices, exert control or actively participate in their own lives, because of their requirement for a high level of ongoing support (Department of Health, 2009). As educators and interventionists it is our responsibility to provide people with PMLD the opportunities to positively participate in their world. It is crucial that we create an environment which is responsive to their actions and interactions to ensure cognitive, social and affective development, but also to ensure that people with PMLD are treated with value and respect (Ware, 2003).

By providing people with PMLD the opportunities to exert control and actively participate we help to facilitate the development of contingency awareness; the knowledge that you are able to have some effect on the environment (Wadsworth, 1996).

Contingency-awareness is a “cognitively significant milestone” (Watson et al., 1982), affecting cognitive development, emotional well-being and quality of life. Without it the foundations for further development are not fully established (Wadsworth 1996). It is only by realising that you are able to affect your environment do you develop the interest and motivation to engage further (Lancioni et al., 2001) - essential if learning is to occur (Hewett, 2007).

Contingency-awareness positively affects the emotional and motivational state of an individual (Brinker and Lewis, 1982a) and is fundamental for the development of communication. If we are to prevent individuals either from resorting to self stimulatory behaviours (SSB) (Goldbart, 1994) or from withdrawing completely from the external world (Brinker and Lewis, 1982a) then it is essential that we ensure they are able to engage with their world in an active and meaningful way.

This article focuses on the development of contingency-awareness in people with PMLD, specifically looking at how switch-technology can be used to facilitate this development.

The development of contingency-awareness

Contingency-awareness normally develops during the first year of life and is a crucial part of the sensori-motor period (Piaget, 1952 cited in Brinker and Lewis, 1982b) (see table 1).

During the first three months social co-occurrences are the main types of contingencies experienced by the infant (Ware, 2003). This is because of the infant’s limited motor ability and because people in the infant’s social environment are responsive to its behaviours (Brinker and Lewis, 1982a). As the infant’s motor functions develop physical co-occurrences, those involving objects and the material environment become increasingly important. Physical co-occurrences have the advantage of being more reliable than social co-occurrences and are more likely to have instantaneous consequences, which makes them easier to detect.

The effects of PMLD on the development of contingency-awareness.

People with PMLD face a far greater challenge acquiring contingency-awareness than non-disabled infants. To understand co-occurrences an individual must first be able to cause events to happen and secondly be able to detect them (Watson, 1966). They must then use the short term memory to associate the behaviour and consequence, and long term memory to retain the information so it can be recalled in the future (Barber, 1994). People with PMLD have severely impaired motor and sensory abilities and their profound learning disability hinders their ability to retain and analyse information.

The indirect implications of PMLD can also reduce the number of social co-occurrences that an individual experiences (Brinker and Lewis, 1982a). The social interaction people with PMLD experience may be reduced due to intense medical involvement or altered because of the attitudes and expectations of caregivers (Brinker and Lewis, 1982a). Typically caregivers work harder to engage infants with disabilities because they may be less responsive, slower to respond or may demonstrate atypical behaviours (Nind and Hewett, 2001). Consequently the infant tends to experience more controlling, less consistent and over-stimulating interactions (Nind and Hewett, 1995), which intensify with the severity of the

Table 1: Cognitive and affective development in Piaget's sensori-motor period. Adapted from (Wadsworth, 1996; Coupe O'Kane and Goldbart, 1998)

Stage label (Approx. age in months)	Cognitive development	Affective development
1. First habits (0-1)	Infants engage mainly in reflex exercise, sucking, rooting.	Instinctual drives and inborn affective reactions
2. Primary circular reactions (1-4)	If infants do something with their own body e.g. thumb sucking, that they find pleasurable then they will learn to repeat behaviour. Early undifferentiated schemes e.g. mouthing, looking, and holding. Intentionality starts to develop; goals are only set after the behaviour has started though.	Feelings are only to do with their own activities and own bodies; feelings of pleasantness and unpleasantness, joy and sorrow.
3. Secondary circular (4-8)	If infants do something to themselves that they find pleasurable, they learn to repeat the action. Shaking, banging and other differentiated schemes (cognitive roles are being established). Infants believe themselves to be the cause of all activity. Infants anticipate positions of moving objects, evidence of object concept.	Feelings of contentment and disappointment linked to the action
4. Coordination of secondary schemes (8-12)	Object permanence fully established; infants' use of familiar objects becomes conventional or 'appropriate'. Start to be aware that something else may be the cause of an event. Intentionality is fully established; goals are established prior to initiation of activity.	Affect involved in activation and retardation or intentional actions. First feelings of success or failure.
5. Tertiary circular reactions (12-18)	Infants demonstrate tool use and new means of achieving ends through experimentation. Aware of relationships between objects in space and between objects and self.	Investment of affection in others.
6. Beginnings of thought (18-24)	Toddlers can predict cause-and-effect relationships; they can form images of absent objects and are aware of movements not perceived.	

disability (Ware, 2003).

The effects of PMLD make it hard to develop contingency-awareness and consequently people with PMLD often have little motivation to engage in a world in which they have no control. This withdrawal further reduces the probability of encountering co-occurrences (Barber, 1994). It is essential that people with PMLD experience a responsive environment in which they are given the opportunity to initiate and take control.

Teaching contingency-awareness using switch-technology

Switch-technology can provide the necessary conditions for the development of contingency-awareness.

For people with disabilities switches are "tools of access" (Lancioni et al., 2001); they enable people to activate a stimulus and most importantly control an aspect of their environment (Lovett, 1985 cited in Barber, 1994). The range of possible stimuli to be activated is vast: a switch can be connected to auditory, visual and tactile stimuli. Switches can also be connected to speech output systems, which through a simple switching action can convert nonverbal communicative behaviours into verbal messages (Lancioni et al., 2001).

The degree of control an individual can attain through a switch is dependent on the complexity of: the input system (the number and type of switches used), the processor (which interprets the instructions) and the output device (which delivers the stimuli), as well the ability of the switch user (Colven and Judge 2006; Hopkins et al., 2008). It is evident that with the appropriate technology the use of a switch or other access device (e.g. touch screen or eye tracking device) (Bean, 2009) can open up the world to an individual with a disability.

Many studies have demonstrated that people with PMLD are able to learn to independently activate switches to obtain rewards (for a review of the literature see Lancioni et al., 2001). The learning which takes place in these contingent sessions does not show "spontaneous extinction"; a commonly reported phenomenon when working with individuals functioning at an early stage of development (Barber, 1994). However as yet there have been no long term follow up studies so there is no indication of how permanent this learning is (Lancioni et al., 2001).

Switch-technology, however, does enable people to interact with their environment which is a necessity for the active construction of knowledge and development of contingency-awareness (Daniels, 1996).

Advantages of using switch-technology with people with PMLD.

a) *Promoting independence*.

Switch-technology enables people with PMLD to do things that they could never do before, it enables them to achieve more (Bozic and Murdoch, 1996). For example the Smart Power Chair enables people with PMLD to control and experience independent motion through the use of a switch.

b) *Demonstrating ability*.

Switch-technology enables people to "do" more and to demonstrate hidden capacities (Detheridge, 1996). People with PMLD may have physical disabilities that are so severe they are unable to demonstrate what they understand, or have communication that is so underdeveloped that it is difficult for others to assess their cognitive capacity. Technology can act as a facilitator to enable an individual to perform an action which demonstrates their cognitive competence or by providing a means through which to communicate (Detheridge and Stevens, 2001).

Assessment is critical for developing appropriate intervention strategies to structure progression, and technology can provide unambiguous and objective measures to assist in this process (Detheridge, 1996). However interventionists need to establish not only where an individual is 'at' but where they need to 'go' (Detheridge, 1996). Vygotsky states that in order learning to occur for it must take place within an individual's Zone of Proximal Development (ZPD); which is the range of functions that currently the individual is only able to perform with the support of a more experienced learner (Vygotsky 1987, cited in Daniels, 1996). It is proposed that switch-technology, along with adult support, will provide a context in which individuals can work within their ZPD, thus facilitating their progression (Bozic and Murdoch, 1996).

c) Altering perceptions and attitudes.

Demonstrating the ability of people with disabilities to learn, through the use of contingent stimulation, has been shown to have enormous positive effects on the caregivers (Brinker and Lewis, 1982b; Dunst et al., 1985; Sullivan and Lewis, 1990). Knowing that an individual has the capacity to learn changes the way in which caregivers interact; it helps them to become attuned to the very subtle developmental changes and encourages higher quality social interaction (Brinker and Lewis, 1982b). Demonstrating capacity to learn provides further evidence in support of the case that people with PMLD are educable (Dunst et al., 1985).

Social interaction is extremely important for the development of contingency-awareness, and by altering the attitudes and expectations of caregivers towards people with disabilities helps to improve the quality and frequency of interactions (Brinker and Lewis, 1982b).

d) Recording and monitoring.
In order to inform caregivers and interventionists about learning, the responses of an individual must be recorded and analysed. Switch-activated computer programs have the advantage that the computer can be utilised to record responses, analyse the data and provide information about the learning experience (Brinker and Lewis, 1982b). This frees the educator or interventionist to support and interact with the learner and provide a social context in which learning can take place (Vygotsky, 1987 cited in Bozic and Murdoch, 1996).

Disadvantages of using switch-technology with people with PMLD.
a) The technology.
Using computers and other forms of switch-technology is not without its disadvantages. A common misconception is that the computer is a time saving device, however Watts (1991) is keen to emphasise that generally it provides "more data, not more time". Setting up the technology and troubleshooting problems can eat into valuable learning time. If the technology fails to work then the individual is at risk of being exposed to the damaging effects of non-contingent or ambiguous stimulation (Glenn and O'Brien, 1994).

b) The dangers of non-contingent stimulation.
Research has shown that when contingency experiences are violated people with PMLD show reduced motivation (reduced responding), negative affect (reduced smiling) and an increase in SSB (O'Brien et al., 1994).

Using switch-technology to ensure reliable and reproducible co-occurrences (Detheridge, 1996), may not in fact be as accurate as we perceive. Generally when an individual activates the switch they receive consistent feedback and consequently may detect a co-occurrence. However what does someone with PMLD think when the switch is given to someone else? Or when they receive that same reward in another, non-controlled, context? For the individual to understand, why in these situations they no longer have control, requires cognitive processes beyond the realms within which people with PMLD are operating. Consequently they will experience non-contingent stimulation.

c) Switching ability is not necessarily indicative of contingency-awareness.
Research has shown that people with PMLD can learn to press a switch to reap a reward. However this response is not necessarily indicative of contingency-awareness. Instead the response may be explained by the operant theory (O'Brien et al., 1994), a behaviourist explanation of how learning occurs. Operant learning occurs when "the consequences of a response determine the probability of it occurring again in the future" (Cardwell, 1999) and is a simple form of behaviour modification which requires no cognitive understanding (Barber and Goldbart, 1998). In contrast, contingency-awareness takes place because the individual *understands* that they can affect the environment (Piaget, 1952 cited in Glenn and O'Brien, 1994). Contingency-awareness involves cognitive processes and therefore is part of the cognitive theory of leaning (Barber and Goldbart, 1998).

Contingency-awareness has been associated with positive emotional responses and increase motivation to act on the environment (Piaget, 1952 cited in O'Brien et al., 1994). Measuring positive affective state is subjective and reports have tended to be anecdotal (Watson et al., 1982; Dunst et al., 1985). Determining the speed of model acquisition (how quickly an individual learns to recognise a stimulus) has provided a measure of cognitive capacity, as recognising and remembering a stimulus involves central processes such as memory (Lewis and Goldberg, 1969). However this has only been shown in non-disabled infants.

O'Brien et al (1994) demonstrated that infants with severe and profound learning disabilities who showed contingent-responding all had positive affective and motivational states, suggesting that it is possible for infants with PMLD to demonstrate contingency-awareness. However the authors acknowledge that these results are "only preliminary and need replication" (O'Brien et al., 1994).

Implications for practice.
Using switch-technology is not as straightforward as it sounds (Ware, 2003). The literature discusses a number of practicalities that need to be addressed in order for the technology to provide contingent stimulation.

- *Accessibility of the switch:* switches are available in a variety of shapes, sizes and modes of activation and an assessment by occupational therapists or physiotherapists may be necessary (Lancioni et al., 2001).

- *Reinforcing power of the stimuli:* it is essential that meaningful rewards are identified for the individual (Wacker et al., 1988). Establishing the preferences of an individual with PMLD is acknowledged to be a difficult and time consuming procedure (Lancioni et al., 2001). Tools such as the Affective Communication Assessment (Coupe O'Kane and Goldbart, 1998) should aid this process.

- *Introduction of the switch:* this is likely to require the use of prompts and demonstrations which are gradually withdrawn (Lancioni et al., 2001). Learning has been shown to take place when individuals are exposed to daily contingency sessions of short-duration (Dunst et al., 1985; Sullivan and Lewis, 1990; O'Brien et al., 1994).

- *Magnification of communication behaviours:* Providing a switch-device to magnify non-specific behaviours that maybe easily missed can help to ensure that staff respond to any communication attempts (Ware, 2003). This helps to reinforce the behaviour and ensure that the individual is treated as a communicator (Goldbart, 1994).

- *Avoiding non-contingency:* non-contingency disrupts expectancies and has a negative impact on affective and motivational state (O'Brien et al., 1994), however avoiding non-contingency is no easy feat!

- *Time to affect the environment:* time must be allowed for the individual to physically manipulate the environment and to express the enjoyment or dislike of an activity.

Where next? It is proposed that developing switch timing (pressing the switch at the right time) is the next step therefore enabling the individual to scan and select (Inclusive Technology, 2008). This is often not a suitable progression for people with PMLD. Limited motor function and the effects of cerebral palsy can make activating a switch at a particular moment extremely difficult, and scanning requires visual ability that many people with PMLD do not have.

Conclusion.

Developing contingency-awareness is fundamental to our ability to be active participants in our lives. Contingency-awareness underpins cognitive development, results in greater emotional well-being and increases our motivation to engage with the environment. It is the foundation on which we learn to learn (Brinker and Lewis, 1982b). Contingency-awareness is also necessary for the development of communication, and this development is the principle factor in improving the quality of life for people with PMLD (Nind and Hewett, 2001).

Switch-technology has the potential to enhance the responsiveness of the environment for people with PMLD and improve their chances of experiencing contingencies. Many studies have shown how switch-technology gives people with PMLD control over aspects of their environment over which they previously had no influence. The results clearly indicate that people with PMLD are able to learn however, only a few studies have been able to show that this learning reflects the development of contingency-awareness. Further cognitive analysis of this learning is necessary for this data to be conclusive.

Switch-technology does permit people with PMLD a level of interaction with the both the physical and social environment that was not previously possible. This is extremely important for people with PMLD if they are to be truly included in, and engaged by, the physical and social aspects of their world.

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Personalised Learning Plans

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A team of teachers from the Specialist Inclusive Learning Centres in Leeds (previously special schools) began meeting in November 2006 to share best practice. It quickly became apparent that we all subscribed to the view that planning based around the National Curriculum Programmes of Study got in the way of the 'real learning' for pupils with complex and multiple learning needs.

'While experienced teachers are able to differentiate the PoS to provide an activity or experience at the appropriate development level for pupils, this does not mean it will be an activity that the pupil is able to learn and achieve from'

Consequently we were all spending hours on being creative with the existing planning structures and paperwork to ensure essentials such as Intensive Interaction, development of visual skills, physiotherapy and MOVE could be delivered.

We discovered it was possible to changing existing practice to support our philosophy that we should be starting with the needs of the individual child.

As far back as 1996, SCAA and ACAC produced the guidance *Planning the curriculum for learners with profound and multiple learning difficulties*. The guidance stated as a first principle that planning should start from the basis of the needs, interests, aptitudes and achievements of the learners. So we decided to write a new curriculum policy and guidance document for pupils with complex and multiple learning needs in Leeds. The 'Additional Guidance Booklet' from the Routes for Learning materials published by the Qualification and Curriculum Group DfE Wales, provided us with the most comprehensive and up to date research on which to base the policy.

The policy recognises that this group of pupils and students have learning needs that requires schools to provide specialised curricula, assessment and teaching

'Learners will not make sense of a fragmented curriculum, divided somewhat arbitrarily into subject categories. Tasks must be relevant and purposeful to maximise motivation and to help learners make sense of the world around them. Curriculum experiences need to be carefully mediated as uncoordinated approaches, particularly those using different sensory pathways, can lead to a range of experiences that carry little meaning for learners'

For this to be achieved pupils must have individualised curriculum plans, we choose to call them 'Personalised Learning Plans' (PLP's) to link them in with the national agenda promoting personalised learning across all sectors of education. To ensure the plan doesn't restrict the range of experiences offered to pupils the policy recommends running topic based planning along side the PLP's with emphasis and outcomes determined by an individuals PLP.

The following extracts from QCA guidelines (Planning, Teaching and Assessing the Curriculum for Pupils with Learning Difficulties) support this approach.

'Although the National Curriculum is specified in subjects, schools are not necessarily required to teach them separately. They can organise their curriculum in ways which provide opportunities for appropriate and relevant learning, have meaning for pupils, parents, carers and staff, and use resources to maximum effect'

What does a PLP look like in practice and what is the impact on an individual's development and learning?

Jane is a lively and inquisitive 7 year old girl who was born prematurely and as a result has cerebral palsy, visual and hearing impairment. Her plan was drawn up by a multi-professional team including her mum, the class teacher, teachers from the visual and hearing impaired services, speech and language therapist and the physiotherapist.
It looks like this

<u>The things that act as obstacles to the effectiveness of Jane's learning</u>

- Visual impairment – sees objects placed within 30cms of eyes. Requires glasses for distance which she does not yet tolerate for longer than 5 minutes
- Profoundly deaf – issued with 2 hearing aids

which she will wear for up to 30 mins when supervised

- No independent sitting balance – supportive seating restricts access to activities and mainstream peers
- Not able to explore her environment independently except when on stomach on floor
- Severely impaired communication
- Limited fine motor control
- Time required for health and care needs
- Restrictions in ability to participate in social activities with peers.

Addressing these obstacles to learning, is now the main focus of the work done with Jane under the following broad headings

1. To increase the amount of time Jane wears her glasses and to monitor the impact on her learning
2. To increase the amount of time Jane wears her hearing aids and to monitor the impact on her learning
3. To improve sitting balance
4. To improve sit to stand transfer skills
5. To improve her ability to explore her environment using her Pacer
6. To develop communication through increased social interaction
7. To develop her ability to indicate choices
8. To maintain hip adductor, hamstring and Ankle/Achilles length

These are broken down into current objectives, for example

1. a) to wear glasses when in her Pacer
   b) To wear her glasses as part of a structured teaching programme to develop her vision – min of 2x5 mins sessions per day
3. a) To sit on a conventional classroom chair for min. of 5 mins per day
   b) To sit in wheelchair with no chest strap when involved in activities that do not require concentration
   c) To sit cross legged on the floor.

They will be broken down further in the short term planning.

The PLP also details 'strategies to maximise learning'

Use brightly coloured or reflective stimuli
Respond to all vocalisations
Allow independent exploration

The policy is now being implemented across the SILC's in Leeds and the team is now developing a modular training programme to support staff in this implementation.

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More information about the Policy and 'Personalised Learning Plans' is available by emailing: cmlnteam09@googlemail.com.

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Mathematics for pupils with Profound and Multiple Learning Difficulties—A Case Study

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Mathematics Co-ordinator

I work in a non-maintained special school that provides education for students with a wide variety of learning difficulties from the age of two to nineteen. The school was formed as a charitable institution in 1912 by the Dominican Sisters, initially for children with physical disabilities, and has remained in their trust ever since. There are 60 pupils throughout the early years department, main school and post sixteen unit. The school has a multidisciplinary approach with the provision of physiotherapy, occupational, speech, massage and music therapies.

The Mathematics Curriculum provision is based on the National Curriculum (NC) and covers all the strands of the Mathematics Curriculum. It has been adapted to the needs of the pupils. I believe this adaptation is essential when considering the learning needs of the pupils with profound and multiple learning difficulties (PMLD). Staves (2001) agrees with this, as neither the NC nor the National Numeracy Strategy reaches deep enough into the lower fundamental levels of mathematics and early developmental learning. The lessons are planned through units of work that relate to the strands of the Mathematics Curriculum. As Mathematics Coordinator, one of my roles is to consider if this is appropriate for pupils with PMLD. Daniels (2003) suggests that even though the NC is both unified and linear, it can be argued that it provides a context to develop the key skills. This is certainly the case within the plans I have monitored, where it became evident that the key skills are an integral part of the planning, teaching and learning. Davis (2001) supports this by stating that there is a close relationship between the NC and key skills. It is also pertinent to note that one of the key stage classes within the school has a mixed ability, where there is a need for subject content to be delivered, an issue discussed by Staves (2001). I believe the key to whether the Mathematics Curriculum is appropriate, is the identification of the learning that is involved within the subject, and that as Davis (2001) suggests, the learning does not remain in subject defined boundaries. Through discussions with other subject leaders, it became evident that the key skills and learning were, in fact, cross-curricular and that the Mathematics Curriculum was an integral part of subjects like Home Economics and Art and Design.

I believe it is a fundamental necessity to consider the pupil holistically when considering learning needs and to achieve this it is essential to include therapeutic targets. What became evident is that the multi-disciplinary team was not involved in the continuous development of the curriculum. It can be argued that if the key skills taught within Mathematics are going to transcend across a holistic curriculum, therapists need to be involved. As Lacey (1998) points out, no one person can provide for the learning needs of these highly complex pupils. However, the development of provision maps that Huggett (2007) suggests is one way to meet the learning needs of the pupils. He suggests they empower all staff to meet the needs of pupils.

Within the school, there is an emphasis on the pupils' interaction and exploration of quantity, their environment and the people within it. Even though Mathematics is taught through the context of the mathematics curriculum, the teaching is not a checklist of behaviours that the pupils needed to fulfil. I feel that this interaction with their environment is necessary for all learners, an idea supported by Lacey (2007). She suggests that it is essential to "start where the learner is and not where you think s/he should be" (Lacey, 2007, p.10). Willis (1993) suggests that, even though pupils may be able to learn behaviours, it does not necessarily mean that they understand it or can apply it to other situations. For example, Harry (pseudonym) is able to squeeze held up fingers one at a time while the teacher counted, but this does not mean he can count or understand the concept of number or quantity. He does it in anticipation of the clapped hands on five, something he has learnt to expect when this stimulus occurs. This style of teaching and learning supports the interactive learning theories, Marvin (1998). However, the NC supports the behaviourist learning theory, where learning is the acquisition of bits of knowledge that are tightly structured in a hierarchical sequence in which mastery of one objective leads to the next (Shepard, 2000). This disparity between curriculum and teaching style, I believe, is overcome by the recognition and inclusion of the therapeutic targets. I think this is essential, as it is evidence that the school recognises the need for a broader curriculum that incorporates the developmental curriculum, national curriculum and additional curriculum described by Ouvry (1991).

The Department for Education and Skills (DfES) (2007) outlines that learning opportunities need to provide an optimum learning environment to enable the pupil to fulfil their full potential. Because of the complexity of the pupils' needs, this cannot be achieved without adult support. The Learning Support Workers (LSW) have a vital role within the learning of the lesson. The LSWs are able to scaffold the pupils' experiences. Without the assistance of the LSWs, the pupils would not have access to the learning opportunity, and the amount of support the pupils need changes as they slide along the continuum from passive to active. This supports the idea that for pupils with PMLD learning is not a discrete entity. Vygotsky's 'Zone of Proximal Development' describes the difference between what a learner can do with assistance and what they can do independently, with the emphasis on the interaction between the pupil and the support (Shepard, 2000, Daniels, 2003). This interaction gives vital clues as to where the learner can learn (Qualification and Curriculum Group, 2006; Shepard, 2000).

I agree with this form of learning experience for pupils with PMLD, as it results in the pupils' active participation and presents a more child-orientated learning. However, there is a need for the teacher to constantly monitor the LSWs' support of the pupils, giving verbal feedback and practical advice. Support is carefully planned so that the LSWs are clear about the purpose of the activities. The constant feedback and support that the teacher provides to the LSWs avoids the teacher losing responsibility of the management of the pupils' needs, a danger Rose (1998) describes. There needs to be a responsive environment to support the interactive philosophy previously mentioned. Davis (2001) points out that this is where adults are encouraged to follow the pupils' lead. Within the lessons, the pupils are also provided with constant and immediate feedback through verbal and non-verbal feedback, such as touch, facial expression and body language. The Qualification and Curriculum Group (2006) suggest that this is one way of overcoming the pupils' 'learned helplessness'. This is supported by Ware (2003), who suggests that a responsive environment promotes quicker learning for pupils with PMLD.

As Davis (2001) suggests, there is a need for the environment to be calm and unrushed. Within the school, extra time is allocated for the pupils to be approached in a holistic manner, making sure they are comfortable and cued into the Mathematics lesson with an object of reference and an opening song (sung at the beginning of every lesson). This gentle start to the lesson, however, contradicts the emphasis on pace that the national strategies, such as the National Numeracy Strategy state, Davis (2001). A sense of rushing can have an adverse effect on pupils who may need time to assimilate their surroundings and changes that occur in their environment. It may result in what the Qualification and Curriculum Group (2006) call an overload of the pupils' senses. This will cause a sense of stress. Stress can have a detrimental effect on the sense of well-being. A sense of well-being and success is an essential need when considering learning. However, with pupils with PMLD, success in the form of hierarchical cognitive achievement is not always achievable. I would argue that there are many forms of success, and academic achievement is only one of them. An example of this is, as Sanderson et al (1991, p. 12) states, "A person who trusts, feels safe and reassured will learn more readily…". An example of this became apparent within a lesson observation where it was evident that Sarah (pseudonym) has a trusting relationship with the LSW she was working with, and demonstrated an acceptance of the LSW's proximity, her use of coactive touch and Sarah's own reactive touch. This is such a vital achievement.

It has become evident from the evaluation that there are examples of good practice occurring within the school. The individual needs of pupils within Mathematics lessons are being addressed through interactive sessions where the pupils are encouraged to respond. The pupils' responses lead the sessions, and through flexibility the pupils share the control. This supports the interactive teaching style which focuses more on the process of learning and not the set criteria of success. The pupils experience the opportunity to learn that their reactions can have as much of an effect on the adults as the adults have on them. The support and responses of the adults enables access to the learning experience and provides a scaffold of support within an environment that is led by the pupils and their needs. The teaching of Mathematics is addressed through a holistic approach with therapy targets being included.

Mathematics with Harry

Harry (pseudonym) has profound and multiple learning difficulties. He is an active member of the mathematics lessons that are tailored to his individual needs. This is achieved through incorporating therapeutic targets that help develop his cognition and his communication. At the start of the lesson Harry is clued into the lesson using an object of reference and a counting activity that he recognizes. This gentle start gives him time to anticipate what is next and allows him to lead the familiar activity. He is encouraged to give eye contact, be reactive in his touch, take turns and to respond to the adult support he works with. This adult is someone who has developed a good relationship, the LSW or teachers in his class, and is someone Harry feels ‘safe’ with. This is evident by his willingness to have this person within his physical proximity and that through this consistent approach to the beginning of the lesson he is beginning to respond to the familiar voice of his support.

The main activity is centred on his response to a stimulus. This stimulus is presented through a mathematical context, such as quantity or shape. However it is Harry’s response to this stimulus that is the main focus of the lesson. Is it consistent, showing likes or dislikes, how is he interacting with the stimulus or support worker? What is vital is that it is Harry that shares the control and his responses that lead the session. When he shows pleasure at a stimulus it may be removed for a moment, moved to encourage him to visually track the object or moved slightly out of reach to encourage him to reach out for it. His support worker constantly gives him feedback through interacting with him using verbal and non verbal communication strategies. He shares the control of the session and through a flexible approach the support worker reacts to the response Harry makes. These responses are recorded on a response sheet and photographic or video evidence is recorded. The Routes for Learning Route Map is used to plan learning opportunities that will encourage and develop responses and interactions. At the end of the lesson the support worker thanks Harry, smiles and stills, cueing Harry into the end of the lesson.

Involvement of Parents

Even though the parents are encouraged to take an interest in the teaching of Mathematics, their contribution is not as valued as I believe is necessary. It was evident that no homework was set and the only contribution and information the parents gain about the teaching of Mathematics was the Individual Education Plan they receive once a term. There is also a need for the parents to be considered as experts where their children are involved. This idea is supported by Brodin (2005) who places the emphasis on the interaction between parents, professionals and the child. She suggests that parents are the real experts. The involvement of the parents supports a holistic approach which contributes to the child’s self confidence and well-being, as previously mentioned.

The main issue that I feel needs to be addressed within the school is the collaboration and involvement of parents that is needed to provide a holistic approach to the individual needs of pupils. Expertise such as that of the therapists needs to be included in the planning and implementation of the mathematics curriculum. This can be achieved through INSET, multidisciplinary ‘mathematics’ meetings and parent workshops. The involvement of the senior management team will therefore be necessary to negotiate the logistics, such as the provision of time to meet.

The development of parent workshops will also provide the opportunity for the interaction between the school staff and the parents as previously discussed. This is very pertinent, as the Mathematics Curriculum will change due to the development of the new 14-19 Curriculum due to be implemented by 2010. The parents need to be actively involved in the development of their child’s progression pathway. These progression pathways will provide a flexible curriculum that will be tailored to the individual and will therefore enhance the provision of learning needs within Mathematics.

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

The Primary Curriculum Review

Rob Ashdown

As Head Teacher of a primary special school I have been waiting with a degree of keenness for the final report from Sir Jim's Rose's review of the primary curriculum. As Sir Jim Rose notes in his introduction many people in primary schools in England looked to this review to reduce prescription and curriculum overload so that they can serve the needs of children even better. Also, as Head Teacher of a special school, I was looking for a framework that would fit the arrangements that are in place for teaching what are widely regarded in special education as key skills and knowledge for pupils with significant developmental delays. The report was published in March, titled as the *Independent Review of the Primary Curriculum* (ref: 00499-2009DOM-EN) and you can order a copy by phone (tel: 0845 60 222 60) or you can download the document or order copies online (at www.teachernet.gov.uk/publications ; or at www. dcsf.gov.uk/ primarycurriculumreview).

Sadly, readers will struggle to find more than a passing reference to the curricular needs and provision for pupils with special educational needs and nothing at all about the pupils in special schools or indeed about special schools. This should not be too surprising given the past history of the advent of the National Curriculum and subsequent curriculum review reports in the past 20 years. Also, there was no specific focus upon these pupils in the remit letter of Ed Balls MP, the Secretary of State. Therefore, readers will have to search in the report for statements about the education of all primary school pupils that offers inspiration for the evolution of a curriculum that makes more sense to parents and helps people working with pupils with PMLD.

There are some key features of the primary curriculum model put forward by this review. There is an emphasis upon the continuing importance of subjects and the essential knowledge, skills and understanding they represent. This is rather disappointing because many parents and many teachers in many special schools still consider it a nonsense to try to meet children's needs through the discrete teaching of subjects. So it is good that the report does recognise that cross-curricular activities strengthen learning in the subjects which make up their content. Furthermore, it states that from the standpoint of 'young learners', making links between subjects enriches and enlivens them. So there is a welcome message here that there are times when it is right to have well-planned, cross-curricular studies that integrate the content from different subjects.

The report recommends that the primary curriculum should be organised into the following six areas of learning:

1. Understanding English, communication and languages
2. Mathematical understanding
3. Scientific and technological understanding
4. Historical, geographical and social understanding
5. Understanding physical development, health and wellbeing
6. Understanding the arts.

The proposed areas of learning are not intended to be rigid structures, and the report emphasises that schools should continue to have the flexibility to organise learning in a variety of ways. This model for curriculum design is intended to build on the Early Years Foundation Stage (EYFS) curriculum which also has six similar areas for learning. However, there are differences from the EYFS curriculum because the primary curriculum is also intended to secure children's introduction to the principal subject disciplines and prepare them for specialist study at the mainstream secondary school. The six areas of learning have at their heart the essential knowledge, understanding and skills that primary school children need in order to make progress and achieve.

Also, available for consultation are draft programmes of learning (www. dcsf.gov.uk/ primarycurriculumreview) which are supposed to show how the curriculum should broaden and deepen as children's capabilities grow between the ages of 5 to 11 years. They represent a national entitlement. Following the recommendations in the report, these programmes aim to show curriculum progression through 'early, middle and later' primary education. They are available as downloadable documents. Again, teachers will have to make modifications to these to make them relevant to children with severe developmental delays even as regards the content of the 'early' phase.

The report recommends that literacy, numeracy and information and communications technology (ICT) should form the new core of the primary curriculum and that schools should continue to prioritise these as the foundational knowledge, skills and understanding of the primary curriculum. Specific requirements for ICT are set out in each area of learning and ICT now becomes a core subject. Helpfully, personal development is included in this core curriculum. Personal development together with literacy, numeracy and ICT are seen as the ‘essentials for learning and life’ but the report focuses upon personal and emotional skills that enable children to develop self-discipline, take responsibility for their own learning, and recognise their feelings and the feelings of others. There is not the focus on the key personal and emotional elements that is necessary for pupils with significant developmental delays. Similar things may be said about the identified social skills for working and interacting with others, although the some of the language is rather more friendly. The report talks, for instance, about the importance of children learning how to adapt their behaviour to suit different situations and take turns and share as appropriate. But the emphasis is still upon the needs of ‘average learners’ at the primary phase. It suggests that schools could use programmes such as the Social and Emotional Aspects of Learning (SEAL) which teach children to state appropriately their own views and needs; to negotiate, respecting others’ rights and responsibilities; to use strategies to resolve disputes and conflicts; and to give constructive support and feedback to benefit others. Such programmes really require much modification and have relevance in special schools mainly only for pupils with relatively good language skills and moderate learning difficulties.

Regrettably, the report endorses the notion of an entitlement for all primary school children to learn a modern foreign language. This is not surprising since a large proportion of primary schools are already offering a language well ahead of it becoming compulsory to do so. The teaching and learning of languages in primary school is enjoyed by children and seen as beneficial for all sorts of reasons by many teachers. But what relevance can foreign languages have for children with profound and multiple learning difficulties? How may this entitlement be delivered in a way that is meaningful and appropriate?

Disappointingly, Sir Jim Rose was not given a remit to consider changes to the current assessment and testing regime. The report does make the point that the current accountability arrangements are in urgent need of reform but only makes recommendations about minor changes to the wording of some level descriptors for Levels 1–3. It says nothing about the so-called P-scales. Currently, schools are expecting (some may not be aware that its coming) imminent guidance on pace and progression vertically, as opposed to horizontally, within the P-scales. There are draft Ofsted papers suggesting idealised rates of progression for pupils from different starting points on the P-scales. It is not yet known precisely what the content of the guidance will be but there are concerns about notions that rates of progress vertically through the P-levels can be described as poor, satisfactory, good or outstanding. Given the real limitations of the P-scales, it seems that an accountability edifice is being built on very shaky foundations. Teachers await with trepidation the outcomes from the experts on assessment and testing that have been tasked to consider and report on these issues.

So the proposals for the new primary curriculum cannot do much to enthuse teachers in special schools. The new framework offers some flexibilities but hardly provides a model for special school curricula. However, the independent review report does stress that a great deal of the curriculum related activities remain within the control of schools. These include:

- teaching methods and pedagogy;
- teaching content additional to the statutory National Curriculum;
- how the curriculum is organised and described, for example as subjects, topics or themes;
- the distribution of the curriculum across each key stage;
- the daily timetable, i.e. start and finish times of the day, breaks and lunch times;
- the teaching hours per week (providing that they are at, or above, the recommended minimum);
- the time allocated to each subject and the length of each lesson;
- the organisation of teaching groups, for example by age, ability or otherwise;
- the resources for learning;
- assessment for learning, and assessments and tests other than for national reporting.

As Head Teacher of a special school, I do recognise that these flexibilities exist. What concerns me is how to make sure that school policy and school programmes of learning meet the expectations of all stakeholders as well as the local authority advisers and Ofsted inspectors who will visit the school. So the report has done really very little to make my life easier, I feel. Of course, there are plenty of models and job aids for organising the school curriculum and assessing pupils’ progress. Certainly, the report’s exposition of the six areas of learning is helpful as a start for curriculum development and for reporting to parents. But overall, the report has done little for special schools.

As a footnote, it is worth commenting that there are far more helpful documents around about the curriculum and assessment, not least of which are the various schemes of work and the framework for key skills produced by the EQUALS groups (www.equals.co.uk). There is a huge array of books providing curriculum guidance from various publishers. In February, a revised set of the rainbow pack of subject-focussed booklets called *Planning, Teaching And Assessing The Curriculum For Pupils With Learning Difficulties* was published by the Qualifications and Curriculum Authority (QCA). The QCA in 2009 also reissued the P-Scales with an accompanying booklet about best practice, *Using the P-scales*, and a DVD with case studies of individual pupils. (For the QCA orderline tel: 08700 60 60 15).

The proposals in the report are subject to a 12-week public consultation period which has almost ended. The new primary curriculum will be introduced in September 2011. Between now and September 2011, schools will need a significant amount of guidance and support to aid planning. There will be an additional teacher training day for the summer term of 2010 and the DCSF has provided an online facility through the QCA for primary schools and other stakeholders to aid implementation of the new primary curriculum (www.qca.org.uk/qca_22256.aspx). For now, all teachers are encouraged to explore the website, the report and the draft programmes of learning.

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Future Focus: Health Care Issues

Loretto Lambe

The next issue of PMLD Link will focus on health care. We have in the past covered this topic but, as achieving a good quality of health care is so important to people with profound and multiple learning disabilities it is inevitable and indeed vital that we return to this topic again and again.

The health care needs of people with learning disabilities have come increasingly into focus through both policy statements[1] and research[2]. For many individuals the conditions that lead to high levels of healthcare needs are multiple and complex[3]. This is nowhere more so than for those with profound and multiple learning disabilities. People with profound and multiple learning disabilities typically have serious neurological damage resulting from trauma or genetic causation leading to two-thirds having epilepsy and severe physical disability, principally cerebral palsy, with resulting postural problems such as contractures and scoliosis, as well as extremely limited movement. Respiratory problems are also a central concern as they are the single largest cause of mortality for this group. A further challenge to carers and health professionals is difficulty in eating and swallowing, i.e. dysphagia, leading to nutritional difficulties for people with profound and multiple learning disabilities and resulting in their being significantly underweight.

How to respond to this multiplicity of healthcare needs poses great challenges to family carers, front-line staff and health care professionals. There is little or no training provided for family carers on how to deal effectively with these very complex health issues. However, it is not all doom and gloom and there is plenty of evidence to show that family carers cope extremely well in caring for a daughter or son with complex health care needs on a day to day basis. There are also many innovatory initiatives run by the voluntary sector on the topic of complex health care, health improvement, mental and emotional well-being that we need to share with others.

We would welcome contributions on specific areas of health such as those I have noted above and would particularly welcome hearing from family carers your experiences, both good and bad, and from those of you involved in projects and initiatives that contribute to improved health for people with PMLD. Please send your contributions to Loretto Lambe:l.lambe@dundee.ac.uk or Ann Fergusson:ann.fergusson@northampton.ac.uk by 6th November 2009.

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Research

Update on Inclusive Libraries Project

Penny Lacey

This is a short update on the Inclusive Libraries project being undertaken by The University of Birmingham, in collaboration with BILD.

The aims of the Inclusive Libraries project are:

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

There are two main stages to this project: the first stage mainly comprises a survey of local authority library services in the Midlands area in search of good examples of current practice. This is being carried out through telephone interviews and we are going to follow some of these with a visit to some services to interview librarians face-to-face and look at some of the resources and technology available in the library or for lending.

The second stage is being driven by action research and covers four distinct strands. There are cyclical trial and evaluation of:

1. the selection, management and lending of inclusive resources
2. inclusive literacy activities within a library context
3. training for library staff
4. dissemination materials, such as a DVD and booklet

We have completed the bulk of the telephone interviews and are beginning to put together what is happening currently in local authorities and individual libraries. We can already see that there is a wide range of practice from libraries who have yet to provide any services or resources for people with SLD/ PMLD through to those who developed particular expertise or played hosts to activities such as story telling. A good number of libraries have at least some resources, eg: easy access information books or Bag Books.

We have also been working with Birmingham Central Library and one of the community libraries to work out what resources they want to purchase with the project money. We have thought about the following:

- Easy access information leaflets
- Simple fiction and non-fiction
- Simple talking books
- Dedicated computer with switch/touch screen access
- Computer software for SLD/PMLD
- Sensory stories eg: Bag Books
- Multimedia hardware eg: cameras

We have also discussed possible projects that might be led by librarians eg:

- Story telling & drama sessions
- Making life story books or special interest books
- Compiling photo albums
- Making videos, Photo Stories & PowerPoint presentations

Some discussions featured around trying to build up a volunteer force to make resources for sensory stories and perhaps facilitate visits to the library by people with SLD/ PMLD.

We have organised the training for the libraries, which will be provided by Openstorytellers (the new name for the Unlimited Company) and in my next report, I can tell you about that.

Finally, we have met (or have plans to meet) with our various advisers:

University colleagues
BILD
Our Way Advocacy

and they will keep us on task and help us to think of every angle of the project.

We are in the third month of the 12 month project and so far, we seem to be keeping to our work plan! Do let us know if you have come across some good practice in your local library. We would like to know about it.

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PMLD Network Email Forum A Digest of Discussions April – July 09

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

1. Blowing raspberries and spitting

A teacher said they have a 10 year old pre-verbal pupil who enjoys playing with his own saliva with his fingers, blowing raspberries and spitting. They asked for advice as it is beginning to distance him from others.

Responses included:
Someone said they knew a child who did this and what he was communicating was that the person was getting to close and scaring him. He had a visual impairment and what he was doing was controlling his environment and how close people got to him. They realised they weren't giving him good notice of when they were going in to his space. His way of getting control and stopping them was by spitting and blowing raspberries. Changing the way they supported him made a difference although it didn't completely change the way he communicated at times.

Someone else said they worked with a young man with a similar interest. They introduced blowing bubbles instead. They showed him how to make them using washing up liquid. After a while, this worked and the situation is now much improved although it was a little problematic in terms of sometimes distracting others.

Someone else said that saliva is a great thing to play with when there is little else you can control. They said the pupil had probably had years of practising with it and was likely to be pretty skilled at it. It is always available to play with when he needs an occupation that is meaningful to him. It is also predictable and consistent. They suggested the person gives intensive interaction a go – and joins in with some of the pupil's behaviours in a gentle accepting way and see if, in his own time, he extends his interest to twiddling with simple objects that are readily available rather than saliva. See www.intensiveinteraction.co.uk

Someone asked if it is sensory driven. They suggested substituting the sensation. For example, with cornflour and water, shaving foam, different textured handhelds, water/sand play, or mini vibrating massagers. They said if that is too distracting within the class, it could be run from a schedule in a designated place.
Someone suggested getting an occupational therapist involved. They said his behaviours sound like he might have sensory processing difficulties. An occupational therapist would be able to advise further following a sensory processing assessment.

2. The Care Quality Commission was seeking people's views

The new regulator, the Care Quality Commission, said they were seeking people's views on 2 things:

1. Their 5 year strategy ie. their corporate plan – what are the most crucial areas that the regulator must focus on?

2. Their learning disability plan which will feed into the 5 year plan – what should the regulator do to make a real difference to the lives of people with learning disabilities and family carers? What would the top 3 things to change be for people with learning disabilities and family carers that the CQC could make an impact on?

They included some easy read information about CQC and their enforcement powers to make it clear what they do:
CQC Enforcement Policy ERS www.choiceforum.org/docs/cqcpol.pdf
Manifesto easy read www.choiceforum.org/docs/cqcman.pdf

Responses included:
Someone said they are concerned about adults with learning disabilities who live in residential care or supported living where there is a bulk contract with the LA in place. They said they have seen little evidence of a person centred lifestyle being possible under this type of regime. They have heard about Individual Service Funds (ISFs) whereby people or their advocates become customers rather than passive recipients. They would like the CQC to look at how widespread this is and how best to make it work to the advantage of the new 'customers'. For more information about ISFs see: www.in-control.org.uk/site/INCO/Templates/Library.aspx?pageid=413&cc=GB)

Someone wanted a way of accessing a list of all day provisions for adults with PMLD. They also asked what inspections are carried out to inform clients of the level of care provided at day centres.

Someone asked if the speed of enhanced CRB checks could be improved as potential employees are losing interest before starting work due to the long waiting time.

Someone said they need to distinguish more between residential care and supported living. They said it can be difficult to shake off a residential care mindset. Their son who has PMLD is moving into a supported living environment. They are quite determined to see that a person centred lifestyle becomes a reality. They said they have had to make sure staff are not in uniform and do not display ID cards conspicuously when they are out. Other issues included a debate about the requirement for visitors to the flat needing to sign in (they said 'do your visitors to your home sign in?). They said they want security for their child but that there are other ways to achieve this.

'Keep the bureaucracy to a minimum please! Standards are written which are so prescriptive that ridiculous decisions occur when a situation which is not anticipated in the standards crops up'.

Someone else said that moving into supported living as opposed to residential care has many advantages although the lessening of regulation is not necessarily a good thing.

Someone said they feel regulation is 'more designed to protect the employers of care workers when things go wrong rather than to protect the interests of our children'.

Someone said that their wife is medically qualified and has trained, observed, and assessed their son's carers for giving medicine via his PEG and that they are happy to do this now in their home. But because their employer has not got round to "signing them off" (due to staff being on holiday) they have been told they cannot give him his medicine when on a trip out. This is because they are fearful of breaching CQC rules. So his son has to wait 3 or 4 hours (for when they come back home) for his medicine which he should have at lunchtime. He said 'I feel as though the rights of my son have been trampled on'.

3. PMLD Voice

Someone asked if anyone had a school council in a PMLD school or students with PMLD on their school council. Or a similar idea in further education or adult services. They wanted to know how to have meetings that students with PMLD will understand.

Responses included:
Someone replied that they don't know of anything specifically on school councils but mentioned that there is quite a bit of work being done on involving people with PMLD in decision making, which might be helpful. They said Mencap and BILD are doing a project called 'Involve Me' that should give lots of ideas when it is done: www.mencap.org.uk/page.asp?id=2361. They also said BILD has a really good book called 'A Voice of Their Own' which they may find useful:
www.bild.org.uk/03books_pca.htm#A_Voice_of_Their_Own

Someone said that they have been involved in client councils for a wide range of abilities. They said that when they suggested including less able service users many staff failed to see why they should, stating that 'the group in question would not be able to participate'! They said that the group who were eventually involved may not have understood the content of the discussion at all times but, from that from the feedback they got from support workers they certainly appeared to enjoy being at the meetings and some were able to communicate some opinions. Where possible, objects of reference were used to help aid understanding of the discussion. (e.g. if discussing an art group paintbrushes were used). 'I don't believe it is possible to make such groups fully accessible to all but I know we have to do the best we can to reach out to and include as many of the people we work with as possible.'

Someone suggested that the person with PMLD on a school council may need an advocate. They said they could see how this would mean their views and the views of students with similar needs were represented.

Similarly, someone said they might need a 'PMLD champion' to remind everyone of the needs of those with PMLD.

Someone had heard a suggestion that Partnership Boards could have a cardboard cut-out of a PMLD person in the room so they don't forget to include the needs of that group. Or the PMLD champion could have a photo of some of the PMLD students in front of them to remind them that they are representing the views of that group. 'Try things and report back'.

4. Valuing People Now for people who have PMLD

An advocacy worker said they were looking at Valuing People Now and how it affects people with PMLD in Somerset. They will spend time observing people in different settings and talking to families, carers and centre staff to gain some insight into how the VPN topics affect and relate to people PMLD. They asked people to share any work they know of that will aid this work.

Responses included:
'The work we do at Frameworks 4 Change is around

the power shift that is often still required to create 'Togetherness' in the lives of all people with learning disabilities including those with the most complex needs. Find out more at: www.frameworks4change.co.uk'

Someone mentioned the Active Support Project they are delivering in Wales. They said that Active Support is 'a proven model of support that supports people with learning disabilities to plan the best use of their time, with the correct level of support, to engage or participate in all activities that make up day-to-day living. For further information and resources go to the ARC Wales website: www.arcuk.org.uk/wales/999095/en/active+support.html

'Mencap is working in partnership with BILD on the Involve Me project which aims to increase the involvement of people with PMLD in decision making processes. We are using 4 different ways to capture the views and preferences of people with PMLD on four sites across the country. Staff at each of the sites will receive training and on going support to help them develop their skills communicating with people with PMLD. We will be working with learning disability partnership boards in each of the four areas to find the best way to ensure people with PMLD can influence decision and policy making. Next year we will be producing training resources which we hope enable supporters and policy makers to think differently about how they involve people with PMLD and ideas of the practical things that need to happen. We will be doing regular updates in the meantime - if you wish to know more please email: involveme@mencap.org.uk'

5. User friendly end of life plans

Someone asked for a good end of life plan document that is user friendly for both young adults and children. They wanted something that is in pictorial format as well as adaptable to the service users.

Responses included:
Someone asked if they had seen the ACT Care Pathway for children with life threatening or life limiting conditions. Copies can be obtained through ACT: www.act.org.uk . They said there is also a companion guide for families which is gently written, jargon free and family centred. They said there is a section on developing an end of life plan.

Someone said they work with young people with very profound learning disabilities and complex health needs often with life limiting conditions. They have developed an end of life plan for use by parents/relatives/significant others. It is a practical format that identifies the wishes of the families in the event of the death of their loved one. The needs of often aging parents are so often overlooked and we as a team felt it was right to try and meet those needs.

Someone said they didn't know of any comprehensive end of life plan documents that are accessible to people with learning disabilities but that there are some quite basic forms in pictorial format that have been used for this purpose. They said 'When I Die', which is really about after-death planning rather than end of life care, is available from www.easyhealth.org.uk/death.aspx

6. Defining a Hospital Standard of Care

Someone said they had been pursuing a legal complaint about the standard of care that their daughter had received from our Health Authority. Their solicitor had asked the consultant physician for his comments. He said that a 'reasonable standard of care' was given even though he contradicted this statement in specific instances by agreeing that a particular emergency requires certain action within a defined and very short time frame.

In discussing these inconsistencies with their solicitor, she explained that a 'reasonable' standard of care is actually defined by the question of whether other hospitals would or would not give that care in that time frame. They asked if others were surprised by the way that a standard is defined or if there are other ways of thinking.

Responses included:
Someone suggested that a step forward would be to contact your local 'Local Involvement Network' (LINk). With Government money, it is an independent group, with a staffed host organisation, to give a stronger, effective voice about both your health and social care. Find out more at: www.direct.gov.uk/en/HealthAndWellBeing/HealthServices/PractitionersAndServices/DG_071867

Someone said that 'another way of thinking about this is that the hospital is required to make reasonable adjustments for your daughter under the Disability Discrimination Act. It is our view that when deciding if the actions of health professionals have fallen within a reasonable range of practice the question about what reasonable adjustments were made should be central. Having supported a number of families through all stages of the complaints process we are however aware that this is not necessarily the standard by which they are judged. At Mencap, we will be continuing to campaign on this issue'.

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

NEWS

Learning Disability Week: Strong Support for Changing Places

New research shows that there is a huge unmet demand for fully accessible toilets

New research published by Mencap in June showed that across the UK, 230,252 people need Changing Places toilets, yet there are only 85 available.

In Learning Disability Week, Mencap and the Changing Places Consortium called for Changing Places toilets to be compulsory in all big public places.

Standard accessible toilets do not meet the needs of many people, including people with profound and multiple learning disabilities, who need Changing Places toilets – with a hoist, changing bench and plenty of space.

Without Changing Places toilets, people are forced to stay at home or change a family member on a dirty toilet floor.

Julie Marriott whose 11-year-old son Toby has profound and multiple learning disabilities, said: "I am racked with guilt every time I lie Toby down on a dirty toilet floor because I know I am risking his health. But I have no other option.We can’t stay at home all the time."

During the week a parliamentary reception was held in Westminster. The event was attended by more than 50 MPs along with Changing Places campaigners, people with profound and multiple learning disabilities and Paralympic gold medallist Dame Tanni Grey-Thomson.

Beverley Dawkins, Chair of the Changing Places Consortium, said, “This year’s Learning Disability Week has been a huge achievement. Campaigners from across the country have joined the fight for basic dignity for people who need Changing Places toilets. More than 70 awareness raising events have taken place, and with over 2000 people taking online action by writing to their MPs and local papers, and over 4000 signatures on our petition already, a big impact is being made.

And MPs are really listening - 51 MPs attended our parliamentary reception during the week, and the Minister responsible for planning has said that considering the inclusion of Changing Places toilets in the building regulations is a priority."

The Changing Places Consortium is calling for people to email their MP and ask them to push for Changing Places toilets to be compulsory in all big public places.

Email your MP at:
http://e-activist.com/ea-campaign/clientcampaign.do?ea.client.id=78&ea.campaign.id=3779

Success ALL the way for students with PMLD

Pictured: St Margaret's pupils Joann, Francies and Jack celebrate their success with staff and family members including Deputy Head Teacher Val Hobbs (green jacket) and Chair of the Governors Dr Mary Greenway (white cardigan)

St Margaret's School, one of the UK's only schools to cater exclusively for pupils with profound and multiple learning difficulties (PMLD) and complex health needs, celebrated the outstanding academic achievements of its students on 10th July.

Holding a special awards ceremony, the school congratulated 13 of its students on gaining certificates as part of the Accreditation for Life and Living (ALL) scheme certified by Oxford, Cambridge and RSA Examinations (OCR).

The students, all of whom have profound and multiple learning difficulties, gained certificates for modules covering a variety of areas including The Community, Creative Arts, Leisure, Personal Skills, Home Management and the World of Work. All students in St Margaret's Further Education classes have gained at least one certificate each this year - with one gaining an incredible six.

They were joined by 17 young adults from two residential homes run by Sussex Health Care who receive education from St Margaret's teachers as part of a special outreach programme. The scheme has been so successful it has expanded and is now run five days a week.

Combined the students gained over 60 certificates this year!

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

A highlight of the event was also the premier of a short film made by St Margaret's Further Education students called 'No Space Like Home' that was entered for this year's Oska Bright Film Festival which showcases pieces made by people with learning disabilities. Students were involved in the filming, props and sound effects for the piece which will be the first of many films they hope to make.

Jan Cunningham, St Margaret's School's Head Teacher, said: "I am thrilled with how much our students have achieved this year - they have worked incredibly hard as all of their certificates show. It's also a great testament to St Margaret's School and our teachers that we can be joined by so many young adults from Sussex Health Care. This is a very special day."

St Margaret's School is hosting a special one day conference for specialists working with children and young people with PMLD on 24 October. For more information visit:
www.thechildrenstrust.org.uk/pmldconference

Seeing Better Together: optometrists learning more about people with learning disabilities

There are well over a million people with some level of learning disability in the UK. People with learning disabilities are more likely to have eye problems, yet traditionally have problems accessing eye care. A new Continuing Education pack produced by Healthcall Optical Services in collaboration with SeeAbility and Replay Learning is aiming to make it easier for optometrists to offer the eye care that this group needs.

Co-author Maggie Woodhouse says, "The pack highlights the importance of eye examinations for people with learning disabilities, because they are at much higher risk of eye disorders. It also demonstrates how poor the access to eye examinations is at the moment for this vulnerable population."

Packed with handy and practical tips, the aim is for the pack to be read by every practitioner to ensure that they, and their staff, are fully prepared when a person with learning disabilities needs an examination. Simple ideas, like ensuring recommendations and outcomes from the examination are written down can make a great difference to the person, as all their carers can then understand about their visual needs.

The pack was sent out to every optometrist during Learning Disability Week in June.

Visit the Look Up website for more information about eye care and vision for people with learning disabilities: www.lookupinfo.org

The PMLD Network calls for partnership boards to include those with the most complex needs

The PMLD Network have launched a 'top tips' guide to encourage partnership boards to include people with profound and multiple learning disabilities.

The guide which includes tips for partnership boards on making sure the needs of people with profound and multiple learning disabilities are represented was launched at the PMLD Network Seminar 2009 on 8th June.

National Director for Learning disabilities, Anne Williams, and co-National Director Scott Watkin attended the event to discuss the implications of Valuing People Now for people with profound and multiple learning disabilities.

Beverley Dawkins, National Officer for people with profound and multiple learning disabilities at Mencap and Chair of the PMLD Network said: 'People with profound and multiple learning disabilities are among the most excluded and disadvantaged people in today's society. All too often their needs are ignored. We hope our top tips will help Partnership Boards ensure that they address the needs of people with profound and multiple learning disabilities in all aspects of their work.'

Download the top tips guide

www.mencap.org.uk/document.asp?id=10020&audGroup=&subjectLevel2=&subjectId=&sorter=1&origin=searchPhrase&pageType=&pageno=&searchPhrase=top

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Consultation on the future of care and support launched

The government has set out plans for creating a National Care Service for England in 'Shaping the Future of Care Together', a green paper published on 14 July. A consultation on the plans will run until 13 November and Mencap will consult widely within the learning disability community to shape its response.

Launching the paper, health minister Andy Burnham said: "We need a system that's fair, simple and affordable for everyone. A system that gives excellent care wherever we live and whatever our needs."

The paper sets out six key principles on which the National Care Service should be based:

Prevention services: Support to stop people's care and support needs getting worse.

National assessment: People will have their needs assessed in the same way, wherever they live. They will also have the right to the same proportion of their care and support costs being paid by the government.

A joined-up service: Social care, health and housing services and benefits working more smoothly together.

Information and advice: A straightforward system, with clear information available and help from advocates if appropriate.

Personalised care and support: A system 'that delivers true personalisation', building on the 'Putting People First' strategy.

Fair funding: 'High quality and cost-effective services'.

Mencap has welcomed the green paper and the government's commitment to a debate on social care. Mencap's chief executive, Mark Goldring, said: "We welcome the vision set out in the green paper. There are clearly elements that will improve the lives of all people who need support services and we are pleased to see a commitment from the government to a portable national assessment system."

Unanswered questions

The paper doesn't, however, address the need for additional learning disability funding. The Learning Disability Coalition, of which Mencap is a member, recently submitted evidence to the Treasury that learning disability services are under-funded by £200 million per year. Over 200 MPs have signed an Early Day Motion (EDM) to plug this funding gap.

'Shaping the Future of Care Together' sets out three possible options for funding, but all focus on care for people over 65. The government says that most disabled people will not be affected, as those on low incomes currently have their care and support entirely funded by the state and 'We envisage that this would continue'. It doesn't address whether things will improve for people with a learning disability who aren't currently getting support.

Mark Goldring said: "It is highly disappointing that the government has failed to provide clearer guidance on how it will provide better services for a growing population of people with a learning disability. Many people with a learning disability are not getting the support they need and better assessment and portability are not enough without the money to respond to people's needs.

"We have asked the government to publish further guidance on what the green paper means for working age adults with a disability. We look forward to seeing this and continuing the debate about social care."

Support the Learning Disability Coalition

The Foundation for Learning Disabilities provides staff training, consultancy on service improvement, and undertakes research into policy and practice development in all areas related to people with learning disabilities. For more information please see http://www.learningdisabilities.org.uk/our-work/

The Foundation for People with Learning Disabilities is a member of the Learning Disability Coalition, a group of 15 organisations fighting to get better funding for services for people with learning disabilities.

The Coalition would like organisations in the sector to sign up as supporters.

Supporter organisations will be kept informed of the latest news about the campaign and what you can do to help.

By becoming a supporter organisation of the Coalition you would also be helping the Coalition to present its case to the Government - the more organisations it can show are standing behind it, the more likely it is that the Government will listen to its case!

If your organisation would like to support the Coalition, please email:
Oliver Chantler
o.chantler@learningdisabilitycoalition.org.uk

For more information see the Coalition's website - www.learningdisabilitycoalition.org.uk

To join, unsubscribe from, or to find out more information about this forum or network please e-mail forum_facilitator@ldforums.org

NEW PUBLICATION

Title: Special Educational Needs, Inclusion and Diversity—Second Edition

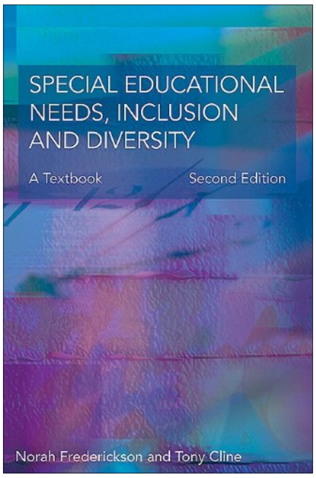
Authors: Norah Frederickson and Tony Cline

Publishers: McGraw Hill. Open University Press

Pub date: 2009

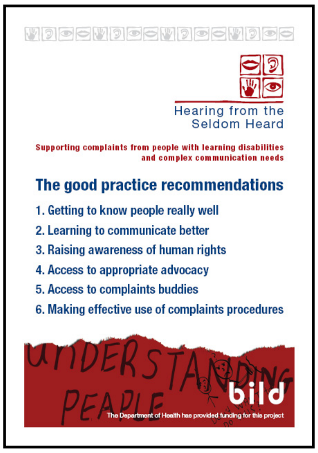
Price: £30.00

Analyses the impact on children with special educational needs of legislation, guidance and other initiatives in education, including curricular, organisational and structural initiatives. This title covers subjects such as dyspraxia, the contribution of neuroscience, and our understanding of SEN.



RESOURCES

Hearing from the Seldom Heard


Hearing from the
Seldom Heard

Supporting complaints from people with learning disabilities
and complex communication needs

The good practice recommendations

1. Getting to know people really well
2. Learning to communicate better
3. Raising awareness of human rights
4. Access to appropriate advocacy
5. Access to complaints buddies
6. Making effective use of complaints procedures

The Department of Health has provided funding for this project

People with learning disabilities face many barriers in being able to complain about the services they receive. Nationally there is a drive to improve access to complaints procedures in both heath and social care through **'Making Experiences Count'** (**Department of Health 2007).** However people with profound and multiple learning disabilities and other complex communication needs are not going to be greatly helped simply by the production of an integrated complaints procedure or an 'accessible' complaints leaflet, however well designed. The **Hearing from the Seldom Heard project** which ran from April 2008 until March 2009 was funded by the Department of Health and undertaken by the British Institute of Learning Disabilities. It aimed to look at how to overcome barriers and create listening cultures within organizations to hear from those who are seldom heard. Six areas of good practice were identified

1. **Getting to know people really well**
2. **Better communication**
3. **Raising awareness of the human rights of people who are seldom heard**
4. **Improved access to advocacy**
5. **Ensuring everyone has their own complaints buddy**
6. **Effective complaints procedures**.

The project has resulted in a resource pack containing practice recommendations, resources and links to examples of innovative work. The pack contains information on each of the key areas identified by the project with examples of good practice, and perhaps most importantly real life stories about people's attempts to hear from people who are seldom heard. There are a limited number of hard copies of the CD Rom available from BILD (for a nominal charge of £3.50 to cover postage and packing) or you can download the information for free direct from the BILD website. http://www.bild.org.uk/humanrights_seldomheard.htm

British Institute of Learning Disabilities
Campion House, Green Street
Kidderminster, Worcs, DY10 1JL
http://www.bild.org.uk/

Any further queries contact
l.brooks@bild.org.uk

Sue Thurman, Project Manager

New transition guide for parents and carers

Leaving school and moving into adult life has challenges for everyone. As well as leaving school and perhaps going to college or training, young people will be making new friends, starting new relationships and maybe thinking about where they want to live. For people with a learning disability these changes can be even more complicated as the support they receive from health, social care, education and other agencies often changes too.

These changes can be difficult and confusing for parents and carers who may be given little or no assistance to help them understand and deal with this transition. Mencap has produced a guide that offers advice and information for parents and carers about the transition process - how to survive it and how to make successful and positive plans for the future.

Download the guide at www.mencap.org.uk/guides.asp?id=9989

REVIEWS

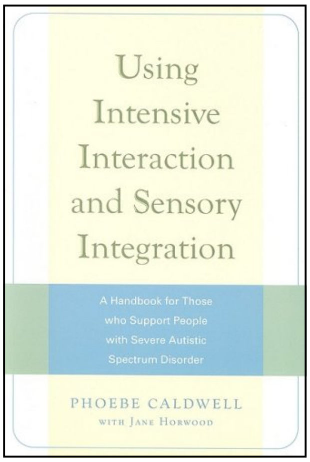
Title: Using Intensive Interaction and Sensory Integration – A Handbook for Those who Support People with Severe Autistic Spectrum Disorder

Authors: Phoebe Caldwood with Jane Horwood

Publishers: Jessica Kingsley Publishers

Pub date: 2009

Price: £12.99



This is slim book provides a guide, as the title suggests, to using two approaches with people who have severe Autistic Spectrum Disorders - namely Intensive Interaction, and Sensory Integration.

As someone who works with children who are autistic, but has made more use of Intensive Interaction with children with profound learning difficulties, I approached the book with a great deal of interest, and a desire to learn more about the different applications of techniques that I was already familiar with.

I was a little a disappointed – the book doesn't really explore any theoretical aspects connected with either Sensory Integration or Intensive Integration in any depth, but I would concede that this is not the intention of this book.

What the book does do, is present a series of suggestions, case examples, and a practical guide, for implementing the suggested approaches in practice – and as such will provide inspiration for parents and carers and other professionals. It is those parents and carers I feel, that are the primary audience for this book.

Phoebe Caldwell is a well known speaker on work of this kind, and presents her ideas here of how Autistic people undergo different sensory experiences to the rest of us, and examines the implications for practice that this presents. She discusses the sensory distortions, emotional overload, and "autonomic storm" that these different experiences can lead to if we do not respond to them in an "Autism Friendly" way, and gives practical examples of implementing Intensive Interaction – using body language to communicate with people on the autistic spectrum who are finding words and conversation so confusing that they may be exhibiting "distressed behaviour"

It's fair to say I think that some of the suggestions are open to question – I'm not convinced for example that it's necessarily advisable for a practitioner to engage in "head banging" or "self biting" in order to communicate effectively with a person. However there are certainly occasions where this might be appropriate.

In summary this is a very readable book, written in a style that will be accessible to a very wide range of people, and offering some very good ideas for interventions with people with autism. You certainly don't need to be a professional or academic, to benefit from reading this book.

It's also presented in an open way, and in a spirit of enquiry and discovering about individual needs in individual situations. As such I think it will prove an asset to anyone working closely with people with Autistic Spectrum Disorders – conditions which are still confusing and frustrating for many – and will help them to understand and communicate with those people in a far more personal way.

Stephen Smith

Stephen Smith is Headteacher of Jack Taylor School, a special school for children with Profound and Multiple Learning Difficulties, Severe Learning Difficulties and Autism, in Camden, London.

Web Review

www.disabledgear.com

This interesting website is a platform where you can buy and sell second hand disability equipment and will also soon be able to purchase new equipment too.

Equipment currently advertised covers everything from bathroom and bedroom equipment to vehicles, lifts and hoists, ramps, wheelchairs and exercise equipment.

All adverts are free to list and there is an impressive list of links too.

This site seems to be in its infancy and is also looking for ideas to develop. It is worth checking it out.

Di Foxwell

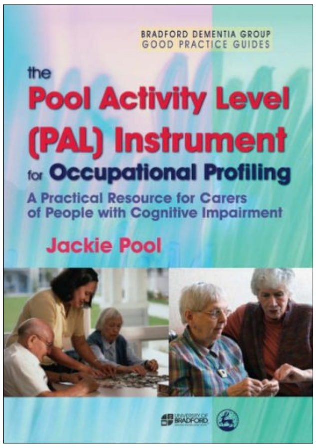
Title: The Pool Activity Level (PAL) Instrument for Occupational Profiling: A Practical Resource for Carers of People with Cognitive Impairment

Authors: Jackie Pool

Publishers: Jessica Kingsley Publishers

Pub date: 2008

Price: £25.00



Jackie Pool is an Occupational Therapist specialising in Dementia Care. She is an approved trainer for the Alzheimer's Society and has published several works on the care of the elderly with dementia.

Although the research for the PAL is based on those people who suffer with dementia, the highly adaptable nature of the tool means that it is applicable to people of all ages who have learning difficulties.

The book explains how the PAL can be used by carers to help those with cognitive impairments engage in meaningful activities. It explains how an understanding of which of the 4 Levels of activity, (Planned, Exploratory, Sensory, or Reflex) those with a cognitive impairment are able to function and will enable the carer to design activities which will prove successful, enjoyable and improve quality of life.

Chapter 1 provides a brief outline of the theoretical models, approaches and underlying principles that have been used in devising the instrument whereas Chapter 3 outlines the statistical analysis that has taken place on the assessment. The statistical evaluation and models of practise are clear, well written, and essential to the professional to critically evaluate the benefits of using the PAL.
It may be rather off putting to the carers of those with dementia for whom the book has been written. However, the remainder of Section 1 then gives good clear instructions on the completion of the PAL, illustrated by case histories. Permission to photocopy all the forms is included and the reader is left in little doubt of how to implement this instrument within the community, a care home or hospital setting.

Section 2 outlines various activities, giving many easy to implement suggestions for those at the Planned, Exploratory and Sensory levels of functioning. However the suggestions for the reflex level (and hardest level to find activities) are more limited.

Although designed for professionals and those involved in the care of dementia sufferers, the ideas outlined may also be of great benefit to those working with or caring for those with cognitive impairments of any age from school age upwards. I have found the PAL instrument very useful with both children and adults who have profound and multiple learning disabilities, although some of the activities/instruments do need to be adapted. I am also aware of another OT who intends to undertake a dissertation around the use of the PAL with adults who have profound and multiple learning disabilities.

The book provides a very easy to use guide to the PAL for both professionals and carers of those with Dementia and/or severe cognitive impairments and would be invaluable in any care setting where these conditions are prevalent.

Susan Rees
Independent Occupational Therapist

Short Courses and Conferences 2009

September

Date: 21st
Title: VITAL Convention 2009: Challenges, champions and children – developing expertise in complex needs and visual impairment
Location: Leicester
Provider: RNIB
Contact: See provider details

Date: 21st
Title: Health and Social Care for People with Learning Disabilities: the Forward Direction for Better Care
Location: RSM, London W1 0AE
Provider: Royal Society of Medicine Intellectual Disability Forum
Contact: Ruth Threadgold 02072903942
E-mail: intellectual.disability@rsm.ac.uk

Date: 24th & 25th
Title: Advanced Sensology Skills reinforcing good practice
Location: Chester Zoo
Provider: Florich Productions
Contact: See Provider Details

Date: 28th
Title: Sensology—A One day sensory journey
Location: Leeds
Provider: Florich Productions
Contact: See Provider Details

October

Date" 1st
Title: Seminar: Supporting the most vulnerable disabled young children and their families
Location: London, Friends Meeting House, Euston Road
Provider: Interconnections
Contact: Peter Limbrick
Tel: 01497 831550
e-mail – p.limbrick@virgin.net

Date: 9th
Title: Foetal Alcohol Spectrum Disorders: implications for practice
Location: Sunfield PDC
Provider: Sunfield PDC
Contact: See provider details

Date: 12th
Title: An Introduction to Autism
Location: Sunfield PDC
Provider: Sunfield PDC
Contact: See provider details

Date: 14th
Title: Sensory Play and Leisure in the Multi Sensory Environment
Location: Glasgow
Provider: Concept Training
Contact: See Provider Details

Date: 19th
Title: Sensology—A One day sensory journey
Location: London
Provider: Florich Productions
Contact: See Provider Details

Date: 19th
Title: Intensive Interaction
Location: Liverpool
Provider: Concept Training
Contact: See Provider Details

Date: 19th & 20th
Title: An Introduction to PMLD—2 day
Location: Sunfield PDC
Provider: Sunfield PDC
Contact: See Provider Details

Date: 21st
Title: Understanding and Managing Sensory Related Behaviour
Location: Sunfield, Clent
Provider: Sunfield PDC
Contact: See provider details

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/

Date: 24th
Title: Profound Education: a day conference centred on pupils with PMLD
Chaired by Flo Longhorn
Location: St. Margaret's School, Tadworth
Provider: St. Margaret's School Tadworth
Contact: Elaine Lush
Tel: 01737 365816
e-mail: stmargarets@thechildrenstrust.org.uk

November

Date: 4th
Title: Introduction to Signalong
Location: Sunfield PDC
Provider: Sunfield PDC
Contact: See provider details

Date: 6th
Title: Using Musical Interaction with Children and Young People with Autism
Location: Sunfield PDC
Provider: Sunfield PDC
Contact: See provider details

Date: 7th and 8th
Title: Conference: Profound and Multiple Learning Disability Seminar and workshop sessions
Location: Blackpool
Provider: Concept Training
Contact: See provider details

Date: 9th
Title: Intensive Interaction
Location: Sunfield PDC
Provider: Sunfield PDC
Contact: See provider details

Date: 9th & 10th
Title: Advanced Sensology Skills
reinforcing good practice
Location: Glasgow
Provider: Florich Productions
Contact: See Provider Details

Date: 7th & 8th
Title: Profound & Multiple Learning Disability Meaningful Activities to Support & Engage Children & Adults with PMLD
Location: The Imperial Hotel, Blackpool
Provider: Concept Training
Contact: See Provider Details

Date: 11th
Title: Vision and visual difficulties in children with downs syndrome and cerebral palsy
Location: Leeds
Provider: Action for Blind People
Contact: Rachel McHale
Tel: 0113 274 8855
e-mail: ActionYorksHumberandNorthEast@actionforblindpeople.org.uk

Date: 12th
Title: Aromatherapy and massage for children with complex needs: Part one – an introduction
Location: Liverpool
Provider: Action for Blind People
Contact: Sarah Crabb or Susan Atack
Tel: 0151 298 3222
e-mail: ActionNorthWest@actionforblindpeople.org.uk

Date: 14th
Title: Sensory Play and Leisure in the Multi - Sensory Environment
Location: London, The IBIS Hotel (Euston Station)
Provider: Concept Training
Contact: See Provider Details

Date: 16th
Title: Exploring the curriculum for learners with complex needs including MSI: an overview of 4 differing models of curriculum provision with an opportunity to examine a selection in more depth, highlighting the implications for practice.
Location: Leicester, Special Needs Teaching Service
Provider: University of Northampton
Contact: Sandra Cartwright
Tel: 0116 225 4800
Sandra.Cartwright@leicester.gov.uk

Providers Details

EQUALS

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

Sunfield PDC

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

Date: 17th
Title: Seminar: Just too many practitioners ….. for babies and children who need ongoing multiple interventions?
Location: Wakefield, Cedar Court Hotel
Provider: Interconnections
Contact: Peter Limbrick
Tel: o1497 831550
E-mail: p.limbrick@virgin.net

Date: 17th
Title: Sensory Play and Leisure in the Multi - Sensory Environment
Location: Birmingham
Provider: Concept Training
Contact: See Provider Details

Date: 18th
Title: Profound & Multiple Learning Disability - engaging children and learning
Location: London, The IBIS Hotel (Euston Station)
Provider: Concept Training
Contact: See Provider Details

Date: 24th
Title: An Introduction to Conductive Education
Location: Sunfield PDC
Provider: Sunfield PDC
Contact: See provider details

Date: 25th
Title: Learners who have multi-sensory impairment: the forgotten sense of balance and pressure
Location: Cardiff
Provider: RNIB
Contact: See provider details

Date: 26th
Title: Seminar: Just too many practitioners ….. for babies and children who need ongoing multiple interventions?
Location: Wakefield, Cedar Court Hotel
Provider: Interconnections
Contact: Peter Limbrick
Tel: o1497 831550
E-mail: p.limbrick@virgin.net

December

Date: 1st
Title: Aromatherapy and massage for children with complex needs: part two – developing good practice
Location: Liverpool
Provider: Action for Blind People
Contact: Sarah Crabb or Susan Atack
Tel: 0151 298 3222
e-mail: ActionNorthWest@actionforblindpeople.org.uk

Date: 3rd
Title: Communication and active learning for children and young people with a visual impairment and complex needs
Location: Liverpool
Provider: Action for Blind People
Contact: Sarah Crabb or Susan Atack
Tel: 0151 298 3222
email: as above

Date: 3rd December
Title: The place of new media in the education of people with intellectual disabilities
Location: London, RSM
Provider: Royal Society of Medicine Intellectual Disability Forum
Contact: Ruth Threadgold
tel: 0207 903 3942
e-mail: intellectual disability@rsm.ac.uk

Date: 3rd
Title: Music gets us going: learning through music for children with complex needs (including severe sight loss)
Location: Leeds
Provider: Action for Blind People
Contact: Rachel McHale
Tel: 0113 274 8855
e-mail: as above

Date: 7th and 8th
Title: Rebound Practitioner Course
Location: Sunfield PDC
Provider: Sunfield PDC
Contact: See provider details

Providers Details

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**

LONGER COURSES (with accreditation)

Updated July 2009

MA in Education
SLD1 & SLD2: Pupils with Severe and Profound and Multiple Learning Difficulties (Contexts & Understanding)
This module addresses the requirements of the Teacher Development Agency (TDA) National Special Educational Needs Standards (Core 1a – 1e, Extension 2.i – 2iv.). It is directly related to the module Curriculum and Teaching – Pupils with Severe and Profound and Multiple Learning Difficulties which addresses further standards. The module provides students with an opportunity to gain an understanding of those influences which impact upon the learning, development and management of pupils with severe and profound and multiple learning difficulties. **Module: EDUM081**
For further Details: The University of Northampton. Tel: 01604 892192. E-mail: admissions@northampton.ac.uk

MA in Education
Physical Disabilities: Contexts & Interventions
This module provides opportunities for those with QTS and professional qualifications & experience in services for children to engage in structured critical reflection, exploration of key substantive issues and overarching policy determinants in respect of children and young people with physical disabilities. The module encourages both the development of enhanced understandings of the dimensions of physical disability, with regard to both their theoretical bases and the policies and practices invoked in meeting identified needs. **Module: EDUM058**
For further Details: The University of Northampton. Tel: 01604 892192. E-mail: admissions@northampton.ac.uk

MA in Education
Physical Disabilities: Curriculum Issues
This module provides students with opportunities to investigate, critique and evaluate a range of curriculum approaches in the field of PD. It engages students in debates concerning the relevance and practical efficacy of recent guidance & legislation in PD-related issues, and offers an in-depth series of curriculum-focused activity which is intended to enhance both the understanding and the practice of those working with children and young people with PD. **Module: EDUM059**
For further Details: The University of Northampton. Tel: 01604 892192. E-mail: admissions@northampton.ac.uk

MA in Education
Understanding Multi-Sensory Impairment
This module addresses the requirements of the Teacher Development Agency (TDA) National Special Educational Needs Standards (Extension 2.i – 2iv.). It is directly related to Pupils with Multi Sensory Impairment (MSI) The module provides students with an opportunity to gain an understanding of those influences which impact upon the learning, development and management of pupils with multi sensory impairment.
It provides professional development for teachers and other professional colleagues working in an area of low incidence need and addresses priorities established by Local Authorities, individual teachers and others working with children and young people who experience MSI. **Module: EDUM054**
For further Details: The University of Northampton. Tel: 01604 892192. E-mail: admissions@northampton.ac.uk

Certificate in Higher Education (CHESL): Supporting Learners with SLD/PMLD
During the course we will be looking in detail at the needs of learners who are known to have severe or profound and multiple learning difficulties. They may also have other additional or associated disabilities, such as physical or sensory impairments. The course will examine topics of both a theoretical and practical nature to provide students with a greater understanding about this group of learners. Together with a broad range of strategies and approaches that can be applied to practice. The sessions will include lectures, workshop activities, discussion and some visiting speakers.
For further Details: The University of Northampton. Tel: 01604 892192. E-mail: admissions@northampton.ac.uk

BSc in Professional Practice (Learning Disability Pathway)

The School of Health & Social Care, University of Chester, BSc in Professional Practice (Learning Disability Pathway) - includes forensic, mental health/learning disability, challenging behaviour, older person with LD and epilepsy modules (plus others)
For further details: University of Chester
Telephone: 01244 511471 (Pat Palser), 511472 (Monica Davies) or 511473 (Ann Ashford)
Email: p.palser@chester.ac.uk, monica.davies@chester.ac.uk, a.ashford@chester.ac.uk

PGCert, AdCert.
Early Years: Sensory and Multiple Needs—This programme begins in January
Distance education.
This programme enables professionals to work more effectively with young children with sensory and multiple needs. Participants may be teachers, who may already hold a specialist qualification in visual impairment, deafness or multisensory impairment; specialist speech and language therapists; health visitors; social workers; carers or others working with young children with sensory and additional needs.
For further details: University of Birmingham Dr Liz Hodges on 0121 414 4873 or email: E.M.Hodges@bham.ac.uk

AdCert, BPhil, PGCert, PGDip, MEd.
Learning Difficulties and Disabilities (Severe, Profound and Complex)
Distance Education
This distance education programme has been developed for the range of staff who work with people with severe, profound and complex learning difficulties, for example teachers and lecturers, nurses, therapists, psychologists and support staff.

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

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

For further details: 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

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

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

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

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

Undergraduate and 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

Information about the course can also be found on the website: www.manchester.ac.uk/education/pcld

MSc in Advanced Practice (Learning Disabilities)

The School of Health & Social Care, University of Chester, MSc in Advanced Practice (Learning Disabilities) - includes generic modules in research and inter-professional working plus 3 LD specialist modules (socio- political themes in LD; developmental perspectives on LD; profound & complex needs).
For further details: University of Chester
Telephone: 01244 511471 (Pat Palser), 511472 (Monica Davies) or 511473 (Ann Ashford)
Email: p.palser@chester.ac.uk, monica.davies@chester.ac.uk, a.ashford@chester.ac.uk

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

MSc Profound and Complex Learning Disability and
Postgraduate Certificate/Diploma Profound and Complex Learning Disability
Distance Learning

Course aims

- To provide an increased knowledge and understanding of children and adults who have complex needs and/or sensory impairments.
- To empower those directly concerned with this group to advocate for the rights of the individuals concerned.

To enable this to happen by providing current information relating to cognitive, emotional, physical, sensory and social needs.

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

For further details: The University of Manchester, Emma Hardy Phone: 0161 275 3463 Email: emma.hardy@manchester.ac.uk
Website: www.manchester.ac.uk/education/pcld

PMLD-Link

Subscription Year 2009

Volume 21 Nos. 1,2 and 3

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

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

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

PMLD-Link also includes:

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

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

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

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

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

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

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

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

PMLD Link

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